FROM THE VOICES OF EXPERIENCE,
THE ROAD TO RECOVERY

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# Abstract

The individualization and medicalization of the emotional distress of those given psychiatric diagnoses deny the social, political, and economic context in which the presenting behaviours arose and leads away from making changes to society. Some people who are psychiatrically labelled join in groups for solidarity in the face of being stigmatized. In these groups the members can resist the disempowerment and helplessness learned in the psychiatric system. With co-researchers from a self-help group this study gives expression to the usually silenced voices of psychiatrized people. Feminist and standpoint theories, co-cultural and living systems theories form a framework for this narrative study. A structural narrative method is used to analyze the stories, found in the transcripts of six individual interviews, told by the co-researchers about their experiences in psychiatric services and in the recovery process. The stories reveal how the ideology and practices of psychiatry use stigma, oppression and the creation of the identity of psychiatric patient for control and management. The stories also reveal the reality of hope for recovery through the support of peers and from the role models of those who have significantly recovered their mental health. Two focus group interviews were conducted with members of the self-help group where suggestions for programs were developed to address issues raised within the groups and in the individual interviews. The findings of the research will be reported to the self-help group who will use the study to back proposals for the funding of recovery-oriented programs. When social workers and other mental health professsionals recognize the importance of supporting the process of recovery, consumer/survivor-run programs will be acknowledged as effective and integral parts of any mental health system

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## Acknowledgments

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# FROM THE VOICES OF EXPERIENCE, THE ROAD TO RECOVERY

## Introduction

The beginning of the twenty-first century is an appropriate time to review how we are doing as human beings, as members of a neighbourhood, a nation, and of a global community. The way in which we treat the most marginalized members of our communities is a measure of how far we still have to go towards realizing the full potential of what it means to be a human being. Some concerned people wish to create a more inclusive society which values and has a place for all of its citizens (Anthony, 1993; Deegan, 1996; Gyatso, 1980; Vanier, 1998).

Those who are designated as 'chronically mentally ill' are one of the most marginalized groups in Western society today. The only group that is possibly more marginalized is those with intellectual disabilities (Vanier, 1998). There is now a recognition that the attitude with which we as a society and as practitioners treat people with a psychiatric diagnosis of serious mental illness significantly affects whether they are able to manage and grow despite their disability. Research has shown that their participation in the decisions that affect their lives empowers these vulnerable people, increasing their ability to live and thrive in the community (Anthony, 1993; Deegan, 1996; Rapp, Shera, & Kisdhardt, 1993).

Changes to policy are being made to attempt to rectify the damage that has inadvertently been produced through the way mental health services have been provided in the past. One of the best practices criteria for mental health is to provide "...mechanisms for meaningful consumer[1] and community involvement in decision-making" (Adult Mental Health Division [AMHD], 1998, p.11). The 1998 Mental Health Plan for British Columbia states that the involvement of consumers, families and caregivers is a core value underlying mental health reform and that the Ministry of Health will work to ensure that they are included in mental health

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[1] Consumer is the term used by mental health professionals for the recipients of their services. It is supposed to represent that former 'mental patients' are now involved in consumerism; they are able to make choices and participate in decision-making in the services they receive.

services planning, delivery, management, evaluation and reform (AMHD, 1998). These changes have given hope to the users of mental health services that their perspective of what is needed will at last be listened to. However, in British Columbia, progressive mental health policies have been made along with promises to increase funding, but the commitment has not been reflected in the government's budgets (Palmer, 2000).

There are now advisory boards and committees throughout the mental health system with members who are consumer/survivors[2]. However there are several problems with this form of participation which are discussed by consumer/survivors themselves: (1), they have reported feeling defeated when suggestions and recommendations which they make are never acted upon; (2), on the boards which they attend, the overwhelming proportion of members are non-consumer/survivors, and the perspective of the consumer/survivor is often lost; (3), often the views of consumer/survivors and their families are in conflict and the representation of one can work against the other (One example is when family members were instrumental in lobbying for the recent addition of community committal to new mental health legislation, one opposed by consumer/survivors as an increased infringement of their rights); (4), many consumer/survivors feel they do not have the skills needed to promote their views or to engage in discussions and believe that they require training in this form of participation to have their involvement be meaningful; and (5), unfortunately, in these early stages, the participation in decision-making is incomplete, with open forum consultations with groups of consumer/survivors taking place after policies have been written up, as in the recent development of criteria for Best Practices in Mental Health Reform for British Columbia by the Vancouver/Richmond Health Board (Adult Mental Health Division (AMHD), 1998)

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[2]Consumer/survivor is a term developed by people who use and have used the psychiatric system. The term consumer implies that people consume psychiatric services, that they are clients of the system. The term survivor represents two views: one that for many people their experiences within the psychiatric system have been traumatic but they have survived; and two that people have survived the experience of having a psychiatric diagnosis and have moved on towards recovery.

Consumer/survivors have until recently been left out of most of the discussions and decisions about the services provided by the mental health system. In order to have a 'voice' in their own lives, they have formed their own groups and organizations. These self-help and mutual-aid groups provide a place in which their members can share their stories, receive and give support, and develop their own perspective on what it means to have been diagnosed with a mental disorder.

The ability to recover[3] from what has been called "serious mental illness" has been recently validated by research and is gaining wider acceptance by those involved with mental health issues (Anthony, 1993; Deegan, 1996; NSMHCS, 1999; Trainor, Shepherd, Boydell, Leff, & Crawford,1997). The concept of recovery "...has long been advocated by mental health consumer/survivors and progressive researchers, providers and policy experts" (NSMHCS, 1999, p.19)

I developed this current research project in conjunction with a self-help organization, The Self-Help Group (SHG) (pseudonym), to explore the experiences and views of consumer/survivors. The SHG is now providing support groups for their members with occasional programs of peer support and access to non-conventional treatment services. They wish to increase and develop recovery-oriented programs to address the issues of their members and provide services which are not covered by the professional mental health services.

## Why this Subject and Form of Research?

This research is motivated by my personal experience, interests and values; my connection with the Self-Help Group; and my training in social work.

The primary motivation for this study arises from my own experience as a consumer/survivor. Thirty years ago I was hospitalized for six weeks in a psychiatric ward after

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[3] Recovery is the ability for people with a diagnosis of mental illness to be able to live happy, full and productive lives whether they still experience symptoms or take medications or not.

a psychotic break induced by a combination of factors, including experimenting with non-ordinary states of consciousness through the use of mind-altering drugs (see Appendix A for details).

My interests in Buddhism have also affected the direction of my studies. There has been an evolution in human consciousness towards a universal responsibility for the earth and all its inhabitants. This stage of evolution moves beyond the greed of materialism, the hatred of wars and the delusion of being separate from nature and not accountable for what we do to the environment. The Dalai Lama, winner of the Nobel Prize for Peace and exiled political and religious leader of Tibet, says that, "...today we have become so interdependent and so closely connected with each other that without a universal responsibility our very existence and survival would be difficult" (Gyatso, 1984, p.16). He also writes that there are two ways to achieve this universal responsibility: to look deeper for the real causes of problems in our world, to not solve things temporarily; and to foster a feeling of friendliness with others as if their problems were our own, "...trying to share the sufferings of others" (p.27). This close connection will lead us to be inclusive of others, to appreciate all beings for who they are and what they add to the world. People who have been labelled with serious mental illness are often excluded from society and shunned by others. To include them and listen to what they have to say will inform us all, as we all have a part to play.

To be happy is the desire of all beings; just to be present to another's suffering can open the heart and lead to happiness. Vanier (1998), founder of l'Arche communities[4], says that "...fear is at the root of all forms of exclusion, just as trust is at the root of all forms of inclusion" (p.71). It is that fear which isolates people and feeds their loneliness. Vanier also writes that in the "...l'Arche communities we experience that deep inner healing comes about mainly when people feel loved, when they have a sense of belonging" (Vanier, 1998, p.11).

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[4] L'Arche communities are places where people who are both abled and disabled live together in order to support and learn from each other.

When we include those who are marginalized we affirm the idea that they have something to give to us all. Our relationships become mutual; we move from individualism and striving for power to opening to each other and belonging with others. "If each of us...opens our heart to a few people who are different and become their friends, receive life from them, our societies would change. This is the way of the heart" (Vanier, 1998, p.85).

Another part of what influenced and gave purpose to this research project arises from my relationship with the coordinator of the Self-Help Group. We had met originally when she answered my ad for a new roommate. She lived with my son and I for a short while until we moved to another home. When I was in a field placement at a community mental health team, the office of the Self-Help Group happened to be one floor down. We reconnected and I found someone I could talk to who had a different perspective from professionals and with whom I could share my concerns about the treatment of people labelled as having serious mental illness.

I discovered that my own experience with the mental health system was triggered by working in this placement and at times I found it difficult to deal with the paternalism and discrimination I heard and saw. I found the professionals to be on the whole, caring, compassionate and likable people, who worked hard to serve the people that were on their case load. But some were imbued with a way of dealing with those who were psychiatrically diagnosed which did not show respect for them as human beings. This puzzled me and added to my concerns about the inconsistencies between the rhetoric of care and the actual practice of psychiatry. Part of my studies has been to investigate why this is so.

I was asked by the coordinator to help develop a constitution for the Self-Help Group so that they could apply for non-profit status. During this process research was discussed. I needed to find a research topic and they wanted research done to back proposals for the funding of new programs.

My training as a social worker has affected the form of this research. The values found in the social work code of ethics are excellent guides for developing research which serves the participants; working for their best interests and for their self-determination, not exploiting them for personal benefit, being respectful, non-discriminatory, working towards ensuring "...that all persons have a reasonable access to the resource, services and opportunities which they require...", and "...to expand choice and opportunity for all persons, with special regard to disadvantaged or oppressed groups and persons (BCASW, 1984, p.12).

## How is this Research Relevant to Social Work?

Part of the relevance for this current research to social work is in its adherence to the principles upon which social work practice is based; principles such as beginning where the person is, fostering self-determination and empowerment, seeking social justice, and supporting and encouraging the development of communities for marginalized people.

Unfortunately, many social workers involved in mental health find it difficult to practice as they were trained. The influence of the medical model is very pervasive in the systems they work in.

> Social work, while always ambivalent in its relationship with medicine, has publicly opted for incorporation in the guise of collaboration...to seek accommodation, compromise or influence within the individualistic medical paradigm. (Smith, 1990, p.20)

When social workers join a system which has been created to perpetuate an imbalance of power in order to provide what is thought to be effective professional medical service, it is difficult to make changes to include the sharing of power with the users of the system.

Forbes and Sashidharan (1997) talk about user involvement in mental health and social services and state that "...the complexities and contradictions in this area are often ignored because the issues raised by users are fundamentally challenging to the way social work and psychiatric services have been conceived and organized" (p.482). Interventions in psychiatry and social work have elements of control and coercion even in supposedly voluntary

transactions, and user involvement is unlikely to result in significant changes because of "...the premise on which psychiatry and social work are organized and provided..." (Forbes & Sashidharan, 1997, p.486). Also, it is often the case that "...user involvement in these services is little more than an attempt to facilitate the smooth and efficient running of existing care provision" (p.486).

We as social workers, working in systems based on the medical model, can add to the suffering of those with a psychiatric diagnosis when we view them in the limiting ways influenced by the science of psychiatry. By working for their empowerment, encouraging self-determination and supporting self-help initiatives, social workers can become good allies. When we are not able to follow social work principles our power to make change is diminished and the quality of our work can suffer as we are relegated to the status of subordinate mental health professionals. The struggle to empower consumer/survivors and change how they are treated so that recovery is encouraged, is also the struggle to become the type of professionals that we may have envisioned when we entered social work training. As Bishop (1994) writes, "I also believe that one must be in the process of liberation from one's own oppression to become an ally in another's liberation" (p.95).

Social workers are trained to look at the web of relationships and structures that affect individuals. The study of how people actually experience the psychiatric system as users can uncover insights that could improve the services they receive. Studying how a person recovers their mental health may shed light on the effect of factors beyond the mental health system. To determine how to best support a person to recover their mental health it seems logical to study those who are in the process of recovering or who have fully recovered.

The development of peer-led alternatives is in part from consumer/survivors not seeing themselves as consumers but rather as 'victims' and 'survivors' of psychiatric services. In order to avoid misrepresentation of self-help groups and their members it is useful to have research

which reveals their perspective and the issues they face in their day-to-day lives. This research, with its participatory approach and the use of a researcher who shares, in part, the standpoint of the members, can provide findings that will inform the practice of mental health social workers and aid them in their work with self-help groups of consumer/survivors.

The inclusion of a narrative style of research and the theories on which it is based are eminently useful for social work practice in all areas. There is the possibility of the transformation of identities and professional practices from the sharing of stories within and between groups. Perhaps this research and the stories told may affect the practice of a future social work professional.

Social work education needs to include the consumer/survivor perspective as well as that of the self-help movement, especially since the results from research show how important empowerment and peer support are for recovery. Presenting research from the perspective revealed by the stories of consumer/survivors can work towards eliminating the discrimination they experience.

## Conclusion

There are positive changes being made to the policies of mental health which allow people with serious psychiatric diagnoses to participate in the decisions that effect their lives. From people, such as myself, who have experienced what it is like to have a diagnosis of serious mental illness and from other concerned people, there are questions about how we as a society and within mental health services are treating these marginalized people. We wish to encourage the inclusion of those who are psychiatrically diagnosed in all aspects of community life, to share what they have learned and to allow them to be empowered to live as full a life as possible.

Social workers with their training and value-base are eminently suitable to be allies to consumer/survivors and their self-help groups. They can learn what these marginalized people

need and want from research which accesses the perspective and knowledge of consumer/survivors.

A frequent complaint by those who use the mental health system is that they are not listened to. This study was conducted to redress this complaint; to listen to the stories of the people who struggle with the experience of being labelled with a diagnosis in their use of psychiatric services, and through the process of recovering their mental health.

## PART ONE: CONTEXT, THEORY AND METHOD

## Chapter One

## The Roots and Practices of Present Day Psychiatry

### Science, the Medical Model and Psychiatry

The psychiatric system is a part of the medical system and derives much of its structure and the form of its practices from the medical model. The medical model in turn has its foundations in a scientific approach to medicine. The scientific method and its base in rational thinking began to take form in the seventeenth century. The Cartesian-Newtonian[5] worldview has dominated intellectual thinking since that time and is only now being challenged by a new non-positivist[6] paradigm (Bordo, 1987). The century, from 1550-1650, when the scientific model emerged, had "...the worst food crisis in history, violent wars, plague, and devastating poverty", and the "...imagery of nature as an unruly and malevolent virago was no paranoid fantasy" (p.111). Nature became a "She", the "Other", "...particularly the otherness of the female...which threatens to swallow the individual 'like a speck'...a reminder of how much lies outside of the grasp of man" (Bordo, 1987, p.111). Bordo (1987) writes that this "...Cartesian 'masculinization of thought'...is an intellectual 'moment' of an acute historical flight from the feminine, from the memory of the union with the maternal world, and a rejection of the values associated with it" (p.9).

This shift in thinking has also been called the "invention of mind"; where thinking became an internal, rational process and consciousness, instead of residing both inside and outside. It was

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[5] The Cartesian-Newtonian worldview combined Descartes' philosophy and his establishment of the importance of rational thinking with a neutral, objective view and Newton's development of the scientific method in his investigations of the physical sciences (Bordo, 1987).

[6] Positivism is a theory which states that " theology and metaphysics are earlier imperfect modes of knowledge and that positive knowledge (knowledge that is independent of changing circumstances) is based on natural phenomena and their properties and relations as verified by the empirical sciences" (Merriam-Webster, 1997, p.909).

believed that consciousness was now lodged only within the skull of a human being. The Western emphasis on individualization was reinforced with this interiorization (Bordo, 1987).

The Cartesian project brought with it doubt and people lost faith in their relationship to their own bodies and the natural world. Bordo (1987) describes the change as a "...separation from the *maternal*--the immanent realms of earth, nature and the authority of the body--and a compensatory turning toward the *paternal* for legitimization through external regulation, transcendent values, and the authority of law" (p.58) No longer could people rely on their perceptions, 'gut' feelings or subjective judgments as being reliable sources of knowledge from which to act. Only what was objective and knowable, rationally and scientifically, had any validity.

The Protestant reformation followed this shift with a purging of the pagan aspects and the more feminine representations incorporated in its practice. This resulted in 'God the father' as the only source of refuge where people could find reassurance for their separation anxiety. This shift in worldview created the so-called 'Cartesian anxiety' with an insecurity which has haunted Western psychological development since that time. Bordo (1987) views this fear or free-floating anxiety as a root of the compulsive need to control nature so that we are not overwhelmed by it, and the blind grasping at material accumulation and progress which has resulted in the degradation of the environment.

Burstow (1992), in a feminist perspective of this time, focuses on the wielding of patriarchal power, through the persecution of so-called witches, in the attempt to eradicate the feminine knowledges held by women healers. The different voice of feminine knowledge is based in what Bordo (1987) calls "sympathy", the combination of closeness, connectedness and empathy. These women healers were "...the inheritors of early religions..." and, "...century after century they defied patriarchy, bringing women's knowledge, spirituality, and ways of healing to

those in need" (p.23). They were very popular with the public and competition for the emerging doctors of scientific medicine.

Progress, since the beginning of this age of reason, has been bound up with the naming and control of the natural world. Since the evolution of science was guided by males, it was men who decided what and who was in need of control. This purging of feminine ways of healing and gathering knowledge served both the male-dominated Church and the male-dominated medical profession, and left them to deal with the problem of madness (Bordo, 1987; Burstow; 1992; Foucault, 1965).

**Psychiatry wins control of 'mad' people.** Foucault (1965), in <u>Madness and Civilization</u> , sets out to track the evolution of the idea that madness is a threat to society, and that madmen (and especially madwomen) need to be named and controlled; in the 1800's, locked in an asylum, in the year 2000, managed by medical treatments. He begins in the 1500's when insanity was considered a part of everyday life, and from there, he attempts to find how and when the wall dividing madness from reason was built.

What is constitutive is the action that divides madness, and not the science elaborated once this division is made and calm restored. What is originative is the caesura that establishes the distance between reason and non-reason; reason's subjugation of non-reason, wresting from it its truth as madness, crime, or disease, derives explicitly from this point.

(Foucault, 1965, ix)

The dividing of reason from unreason occurred alongside the development of the scientific method, the ultimate tool of reason. Doctors, with their enlightened scientific background, announced that madness did not arise from demonic possession or distressing life circumstances, but from a disease process in the brain. And so psychiatry as a medical profession began. These doctors became the custodians of the 'mad' in asylums and promptly set about testing physical treatments to 'cure' their patients (Burstow, 1992).

In the West, the scientific framework and successful research into the theory of germs, led to an advancement of medicine and the development of the biomedical model in the 1800's. The biomedical model is based on the idea that every disease has a pathogenic cause; that it is caused by a bacterium or virus, or by a malfunction of the physical system. Mental illness was thought to be an organic dysfunction of the brain which precipitated biochemical changes in the nervous system due to the disease process. However, in the 1800's, even with an alliance with neurologists, other than syphilis, cerebral atherosclerosis, chronic intoxication and brain injury, doctors were unable to find evidence to validate this medical model (Cockerham, 1992).

Doctors' control over madness was based on the belief that it arose from physical pathology. The use of physical treatments and the consequent success in `controlling' madness (not curing it) was proof that it must have a biological cause. The movement away from asylums and into general hospitals also legitimized psychiatry as a medical science. Today, treatment by medications is profitable business for pharmaceutical companies. Control by drugs is cheaper than human intervention for the elderly, the disabled, restless children, as well as distressed psychotics. If control of the disruly is one of psychiatry's functions, then medication treatments which can be forced are better than talking therapies which cannot (Pilgrim & Rogers, 1993).

**Can humans be repaired like a machine?** The medical model views the body as a machine; disease and illness are explained, "... through an engineering metaphor in which the body is seen as a series of separate but interdependent systems. Ill health is treated as the mechanical failure of some part of one or more systems and the medical task is to repair the damage" (Doyal, 1995, p.3). The focus is on a part of the individual, not the whole, or the context in which they live, their environment and relationships with others.

The medical model reduces all the causes of disease to biological determinants, and "...works most comfortably where there is a biochemical and/or structural defect that provides a simple key to understanding the disease being studied" (Gillett, 1994, p.1127). This

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reductionism becomes too narrow even in physical medicine, in that it ignores the social and economic factors relating to illness and health. Using the determinants of health, the authors of the literature on health promotion recognize that the lack of safe and suitable housing, poverty and isolation are strong factors in the ill health of individuals, especially women and minority groups (Adult Mental Health Division, 1998).

**Scientific medicine and how to 'empty' a patient.** Sociologists, in studying the institution of scientific medicine, raise concerns that human rights and health come second when they conflict with the protection of the internal structure and social power of the institution. The institution of medicine follows the dominant paradigm with its assumptions of objectivism, reductionism and mechanic determinism. Humans are seen as conglomerations of bits of matter and disconnected parts. People are treated as totally separated from the context of their lives and from each other, ignoring their relationships and emphasizing their independence. Institutional power has developed and been accepted which legitimizes treating human lives mechanically ( Stambolovic, 1996 ).

A human being treated by scientific medicine becomes a patient and, "...is treated as `emptied', i.e. as an entity deprived of internal reality, without subjectivity, without intentions, without any purpose of personal existence " (p.302). The good patient is passive and dependent on the medical experts. When the gap between the experience of the patient and what the experts accept as real and possible widens, "this imbalance of power reduces the patient's self to the expert's definition, reinforcing the latter's power and further subduing the patient" (p.302). This gap is particularly large when the expert is a professional in biological psychiatry and the patient is a person in the midst of an emotional crisis. The identity shift is completed after a person is given a diagnosis and then is treated as being equated with their illness.

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The process of losing one's previous identity and taking on one as a psychiatric patient has been called a mortification; a process where the person is shamed and humiliated, stripped of their rights and their position as a subject in their own lives . People become the institution's objects and are detached from the rest of their life and history (Smith & David, 1975). And as has been clearly the case in psychiatry, "...for individuals conceptualized by scientific medicine, human rights are irrelevant, in establishing therapeutic transactions they even present an obstacle" (Stambolovic, 1996, p.302).

## Medicalization: Don't Worry You're Just 'Sick'!

**The medicalization of deviance.** The medicalization of deviance is the application of 'disease' explanations to certain types of deviant or abnormal behaviour. Conrad (In Dickenson & Andre, 1988) proposes five parts to this process: (1) group(s) holding some level of power define a behaviour as deviant and problematic; (2) current forms of containing the behaviour are deemed inadequate or unacceptable; (3) medical professionals accept that this deviant behaviour is within their domain; (4) some form of medical control/treatment is available; and (5) there must exist "...ambiguous organic data as to the source of the problem" (p.298). At times, medical researchers, possibly funded by pharmaceutical companies, investigate the possible deviance and make discoveries which may legitimize its medicalization. Finally lobbying is made to the appropriate organizations, and if successful, is followed by the institutionalization of a medical deviance designation (Deutschman, 1998).

Behaviour that has not before been defined as medical is now seen as being indicative of illness and disease and the person is designated as 'sick'. This sick role has four components, with the sick person : (1) excused from the obligations of social roles; (2) exempted from negative judgment, including penalties from the failure to perform duties; (3) obligated to recognize the illness as undesirable and to want to get well; and (4) bound by duty to seek and cooperate with competent, medical treatment (Deutschman, 1998).

Medicine inscribes the body into a discourse of objectivity. The body is materialized even

as the self is banished, creating the disjunction which is the core of...the mind/body problem.

In the realm of the ordinary, the body is the self, the site of my experiences, the fulcrum of my

movements, the source of my perspectives. I experience myself as embodied. In the realm

of medicine, the body is rendered an object. It is inspected, palpated, poked into, cut open.

From being a locus of self, the body is transformed into an object of scrutiny.

(Young, 1998, p.3)

Applying the 'sick' role to psychiatric disorders helps the psychiatrist and other mental health

professionals exact control of the patients they see. The other arm of psychiatry is the legal

powers invested in the profession. Those considered 'dangerous' to themselves or others can

be committed to hospital. Many consumer/survivors say that they are grateful that they were

scooped up before they did any harm. However, research has shown that psychiatrists are not

able many times to predict 'dangerousness'. Abuses can and do occur and people with a

psychiatric diagnosis lose their rights as citizens when committed. In the new Bill 22, to be

'deteriorating' and non-compliant with medication is grounds for one psychiatrist to commit a

diagnosed person; there is no longer the requirement for a second opinion by another physician

to insure the committal is absolutely necessary.

**They say they can tell if you're normal or not.** Abnormality (or deviance) is defined in

sociological terms as behaviour "..which fails to conform with the accepted norms and

standards of a social group or system..." (Knuttila, 1996, p.248). Abnormality can be seen as

being socially constructed and is variable through time and space. Once labeled a mental

illness, homosexuality is now considered a somewhat accepted form of sexual orientation.

Social action removed homosexuality as a psychiatric diagnosis.

Whenever we hear someone labeling another as abnormal we need to ask for what purpose

they are making the judgment. Are they trying to help the person they are labeling, or are

they trying to show that they are different from, and better than that person? And if their intention is to help, is there any evidence to suggest that applying an abnormality label will actually further that intention? (Caplan, 1995, p.44).

While all cultures recognize madness as in psychosis, some do not see it as an illness, while others differentiate between psychotics as deviants or as shamans. Other forms of distress, and behaviours that are seen in the West as `illness' are not medicalized in other countries. (Bowers, 1998; Fernando, 1991, 1995).

The psychologist Caplan (1995) writes about how psychiatrists developed the Diagnostic Systems Manual (DSM). She states that these men, with now a few women, have decided what is and what is not normal, and developed diagnoses that appear to have scientific significance but which often don't. Other feminists have been very critical of the diagnostic system and its role in medicalizing problems, especially women's problems. Psychiatry is a billion dollar, growth industry, tied into the pharmaceutical companies and serving the interests of patriarchal capitalism, which seeks to control or incapacitate any deviance from traditionally assigned roles (Burstow, 1992). As the feminist economist Marilyn Waring (In Nash & Martin, 1995) pointed out, tragedy may be profitable; what may look dehumanizing and distressing is actually providing growth in the economy, contributing to the gross national product. Human pain is not an item on the ledger which shows profits and expenses.

Diagnosis has become a way in which therapists can make their clients into the `other', the `not me', not truly human but rather a label or a case...Diagnosis contradicts a political analysis, because it locates the problems in the individual, thereby privatizing both the distress and its implied solutions, and defines the distress as illness, moving the locus of analysis from context to person. (Brown, 1994, p.125)

The assumptions and beliefs of the person who makes the diagnosis are also not looked at. How they view their client has tremendous impact on how they will diagnose. Fraser (1999)

quotes Jung and his insight into how medicalization was reflected in Freud's diagnoses. "Freud always remained a physician. For all his interest in other fields, he constantly had the clinical picture of neurosis before his mind's eye--the very attitude that *makes* people ill and effectively prevents them from being healthy" (p.13).

Coates (1997), himself a psychiatrist, points out that a practitioner makes a diagnosis as if it has scientific validity while in fact disregarding what he or she does as an observer. He describes how this occurs: If someone's behaviour is troublesome to me and if I disregard the criteria by which I make this observation, then I am free to attribute any discomfort I experience to the other person. If I can construe his or her behaviour to chemical imbalances and problems within his or her 'self' then I can delegitimize "...his or her conduct as an expression of an autonomous unity" (p.2). I can do the same to others with the same presenting behaviours. I can do this and

> ...take no heed of the context of myself asking questions, or the assumptions I make to generate them...I can persuade people they are ill, persuade them to be patients through psychiatric rhetoric alone. No physiological evidence is required or even necessary. This is a domain of power and ethics, not medicine. (p.3)

**Whatever your problems, we have a pill for you.** There are concerns that psychiatry is expanding its definitions of mental disorder to include problems that are truly from social and economic causes. Robert Spitzer (Cited in Brown, 1994), a leading psychiatric diagnostician, displays a strange circular logic in the following statement, "If we treat it, it must be diagnosable, since anything that is not diagnosable would not require treatment from a professional" (p.130). Whomever psychiatrists treat must exhibit a pathology which fits some psychiatric diagnosis as they only treat people with serious mental health issues. This view does not admit to mistakes being made, or temporary states being misdiagnosed as permanent.

Caplan (1995) warns that diagnoses are determined by fewer than two hundred people who are listed as being consulted in the production of the DSM-III-R, and these are mostly psychiatrists, males and whites. It is "...a small group to make pronouncements about normality and mental health and disorder" (p.110). Caplan and other feminists fought hard to get the diagnosis of premenstrual dysphoria disorder, which pathologized the extremes of the premenstrual syndrome, taken out of the manual. But it was still put into the DSM under the 'provisional' appendix, a place to include diagnoses which still need more research for full approval. The name was changed to the late luteal dysphoria disorder, and psychiatrists were told "...to go ahead and use them as if they were official...And they...were widely used without much regard for their unproven, unsupported status" (p.109).

Many believe that it is their internal thought processes and emotional states that are the cause of their unhappiness. This leads them to seek help from mental health professionals. However, their unhappiness could actually stem from discrimination because of race, sexual orientation, appearance, mental or physical condition, or, as many women experience, from being overworked, undervalued, and poverty stricken. Professionals often reinforce that it is their individual psyches that are at fault, and that they must adjust to the circumstances in their lives. And even if they identify social causes they are not trained to think in terms of social action or have any mechanisms to effect change. They often feel the best they can do is to help by providing relief through medication. Unluckily, instead of relief, many people find more suffering from the treatments psychiatrists prescribe, with powerful drugs, electroshock treatments, isolation and physical confinement. They can end up traumatized by these 'cures'.

## The Current Rule of Biological Psychiatry

The medical model, with psychiatrists who are trained in scientific medicine, has the most influence over the processes which occur in the mental health system, even though there are other mental health professionals, such as social workers, who base their work in different

models.  The illness framework dominates mental health services because psychiatrists are the dominant professionals (Pilgrim & Rogers, 1993).

Halasz (1994), a psychiatrist, uncovers what he calls the pseudo-science of biological psychiatry.  He refers to several research projects which highlight that science is culture-bound, in conflict with the "...widely held orthodox views of the impartial, value-free status of science" (p.8).  The explanation of the nature of mental health and illness is complex and filled with inconsistency and paradox. Halasz (1994) says that by side-stepping this reality biological psychiatry turns into scientism[7], "...a very prejudiced approach which, before it has considered its subject, claims to know what is the most appropriate way of investigating it" (p.9).  Halasz (1994) states that only lip service is paid to the integrative paradigm of the 'biopsychosocial' model.  He joins others in cautioning that this biological reductionism "...could legitimize psychiatric treatment being reduced to this or that pill..."(p.10).

In psychiatry, even though there is some recognition that social and economic factors affect and may cause some forms of mental illness, practioners do not respond to these non-biological factors.  This negligence is justified by biological psychiatrists who believe that the results are biochemical disturbances in the brain, whatever the reasons or causes.  The biochemical determinism is pervasive and psychiatrists view that whatever the causes, they have physical treatments that work with psychopharmaceuticals and electroshock therapy.

Genetic research is said to reinforce the medical model in psychiatry.  Behavioral genetic research has attempted to show the importance of genes in the transmission of certain mental disorders.  Schizophrenia and mood disorders are found to run in families, even though this does not account for the majority of cases.  The relationship between heredity and the role of

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[7] Scientism has an exaggerated trust in the efficacy of the methods of natural science as applied to all areas of investigation, especially in non-physical sciences (Merriam Webster, 1997). It "...involves a mechanical and uncritical application of habits of thought to fields different from those from which they have been formed...", and as such, "...is decidedly unscientific in the true sense of the word" (Halasz, 1994, p.9).

environment is still not clear, but psychiatrists think that a person may be genetically `primed', and the onset of mental illness is dependent on triggers from environmental factors such as stressful life events (Cockerman, 1992). In contrast, the proponents of social learning theory believe that upbringing and learned behaviour may be at the root of mental disorders. The disposition for mental illness to be transmitted in families may not be proof of biological cause. The twin studies that some researchers believe prove biological cause are contested by others (Pilgrim and Rogers, 1993).

**The home team approach to psychiatric control.** Dickenson & Andre (1988) call the rise of community psychiatry a "...break with clinical (medical) psychiatry and its replacement by a nationalized form of industrial psychology" (p.298) Some professionals in community mental health have challenged the medical viewpoint; where psychiatrists treat *mental illness,* social workers and psychologists are emphasizing *mental health.* The use of psychotropic drugs did help legitimize psychiatry as a medical profession but "...still did not prove that mental disorders had organic causes" (p.300). For example, even with all the research into the possible organic causes, a recent "...extensive review of the neurochemistry and neuroendrocrinology of schizophrenia (Lieberman and Koreen, 1993) found a 'fragmentary body of data which provides neither a consistent nor conclusive evidence for any specific etiology' " (Fernando, 1995, p.13).

The 'biopsychosocial' model was developed to add the psychological and social factors to the possible causes of mental illness; the model covers all bases as there has been no real proof of organic causes. Many psychiatrists and neuroscientists believe it is just a matter of time until incontestable proof is found. The disputes as to causes are relevant for professional power, pay and prestige (Dickenson & Andre, 1988).

There have been attempts to broaden the view of how mental illness is perceived; for example, the Canadian Mental Health Association has developed a knowledge resource base. This knowledge resource base recognizes experiential, and customary/traditional knowledges

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as well as the usual ones from medical and social science. The experiential, the direct experience of the mental illness and the knowledge that it gives, is usually discounted and discredited. The traditional or informal knowledge, conventional wisdom of family, friends and community, is also not often accessed, although it could be used to advantage. Trainor, Pomeroy, and Pape (1997) hope that Canada, with its history of public involvement in health care, may be able to "...explore a more comprehensive approach to understanding mental Illness" (p.115).

With the prominence of biological causes and treatments of mental illness, psychiatrists diagnose and treat with medications. Talking therapy has been relegated to the `assistant' mental health professionals. Nurses, social workers and psychologists do clinical work with patients addressing their psychosocial needs and counselling them about their problems in day-to-day living . The involvement of counselling at this level can be very helpful, but still there can be many problems. These arise mainly from the fact that the power and legal authority rest in the hands of psychiatrists. Problems can also be due to the power imbalances between therapists and clients, and/or the paternalism of mental health professionals working in a system based on the medical model.

Rapp, Shera and Kisthardt (1993) speak of the negative side-effects of talking therapy in a clinical setting. What they call the social iatrogenesis[8] of this intervention can increase stress and dependence while reducing choice and self-responsibility. The counselling therapy may negatively impact empowerment, self-esteem and self-efficacy. In my practicum at a community mental health team, I saw instances of the paternalism, infantilization, disempowerment, and reductionism that I had read about. On the other hand, there were also professionals who cared for the people they saw, who worked for their empowerment within the restrictions of the system.

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[8] Iatrogenesis is the process of inadvertently inducing an effect in a person from an intervention by a surgeon or physician, or from a treatment or diagnostic process.

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What compounds the dual problems of control and consent is the iatrogenic effects of physical treatments. Parkinsonism and Tardive Dyskenesia, Tardive Dementia and occasionally death from Neuroleptic Malignant Syndrome all result from the use of neuroleptics; tranquilizers are highly addictive; and electroshock therapy erases memories and may cause permanent brain damage.

**Just take this pill and go buy yourself a hat.** From numerous epidemiological surveys it has been shown, "...that depression and anxiety are the leading mental health problems among women but are found less frequently among men" (Padget, 1997, p.523). One in four women suffer from domestic abuse. There is also the potential of experiencing sexual abuse as girls, sexual harassment, and rape as adult women. These all too frequent traumas result in major depressive episodes being many times more likely for women unfortunate enough to be victims of abuse. Women's position in society, their devalued status, chronic strain from poverty and sex role burden also have their impact. Poverty has been shown to be linked to higher distress and depression (Padget, 1997; Stolzman, 1988).

Feminists believe that the established social norms are not acceptable as the standard for which abnormality is to be defined, or if it should be defined at all. The norms of our society are under a patriarchal, capitalistic umbrella, and as such can be injurious to women and minority groups (Brown, 1994; Burstow, 1992). Diagnosis has a gender bias when women are more easily diagnosed as having a mental disorder and more often diagnosed as having depression and histrionic personality disorders (Caplan, 1995; Padget, 1997). When men manifest antisocial behaviour or alcohol abuse they are less likely to be diagnosed by physicians as having mental disorders (Padget, 1997). The power to diagnose is the power to define another's reality and potentially to restrict their freedom. A woman diagnosed becomes an object, no longer subject or in control of her own life (Brown, 1994; Smith, 1990). Smith (1990) describes the patriarchal nature of psychiatry:

The standpoint of men is built into the traditions of its theorizing and knowledge; that effect is reinforced by the continued predominance of men, particularly in dominant psychiatric profession. Beyond that, however, psychiatry participates in and reinforces the patriarchal character of locally produced orders, such as families, as a routine effect of its operation. (P.32)

Being diagnosed means treatment by medication, the main treatment unless one is able to afford private therapy. Women in many countries are prescribed more psychotropic drugs, twice as often as men. It has also been found that women are more likely to suffer from side-effects and to be at risk of drug interactions with their hormonal fluctuations (Padget, 1997). The interaction of medications with women's life cycles, menses, pregnancy, or menopause need to be clearly investigated or explicated in drug research (Morrow & Chappell, 1999).

Explanations of women's differing ways of accessing health care such as having greater need, being higher health care users, or more amenable to drug taking were all dismissed by several studies made. The final explanation left was gender stereotyping in drug prescribing, which, "...fits social control (Zola, 1972) and, in particular, as a means of managing and controlling women's behaviour" (Padget, 1997, p.527).

Women are at risk of acute stress responses[9] and Post Traumatic Stress Response (PTSR) from family violence and sexual abuse. Many women who end up in the mental health system have histories of abuse which are not elicited and/or addressed and are then revictimized by the coercive and restrictive treatments. As reported by the Human Resource Association of the Northwest, "...two thirds of women who are chronic users of public mental health have experienced early childhood sexual abuse " (Caras, 1999). In another study of women psychiatric inpatients, "...83 per cent had experiences of severe physical or sexual abuse as

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[9] Following the terminology used by Morrow and Chappell (1999), I use stress responses rather than stress disorders as they assert that the distress that is experienced is a natural response to trauma not an aberration.

children or adults" (Morrow & Chappell, 1999, p.33). To avoid revictimization and stigma, services need to be tailored to the women's needs for safety with non-coercive protected environments and with the provision of appropriate psychosocial treatments.

Many feminists have written that the medical system and psychiatry in particular perpetuates gender inequality (Brown, 1994; Burstow, 1992; Smith, 1990).

> Women who characteristically act "inappropriately"--who defy their role as being-for-man generally and as body-for-man in particular--stand a very strong chance of being labeled "borderline personality disorder" or psychotic and of being institutionalized.
>
> (Burstow, 1992, p.34)

Besides being a place that is the, "...ultimate enforcer of patriarchal norms" (p.33), psychiatric institutions also divert attention from the consequences of the inadequate support for many women in society today. "Women have been mislabeled profoundly with psychiatric disorders and individual psychopathologies, which are instead the consequences of social, political, economic, psychological, and physical oppression of women" (Caplan in Cowan, 1996, p.21).

Children are apprehended and often never returned to mothers who are labelled with chronic mental illness. "Societal Attitudes and wide spread myths and stigma surrounding mental illness continue to perpetuate the belief that women with mental illnesses are incapable of having and caring for children" (Cowan, 1996, p.40). Instead of looking at the social problems, lack of support, and inadequate services they encounter, mothers are individually blamed and punished.

In addition to being women, those with different sexual orientations, those from minority ethnic backgrounds, and/or with other disabilities may also find themselves with psychiatric diagnoses and prescribed medications instead of receiving counselling for the distress from their problems in living and the discrimination they suffer from.

There are gaps through which many consumer/survivors in need of support will fall, including the problems of dual diagnoses which also are not well addressed. "Most resources for substance abuse are not designed to help women who have a mental illness diagnosis" (p.41). Morrow and Chappell (1999) recommend, because of the lack of understanding about women who are dually diagnosed, that there needs to be more recognition of the interconnections between substance abuse, mental health problems and histories of physical and sexual abuse.

**'Damaged' people don't recover!** Medical authority, with the economic backing of pharmaceutical companies, has control of the mental health system. Based in an illness-based paradigm, psychiatry looks for pathology in the behaviour of their patients. Progressive mental health professionals, with knowledge of the process of recovery for people diagnosed with serious mental illness, believe they can recover, support their strengths and abilities, and encourage them to take responsibility for and control over their illness and recovery. This support is needed to counter the internalized stigma from a psychiatric diagnosis and the disempowerment of a system which requires passive patients who are controlled and managed.

Unfortunately, the ideology of biological determinism, which many psychiatrists endorse, precludes the possibility of significant recovery for those whose brains are believed to be defective. The maintenance of stability is the primary goal of treatment and keeping stress to a minimum is part of what practitioners try to control to protect their patients from relapse. Because a psychiatric disability discounts people's ability, and/or includes the propensity for delusional thinking, people are not encouraged to take control of their lives. They are often supervised to ensure they comply with taking their medications. Even with the best intentions empowerment in a recovery process can not be sustained in a system which has power imbalances and the ability to coerce and commit (Segal, Silverman, & Temkin, 1993).

**The exploitation of peer support .** Mental health systems are discovering that peer support is a valuable addition to their services. Research on the importance of peer support

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and role-modeling, as well as the usefulness of peers to reach those distrustful of professionals has meant that peer support workers and peer providers are increasingly being hired in psychiatric systems. The participation of consumers, backed by mental health policy, will hopefully help the shift to a healing paradigm.

The concept of using the special skills and knowledge gained from achieving recovery as part of a treatment approach to help others recover is exciting. The opportunity this presents for consumers to shape the system to more effective and empowering models of support, based on the recovery experience, is intriguing. The tension that will inevitably arise between traditional approaches and consumer views should be salutary for programs and clients. (Fox & Hilton, 1994, p.629)

There are several issues around providing peer support within the structures of the mental health system. Forbes and Sashidharan (1997) note that, "...typically participatory schemes have mirrored rather than challenged broader oppressions and discriminations" (p.493). Racist stereotypes of `mad, bad, and dangerous' for black people, and `control' in the guise of protection for women, are only two of the problems of diversity in mental health. Forbes and Sashidran state that "..pressure for change has come primarily from *outside* participatory debates and structures, from feminist and black organizations. Any attempt to locate such oppositional strategies within an undifferentiated model of user involvement will only blunt its oppositional strength " (p.495).

Other articles warned that consumer participation will moderate the oppositional force trying to protect consumers' rights, and engage in anti-discriminatory activity (Bowl, 1996; Fisher, 1993). Although there is no guarantee that consumer/survivor-run programs will not also discriminate, consumer/survivors' own experience from the stigma of a psychiatric diagnosis will hopefully sensitize them to other peoples' stigmatization. Groups must be self-reflective to avoid the danger of replicating hierarchy and discrimination.

Employment in mental health services is opening up at all levels but there are now positions especially designated for consumers. Some of these are consumer advocates, peer support workers, peer counsellors, and assistant case managers. They provide support services, extension of services provided by professionals, advocacy and resource acquisition, teach coping skills and problem solving, act as role models and engage consumers in socialization.

Consumer/survivors experience difficulties providing services in conventional mental health facilities or organizations (Mowbray, Moxley, Jasper, & Howell, 1997). The creation of the identities of chronic mental health patients in the psychiatric system can be counterproductive to the process of recovery. Strong resistance to labelling and stigmatization along with well-established identities, not based on an illness paradigm but on the reality of recovery, are needed to be able to work within the system. There are professionals who believe in recovery and are of great assistance to consumer providers, but often the support needed to be successful is not available. Mowbray, Moxley, Jasper and Howell (1997) state that consumer providers who want to hasten their recovery and help others recover experience fewer difficulties in providing services that are controlled by consumer/survivors, but they encounter more difficulties in accessing sufficient funding.

There is dissonance in the call for more participation of consumers in mental health services, and some professionals' desire for further restrictions and coercion with community treatment orders. This reflects the ambiguity of a system that is supposedly supporting the recovery of those with emotional difficulties while also acting as a police force, enforcing social control.

## Conclusion

The domination of the Cartesian-Newtonian worldview and the 'masculinization' of thinking in science has resulted in a medical system which treats people like machines needing repair and which ignores the subjective and relational aspects of people's lives. This results in a practice of psychiatry which invalidates people's own experience and individualizes problems that may

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be more appropriately looked at in the context in which they arise. The 'science' of diagnosis is not as scientific as it claims to be with the disclosures of how a new diagnosis is, at times, arbitrarily included into the bible of mental health, the Diagnostic and Statistical Manual, without any substantial base of research to support the claim (Caplan, 1995; Brown, 1994; Burstow; 1992).

The biases and prejudices of psychiatrists who diagnose are ignored in the process of the supposedly 'objective' observations of pathology in behaviour which is taken out of context. Abuses can and do occur when people are labelled with a psychiatric diagnosis and lose their credibility and rights. Feminists complain about how women's problems are overmedicalized and how they are misdiagnosed in the institution of psychiatry which serves the interests of patriarchy and capitalism (Burstow; 1992; Brown, 1994; Caplan, 1995, Lerman, 1996; Smith, 1990).

The process of recovery is not feasible in a system which denies consumer/survivors the dignity to risk and the right to failure (Deegan, 1992). The integration of peer support services into the psychiatric system has some people concerned that the struggle against stigma and the abuses found in the system will lose support. But, the inclusion of consumer/survivors into the mental health system as members of boards, committees and in peer support positions also gives hope that their perspective will be listened to.

## CHAPTER 2

## A Review Of The Literature

## Researching The Voices OF Consumer/Survivors

If knowledge is power, then the results of research must be placed in the hands of those we seek to empower. (Rapp, Shera, & Kisthardt, 1993, p.733)

Unfortunately, there has been very little research which has accessed the views and perspectives of those who use the psychiatric system. These people have not been considered important informants for research in this area. Although empowerment[10] is a well accepted social work and mental health principle, "the research in the field often fails to reflect or support it" (Rapp et al., 1993, p.733). In fact, "the definition of problems conducive for blaming the victim is not only descriptive of mental health research but of much of the research in both social work and psychology" (p.728). Sympathetic and concerned mental health professionals advocate for research that instead empowers people with the label of severe mental illness (Chesler, 1991; Rapp, Shera & Kisthardt, 1993; Rogers & Palmer-Erbs, 1994; Swigonski, 1993).

In their study, Calsaferri and Jongbloed (1999) explored rehabilitation needs from the perspectives of consumer/survivors, their families or caregivers and their case managers. The study showed that "...far greater needs for services were expressed by consumers and significant others than by case managers, indicating that case managers pay insufficient attention to what consumers want" (p.199). The authors focused on the need for the empowerment of consumer/survivors through greater control of the decisions made about the amount and types of services they receive. Calsaferri and Jongbloed wrote that consumer control "...may be difficult for some professionals, because it involves redefining what it means to be a professional (as cited in Vandergang, 1996)..."; and because "...they need to listen to

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[10] Empowerment is defined as the "process of gaining influence over events and outcomes of importance to an individual or group" ( Foster-Fishman, Salem, Chibnall, Legler, & Yapchai, 1998, p.508).

what consumers say about their needs and lives and to value personal experience and emotions as forms of knowledge" (p.208). The study and its findings were used to promote change within organizations as well as with individual professionals, and increased the awareness of the staff about the needs of the people they serve and their rights to make decisions about services (1999). This recent Vancouver research project validates the importance of accessing the voices of consumer/survivors and then using the information gathered to make progressive changes to how services are delivered.

Researching the lived experiences of consumer/survivors is acknowledged by many researchers as a respectful way to access their expertise and knowledge, to explore as much as possible a perspective which has been previously ignored (Chesler, 1991; Constantino & Nelson, 1995; Kaufman, 1994; Rapp, Shera & Kisthardt, 1993; Rogers & Palmer-Erbs, 1994; Swigonski, 1993). New research initiatives include consumers in the design and implementation of research and promote the "...incorporation of consumer experiential knowledge as a basis for inquiry and understanding of mental illness and its treatment" (Kaufmann, 1994, p.170).

The consumer/survivor perspective may also bring necessary information which is missing when only professionals' voices are listened to. Rapp, Shera, and Kisthardt (1993) point out that efforts at deinstitutionalization in the mental health field that rely on professional judgments "have failed miserably", and that recovery and employment have had poor results from "...professionally designed interventions (Bond & Boyer, 1991; Dion & Anthony, 1987); it is possible if not likely that more effective alternatives could emerge from asking consumers" (p.730).

However, there are those who see that the current movement to include the voices of marginalized people in the development of services they use can in fact be undermining to their interests and needs unless the opportunity is taken to "...further politicize the debate, and to

challenge the interests of institutional agencies which are often inimicable to those of users"
(Forbes & Sashidharan, 1997, p.496). They also point out that "...the oppositional voice of the
users has always been articulated, long before 'user involvement' in services began to be
discussed. However, it is this voice which risks being silenced within current models of user
involvement..." (p.496). It is not only important to give expression to the voices of marginalized
people but also to ensure they are empowered by the opportunity.

Some professionals in the field of psychosocial rehabilitation promote empowerment
because they have observed how important it is in the recovery of consumer/survivors' mental
health (Anthony, 1993). The Center for Psychiatric Rehabilitation at Boston University has been
actively exploring how "...to increase participation by consumers of mental health services in
research" (Rogers & Palmer-Erbs, 1994, p.7). They are asking consumer/survivors to help
design and direct current research and are exploring how to develop participatory action
research[11] (PAR) by and for consumer/survivors. "It is critical that the "voice of the consumer"
be acknowledged in research and evaluation studies...This approach may change the "power
distribution" for consumers" (p.10).

## Research with Consumer/Survivor Self-Help Groups

One participatory action research investigating self-help programs (Chamberlin, Rogers, &
Ellison, 1996) was led by professional researchers from the Center for Psychiatric Rehabilitation
at Boston University. They included as the project director, Judi Chamberlin, a
consumer/survivor and author of the popular book, On Our Own; Patient Controlled Alternatives
to the Mental Health System (1978). A consumer research advisory board considered to be
representative of diverse opinions of the self-help movement was consulted in the design and
plan of the inquiry; the board also contributed to the development of questions to be used in an

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[11] Participatory action research is a method which is well suited to self-help groups. It is
designed and conducted by a group by themselves or in collaboration with an outside
researcher(s). The goals of the research are pragmatic and aimed to facilitate changes which
the group wishes to initiate (Chesler, 1991).

evaluation survey. This was a quantitative study which gathered information on demographics, quality of life, self-esteem and social supports of members as well as their opinion on the value they received from attending the self-help programs.

The study found that members of self-help groups were very satisfied with the programs; they reported an increased quality of life, with improvements in social support, self-esteem and self-respect. Members were able to "...meld services from traditional sources with those offered by the self-help program" (Chamberlin at al., 1996, p.40). It was found that the members' levels of community and political involvement were high, contradicting a widely held stereotype about the apathy of consumer/survivors.

In their final statement the authors stated that, "as we learn more about self-help programs and their participants, we may learn about different ways that quality of life and community tenure can be improved" (p.41). The self-help groups also gained by having research which shows the benefits of their programs to current and potential funders.

Trainor, Shepherd, Boydell, Leff and Crawford (1997) investigated the outcomes of the Consumer Survivor Development Initiative (CSDI), a program which funded thirty-six consumer/survivor-run organizations in Ontario. This was both a quantitative and qualitative study which used questionnaires to collect quantitative information and focus groups to gather qualitative data.

Some important findings of this study were that all consumer/survivors, who joined a CSDI decreased their use of mental health services; especially significant were reductions in inpatient bed use, rates of hospitalization and outpatient visits. The members increased their contact, involvement and people skills both with other consumer/survivors and those in the broader community. And the CSDI groups were ranked as the most helpful of all of the services they received, and consumer/survivors as "...significantly more helpful in dealing with their mental health issues than any professional group" (Trainor et al., 1997, p.138).

The authors' recommendations for increased recognition and funding for consumer/survivor self-help groups reflects that they are good allies for the aims of these groups. The report, however, did not reflect the presence and the voice of consumer/survivors themselves. The report was in a publication targeted for an audience of mental health professionals which would have influenced its design. To be acknowledged as legitimate holders of knowledge and experience, consumer/survivors need to be visible and audible in the reports of the research of the organizations they run. The CSDI groups represent innovations developed and run by consumer/survivors and deserve the respect that is accorded other mental health organizations.

> Since issues of personal and collective empowerment are crucial in self-help groups, inquiry methods and actions for change that explicitly empower participants (see earlier comments by Cancain and Armistead,1990; Gaventa, 1988; and Rappaport et al.,1985) become extremely important. (Chesler, 1991, p.764)

St-Amand and Clavette (1992) write an account of another research project studying self-help. The authors used the voices of self-help members to tell the stories of their experiences both with professional services and within the self-help group. They rely on the power of these words, "...spoken out of direct experience, to convey important lessons about the need for professional humility and recognition of the fortitude and ingenuity that people bring to the multiple tasks of managing their own lives" (p.xi). They used personal accounts "...to get as close as they could to the point of view and the experiences of people with mental health problems" (p.50) as well as to conduct an in-depth exploratory study of the process of mutual-aid.

The authors set out to analyze the stories for what they revealed about how the participants sought help and what it meant to them. The aim of this study was to develop an understanding of "...the diverse modes of social resourcefulness exhibited by people with psychiatric problems

and contribute to the development of a more comprehensive approach to the training of professionals who are called upon to provide them with the help they need" (St-Amand & Clavette, 1992, p.56).

This research again benefits professionals and the development of their services, but also meets the needs of the self-help groups for positive reports of their "alternative" practices. The self-help members were seen as the 'objects' of the study, not as subjects involved in the research process.

The authors do ask the questions of how professionals can be involved in the development of self-help groups without co-opting or impeding autonomy, and how to accept that professional services are often not useful for self-help group members. They end by linking the rise of mutual-aid in the mental health area to "...a global social movement aimed at returning people to their rightful place in social organizations and "therapeutic" relationships...involving the humanization of social relationships and a new ideal of justice and equality between people, cultures and nations" (p.140).

These research approaches attempted to access the voices of consumer/survivors but were conducted from the standpoint of the professional researcher. To do full justice to the viewpoint of these marginalized groups, to truly reflect their voices, research should be conducted from as close to the standpoint of consumer/survivors as possible and of course be of benefit to their goals.

**The Transformative Power of Stories**

Powell (1994) edited a collection of essays and reports of research with self-help organizations. In one article by Rappaport (1994), the narrative approach to research is promoted "...as a way to understand human experience, memory, and personal identity from the point of view of a person in a social context " (p.115). Rappaport's thesis is that

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the narrative approach is a "...powerful analytic and methodological tool..." (p.116) for the study of mutual help. When self-help groups are viewed as narrative communities, researchers "...avoid the professional centrism that necessarily emerges from conceptualizing mutual-help organizations as alternative treatments...for people with problems in living" (p.116). Professional centrism occurs when professionals may see the positive value of self-help but always view their own group as more helpful than self-help groups.

Rappaport points out that the medical-social service model defines these groups as alternative treatments from the professionals' own perspective of service delivery and for their own purposes. As in the previous studies reviewed, this perspective leads researchers to focus on what professionals can gain from the research. These studies can lead to funding and collaborations, based on the treatment and service delivery model, which may make the groups vulnerable to take-overs by well-meaning professionals.

Rappaport also sees that the nature of self-help includes the rejection of the status of service recipient expressed by "...the adoption of a new ideology and a transformation of identity, or sense of self, according to a narrative provided by the organization" (Rappaport, 1994, p.118). He points out that when self-help is seen as an alternative treatment service, studies can yield information about the effectiveness of the group but they cannot capture the experiences of the members or inform the researchers as to why people and their identities were transformed by belonging to this mutual-help group.

"Researching mutual-help as "the stories people tell" has several advantages, not the least of which is to free the idea of mutual help from the stigmatizing implication that those who are involved in such organizations are more needy or less competent than those who are "on their own" or that the implicit standard for comparison is professional treatment" (Rappaport, 1994, p.121) Rappaport observed that the stories told by members of self-help groups were very different from those told by people who only accessed help from professional services. "Typical

professional patient stories often revolve around learning to see one's self as sick and dependent on medications to control behavior...Professional patients...see themselves as dependent recipients of services who have little to offer others" (p.122). Members of self-help groups see themselves as givers and receivers, who have hope and a capacity for positive change within a caring and sharing community (Rappaport, 1994).

Rappaport sees these groups of consumer/survivors as no different from other communities where a change of identity and behaviour is seen as a change of membership and lifestyle, not as a "treatment outcome". In this way the self-help community can be seen as a normative structure in social experience; it is not people receiving services, it is people living lives. This normative view allows members to be seen as no different from "...people who also continue to develop and change their individual identities in the context of social and community life throughout the life span" (Rappaport, 1994, p.124). Joining a self-help community is a way to ask the question, "Who am I?" and to reject the professional treatment story and the identity it offers for recipients of professional services.

Rappaport writes that narrative studies have the advantage for self-help "...of not doing violence to the perspective of the members...or to the self-help ethos (Riessman, 1985) because it requires understanding the world from the point of view of the individual members and their community" (p.126). Narratives also leave the context within which people live; the place, time and action of experiences and what people find meaningful about them. Rappaport proposes "...that self-help organizations can be viewed as a special class of communities in which an alternative identity is provided..." and that, "...a change in one's community of membership can be an important source of change in personal identity" (p.128).

Rappaport (1994) comments on the ideas of Schank, a cognitive psychologist, who says that the telling of negative stories might actually reinforce the problems that people experience. When people tell positive stories these become reinforced and people see themselves in a

better light. He also "...suggests that untold stories can be troubling in part because if not expressed they can remain less coherent. Stories told only to oneself do not benefit from the modification and coherence required for a listener" (Rappaport, 1994, p.129). The untold stories may retain childish meanings and provide bad explanations for present. Schank suggest that negative stories should be told to a person once and never again, so that the memories are not reinforced and are allowed to disappear. Members of a mental health self-help group were delighted with this information as they said their members were tired of telling bad stories to professionals and saw their group as doing its best for people when new stories about dealing with the tasks of life were being told.

Rappaport (1994) states that he believes that "...personal reality is constructed (and therefore can be reconstructed throughout the life span) and that there is an iterative process between the internal and external" (p.131); the stories incorporated from community narratives modify the personal life stories of individuals and vice versa. These concepts validate the importance of researching the stories that consumer/survivors tell about their experiences with psychiatric services, self-help, and the transformation of identity; by hearing each others' stories they can reconstruct positive personal realities. This article inspires the use of the narrative research approach and validates that it is appropriate for the study of members of a self-help group.

In Holland, research was conducted at a mental hospital with both patients and professionals as participants. The form of the study was a narrative inquiry which focused on a vocational rehabilitation project to provide patients with employment as staff of a boutique in the hospital. The researcher, Tineke Abma (1998), found that the standard story that led the professional practice of the therapists "...supported the idea that psychiatric patients were dependent on the expertise, care, and protection of therapists" (p.822). The result of the routines based on this story was passive behaviour from the patients when what they really needed was to take responsibility for their lives in order to recover and return to society and the work force.

Abma (1998) reasoned that for a transformation of professional practice, the standard story "...had to become the subject of doubt and critique" (p.822), and that the introduction of new stories which deviated from the standard would result in more critical awareness. He found that some professionals would not easily leave the standard story and opposed the proposal.

Abma proposed to conduct a cooperative inquiry with those who had an interest in the project, and to engage the participants as partners in the inquiry process, a strategy aimed at overcoming the participants' resistance and ensuring their openness. The process involved the sharing of stories both by the patients and professionals. The design was allowed to emerge in response to these stories.

The study was grounded in a social constructivist perspective which views the world as constructed by people who tell stories about their 'lived' experience from their own specific standpoint, in order to make sense of what happens to them. There are standard stories which provide a base for many of the beliefs and activities in society. "The standard story is...so self-evident that its claim to validity denies the need for justification or proof " (p.825). Abma believed that when stories which are marginalized, because they deviate from the standard story, are "...invested with powerful symbols, they can enrich the standard story with other experiences and generate changes in practices" (p.825).

When the patients told the stories of what working in the boutique meant to them, they talked of how it "...touched their whole being. They no longer were objects; they were becoming subjects" (p.827). They spoke in a 'natural' common language. In contrast, the therapists spoke with abstract formality and told a 'therapeutic' story which related to a functional rather than existential meaning of experiences. The researcher suggested that for the therapists "the abstraction of experiences is a routine solution for managing their own feelings; it protects them from the suffering experienced by their patients" (p.827). The distance kept by the professionals was "...experienced by the patients as a denial of their life stories and existential

questions" (p.827). The power differences led to a 'narrative imbalance' in which the patients' stories could not develop. "Their uncompleted stories were not heard and, hence, were not validated" (Abma, 1998, p.828).

One theme found in the analysis of the therapists' stories was that "...they felt bound by the organizational context in which they worked...one dominated by large numbers and a lack of time" (Abma, 1998, p.830). Because of these demands of the organization "...they fell back on the routine solutions supported by the standard story of the therapist as expert" (p.830). When the therapists recognized that it was their practice which determined the dependent behaviour of the patients, the standard story was seen as inadequate. Their feelings of frustration and disquiet led them to realize that a new story was needed.

From hearing the stories of the patients, the therapists saw themselves differently; the stories acted like mirrors and they did not like the discrepancy between what they thought their practice was and how it was reflected back to them. The therapists then opened to the patients' stories and "...this led to an adjustment of professional practice because therapists redefined their relationship with patients as well as their own identity and role" (Abma, 1998, p.835). The transformation allowed the therapists to care and watch out for their patients' health while also encouraging them to take responsibility and make their own decisions.

This study illustrates that through cooperative inquiry, sharing stories, and inviting mutual reaction, stories can be changed. And when stories change, people change, resulting, in this case, in transformations of professional practice. Abma (1998) reflects that "...development and change in practice do not come from the rational application of formal abstract knowledge and information but rather from *new experiences*" (p.836). Detailed narrative accounts can give people these new experiences by the "transport of knowledge from the setting of another to a context of their own" and then through the incorporation of this knowledge by its meaning and validity to their own life (p.836).

The use of a narrative style of writing in the research report increases its impact. Its importance is that it relays a method of bridging the experiences of two very diverse groups who have been polarized in their roles and behaviour towards one another. The article inspired my research project with the possibilities of transformation from the use of narrative research and validated the use of stories as an effective way to transmit the experiences and the meanings behind them for people who use or have used the psychiatric system.

## Research on Empowerment and the Recovery Vision

Wilson (1996) advocates for the need for further research on the role of empowerment in consumer/survivors' mental health, and "...the interplay between personal and community involvement, such as factors that contribute to successful consumer initiatives" (p.82). The involvement of consumer/survivors in self-help and consumer/survivor-run organizations has been identified as contributing to their empowerment as well as significantly reducing their use of professional mental health services (Anthony, 1993; Rappaport, 1994; Trainor et al., 1997).

Foster-Fishman, Salem, Chibnall, Legler, and Yapcai (1998) report on a case study designed to explore the assumptions of empowerment theory. The authors discuss the importance of a collaborative or joint insider-outsider approach for research with community groups. They argue that "...inquiries directed solely from the outside cannot reveal the insider's lives" (p.532). They use a phenomenological stance for their inquiry and questioned the accuracy of the representation when insiders are not included in the writing of a report.

At the National Summit of Mental Health Consumers and Survivors (NSMHSC) (1999), consumer/survivor participants discussed the need for more research on peer-run alternatives; to generate funding, to document what works for whom and at what cost, as well as to gather knowledge to improve existing programs and to develop new ones. "Research can help promote peer-run alternatives as a promising way to reach more people and better support their

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recovery and respond to their social needs" (p.28). The facilitator, a university researcher, found from experience that scientific methods of research are often at odds with the values and capabilities of peer-run alternatives. The leader of the workshop noted that there are many problems with the involvement of consumer/survivors in research projects; from turf wars about power and control, to conflicts over interpretation and the use of findings, to inadequate resources, pay, and technical assistance. All of these problems "...undermine trust, cooperation and sustained commitment...There is a danger that consumer involvement in research is creating stigma, exploitation, and tokenism even as researchers attempt to be inclusive" (NSMHCS, p.29).

These dilemmas require researchers to be vigilant and self-reflexive about their motivations and attitudes towards consumer/survivors and to work in collaboration with them as much as possible. Consumer/survivors need access to training and information to be equipped to be involved in a meaningful way. The goals of research and the use of the findings must also benefit the aims of consumer/survivors and their groups. As much as possible research could be conducted by and for consumer/survivors with methods such as participatory action research and with the provision of adequate funding and support.

Anthony (1993) writes that "...recovery is a simple yet powerful vision" (p.16). "It speaks to the heretofore unmentioned and perhaps heretical belief that any person with severe mental illness can grow beyond the limits imposed by his or her illness" (p.22). He talks about developing a recovery-oriented mental health system but admits that there has been no research about the process of recovery. He recommends that both quantitative and qualitative research be conducted, but suggests that qualitative research is appropriate for understanding "...the experience of recovery from mental illness from those who are experiencing it themselves" (p.20).

## Consumer/Survivors Writing in Their Own 'Voice'

Over the last thirty years, alongside the development of the consumer/survivor social movement, many articulate consumer/survivors have published books and articles expressing their views and telling the stories of their experiences. Irit Shimrat (1997) told her own story and the stories of leaders of the 'mad movement'[12] in Canada. These leaders have many different viewpoints about what "mental illness" is but are in agreement about the inhumanity of many of the practices of psychiatry such as electroshock treatment and forcible drugging. The contributors have been advocates who have fought many battles in defence of their own and others' rights, almost all of them consumer/survivors themselves; the exceptions are sympathetic professionals dedicated to supporting consumer/survivors. They all see that there are better ways to help people recover than is provided by the mental health system.

One of these leaders, Gisela Sartori, is a founder of the Second Opinion Society (SOS) of Whitehorse, Yukon. Her group was asked, by the then Minister of Health, Joyce Hayden, to survey the needs of the psychiatric survivors in her area. Hayden had commented in reading a proposal put forth by the local Canadian Mental Health Association, "Where are the *people* here?" (Shimrat, 1997, p.126). Hayden found that the plans for a half-way house were too medically oriented and controlling, with no input from the people it was meant to serve. The federal health promotion department called the assessment, "...one of the best participatory research projects that has ever been done in Canada" (p.127). Sartori strongly suggests other groups do similar projects. She concluded that having research behind proposals almost guarantees they will be funded (Shimrat, 1997).

Shimrat says that the 'mad movement' activists "...have started self-help, political and creative groups that have made a difference" (p.152). She ends by saying that "I and my crazy friends have a great deal to teach people about alternatives, not only to psychiatry but to other

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[12] The 'mad movement' is a social movement of consumer/survivors who have banded together in solidarity against the abuses and loss of human rights for those who are treated in the psychiatric system.

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ways in which people are oppressed...Surely we can create a thousand things that really work, not for settling people and making them normal, but for relieving their pain and freeing them to think, feel and do" (pp.169-170).

Another author, activist, and teacher is Patricia Deegan (1996), a consumer who developed a 'survivor mission' in resistance to the pronouncement by a psychiatrist that the best she could hope for was to take her medications, avoid stress and cope. Her mission was "...to get a powerful degree and have enough credentials to run a healing place myself" (p.96). She slowly recovered, read tons of books, and eventually received her doctorate in clinical psychology. She began in the traditional role of psychologist but left it when she disclosed that she was a consumer/survivor and began working with and for her 'peers'. She joined a branch of the L'Arche Community, one of 125 around the world founded by the Canadian Jean Vanier. Here people learn to live with those with disabilities, sharing their life with them. Deegan quotes Vanier, "People come to l'Arche to help wounded people and stay because they discover that they, in fact, are wounded too" (Deegan & Smoyak, 1996, p.45). Deegan is currently the director of training at the National Empowerment Centre, a completely consumer-run and controlled national technical assistance center, with many innovative trainings and resources, courses such as Hearing Voices That Are Distressing: A Simulated Training Experience and Self-help Strategies.

At a conference, Deegan (1996) addressed students in the mental health field advising them on how to approach people with psychiatric disabilities. She told them that "people who feel powerless also feel that what they say does not matter. Taking the time to listen to people and help them find their own unique voice is important" (p.95). She also told them how "...people who are psychiatrically labelled are organizing...developing a collective voice and are fighting to overcome oppression, poverty, discrimination, and stigma...We are also beginning to define our

experiences in our own terms and to educate professionals about our experience and what helps" (p.97).

Deegan & Smoyak (1996) present a story Deegan tells to the teenager she was when she was 'psychiatrized', and that she wished she could tell all teenagers who had just been labeled with the major mental illness of schizophrenia. This narrative style is very moving and really exemplifies the difficulties faced by a young psychiatric patient. Deegan describes how people treated her as a schizophrenic.

It is as if the whole world has put on glasses that blind them to the person you are and leaves them seeing you as an illness. It seems that everything you do gets interpreted through the lenses of these warped glasses. If you don't laugh, that is worrisome, and if you laugh too much, that is also worrisome...The range of behaviors and feelings you are allowed has been dramatically narrowed as a result of the blinders that those around you have put on. (p.41)

Deegan also talks about how recovery is not just the recovery from mental illness but also from the effects of being labelled mentally ill. "I believe many of us emerge from mental institutions with full-blown post-traumatic stress disorders that are a direct result of the trauma and abuse we may have experienced or witnessed in mental institutions or in community-based programs" (p.43). The following are her final words to herself as a teenager.

You have the wondrously terrifying task of becoming who you are called to be...You are not called to be a mental illness...You were born into this world to grow and it is possible to grow into a whole healthy person who also has a psychiatric disability...Your life and dreams may have been shattered--but from such ruins you can build a life full of value and purpose" (p.44).

These are stories told by people who have recovered and are whole vital people, in spite of a label or continued symptoms. They are the inspiration that others need to believe that there is

hope for all who are given psychiatric diagnoses to grow beyond their labels and be all that they wish they could be. It is important for these stories and views to be researched and published to promote understanding of people's psychiatric experiences and the recovery process, as well as to work against the harm of stigmatization.

## Conclusion

The perspective of mental health professionals is practically the only one that is reported in texts, the media and throughout the general public. The alternative perspective of consumer/survivors is only just beginning to be heard, and is mostly listened to in order to improve already existing services or to reduce the costs involved. There is a whole body of knowledge and expertise that is being missed when the consumer/survivor perspective is minimized and only parts incorporated. Within self-help groups, consumer/survivors are developing the confidence in their own expertise and wish to develop programs which they know will help their members to recover.

This review of articles points to the need for research which is conducted from the standpoint of consumer/survivors, ideally with participatory action research by and for consumer/survivors, or with as much participation and collaboration as is possible. Accessing the voices of consumer/survivors who have experienced recovery is also important for understanding the recovery process to aid the development of recovery-oriented services. Self-help groups are in need of research to back their proposals for funding and to develop programs which address the issues of their members. If these consumer/survivor-run groups are to achieve the potential they have to be instrumental in the recovery of mental health for their members, they will need the support of allies, research to further their development and the provision of an adequate funding base.

# CHAPTER 3

## Theoretical Framework: Stories Researchers Tell Themselves

Social scientists have in the past followed the paradigm of the traditional scientific method to gain legitimacy for their work. Fortunately, in part due to the feminist movement and the followers of critical theories who focused on marginalized groups, there has been a shift away from approaching the study of humans in society as if they were parts of a machine. There has been an acknowledgment that too often knowledge gathered by supposedly neutral, objective researchers has in fact been used to further oppress certain groups (Denzin, 1994). One such group is composed of people who end up in the psychiatric system. Much of the research on this population is from the perspective of scientific medicine which investigates the great distress of these people as a way to learn how to better manage or control symptoms and behaviour. Most of the recent research looks at the interaction of medications and the physical structures of the brain, with some research into the differences in the size of particular areas of the brain thought to represent the source of problems or the result of brain defects.

Some sociologists have examined how psychiatry has created a legitimate medical profession from the medicalization of people's distress (Pilgrim & Rogers, 1993). Sociologists and social workers have looked into how people have been oppressed by the structures developed to manage this "psychiatrized" population. Theories have been developed by feminists to address the issue of the oppression of women in our society and the uncovering of the social structures which perpetuate this oppression. From these, feminist standpoint theory developed to promote inquiry from the perspective of women, emphasizing how their views on society are necessarily more inclusive and broader than the male perspective (Smith, 1990).

The theory which most informs this current research is standpoint theory. This theory arises from a critical paradigm and permits the investigation of the social structures that are embedded in the ordinary day-to-day lives of marginalized groups using the knowledge they have gained

from their standpoint. Feminist theory emphasizes that the voices of oppressed groups be accessed and given expression.

Other theories are incorporated when they are pertinent to this research. Phenomenology, an interpretative theory, looks for the meaning of individuals' lived experiences situated in a particular time and place. Poststructural theory reveals multiple, socially-constructed realities and permits the deconstruction of taken-for-granted discourses. Co-Cultural theory uses muted group theory and feminist standpoint theory as a base for its study in communication. Other theories which inform this researcher are those dealing with systems, particularly living systems as they apply to the social sciences.

## Feminist Standpoint Theory: We can see more than you can!

Swigonski (1993) states that feminist standpoint theory "...provides the tools to construct social work research that honors the profession's primary practice imperative" (p.171). The primary practice imperative being that of beginning from where the client is. Orbe (1998) believes that "standpoint refers to a specific societal position, the result of one's field of experience, which serves as a subjective vantage point from which persons interacts with themselves and the world" ( p.26). In social science research, people's standpoint is their social position as revealed by its location in social structures and informed by what relationship this location has to their lived experience. This standpoint reflects how a person's gender, culture, ethnicity, class, ability and sexual orientation affect their everyday life (Swigonski,1993).

Muted group theory was developed by anthropologists to describe the phenomenon of what happens when a group is marginalized; their views are not heard, and their perspective is in fact rendered invisible (Orbe, 1998). Foucault (In Riger, 1992) also coined the term `subjugated knowledges' for the silenced perspectives of these people on the margins of society. With their control of communication, only the views of the dominant culture are heard as legitimate.

Research is generally conducted from the perspective of the dominant culture which controls the creation and legitimization of social structures. Social work research often focuses on individual differences which can lead to blaming the victims of social inequities. This type of research can then be the base for the creation of policies aimed at personal change rather than policies which seek to change the underlying social structures. The result is the maintenance of the status quo.

Research from the standpoint of marginalized groups has as its aim to move the groups out of the margins and to place their daily experiences in the centre of the focus of research. "Research from the standpoint perspective attempts to understand how the social structure contributes to the problems found in day-to-day life and seeks the emancipatory transformation of the social structure" (Swigonski, 1993, p.173) It is a theory which promotes action research with the goal to liberate marginalized people from oppression. One of the tenets of standpoint theory is the significant involvement of marginalized people, such as consumer/survivors, in the process of conducting research in order to further their empowerment, to ensure their views are respected, and to guard against errors.

The benefit of research from the standpoint of marginalized groups is that the members of the groups have a different perception of reality as a result of the oppression they experience. Their alternate worldview is necessary to obtain a more inclusive and complete understanding of society. Not only do the marginalized have their own alternate view of reality, they have an understanding of the reality as experienced by the members of the dominant group. "To survive, they must have knowledge, awareness, and sensitivity of both the dominant group's view of society and their own--the potential for "double vision" or consciousness--and thus the potential for a more complete view of social reality" (Swigonski, 1993, p.173). In contrast to the notion of "double vision" is the notion that priviledge is invisible to those who have it; the priviledged have no reason to question the rights they possess and so assume them as

naturally occurring phenomena. They do not need to view the world from the perspective of less advantaged groups. The standpoint approach to research has the potential to expand people's views of reality and to avoid the dangers of unwittingly victimizing and oppressing the participants.

**Dorothy Smith: A diva of inquiry.** Dorothy Smith is a sociologist who participated in the development of feminist standpoint theory. Smith and others in the emerging women's movement saw that there was "...a standpoint from which a woman might know the world very differently from the way knowledge had already claimed it...We became aware of modes of speaking, writing, and thinking which took our powers of expression away from us even as we used them" (Smith, 1990, p.199). Her aim was "...to work from outside the conceptual and methodological procedures that objectify knowing as knowledge..." (p.200).

Smith, in her studies of the writings of Marx, found "...a method of reasoning and investigation that would connect up concepts and theories with the actualities of people's lives...", which would also allow the study and the expression of the social processes found within organizations and relations (p.200). "...It is the relations coordinating peoples' actual sequences of action that must be central to our investigation" (p.201). Standpoint theory is capable of

exploring and mapping actual organization and relations that are invisible but *active* in the everyday/everynight sites where people take up resistance and struggle, capable of producing a knowledge that extends and expands their and our grasp of how things are put together and hence their and our ability to organize and act effectively.
(Smith, 1987, p.96)

Smith herself has been diagnosed and hospitalized. As a sociologist she has analyzed the way a person, particularly a woman, receives a psychiatric diagnosis and is subsequently treated. She also has conducted inquiries into how written texts are used in psychiatry to create and maintain this new identity. She "...evaluates a text by its ability to reveal the invisible

structures of oppression in women's worlds" (Denzin, 1994, p.509). Some of these written texts are the mental health statistics, diagnostic manuals, and psychiatric and social work clinical case notes. For example, in case notes, "...typical constructions organize the account around the individual, obliterating the local contexts of her life and in particular the local contexts of the production of the account" (Smith, 1990, p.93). Who makes texts is also pertinent; the closer the person to the actual lived experience of the client, the less likely they will have authority to create texts as they wish. In mental health, nurses and social workers who do have direct contact with patients' experiences are subordinate to psychiatrists. They will also be constrained by the form of recording which is required. What does not fit into the organizational form of reporting cases is left out. "Accounts are shaped to fit the textual realities called for within the relations and apparatus of ruling" (Smith & David, 1975, p.103). Smith notes that once the information is developed, the descriptions, theories and practices in psychiatry move into use with popular media and the training of professionals, thus creating a general public knowledge about psychiatry. How people see and make descriptions of their own and others' experiences as a matter for psychiatric care is determined by this knowledge. "To be able to make such a description is to know how to make what I feel or you feel or she is doing, into a matter which is psychiatrically actionable. The reality of mental illness is a recycled reality" (p.102).

Smith uses standpoint theory in institutional ethnography to inquire into how things work and are actually put together. This method begins its study in actual situations and then explores the social relations that organize it. It is an inquiry into how institutional practices penetrate and organize the experiences of individuals (Smith, 1987). Institutional ethnography could be the method used to extend this current research and study fully the oppression experienced by people within the institution of psychiatry in order to uncover the relations and "apparatus of

ruling" embedded in its structures. Included in the study would be the experiences of mental health workers and professionals as well as of those they provide services for.

Standpoint theory, as a base for social work research, honors the profession's commitment to the empowerment and social transformation of clients. The consciousness-raising and critical thinking components of this type of research can be emancipatory for both the researcher and the subjects. (Swigonski, 1993, p.181)

**The disabling of ability.** In discussing disabilities, a feminist sociologist, Wendell (1996), writes that "...defining disability and identifying individuals as disabled are also social practices that involve an unequal access to power and have major economic, social, and psychological consequences in some people's lives" (p.23). She adds that one must not assume that people with disabilities share the same perspective or even have their disability be the most important aspect of their life. She poses that the medical model of disability tends to universalize the experiences of those suffering under the same category of disease or disability, while disregarding the social, political and economic factors that determine how disabling their situation actually is. A person with a psychiatric diagnosis from a high socio-economic level will have different experiences from one who must subsist on a disability pension. Finally, she says that people with disabilities have gathered a significant body of knowledge with a different standpoint from those without disabilities, and that this knowledge, "...which has been ignored and repressed in non-disabled culture, should be further developed and articulated" (p.73).

**Poststructuralists say, "How dare they tell the truth!"**

Standpoint epistemologies are criticized because the research from the standpoint of a marginalized group is said to gloss over the differences among the people in that group (Allen & Baber, 1992). Poststructural theory has as one of its tenets that there are no absolute truths or realities, only relativism; only situated and relative knowledges gained from being in a particular situation at a certain time and place. As Hawkesworth (as cited in Oleson, 1994), a political

scientist fears, "in a world of radical inequality, relativist resignation enforces the status quo" (p.164). This relativism means that there is no common ground from which to articulate political action for change when there are supposedly no real common issues, only situated knowledges as a basis to work from and develop collaborative action. And so the challenge for "...standpoint epistemology is to identify the commonalties of subjugated experience among different groups...without losing sight of their diversity" (Riger, 1992, p.734). "Smith (1992) describes standpoint theory not as a 'totalizing theory' but as 'a method of inquiry, always ongoing...relevant to the politics and practices of progressive struggle' (p.8) " (Orbe, 1998, p.26).

Riger (1992) writes that " one goal of feminist constructionist science is 'disrupting and displacing dominant (oppressive) knowledges' in part by articulating the values supported by alternate conceptions of reality (Gavey, 1989, p.462)" (In Riger, 1992, p.735). This goal definitely fits a standpoint epistemology. It also supports the work of this current research to articulate the values arising from the reality of the lived experience of those who have received psychiatric diagnoses.

**Deconstruction: The stripping of the veils of illusion.** One of the ideas from postructuralism that is useful in disrupting dominant knowledge is its method of deconstruction. "Deconstruction can be defined as an analytic strategy that exposes, in a systematic way, multiple ways a text can be interpreted... Deconstruction peels away the layers of ideological obscuration, exposing the conflict that has been suppressed; the devalued "other" is made visible" (Martin, 1990, p.340) It is the silences, gaps, contradictions, disjunctions, and disruptions which reveal ideology at work. Dichotomies are often candidates for deconstruction; they are mostly based on false distinctions, where what appears to be mutually exclusive opposites are in fact inextricable intertwined.

Poststructuralists state that there are multiple realities which are socially constructed and it is their power that dominant groups use to construct and define what is and what is not knowledge. This power is held through the command of language and the control of communication. The social construction of dominant discourses determine what are and are not social norms and standards. These dominant discourses are often composed of taken-for-granted assumptions and beliefs which are not questioned. In the process of deconstruction a critical perspective is used to examine discourses in order to show how other interpretations can be made. A dominant discourse can be deconstructed to reveal, in one possible interpretation, how it functions to maintain the status and power of the dominant culture.

A poststructural analysis of psychiatry can reveal a dominant discourse which justifies, backed by legislation, the right of a psychiatrist to take away another's freedom and lock them away, to enforce medication and other invasive physical treatments. The dominant discourse can also be used to determine what behaviour is pathological and in need of treatment and which is 'normal'; which person receives a psychiatric diagnosis and who does not. The accepted discourse promotes psychiatrists as caring and compassionate at the same time it emphasizes their need to control and manage people who may be 'dangerous' to themselves or others. It legitimizes their use of physical treatments without the consent of those who are suffering since they do not have insight into their illness. It appears reasonable and quite appropriate to describe their work in that way. But many argue that the deconstruction of psychiatry reveals hidden agendas. One agenda is to use physical treatments to promote psychiatry as a legitimate scientific medical profession with a high status and salary, as well as to increase profits for the pharmaceutical industry. Another agenda is to manage and control people who are discarded from society, while appearing to provide medical care for people who are said to have a disease of the brain (Cowan, 1996; Lerman, 1996; Pilgrim & Rogers, 1993).

## Feminists Teach How 'the Other' is Constructed

Feminist theorists have developed the concept of 'the Other' which can be used as another way of understanding the stigma experienced by marginalized people. When people are made 'the Other' they are grouped together as if they were objects rather than subjects who could be identified with. In this case, 'the Other' also become symbols of something to be rejected, feared and projected onto.

" 'Every version of an `other'...is also the construction of a self' (James Clifford, 1986, p.23). And I add, every version of a self must be a construction of the other" (Gergan, 1997, p.205). One's identity is determined by there being an 'Other'. "The exploitations endured today are protected/projected onto Others of varied colors, classes. sexualities, and bodies" (Fine, 1994, p.72). Working the hyphen of Self-Other (e.g. dominant-oppressed) is working *with* the marginalized and exploited, studying what is and is not in between Self and Other, revealing how `Othering' occurs and how we ourselves contribute to it.

It is argued that the dominant discourse or master narratives maintain social order while hiding the priviledge of researcher/writers. In many types of social research, "...texts that sought coherence of Master Narratives needed, and so created, Others. The clean edges of those narratives were secured by the frayed borders of the Other" (Fine, 1990, p.73).

The feminist Wendell (1996) writes that the social construction of disabilities is due to "the failure or unwillingness to create ability among people who do not fit the physical and mental profile of 'paradigm' citizens" (p.41). Wendell also points out that cultural stereotyping and the lack of cultural representation in society also contribute to disability.

The lack of realistic cultural representations of experiences of disability not only

contributes to the `Otherness' of people with disabilities by encouraging the assumption

that their lives are inconceivable to non-disabled people but also increases non-disabled

people's fear of disability by suppressing knowledge of how people live with disabilities. (Wendell, 1996, p.43)

Even when society recognizes disabled heroes, people who achieve some greatness or fame regardless of their symptoms or handicaps and because of their advantages and supports, it only reduces the `Otherness' for a few people with disabilities. Meanwhile it increases the `Otherness' for those who do not have same supports and advantages as these 'heros', as well as sets up ideals of achievement that most disabled people cannot meet (1996).

Social research with people who use the psychiatric system may not be of benefit to those who are studied. In fact, as with research with other marginalized groups, it

...constructs, legitimates, and distances Others, banishing them to the margins of the culture. Sometimes these texts are used to deprive Them of services; always to rob Them of whole complex humanity...These Others are represented as unworthy, dangerous, and immoral, or as pitiable, victimized, and damaged. (Fine, 1994, p.74)

One way for researchers to counter this Othering, to create resistance, is to "...construct texts collaboratively, self-consciously examining our relations with/for/despite those who have been contained as Others..." (Fine, 1994, p.74). Instead of getting to know or give voice to Others, researchers must listen to "...those Othered as constructors and agents of knowledge" (p.75). There are activist researchers struggling to develop "...qualitative research that is designed *against* Othering, *for* social justice, and pivoting identities of Self and Other *at* the hyphen" (p.81). It is hoped that this current research follows their lead.

## Co-cultural Theory Communicates

Co-cultural is a term used to avoid negative connotations such as *min*ority or *sub*culture and to recognize the diversity of cultures that exist through society. Co-cultural communication theory uses muted group and standpoint theory to provide a framework for researching the "...communicative lived experiences of co-cultural group members" (Orbe, 1998, p.10). This

theory includes the following five premises: (1), the hierarchy in society priviledges specific groups; (2), dominant group members "...create and maintain communication systems that reflect, reinforce, and promote their field of experiences" (p.11); (3), dominant communication systems block the development of those whose lived experiences are not reflected in these dominant structures; (4), co-cultural groups have diverse experiences but they are similarly marginalized within the dominant structures; and (5), "to confront oppressive dominant structures and achieve any measure of 'success', co-cultural group members adopt certain communicative behaviors when functioning within the confines of public communicative structures" (Orbe, 1998, p.11).

The following are some of the `subordinate' communication strategies used by marginalized co-cultural groups: `tomming' is conforming to stereotypical expectations of the dominant group; `passing' is behaving as if a member of a dominant group; `shucking' is adopting stereotypical behaviours while cognitively rejecting the meanings associated with them in order to accomplish a goal; and `dissembling' is conforming to stereotypes which the group embraces as their own, where they "...create an ingroup meaning oppositional to dominant group codes" (p.33). An example of the communication practice of `shucking' among consumer/survivors, is called `shuffling'. When hospitalized, people adopt stereotypical `mental patient' postures and movements such as `shuffling', maintaining a low profile while appearing to be well medicated in order to be released as soon as possible.

The co-cultural perspective "...simultaneously unites and differentiates marginalized group experiences without essentializing[13] them" (p.12). The oppressive practices of sexism, racism, heterosexism, ableism and classism at the levels of the personal, social, organizational and institutional are recognized as similar, at the same time as acknowledging the different ways in

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[13] Essentialism is the view that facts about the nature of the world are essentially there, they exist independently of us and we can come to know them as they are through observation and objective rational thinking (Schwandt, 1994).

which they are manifested in the daily lives of co-cultural group members. This perspective also recognizes the diversity of experiences within groups (Orbe, 1998). Deegan (1992) identifies 'mentalism' as the oppressive practice which make consumer/survivors into second class citizens. Mentalism is the assumption that people who are given psychiatric diagnoses: "are dangerous, unpredictable and to be feared...are less than human and more like children than adults...are fundamentally different from other people...do not know what they need"; say crazy things that can be ignored; need others to make their choices; "...should not take risks and should be protected from failures..."; need others to decide what is in their best interests; "...should strive to be normal...and that they are disabled people rather than people with disabilities" (p.14).

Co-cultural theory explores the way co-cultural groups communicate within the structures of dominant society; what tactics they use to get along in a "network of already established forces and representations" (p.14). Through discovery-oriented phenomenological methods twenty-five different co-cultural communicative practices have been identified. One of these practices is called `strategic distancing', which is defined as avoiding association with co-cultural group members in order to promote one's distinct individuality. The practice of `embracing stereotypes' changes what were from the dominant perspective negative stereotypes into a positive aspect of the co-cultural self-concept (1998). One example is Gay Pride Day, where dressing up and participating in a parade is a joyful celebration of the diversity of sexual orientation.

Van Manen (In Orbe, 1998) writes that the researcher works to "...become a medium for the voice of their co-researchers without necessarily manipulating, altering, or reshaping their life experiences" (Orbe, 1998, p.13). The term `co-researchers' is used to promote the respect for the uniqueness of the human beings involved in the study. It is important in this process that the co-researchers' expertise in their own life experiences is acknowledged and respected. The

researcher is also called "...to acknowledge the ways in which they are positioned within the discourse that they are seeking to understand" (p.36). As there is no such thing as an objective researcher, their assumptions need be clearly stated.

## Living Systems Theory, 'The Web of Life'

Traditional science, with its belief that the world is mechanical and can be perceived objectively and controlled externally, is not able to explain for biologists the self-renewing processes of life (Macy, 1998). These life-scientists have moved away from looking at the basic building blocks of life to looking at the wholes and the processes instead of the parts and substances. This movement represents a paradigm shift from one that is mechanistic and reductionist to one that is holistic or ecological. This holistic perspective is called `systemic' and the implications for a way of thinking, `systemic thinking' (Capra, 1996). Systems thinking is being applied in many of the scientific disciplines including the social sciences.

The 'web of life' is composed of communities and the networks which link them together. Its web-like form affirms the ancient view of the interdependence of all phenomena. Instead of a hierarchy, with rule coming from above, these systems are networks nesting within other networks and order tends to arise from bottom up (Capra, 1996; Macy, 1998). Living systems can only be understood in context of the larger whole. "Systems thinking is "contextual" thinking...we can also say that all systems thinking is environmental thinking" (Capra, 1996, p.37). Systems thinking is always process thinking as every structure in systems science is seen as the manifestation of underlying processes.

General systems theory, cybernetics and information theory, are concerned with the logic of organization and communication. Those interested in social science, such as Gregory Bateson, saw the application of systems theory to the disciplines of anthropology, sociology, psychology and psychiatry. Bateson with others, studied schizophrenia and developed family therapy using systems thinking (Capra, 1996).

One of the early concepts in this theory is that living systems are open systems that operate far from equilibrium. The formation of complex systems involves the tension between crisis and transformation, with an organizational crisis manifesting as a breakdown of systemic balance, while also representing an organizational transition to a new state of balance (Capra, 1996). From cybernetics came the concept of the feedback loop, a circular pattern of causally connected elements. This "...led to new perceptions of the many self-regulatory processes characteristic of life" (p.59). Using systems thinking, a social system can be seen to have a system of communication which has feedback loops as one of its properties. In social systems, ideas such as a 'vicious circle', 'self-fulfilling prophecy' or the 'bandwagon effect' have been recognized for a long time as obvious forms of self-reinforcing feedback loops.

Using systems ideas, a community has the ability to regulate itself and learn from its mistakes if it has an active network of communication through which the consequences of actions can be transmitted and returned to the source via feedback loops. The community can therefore correct mistakes, regulate and organize itself (Capra, 1996). Karl Deutsch (In Macy, 1998) writes that in social systems "...free circulation of information was essential to health and survival" (p.43). The power of a dominant group in society to control the flow of communication and information may be effective for its own growth. If it directs the flow of information from its own self-interest it may block or distort the flow of communication to and among other groups. These groups then become marginalized as a result of insufficient information to regulate and organize efficiently.

Self-organization is "...*the* central concept in the systems view of life, and like the concepts of feedback and self-regulation, it is linked closely to networks. The pattern of life, we might say, is a network pattern capable of self-organization" (Capra, 1996, p.83). In the study of chemistry, scientists discovered that the dissipation of energy in open systems becomes a source of order. When the flow of energy and matter increases, at a certain point these systems transform into

new structures of increased complexity. In open systems, there is a phenomenon of self-organization such that "...coherent behaviour emerges spontaneously at critical points of instability far from equilibrium" (Capra, 1996, p.88).

Scientists and mathematicians involved in complexity and chaos theory developed the mathematical tools that could model the nonlinear interconnectedness found in networks. This mathematics "...embodies the same shift of emphasis characteristic of systems thinking--from objects to relationships, from quantity to quality, from substance to pattern" (p.113). Scientists, such as James Lovelock and Lynn Margulis, examined the earth as a complex living system and generated the Gaia theory. "No longer a dead rock we live upon, the Earth is a living process in which we participate" (Macy, 1998, p.44)

**Autopoiesis.** The Chilean biologist and neuroscientist, Humberto Maturana, developed the theory of autopoiesis, the organization of living systems, to distinguish between living and non-living systems. Autopoiesis derives from the Greek language, with 'auto' translated as 'self' and 'poiesis' from the same root as poetry and translated as 'making'. His innovation was to link both cognitive and biological structures into the organization of life. His first conclusion was that a network pattern is the basic organization of living; a pattern "...in which the function of each component is to help produce and transform other components while maintaining the overall circularity of the network" (Capra, 1996, p.96). His second conclusion was that the nervous system was not only self-organizing but also self-referring; perception or cognition "...do not represent an external reality but rather specify one through the nervous system's process of circular organization" and "...the continual creation of new relationships within the neural network" (p.96).

Maturana worked with another neuroscientist, Francesco Varela, to develop the Santiago theory, a systems theory of cognition. The idea that life and cognition are inseparably connected is a radical new concept which promises to change the Cartesian concept of the

division between mind and matter. "Thus Mind--or more accurately, mental process--is immanent in matter at all levels of life" (Capra, 1996, p.172). The mind is a process of cognition and the brain is one structure through which this process operates. The relationship between the mind and the brain is the relationship between process and structure.

**Psychosomatic processes.** Recent research has found that the nervous system, the immune system and the endocrine systems all form one cognitive network with each system having structures through which the process of cognition operates. The understanding of the 'psychosomatic' or mind-body view of health will grow as these three systems are seen to be communicating and interacting.

The neuroscientist Candice Pert (1997) and her colleagues identified groups of molecules called peptides and discovered that they function as messengers between the nervous and immune systems, showing how all three systems link into one network. "Peptides are the biochemical manifestation of emotions; they play a role in coordinating activities of the immune system; they link and integrate mental, emotional, and biological activities" (Capra, 1996, p.283). One ramification of the discovery that there is a biochemistry of emotion, is that "...repressed traumas caused by overwhelming emotion can be stored in a body part" and the body thus becomes the receptacle for the unconscious mind (Pert, 1997, p.141). Pert also sees hope for treatments that use the results of her research into the molecules of emotions; treatments which use bodywork to release traumas stored in the body and biofeedback, visualizations, relaxation and meditation to help people control their own bodymind systems. The belief by some consumer/survivors in the efficacy of these non-conventional treatments for the recovery of mental health is validated by this new research.

Pert (1997) is concerned that drugs, such as those that are being used to treat depression and psychosis, are cascading too many changes throughout the bodymind system. She says that the implications of her research are that "all exogenous drugs are potentially harmful to the

system, not only as disrupters of the natural balance of the feedback loops involving many systems and organs, but because of the changes that happen at the level of the receptor" (p.271). She says that research needs to focus on how our own body creates endogenous drugs, then to aid their creation to bring the systems back to balance. And if researchers are not able to make conditions appropriate for this to happen, to create exogenous drugs that mimic the natural ones and "...cause minimal interference with the bodymind's balance because they have been developed with an awareness of the whole psychosomatic network" (p.272).

**Bringing forth a world.** There are other important characteristics of living systems. Their autopoietic organization always includes a boundary which defines the system as a unit. Living systems interact with their environment through 'structural coupling'; that is, each interaction triggers a structural change in the system. This 'structural coupling' fosters creativity as the system adapts and learns, a key property of all living systems.

The structural changes in the system constitute acts of cognition. By specifying which perturbations from the environment trigger its changes, the system "brings forth a world"... Cognition, then, is not a representation of an independently existing world, but rather a continual *bringing forth of a world* through the process of living. (Capra, 1996, p.267)

The world brought forth by a certain organism in the process of living is determined by its structure (1996).

As an organism develops complexity, at a certain point, it couples structurally not only to its environment but also to itself, and brings forth an internal world as well as an external one. "In human beings the bringing forth of such an inner world is linked to language, thought and consciousness" (Capra, 1996, p.270). This self-awareness, or consciousness, is tied closely with language and communication. Maturana (In Capra, 1996) says that communication is not a transmission of information but a "...coordination of behaviour among living systems through mutual structural coupling" (p.287).

As humans we exist in language; together in language we coordinate our behaviour and we bring forth our world. "In a human conversation our inner worlds of concepts and ideas, our emotions, and our body movements become tightly linked in a complex choreography of behavioural coordination" (p.290). A film analysis of conversation shows that it is a dance between the sequence of speech patterns and the coordination of minute movements of the bodies of both speaker and listener. In this theory of living systems by Maturana is the scientific basis for the belief in the social construction of our world.

According to Maturana's theory, the explanations of consciousness in terms of neurophysiology, physics, chemistry, or even biology and psychology are not possible. He believes that "...we can understand human consciousness only through language and the whole social context in which it is embedded" (p.291). Maturana believes that early human beings were able to cooperate and form communities because of the development of language. It was not information exchange, it was the increased ability to cooperate which was the crucial role of language (Capra, 1996).

## The Doctrine of the Impermanence of Self

From the view of Buddhist philosophy, "...existential human suffering arises...when we cling to fixed forms and categories created by the mind instead of accepting the impermanent and transitory nature of all things" (Capra, 1996, p.294). Cognitive science has come to the same conclusions as two thousand year old Buddhist thought. "We bring forth a self just as we bring forth objects. Our self, or ego, does not have any independent existence but is a result of our internal structural coupling" (p.295). Clinging to the idea of a permanent fixed self is the root of much suffering, it is a 'Cartesian anxiety', an ontological insecurity. Our dilemma is that we create abstractions and then believe they belong to an objective, independently existing reality. This anxiety is relieved by shifting our focus from objects to relationships, then "... we can realize that identity, individuality, and autonomy do not imply separateness and independence" (p.295).

It is abstract thinking that has led us to see nature, as well as our human society, as fragmented and composed of separate parts. This in turn "...has alienated us from nature and from our fellow human beings and thus diminished us. To regain our full humanity, we have to regain our experience of connectedness with the entire web of life" (Capra, 1996, p.296). This is the basis for the study of deep ecology. Deep ecology is a philosophy and a movement which questions fundamental premises of our society created by industrial and technological growth and the notion of economic progress at the expense of the natural world. "It holds that we can break free from species arrogance which threatens not only ourselves but all complex life-forms within reach" (p.46).

## Reconnection to the Web of Life

The web of life is composed of interconnecting systems at different levels and of varying complexity. Every system is a 'holon', it is both a whole, is made up of subsystems and is also part of a larger system. Just as organisms evolve and develop emergent properties at new levels of complexity, humans have developed a self-reflexive consciousness in response to the greater complexity of their systems which could not be dealt with by instinct or trial and error. Thus "a new level of self-monitoring emerged--feedback about feedback, in ever-complexifying assemblies of loops" (Macy, 1998, p.43). The next holonic level, social systems, is not self-reflexive. Complexity is increasing with the expanding networks of communication in the globalization of society. Some people believe that there is now a survival crisis and that the current level of systems are breaking down because of ever-expanding industry and technology and its consequence of environmental degradation of the earth. "Dangers to their survival move living systems to evolve" (p.44).

New views of mental health such as in transpersonal psychology and ecopsychology reflect the change of perspective from reconnecting with the web of life and the development of a more spiritual outlook for understanding distress. With the alienation from nature comes an existential

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anxiety; people experience distress when the earth's survival is being questioned; there is anxiety and insecurity in a time of rapidly changing social, economic and political systems; and many communities feel powerless to control what is happening around them. These all contribute to a pain and anguish which people experience that can be pathologized in traditional psychiatry. "Our cultural alienation from nature engenders not only careless and destructive behavior toward our environment, but also many common disorders such as depression and addiction" (Macy, 1998, p.49).

Transpersonal psychology redefines some of what is labeled and treated as psychosis in psychiatry as non-ordinary states of consciousness and indicative of 'spiritual emergencies' or 'transpersonal crises'. "If properly treated they can result in psychosomatic healing, personality transformation, and conscious evolution" (Grof, 1983, p.23). The content of spiritual emergencies is divided by Grof and Grof (1989) into three categories: (1) the biographical, experiences related to an individual's life history; (2) the perinatal, experiences related to traumas around birth; and (3) the transpersonal, experiences that are far beyond the limits of ordinary human consciousness. "Biographical aspects of spiritual emergencies involve the reliving and healing of traumatic events in one's history" (p.9). The perinatal involves the reliving and healing of the birth trauma which often entails encountering aspects of what Jung called the 'collective unconscious' and the themes of death and rebirth. Transpersonal experiences involve "..the transcendence of the ordinary boundaries of personality...and those that have been called spiritual, mystical, religious, occult, magical, or paranormal" (Grof & Grof, 1989, p.10). Grof and Grof view these spiritual emergencies as crises of the evolution of consciousness. With the ideas from deep ecology and the holonomic shift of consciousness, an increase in spiritual emergencies would be predicted with the transition to a new world consciousness.

There are many people in our society who have taken up spiritual practices as part of their search for a better quality of life and these are many of the people who are encountering spiritual crises. It is those who know what they are experiencing, from having experienced it themselves, who need to be involved in their treatment so that these people are not pathologized and enter a cycle of drug dependency and regression under psychiatric care.

There is the need for free circulation of information in order to create a 'Life-sustaining' society. Blocking this circulation is institutionalized secrecy and the protection of the vested interests of corporations which even democratic governments engage in to suppress information injurious to business interests (Macy, 1998). "...Any system that consistently suppresses feedback--closing its perceptions to the results of its behavior--is suicidal" (p.54).

Macy (1998) has developed personal and group work to aid the reconnection of people to the 'web of life' and to counter the despair and grief that is causing so much of their distress. This work includes unblocking our emotions; our feeling of pain for the world is natural as we are interconnected to all that lives. "When we deny or repress our pain, or treat it as a private pathology, our power to take part in the healing of the world is diminished" (p.59). When we are able to express the pain and grief that we feel, then we can experience fully our connection to the community of life on earth. When we become more fully connected to the web of life, we may become empowered and it will serve our own self-interest to become active in the creation of more cooperative and ecologically-minded worldviews which will influence the shift to self-sustaining rather than self-destructive global human practices.

The living systems theory, the discovery of the molecules of emotion, and the study of deep ecology are all in support of the shift away from the individualization and pathologization of people's distress to a more relational and empowering perspective. A perspective which uses not only the bodymind system and the reconnection to life, but also the co-construction of the reality, how we `bring forth our world', to further understanding and liberation.

# The Researcher's Standpoint: Transparent, Located and Identified

In order to clarify my stance as a researcher I return to the ideas of standpoint theory. Swigonski (1993) states that there are three questions asked by standpoint research: What are the values and methods at the base of this research? What is its purpose? And how can the researcher's reflexivity be incorporated? I shall use these questions to clarify my position as researcher.

The first part, developing the base of research with people who have used or are using the psychiatric system, can be best determined in interaction with representatives of this group with as much collaboration as possible. The research question and methodology were discussed in several meetings with the members of the Self Help Group who were working to develop a constitution for their application for non-profit status. The mission statement and purposes developed for the constitution were relevant to framing the issues that these members faced in their day-to-day lives and gave a good base from which to discuss research questions.

The purpose of the research for the members of the Self Help Group (SHG) is to have information available to support proposals for funding, and to direct the development of future programs and services. The core group of the SHG wished to access information on the views of the members of the SHG about issues they faced in the psychiatric system, and about the activities or services which have helped them in the process of recovering their mental health.

One of the purposes behind my collaboration with this group for research was the aim to follow social work principles while conducting research; research which is participatory, which has the potential to aid the members' liberation from oppression and their empowerment to develop self-help programs and to determine services to aid the recovery process. The other purpose is to produce original research for a thesis towards a master's degree in social work. This degree is necessary for access to employment as a social worker in the mental health system or on a palliative care ward of a hospital. This employment will also ensure a good

wage, a respected professional position, social status as well as authority and a certain amount of power. My hope is to achieve this self-interested goal while also acting as an ally in the promotion of the aims of the SHG.

The third question is, how can the researcher's reflexivity be incorporated in the project? Social workers are trained to develop professional self-awareness. This self-awareness will be expanded by researchers "...to include an analysis of their impact on the research as socio-political-historical beings" (Swigonski, 1993, p.179). Researchers must examine their social position and how this effects the research. "Their class, culture, ethnicity, and gender assumptions, beliefs, and behaviours must be placed in the frame of analysis and in the research report" (p.179).

My own standpoint is different from many of the members of the SHG in that I was not labelled as having chronic mental illness. I was able to recover relatively quickly because, I believe, from the advantage of coming from the dominant class, having a supportive middle-class family with a mother at home to care for me after the hospitalization, and being able to develop confidence in my future by returning to university and successfully completing my degree. I was fortunate that I was not told my potential was limited, or that I would have to be on medications forever, and so did not lose my hope for a brighter future.

However, my reflexivity is addressed with my own history of involvement in the psychiatric system. The result of conducting research in an area I also have experience with has increased my tendency to be self-reflexive. In fact, I found it impossible not to be reflexive when my own identity was affected by stigma, even if my psychiatric experience began thirty years ago and only lasted for two years. The reality of the oppressive nature of that experience still reverberates in my being.

There is also the difference that although I am a single mother who has experienced poverty and discrimination, I also have had the opportunity to access higher education and so have the

potential for employment with a good income. My position of priviledge from my background in the dominant culture has enabled me to believe in my right to education and professional employment. My fortune in recovering from the emotional and mental distress which brought me into contact with the mental health system, part of which was completed away from the system, also enables me to believe recovery is possible for more people. Although many consumer/survivors were not fortunate to have the supports that I had, or the possibility of recovery away from the mental health system, they can be assisted through self-help and the support of their peers; especially by their peers who are role models of significant recovery from the label of serious mental illness.

I must emphasize that recovery does not mean a return to the same state of mental health held before the development of the emotional distress. Many people live full and productive lives while still experiencing occasional symptoms and/or still taking medications (Anthony, 1993; Deegan, 1996). For others, their experience was part of a personal or spiritual growth within a holistic healing process and their mental health is improved in recovery (Laing, 1989; Grof & Grof, 1989).

Reflexivity also promotes using oneself for research, besides one's knowledge of theory and literature, using one's own reactions and experience of the material as a tool for research. Using concentration and contemplation, one becomes immersed in the texts of the interviews, observes one's reactions to the narratives, allows reverberations to occur from these experiences, and insights to arise. Having a common experience but being priviledged can lead to both the possibility of some accuracy of view and of some blindness to aspects of diversity in the research. This awareness is necessary to be vigilant for where errors in view can arise.

Bleier's guidelines (in Swigonski,1993) for reflexivity in reports calls for researchers

...to be explicit about their assumptions, honest and thoughtful in their choice of methods, open in the interpretation of each study and its significance, clear in describing possible pitfalls in the work and its conclusions, and responsible in the language used to convey their results. (p.180)

In the attempt to answer questions from my own experience over the years I have developed a stance which questions the assumptions and role of the past and present mental health system. I did investigate psychological theories but found that there was still little understanding of the experiences I had undergone. I looked to eastern religions and philosophy to find out more about how the mind/body/spirit is viewed from those perspectives. There are still more questions than answers from this study but I have found a base to work from with the values of Buddhist philosophy. Finally, I returned to university and in social work I have studied social, political and economic factors and how they interact with individual distress. The emancipatory potential of social work is what attracted me to this profession as well as a desire to be engaged in the work of compassionate action.

Using standpoint and participatory research raises the possibility for the participants to develop a critical consciousness of their oppression and the methods used to maintain their marginalization. Developing the most involvement in the research possible for the participants is effective for their empowerment. Bringing the ideas I have learned from the school of social work to my interactions with the Self Help Group has begun an exchange of critical views. I have learned much from their expertise as people who have been given the label 'chronically mentally ill', who are questioning what that actually means to them and are learning to define their experiences for themselves.

"The purpose of research must be *for* the subjects of the research, to advance their causes" (Swigonski, 1993, p.178). The report of this research, which will be developed for the SHG and its members to aid the group's future development, can also be distributed to organizations with

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which they are connected, and act as a means of publicity for their goals for future programs, seeding the way for accessing funding, and gaining legitimacy as an organization.

## Limitations: What Parts of the Puzzle are Missing?

Some of the pitfalls in this study arise on one hand from not being able to convey the full range of views from the diversity and heterogeneity of members of the population, and on the other hand from the interpretation and analysis being conducted only by one person. The ideal would have been that the whole project be conducted by a team of members from the Self Help Group.

The advantage of my position is that I straddle several groups, some oppressed and some from the dominant class. But my background in the dominant culture means a lack of experience with some diversity issues. Being physically able, of heterosexual orientation, and from a white Anglo-Saxon background, means that I do not have a full appreciation of people's experience from other standpoints.

The ethnicity, sexual orientation and ableism of people who use the psychiatric system greatly impacts their experience. Some people believe that the difficulties of dealing with discrimination in our society is the cause of the distress which brings many people to seek help in the psychiatric system. The Self-Help Group wishes to start gay and lesbian support groups from the wishes of those who find it difficult to have it known that they have a psychiatric diagnosis within those communities. Other studies need to be done to investigate how diverse groups experience psychiatric services and the process of recovery. The complications of problems such as physical disability and psychiatric diagnosis, or psychiatric disorder and substance abuse, need also to be studied from the perspective of those who are given these multiple diagnoses.

The focus of this study being the members of this one consumer/survivor-run group does leave out many of the members of the total population of those who use or have used the

psychiatric system. There are consumer/survivors who wish to remain within traditional psychiatric services under the supervision and support of mental health professionals in order to further their own and others' recovery. There are also people who have recovered their mental health and have moved out of the psychiatric discourse severing connections to all groups or services dealing with mental health issues. These peoples' voices have not been accessed in this study.

There is a danger of becoming entrenched in a standpoint to the extent that by defining oneself as having a specific stance one is actually creating the "Other" in the process. The polarization of 'consumers' and 'survivors'[14] gives an example of this process; each stance can be defined in contrast to the other which is seen to be misinformed, led astray by influential people, and actually blocking the progress of mental health reform. It would be productive to provide increased venues for dialogue between 'consumers' and 'survivors' to decrease their polarization and re-focus on their commonly held goal to promote and increase the orientation of services away from a focus on pathology and 'mental illness' and towards the process of recovery.

By immersing myself in the Self-Help Group, with its stance arising from the experiences of its members and its struggle to provide peer-run programs, I have emphasized their standpoint in my interpretations. This standpoint is not a unified one; there are multiple viewpoints from those who support the work of the traditional mental health system to those who believe it should be replaced by more humane and less hierarchical and oppressive services. My own experience with part of my recovery outside of the mental health system also leads me to believe that some people's ability to fully recover depends on transforming and then leaving the psychiatric discourse. These beliefs should not mean the denigration of what others believe

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[14] "Consumers" are those who use psychiatric services and who believe that by remaining in the system they can more skillfully assist in the reform of potentially abusive mental health practices. "Survivors" believe that traditional psychiatry needs to be abandoned for more humane treatment services under the control and guidance of those who use the services.

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and have experienced. People hold different views and have varied experiences in the field of mental health and these cannot be encompassed by one perspective.

My position and my background are part of this research. Because of my perspective certain aspects of the study will be investigated and others will be left out. All of my previous life, the changes that I have encountered, affect the analysis and interpretation of this research.

## Conclusion

Witkin (1993) explores a human rights approach to social work research. He calls research a practice, and practice research, because they are both "...disciplined, reflective, value-based, social practices that attempt to further social work goals" (p.250). He acknowledges constructionists, feminists and critical theorists who attempt to use the power of social research to gain new understandings of the social and political dimensions of research. "Who would deny that the power to name is the power to differentiate, to decide what is to be included and excluded from our discourse, and hence our imaginations" (p.250). When this power is used to promote human rights it can foster change which will benefit all of society.

The inclusion of the voices of those who use or have used the psychiatric system in social work research can help to reveal the nature of the social construction of their psychiatrized identity, and work to address oppression by the institution of psychiatry and the loss of the human rights to freedom and self-determination. Feminist and standpoint theories, co-cultural and systems theories provide a framework which arises from a paradigm which focuses on interdependence, consensuality and shared responsiblity. This theoretical framework can be the foundation for respectful research methods for use with groups who are oppressed and marginalized; it can broaden understandings and gain insights into the ways things work; give expression to usually silenced voices; and provide a vehicle for the social transformation and empowerment for all those involved in the research.

# CHAPTER 4

## Research Methods: How to Find Out

Too often the wishes of people who use or have used the mental health system are cast aside as others determine what is in their best interests. Their thoughts and ideas are often discounted as being a part of the symptoms of mental illness and hence `pathological', definitely not the basis from which to make inquiry. Researchers honour members of a marginalized group when they involve the members in the research process and when the findings can further the group's aims. Otherwise, they run the risk of the being exploitative, or even harming these vulnerable groups. Participatory action research can be the most useful to marginalized groups and sets their aims as its central focus.

## Participatory Action Research: Co-conspiracy

Participatory action research involves as much as possible the members of the group being researched. This involvement could range from full control of the project with no outside researcher, to collaboration with a professional researcher on the planning and design, perhaps conducting interviews, maybe analyzing the data, and possibly the writing of the research report. The orientation for this type of research is to realize an aim or goal of the group being researched so that the findings lead to some form of action. For example, this action could involve changes to existing programs or the initiation of new ones. Research which supports the goals of people who use or have used the psychiatric system can also support their empowerment and consequently their process of recovery. Rogers and Palmer-Erbs (1994) say that this type of research is more pertinent and meaningful to consumer/survivors. These authors believe PAR must receive sufficient funding and not be discounted for lack of rigor, for it has practical meaning. In conclusion they say that,

It is critical that the `voice of the consumer' be acknowledged in research and evaluation studies...Allowing consumers to control and conduct research and evaluation projects will

afford them the influence, status, and power that has long been available to mental health and rehabilitation researchers and evaluators. (p.11)

Emerick (1996) writes that traditional self-help researchers would only use 'therapy' self-help groups as valid subjects because of their scientific biases towards individual change. He proposes that there is a need for more self-help research which "...reflects the philosophy of *social realism*, emphasizing the importance of the social and cultural context, and adopting biases of an overtly political and social systemic orientation" (p.156).

Rapp, Shera and Kisthardt (1993) write that defining problems as the fault of the victim is not only common to mental health research but also to research in social work and psychology. They advocate for research that empowers people with severe mental illness; examining consumer/survivors' strengths, and the way these strengths are manifested in self-help groups. The perspective of consumers/survivors needs to be brought to light and the importance of this is revealed by examining the results of research with family members of consumer/survivors. "A major reason that research on the role of the family has moved from person blaming has been the recent literature and research based on the family's own perspective" (Rapp et al., 1993, p.729). These articles confirm the importance and the need for more research that brings out the voice and ideas of those who have used or are using the psychiatric system. The collaborative method of PAR will empower the members of the Self-Help Group. The research will be useful to further their goals, and provide benefit and interest for me, making winners out of all the co-researchers.

## Research Design

My desire was to conduct a participatory action research by enlisting members of the Self-Help Group to become full researchers and by eliciting ideas for actions for change to follow the study. Unfortunately, I could not find members who wished to conduct interviews or assist in the analysis. I believe if I had been able to offer remuneration it would have changed the response.

Many who are asked to volunteer their work alongside paid mental health workers have become cynical and wary of joining projects which are not their own. They often report that their participation is token, is ineffective in realizing any of changes which they suggest, or serves a political agenda with agencies appearing to collaborate while actually patronizing and discriminating against the users of their services. I was able to involve the members of the Self Help Group (SHG) in the decision-making of the research, asking for their opinions on the topics to be covered and on the questions used to explore them. I also made plans to include feedback from the co-researchers.

The first part of the research design was to conduct interviews with six individuals. I wanted to ask a minimum of questions in order to elicit stories about the co-researchers' experiences in the psychiatric system and in the process of their recovery. The follow-up of two focus groups was planned to increase the participation by other members of the SHG, to validate and add to the issues raised in the individual interviews, and to develop plans for programs that would address the members' concerns. Focus groups are useful ways of increasing participation by accessing more perspectives and of pulling out new ideas by encouraging creative dialogue between participants. Focus groups can be action-oriented and their success can inspire and increase the groups' involvement in other participatory projects (Krueger, 1994). I also planned to return the analyses of the interviews and focus groups for feedback from the co-researchers to further increase their participation and to improve the validity of the interpretation. This would also sensitize me to the issues of what was appropriate to reveal and what constituted a respectful rendering of the dialogues from the interviews.

## Data Collection: Tell Me a Story!

**Sampling.** The choice of the research topic and population to be sampled came out of a joint decision by myself and the members of the SHG. Members of the group were applying for non-profit status and they wanted to have research to back proposals for funding once they had

received that status. I wanted to conduct a participatory action research which furthered the aims of a marginalized group; I believe this type of research is an ideal match for social work values.

The sampling criterion for the individual interviews was quite wide; respondents were people who use or have used the psychiatric system. The members of the SHG are people who fit the population and who also have experience with the ideas of self-help. The support groups are normally organized by gender and/or ethnic background, the exception being a new group which will focus on the development of consumer/survivor-run businesses.

I will use the term co-researcher in the place of the term participant or interviewee to honour the co-construction of the research. The co-researchers for individual interviews were recruited through the use of a flyer which was handed out by the facilitators of the SHG support groups. Following the method of snowball sampling, the members of the groups were also asked to pass on the information to others outside of the SHG who would be interested in participating. There was also a request for people who were interested in becoming researchers and wanted to learn to conduct interviews and analyze data.

Those who consented to be interviewed were all members of the SHG, three women and three men, Valerie, Jane, Kanti, James, Ray, and Jeff (pseudonyms). They range in age from thirty to fifty years of age, with two of the members raised outside of Canada.

The criterion of the sampling for the focus group interviews was different than for the individual interviews. The focus of these interviews was to verify the issues found in the individual interviews, to add any new ones, and to develop ideas for programs which the SHG could offer. Only members of the SHG were recruited for these interviews. The support groups of the SHG were sent flyers asking if they would participate in a focus group interview. Two groups, one a men's, the other a women's group gave permission for the interview to be

conducted. They were not originally chosen because they were gender-specific; they were simply the groups which consented to a focus group interview.

The research question was developed in collaboration with members of the Self Help Group: " What are the experiences of those who have used the psychiatric system ? "

**Individual interviews.** In this initial phase of research, six one-hour long or longer in-depth, semi-structured interviews were conducted and recorded on tape. Field notes were made after each interview and memos were made when insights arose. The place where the interview was conducted was chosen by the co-researchers. Three were conducted in the co-researchers' homes, two at the office of the SHG, and one in a meeting room at a local drop-in centre. There were basically two questions in the interview guide: "What has been your experience of the psychiatric system? And what experiences have you had in your process of recovery?"

The relatively unstructured nature of the interview allowed the co-researchers to tell their stories in the manner they chose. "We are more likely to find stories in studies using relatively unstructured interviews where respondents are invited to speak in their own voices, allowed to control the introduction and flow of topics, and encouraged to extend their responses" (Mischler, 1986, p.69). In this methodology, the interviewer is to encourage the co-researchers with active and interested listening, extending and clarifying their stories with the use of probing questions.

The co-researchers' role is to co-construct their story with the interviewer; the stories are formed from the discourse spoken in context; the questions, replies, and the non-verbal communication are influenced by the expectations both bring to the interview. The researcher's skill, the relationship between the researcher and the co-researcher, their respective positions of power and social status all influence the story told (or not told) (Lieblich, Tubal-Mashiach, & Zilber, 1998). With a researcher who has a history of similar experiences, who does not have institutionalized power to wield, and who is sympathetic to the aims of the co-researchers, there

is more chance to hear stories which are normally censored in interactions with those in dominant positions.

The transcripts of interviews are social constructions of experience. Verbatim transcription captures as much of the interview as possible. The interviews were cleaned up a little, some of the excess `ums' and `ahs' were deleted, when the transcripts were returned for co-researcher checking.

**Focus group interviews.** Following the completion of the individual interviews focus group interviews were conducted. The first, with the men's group, met at the office of the SHG. A list of issues taken from the individual interviews was given to the co-researchers and they were asked to comment on whether they agreed with these issues and if they had others to add. They were also asked to brainstorm ideas for programs which could be developed to address some of these issues.

The second group interview was held at a community agency, the usual meeting place for the women's group. The issues from the individual interviews, and the issues and ideas raised in the men's group were all brought to this interview and the women were also asked to consider these issues, add more, and brainstorm for additional program ideas.

The benefits of a focus group interview are that "...people spark off one another, suggesting dimensions and nuances of the original problem that any one individual might not have thought of " (Rubin & Rubin, 1995, p.140). Problems with many focus groups are that they are a collection of strangers and the facilitator has to work to create a comfortable climate for sharing ideas. With these support groups the advantage was that they knew each other and were already comfortable with sharing. The work was for myself as the facilitator to be accepted as a safe person with whom to discuss difficult issues with. I had met a few of the co-researchers in previous group meetings. This, plus the information about my own background as a consumer/survivor, and that I was wanting to contribute to the development of the SHG, all

helped to assure them that I was sympathetic and would respectfully listen to them as having knowledge and expertise.

With the men's group the disadvantage was that I was female and more personal subject matters may not have been addressed because of this. I did meet with them prior to the interview to explain what the research was about in order for them to decide whether they would participate or not. I felt quite comfortable with both groups and there appeared to be no difficulties in sharing ideas.

The transcripts from the focus groups were taken back to the members to check for accuracy. After analysis the findings were also shown to the groups to check if they honoured the perspectives of the co-researchers. The whole research process was described in a University of British Columbia Ethics form. The form was entered for their inspection and permission to begin this research was received from the UBC Ethics Board.

## Data Analysis: Now I'll Tell You a Story!

According to Rubin and Rubin (1995), data analysis is a continuation of the dialogic process of interviewing. It is "...the final stage of listening to hear the meaning of what is said" (p.227). By transcribing the interviews, the long hours of listening and typing were balanced by the experience of full immersion.

The enormous amount of material gathered in these in-depth interviews is daunting. But as the ideas emerge and the process of discovery unfolds, rereading with the insights gathered from previous readings highlights the most impactful stories and their themes become clearer. This process is a personal search by the researcher who uses intuition, reasoning, theory, as well as previous knowledge and experience to illuminate the journey. Wandering in the wastelands on a foggy day looking for signs that point to a path is the metaphor that best describes the process. The path becomes clearer with each passage through the text until no new signs or insights arise and the path is clearly visible. Using stories told in peoples' own

words and being able to consult the co-researchers themselves about the analysis serves to ground the ideas in the reality of their lived experience.

**Narrative research: Discovery through storytelling** Narrative is defined as a "...discourse, or an example of it, designed to represent a connected succession of happenings" and narrative research is "...any study that uses or analyzes narrative materials" (Lieblich et al., 1998, p.2). A personal narrative

> ...imposes an order on life events and "represents the most internally consistent
> interpretation of presently understood past, experienced present, and anticipated future at
> that time" (Cohler, 1982). (Mathieson & Barrie, 1998, p.581)

Using narratives developed in interviews creates a dialogue between the voice of the researcher who constructs the report of their research and the voice of the co-researchers telling their stories. "Commitment to a dialogic methodology...implies the representation of actors' own narrated lives (Guba & Lincoln, 1994, p.110).

Narrative inquiry can be used to provide expression to the unheard voices and give a more in-depth understanding of discriminated-against minorities. Feminists and post-colonial critics argue for "...the presence of voices of women, people of colour, and other oppressed people in the studies that so often make them the object of scrutiny (Coffey & Atkinson, 1996, p.79).

The impact of a story, told by those who are used to being silenced, allows the reader/listener access to both the knowledge of the factors of oppression and the feelings that are generated from its experience. The result for the reader/listener is a deeper understanding of the narrator's situation. This understanding is not as easily conveyed with the words of a researcher who had not had similar experiences.

Using personal narratives moves research further away from the reduction of human lives to objects and statistics of scientific processes. These processes often exclude humanizing elements and impose an unquestioned master narrative as the only legitimate voice of truth.

Master narratives are derived from "...tradition...and they hold the narrator to culturally given standards, to taken-for-granted notions of what is good and what is wrong" (Talbot, Bibace, Bokhour, & Bamberg, 1996, p.243)  Mischler (1995) defines master narratives with a more critical view.

> Master narratives define rights and duties and incorporate the values of dominant social and political groups. Their unexamined taken-for-granted assumptions about how the world is and ought to be conceal patterns of dominance and submission. Like all narratives, these are selective representations, excluding experiences and views of some sectors of society while including and privileging others. Their legitimating function may be resisted and subverted by counternarratives reflecting these excluded perspectives. (P.114)

This research brings out excluded perspectives in the narratives of resistance to the dominant discourse of psychiatry. It does at the same time reveal the patterns of dominance and submission found in the mental health system. These narratives are also selective in their representation, although from their standpoint consumer/survivors have a broader view than mental health professionals.

Essentialism occurs when a point of view or belief is promoted as representing some absolute truth, or a theory is seen as universally applicable. Essentialism is a problem for those who wish to honour differing perspectives and relative views. This is avoided when researchers listen carefully to peoples' voices and the perspectives that arise from their respective locations without granting any one story the position of a universal truth.

Although there are many individual perspectives, subgroups of people, joined by some thread of common background or experience, tell similar stories which have common themes. From these themes, which can be against a common injustice or for a yet-unmanifested goal, stories can be co-constructed. The affirmation of values which are held `universally' does not mean that there are universal theories about how people's lives are lived or should be lived.

Group narratives become the glue joining the people involved together. Of course, when a story becomes one for many, individual details, inconsistencies and incongruent views are smoothed over or not represented. It is impossible to present each individual nuance and perspective when attempting to address issues of common concern. Narrative research, giving people a place to express themselves and tell their stories, helps bring context and portrays lives as they are lived into research which is also trying to give expression to the common concerns of the group they identify with.

The process of narrative analysis requires the researcher to stand in the shoes of the interviewee as well as reflect on their own perspective. Narrative inquiry is an interactive process where the researcher allows him/herself to be affected by the stories and to become sensitive to the narrator's voice and meaning.

Narrative analysis involves "...dialogical listening (Bakhtin, 1981) to three voices...: the voice of the narrator...; the theoretical framework...; and a reflexive monitoring of the act of reading and interpretation" (Lieblich et al., 1998, p.10) Being reflexive is not only reflecting on the material being interpreted but also being aware of one's own reaction to the ideas being developed, one's own understanding of the theory used and the literature read, one's life experience and the effect that all these have on the interpretation.

A point to note is that the story told in an interview is like a snapshot of a person at a place and time; stories change and develop, reflecting the ever changing relationships, identities and purposes of the people who tell them. With this limitation in mind, stories can still provide researchers with understanding about the narrative both as representing the life of a 'real and historical' person as well as a narrative construction.

"...Narratives have both a reconstructive and coherence function, which Mischler refers to as the "narrativization of identity formation" " (Mathieson & Barrie, 1998, p.581). Some researchers "...advocate that personal narratives, in both facets of form and content, *are,* people's identities"

(Lieblich et al., 1998, p.7). Denzin (1994) also says that narrative methods of research "...seek a morally informed social criticism, a sacred version of science which is humane, caring, holistic and action based" (p.511).

**The stories that 'sick' people tell.** The interaction of patients with the medical system accounts for their personal experiences, and the social organization of their world, outside and within the context of medical institutions. Patients begin to think of themselves as changed when they are treated differently after becoming ill. "Narrative accounts allow the ill the opportunity to examine a life transformed by illness" (Mathieson & Barrie, 1998, p.582). When people become ill their identity is challenged, if not altered, and storytelling is a way to renegotiate this identity.

Many patients experience difficulties in dealing with mental health professionals and this may lead to unsatisfactory working relationships. Mathieson and Barrie (1998) acknowledge that negotiating one's identity with health care providers is a continuous struggle, and that the story about the distress that the struggle creates may not be easily constructed or listened to by others. Mental health professionals who use the medical model with its reductionist methods often neglect to access the views and feelings of their clients while making treatment decisions. The position of the patient is such that they feel obliged to be grateful for whatever assistance they receive and therefore are ambivalent to complain about their lack of input.

Heidigger (In Polkinghorne, 1991) proposed the view that there are only two possibilities in life; two ways to construct a self-identity. One choice is to be the author of one's own story, the other choice is to follow someone else's script. Self-authorship occurs when "...I assume responsibility for my life plot and for undertaking those decisions and actions that further this plot" (p.145). The narratives which people construct can also allow them to adapt to adversity, "...to repair and make meaningful disruptions and discontinuities in development" (Mischler, 1991, p.105).

The construction of a personal myth is said by some to be essential to mental health, with myths providing a sense of self-identity as well as schemes for dealing with situations and relationships. "A myth...is a story having the power to provide life with meaning--that is a self-narrative" (Polkinghorne, 1991, p.145).

**Narrative analysis: What does the story tell?** Narrative research uses a methodology that attempts to honour the co-researchers' voices of experience. Narrative analysis of the text of the transcripts can uncover stories related to the co-researchers' experiences with psychiatric services and from the recovery process. There are many ways of analyzing narratives, focusing either on their content, their form, how the story is told, the context of how the stories fit into texts or transcripts of interviews and how the story illuminates the relationship between co-researcher and interviewer.

Some researchers use a phenomenological stance in representing what a person says at face value, respecting the story as it is told. Others use theoretical assumptions to focus on and look for what underlies the narrative, the hidden and unconscious, what is excluded and contradictory (Lieblich et al., 1998).

For this research, I take a phenomenological stand as the experience of people who have received a psychiatric diagnosis is full of their stories being examined and interpreted by professionals with the intent of showing underlying pathologies. The interpretation by myself as the researcher, which moves beyond the co-researchers' own construction, is from the immersion in and investigation of all the stories, the knowledge developed from readings and informed by theory, as well as from personal experience. "We too are storytellers...we construct the story and its meaning...The version we hear is shaped by both the content of its telling and the history of earlier retellings" (Mischler, 1995, p.118).

When we hear or read peoples' stories, the meanings behind their experiences are not immediately available. The recounting of the story; the manner in which it is told; what is

included and what is left out; how it is structured from beginning, through the middle and to the end, all work together to reveal its relevance to the meaning behind its telling. Sometimes, as a person tells a story, the listener, at a certain time after enough information has been transmitted, will 'get the point' and will feel that they understand or can relate the story to their own experience. Other times the story needs to be digested and mulled over after its telling before its significance is gained. Much of the meaning of the experience related in a narrative is revealed in the structure of its composition.

**Who, what, where, when, and why.** The structure of narratives includes story elements such as the time, place, plot, and character. The place and time create the experiential quality; the scene is where the action occurs; characters are developed in relation to culture and social context; and the plot is placed in a structure of past, present and future time. These times are related to the "...three critical dimensions of human experience--significance, value, intention--- and therefore of narrative writing" (Clandinin & Connelly, 1994).

The model of narrative analysis used in this current research is taken from Mischler's (1995) typology. "Labov and Waletzky (1967) specified the structure of a fully developed narrative as consisting of six components: "Abstract, Orientation, Complicating Action, Evaluation, Resolution, and Coda " (p.93). The Abstract summarizes points of the story; in the Orientation, the time, place, and characters are set out; the Complicating Action is the main narrative sequence or body of the story; the Evaluation is defined as "...that part of the narrative that reveals the attitude of the narrator towards the narrative by emphasizing the relative importance of some narrative units as compared to others" (Labov & Waletzky, 1997, p.32); the Resolution is the outcome or resolving of conflicts at the end of the narrative sequence; and the Coda encapsulates the experience and/or relates it back to present circumstances. Not all the elements need to be present to create an interesting narrative.

Labov and Waletzky (1997) have developed this model as the most complete but simplest structure of a narrative from their years of studying personal experience as told by English-speaking people. They conjecture that structures of stories may differ in other languages and cultures. Although stories told in other forms have a validity of their own in describing people's experience, this structure was chosen because it does have an impact precisely from having most of the elements of a complete story present.

Using the model developed by Labov and Waletsky, a complete story is identified from the transcript of an interview, or is constructed from elements scattered throughout the discourse which together compose a core narrative,"...a sequence of events which exemplify the main point of the account" (O'Neill, 1995, p.1). The narratives bring out points of importance which reveal the narrators' self-identity; the traumas they have lived through; their experience of power in relationships with care providers and psychiatric institutions; their acts of resistance to marginalization and stigmatization; and the dreams and desires which motivate their recovery process as well as impel the expression of their 'voices of experience'.

**Pulling the ideas and issues out of the stories.** The issues from the individual interviews brought to the focus groups were found through a process of analysis by reading and rereading the transcripts until no new issues arose. The focus group interviews were analyzed both using discourse analysis for meaning statements and categorization to bring out common themes, issues and ideas for programs.

## Ethics: Striving for Harmlessness

Research which explores people's lives and experiences has the ethical responsibility of honouring their perspective. Oppression and exploitation occur when this responsibility is not acknowledged and taken on. Those from groups that are left out of any consultation process for research do not get an opportunity to say whether research is harmful or not to their lives. They may be misled when asked for consent; this may not be intentional, but due to a lack of

attention to the difference in the values between the researchers and the subjects of their research. The activists in the consumer/survivor movement have made many campaigns to try to ensure that research with consumer/survivors is in the best interests of the co-researchers.

Using participatory action research to the greatest extent possible, bringing out the narratives told by the co-researchers and maintaining a strong connection with the population researched, becoming involved as an ally, are all methods which attempt to bring the research as close to the group's aims as possible. Research from the standpoint of someone who has shared experiences of the population researched can increase the likelihood of an interpretation which honours the co-researchers.

However, the individual's motivation for this type of research is also a determinant of its integrity. I need to be aware of my own processes which motivate me to work with marginalized people and also of the dangers of maintaining distance by creating difference. Without this reflexivity, I could view myself as apart, untouched and a disinterested observer, researching with altruistic aims. This altruism is of course separate from the self-interest of acquiring a masters degree leading to a career with a good wage, social status and power. Self-knowledge is an insurance against ethical errors from unconscious or incorrect motivations.

By returning my interpretations to the co-researchers, giving them the stories of their lives on paper, I was able to see the effect this had on them. Much of what was told was difficult for them to experience and to relive. When they read about their lives some of what they told was too painful and they asked me to leave it out. Even when some of the co-researchers said that they did not mind what I had written I could see there were sections which caused them pain.

If I had been too earnest and righteous about the importance of the research and the need to include passages which were painful for the co-researchers I would not have asked for their feedback and would therefore not have seen the potential harm. I was moved by how vulnerable this population was and how brave they were to disclose their pain and humiliation.

Even with confidentiality assured there can be harm from interpretations which either diminish the importance of the sharing or lay out material which is too raw. There are occasions when material is included, not because of its significance for understanding, but as a form of voyeurism or sensationalism. The researcher can be just as guilty of victimization as a mental health professional caught in countertransference who unconsciously takes on the role of perpetrator of abuse.

The consent forms, the promise of confidentiality, having someone they could phone if needing to complain or to check my credentials, the care in keeping materials unidentified and secure, helped to reassure the co-researchers of their safety, understandably an important concern for them.

## Quality and Rigor: Measuring Integrity

Interpretations are often criticized when they do not adhere to traditional or positivist external standards of evaluation. The criticism about the lack of internal or external validity, reliability, and objectivity promoted by positivists is rejected by others with their observation that "...knowledge produced under the guise of objective science is too often used for the purposes of social control" (Denzin, 1994, p.511). The objectivity sought by positivists, not only is impossible to achieve, but can actually be an impediment to understanding marginalized people.

The nature of interpretive work is that it is not subject to the same rules and conditions as quantitative research. The evaluation of the quality of the work has different criteria. The terms used for quality or validity by some interpretive researchers are trustworthiness, credibility, authenticity, relevance and goodness (Lieblich et al., 1998).

Focusing on trustworthiness rather than truth displaces validation from its traditional location in a presumably objective, non-reactive, and neutral reality and moves it to the social world-- a world constructed in and through discourse, and actions, through praxis" (p.172)

Credibility and authenticity are found in the narrative approach which tells stories in the words that the co-researchers tell them. For the research to be led from the standpoint of a consumer/survivor increases trustworthiness as well as credibility and helps to assure that the aims of the research are acceptable to those being researched . The training in research from the school of social work and the support of an expert researcher give credibility and thus legitimacy to the research. By returning the analyses to my advisors for their input there can be checks for errors in interpretation which their expertise can identify.

The criticism that my involvement with the group leads to biases in the research is valid but I do not see it as a problem or error as it actually balances out to be a benefit for this type of research. My involvement in the group to be researched is akin to an ethnographic research where immersion is part of gaining understanding; without it errors of view may occur.

It has been a continuous, conscious effort to separate or distinguish myself as both an individual who has recovered from a psychiatric diagnosis and as a researcher and student of social work. The nature of stigmatization and discrimination, both external and internal, requires that I make a conscious effort to be self-aware as well as being aware of the stereotypes and myths that others hold. I have learned to be reflexive in the process of identifying myself as an ex-patient, working with mental health professionals in a practicum, and joining in work with the SHG. This reflexivity has in fact been the source of many personal insights about identity and the nature of oppression in society and the psychiatric system. The transparency of my standpoint, biases, and reflexivity, that is, the use of myself as an object of research, as well as the transparency of the process of data collection and analysis are all important for the quality of this research.

There is a pragmatic validity or relevance in participatory action and narrative research. Plans to use this study as the basis for funding proposals and to inform the development of programs for the SHG support the relevance of this research project. The narrative approach

gives expression to the 'voices' of marginalized people and makes their perspective relevant to the concerns of policy makers, funders, and other researchers. To effect changes to social work practice requires that this research be valued and promoted. Writing articles for journals and presenting at conferences can help this aim.

A process of consensual validation--namely, sharing one's views and conclusions and making sense in the eyes of a community of researchers and interested informed individuals--is the highest significance in narrative inquiry. (Lieblich et al., 1998, p.173)

The final criteria of goodness, as proposed by Lieblich, Tubal-Mashiach, & Zilber (1998), reflects back to the purposes behind focusing on the experiences, voices and views of individuals and groups. With the purpose to give expression to those who are silenced or who have no venue to share their perspective, the research involves the critical aspect of promoting social justice in a democratic society. If we do not expose the oppression and suffering of marginalized people, as social workers we become part of the problem and effectively are oppressors in our own right.

Goodness can be a base for social work practice and research, ensuring that we be allies and empowering agents, engaging in the struggle for our own liberation from being oppressed or oppressor as well as on the behalf of others less advantaged. The Dalai Lama (Gyatso, 1984) talks about the need for a good heart and universal responsibility while engaging in social action. He describes the work of compassionate action in the following passage.

I feel that the essence of all spiritual life is your emotion, your attitude toward others. Once you have pure and sincere motivation, all the rest follows. You can develop this right attitude toward others on the basis of kindness, love, and respect, and on the clear realization of the oneness of all human beings. This is important because others benefit by this motivation as much as anything we do. Then with a pure heart you can carry on

your work...and your profession becomes a real instrument to help the human community. (P.44)

**The issues around generalizability.** In qualitative studies claims of generalization to larger populations than those sampled are not usually made. The small sample size is one factor, but the purpose and aims of this type of research have more to do with the depth than broadness of knowledge. "...The value of a qualitative study may depend on its *lack* of external generalizability, in the sense of being representative of a larger population" (Maxwell, 1996, p.97). For example, this current research aims to specifically bring out the perspectives of the members of the Self-Help Group. This group wishes to develop programs which will address the concerns of its members. They recognize that there are many variations in mental health and a single approach will not cover the needs of all those who seek help. This is precisely why the members of the Self-Help Group are attempting to set out their own criteria for what will aid their recovery in order to develop the types of services that are not available within the traditional mental health system.

There is a distinction made between internal and external generalizability. Internal generalizability "...refers to the generalizability of a conclusion *within* the setting or group studied..." (Maxwell, 1996, p.97). Internal generalizability is a relevant issue in qualitative studies. In this study, the use of focus groups and the group examination and discussion of the issues raised in the individual interviews can be said to establish solid ground for internal generalizability. Other ideas, such as the generalizability of theory developed in a study or the corroboration from other studies lend some credibility to generalizing, but they do not "...permit the kinds of precise extrapolations of results to defined populations that probability sampling does" (p.98). Mental health is a vast and complex area with many different viewpoints. It will take many of these types of research studies to begin to form a holistic perspective; one that takes into account all the standpoints of the individuals and groups involved.

## Conclusion

Narrative research is an exploratory inquiry which can reveal aspects and the meanings of people's lives found in the stories that they tell in the context of their `lived experience'. Co-researchers become 'witnesses' to the testimony of their lived experience and the impact of this testimony impels the researcher to respect this voice of `embodied' knowledge. In this process the researcher honours the co-researcher and the group they belong to in pursuit of understanding and/or justice on the basis of the universally held values of human rights and freedoms.

The use of participatory action research is suggested for research with self-help groups and those who are often marginalized in traditional research (Rogers & Palmers-Erbs, 1994). The input of the members of the SHG increases the credibility of the study and the use of the research to further the group's development gives it relevance. These two approaches to research ensure that the method is consistent with both the theories it is based on, the aims of social justice and the promotion of recovery-oriented mental health services.

The values of social work are also well represented through this research methodology. Moreover, the process involved in conducting this type of research leads to a deeper understanding of how research can be an emancipatory activity for both researchers and co-researchers. It is a priviledge as a researcher to be a `witness' to the testimony of those who have been oppressed and silenced; to witness their courage and honesty. It is also instructive to see how the self-authorship of narratives has the power to deconstruct psychiatric identities and to reconstruct identities based on recovery and the freedom from oppression.

# PART TWO: THE FINDINGS

## Chapter Five

### Interview with Jane

Jane is a woman in her fifties who immigrated from Scotland as a child. She has for the last

six years been employed in peer support of consumer/survivors. The interview began with a

chronology of all her experiences with the psychiatric system. After having experienced

violence in relationships Jane was in and out of psychiatric hospitals and wards from 1969 to

1977 because of her depression and suicide attempts. In the first narrative Jane tells the story

of a suicide attempt while in an abusive relationship and the treatment which she received.

#### "It seems that what is going on in your life has no relevance"

**Orientation:** I went to Montreal for a year out.
**Abstract:**   And then I got involved with a really violent man...
that led me a couple of years later to...try suicide again.
And this time...he was really violent to me...
**Complicating Action:**
One night we were out for a walk
and he was going to get violent with me again, I knew that.
And two policeman were there, and so I asked the policemen to take him away
and then I went back to the apartment and I tried to kill myself.
And I had been planning it actually 'cause I felt like I really was living in hell.
So I went to the Hotel Dieu in Montreal, first to the regular ward...they gave me surgery...,
(I had put a knife in my stomach) to see if there was any internal damage.
And then they put me in the psych ward.
And then...this psychiatrist was asking me about sex...
and he asked me...why I felt so guilty about sex.
And I just said that I didn't know that I was...
**Evaluation:**  I probably was but at the same time
there were other things going on in my life, like this guy pounding me.
But to me the psychiatrist was like an agent of the state
**Resolution:**  and I just decided that I couldn't talk to him,
I couldn't trust him at all. (16-41)
**Coda:** ...Nobody wants to find out what's going on in your life.
It seems that what is going on in your life
has no relevance to your being in a bad place. (236-239)

Jane found that she did not get the help she needed to recover her mental health in

mainstream psychiatry. In fact she felt alienated and diminished by mental health professionals.

Not somebody again who thinks that they're perfect and everybody else is screwed up...I
don't bloom in those circumstances to say the least...(401-403) I didn't feel any compassion

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coming from them (psychiatrists) to me, who was really struggling and...in pain. I didn't feel
any compassion at all...(4-411)

In the second narrative Jane graphically describes the oppressive nature of her relationship

with one male psychiatrist and the anger she feels at the life she could have had.

## "I could have had a different kind of life if I'd got some help earlier..."

**Orientation:**...I spent a whole year of my life at Riverview...
**Abstract:**    ...any kind of contact with the psychiatric system
                really scared me. So I was always quiet,
                and very obedient, compliant. (108-110)
**Complicating Action:**
                I would go and see this one psychiatrist at VGH.
                I would cross this huge room, with a big carpet,
                and here is this normal, white male
                with his three piece suit behind his desk...and so I mean,
**Resolution:**    I would shrink as I walked across.
**Evaluation:**    And so I thought that the word shrink is really, like, apropos. (251-259)
                Because, I always felt that power differential really strongly.
                They can lock the door and throw away the key right now...
                just one doctor...( 392-395)
**Coda:**        And I could have had a different kind of life
                if I'd got some help earlier.
                And I have a lot of anger,
                I really have a lot of anger about that. (195-198)

The trust needed for healing relationships was not fostered by the mental health workers she

encountered.

> ...I had learned in the psychiatric system...just all these different people who wouldn't talk to
> me, and who patronized me, and who ignored me, and who belittled me. And I didn't want to
> tell them everything. I just couldn't. (278-282)

She also describes how she felt she was supposed to change herself to match the

conventional ideas of what it means to be a woman.

> I wasn't allowed to ask them anything. I wasn't allowed to say anything, I was just supposed
> to be docile. And I always they felt that they wanted me to end up in Coquitlam with a charge
> card...
> I didn't want that, I wanted to study...travel and...have this bohemian life...And...I really felt
> like they were trying to impose  their ideas of what a woman should be onto me. (447-455)

In fact, as the therapist she went to at the drug and alcohol treatment

centre told her,

not only did I have to recover from the problems that led me into the psychiatric system, but
I had to recover from the treatment I got in there...(200-204)
And in that system...the thing is your expectations become so low. (646-647)

Jane managed in the community from '77 to '91 without any hospitalizations, "...by being very

isolated, not knowing anybody, having really low expectations of what life could be like for me"

(146-148).

Jane's self-identity was changed by feminism. "...I read a book...the Female Eunuch. I

stopped trying suicide after that..." (69-72). Her revelation at discovering feminist ideas was

described as, "... it was like coming out of a fog...and seeing things written down. It was...such a

relief..." (494-496).

Jane's recovery began when she took control and sought help that she could trust. She says

that in a way she was only able to get help she could access because she had so many other

problems besides her psychiatric diagnosis.

And I really believe it's because...through my various problems,
I've been able to access some real meaningful help. (384-386)

Jane found help through attending mutual-aid groups for battered women, adult children of

alcoholics (ACOA) and those with substance abuse issues (NA) where "...it was really

astounding for me to find out that other people were struggling" (266-267). She also started to

see a drug and alcohol counsellor whom she was able to slowly begin to trust because

she was an addict...somebody who knows what it's like, and
respects my various struggles...because she involved in her own...
..she doesn't patronize...she doesn't have a lot of power over me.

The final turn around was when she began her present job.

**"...my life has really, really, really changed, in the past ten years."**

**Orientation:** ...This was in '91, '92 actually
because I had come out of Riverview
...my parents were always after me the day
I would come out of the hospital...to go look for a job...(328-334)
**Complicating Action:**
But this time I decided that I wasn't going to do that, and
I moved into the (Mental Patients Association) house.
And so for a year I did nothing but go to ACOA, and NA,

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|  |  |
|---|---|
|  | and the alcohol and drug counselor, which was really, really |
|  | hard. And then I was starting to look around for work and I |
|  | applied for a job...didn't get it and then I just heard about |
|  | this job at the Self Help Group, I didn't even know what it |
|  | was, and I applied for it. |
| **Abstract:** | And I thought, well, if I don't get this job, I'm leaving Canada. |
|  | Because I really felt like I had tried, you know. |
|  | I have a good education. I'm willing to work hard. |
|  | I know that my personal problems had really prevented me |
|  | from doing a lot of stuff. But I was just... |
|  | getting really fed up with it. |
| **Resolution:** | And then I got this job, it landed in my lap, |
|  | like I can't believe it, you know. |
| **Evaluation:** | My job has been really healing for me, |
|  | it's really politicized me a lot, you know. |
|  | Um, I feel really good about it. And also it enables me to do, |
|  | um, to do nice things for myself. (338-358) |
|  | And so, you know, materially my job has just been like (wonderful)... |
| **Coda:** | It's just like...my life has really, really, really changed, in the past ten years. |
|  | Especially...in the last six and a bit ever since I got my job...it's really changed. |
|  | (364-369) |

Some of the nice things Jane did for herself because of her paid employment were to buy vitamins, go to a yoga class, live in a decent apartment, and be able "...to buy a cup of coffee, and take the bus, not like either/or, like I lived for a long time" (360-362) She's been able to travel to Britain and South America and to make payments on a piece of land she shares with some friends.

Jane knows the importance of keeping up with the body work and the counselling which have helped her recover.

> I have much more love and respect for myself...And its growing.
> Because I know for me...I have to keep working on my issues.
> Because it's a way that I get to know who I am.
> That, to me, is completely miraculous...(542-547)

In her work Jane is helping to set up programs of peer support. She meets with many consumer/survivors and advises them on the services and resources which they can access. She is also networking with women's groups, sympathetic mental health professionals and researchers.

Jane sees people who say that they are lucky that they found help in the mental health system.

> ...I look at people and they say they were lucky because they got whatever kind of help. But then I see that...it's fifteen years later, and they are still on medication and they're still unemployed and they're still...going and sitting on some committees that don't make any kind of change. And then they tell me they are lucky! (637-645)

Jane speaks of how tragic it is to see people who have been thirty years at Riverview and how many have been placed in the community but are still living institutionalized lives.

> If you are in that system, a lot of people feel really, really, totally marginalized, you know, totally marginalized. And they go to these ghettos of drop-in centres and clubhouses and, you know, nothing changes, except things get worse for them. (694-698)

She sees that many people have potential which could be developed and which hasn't been in the mental health system.

> ...But there've been other things going on in our lives besides the fact that we ended up in the psych ward. And...a lot of us around the SHG are really highly educated, have a lot of other skills, and we have been, just kind of like been thrown on the garbage heap. (801-806)

By supporting the Self Help Group, Jane is fighting the marginalization of stigmatized people who without hope are merely existing.

> Because people are so desperate, you know, that something has to change, something has to change, a lot has to change. (818-820)

The peer support group acts as a beacon of light to people who have been told they have a limited future. Jane says the aim of the group is to "...offer hope to people, to offer recovery, to offer...that you can get well."

## Discussion

In the first narrative, Jane describes her interaction with a psychiatrist who asks questions which to her are irrelevant to her "...living in hell" (27) with an abusive partner. She decides then that she can not trust psychiatrists, "...agents of the state...", and this lack of trust continues throughout her experiences in the mental health system. Jane, by her decision not to talk, resists the attempt to blame her for her abuse and to see that her suicide attempts are from

inner psychological problems rather than from the trauma caused by the terrible circumstances of her life.

Jane's experience of the oppressive nature of psychiatry is succinctly summed up in her second narrative. The power differential that she felt is graphically shown in her description of walking across a psychiatrist's office. Physical settings can contribute to the disempowerment of oppressed people. The mental health care team at which I was placed for a practicum, had a long corridor which I can now imagine contributes to the client's feeling smaller and smaller as they walked to their appointments.

Jane's anger is understandable; for twenty years she was "obedient" and "compliant " (110) but unable to find the help that she needed. Both Valerie (later interview) and Jane expressed their anger at the inappropriate treatment they received, that no one listened to them, and the fear they had because of the power that the professionals and other mental health workers held over them. Both these women reacted to the psychiatric system as if it was just another abusive situation. If they were remained obedient and compliant they would not be attacked. Unfortunately, the system often fulfills many people's expectations of continued abuse with its oppressive, coercive methods.

The contrast in the types of help Jane received is clearly apparent between the second and third narratives. Meaningful help for a woman who has been traumatized by violence at the hands of men, is not a man in a suit behind a desk who carries the power to "...lock the door and throw away the key..."(395).

Her experience as a woman who had been battered, which precipitated her suicide attempts, was clarified and put into perspective by the work of women's liberation activists. She was relieved to read that it wasn't just her but that many women have been abused at the hands of men and oppressed in a patriarchal society.

Because of the traumas she received from men Jane cannot trust male psychiatrists who also have power over her, and will not, cannot discuss her abuse with them. It then becomes important for Jane's recovery to receive counseling from a woman who also, "...knows what it's like.." who has no "...power over me..." and, "...who is involved in her own struggles " (398-399).

Looking back, Jane also saw how psychiatry tried to exert social control in their attempts to have her become the 'woman' that a patriarchal society wished her to be, charge card and all, discounting her desires to travel and lead a 'bohemian' life.

Jane's work is to counter people being "...thrown on the garbage heap" (806) when they receive a psychiatric diagnosis. Instead of being the wastes of society, as Valerie voiced, they have many skills, abilities and potential to be developed which can contribute to their recovery and a place in society.

Jane has not only recovered significantly, "...I have friends...I go out...it's wonderful, I have fun..." (375-377), but she has moved into self-actualization. "...I am 56 and I feel better than I have in my life before" (383). Jane's active life full of meaning and her ability to know when to work on her issues make her an ideal role model for consumer/survivors.

# Chapter 6

## Interview with James

James was born in the United States near the Canadian border to an Ojibway mother and a father of German heritage. He exiled himself to Canada to escape being drafted into the Vietnamese war and made it permanent with his marriage to a Manitoba woman of First Nations' ancestry. He had three children, two girls and a boy.

James is a very active man, attending drop-in centres, visiting many in the mental health community, volunteering for the Self Help Group on the board of directors and working in peer support.

The first narrative describes Jame's initial trauma.

### "...I'm a Self-made man."

**Orientation:** My life was ruined right from the beginning.
**Abstract:** My life's been cursed and doomed, the whole damn thing.
**Complicating Action:**
My mother committed suicide due to racism.
And I was six years old. (627-632)
...but my grandmother knew... that Indians were trash
and he had brought home trash
and she screeched and screeched and pushed her to suicide...(656-659)
And I guess my father slumped off in an alcoholic depression
and left me to my grandmother and my aunt and uncle.
**Resolution:** So I pulled myself together, OK. (633)
**Coda:** OK. So you know I'm a self-made man, OK.
**Evaluation:** Society isn't pleased with that
and I've been marginalized because of that,
but I'm a self-made man. (637-639)

James says he has been marginalized precisely because he is not one of those, " ...persons who do exactly what they're told...or follow the leader" (41-42). He has followed careers on the edge of society. He once earned a living by channeling for those in a meditation group. He also identifies with his "...fellow mental health consumers..." (134) whom he sees as having this same level of independence and resultant marginalization.

A lot of people in the mental health system...have different values than the main population...the reasons why some of them are there are they aren't robots or sheep.

(34-41)
As far as I'm concerned... if the people who are mental health consumers are
the...outsiders, the bad guys, then I'm a bad guy too because they're just like me. (140-143)

His resourcefulness and ability to maintain independence is admirable. " I'm strong and
intelligent, self-taught, self-educated and everything like that, you know " (640-641). I was also
impressed by his eloquence, knowledge and self-development. "That's (spirituality) has helped
a lot...And I've seen what meditation and spiritual development can do for you..." (564-566)

James is a man who has avoided the mental health system for twenty-five years as he says
"because I kind of have a therapist phobia, OK?" (12) and because

> of all the things my friends who have been in the system have told me had happened;    stuff
> like electroshock therapy and...the heavy drugs that schizophrenics have to take...and plus
> my lifestyle tends to be...something that would ah, ah, certify me for sure. (17-22)

James talked about his own experience with almost dying and how he had what was
identified as a manic episode when he realized he was alive.

> So...that was when they were going to...transfer me to the psych ward because, like, if
> you're dead, if you're dead, you know, and you come back to life, I mean, you've got to be
> manic, 'cause you're alive!  But that was...a real life sustaining, a life changing thing there.
> (183-193)

He said that looking back he recognized he had experienced mental health challenges before.

> I can see now, I've been a life-long manic and...depression for sure absolutely, like long,
> long, long depressions. (194-195)

But James with his great independence and fear of the psychiatric system had the strength to
hold himself together.

> Both physically and...psychologically just...sort of a re-stitched together person...both
> because...I was stitched together in... surgery...And ah...and psychologically, well I sort of
> stitched myself together for as long as I could...(110-116)

James regrets not accessing earlier the help that he could have used.

"...I have to admit I made the wrong choice. I think just even a few tranquilizers...would have
made a whole lot of difference " (89-90).

> ...my children have been raised by a manic depressive
> and they're kind of crazy now too, OK.
> I had a daughter and two sons...Especially the boy...

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You see if I had had a valium or two a day, a valium or two a day,
I wouldn't have damaged him because of a bad marriage...
A bad, incompatible...marriage that lasted for 10 long years.(685-695)

He said he became depressed after the end of this marriage "...because it's your whole life, 10 long years is a life...(and) because the dad is cut out you know " (697-700). James also talked about being manic for three months after his second marriage failed. "Ya, I didn't sleep for 3 months. That was divorce, right?" (103-104).

The turning point for him was the last time he became seriously depressed. At this time he no longer had the resources to maintain his independence. His account of how he finally went for help to the mental health system is found in the following narrative.

### "I wouldn't be in such a...rough shape, if I had...got some help before."

**Abstract:**    Ah, because of religious beliefs, or...philosophy, or...learning experiences...or life crises, I've, ah...actually psychologically crushed myself, well, ah, at least a dozen times. (207-211)

**Orientation:**    Manic depression is virtue. all right?
But like, you know...because when you're depressed
you tend to reform and discipline yourself. (201-205)

**Plot:**    Well for instance even in my latest crisis...
I wanted to combine all the disciplines,
all the disciplines into one big package, boy.
And like, ah, oh, wow!
...I had to exercise and (controlled) what (I) ate
and you know, even the littlest things. It was really heavy

**Resolution:**    and I cracked. Ha, ha. I just cracked right up.
And this time too old and too, you know, too poor to do anything else but to seek regular doctor therapist.

**Evaluation:**    It's just that I really, should've...got some help in the past,
I really should have got some help because

**Coda:**    I wouldn't be in such...a rough shape,
if I had of got some help before. (217-231)

James has been taking a mood stabilizer for the past year and has found, "...I've actually grown because I was given some medication to settle down and get a good night's sleep " (329-33). He pointed out that now he was able to choose to accept help, he was collaborating and taking responsibility for his mental health which supported his recovery.

It turned out to not be as awful as I thought it would because...
If I had just fallen down like a limp wrist dish rag, and said.
"Do what you want", well I think it would have been worse. (26-32)

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Besides being angry at himself, he also pointed out that,

> ...for thirty years people have known I've suffered from manic depression...My doctor knew...five years ago...But nobody has guided me or directed me to take it (the medication). (356-360)

James has worked on his body and mind with yoga, tai chi and meditation. He recently discovered nutritional supplements, a part of a weight-lifter's diet, which counteracted the side effects of his new medication. His self-therapy also included throwing himself into work to pull himself out of depression. He has dedicated himself to helping others, is part of peer support at the Self Help Group and through another agency doing outreach to Riverview Hospital.

James says that the Self-Help Group has also been central to his recovery. He explained that with the use of anti-depressants "...you lose your mental and social tactility..." (256), which means that a person's judgment is impaired, helping lift depression which is usually heavy with negative judgment. But he also said that

> ...every last second of every day, waking or sleeping, on anti-depressants, I have to be careful of every thing I do. And it has to be willful, determined, evaluated and everything else, because either I will just not pay attention and walk out in front of a bus. (272-276)

He warns that depression may only be traded for a milder version on anti-depressants, "there's sleep depressions " (299), if the dose is too high.

> I'm really behind the Self Help Group because...it really saved my life...(248-249) (The coordinator) told me to take only half, OK...and a half dosage worked just fine...I was gonners...because...I really didn't know what a full dosage would do. (284-289)

James said he took one year of psychology at university, and has counselled others informally with "pop psychology" for many years. From his own experience and working with people he has come to the following conclusions.

> It appears that people really need just to...talk and really talk...
> ...I find that you have to be an interested participant...an active participant...(152-162)
> 'Cause taking the ball away from somebody when they're trying to express their feelings...what their real needs are, that is one of the big mistakes in psychology...I know they are trying now...to listen.

James is working in peer support; he visits mental health drop-ins, takes people out for coffee and listens to them.

> ...A lot of people will never hit the mental health system if they just could have somebody to...talk over their problems for a little bit... (164-174)

He is contributing to the Self-Help Group by helping them fundraise and expand their membership. James is a role model of the power of working for others which in turn helps him in his own recovery.

## Discussion

The first narrative poignantly describes an image of a strong, solid man, whom "...society can't break..." (563) and who values extreme independence. He attributed his ability to survive all the crises he experienced to the development of his spirituality.

> ...Because to hold out in the financial, social, ah, psychological setbacks I've had...to never cave in, you know, that's been amazing, that's spiritual development. OK? (596-600)

James did avoid being taken under the care of the psychiatric system, "I somehow managed to get out of that..." (56-57) and continued to work on the development of his spirituality after his near death experience which he called, "...a real life changing thing " (193). Psychiatrists, some of whom only see spirituality as supportive at best and delusional at worst, could see his conversion from surviving a near death experience as a symptom of psychopathology.

Authors in transpersonal psychology draw attention to the fact that life threatening experiences can trigger a reaction which may appear to be a mental health problem but is in fact a spiritual emergency. It is extremely important for those helping to "agree that the difficulties are not manifestations of a disease, but of a process that is healing and transformative" (Grof & Grof, 1989, p.194). With the correct guidance this crisis can lead to a spiritual transformation. This guidance can involve bodywork, therapies to help the expression of emotions, advice from spiritual teachers and the support of those who respect the healing wisdom of the transformative process (1989). Some crises require 24 hour support which is

difficult to find. Often these people end up in the psychiatric system drugged and their potential for transformation blocked.

James has roots in both First Nation and German heritages which left him with a foot in both groups and a member of none. He is able to work and socialize well with consumer/survivors because he identifies with being an outcast. His position as outcast, his history of trauma, and his development of spirituality have all affected his mental health. Whether he suffers from pathology, problems based in social and economic disadvantage, discrimination, or from a spiritual emergency, James wishes to now seek help.

The second narrative tells how James became involved with psychiatry. He said that because he was too old and too poor he had no alternative but to seek help from the mental health system. Alternative or non-conventional therapies are expensive and not easily accessed by consumer/survivors.

James has been able to find security with the disability pension and relief from his depression with medication. He has accepted the diagnosis given him and believes he will have to take medication for the rest of his life. However he has chosen this help and feels self-efficacy from the choice he made. He also is active in creating a place for himself working with the SHG and in peer support.

A question that can be made is, was his insistence on independence honoured and was he less insistently advised to use services, because he was male? Women's experience from research, and in this small sample, as Jane relates, "...If you're a woman...you are more than twice as likely to get medicated if you go to your doctor than men are..." This shows that they often receive too much, unwanted treatment. The differences in the type and amount of treatment received by men and women would be another interesting topic to research.

What James has learned in his years of caring for himself still support his recovery today. He knows the value of body work, appropriate nutrition and supplements, the worth of meditation

and the healing powers of work.  But especially he knows how important it is for his own mental

health to move out of worrying about himself into caring for others.

> If there's no one to take care of, why live, why eat, why have a house, why have anything,
> why have anything...? Right, right?
> So that's my big secret, eh! (834-837)

James, with his desire to train and work full-time as a peer counsellor and using his wealth of

knowledge and experience, will be invaluable to consumer/survivors on their road to recovery.

## Chapter 7

## Interview with Valerie

Valerie is a woman in her forties, who both works as a volunteer and as a paid part-time employee. She began by identifying barriers to her recovery.

> I think the thing that has been the hindrance for me has been the mental health system itself. It has been a big barrier...in my way all the time to getting better and to seeking access to getting the kind of help I need to recover from, quote, being labelled mentally ill. (11-16)

She said that she received improper diagnosis and treatment when she first entered the psychiatric system and for a long time after.

> I got into more trouble after I was...given treatment...I got into all sorts of trouble with all sorts of difficulties...And...my doctor tells me now that I didn't get proper treatment when I first went in...(I was) misdiagnosed...given, lots and lots and lots of medication and basically neglected. (678-692)

She told several stories of her experiences with the staff of mental health services. Her stories were about those whom she experienced as being good, as well as bad; those who created barriers and those who helped clear the way to her recovery. The first narrative describes some of these workers.

### " ...Just see what I've been through..."

**Abstract:**  Perhaps the good ones have more compassion to others,
  ...kinder than the ones who don't know what they're doing...
  and they're just there for the power.
  I figure they get really twisted out of shape...(99-103)
**Orientation:** And another incident that happened at Venture was...
  And this has happened dozens, and dozens of times with staff.
**Complicating Action:** Is, uh, I had a friend come and, uh, visit me at Venture
  and we went into one of their little rooms...
  just having a conversation and this nurse walked in
  and she said something to me, and she was deliberately cruel, mean to me.
  And I just sat there while she went into the dispensary,
  got something out of the dispensary...And after she left the room,
  I just started crying, and my friend was comforting me.
  And she said, " Oh wow ! That was so deliberate! "
  And I said, " See what I've been through, that's happened to me,
  multiply that by a hundred thousand times, just see what I've been through "
  (105-121)
**Resolution:**...This time I actually have a witness to this...(106)

**Coda:** So that kind of abuse, it doesn't show on the body,
that kind of psychological abuse. (121-123)

She had many stories of abusive encounters with mental health staff. One nurse told her, as

Valerie was in friendliness explaining she was going out to eat and when she would be back,

"You have a psychiatric disorder and you're being manipulative." (50-51) She describes the

mental health workers, reflecting that,

> ...it's a mixed bag...you can't choose who you get to work with...If you're lucky you get a
> good worker, and it you're not lucky you get one that...can really give a hard time. (135-140)
> ...a lot of the staff are mixed-up people...(364)
> ...that system, the way it's set up, is such an unnatural system,
> it twists--it takes the staff and twists them around.     ,
> They get twisted really quick, really quick, you know. (698-700)

Another narrative describes how she was able to stand up for herself against an oppressive

mental health worker.

### "...You know it never gets anywhere but...I stood up for myself."

| | |
|---|---|
| **Orientation:** | And another incident I had, I think it was the same time I was there... |
| | So I went into Venture and |
| **Action:** | there was a staff person there and I made a sarcastic remark to them... |
| **Abstract:** | I don't usually go around making sarcastic remarks, but I resent |
| | what they did to me... |
| **Action:** | So he said," One more comment like that and we're going to kick |
| | you out. You know we're going to have you leave." |
| **Evaluation:** | And I had nowhere to go. |
| | I was ready to...literally jump off a bridge. |
| | I was just so distressed, |
| **Action:** | I started to cry...(65-78) |
| | ...I went around the corner and I just like, |
| | made...a phone call to a friend who came... |
| | And then I confronted the worker... |
| **Evaluation:** | you know it never gets anywhere but... |
| **Resolution:** | I stood up for myself. (85-93) |
| **Coda:** | I can be really quite assertive, or if I have to be, and |
| | they don't like that because you talk back to them. (62-64) |

One worker harassed Valerie, made inappropriate comments about her weight, and, "...he'd

say different things every time I went there" (156). She asked to change workers, and "...they

wouldn't give me one at first and then I just kept (asking)...but finally they gave me another

worker..." (158-162).

Valerie talked about the childhood sexual abuse she experienced.

> Well It started early on in my life. I guess like when I was really young...I must have been eight, seven or eight...But I never told my parents, so, which is probably a good thing. So I think that's probably part of the reason why I had mental health difficulties when I was older. (383-387)

She also disclosed that she suffered " some bad, terrible bad abuse" (436) in her teenage years as well.

> That was a very terrible time for me. I mean it was good like in some ways, it was good 'til this abuse started happening, and that was sort of let go, you know, and it just trashed me, at least that was my experience...(445-449)

In reply to the question of whether anyone asked her about these traumatic experiences in her treatment she said,

> Oh no, oh no not at all, no not at all...(397)
> They take the person away...out of their environment and what's going on around them and say well this is your problem.
> It doesn't matter if they are starving to death and...committing suicide. And another reason...is they are being placed in such awful situations...they can't see any way out. (403-412)

Valerie was angry at the way she was treated after being hospitalized.

> They'd just put me in the hospital and then they would dump me out in the street, like I was a piece of disposable trash. (221-223) They would dump me out and put me back in the same situation over and over again. It was terrible, it was terrible. (465-468)

After Valerie was `dumped' out into the community again she faced the difficulties of unsafe housing in the area she could afford to rent, the downtown eastside.

### "...I was easy prey, easy prey for people..."

**Coda:**       ...I was easy prey, easy prey for people, you know.
**Abstract:**   And my mind wasn't functioning at that time.
                It wasn't my fault, but...I certainly paid the price for it...(231-233)
**Orientation:**
                Well for example. I guess I must have been about 28...
                I rented a little room in a boarding home...(not) a government...home, but it was
                a real dive, but that's all I could afford.
                ...The third day I was there someone kicked down my door
                ...it was about 4 o'clock in the morning and
**Plot:**       all of a sudden I heard this noise and I got up and looked in my kitchen,
                and my door was being kicked down...I was this skinny little kid off the street...
                my door's being kicked down and my mind's not functioning properly.
                So I was just standing there thinking, "What am I going to do?"

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...So this guy comes in and I thought, "He's going to rape me!"
...So I said to him, "What are you doing here?"
He says, "I'm looking for so and so."
So I just acted really tough, I said, "He's not here. Get out now!"

**Resolution:** And he just turned around and walked, walked out.

**Evaluation:** He'd been drinking. But...it could have been a really dicey...
having your door (kicked down)...it was a really strong door.
It was like...survival, it was a totally instinctual reaction. (237-264)

But there were times where she didn't avoid becoming prey; "...difficulties, mostly with men...stories that would make your toes curl" (377-379). These were stories she would not tell in the interview.

Ya, it was a really terrible time. I can't believe I made it through, it's amazing...I don't even tell that part of my story, I tell other parts of my story to people and they go, "It's amazing you're still alive...". (372-377)

When there was some attention to her housing, Valerie would be put into a group home.

I think everybody just thought I was a hopeless case...
we'll just stuff her in a home and leave her there. (1082-1085)

She mentioned some homes that were pleasant with supportive staff. A few were as bad as the rooming houses she described in the last narrative.

...They were awful, this was like twenty years ago...I mean they are bad now, they were really bad back then. They put me in a house with people that were hooking and drug addicts and you know I was very suicidal...and the co-ordinator's boyfriend used to tell me all the different kinds of ways to kill myself every night.(335-342)

It was a turning point in her recovery when she was able to find kindness, someone who "...was impressed with me..." (638) and took the time to help her with her self-destructive behaviour.

### "...that you were worth it."

**Orientation:** I started to see a really good therapist
who helped me out a lot...a private therapist, (631-637)
I've been seeing her probably for 15 years now...(644-645)

**Abstract:** She just talked to me...listened to me talk...
and she'd give me advice...
And I'd say just tell me what to do to get better I said and I'd do it.
And she also didn't blame me for being sick.
"But you are responsible for getting better..."
When she said that I was happy to take on
the responsibility for my recovery.

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**Evaluation:** ...because you have it taken away from you.
And you don't know how to take it on after a while,
you just become totally helpless,
just like you've no sense of---
I just lost all sense of---too, limits...(1054-1072)

**Complicating action:**
I used to hurt myself a lot, cut myself a lot,
because I had a lot of pain inside.
This therapist I went to see 15 years ago,
we went into in-depth discussions around that.

**Resolution:** I eventually got out of doing that,
and I haven't cut myself in years. (1077-1082)

**Coda:** So I think people in my recovery have been important to me.
People that have respected you, and have seen
that you could recover, that you were worth it.(1072-1075)

Valerie also discussed her current psychiatrist at the community mental health team whom

she has found to be a helpful professional. She sees him only once every six months and finds

that,

He's very good because he listens. A lot of them don't listen to you.
You're just some crazy woman, that...they don't listen to. (184-187)

But even so she doesn't trust him,

I never tell him anything. I would never be so foolish, pardon my sarcasm, but...I've had a lot
of bad experiences.(172-175) He would...help me more, but I don't feel very comfortable.
(181-183)

She appreciates that he responds when she wishes to change the medication because of side-

effects or to raise or lower the dosage. He has suggested she try to do without drugs

altogether, however she is too afraid of deteriorating to try it yet.

So I got a lot of my decisions...I like him, he's a good guy, he's a good guy, he has a good
reputation, he's a good doctor. (205-213)

The good mental health professionals, the group home staff and other workers have helped

Valerie to love again.

The staff were really good to me, they just gave me lots of love, they treated me with
respect and I just blossomed...I just blossom when people give me love...(512-517)
So now I can give love 'cause I'm more able, so that makes me feel good. (531-533)

Now that Valerie lives in a beautiful apartment and receives a disability pension supplemented by her volunteer and paid work, she has the basics for recovery. There are drawbacks. Her apartment is in a supported building for consumer/survivors run by a mental health organization. When one of her male neighbours became distressed, banging on her door and screaming in his apartment, Valerie had to leave for a while because she became too frightened.

The healing relationships with the good professionals and from peers at the Self Help Group give her the support to work on her recovery. For her well-being Valerie makes sure she has good nutrition, exercise, and expresses herself through her creative writing. She has developed her spirituality and credits her beliefs and practices as another strong support for recovery.

Valerie found some help in a twelve-step program and at a codependents group which also enriched her spirituality. Another important aspect for her health is her social life, being surrounded by people she likes and who like her. She believes the work of the Self Help Group is very valuable, and sees the need for more peer counsellors.

> I think that's definitely very important because you need someone around you to say I feel the same way and this is how I got through this, or I've experienced the same thing. (959-962)
> I think when I was younger, I was just starving to find someone who was going through what I was going through. Because it was really, really intense, really, really heavy. People out in the community couldn't handle it. (916-921)

Valerie has had a long time dealing with the effects from the trauma of childhood and adult abuse, the inappropriate treatments, and the lack of proper housing and funding. She has now found the help that she needs to increase her well-being and recover her mental health.

> My experience with the mental health system was it's basically like `One Flew Over the Cuckoo's Nest'...This was not a two-hour movie but...like...a 12, 15, 17-year experience and it's enough to really mess you up. So it's taken me a lot of years to get where I am and I still suffer quite a bit emotionally...

## Discussion

Valerie is a woman who has survived. She has resiliency, and the strength to confront, stand up to and refuse to be the victim of oppression.

The mental health system appears to have failed Valerie; with inappropriate treatments; not taking into account or even finding out about her history of trauma; not giving the support that she needed to avoid more victimization and a fall into substance abuse; and not providing the healing relationships which she needed.

In the first narrative it can be seen that Valerie is in a vulnerable social position as a marginalized and stigmatized person who can be revictimized in this system. She is powerless in this situation, as she needs a place to go when she is in crisis. She shows her resilience in how she is able to confront the worker in the second narrative. She may be oppressed but will not be a silent victim and it gets her into trouble with the 'twisted' workers who are only there for the power.

The third narrative again shows Valerie as resilient as she "...just acted really tough..." (255) avoiding becoming a victim to the drunk who broke down her door. But she had a terrible housing situation and poverty such that she stood in soup lines to avoid more harmful ways of feeding herself. Even though she doesn't tell all of what happened in her life on the downtown eastside, it may be inferred that she suffered from sexual, and/or physical, and/or emotional abuse, "...difficulties with men...", which she managed to live through.

One of the factors for her recovery was the support of someone who "respected you" , saw, "that you could recover" and "that you were worth it." (1074-1075) The attitude of the mental health professional shown in the fourth narrative contrasts greatly to the first two. The in-depth discussions, the respect and long-term commitment from this therapist changed Valerie's self-image, and enabled her to stop hurting herself and move toward health. Her narrative tells of the support for her to take responsibility for getting better, another major factor for recovery. She, "...talked to me and listened to me talk..."; a dialogue between women, she even, "...gave advice." This woman was a private therapist, she was not a part of the public psychiatric system with its coercion and control.

Also in this narrative, Valerie reveals the negative self-identity she developed in the psychiatric system which takes away responsibility and engenders dependency to the extent that, "...you don't know how to take it on...become totally helpless...like you've...lost all sense of...limits" (1069-1072). This dependency on a paternalistic system is one of the key elements of a psychiatrized identity (Smith, 1990).

Valerie's story is an example of the difficulties faced by women who have histories of trauma, who are not identified as having a post- traumatic stress response and who are then revictimized by the lack of appropriate treatments and care as well as the oppression and abuse found in the system. Her story is consistent with the results of a research study on women's mental health, part of which focused on women who had experienced trauma, conducted here in British Columbia by Morrow and Chappell (1999).

The lack of community supports led Valerie to more abuse, unsafe housing and eventually drug and alcohol use to "...stop the pain...". As Valerie says herself, what she experienced, "...was really, really intense, really, really heavy. People out in the community couldn't handle it" (919-921). This type of distress is difficult for professionals to deal with (the self-mutilation, etc.), and medications do not manage this behaviour as well as they would like.

It is only in a long-term healing relationship that traumatized people like Valerie can develop trust, allow themselves to feel, express themselves and learn to love again. What Valerie could also have used as a young woman was the support of people who had similar problems. She now wishes to provide that type of support to others in the Self Help Group.

# Chapter 8

## Interview with Ray

In his interview Ray, a man in his late thirties, gave a chronological account of his experiences with the psychiatric system and his subsequent recovery. The first narrative describes what he calls his first "real" treatment which included severe side-effects from his medication.

### "It's like being tortured or something, slow torture."

**Orientation:** In 1989, I really received the first...real treatment for my illness. I was, ah, taken into St. Pauls Hospital in the summer of that year...

**Complicating Action:** I was given Haldol. (19-22)
...I was told that, you know, I had a serious mental illness and that I could expect to be on these medications for the rest of my life. (37-39)
...I became tired...at all times...during the day I would feel a restlessness...It's known as Akathesia. ( 67-68)

**Coda:** It's like being tortured or something, slow torture. (71)

**Complicating Action:** And, ah, the whole time, the whole period during the day, from getting up 'till night time, I had a severe tension in my body, which was, ah, I couldn't relieve in any way.
The only way to relieve it was to move around, shaking yourself a bit or something like that, right. (105-108)
I thought of suicide in those days.
Not out of the illness but just because of the side effects. (110-111)

**Evaluation:** So it was a very, ah, tough experience...(109)
And...the care team didn't really address this problem.
I'd say, "You know I'm having some problems." and they said,
"You know you have to stay on your medications." (69-74)
...No one...mentioned (even at the team)...
that there might be any options regarding medications. (30-35)

**Resolution:** ...But it was some months before anyone provided an alternative. (81-82)

**Evaluation:** And, ah, that was a real failing of the system.

**Coda:** You know they should make you aware that there are alternatives at all times. (83-86)

After being discharged Ray found housing he could afford. He gave examples of what happened in the cheap rooming house that he found in the downtown eastside (DES) in the next narrative.

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### "...The housing was a pretty atrocious...a pretty terrible experience."

**Orientation:**   ...After I left the hospital(48)...When I was first on Haldol...(560)
I rented...the cheapest room I could find
in the downtown eastside...(50-51)

**Plot:**   There was a guy down the hall who was schizophrenic
and a ex-welder and...he drank like a fish. (561-563)
I had a person attack me...he threw a glass at my door
which shattered on hitting it.(570-572) He...was, um, a bad character...
...I went over to...his room and asked what time it was and he got very
upset.   And I went back to my room and he chased me,
threw himself against the door...So I slammed the door on his hand...
it didn't close completely but he was pretty badly bloodied by that.
There were fights in my rooming house. (575-581)
Um, some of the people were taking drugs there. (584)
There's racial tension, there's thefts and
break-ins due to drugs...people out of jail there...
...Someone came to my door with a knife and was stabbing at the door.
(590)...He was calling me white boy, I'm going to get you white boy.
I think he was just trying to scare me.(593-596)

**Resolution:**   Ah, it was made known to MPA (Mental Patients Association)
that I was, I was in need of better housing. (92-93)

**Evaluation:**   So there's some strange things go on in that neighbourhood.
...It's not a great neighbourhood to be in, a lot of problems. (598-603)
And the housing was a pretty atrocious...(53)

**Coda:**   So it was a pretty terrible experience.
And if you add to that the side-effects...(57-58)

Next Ray talked about what it was like to take on a psychiatrized identity.

It's a real, ah, ordeal a person goes through when they become psychiatrized you
know...when they first get into the system.
...You lose rights, civil rights, you're incarcerated ah, you know you can't move, go out for a
cigarette let's say, you can't leave the (hospital)...you know you're imprisoned.
...So, you know that, that is a sort of, a kind of assault. (683-693)

He corrected the view that he was hopeless and helpless at the onslaught of his psychosis.

It was not necessarily when I was ill that I was feeling helpless. When I was ill I had enough
confidence. When I was first medicated that was when I was feeling helpless. (679-681)

While attending a day center Ray was fortunate to meet an old high school friend who was an

intern at the hospital.  After hearing about the unbearable side-effects Ray was experiencing the

intern was able to have the medication changed and reduced to a low dose.  It made an

incredible difference, he no longer had Akathesia and his symptoms were manageable.

After Ray inquired about housing he was directed to the Mental Patients Association (MPA). Subsequently he moved to an MPA group home. Soon as he could, he went off the new medication, feeling that he was no longer in need of it. He avoided the psychiatric system as much as possible (two short hospitalizations) for the next four years. Ray was living in a group home, then a private apartment, both part of MPA housing, when he went back to university. He moved out of the supported housing because of a personality conflict with the apartment coordinator and from what he called, "...my antipathy towards the psychiatric community" (169).

Ray said in 1995 he deteriorated, was failing some courses and was unable to keep up with the work-load. He then went for help to the hospital at UBC. The next narrative describes the treatment he received in the emergency ward.

### "...Without any warning I was set on by three or four security guards..."

| | |
|---|---|
| **Coda:** | And I had an experience that to this day bothers me a little bit. |
| **Orientation:** | And, ah, I was in the emergency, ah, place of UBC hospital. |
| **Prologue:** | I was quite ill, ah, but I contained myself. |
| | And, ah, I was just, ah, sitting waiting for a treatment with a doctor, for a psychiatrist to see me, or ah, maybe I had seen a psychiatrist (194-201)...I wasn't causing a disturbance. |
| | I might have been behaving a little strangely, you know looking around a little too much or facial expressions |
| | but no real disturbance and...(230-234) |
| | I wasn't threatening anybody. (241) |
| **Action:** | But ah, you know, without any warning I was set on by three or four security guards and brought into a side room, |
| | and, ah, then I was given some medication.(202-206)... |
| | they held me down (211) and that, ah, you know, ah, |
| | they didn't make any effort to tell me what they were doing to me. (223-225) |
| | They just came in with, ah, the needle and stuck it in me. (227) |
| | I didn't know what the medication was. (210) |
| | I was afraid it was Haldol, |
| | which was...I'd had a bad experience with...(215-216) |
| **Resolution:** | So I got very upset.(220) |
| **Evaluation:** | You know, I could have been wheeled away to electroconvulsive therapy and I wouldn't have known. (250-252) |
| **Coda:** | So you know I have an issue with the emergency ward there...(222) |
| | I think a patient has a right to know...even if they seem ill, |
| | there should, there should be an effort made |
| | to tell them what's happening to them. (246-249) |

I asked Ray if he had complained about this treatment.

Ya I did, I wrote a letter to UBC hospital, received a reply to the effect that the records show that you were quite ill at the time and the treatment was necessary and that was the end of it. (256-259)

After this Ray became a compliant patient who attended a community care team. He moved into a fraternity house and found work as a painter.

...But I was still feeling some side effects and, ah, you know, it was pretty tough getting up in the morning and having the stamina to carry through the day at my work.

He said that he was, "...very discouraged" at this time, "...there seemed to be no future". He was then thirty-four, he had failed his university courses but still had debts from his student loans (which he still has), had no real resume having no recent work, and had lost contact with his friends.

Looking back at the time before his assault he now says that, "...I was severely ill during this time. I mean I was able to function, but I was still carrying around this illness with me" (139-141). He was briefly hospitalized twice in the four years he was off medication but received no other treatment.

Ray describes his treatment by the psychiatric system as on the whole good. He felt he was treated at the community care team as a whole person but, "I don't think they really covered all the bases in informing me in what was going on and what I could do. So I think there are some failings there" (465-467).

Ray's turning point in his recovery was his attendance at a vocational training program which, "...got me doing something, looking towards the future" (348-349). He gained confidence in himself and after a practicum as a computer office assistant landed a job with a mining company. He was laid off but still maintained his confidence and found on-call work at a mental health agency. As those hours were reduced he found another part-time position as a Consumer Program Organizer/Advocacy Assistant, heading a committee of consumers created to provide advocacy for their peers and input to a care team, but who presently organize events and speakers. He is also paid to do camera work video-taping a monthly coffee house.

Ray has never been on disability benefits. He has been maintained through welfare payments, although he would like to find full-time work as a consumer provider of mental health services. He has been trained to be a peer support worker and is now taking courses as a mental health worker. However he is not confident of finding enough work,

> ...because a lot of the work is unionized, and the unions don't want people being hired just on the basis of just being consumers, and ah, so there is a big problem with that. (454-456)

Ray also volunteers as a member of a committee which funds consumer projects, as a board member of the vocational training society, as treasurer on the board of the Self Help Group and sits on an editorial board for a consumer newsletter. He is in many ways a model consumer trying to help as much as he can within the system. When it was said that he had a lot of irons in the fire he replied, "You know it's funny, I do a lot of stuff in that way. But I don't bring in enough income every month" (444-445).

Ray believes that the peer community is very important for people's recovery.

> ...They understand where...you're coming from, you don't have to explain to them about your illness, and...we all have something in common in that we're concerned about, ah, how the system is working and where it can be improved and that sort of thing...(492-496)
> They're all potential activists.
> But, no, the community is good, I've made some good friends in the community. (502-503)

He notes that there are many people who because of their situations do not use peer support to the extent that they could.

> But, ah, a lot of them don't really participate that much because, ah, they're discouraged, they're overmedicated and that sort of thing. (499-501)

Ray thought the Self Help Group was valuable in comparison to other mental health agencies or organizations because:

> ...it's small enough to...allow a person to...not be intimidated, or feel uneasy because there's some mental health professional looking over their shoulder. (654-656)
> ...Being...a smaller organization is a good thing...It's a draw back too, you don't get the word out to as many people as you could...(658-662)

Ray talked about the men's support group, their outings to shoot pool, share a small meal or coffee, and their discussions about their, "...illnesses and issues and things like that." (620) The

men reported that they enjoyed the support group and were very supportive of the work of the Self-Help Group. ·

Ray discussed the differences between consumers and anti-psychiatry, and that consumers like him have found the system works for them. He found other people who had difficulty functioning under high doses of drugs, and "...the medications were changed and they came to life again, they came back....So I do think the medications do make a difference." (711-712, 714). He added that he agrees with psychiatric survivors on some points. "...forcing people to take medications, say out in the community, is the wrong thing to do..." (766-767). Not only does it set up a distrust of services but it also denies the fact that the medications can be extremely debilitating.

> I've compared being ill and on Haldol and I think I'd rather be ill. That's a tough decision to make too...When I was ill I was able to hold onto a little bit of reality but you know (with the wrong drugs or dosage) everything goes down the tubes, really you can't function properly. (768-773)

He made the point that even though there is a bill of rights at the care team that says every person should be treated with respect, be well informed and participate in his own treatment, this ideal has not yet been realized.

> ...People also have a right to treatment but they should be well-informed about what treatment is available, they should participate in their treatment. (756-759)

Ray has faith in medication but also realizes that others don't for various reasons; either they don't work for them, they, "...still hear voices and things like that" (540) or, "a lot of people...seem to be overmedicated" (544-545) and, "there is the odd person who doesn't have an illness and ends up getting medicated..." (536).

Ray made some suggestions of what the Self Help Group could do to help people recover. He said it would be useful to provide information about how the psychiatric system works, what resources are available, how to find housing, what options there were for medications, and how

to begin grievance procedures. It could offer educational workshops, and develop "...a deeper understanding of psychiatry and how it can potentially help people" (873-875).

> ...I think that's one of the big drawbacks in...entry into the psychiatric system, when you first get ill, the first time you get medicated, you don't know a lot. It would be really helpful to have people who could inform you about what's going on, where you can go, what are your options. Ya, it would be important. (1005-1010)

He spoke of the importance of developing alternative services, such as a safe house, a place people can go to for peer support when feeling unable to cope but not in need of hospital care.

> ...I even think government should fund it because we need alternatives available to the people...if we are ever going to find out what works. (904-907)...If there are alternatives then there's an opportunity for growth to occur, maybe where we don't expect it. But if we are just going with one model then we are, ah, shutting out a lot of opportunity. (910-913)

## Discussion

Ray discussed the onslaught to his self-image and identity with the loss of rights that came from an initial hospitalization and psychiatric diagnosis. The negative change to an identity of a person with a psychiatric diagnosis was compounded by the "assault" of being "imprisoned" and the helplessness that he felt after being medicated. He was outraged that information was withheld from him, suffering as much as he was, as well as by the indifference to his living situation.

Hospitalization means becoming an object of the medical gaze with its focus on the pathological aspects of a person. The mission of symptom and behaviour management does not allow a person-to-person relationship where a concern and empathy for the patient could be developed and where it could become apparent that the side-effects are more harmful than the illness itself. Ray says he had confidence and was not hopeless or helpless while ill. He became hopeless and helpless because of his unsafe living situation, the demoralization of being seen as a diagnosis, under the ever-present threat to his freedom, and with a treatment that was like "slow torture". In a book about the effects of psychiatric drugs (Breggin & Cohen, 1999), the side-effect akethisia is also reported as torture. An "...individual is virtually tortured

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from inside his or her own body as feelings of irritability and anxiety compel the person into constant motion..."(p.78) and which, "...in the extreme case, can lead people to suicide or to homicide" (Putten & Marder in Breggin & Cohen, 1999, p.78);

Ray experienced the oppression of the system in that he was not listened to, important information about alternative medications was kept from him and the social and economic determinants of his health, his living situation, were not looked into. For example, he would not have been helped with his housing unless he had initiated it. "...There was no effort to do anything about my housing" (88-89).

The debilitation that Ray felt from the medication, the lack of dialogue, "...no one really talked to me about the illness" (29-30), his history not listened to, and his terrible living conditions all had a negative effect on his self-image. He was reduced to the identity of a defective human being living amongst other outcasts of the social system in the downtown eastside. He saw suicide as a possible option, offering potential relief from his suffering.

Ray said that the lack of information about alternative drugs was a real failing of the system. He felt betrayed and distrustful of a system that without his connection to someone in authority would have left him in that unbearable situation. This distrust lead to his avoidance of the mental health system for the following four years. There were no alternative services that he knew of that he could access.

The assault at the UBC hospital emergency room, compounded by Ray's fear of re-experiencing the horrors of being on Haldol, was a traumatic event. Whatever rationalizations they had about Ray's level of dangerousness, the results of this 'show of power' was a conversion; from the mental health professionals' viewpoint he had seen the light, had insight into his illness, and after that would comply with taking medications. He now believes that he will have to take medications the rest of his life.

> I'm quite confident that if I go off them I'll get ill again. (734)
> ...You could go off, if you were seeing a psychiatrist, ah, every week or so.
> The thing is if you get ill you get delusional, if you have Schizophrenia, this is crazy.

Going to see the psychiatrist they're going to put me back on eventually. (740-743)

Ray has accepted the medical version of what he can expect from his life, particularly because he was shown that he couldn't escape. He has been a cooperative compliant client at his care team; At his retirement party, Ray's psychiatrist told him, "Well you know you have a great future" (479-480).

In talking about his extensive work and volunteer positions, Ray was discouraged that even with all this work he still does not make sufficient income. Many consumer/survivors have worked a lot within agencies, until they burn out, because they have a mission to help their peers, but who still live in poverty despite their proven capabilities.

Ray's position that the dramatic improvement from switching medications proves that medications work has a similar logic to there being a great improvement when a person stops hitting her head against a wall. Ray did not have alternative treatments, other ways to reduce the effects of his symptoms, to measure the good medication against. The social approval of being a compliant client and the encouragement that he has a great future balances the side-effects that he still experiences. If he left psychiatric `care' and resisted taking medication he knows he would potentially risk another trauma from coercive treatment.

Ray's suggestions are useful to provide direction for the Self-Help Group. His views on alternatives touched on an important aspect of the narrowness of providing only biological treatments. By "...just going with one model..." and "shutting out a lot of opportunity" (912-913) how are we "...ever going to find out what works (906-907)...There's an opportunity for growth to occur, maybe where we don't expect it" (910-911) Ray moves beyond his consumer position when he heralds such possibilities and hope for the opportunities of exploring alternative treatments, and by supporting the Self Help Group which could be instrumental in providing them.

# Chapter 9

## Interview with Kanti

Kanti is a woman in her early fifties who was raised in India. After her European father left, her mother married an Indian man and had five more children. Her mother died when Kanti was a young woman. Kanti joined her aunts in Canada and the rest of her family followed soon after. The interview is reported chronologically following how Kanti moved from one subject to another and back and forth in time.

Kanti had only one experience with the psychiatric system before she had a heart attack. After one of her sisters died in 1970, Kanti was worried that instead of grieving she had shut down, that she `blanked out' everything. For about six weeks she went to a psychiatrist who "...just sat and didn't say much...he didn't draw me out...and we talked about everything except my sister" (19-20). And so she decided to miss her last appointment without telling the psychiatrist why as a way to express her anger at his inadequate treatment.

> And then...I didn't have anything to do with the psychiatric system.
> I kept telling people that my father had raped me, molested, (and) abused (me)... (27-29)
> I was telling my peers, my siblings and there was no response,
> as if I hadn't said anything...So I just sort of muddled along. (34-36)

Kanti was not encouraged to find counselling assistance before or after this attempt with psychiatry. She finally accessed help from a twelve step self-help group, Codependents Anonymous (CODA) after she found herself in an abusive relationship. The twelve-step group helped her to move from focusing solely on her partner to looking at her unresolved issues. Their support gave her the courage to leave the relationship. In the group she found it wonderful to be with others who had similar experiences.

> ...I just cried because someone else was saying they had been abused...
> Oh God, it was like a relief (264-266)...
> And there was this enormous understanding and these were strangers..." (275-276)

Reflecting on the freedom to talk about her abuse in this group, Kanti next described the effect on her sexuality of her stepfather's unwanted attentions. Her first sexual encounter felt

good at times and she has to deal with this fact. "I still resent the fact this man imprinted certain things on me..." (282-283) And Kanti's sexuality is still not free from the effects of this abuse.

> So I'm celibate, it's easier but I don't want to be. (291)
> I've never really had a relationship where I can just enjoy sex without hang-ups. (294)

Throughout her life Kanti had managed to avoid addressing the issues of her childhood abuse by throwing herself into work, becoming a workaholic, and ignoring the symptoms she experienced. She worked as an administrator in business for many years. Then she opened up her own family daycare. Before her heart attack she was working, going to school for early childhood education, and storytelling using puppets which she made, all without any rest. "...No Saturdays, no Sundays, just nothing, just keep going whatever it is" (57-58).

Around this time she accessed some crisis counselling from a social worker at a neighbourhood clinic who helped her again to address the issues of her abuse.

> ...She was really good...there was some exchange taking place not this man sitting over there...(216-218) I phoned my stepfather, called him an asshole. So yeh, she was a lot of good... (209-210).

When Kanti was hospitalized for her heart attack she could not use her usual coping mechanisms.

> ...I couldn't do anything and all my body was concentrating on this physical pain and keeping me alive. (65-67) I was just crying...I was nervous, (I had a ) needle phobia...(68-70) I was a very difficult patient and then finally the psychiatrist came to see me. (73-74)

Kanti began by shouting at the hospital psychiatrist.

> What are you going to do? Are you going to see me for 15 minutes and write my life in one session, you know, solve the problem of being abused and having all that? (84-86)

She burst into tears and couldn't stop crying. Another psychiatrist arrived, the two conferred and she was left alone. After she was discharged she was sent for a psychiatric assessment. She related that she realized that "...all men are not Ted (her stepfather), you know like Ted is not all men" (102-103), but still she found difficulty with the assessment because it was conducted by two men even though she found them to be compassionate.

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Soon after Kanti left hospital, her beloved companion, her cat Puffa, died and then she lamented, "...I was alone, I had a heart attack, I was scared and I couldn't walk" (95-96). Her fear of another heart attack was so great that she could not exert herself even with walking.

Her doctor, a male physician, prior to her heart attack had not listened to Kanti's concerns.

> I kept telling him for a year before that there is something wrong with my heart. (He said) that it was menopause or da, da, da, da, da, but I'd say heart, heart, heart...He was not a very good doctor other than he did take instructions well to a point.
> Especially after I had a heart attack. Then he listened. (183-189)

After she left the hospital he prescribed Paxil and Ativan to help her quit smoking and relieve her anxiety. Luckily she avoided becoming addicted to Ativan. Her doctor heard through the neighbourhood clinic about a psychiatrist who provided a twelve week program preparing people with anxiety disorders to return to work. He referred her to this woman psychiatrist who told Kanti to give herself permission to look after herself.

> ...She was wonderful...very wonderful gracious woman. (134)...She saw my goodness you know...(139)...She did help me...saying things like I don't have to do anything that I don't want to do, that it's OK, all I wanted to do was read, sleep and watch TV...she said ...that's what you're supposed to do when you're healing.(197-202)

She also attended a healthy heart exercise program at a hospital where the women who ran the program "...were just incredible" (151) with their patience, understanding and compassion. After I asked why she was crying while she was being assisted to walk at her first exercise session, Kanti said it was from fear and that this fear was not a new thing for her.

> ...Before it was bad, like going to the hairdresser I would always think that I would die.
> This is part of being abused and not treated, it's extreme...
> Things are going too good, I'm going to die, things are not going good, I'm going to die.
> Because it is the worst thing that can happen, it's oblivion.
> And yet at the same time...the act of dying is very scary but
> once you're dead well nothing can hurt you right?
> So I wouldn't actively do something, but passively...I don't know. (162-172)

From the specialist on anxiety disorders, the woman psychiatrist, Kanti learned that

> ...I had very good reasons to feel this way. I had a right to feel this way. (491-492) And I also had the right to feel another way you know and that was my choice and when I was ready to choose to feel another way I would do it. (494-496)

The psychiatrist referred Kanti to an anxiety disorder clinic where she met other people who experienced anxiety.

> ...(It) was so wonderful to hear that there were other people who thought they were going to die if they have their hair cut...It was like wow! (239-241)

There she learned techniques to help her cope, like breaking down activities into manageable steps and writing up a transcript in a book that she would carry with her.

After the anxiety disorder clinic Kanti was able to return to counselling with the social worker at her neighbourhood clinic. She dealt with her abuse and the anger she felt towards those who discriminated against her because she was illegitimate and half-caste.

Kanti was also angry at her mother whom after her disclosure no longer treated her with the love that she experienced before. The following narrative tells how Kanti disclosed her stepfather's abuse, how she left home, and why she returned.

### "I just wanted to go back to being a little girl 'cause that's what I was."

**Orientation:** And my mother, when I told her, I was ten years old.
**Complicating Action:**
> ...And she kept questioning me whether it was one finger or two and
> I said well it wasn't his penis because
> I was really upset with her...And then she said,
> "Why, why was he going to you when he had his wife next door?"
> She confronted him, he said, "No" of course, but she didn't
> believe him, she believed me 'cause I was really a good child.

**Explanation:** I was a good child, I hadn't been beaten or abused and my grandparents looked
> after me with mum...
> I didn't know fear...that was my sanity,
> I always knew (that my grandparents loved me) and I did (love them). (308-326)

**Complicating Action:**
> I wrote to them...and my aunt...a G.P....she came, and...
> my grandpa and grandma just sat there
> that evening with my mum and dad.
> They said, "We're taking her." and they called me and
> they said..." Do you want to come with us?" and I said, "Yes."
> "Do you want to stay here?" and I said, "No."
> That's how I left. (345-352)

**Resolution:** ...They came and took me away.
> I didn't tell them why but they just insisted. (334-335)

**Coda:** I just wanted to go back to being a little girl cause that's what I was. (313-314)

**Epilogue:** But then I went back (to my family).
> Yeh, because this was my mother...

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**Coda:**      So that whole thing too is the coldness of my mother
who tortured me as the other woman and I was only ten years old. (352-356)

Even with the anger that she feels, Kanti says she misses her mother who died when she

was forty-two years of age. "I...miss the relationship that I could have had with her maybe..."

(360-361) Just before her mother's death Kanti became pregnant. She says she would have

kept the baby and not had an abortion if her mother had not died.

> I'm...sometimes still angry with my family...they ignored me ...except for my grandparents,
> there was so much pressure.
> It was pressure to have this abortion you know and for why?
> ...That it was like the shame you know.
> I was a bastard having a bastard sort of thing, like, Ohh! (370-378)

The common course of heart disease is that people often have another attack in a year or

two, but Kanti told herself, "No fuck way!" (398). She changed her diet reducing the level of

cholesterol, she quit smoking, she exercised and then took two sessions of art therapy

"...because I realized that there was still a lot of sadness in me...that needed to be let go of "

(408-410). She was sad but often covered it up by making people laugh.

> ...It's a way of keeping myself safe...You make people laugh and they like you so you're
> safe...And that's how I've coped...(423-427)
> If they're laughing at you they're not going to hit you...(445-446)
> they're not going to put their fingers on your private parts if you laugh. (448-449)

Kanti was fortunate to meet the leader of one of the support groups of the Self Help Group

(SHG) in a shared house which she moved into. This group that she eventually joined was

especially for South East Asian women. These women found it difficult to work in a group.

They were very affected by their culture's expectations for them to marry and have children.

Kanti said she was different because she was already an outcast, so in a way she was freer of

those expectations, but also she wasn't. She had a tubal ligation at around 27 years of age.

She has three sisters left alive and one brother and none of them have children.

> So in a way we are free but at the same time, you know...it kept...
> all of us in this thing where children...aren't a joy.
> Obviously that's what we experienced right? And we'd been told,
> "Your mother almost died giving birth to you." (But I reply)...didn't you have 6 more?
> You know, like, god! Oh I mean it wasn't her it was him. (616-622)

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Kanti volunteered as a board member at a community center, participating on committees, and in a project called `Your Own Backyard'. Now she is the leader of another of the women's groups of the SHG. Kanti has recognized her progress through working on her issues and joining with others. As a group facilitator she is able to listen to the women then ask questions to bring out ideas, rather than trying to control the process and impose her ideas onto them. "It was also really good to hear people say, "Thank you, we had a good meeting." "(730-732). Kanti has also contributed by writing an article about her recovery in the SHG newsletter.

Kanti wants to continue with art therapy as it combines both her interest in developing her artistic side and freeing herself from the effects of trauma. "I realized that there was something that needs to come out" (808-809). She is able to open up, explore her feelings and express herself from "...my deep inside of me, from some lonely realm...of the shadows of my soul...(805-806) This outlet is important, as Kanti says, "I wouldn't be able to go on without it" (838). The art therapy is affordable since it is conducted in a group and provided in a community program which subsidizes half of the cost for Kanti.

In talking about stigma, she relates how people can't understand her difficulties. She says that yes she is 'wounded', she calls it a `mental disability' "...because I don't know what else to use" (893). People don't understand that Kanti is not just making an excuse not to go to rallies and large groups, she really cannot.

> ...There are people who say well...
> I guess you are making a choice about where you want to go...
> I say, "No, listen to me, I don't have a choice. I wish I did, but I don't...I cannot do it.
> I have a condition for reasons that I'm not going
> to go into with you but don't lay this guilt trip on me..." (906-912).
> ...Or people will say that, "You don't look (disabled)... " (915).

Also in relating to stigma, Kanti recounted her experiences with men who have expressed interest in her.

> ...then I let them know that I have a mental disability and these are my conditions,
> agoraphobia, panic disorder. And my god, man, I don't hear from them. (939-941)

The "...anxiety and panic disorder...has kept me safe from a lot of things" (979-980).

Kanti discussed how harmful her usual angry response was in the abusive relationship she found herself in. She describes how she learned to respond with anger and how the response had almost fatal results in this next narrative.

### "I was becoming dangerous."

**Coda:** I'm...sometimes still angry with my family...(370)
**Abstract:** I had to deal with a lot of things, like not just the abuse
but being an Anglo-Indian bastard in India... (300-302)
and the anger I have to...the Indian people...the ones who rubbed it in and the Europeans...my father who fucked off...
and left me to be molested by this asshole. (305-308)
Because that's what I learned as a child was that you get angry because crying is weakness, anger is adrenaline, so I respond with anger...
**Evaluation:**...Now I have learned (that anger is dangerous). (1017-1020)
**Action:** And my brother said to me "...When you get angry...
it's like you are killing us your anger is so strong.
Ya, it's like if you had a knife you'd be stabbing us."
And then I threw that knife. (1040-1043)
I freaked out, you know, I threw a knife at him (her abusive partner)
and if he hadn't ducked...
**Resolution:** And that's when I realized I had to do something...
**Coda:** because I was becoming dangerous. (1032-1036)

Kanti described her sister's dysfunctional relationship, she talked about how her brother is now an alcoholic and has no friends, becoming just like her stepfather who had no friends to attend his funeral.

So I come from a damaged family all right...(1109).
And this is what his father told him, "You are nothing." This is what he told me. (1161-1163)
And all that time I bought (what he said)...
I'm just starting to realize that I have a right to the...good life...
And it can be on my terms. Ya, but I never really thought that...
because (of) being the bastard child, passed around...with no-one.
I never thought that whatever I had was my right, you know.
And still I sometimes feel that way. (1164-1173)

## Discussion

Kanti is one of the few members of the SHG who has not had extended contact with the psychiatric system and/or experienced a psychiatric hospitalization. Even so she has experienced debilitating symptoms all of her life. The psychiatrists who saw her in hospital may

not have considered moving her to the psychiatric ward because she immediately disclosed her history of abuse; psychiatric hospitalization is contraindicated for victims of abuse. But Kanti realized that to almost be the cause of someone's death and to suffer from frightening anxiety attacks was a huge problem and that she did need to heal herself.

Kanti's childhood was traumatic; the sexual abuse by her stepfather; then having to live with him and a mother who saw her as competition; the stigma she endured by being both illegitimate and half-caste; her mother's early death while she was single and pregnant; and her subsequent pressured abortion. As a young girl and woman she coped by `blanking out'; repressing her feelings, forgetting what happened and remaining in a `frozen' state. These unexpressed feelings found their outlet in unreasonable anxiety and panic attacks.

When I met Kanti I noted her intelligence and ability to reason not her anger which came out as we began to discuss her traumatic past. She directs her anger towards those who harmed her; her stepfather, her `cold' mother and her `damaged family' who ignored her cries for help when she disclosed her abuse. She also shows in her interview her ambivalence about relationships, towards her mother, with men and about sex.

Kanti's bottled up anger, which her brother called `murderous', almost resulted in serious physical harm to her abusive partner. Here is a clear example of how unresolved emotional issues fuel violent behaviour.

Kanti talked about her symptoms and how they usually involved the fear of dying. Yet she was also somehow attracted to the idea of death as the end of suffering. "So, I wouldn't actively do something but passively I think...I don't know" (171-172)

Kanti's anxiety disorder was acknowledged and she was able to accept financial support after her heart attack, her almost final cry for help and fulfillment of a death wish. She had finally earned the right to treatment. Kanti has chosen the treatments she received; she never was forced to take medications, and she actively participates in what her doctor prescribes.

Kanti had been able to 'pass' all her life, maintain social acceptability and not fall into an obviously destructive lifestyle because the negative effects from the abuse were balanced by other mitigating factors; the sexual abuse itself was short-lived, her disclosure was believed, and action was taken at her request. Kanti saw the unconditional love she received from her grandparents as the grounding force that enabled her to remain 'sane'. However Kanti's sexuality was permanently damaged by this first sexual experience, she suffered from either 'blanking out' or anxiety all the rest of her life, she found herself in an abusive relationship and she developed heart disease.

Kanti is an intelligent, articulate woman who has claimed her right to heal. From the effects of discrimination and the lack of support, "I never thought that whatever I had was my right...And still I sometimes feel that way" (1172-1173). Natural helpers in the form of her peers or her family did not want to respond to her suffering. The shame of sexual abuse, the difficulty that people have facing anger and suffering make it hard to find natural helpers. She said, "So I just sort of muddled along" (36).

Kanti, like others, was helped by the support of self-help groups and community counsellors only because other elements brought out the extent of her suffering, such as the domestic violence. "I was getting some kind of counseling you know. Catch as catch can sort of thing" (114-116).

Kanti, for her recovery, has taken on an 'illness' identity, both for her physical and mental states. She is taking the time now to learn how to truly care for herself, something that was probably interrupted at the age of ten and discouraged by the stigma of being illegitimate and half-caste. Kanti has been able to find healing relationships with women who respected her and supported her recovery. She needed to work with women as her trust in and opinion of men is low. Her experiences with the male psychiatrist and physician did not improve it.

Training herself to help others and contribute to her community has given Kanti confidence and self-respect as well as allowing feedback which confirms she has wisdom to give and that she is on the road to recovery from the effects of her traumatic experiences.

# Chapter 10

## Interview with Jeff

Jeff is a man in his forties who worked part-time for the Self Help Group as well as at a mental health agency. He entered the psychiatric system ten years ago. Jeff decided to first talk about his positive experiences. He began his interview with the following statement.

> Despite all the confusion in the system, and despite some of the power tripping that still goes on, you can still find workers as well as consumers willing to go the distance for you. And once that hits you, that they really care and not just toeing the line to look good or to fulfill some quota mandate, you start believing in yourself. And that's the most positive thing that has occurred to me. (10-16)

The clubhouse he attended two years after his entry to the system was an empowering place where he made friends, had fun, was given the "the opportunity to express my talents...", where the staff, "...believed in me" (28-29) and " the greatest thing that happened to me there was I was given responsibility..." (36-37). Jeff praises the staff who "never condescended which is unusual...for...workers in the system..."(54-55), who treated him with respect, as a regular human being instead of a "poor little mental patient who... can't...help their behaviour..."(61-62).

> ...If we were exhibiting bad behaviour, if we were just being plain lazy, and they knew it because they knew us, then we'd get... called on it. And so it instilled in me, in particular, the idea that I'm human like anyone else and I have responsibilities and obligations like everyone else...(55-61)

Jeff was a writer, editor and also cover designer for the clubhouse newsletter. "...My artistic talent had sort of died for a while and then it was brought to life again." (34-35) He acted in the clubhouse theater company and designed the logo for their T-shirts.

> ...We had a great time putting on plays...it helped my communication skills...because I'm a very shy person at heart...and (it) gave me confidence to speak before public.(74, 78, 85-86)

Jeff began to talk about his negative experiences prefacing it with the statement that "I would say the positives outweigh the negatives" (90). He said, "I didn't even know the mental health system existed" (22) when he was introduced to it at the hospital. He describes his initial experience in the following narrative. (J signifies Jeff, I, the interviewer)

**"And (I had) brutal experiences because I didn't know what was going on"**

**Orientation:**  J: 10 years ago, that was first when I entered the system...(20-21)
**Complicating Action:**
        I was extremely distraught, very scared.
        I was having a quote, paranoid delusion, unquote,
**Evaluation:**  which was true, I'm not denying that.
        Ahh, but it was probably a...temporary psychosis. (96-99)
**Complicating Action:**
        I was taken to...emergency...transferred to...(an) inpatient unit...for a week...
        put on medication which totally I was unprepared for...
        Loxapine, which is a very heavy anti-psychotic...(100-106)
        And I wasn't told about the side-effects at all... (109)
        I came down with severe back pains and stiffness. (112)
        And I just, I asked the nurses there,
        "Well look I've got a very painful back",
        and...they told me it was the bed...
**Evaluation:**  Which was ridiculous...(109-116)
        ...that was directly related to the medication
        'cause that's one of the side effects, stiffness. (112-113)
        I: Even if they...did they know?
        J: Oh sure, oh sure, oh, sure.
        In those days especially they didn't want to inform...
        patients about a lot of the side effects because
        the patients simply wouldn't take them (the drugs).
        And the restlessness, I think that was the worst part.
**Complicating Action:** It's called Akethesia or something like that...
        (I) couldn't concentrate, couldn't sit down for longer than a minute without having
        to get up, just a horrible, horrible feeling.
        And again I wasn't informed about that. (117-125)
**Resolution:**  And (I had) brutal experiences because
        I didn't know what was going on. (106-107)
**Coda:**  ...I had no idea of what was going on. (126)

After being discharged Jeff was referred to a psychiatrist at the community mental health

team and was placed in a boarding home.  He said the home was good because the workers,

    ...treated its residents as if they were adults and not children...they expected the residents
    to be responsible for themselves rather than the kind of big mother, big brother sort of thing.
    (141-145)

But over the year he was there he found it tough to live with twenty-one other men and became

depressed " ...because I wanted housing, I wanted to get out of there." (155-156)

    They almost did not want to give me subsidized housing. (151-152)
    ...They saw the depression and thought... "You're not ready to move out." I had to impress
    upon them that, "Hey, the reason why I'm so depressed is because I want to live on my
    own." (156-160)

Jeff next described what led up to his hospitalization. He was doing his own research on the rise of neo-nazism. "...No one really particularly cared to look at it deeply. I did" (187-188) He said he had a strong Catholic Christian background which motivated his study. He thought that "...because of the millennium madness..." and "...with the end of the world and nationalism, and globalism..." (195-198) that

> ...Some day, a whole bunch of people are just going to be...killed.
> And I had meant something like Oklahoma...(199-201)
> It was nothing to do with (being) psychic...it was a rational thing. (206-208)

But he then "...broke apart 'cause I couldn't handle...my feelings towards it...", and because he was "...going through extreme family troubles at the same time."(212-215)

> ...I had come back to live there (with parents) for a while...I didn't have any employment at the time. And I guess that contributed to a lot of depression and stress, especially amongst my family members. And my brother and I were just like enemies. And it just sort of blew up. (223-226)

It was interesting that a mental health worker had told him that what led up to his hospitalization might have been a family systems problem; that he had become psychotic

> ...because I was trying to save the family. Which may actually have some truth... (230-232) 'cause once...I went to hospital the family stress almost dissipated...completely and it was so high at the time. (239-241)

Jeff talked about the diagnosis he received, how he had been told that he would be on medication forever and that the best he could do was get a simple, part-time job. This limited prognosis, and

> ...the stigma attached to being labelled paranoid schizophrenic
> almost destroyed me. (I was) suicidal. (275-278)
> And this crushed me...because I'm a college graduate...very educated and very intellectual.
> And I wanted to do something with my life...(286-291)
> So I kind of lost my will for a while. Got into alcoholism... about 6 years ago. (298-301)

Jeff went on to talk more about his diagnosis and that "the horrible thing about it was, is that it wasn't accurate. To say the least it wasn't accurate" (163-164).

> ...From my perspective, I didn't have any of the positive and negative symptoms of schizophrenia at all. (169-171) I never heard any voices... didn't really entertain any real weird delusions either. (173-174)

At this time two workers were especially difficult for Jeff to work with as the following narrative relates.

**"...You had no choice whether you wanted to deal with him (/her) or not."**

| | |
|---|---|
| **Coda:** | J: ...There were a couple of people...that I just could not stand. (333-334) |
| **Orientation:** | First...they gave you a psychiatrist... |
| | This was when I was in the boarding home...(334-335) |
| **Coda:** | You had no choice whether you wanted to deal with him or not. (336-337) |
| **Evaluation:** | I didn't like this guy. (339) |
| **Complicating Action:** | |
| | I go into his office. He has his head buried down in the file or something |
| | and he just mumbles, |
| | "Has anyone ever told you, you're paranoid schizophrenic." |
| | I: That's the first thing he said to you when you went in? |
| | J: Ya, the very first. (341-344) |
| **Resolution:** | ...(Luckily) there was cutbacks in staff...(386)... |
| | (they decided I) didn't need...monitoring...(391-392) |
| | I didn't really need a psychiatrist...(394) |

| | |
|---|---|
| **Orientation:** | And he had a partner with him...a psychologist... |
| | sometimes, not at that initial time but eventually yes. (349-353) |
| **Evaluation:** | Anyway, she was brutal...(355) |
| **Complicating Action:** | |
| | I would come into the office and I'd just sit there, |
| | sure I had a lot of anger inside me, but she would say, |
| | "You know you're livid, you want to beat people up, you want to, you know..." |
| **Evaluation:** | I: Why was she saying those things? |
| | J: I don't know. I guess it's to try and get into your true |
| | feelings and bring them out or something. (359-365) |
| | ...She kind of played a game at coercing me to say I heard |
| | voices when I actually didn't by using certain language that |
| | appears that I was hearing voices which I wasn't...(368-370) |
| | I knew what was going on. (375) |
| **Resolution:** | And...she's the first and only therapist that I opted out of |
| | seeing 'cause I did not go...(and) I think she got fired... |
| | because there were too many complaints against her. (376-380) |

Because of economic restraints Jeff was able to stop seeing the psychiatrist he didn't like and went to his private physician for his medications. But he still went to his therapist at the community mental health center whom he said was "...a decent man and he gave me encouragement to move up and out" (405-406).

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Jeff described another mental health worker whom he said was like others who "almost

destroy your hope " (413). He said he just didn't want him but while at the boarding home he

was his primary, someone who was in charge of his social development skills and other things.

Jeff was considering going to theological school, which he had planned to do before his

'breakdown', and the worker,

> ...he made a comment to me that just, it was like a, a punch in the gut.
> And he didn't know me, you know?
> He said, ah, "Well do you think that someone with your illness would be accepted there?"
> And I just went, "Aahh shit!" you know?...It's those kinds of comments,
> it just takes one, just one, you know, and (your hope is destroyed)...(423-428)

But again Jeff counters this negative situation with a positive evaluation of many mental

health workers.

> Overall I found my experience with the mental health system to be
> a chance for growth...I have a lot of emotional problems....
> I was helped genuinely by a number of people...( 432-437) and very
> often these are the kinds of people that often find themselves in
> trouble with the authorities...But they're very good. (440-443)

Jeff next talked about his "...first job, first paid job in years..." (493) at a mental health agency

in Richmond. He and his co-worker place their clients into volunteer positions in the community.

The volunteers receive a monthly honorarium for their work.

> And it was, it is an absolutely drenching job...(494-495)
> The pay is low, it's not comparable to what the others in other programs make. (503-505)
> We are hired as quote, consumer positions...so they start at...a lower rate...
> Ooh and it makes me mad. (507-510)
> But...it's a very, it's been a very stressful job and
> I've almost quit twice, so has my co-worker. (521-522)

Jeff says that he and his co-worker have difficulty with their coordinator who is a young woman

of twenty-six years of age.

> And, um, the amount of input that we are allowed to give to our coordinator is almost nil. And
> that's one of the points we've almost quit over. And ah, ya, it's been difficult, very difficult.

He complains that his coordinator "...does not relay information to us about matters that should concern us..." (546-547), and as the next narrative shows, " I can give you a very good example..." (548)

### "...I just lost faith and trust in the staff that I was working with."

**Coda:** There has been a number of experiences...which, um, anybody else undoubtedly would have walked out on. (544-546)

**Orientation:** ...It was...in November of last year. I was alone in the office. It was 3:30 in the afternoon. Um, there weren't too many people in the downstairs office...I was sitting by the computer.

**Complicating Action:**
One of the people, the clients that I work for...
comes through the door, shouts, (in an) extremely agitated mood...
a violent mood, and saying that he hadn't had his cheque.
...So I calm him down (I've taken training in...non-violent crisis intervention, so I knew how to do that).
He apologizes and the pay role clerk comes upstairs just to check things out...
and then he leaves.
It's the next day I find out that he had actually threatened to beat me up and that was what he was coming upstairs to do. (556-571)

**Evaluation:** When I heard that I kind of felt betrayed. No one warned me.
All they had to was pick up the phone, dial the extension.
I would have locked the door...
Don't be a hero's the first thing you learn...(574-580)

**Complicating Action:**
But my coordinator at the time didn't think much of it.
And...I said, "Well look, the guy threatened to beat me up.
What...are you going to do about it?" And um, she kind of retorted (in a dismissive tone), "What do you want me to do? I'm doing it."
I didn't even have input in that.
All she did was bring him in and warn him not to do it again.

**Evaluation:** And I was just taken aback simply because that is just not done...
It was almost like she was criticizing me...for asking for a suspension (just two weeks) for the man...(584-606)

**Complicating Action:**
...and when I brought up that, "Look, I have to work with this guy next week",
she said, "Well I guess you're going to have to deal with it"

**Evaluation:** Which is really, really a stupid comment to make.

**Resolution:** I: So you felt unsupported.
J: Completely. (629-634)

**Coda:** ...and ah, from then on I just lost faith and trust in the staff that I was working with. (624-625)

As well Jeff felt betrayed because the staff who did not warn him were not reprimanded for it.

Jeff talked about how hard it was "fitting square pegs into round holes..." (638); people who either shouldn't be placed as volunteers or are put in the wrong agency, "...just because we have to have the numbers to justify budget and grants..." (639-640).

> ...I was working with one person who eventually took off, um, to North Vancouver and
> eventually wound up robbing three banks in a row, high on crack cocaine. They just didn't
> want him back and they didn't want to have anything to do with us.
> And we lost a couple of other sites because of that.
> And we feel helpless...(643-652)

Jeff finds it frustrating as well that, while they say they are following the current psychosocial philosophy, mental health workers do not understand the meaning of empowerment for consumer/survivors. He says it is not `politically correct' in the agency, " to give an opinion for anything to anyone...to show any kind of displeasure at some kind of behaviours or encourage people to do the best that they can " (551-554). They say that you must avoid doing anything which may be seen as giving therapy, "you're not supposed to give therapy" (568). Rather than helping them it leaves the clients without any feedback on how they are doing, all in the name of non-interference.

Jeff went on to discuss the effect on consumer/survivors of the goal of stabilization. "The system has this fuzzy idea that stability equals recovery equals good" (777-778), and in emphasizing maintenance says what chronic users can and cannot do.

> ...people...will try and avoid all stress and all conflicts possible
> which is not life, it isn't and you can't heal that way. (792-794)
> ... First sign of stress,(snap fingers)...they're gone. (798-790)

He talks about how just simple things like getting up in the morning to go to a volunteer site, or to take the bus are considered stressful by some of the people he works with.

> They're chaining themselves (by acting like this) and they'll also
> manipulate a lot...workers say, "OK, OK, we don't want you to have
> a relapse or go into psychosis so we'll give them what they want."
> Which is basically nothing except the easy way out. (810-813)
> That's the only criticism I would have of my fellow consumers is
> that they are not willing to take risks. (815-816)

Next Jeff says he has noticed that many consumer/survivors are stuck developmentally and are not able to grow beyond the stage of adolescence. Some even look younger than their years because "...there's no stress, there's no toll on the physical body" (844).

> They behave like adolescents, they respond like adolescents.
> It's a sad tragic thing, but it's true. (826-828)

He adds of course that there are mature consumer/survivors out there but because of the agenda of stabilization many do not grow to maturity.

> Yes they have to deal with their illness, but if they are stable and don't have...opportunities for challenges...are kept in cotton wool and everything's done for them, of course there is going to be no stress if their body's in stasis. (845-849)

In relation to his work with volunteers Jeff talks about those who act like teenagers when they lie and try to manipulate; they try to make deals to avoid work but still get their honorarium, they lie about why they couldn't get to a volunteer site, and many never show gratitude for the things that are done for them.

> It's, it's more like a kid, because I mean they can express gratitude without actually bubbling over with it...I mean they could show their gratitude just by saying, "Heh, do you need a hand helping clean up?" (886-891)

Jeff relates the state of adolescence to one of powerlessness and that just as adolescents use tactics of manipulation to wrest a little power from authority, so do some consumer/survivors.

> I've seen that an awful lot...(of) people have absolutely no power whatsoever, and so what way could they express that power? ...Usually manipulation and splitting one staff against the other, making false accusations, getting other staff into trouble. That happens all the time...I've been through that myself to a smaller extent, not nearly as bad. (897-911)

Jeff discusses the ghettoization of consumer/survivors with an insight from his own experiences. He sees that poverty effects them, that they

> stick with the same group that has the same financial power...besides they feel more comfortable, which is actually a mistake. We can get very stuck there. (683-688)
> And...you get into a certain lifestyle (694)...bumming cigarettes, borrowing money, um, big problem borrowing money. (698-699)

Jeff says that people develop a false identity. "Like...you're no longer like everyone else...almost like being part of a cult or...belonging to a religious order..." (689-691) He says it is

"...a group identity that fulfills individual identity at the same time" (727-728). Getting stuck in a consumer/survivor identity, Jeff says, can also be from the lack of an orientation to recovery by psychiatry.

> To be told that someone has to be on medication forever is one thing. To infer that they can't live a normal life is something different because it's baloney. (738-740)

He then gives another example of a man who had been in Riverview for twenty years who when he got out found work as a janitor. He has just retired, is healthy and totally recovered.

> Jeff asserted that paid work or volunteering is important to recovery,

> feeling that you can contribute, and you have a talent somewhere to contribute. (759-760) ...Participating and giving is probably the single most important aspect of recovery. (763-765)

And he said another important aspect of recovery was

> to have people believe in you too, as opposed to people who are saying...this (or)...that goal is unrealistic. Some people are actually told that, ah, they shouldn't marry, or can't marry, or better not marry...(765-771)

Jeff talked of how hope for the future helped him through. "The people who gave me hope, they're out there" (936). He also is thankful for the people who challenged him, the staff at the clubhouse who had known him for seven years,

> ...so they knew me inside and out...We had a rapport, which happens after you know people for a long time, an easy rapport. And it worked out. So it was good. (975-979)

The next narrative gives an example of the support from this staff.

### "...Sometimes you do need that little push."

**Coda:**        (It's good) to be kicked in the rear.
In...a loving way, not in a sort of a power struggle. (942-944)
**Orientation:**    I had terrible teeth, about...5 years ago.
I didn't want to go anywhere near a dentist.
I had a phobia besides that, I just didn't want to go.
**Complicating Action:**
...I was pushed to go, over and over again...
by one of the staff from ...the clubhouse I went to.
**Evaluation:**    But she did it not because she was
trying to get control...or we'll kick you out...
She simply knew that I could do better.
And she basically wanted it for me,
not for her or for her record.
**Complicating Action:** So she kind of got me over the hill.

|              |                                                          |
|--------------|----------------------------------------------------------|
|              | So I went and saw the dentist.                           |
| Evaluation:  | Of course once I did that, getting the teeth done,       |
|              | it was nothing.                                          |
| Resolution:  | So my phobia's cured.                                    |
| Coda:        | So sometimes you do need that little push, you know. (947-964) |

Jeff next talked about his experiences with psychiatry and religion. The first psychiatrist that Jeff saw was not a Christian and was unsympathetic to his beliefs. The therapist with whom Jeff felt well supported was not Christian but Islamic but did respect Jeff's religious life.

> There is a bias in the system against religion itself and spirituality (in general)...(994-995)
> I don't think any psychiatrist has the right to determine what is delusion and what is not when it comes to pure religious beliefs...or experiences. (1002-1004)
> Now what would they do to the Pope...who worships Mary and believes
> he has visions and miraculous experiences...?
> what may have happened to Joan of Arc...? (1006-1010)

He briefly described his beliefs in the following statement.

> ...I basically follow more or less a conservative Roman Catholic position...(1028)
> Visions, ya I believe in them. I believe in miracles and...
> religious experiences and the power of prayer, all of that.
> But...it comes down to the psychiatric system not trusting any of that at all. (1032-1035)

Jeff said that a written assessment in hospital asked many questions on beliefs, such as whether he believed in God, ghosts, UFOs, the second coming, and etc. He thinks that this questionnaire is "...actually, it's basically against the human rights code" (1052). He added that if the psychiatrists you see have a bias against your beliefs then "...they have a tendency to see it as a manifestation of a delusion" (1059-1060).

In discussing psychiatry's bias against religion Jeff brings up a historical perspective for psychiatry's viewpoint by seeing its roots in the rise of rationalism in the nineteenth century.

> ...Psychiatry's based on almost like a 19th century rationalism, the enlightenment, where emotions were castigated in something that men and women should evolve away from. That caused a lot of trouble even for women and their subjugation ...feminine attributes and feelings...were...seen as inferior. And...so intuition was...not trusted, considered crazy... (1012-1022)

Jeff affirms how strong religious belief has helped him and others to survive in the psychiatric system. He said he is angered by the way diagnoses are developed for the Diagnostic and Statistical Manual (DSM).

> ...A person who may worship...a tape recorder, if it's just one and they worship a tape recorder, it's schizophrenia. On the other hand if fifty worship a tape recorder it's no longer schizophrenia. (1071-1075)

Jeff talked of his beliefs about neo-nazism when he was hospitalized as being "...out on a limb..." (1088), that they were beliefs on the margins of social acceptance and so would not be seen as reasonable, only paranoid.

He admitted that he had emotional problems from his troubles with his family but that his religious beliefs were standard Catholicism which his psychiatrist did not understand.

> I mean but how do you tell a psychiatrist who knows nothing about Catholic terminology or mysticism, "Well I've experienced interior locutions." They have no idea what that is. And they don't even bother finding out. (1096-1099)

Jeff explained 'interior locutions' as that which sometimes occurs while praying; a mystical, euphoric state, in which there is the sense that the holy one you are praying to is present.

When asked if he would still like to go to theological college Jeff said that "...the intense feelings of wanting to be a (Catholic) priest are gone, besides I don't think my girlfriend would like it very much" (1213-1215).

Jeff said previously that he had been misdiagnosed and that his diagnosis of paranoid schizophrenic had been wiped from his record. He replied to the question of how that had happened by saying that he had taken himself off the anti-psychotic, Loxapine. He said that the drug "...can give a person the illusion that they're disassociating...messed up emotionally and mentally" (1117-1118). His therapist explained afterwards that using the Loxapine was contraindicated for him, that is that it "made me more psychotic on it than off it, and more paranoid on it than off it" (1127-1128). He threw the pills away and took the chances of

withdrawal. "Pretty nasty... for a minute I thought I was going crazy but I held on 'cause I knew it would pass" (1137-1138). It took two months for him to recover.

When Jeff revealed what he had done his worker said, "OK, this time" (1151), and his physician put him on a low dosage of Stelazine, a tranquilizer, "...just to get me through the rest of my withdrawal...to take away the edge" (1176-1177, 1181). After that he was put on anti-depressants which "...were really probably the kind of medication I should have had in the first place" (1185-1186). More recently Jeff had also taken himself off the anti-depressants. He had not taken it for some time "...until all the problems at work...But eventually I'll be able to get off that too" (1201-1203). Jeff ended the interview by saying,

"Well I guess my objective in life is to lead a normal life, that's it" (1209).

## Discussion

Jeff made positive statements, at the beginning and a couple of times as the interview progressed, aimed to balance the many negative stories and statements that he made. His statement that the positives outweigh the negatives was not really reflected in the rest of the interview. But it must represent that the effect of the positive experiences, the support for recovery that he found with some mental health workers, helped him enough to counteract the effects of the negative experiences, and still does.

The first narrative tells how Jeff as a new patient was left suffering because he "...had no idea of what was going on" (126), no information about the medications and their side-effects, and worse still he was given misinformation to ensure compliance. He called the side-effect, Akathesia, an awful experience and his account of it is similar to the `slow torture' described in Ray's interview.

Jeff says that he has since figured out that what he was suffering from was a temporary psychosis. When medications are advised to be given as soon as possible to those assumed to be schizophrenic, as is advised by some professionals, there may be no chance to recover

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naturally from a temporary psychosis. As Jeff finds out later, some medications because of their interaction with brain processes can actually induce symptoms of psychosis and paranoia.

Jeff almost stayed at the boarding home he was placed in because he was judged to be in a fragile emotional state. If he had not had the fight and sufficient self-worth to back his claim that it was living there that caused his depression, he would not have been able to move out of the home.

The research that Jeff conducted into neo-nazism was on a horrific subject focusing on the potential for violence and a possible millennial catastrophe, perhaps the day of reckoning predicted in the Bible. This, in combination with the animosity he was experiencing at home, led Jeff to despair and break down. His emotional disturbance combined with his exaggerated claims, which he admits were delusional at the time, were seen as signs of a permanent break with reality and the symptoms of paranoid schizophrenia.

It was interesting that someone had talked to Jeff about family systems theory as an explanation of his breakdown. The idea of the family anxiety being projected onto an individual, in this case Jeff, appears to be born out by the complete drop of anxiety and tension in his family.

The stigma Jeff felt from the diagnosis, and the prognosis of a limited future on debilitating drugs resulted in suicidal thoughts, and alcoholism. It wasn't his `illness' itself that led him to wish for oblivion. It was the story of limitation and drug dependency, created and believed in by many mental health professionals, which renders psychiatric patients compliant and therefore manageable. This shows the dangers of universalizing theories that relegate an individual's personal experience only valid in relation to categories that are delineated in the theories. Psychiatry's pigeonholing style of diagnosing has the potential to mistake an individual's experience because they have to be fitted into a slot.

Jeff's second narrative shows how psychiatry can strip a patient of their former identity and replace it with a psychiatrized one. The psychiatrist made a power play in his first statement to Jeff. It effectively diminished Jeff and left him without any ability to speak from his own perspective. The psychiatrist did not even look at Jeff while he pronounced his sentence, maybe signifying that Jeff was now invisible, no longer subject, only the object of the psychiatrist's gaze.

The coercion and trickery attempted by the psychologist to have Jeff admit to being violent and potentially dangerous, and to confess to symptoms of schizophrenia that he did not experience seem reprehensible. However if we look at the theories of how mental illness is constructed it makes sense (Farber, 1993; Smith, 1990). The psychologist was doing her job in teaching Jeff about his role and constructing his condition as fitting the label of paranoid schizophrenic, the diagnosis chosen as closest to his presenting behaviour.

Jeff had no choice, he could not switch these professionals whom he did not respect or trust. But fortunately Jeff had sufficient self-esteem, self-reflection and faith in his own logical processing to question this diagnosis. He resisted and did not succumb to the psychologist's tricks to confess to what he did not experience. The psychiatrist and psychologist did not completely succeed in creating a psychiatrized identity, but Jeff was still controlled and managed by the mental health system, medicated and placed in supervised housing.

Stigma and the negativity of beliefs about schizophrenia are effective in keeping people in their roles and acting with appropriate behaviour. Jeff still had some hope of returning to his previous goal of becoming a priest when a mental health professional made a comment about whether he would be accepted by a theological college with his `illness'. Jeff said that "I kind of lost my will for a while" (298) when he was told his future would be limited. This comment was another blow to his ability to hope.

It was interesting to see the perspective of a consumer/survivor providing services to his peers, and how he and his co-worker were treated by the staff of the agency. Their position was stigmatized by having the lowest wages and no possibility of full-time work, reflecting a belief in their inability to handle stress. Stigma was also reflected in the way their coordinator treated them, not listening to any of their input , not acknowledging their expertise as consumer/survivors, and not informing them "... about matters that should concern us..." (547).

Jeff and his co-worker felt the effects of being marginalized, having no input yet required to place as volunteers those not really acceptable. Jeff also felt frustrated because he could not treat his clients as he wished, which meant giving them a little push, calling them on their bad behaviour, and helping them to risk rather than play it safe, ways in which he was treated and benefited from at the clubhouse he attended.

He is told by the agency he works for that he cannot form close supportive relationships or have the rapport with his clients which he found was so helpful to him, that it would be disempowering. The idea of empowerment may be not understood, or not integrated into practice by the staff Jeff dealt with. They may not have been well educated or instructed on how to support empowerment and so apply a policy of non-interference instead.

Jeff was disappointed, first, by the staff who did not call him to tell him that a man was coming to beat him up, and then again, when there was no reprimands for not informing him of a threat to his safety. His boss did not acknowledge how difficult it was to have to deal with the threat of violence, or honour his request for a two week suspension. In fact she was critical of him and challenged him with, "I guess you're going to have to deal with it" (630). It was from Jeff's perspective as if they wanted him to fail, wanted him to quit to prove that consumer/survivors could not do their job.

One of the problems is that staff are often oppressed themselves by the system they work for. They are handed down directives to include consumer/survivors in planning and providing

services, directives that they have had minimal chance to influence, and even if are opposed to them still are supposed to implement. The resulting frustration can lead to passive aggression directed towards the consumer/survivors, which can totally undermine the purpose of their inclusion, and encourage their self-fulfilling prophesies of failure.

Consumer/survivors require a lot of support to join staff that is not used to their inclusion; they need allies with whom they can consult and who can advocate for correct treatment, they need a support group of other consumer providers to discuss their issues with, and they need reasonable accommodations. The staff need to be educated to see the benefits of using consumer/survivor expertise to help them do their own job (Mowbray, Jasper, Howell, & Mozley, 1997).

There are many who say that the employment of consumer/survivors is helpful for both the consumer/survivors and progressive mental health and rehabilitation systems. However some of the motivations for including them may be suspect.

It is a strategy to improve service delivery by personalizing, humanizing, and/or expanding it. Unfortunately it may also constitute a strategy of substituting lower paid positions for higher paid ones. (p.25)

Advocates for consumer/survivors and their roles as providers of services believe that, "...consumer service provision may be essential to the achievement of a good system of community support" (p.27).

Jeff also presented the picture of what he felt like to be the service provider. He remarked on the immaturity of his clients, their manipulative behaviour and ingratitude, complaining just like any other staff may do. However, he understood based on his own knowledge and experience that it was the lack of power and the conditioning to never risk which lay behind their immature behaviours.

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The right to hold religious beliefs and not have them pronounced as part of delusional thinking was for Jeff a human right that should be protected for those psychiatrically diagnosed. He thought that it was unacceptable for psychiatrists who have not studied religious thought to make judgments from ignorance. Especially with the diversity of ethnic and religious backgrounds in our society today, psychiatrists should have some knowledge and respect for different beliefs. People who enter the psychiatric system should also be able to choose psychiatrists and find those who are sympathetic, those who understand their religious beliefs thus preventing misunderstandings and distrust.

Jeff trusted his own reason, allowing his own judgment to determine that he did not have the symptoms of schizophrenia. He was able to resist the loss of will that is part of being managed, took control and experimented with taking himself off medication. His therapist, after Jeff's confession and subsequent mental health, had the diagnosis of paranoid schizophrenic taken off his records.

Jeff gives several explicit determinants of recovery in his interview. His experience with recovery validates others who say that healing relationships are important; the support of compassionate people who believe in the person's recovery, who respect them, support their goals and encourage them to take responsibility (Anthony, 1993; Chamberlin, 1997; Deegan, 1996). Also his experience that work, participating and giving are keys to increasing recovery is also voiced by those who support the development of innovative consumer/survivor run businesses and the inclusion of consumer providers in mental health service delivery (Mowbray et al., 1997).

From Jeff's interview it is easy to see that resistance is an important aspect of recovery. His narrative includes suggestions to acquire knowledge of the diagnosis received, the effects and side-effects of medications, and to be self-reflective and trust your own logical judgment of whether you agree with the prognosis and diagnosis. He advocates for consumer/survivors to

risk, take back control and responsibility for themselves and attempt whatever they believe will help them to recover.

Jeff also advocates for a state of suspicion, to be alert and on guard rather than naively trusting the motives and methods of mental health professionals until they have proven themselves trustworthy. His observation and reason gave him cause to be suspicious rather than it being an aspect of paranoia. Finally he advocates to get out from under a psychiatrist's gaze, not only because of their legal powers but also because of their biased pathological focus which may impede recovery.

What is troubling is the numbers of people who may be misdiagnosed because of their lack of access to information, the coercive nature of psychiatry and the loss of identity as a person capable of decision making and action. Consumer/survivors and their allies need to speak out about the possible mistakes that are made. When the people under psychiatry's care are not listened to, mistakes and misunderstandings will occur, oppressive methods will still be used and needless suffering will continue.

Jeff's example can be disturbing to workers in the mental health system. Here is a man who was under psychiatric care for close to ten years who may in another time and place have recovered in one. His therapist, to his credit, in recognizing and acknowledging the misdiagnosis and the contraindication of the medication, admits that mistakes can be made.

Jeff's final words were that he wished to lead a `normal' life, for him this means to be a free citizen with his right to follow his chosen religion and with the opportunity to have meaningful work with an adequate wage.

## Chapter 11

### Part One: The Issues Raised in the Individual Interviews

I reviewed the content of the six interviews and pulled out the issues that the co-researchers had brought up. These were sorted into issues that arise from interactions with the psychiatric system and those that relate to the process of recovery.

### Issues in the Psychiatric System

**Hospitalizations.** The co-researchers raised concerns in their interviews about the coerciveness of the committal process and consequent treatments in hospitalizations even when they were not their main experiences; treatments such as enforced drugging, the use of four-point restraints and isolation rooms. Several of them had experienced trauma from this coerciveness. And some of the co-researchers brought up the fact that they were not asked about previous traumas or present abuse and so were at risk of being retraumatized by the coercive techniques used.

**The psychiatric diagnosis.** There were quite a few references to how a diagnosis changed people's lives. Many were told that this diagnosis would be with them for the rest of their lives. This labelling gave them a new identity as a person with a psychiatric disorder, a patient of the psychiatric system. The loss of identity as a `normal' person was in addition to whatever deprivations they experienced in losing their mental health. Along with the loss of identity was a loss of rights. A citizen's basic rights to freedom are waived when a person is considered mentally ill and a potential danger to themselves or others.

All the women and some of the men had histories of trauma, violence and/or sexual abuse in childhood and/or as adults. The effects of trauma are often misdiagnosed and mistreated as is suggested by this small sample.

**Medication issues.** The co-researchers all had concerns about medications. Some focused on the lack of information that was given about the medications they were prescribed;

for example, they were not informed about the full effect and side-effects of the drugs, that irreparable damage can occur from long term use, or that alternatives medications with less side-effects were available. They were also distressed when they were told they would have to be on drugs for the rest of their lives. There was no encouragement that in the future the amounts would be reduced, or of the possibility that they would be able to cope without these damaging medications. Several spoke disparagingly of the way they had been managed with incorrect or over-medication.

Another point brought out in one of the interviews was that anti-psychotics change the structure of the brain and so actually can create symptoms of psychosis and paranoia. The withdrawal process can then bring on a severe psychotic episode, especially if not done gradually, which can be seen as proof of the need to be kept on medications instead of a temporary state that will pass.

**Relationship with mental health professionals.** The co-researchers mostly gave a balanced view of the professionals that they saw. Some of them had been helpful while others were the cause of great distress. They said good professionals showed respect and compassion for them, encouraged their abilities and strengths, empowered them by their participation in treatment decisions, and supported them to reach their goals. Other professionals could treat them as being damaged, looked only for pathology, were paternalistic, demeaning and discriminatory, and in the worst cases, abusive.

For women with histories of trauma at the hands of men, having male mental health professionals was often counterproductive; not enough trust could be developed for a healing relationship. One of the co-researchers talked about his human rights being violated from the pathologizing of religious beliefs and practices by many mental health professionals. The inability to choose or change mental health workers was an obstacle for the participants of the interviews to access appropriate help which is also sensitive to their diversity issues.

**Mental Health Services.**    Some of the co-researchers viewed services as centered solely on ensuring stability.  Workers in these services have low expectations for their clients and do not believe recovery is possible.  Many services were characterized as ghettoes, places without hope where people with mental health challenges gathered, became dependent on service providers, and did not risk moving out of these enclosures into the broader society.  Another major complaint about mental health services was that co-researchers did not have enough participation in the decisions that affected them, that they lacked control over their lives.  There was also a consensus that people want talk therapy as part of their treatment; they wish to be able to tell their stories and to have their perspective listened to.

Several of the participants discussed their experience of unsafe housing and its deleterious effect on their health.  One participant with abuse issues found mental health housing problematic with the mix of male and female consumer/survivors.

**Financial Services.**  Some talked of the difficulties in being registered disabled in order to make ends meet.  They were upset that the same punitive, suspicious system that handles welfare cases also gives out disability payments.  The co-researchers talked about the lack of incentives to move off the disability roll.  The limit of earnings with work created just to top up, not get off disability is frustrating to people who wish to move into work but do not feel supported enough to take the risks necessary.

The experience of one of the co-researchers as a peer support counsellor illustrated the problems that some people experience working in peer support within the mental health system. Low wages, lack of access to full-time work, lack of respect for experiential knowledge, the discrimination from professional mental health workers, lack of accommodations and insufficient supports made it difficult for this consumer/survivor to succeed.

**Stigmatization.**  The stigma of having a psychiatric diagnosis was felt by the co-researchers both within the mental health community and out in the general public.  The stereotypes,

incorrect or exaggerated portrayals of mental illness are everywhere, in the media and as general public (mis)information. They particularly pointed to the public's fear of mental illness and violence. They affirm that the small percentage of violence perpetrated by those who are mentally ill is blown out of proportion when the statistics show that in fact the risk of violence by a person who has a psychiatric diagnosis is actually the same as someone out in the general society.

The stigma the participants experienced in the mental health system was as if they could never be full members of society; that their futures had limited prospects; that they were treated as if they were "disposable garbage". Many mental health workers, from the imbalance of power and the emphasis on stability not recovery, would with words, actions (or inactions), or even from the physical settings they met in, remind the co-researchers of and reinforce their status as psychiatric patients.

## Issues Related To Recovery

**The importance of peers.**  Many of the co-researchers remarked how wonderful it was to find others who had similar experiences and that they were not alone. They found they were able to freely share what had happened to them and receive support when they needed it. The relationships with their peers helped to develop information sharing, allowing those who were recovering to help each other, expanding their base of knowledge and expertise.

**A place of our own, a safe place to recover.**  The organization of the Self-Help Group (SHG) creates a space where peers can share ideas with each other through the newsletter as well as in the groups and at social events. The members attend the support groups to help them with day-to-day living and to develop a community they can draw on. The SHG already has a vision of programs that can help their members in their recovery. One such program is the safe house for women; a place of refuge when a woman feels unable to cope, where she is supported by peers and has available to her a choice of non-conventional treatments such as

bodywork and relaxation techniques, and services such as trauma counselling not easily available the psychiatric system.

**Healing relationships.**Throughout the interviews it was clear that it was important to have relationships with people who believed in their recovery, be they counsellors, mental health professionals or peers.  Healing relationships were with people who were able to empathize and show compassion, who gave respect and fostered trust, and who also recognized strengths, encouraged abilities, supporting people to reach for their goals.

**Safe housing and adequate income.**  The co-researchers were united in saying that the basics of recovery were  safe, affordable housing with an income allowing a measure of security and the possibility of adequate nutrition.  The burden of poverty, just striving to survive, works against recovery.  A couple of the co-researchers actually took on a disabled status in order to give themselves an adequate economic base to help themselves to recover.

**Meaningful work.**  The co-researchers often spoke of the need for access to work that gave besides income, meaning to their lives, as well as the opportunity to play an acceptable role in society.  The training for work that is available in mental health services is often in areas where some people have no interest or aptitude. Finding work that inspires and motivates goes a long way to having people feel good about themselves and their ability to risk.
It is also important to have appropriate accommodations, flexible work arrangements and good supports for helping people get back to work

**Hope, possibility and the reality of recovery.**  The co-researchers said that for people to believe that they can recover they need to see role models of recovery, people who can say, " I've done it and so can you".  It is also important for their own recovery when people provide peer support and move to caring for others.  Peer support groups such as the SHG can provide hope and educate members on possibilities and alternatives not promoted in the psychiatric system.

It was brought out in the interviews that resistance is an important aspect of recovery. Strategies of resistance are ones that counter the identity of a psychiatric patient, lead people to take control of their lives and make decisions about what will help them to recover. It was also suggested to be cautious, not to trust professionals until they have shown they are trustworthy, to be wary of their motives and methods which may prove not to be in people's own best interest. The last suggestion is to leave the psychiatric system as soon as possible, and to find counselling or other treatments where practitioners believe in recovery and do not pathologize or use `power over' methods to wield control.

## Part Two: Discussion Of The Interviews

The major themes of this discussion are the role of identity in mental health, the oppressive nature of treatments and practices in the mental health system, and the liberation found in the recovery process. The interviewees told stories that ranged from their experiences of violence, abuse and trauma before and after entering the mental health system, their first and subsequent encounters within the psychiatric system, and also to their process of recovery. The narratives chosen are examples of these stories which fit the criteria of a fully developed story (Labov & Waletsky, 1997). The narrative approach attempts to convey without translation the experience of being in the interview at the time of the telling of these stories. The emotional impact of this direct `hearing' is such that the reader can not remain unmoved. It replaces objectivity with understanding; a heartfelt speech transmits more than just the words spoken.

## The Creation of a Psychiatrized Identity

Some of the stories clearly show how a person's identity may be radically changed by entering the mental health system. In several passages, interviewees talked about their self-image when they were `ill' before accepting or being coerced to accept help from the system. They described having some self-worth and positive aspects to their identity at this time. It was when they were given diagnoses, prescribed medications with difficult side-effects, and told that their future was now limited, that their identity was assaulted. Several of the interviewees described becoming suicidal and/or abusing substances as a result of this assault.

Two of the interviewees actively took on an illness identity so that they could receive the support that they believed they needed to recover. Others received help they did not want; they were involuntarily committed, received incorrect diagnosis, treatments or worked with incompatible professionals. These two interviewees entered the system because they could no longer manage on their own. They were both able to maintain an efficacious identity because they had actively chosen to seek help. By taking on responsibility for their recovery, by finding

sympathetic professionals in one case, and following advice from respected peers in the other, they were able to have some control over how this help was administered.

The `social construction' of the identity of a mental patient can be well illustrated from these interviews. This shaping of the `psychiatrized identity' can be seen in the descriptions of the many instances of how power was used to manage behaviour and how professionals attempted to have people conform to their perspective and expectations. This construction is also apparent with peoples' lack of `voice'; their stories not listened to; their histories not investigated; and what they wished to talk about, the actual circumstances and context of their lives, discounted as almost irrelevant to their emotional and mental health.

With the change of status from healthy to `ill', one becomes an object of scientific medicine's gaze, one's identity is transformed for the purpose of medical treatment. Without this active negation of a subjective stance it would be difficult for medicalization to occur. Being a good `patient' is about becoming an object which will remain unmoving so that the `treatment' can be performed on the body with the least interference. This approach to the provision of medical services explains in part why participation of patients in their treatment has historically not been encouraged by medical professionals.

Scientific medicine, based on the Newtonian-Cartesian paradigm, wishes to remove the human relationship in order to proceed with treating the body as a machine. In psychiatry, this creation of a suitable medicalized identity is also effective in achieving a manageable `patient'; one who has been entrusted to the mental health system for caretaking after being rejected from `normal' society.

## Hope and the Resistance to a Psychiatrized Identity

Some of the stories from the interviews give hope that there are competent professionals who believe in and foster recovery through healing relationships and empowerment. They also show that there are services in the broader mental health field from which effective treatment

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can be found. The effectiveness of peer support and meaningful work (volunteer or paid) for aiding a return to health is also demonstrated in these narratives.

But it is not just sufficient support it is also the resistance to a `psychiatrized identity' that is a necessary component of the recovery process. It was heartening to find that some mental health professionals worked with rather than against this resistance.

Jeff, in his description of resistance, particularly illustrates its value. However, he had sufficient self-worth and focus to gather knowledge and then to trust in his own judgment that he was dealing with a misdiagnosis. Other interviewees showed resistance in their criticism of the mental health system's focus on stabilization which negates taking the risks necessary for growth; of the paternalism which encourages dependency and helplessness; and the oppressive methods of managing behaviour which foster fear, low self-worth and internalized stigma.

Much of the development of resistance is created by the interactions with peers and from the examples of those who have recovered significantly. It is therefore important for consumer/survivors to have places free from psychiatry's gaze; where they can exchange information and tell their own stories; and where they feel free to discuss any issues they wish.

## Why are the Effects of Abuse Hidden or Denied?

In these interviews there were instances related of violence perpetrated between men, between men and women, as well as self-inflicted. Also there was the disclosure of childhood sexual and/or physical abuse. Many of the people who become psychiatric patients have histories of childhood sexual and/or physical abuse. "In one study of psychiatric emergency room patients, 70 percent had abuse histories" (Herman. 1992, p.122). Recent research conducted with focus groups and individual interviews throughout British Columbia has found "evidence that experiences of violence were often what brought women into the mental health system" (Morrow & Chappell, 1999, p.34).

When survivors of abuse seek treatment they often have a 'disguised presentation'; they come for help with other symptoms and difficulties. "All too commonly, neither patient nor therapist recognizes the link between the presenting problem and the history of chronic trauma" (Herman, 1992, p.123). Also, women have reported that they were rarely asked about and didn't feel safe enough to initially disclose information about abuse. With this lack of knowledge "...traumatized people are frequently misdiagnosed and mistreated in the mental health system" (Herman, 1992, p.123). Recent research also found that, "women who are experiencing mental health problems are often more vulnerable to sexual or physical abuse" (Morrow & Chappell, 1999, p.34). Many of the people interviewed in this present research experienced misdiagnosis, incorrect treatments, and not being asked about, or feeling safe enough to disclose abuse issues, as well as being vulnerable to abuse after entering the mental health system.

Those who were abused often receive diagnoses that bring out negative responses in professionals (Herman, 1992). Some of these diagnoses are somatization disorder, multiple personality disorder, and borderline personality disorder.

> The *physioneurosis* of post-traumatic stress disorder is the most prominent feature of somatization disorder, the deformation of consciousness is most prominent in multiple personality disorder, and the disturbance of identity and relationship is the most prominent in borderline personality disorder. (p.126)

The common denominator for these three diagnoses is their usual origin in a history of childhood trauma. These three labels are usually given to women; in the past they were put together under the category of hysteria.

Especially negative is the borderline designation which one psychiatrist confesses, " strikes terror in the heart of the middle-aged, comfort-seeking psychiatrist" (Herman, 1992, p. 123). There has been a poor prognosis for this diagnosis, originally thought to arise from problems in

psychological development at an early age, and therefore little effort is made to help the person recover. Some people suggest the term should be abandoned because it is so prejudicial.

Herman (1992) sees that complex post-traumatic stress disorder is the most useful diagnosis to replace all three of these negative labels. The "...most troubling features of the three disorders become more comprehensible in the light of a history of childhood trauma...", and "...the survivors become comprehensible to themselves" (p.127) When the origins of their difficulties is recognized to be their abusive environments, survivors no longer need to look for the defect in themselves. This changes the survivors' perspective and "...the way is opened to a new meaning in experience and a new, unstigmatized identity" (p.127).

With people who have been abused, hospitalizations do not help and drug therapies can be useful but are only adjuncts to trauma therapy, the treatment that actually works (Herman, 1992). Talking or group therapy and the slow development of trust in healing relationships with compassionate facilitators are the treatments suggested. But long-term talking therapy is expensive. It does not fit with the cheaper treatment of drug therapy which is currently provided in the mental health system. It also does not fit with the medicalization of psychiatry where biological causes and treatments create a more scientific and thus more legitimate profession

The point could be raised that some policy makers have known that talk therapy is effective but expensive and have had to choose, for economic reasons, to provide cheaper services to those with serious mental illness. Social workers, nurses and psychologists are professionals who provide therapy in community mental health teams. This is an attempt to provide healing relationships and a place for people to talk at a lower cost than with psychiatrists. As can be seen from the interviewees in this research finding the trust and support needed for a healing relationship is hit and miss when patients are not allowed to choose their own therapist.

The abuse that people suffer from often results in anger. This anger is not necessarily out of proportion to the abuse; those who have experienced sexual or physical abuse often

experience great anger. How the anger is dealt with determines their behaviour. It can be expressed, repressed, suppressed or sublimated. Many criminals find expression for their anger in their anti-social activities. After much abuse, the battered woman's syndrome (another medicalization and individualization of a social problem) can finally lead to outbursts of violence, with many women ending up in prison as a result (Morrow & Chappell, 1998). In one of the interviews the potential for violence by a battered woman was well illustrated.

Most violence is driven by enormous rage which breaks through when anger has been repressed, or suppressed and not sublimated. Unexpressed anger along with the shame of abuse can be directed inwards resulting in self-mutilation or other self-destructive behaviours such as substance abuse, attracting abusive partners or engaging in dangerous sexual practices.

The psychiatric system relegates the treatment of many who are abused to other agencies, claiming their illness does not fit the criteria for serious chronic mental illness. Is this because they are unsuccessful in managing the often self-destructive behaviour and have low rates of recovery? Is it because the major treatment of medications is not effective with this population? Or is it the difficulty of dealing with abuse which arises in families and/or produces great shame? For many who are abused their lives are seriously affected. They often live in poverty, end up in abusive relationships, or become self-abusive, use addictive substances to blot out the pain, and have great difficulty surviving without sufficient support. They also often end up in the criminal justice system (Herman, 1992; Morrow & Chappell, 1999).

Throughout history, society has not wanted to hear the claims of victims of sexual or physical abuse that is found within families. A broken taboo is seen as both horrendous and fascinating. The victims are tainted by the act and there is great shame and guilt. Somehow it may be easier for others to not acknowledge the victims' innocence and their right to appropriate care, they may rather pretend the victims themselves were to blame or better still that it didn't

happen, it was in their imagination[15]. "Denial, repression, and dissociation operate on a social level as well as an individual level" (Herman, 1992, p.2). This may have happened because the perpetrators of childhood abuse in families are usually powerful members. Perpetrators can also be victims of abuse and may be impelled to abuse others, and so it can be passed down through families.

Until fairly recently in the history of western society the male family member has been legally in possession of the other family members, the women and children. They have been their possessions to mostly do with as they so desire and social norms and standards have allowed. Until relatively recently, under law a man was allowed to beat his wife with a stick no larger in circumference than his finger. Laws have had to be passed to liberate women from being objects to be possessed and to ensure compliance with a higher level of humane treatment.

Acknowledging the shameful secrets of families along with the failure of our current social system to care for vulnerable members could make too clear the need for long overdue changes. The psychiatric system also wishes to rid themselves of difficult cases often with multiple problems, outcasts of various ethnic backgrounds, those of lower economic class, and especially those with substance abuse issues.

Biological psychiatry's scientific basis, with the primary focus on the premise of genetic defects leading to brain dysfunction, is called into question when emotional and mental damage can be seen to be clearly a result of abuse and the trauma experienced. The data is clear that, "the mental health system is filled with survivors of prolonged, repeated childhood trauma" (Herman, 1992, p.122). Even so, environmental factors are downplayed, and seen as only triggers to already present underlying defects.

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[15] There have been cases of false memories of abuse aided in their creation by over-zealous therapists. However, throughout the last century there has been much denial of real abuse by families and therapists (i.e. Freud), the disclosure of which is credited to the victim's imagination.

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As biological psychiatry is still only suggested not proven by research, it is interesting that most professionals believe that there had to have been these underlying defects to explain why some people who are abused do not develop serious mental health problems and recover on their own. Perhaps there are other factors which determine if a person can adjust after great trauma which are being discounted? Perhaps any person even with non-defective genes who is subject to serious trauma can develop dysfunctional methods of coping which interfere with their ability to live a `normal' life and have `normal' mental health? It becomes interesting that professionals are not open to the belief that trauma on it's own can be one cause of what is presented as `mental illness'. It is just as logical an assumption as an unproven brain dysfunction.

What is not heard is the logical possibility that environmental factors can also trigger the recovery process, if one believes in a base of biological psychiatry. The holographic nature of the structure of the brain and the research which shows that different areas of the brain take over the functions of those which are physically damaged may actually back the theory of recovery from mental illness. With the physical etiology of emotional disturbance or `mental illness' still not proven this alternative is also not able to be confirmed.

## Pressure to Be a 'Normal' Woman

In one of the interviews, the concern was raised that psychiatry forced women to take on traditional roles; roles suitable for a `normal' woman. Including Freud's definition of what it is to be a woman, which he asserted had a biological basis, there have been many stereotypes of both negative and positive qualities put forth as natural to a `normal' woman. Psychiatry has taken these as guides for the normalization of its female clients. "Throughout the literature, the female who does not conform to the "stereotype" is labelled at least abnormal..." (Smith & David, 1975, p.23) And not only was she abnormal but any deviation in her family was seen to

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be her responsibility. This was not shared by the male family member to anywhere near the same degree.

Feminists have made a "...specific political critique in which the psychiatric institutions are understood as extensions of patriarchy..." regulating, "...the lonely and inchoate resistances of women trapped in oppressive personal situations vis-a-vis men, or caretaking the end products of such solitary struggles" (Smith, 1990, p.108). Dorothy Smith has met `psychiatrized' women just like Jane who are still angry and unwilling to trust the psychiatric establishment. She says that they know their anger comes from how the psychiatric institutions use their power to "...enforce their interpretations and dispositions on the everyday lives of individual people" (p.32).

Psychiatry intervenes as an organized power into the social order "...that an individual disrupts or disorganizes in some way" (p.32). This intervention invalidates and discounts mental health patients, suspending their capacity as subjects. The study by Rosenham in which sane subjects entered a mental hospital in California and were not detected by the staff as impostors, shows that, "...it is the status of patients, not their behaviour, that governs how they are "read" " (p.133)

**Without the Labels How would they Treat You!**

One of the interviewees condemned the social construction of diagnoses. This is echoed and extended by others who also find that the creation of diagnoses is less subject to scientific rigor than to a consensus among the psychiatrists, part of a hierarchical, patriarchal and social elite (Brown, 1994; Caplan, 1995). These critics also talk about the economic benefits shared by the publishers and pharmaceutical companies who back the creation of a succession of manuals with new diagnoses that will use new drugs to manage them.

Another concern that some feminists raise (Caplan, 1995; Smith, 1990; Smith & David, 1975) is the tendency for psychiatrists to look for problems, that just seeking help means there must

be something clinically wrong; as one psychologist said, "...normal people do not come into a clinic" (p.66).

Studies have been made on "...the social psychology of clinical diagnosis...", where researchers saw "...the effect of suggestion on whether clinicians believe they are looking at psychopathology" (1995, p.64). This is not only because of their training and expectations but also from their peers who encourage each other to look for abnormalities.

In a study by Temerlin and Trousdale (In Caplan, 1995), they filmed an interview using actors and a script which creates a client with no psychological problems. The interview was shown to law students, and students and practitioners of psychology and psychiatry. In the introduction a psychologist casually remarked that the person, "looked neurotic but was actually psychotic" (p.65). The participants were asked to choose from a list of disorders as well as one category for a healthy personality. The findings were that significant numbers diagnosed the person as psychotic and if not psychotic then neurotic. Only a tiny percentage found him normal. In the control group, where no suggestion was made, most said he was healthy or just had mild adjustment problems. It was also found that if one mental health professional found a client to be 'normal' and others did not, the professional was more than likely to reverse their opinion after discussing the case with them (1995).

In other studies, psychologist researchers looked at stereotypes and their effect on people. "Evidence indicates that negative stereotypes automatically influence behavior even in people who consciously denounce such attitudes" (Bower, 1999, p.281). Then without consciously wishing to, even mental health professionals who work to reduce the stigma of mental illness are influenced by negative stereotypes. This unconscious reaction to negative stereotypes then adds to the influence of the stigma found in the training and workplace of psychiatrists and other mental health professionals. Researchers found that, "..,they can influence volunteers' behavior noticeably by providing subtle unrecognized reminders of a group's stereotypical

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characteristics" (p.281)  The stereotype of a mental patient which if accepted by or even suggested to a person seeking help for their distress may prompt them unconsciously to behave so that they fulfill that stereotype.

When mental health professionals are diagnosing or treating a patient they do not often want to put themselves in the patient's shoes; the rationale being that perhaps they would then buy into a psychosis.  Studies by psychologists (1999) show that mimicry acts a social glue and is one of the ways to develop goodwill between two people.  When people are showing high degrees of  empathy they are seen to increase the mimicry of their partners.  These studies show how a professional distance is kept, how stigma can be maintained and how the construction of mental illness is aided by not empathizing with psychiatric patients.  In fact, in one of the rules which Dorothy Smith (1990) developed to define how to treat a person as a mental patient, it is important that one should never view the patient's situation from their own perspective.  Another point which shows the problematic nature of diagnosis is that people under great stress and in difficult emotional states can be vulnerable to the beliefs of those from whom they seek help and in their neediness often try to win approval by meeting their helper's expectations.

 Concern is also raised by feminists about patients who have physical problems for which physicians cannot find causes whom are then assumed to have a mental disorder.  Apparently there is an increase in the diagnosis of somatization which can have life-threatening consequences (Caplan, 1995).

It is then ironic that psychiatry and many scientists have been trying for years to find a physical base for mental disorders.  As Szasz (In Caplan, 1995) said, " "Respectable scientists have been interested in afflictions of the body," and so, in order to enhance their professional status, those who dealt with "problems in living" have treated them "as though they were manifestations of physical illness" " (p.68).

Richard DeGrandpre (1999) restates his argument.

By failing to distinguish between causation and correlation, and by playing on the dualistic sensibilities of the media and public, scientists have pushed away from a preventative, social model of mental health and toward an individualistic, "consumer" oriented model that emphasizes only symptom or "disease" management. (p.48)

As an example, he says that the public is misled when differences in brain scans are used as proof of a direct causal link from brain to behaviour for Attention Deficit Disorder (ADHD). These scans are offered as proof even though at a conference on ADHD, in a consensus statement by the participants, it says that "...further research was needed to establish ADHD as a brain disorder" (p.48).

This misrepresentation aids the mission of legitimizing psychiatry as a fully-fledged and respectable medical profession by using only "physical" causation as its base for diagnosis and treatment. It also aids the move away from looking at the social, political, or economic determinants of mental health thus avoiding the need to make changes in those systems, and maintaining the status quo for the benefit of the dominant class.

## Drugs that Create Compliance to Life-Time Use

One issue raised in an interview was about medications and their interactions with brain processes to change structures in the brain. As Jeff found these changes can actually produce additional symptoms; in the case of neuroleptics, symptoms of psychosis and paranoia. Researchers from Turku, Finland, in a study of first-time psychosis and anti-psychotic medications found that after "...three weeks without neuroleptics virtually all the patients had overcome the psychosis and the drug no longer appeared to be justified" (Martensson, 1998, p.50). This outcome was not only from three weeks without drugs it was also because the patients were surrounded by people "...who regarded a psychosis as a human crisis" (p.50).

Members of a psychiatric team in Falun, Sweden also see psychosis as a crisis and work to avoid hospitalization and neuroleptic drugs. They meet with the whole family as soon as possible and together they work to contain and solve problems. The patient often "...emerges from psychosis during this first session..." (p.51) and is almost always able to return home the same day. Members of the Falun team describe why they believe they are successful:

We think our way of working means that the patients do not lose hope. That's why we are able to overcome their psychosis. That's why they do not become chronically psychotic. That's why they do not become schizophrenic. (p.58)

Hope is not encouraged in the conventional psychiatric system. The aim of stabilization places the focus on drug treatment and on making sure the patient accepts their diagnosis and becomes compliant to taking the medications. Patients are taken away from their family and friends, isolated in hospital so that medication can be adjusted to ensure they are stabilized before leaving. The meetings with family are usually to inform them about the diagnosis and to ensure their support of medication compliance.

Because professionals have to diagnose before they can treat or even to accept a patient for treatment, and because of the need to manage the behaviour of people in hospital wards, there is a tendency to make provisional diagnoses fairly quickly. A person's hope is effectively destroyed by a hasty diagnosis which can bring the verdict of a life sentence to take medication, and by a prognosis which severely limits their future potential.

The fact that medications can induce symptoms is disturbing. How can the ones induced be separated from the ones that occur naturally? Can the only test be to withdraw from drugs? It has also been shown that the withdrawal from anti-psychotics becomes problematic by the changes they have made to the brain processes. "...The drug alters the brain so that psychotic pressure increases when the drug is withdrawn" (p.37). A person can experience a severe psychotic period before they are able to recover from the effects of the drug, especially without

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a carefully monitored, gradual reduction in dosage. "Researchers now realize that abrupt

withdrawal--an exceedingly common practice--escalates rates of "schizophrenic relapse" "

(Breggin & Cohen, 1999, p.161). The `neuroleptic trap' is that the relapse which may occur

leads many back to taking the drugs and believing finally that it is proof that their sentence is for

life, that there is no chance of recovery beyond that afforded by taking the medications.

The diagnosis of schizophrenia is not supposed to be applied until after observation for six

months. If neuroleptics are used to control psychosis at the beginning, how will they distinguish

between a temporary psychosis and schizophrenia when symptoms are induced by the drug

itself? In Jeff's case, there was an active attempt to coerce him to admit to symptoms which

would confirm the provisional diagnosis of paranoid schizophrenia. If he had not taken himself

off the medication he would still have the status of paranoid schizophrenia and not depression,

the diagnosis which he affirms. How many consumer/survivors are caught in the neuroleptic

trap? One author renamed neuroleptics, neurotoxics, emphasizing their poisonous qualities.

When used for long periods of time, they can have devastating effects on your brain.

Studies show that the neurotoxics cause Tardive Dyskinesia, an often permanently

disfiguring muscular disorder, in 20-65 percent of longer-term users. This condition is almost

invariably accompanied by Tardive dementia, a kind of dementia which severely hinders

your ability to think and feel. An estimated three million people in the United States alone

take these drugs on a regular basis. (Faber, 1993, p.201)

## Pathologizing the Love of God

Another issue found in one interview was the bias against religion in psychiatry. It is a

protected right in our society to follow the religion of our choice. Especially with the diversity of

ethnic and religious backgrounds in our society today, psychiatrists should have some

knowledge and respect for different beliefs. People who enter the psychiatric system should

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also be able to choose psychiatrists and find those who are sympathetic, those who understand their religious beliefs thus preventing misunderstandings and distrust.

It is interesting that the same interviewee looks to the historical roots of the modern conception of psychiatry in the advent of the age of reason at the end of the eighteenth century. In Europe, before the age of reason, madness was an accepted part of life signifying either a saintly person, a foolish character, or someone possessed by a demon. After, madness was medicalized and pathologized as being a disease of the brain.

Michel Foucault (1988) wrote about how the development of science created a separation between the sacred and the secular, and how madness came to be under medical authority. He points out that with "...the constitution of madness as a mental disease, at the end of the eighteenth century..." (p. x) there is no longer a dialogue between madness and reason. "The language of psychiatry, which is a monologue of reason *about* madness, has been established only on the basis of such a silence" (p.xi). Foucault points out that reason cannot be without the irrational to define it, they are both aspects of experience and to suppress one does not eliminate it, nor should it.

The denigration of emotions, feminine attributes and intuition came as a result of the rise of reason as the only proper tool of the mind. Not surprisingly, scientists have often been disdainful of religion and see it as leading people into realms of fancy and impractical actions. There are of course noted exceptions; Einstein, voted man of the century by Times magazine, had a strong spirituality which he found not diminished but affirmed by his scientific research.

The most beautiful and most profound is the sensation of the mystical. It is the source of all true science. He to whom this emotion is a stranger, who can no longer wonder and stand rapt in awe, is as good as dead. To know that what is impenetrable to us really exists, manifesting itself as the highest wisdom and the most radiant beauty which our dull faculties

can comprehend only in their primitive forms--this knowledge, this feeling, is at the centre

of true religiousness.

<div align="right">By Albert Einstein (In Reagan, 1999, p.37)</div>

Knowledge is lost from the insights received in unusual states of mind if they are

pathologized and medicated away. Many of the geniuses in arts and science as well as great

religious mystics had touches if not large brushes with madness and credit unusual states of

mind with producing great insights (Grof & Grof, 1989; Pickover, 1998; Stern, 1972).

Men have called me mad but the question is not yet settled, whether madness is or is not the

loftiest intelligence--whether much that is glorious--whether all that is profound--does not

spring from disease of thought--from modes of mind exalted at the expense of general

intellect.                                    By Edgar Allen Poe (Pickover, 1998, p.ix)

## Recovery from a Psychiatrized Identity

The recovery process is well delineated from the stories and comments in the interviews.

Recovery involves taking on the responsibility for one's own health and becoming as

independent as possible. Besides the basics for health, safe housing, adequate income and

social support, what may be of prime importance for recovery is losing the identity of psychiatric

patient; that of being someone who is almost solely defined by their diagnosis.

As is evident from the interviews, recovery does not always mean a return to the state of

mental health held before contact with the mental health system, and does not always mean

doing without medications. The difference is that for recovery the decisions about treatment

allow full input from the consumer/survivors themselves. Those who have recovered

significantly tell of the ability to be in control of their medications; knowing when to take them,

and when to increase or decrease the dosage (Chamberlin, 1997; Deegan, 1996).

A change of identity occurs when people restory their lives, see and accept that hope for

recovery is real and place themselves into their own narrative of recovery. This can and does

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occur within the mental health system when consumer/survivors find trust, mutual respect and healing relationships with compassionate professionals who believe in their recovery. Because of power imbalances and controlling institutional structures, the mental health system can work against a recovery orientation. The ability by consumer/survivors to choose the professionals they see would go a long way towards an increase in the possibility of healing relationships and recovery.

Mental health reforms which use current research about recovery and are influenced by the federal government's development of health promotion policies (Adult Mental Health Division, 1988) are slowly being implemented at the provincial level. British Columbia's best practices in psychosocial rehabilitation and recovery document (Calsaferri, Treherne & van der Leer, 2000) explicitly uses many of the determinants of recovery and mentions the importance of peer support. The recommendations include the incorporation of recovery concepts and psychosocial rehabilitation principles into all mental health services, and increased funding and opportunities for supported education and employment. The report also mentions that consumer-run peer support groups and businesses can provide additional choices for consumer/survivors.

In the process of recovery a psychiatrized identity based on pathology, stigma and despair can be replaced by one based on self-worth, hope and possibility for the future. The change to a more positive identity can result from the narratives told in interactions with peers. With peer support and role modeling, consumer/survivor knowledge and expertise is valued, and people can receive support to make the changes needed for recovery. As reported by co-researchers in this current study, it is in consumer/survivor-run peer support groups and services that these consumer/survivors develop the trust, the safety and the freedom needed to be able to tell their stories, express their feelings and voice their issues and concerns.

# Chapter 12

## The Issues and Programs from the Men's Group Interview

The men's group meets at the Self Help Group's (SHG) office. Initially there were four men at the focus group interview, and one who came about half way through. I gave the men the list of the issues that I had gathered from the individual interviews. I asked the group to read them and comment on whether they agreed with them or not. I also asked them to brainstorm ideas for programs that could address these issues, programs that the SHG could develop.

After the men had read through the list of issues they agreed with nods of their heads that they were all relevant. When asked to comment they pinpointed specific issues in their discussion.

## Issues Arising from the Psychiatric System

**Medications** was one of the areas that the men focused their attention on. Several of the men were on the new atypical anti-psychotic medications, atypical because they affected different parts of the brain than previous ones, and were said to have far fewer problems with side-effects. They talked about how devastating to their lives were some of the previous medications. "I've been on Haldol and it's terrible, absolutely terrible. The paranoid episodes were just overwhelming..." (98-99) They also talked about how the professionals did not make it clear that the lack of energy and interest, and/or paranoid symptoms that they were experiencing were side-effects of the drugs, not from their illness. It was only when they had switched to the new medications that this became clear.

> Talking from personal experience there are medications with huge side effects. I mean medications that just literally flatten you. I mean I thought that when I was on some of the medications that it was me, that I had no energy, that I had no interest in life and interest in things I used to enjoy. And a week after I got on the good medication for me, I realized that it's not me that was at fault. It's not me that has low energy and has little interest in the exciting things in life, it's the medication that just flattened me for like (splat, hands together), two years, two solid years! (56-63)

> And ah, a week after I was on clozapine, two weeks after I was off the other medications, started feeling better. (83-86)

There was a discussion about why they were not more fully informed about the side-effects of the medications, why they were left to believe that what they were experiencing was only from their illness. There was speculation that because the professionals were afraid of non-compliance they did not fully explain the effects of the medications.

> I've had that experience as well...the experience of having easy-rosy and that's caused by thinning out of the blood and that's caused by anti-depressants. Of course my worker says, " Gee I don't think that."...Despite the fact that it's in the DSM (Diagnostic and Statistical Manual) for side-effects and stuff like that. This is the kind of stuff that needs to be dealt with. (245-253)

The men gave both praise and criticism for the **professionals** they had been treated by. The consensus was that people were either lucky or not with the professionals who treated them; some gave respect and allowed participation in the treatment decisions, while others would not even listen to what they had to say about side-effects.

> When I was dealing with mental health I was treated fairly well. There is, they've got some power, definitely they have some power and it's a source of anxiety. (22-26)

> Depending on who your psychiatrist is, they to different degrees involve you in the choices about medications. (54-55)

> ...There are huge medication issues, surrounding what medications work and which ones don't, and there's not a lot of choice given to consumers about their participation. (18-20)

One of the areas they addressed in their discussions about professionals was that of enforced medications. A man spoke of the frustration that he felt one time when his complaint about debilitating side-effects was not listened to.

> I just got that clear impression that, "Since this person's been psychotic, nothing they say I can trust, nothing that they say I will consider." (100- 101)...Regardless of what you say about how you feel about your medication you know we're not going to listen. This is what we prescribed and that's what your taking."(108-113)

Another of the men thought well of a social worker he saw but even she didn't give him full information.

> ...the social worker...told me there's light at the end of the tunnel. And that's all she said, she didn't tell me that medications just basically flatten people, they just (slap hands together)...It completely takes away any enthusiasm you have in life, it's just, it's just overwhelming. (67-75)

No matter how good the professional the power imbalance was always there. In talking about the psychiatric system one man compared it to a caste system with hierarchical levels of authority. "...Those considered at the bottom in most cases are consumers." (546)

The men focused on the **drop-in centres** as places that embody the **ghettoization** of people who use mental health services. They were concerned that the people who went to drop-ins were full of anger and depression, having no sense of hope or possibility.

> ...They're...holding tanks for consumers...a ghettoization of consumers, people who are sort of entrenched in their anger and ah, don't know what to do about how they feel...
> They sort of internalize their anger. (338-345)

One man in his visits to these centers noted that although many of the people were bright, they were just managing to survive.

> ...It's too bad because...I think there's a lot of really bright people down there. But they're just sort of in a hopeless environment...like they're in a dead end...they get a bite to eat and a roof over their head and, and that's about it. (359-364)

Another man added that he thought it was a shame that many people isolated themselves by only associating with their peers.

> Consumers go to certain places and they hang around with certain people and they live in certain areas...they're cutting themselves off from the rest of society, you know. (999-1001)

Another focus of attention for the men was **financial services**. The men were upset about feeling powerless and having no right to privacy when dealing with financial aid workers.

> There's almost an attitude, it's just a power, an institutional feeling of helplessness. I mean they, they've got access to so much information that you feel like they can reach inside your gut or your soul, you know. It's really, ah, it's...I don't think it's right. It's going too far. (6-9)

One of the men described the humiliation of being in a line-up to pick up a cheque at the welfare office.

> And that is the most humiliating experience a person can have, standing out there, with the cars going by. It's very, very humiliating. (40-42)...
> It's almost like we become farm animals going into a pen or something. (50-51)

Another area of concern for the group was the **barriers to their employment**. One man pointed out that service providers say they don't want to provide accomodations, adjusting work

conditions for people who have psychiatric diagnosis, because they do not want to patronize them. However this effectively keeps them out of positions that could be modified, at least to start with.

> You know, I mean, there should be some flexibility around these working things and flex time...because you know a lot of consumers their energy is not as consistently there as others, so, why not give them a little, why not give them a break? For God's sake! (512-516)

The lack of accomodations means that there are many positions that are not accessible for people who use the psychiatric system.

> I think most people, given the choice, I think most people prefer to work. But it's like when you get ill, like that it's so devastating, you know, um, you kind of lose everything in effect so that it's hard. In all kinds of different ways it's so hard to get back if you ever do and of course some people never do. (896-900)

Another barrier to employment identified by the men is the **disability benefit**. It provides an assured income without the stress of working, and as one man said, you can't get fired. Even though people may be capable, the rules, allowing only $200 to be earned before the extra is taken off the payments, are a barrier to people taking the risk of more employment, more stress and possible failure.

> I just think that the disability payment is kind of a dangerous thing, some people do...give up on their ambitions because...they've a fixed income...(850-852)

> It seems to me I've seen a lot of people, ya there's a lot of people on (disability) pension who seem capable, just some doors need to be opened for them... (854-855)

> The way it is now you're either on, or (off), so there's no incentive unless you get a full time job, and that's a pretty scary thing. (870-871)

The **stigma** of a psychiatric diagnosis affects many areas of peoples' lives. The men added to the list of issues that there was a taboo around sexuality and marriage, and that there was a high rate of apprehension of children whcih often results from the discrimination of people who use the psychiatric system. With the current view of biological psychiatry that the cause of psychiatric illness has a strong genetic component, and with some not believing that recovery is possible with such a brain defect, the roles of husband and wife, and of father and mother

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may be deemed unsuitable or unwise. With some mental health workers even the idea of a

regular sexual life is inconsistent with having a so called `mental illness'.

> 'Cause very often, for whatever reason, mental health workers tend to see many people, many consumers as almost, as they don't, they shouldn't have any sexuality. (1032-1035)

One of the men was told it was unrealistic for him to think of marriage or raising children.

> Like dissuading you from thinking about, ah, delusions of grandeur, like marriage or something. (1037-1038)

> A: Ya, but unrealistic to have sex, like raising a family.
> B: How could you do that with your illness, is that what you mean?
> A: Ya that's basically it. (1044-1046)

> If you've got mental illness then you shouldn't have kids. That's the thought you know. (1060-1061)

The men talked about the problems with apprehension of children that parents who have a

diagnosis of mental illness are faced with. Later in the discussion, one of the men, a board

member of a advocacy group, gave hope when he told the group about new housing that is

designed to support families.

> People have lost their kids, mothers have lost their kids due simply because they have mental illness...Instead of getting support, the ministry just comes in and takes them... (1046-1049)

The men were very critical of a radical activist who had recently demonstrated by threatening

to blow up the premier's office if he was not listened to. They felt he negatively impacted the

public's perception of their issues and increased the stigma of a psychiatric diagnosis.

> A: He's like...the shock troops...storm the barricades! (333-334)
> ...To me he's a very loose canon. (978)
> B: I'm afraid this business about...the bomb scare in the premier's (office).
> I think, I think that rebounds on all of us...
> A: Is that the mainstream...of mental health? I don't want to be part of it...
> I want to try to be rational. (983-986)

## Issues Related To Recovery

All the men agreed that **contact with peers** was important for recovery. The value of a peer

is that they can share what it has been like for them, their perspective of what professionals say,

and what they found was actually helpful or not. The men said it was important to have people around you who understand your experiences without condescension or any power imbalance.

> ...There is nothing like knowing you're not the only one. Like you've got other people...around you...who go through the same kind of struggle because they've got the same, or related illnesses. (556-559)

> I think community is important. I think...an environment where a person can...meet other people with similar problems and then share their problems...share their hopes...that's very important. (583-585)

> And talk on the same level. You've not got someone up here and someone you know talking down or...thinking you're different. (586-587)

> ...But the thing is professionals, unless they've been there...that component (peer experience) is missing and I think it's been proven time and time again that that's...priceless, it's so priceless. (581-604)

The men's group agreed with the need for people who have used the psychiatric system to have **a place of their own**, where they were all equals and could find the support they needed for recovery. The Self Help Group is a place where someone will not be discriminated against, it can provide a safe place to recover.

> A: A safe place to recover. That's what I was thinking this Self-Help Group is kind of like that, a place that isn't..."
> B: Discriminatory?
> A: Ya. (653-656)

The men affirmed the importance of a healing relationship with someone compassionate, who will respect them, listen to their pain, believing in and supporting their recovery. The men brought up their concerns that counselling or `talking therapy' was not available for many of their peers. One man said he was lucky to attend a therapy group, one of the few available to those in the community. They raised the issue that people who had been traumatized needed some form of `talking therapy' to help them recover. But the reality was that, at this time, only those with sufficient income can afford this therapy.

> Well you think you get the medication but the therapy you've got to pay 100 bucks an hour. No one can afford that, so it's ridiculous. (758-759)

When one of the group said, as he has experienced and also read the combination of medication and psychotherapy were the best treatment, a debate arose as to the causes of mental illness. They discussed whether the causes were biological or environmental, and questioned where economic and social determinants fit.

A: But it's both (biological and environmental), the problem is, is that
   only one aspect is being funded...I don't entirely reject it at all.
B: The biological model?
A: No, it's a part of it for sure.
C: ...And also to deny the, to deny just having to survive on disability,
   just having to survive under stigma, I mean how can anyone recover in those situations...
B: It's a real struggle. (821-833)

The men spoke of **safe housing and adequate income** in relation to those who lacked both.

While talking about the drop-in centers the men touched on the problem of homelessness.

Some of the men had met homeless people at the centers.

Some of them are living in their cars, living on the street, and they depend on the CRC (Consumer Resource Center) to get a shower and a meal and ah, and contact with humanity at some level, some way, something. (367-369)

The group debated whether these men who survived by going to the drop-ins had character defects because they could not take on responsibility. There were questions about whether they were demoralized by being told they were in a dead-end situation, or was homelessness and freedom better than the 'management' by medication and psychiatric control?

In their discussion about the development of **peer-run housing** the group addressed the idea of providing shelter for the homeless who had mental health challenges. One member thought it was inadvisable as they weren't under treatment and thus would create problems. While another thought it would be a useful service to provide housing for those who were afraid of, or had bad experiences with the psychiatric system and who may be able to access alternative treatments through non-threatening peer support.

To illustrate the reason for remaining **homeless**, another debate arose when the men talked about psychiatric workers who picked up homeless people and took them to Riverview.

A: But...once a person's been freezing until they're fifty years old...I'd rather be in Riverview than freezing in Stanley Park. (739-741)

B: If you had the choice of no medications and living in the forest and bad medications and Riverview, I'd almost choose the forest, I've had such bad experiences with medications. (747-750)

A couple of the men found **disability benefits** to be adequate if you shared accomodation and didn't smoke or drink. One defended the adequacy saying it only seemed inadequate because we were an irresponsible society wasting resources, in other cultures it would be a comfrotable income.

Also in talking of adequate income, one of the men pointed out that medications, which rob a person of energy and vitality, create large barriers to gaining and keeping employment, relegating that person to a life on a disability pension.

The men spent quite a lot of time discussing the difficulties for them **returning to work**. Most of the men had part-time employment and/or were active as volunteers on boards and committees. Most of the work they accessed was designed to add to the maximum level allowed on top of their disability benefits, and no more.

They were all interested in developing self-run programs, and many with working to support their peers. In the discussion about anger, the group pointed out the value of chanelling that energy into working in advocacy for their peers; not only is it meaningful work but also helps in their recovery.

The men saw that the value of developing peer support is not only to create a place to freely share stories, but also a place where people " ...share their hopes...That's very important..." (585) to instill **hope** to those who may have lost it when they took on the identity of a psychiatric patient. The group again validated the importance of the peer community with the need for **positive role models** who can transmit what they have learned about recovery.

The way to...feel better about yourself is to find people who've got positive experience, who have the same experiences as you, and they've got some, perhaps some insight as how to...overcome some of the problems... (591-595)

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## Themes Of Resistance

There were dialogues that arose in the discussions which countered the mainstream psychiatric discourse and showed resistance to the pathologizing views of psychiatrized people. These dialogues I will term narratives of resistance.

The first narrative of resistance is the idea that **people are being wasted**; their potential and their possible contribution to society unrealized. Instead of viewing psychiatrized people as damaged and defective, it would be more useful for society to focus on their strengths and abilities. Perhaps the very differences from so called `normal' people are valuable, can provide unusual perspectives, and contribute to society in some way.

One of the men was concerned about this waste of human potential in the drop-in centers where he recognized that some of the people were of very high intelligence. He proposed that effort should be made to include them in some form of work by moving towards them, making adaptations for them.

> ..Down in the drop in center, I ah, I met some people who seemed just brilliant to me but they couldn't...function very well in the world...but maybe if the world came to them a little bit...they'd be able to do something...(419-422)

The second narrative of resistance asserts that the **possibility of healing** and regaining mental health is sacrificed by the psychiatric system with its agenda of stability as its major focus. The group spoke of their objection to the idea that the most important thing is to keep people stable.

> ...I think the system is still geared to the philosophy of keeping people quote, stable, "Above all else, keep them stable." (526-527)

> ...That's just like (death)...you know, and the corpse is stable...(932)

The men said that from their experience in order to heal you have to feel your pain, not have it medicated away.

> A: You're just going to rob people of their...(potential of ) healing themselves. I mean in order to heal yourself you're going to have to feel some pain.

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B:...We'll give them some drugs and as long as they're stable that's at the top of the list and whatever else they have in terms of quality of life because they're on drugs is (not important)...(926-944)

The next narrative of resistance is about **social control**, one of the roles of the psychiatric system. The men talked about how perhaps people are controlled by medications in part to preserve the illusion that everything is all right. They spoke about society's discomfort with insanity and peoples' denial of their own crazy side. Another motivation for keeping people shut down with drugs, not expressing their pain, is that it may be disturbing for others.

...That's society's problem because...they're in denial about their own insanity...they don't want to look at that...crazy wild side of them...Let's shut everyone down...and make sure everything's nice. (946-949)

The fourth narrative of resistance speaks about how in many cases **anger** is not a pathology but a natural reaction to the situations psychiatrized people find themselves in. Anger is often seen as a symptom of mental illness, one that has to be controlled so that violence is avoided. The men saw that this attitude sometimes leads to a suppression of people's feelings, pathologizing anger, and denying that it is natural to be angry at times. The anger, which can be a natural result of frustration at the losses and difficulties that a person with mental health challenges experiences, can in the recovery process be channeled and used as energy to make changes.

A: It's like there's some threat to them (professionals)
   ...If you can channel people's anger, give it an outlet and then somehow channel it, that can be energy. (964-968)
B: ...In working for issues you feel are important, that's a way to use anger. It's like ..."Hey! This is not right, we're going to do something! (971-972)

## Suggestions For Programs

The men spent a lot of the time in the interview brainstorming ideas for programs and developing how they could be implemented. The programs are ordered chronologically, in the order they arose in the interview.

**Mental health information line.** The first suggestion for a new program to be developed by the Self Help Group was an information line. The fragmented services and lack of a broad-based information system were seen to be barriers to people who have just entered the system, barriers to being able to find out what was available to them. The mental health telephone information line would give people information about where to go for both mainstream and alternative treatments, how to find out about rights and responsibilities, legal issues, peer support, where to find advocates, etc. The men discussed the importance of trying to make this line be without a bias either toward or away from the mental health system. It would refer people to the mainstream services, peer support or alternative groups and complementary treatments, whatever the caller asks for.

> You feel so overwhelmed at the time (first contact with the psychiatric system) that you don't know where to turn. (135-136)

> ...You need...a place where you...can get some clarity, well this is where you need to go for help, if you're on the wrong medication or the medication is really bothering you, or you don't really trust your psychiatrist. (146-149)

> ...If the health board won't do it, darn it they should fund it at the Self-Help Group, there should be something. (176-178)

**Peer advocacy.** The group agreed that there were too few advocates and that the ones that were there were difficult to access. They suggested that peer advocacy could be another program provided at the Self Help Group.

**Hospital outreach program.** The discussion of a hospital outreach program arose out of the idea of the information line. The men thought there was a need to get information to people who are in the hospital, especially for first time hospitalizations, to show them that there was a consumer/survivor community and alternative support available, as well as to inform them of the services they could access.

> But still I mean if you're in the hospital you don't think of it, you've never been hospitalized before, you don't know there's a community out there with professionals and consumers. (205-207)

...Advocacy in hospitals (would be good, especially)...if you can catch people with their first real experience with the mental health system (which) cannot...inform them, educate them about...what options are available for consumers. (610-613)

A: I think the information referral and the outreach are huge, really big ones for Vancouver.
B. Ya, really needed as well. (1095-1097)

**Development of grievance procedures.** One of the men was concerned that there weren't sufficient guidelines for how to make a grievance within the psychiatric system and that the Self Help Group could support the development of clear unbiased information about rights and grievance procedures.

You need for these kinds of problems, (being) misinformed, and ah, mistreated, you need some sort of, form of grievance procedure. (259-261)

**Educational workshops.** It was suggested that the Self Help Group could put on educational workshops, such as one to address problems with adjustment to medications, and increase their members' knowledge as well as address some of their concerns.

**Counselling and alternative treatments.** One of the men remarked on the lack of affordable complementary or alternative treatments, especially "talking therapy", and implied that there is a two-tiered system of access to these treatments. He suggested this was an area that needed to be developed and should be funded by the psychiatric system. The Self Help Group could advocate for more funding to be put into counseling and therapy services.

The problem is that alternatives are not funded by the mental health system. (756)

Counselors, they're, they're outside the system and they charge from 60 to 100 bucks an hour and no consumer can afford that. And that's a huge lack in the system. (777-779)

**Consumer-run housing.** In the discussion on housing it was decided that there was a place for housing that is not connected to the psychiatric system. Housing for those who are afraid of, or who have had bad experiences with mental health services.

Ya, I think for people who've had bad experiences with the system, ah, houses like that (consumer run) would be valuable...(699-700)

The men did include that they would need to have trained peer support workers so that they would be able to know what to do when dealing with the `untreated' homeless people with mental health challenges.

**Supported employment.** One man suggested that there could some form of assistance to help people develop their own business, some funding and support for the initial phase of setting it up. The Self-Help Group could also advocate for flexibility and support for people who want to move out into jobs, especially in the mental health field.

> (It would be good)...if they could support people...allow them to take (extra benefits) for 6 months, or a year until they get established and get used to the work... (864-866)

> ...We're sort of wanting to get back into the system in terms of part time, or maybe even full time work. You know it's like...there's still a huge number of hoops around and the mental health agencies...they could do a lot more...in making it easier. (490-494)

> The idea of...building some flexibility for the job thing in certain areas for people with mental disabilities...is not a huge thing, there, it's not patronizing!...It makes the system a bit more human, that flexibility anyway. (524-529)

> ...That's another thing for the Self Help Group...work kind of stuff and applying for grants...being a channel for that. (439-440)

**Connections/Alliances.** In the discussion about hospital outreach one of the men suggested making allies with sympathetic professionals who could advocate with other doctors and provide medical information for consumer/survivors.

# Chapter 13

## The Issues and Programs from the Women's Group Interview

The meeting of the women's support group was held in a neighbourhood house. There were ten women present at the meeting I attended. One woman left after about half an hour. Two women were there as interpreters for a deaf member. The women participated in the focus group interview which lasted about one hour and a half.

I introduced the meeting by talking about how I came to be doing this research. I passed out a handout that listed the issues that were brought up in the interviews and the programs that were suggested by the men's focus group. I asked the participants to read the handout and then discuss whether they agreed with the issues, if they had others that they could add, and to give suggestions for programs that could be developed to address the issues. The women who participated were quite outspoken and the discussion flowed easily.

The handout that I gave the group included an extensive list of issues which the women said they fully agreed with. They approved of the programs that the men had developed and added their ideas to some of them. I believe that because many of the issues and programs were already set out, the women felt free to bring out narratives of resistance; viewpoints and beliefs that counter some of the views held by the mainstream psychiatric community. Whereas the men's group focused mainly on developing ideas for programs with some narratives of resistance, the women took the opportunity to say, "...things that dare not be said elsewhere." (885)

## Issues Arising from the Psychiatric System

The women pointed out that the current mental health system is a **two-tiered system**. One woman, an active participant on many committees and boards, speaks as an advocate when she points to the socio-economic factors that affect the treatment of someone who enters the psychiatric system.

Wealthy people have the option of going to a psychiatrist and taking medications or paying two hundred dollars an hour to go to a registered psychologist, or have acupuncture, or reiki, or herbal remedies. The poor people have to go to ah, ah, state psychiatrists and have state medications. And they have no choice...they can't afford to go and have lots and lots of talk which is what many, many of them are asking for and actually need. And so it is in fact a two-tiered system even now. (280-290)

The women pointed out that the two-tiered system is apparent in the access to effective medications. As the men also brought up, there is a great difference between the types of anti-psychotic medications used. Psychiatrists need special permission for funding to prescribe the expensive atypical drugs to people who are either unresponsive to other drugs or suffer from severe side-effects, and who cannot afford them themselves. There is concern that again it is a matter of luck whether a person will be chosen for these medications or not, the power being in the hands of the professionals.

There were many concerns voiced over the **lack of decision-making power** about treatments. In contrast to being able to access expensive medications, a common problem is that it is difficult to attempt to reduce and eventually stop taking drugs. The women talked about the fact that without the ability to make decisions about treatments, if a person wants to reduce or get off medication they have to do it on their own. It was pointed out that because of the way the medications work by changing the brain processes, there is the risk of a serious psychotic episode in the withdrawal process.

"...they don't respect your desires to start to get off of it. So I'm going to do it myself, cut the pills and do it gradually." (300-301)

The side effects of anti-psychotic **medications** were discussed as well as the lack of information about the consequences of their long term use. One of the participants describes the permanent side-effect she suffers from:

I've got it (Tardive Dyskenesia) a little bit and I'll always have it but fortunately (it's not too bad)...It's caused by neuroleptics, and my tongue has a worm-like movement in my mouth and I know there is nothing I can do about it. (417-419)

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The women talked about how to make the system more accountable for the damage from medications. They talked about the law suits that have been successful in the United States, won because people who developed Tardive Dyskenesia were not informed of the possibility of this side-effect of neuroleptics. The apathy, or passivity of Canadians was seen as a factor in the lack of activism around these issues.

The women also pointed out that there was a lack of freedom to choose the **mental health service** they wanted to access. One of the women found that the Assertive Community Team (ACT) was more respectful and useful for her than the professionals she regularly saw at the community mental health team.

> There is one organization out there that is doing what you are talking about and they come to your house, they're called ACTS, the community team. (244-246) I find...you're treated like a person, a human being...The mental health teams...are absolutely useless. It's ten minutes, they ask the same four questions: Are you sleeping? Are you eating? Um, do you have suicidal thoughts and do you have suicidal plans? (250-258)

The group noted that there is a discrepancy between their view of the treatments they valued and the views of psychiatric professionals. They said that the counsellors that some of the women saw through other agencies were of much greater value and gave much more of their time than the mental health professionals in the psychiatric system.

> Ya, I see a counselor through Watari (youth drug and alcohol)...The psychiatrist spends ten minutes with me, and this person spends some time, we've even sometimes gone over the hour, an hour and a half, you know, if I need it. (1039,1045-1047)

Instead of drop-in centers the women focused on **housing** for people who use the psychiatric system as an example of **ghettoization**. There are far fewer women than men at the drop-in centers. Many women say they do not feel safe attending the drop-ins.

There was concern that people who use mental health services are put all together and are not integrated into mixed housing. If they were integrated the women said it would help people to feel accepted as members of society, and therefore aid their recovery. They also were

cynical of the professionals attempts to equate mental health challenges as a disease such as diabetes.

> It's the same old paternalistic paradigm. Well if they tell you it's like...you have a disease like diabetes, you know that old line. Why don't they put all the people with diabetes in the same housing? (555-557)

One participant of mixed ethnic heritage took exception to the type of charity that the housing ghettos represent.

> You know it reminds me of Oliver Twist and that whole mentality, "Here be grateful for what you get. One potato, I know it's a little scummy and moldy but what the hell it's better than nothing."...I was made to feel like a charitable institution of my own by my family. I hated it and I feel very strongly about it now, about having rights. (582-592)

Just as the men were, the women were concerned about the barriers to securing **employment**. One woman who is extremely knowledgeable about services and rights, talked about the difficulties she faced.

> I'm facing the glass ceiling. I've got a fifth year university degree. I'm a licensed practical nurse. I'm fifty-two, so there's an age barrier. And um, there's the history of mental illness. So there's all these barriers that I've got against (getting work)...And I'm a single parent, never married single parent. (855-860)

When asked why she didn't work as an advocate she said all her work was as a volunteer and that there were no full positions for her, just jobs made to top up her disability. She talked about the disincentive to work inherent in the rules surrounding disability benefits.

> ...To top up your, um, disability thing but not get off it. That's my pet, pet peeve! (854)...But the minute you earn over two hundred dollars more, they, um, start deducting from you, so, you know. But I purposely don't do that because why break my heart even though I'm qualified up to here. (975-977)

Some of the women questioned why other people were bothered by those who experienced `different' realities, or exhibited unusual behaviours, if they weren't hurting themselves or anyone else. At a seminar on mental health, stigma and the media, the psychiatrist leading the seminar directly identified psychiatry as an agent of **social control**.

> ...R.D.Laing was one of the people who said that people with psychosis...had every right to live in their realities...and they should be left alone. And what's wrong with that as long as they're not hurting themselves or others, that's the main thing again...What the psychiatrist said was that would be an ideal, that would be a utopia. But what we live in is not that, and

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we do have social sanctions, and we do have codes of behaviour and so we can't do that..."
(755-760)

Interestingly there was quite a bit of discussion of how the developmentally delayed or mentally challenged, and the physically disabled were treated, their level of **stigma**, in comparison to those with psychiatric diagnoses. The participants talked about how the physically disabled have worked for the rights to manage their own personnel, to hire and fire the home support workers they use. They talked about all the programs and services that are available for the mentally handicapped and how the strongest advocates for these services have often been the parents. The parents of those with psychiatric diagnoses advocated for less freedom and more control, and told them to, "Stop being silly!" (680)

There was also discussion about the relative lack of stigma for physically and mentally challenged people. The women discussed that they believed that the difference in stigma between other disabilities and those in the psychiatric system was that in psychiatry the cause was seen to be within the person, that they brought it on themselves, or that there was some individual defect and somehow they were to blame. "It's like being raped (and being asked) like, 'What were you wearing?'" (698)

## Issues Related to Recovery

The women mentioned two viewpoints about recovery in their discussions. The first said that for one **path to recovery** one had to find meaningful employment, get off disability benefits, and integrate back into society away from the identity as a consumer of psychiatric services. People develop an 'institutional helplessness' when they are not allowed to take responsibility for their lives. The second said that a person needs to accept their disability, get onto disability benefits and start looking after themselves in order to heal and recover. People can deny and avoid problems through overwork.

The women also had issues with the **terms** used to describe those recovering from a psychiatric diagnosis. To one of the participants none of the expressions, consumer, psychiatric

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survivor or ex-patient, were acceptable and did not reflect her experience. Others thought

psychiatric survivor was able to convey the strength of surviving the traumas before and during

their use of the psychiatric system.

> I still am a little bit of a consumer I guess, 'cause I take the drugs still... (1123-1124)
> ...We are survivors of the system, of the drug sellers, of the people who try to buy us and buy
> our souls. (1141-1142) I can't believe that the choices we have are survivor or consumer,
> that can't be how to really describe us. (1144-1145)

In discussing the issues of **destigmatization** there were reminders about the larger picture of

mental health, how extensive the community actually is.

> ...I just think that we should remember that we are actually part of a larger community...in the
> statistical manual...they say one in five Canadians, so it's a national phenomena, will
> experience a mental illness in their lifetime. That means the whole society and the whole
> country. And that's not just schizophrenia, which the SS (The BC Schizophrenia Society)
> would have us believe is the only mental illness. (1298-1307)

The women talked of the advantages for the Self-Help Group to make alliances with the

broader community of people affected by mental health challenges in order to attack the

damage caused by stigmatization.

Finally, it was brought out that **peer support** is of great importance for people with a

psychiatric diagnosis. It was while relating with peers that people felt understood and were able

to talk about their issues.

> A: Ya, and...it's people who are peers, meaning somebody who is in the same...
> B: Who's been there.
> A: Ya. Because I have friends who they don't...they just don't get it...
> C: It turns out for me it has evolved, that I...I'm fifty two now and I have more friends now
> than I had when I was twenty. And all, most, the best friends I have are psychiatric
> survivors...(With my peers) I am able to get demons out in a more, um, acceptable
> climate. (1085-1090)

## Themes Of Resistance

The most striking point in the women's focus group was the alternative viewpoints, the

narratives of resistance that were brought out in the dialogue. Narratives of resistance are

stories and views that counter the disabling, demoralizing and stigmatizing discourses in the

dominant narratives of the psychiatric system.

In one narrative of resistance the women stated that there was a lack of acceptance in our society for the **expression of difficult emotions**. This was similar to the men's point that they were not able to fully express their pain. "Oh my God! Someone steps out of line, we're so rigid." (723)

It was brought up that in some cultures it was recognized that sometimes people needed to behave erratically, pull their hair, wail and gnash their teeth in order to express and work through difficult feelings. Whereas in this society, behaviour of that sort is unacceptable and suppressed. In the DSM, grieving is considered pathological if it continues over an arbitrarily set time. Pain, to be `normal', must be of short duration, no suffering is allowed over the time limit. This viewpoint makes no allowance for the differences in people's temperament, how their loved one's died, or if they have had a series of losses that would make it difficult to stop grieving according to some schedule.

There was a discussion about the **environmental** rather than individual **basis of the emotional distress** felt by people with psychiatric diagnoses. The idea was voiced that they are often the people who are the least resistant to toxic environments, more sensitive to the paradoxes and stresses in their social systems. They were compared to the canaries that were used to test the air down in mines.

The women also talked about how different the level of **stigma** experienced is for a person with mental illness who is a professional or works for a corporation.

> And in fact the thing that is statistically more epidemic is depression. And it happens to...people in big corporations...Their experience of mental illness is different, because...their corporation in their benefits package...covers them going for therapy which is...accepted in their level of society. And there's no stigma for them, and they may be actively be encouraged by their employer...When I was employed in the public school system, (they) would say...take a day off a month for a mental health day if you need to. Go to this agency, we'll pay for you to have counseling. (1298-1332)

The women stated that the lack of status in society effects how one creates a **self-identity** when given a psychiatric diagnosis. Instead of being able to choose the treatment that they feel

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they need, poor people must change their identities, their values and beliefs in order to receive mental health treatments decided by others. Thus their socio-economic status determines their level of internalized stigma and impairs their ability to heal.

> So it depends on where you are in society. And unfortunately, once you get below the poverty line, which is where most of us are,...you get into poverty line mentality where you are...forced to...change your whole...perception of what is important, or what is of value. And sometimes it becomes intrinsic too, you know. (1333-1339)

Alternatively, some of the women were quite resistant to the notion that their diagnosis signified a disability, stating unequivocally that they were definitely **not disabled**. They believed that in fact the problem was within those who could not handle their different beliefs and behaviours.

> A: I don't see my so called diagnosis as a disability, I see it as like a power that I have. I mean I have this power to imagine things that most people don't imagine. I have this power to get this incredible energy to do and feel amazing within my own self without taking drugs, without...So, it is not a disability, you know. It, it bothers me sometimes, it disrupts my life, but mostly it bothers other people. (729-734)
> B: And do you know what?...That's when you get committed, it's when what you do bothers other people. You're fine, but you're upsetting mum, you're upsetting dad. (737, 739-741)

They continued the discussion talking of how to keep one's psychosis from bothering other people. The argument was taken a step further by insisting that people should be able to experience and go through their psychosis without interference.

> A: And part of the trick, and I was actually reading a book about this, they were saying, part of the trick is being in your psychosis...and being able to try and get kind of like a grip on it so you don't bother other people. So you may want to say so-called crazy things and do crazy (things)...But if you can gain some control, and not let it bother other people you should be able to kind of (get by and not be committed)...
> B: It's your psychosis dammit, you should be allowed to go through it!
> A: Well you know, why, why does it have to bother other people?
> Well it's just another way of coping...We behave (differently) because we're trying to adapt and cope to the stressors in our life. (742-752)

The deaf member of the group tried to talk about people with other disabilities, **cross disabilities**, and how these disabilities were defined and compared to those with a psychiatric diagnosis. Instead of following that discussion, two of the women reacted strongly to the idea of being called disabled. The group's recently chosen name, 'The Twisted Sisters', is referred to

in this narrative of resistance which points out the belief that it is not the women, it is that

**society needs to change.**

> I said, OO! No, I am not disabled. I don't consider myself disabled, because I have a great imagination. And you know, I mean I'm sorry I don't think that's disabling. I think society has a disabled view of me. That's what needs to be changed. I don't think I need to change really. I mean I'm going to grow, and do all these healings I do for myself and continue to grow, but I think that what is twisted is not us sisters. Ha, ha, ha, (raucous laughter from the group)... (1162-1184)

The women were quite excited by this viewpoint and discussed having T-shirts made up with

the quote, "What is twisted is not us sisters!" on them.

One of the women talked about the **tokenism** that occurs when consumer/survivors are

invited to participate and give input into policy development. She was able to relate what she

thought about the process of consumer involvement and the attitudes of the mental health

professionals she sat beside at the many meetings she has attended.

> The people who go on all those committees they get paid, it's part of their job. Ha, ha, and it's very hypocritical...To the point where sometimes, if it really comes to it...
> We're talking...we're over the top tonight,
> we're saying things that dare not be said elsewhere.
> But those people have their sixty thousand dollar jobs,
> and when it comes to a political policy decision,
> they will protect their salaries before they will go over the top
> and go for what we're actually discussing. (879-888)

Another narrative of resistance that the women brought out involved the **cultural** aspect of

the attitude towards mental health challenges. People with `problems' were accepted and

looked after in the community she grew up in India.

> A: You know what you're saying about is cultural...In my home town we had these...three people...One was Billy boy...he would walk around stinking and someone would grab hold of him once every little while...give him a bath, put him in clean clothes, and then he'd wander around...It was just a community responsibility...We weren't allowed to treat these people badly...to treat them with disrespect...
> B: And I think some people would say how sad that was that those people didn't get any treatment.
> A: But they were happy...no one was telling them what to do, they were accepted. So I don't know what the answer is. (793-816)

After the talk about the community care and acceptance of people with psychiatric diagnoses in India, another woman related the difference in care to the **individualism** which is at the base of North American society.

> A: It was just a community responsibility...And I think that...
>    North America is probably the only continent where this isn't done.
> B: Ya, we're so individualistic, which is great for sometimes...If you belong to any network, you believe everybody's part of your community, you embrace and you help them. But...when your in individualism, it's like, "Well you should be able to take care of yourself. Like I'm not going to take care of that person, because you know they're an adult. They shouldn't be, you know, running around saying this, whatever...I'm not going to help him."
> C: What we need to do is clean them up off the streets so they don't disturb other people. (815-851)

From a discussion of how other very marginalized people are treated, the group were agreed that **education** is needed to counter the inhumanity and the stigma that many people experience.

> A:...A while ago there was a program where the police, who have their handy dandy office at the corner of Main and Hastings there, would go out in the morning and pick up the drunks and the drug addicts that had passed out on the sidewalk, so that the motorists coming into downtown Vancouver to the corporate world wouldn't have to see them on the sidewalk...That is what we're up against.
> B: That's the society we live in.
> A : The stigma of insanity.
> C: So the cops need an education. A lot of people need an education. Oh there's lots of education needed for sure. (1392-1407)

## Suggestions For Programs

The women added onto some of the programs that were suggested in the men's group. They approved of the information line and of the hospital outreach program adding the need for information on panel reviews and how to access committal papers. They agreed with finding allies in sympathetic professionals, the need to participate in treatment decisions, and for the freedom to choose the services they used.

Specifically, they advocated for increasing access to counseling services and developing peer counseling. The development of information workshops was extended to education on symptom control, destigmatization and training for peer support, counseling and advocacy. The

women included advocacy and activism to increase the participation in treatment decisions, especially for health plans that can set out what treatment someone wants when experiencing a crisis.

**Information line.** The women did not extend the ideas that the men developed about the information line except to include information on panel reviews and the right for your doctor to read the committal papers.

**Activism and advocacy.** There was discussion of advocating for health plans as a choice for people. A health plan, an advanced directive, or what is called a ulysses agreement, is a plan set up when a person is considered stable, of what treatment they did or did not want if they are hospitalized. A person is chosen to act as a proxy to ensure that the plan is followed and to make any necessary additional decisions.

The women also thought there should be advocacy for more participation and choice in treatments. One suggestion to allow for more choice of the treatments used is to have a general practitioner handle the prescription of medications.

> If you can move from getting a psychiatrist to prescribe, to getting a doctor to prescribe, then you have more control over what is happening. (328-330)

**Hospital outreach.** It was suggested that hospital outreach would be invaluable to inform people of their rights to a panel review and to encourage its use.

> And every psychiatric survivor in the province should be informed
> that they have a right to a panel review. And the minute you say you want a panel review,
> you are treated better than if you are just in a daze. (106-109)

> ...It took me 19 times of going through that (hospitalizations) to say it when I woke...Because I've had a panel review before, I knew that that was what I wanted...It was (from) hard earned experience and...the reason I'm bringing it up at this meeting is that I would like to spare others. (132-137)

Legally a notice about panel reviews is supposed to be visible on hospital wards, but realistically the patients either don't see them or can't read them, don't feel able to put them into

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practice because they are so drugged or afraid, and even when they do ask for it they can have problems.

> Oh yes they have it on the wall which they are supposed to have, which is an edict of the mental health law. But they're so dodgy about actually giving you what you're asking for, you know, getting your signature and getting you a para-legal, all of the things you are entitled to. (118-122)

The women spoke about advocating to have the rights to a panel review told to people as they were being committed, just as police inform people of their rights to an attorney when they are arrested.

Another use of the hospital outreach would be to inform people of their legal entitlement to have their doctor read what is on the committal certificates in order to clarify the reasons why they were committed.

**Counselling and alternative treatments.** The women affirmed the need for more access to and funding for counselling services. Several of the participants talked about the benefits they received from counseling outside of the psychiatric system. They extended the men's idea of advocating for funding for counselling when they suggested to get funding to train consumer/survivors and provide services as advocates, peer support workers and counselors.

The women also spoke of advocating to have complementary treatments, more holistic therapies available and funded by the psychiatric system.

**Educational workshops.** That educational workshops could include information on symptom control was brought out by one of the women. She talked about workshops where people could learn to control psychosis so that it would no longer bother others. Practical ideas from people who have learned to control their reactions to their active inner lives would help others to cope. Just the knowledge that people can be in control of their experience is liberating; that they can continue active lives while still having unusual perceptions and not be so medicated that they are incapacitated. Educational programs on a variety of issues, such as destigmatization, could bring important information to those that need it.

**Supported employment.** There was discussion about the development of self-run businesses for the employment of members. It was pointed out that there were abuses that occurred in work situations for the mentally challenged; hardly any remuneration for boring repetitive work with long hours. There were implications about the difficulty to have both accommodations and good wages without some form of funding to supplement incomes until the businesses were well-established. When businesses are run by consumer/survivors then the ability to factor in accommodations as needed would not be seen as paternalistic.

> Well, in Toronto there are quite a few businesses, programs that have been started up...(and) they've had some government funding but there could be funding from both areas...They have one business which is a courier service between the various branches of...the mental health system and that's run by consumers...(929-935)

**Connections/Alliances.** Another suggestion was to find allies in professionals who are supportive of peoples' right to choose, the right to the best medications, or to try to reduce, or get off them. The women suggested that the Self-Help Group could seek funding from foundations such as the Bronfman foundation to support the development of programs. The group thought there were ethical issues about where funding came from. For example, funding from pharmaceuticals was unacceptable.

One woman thought it would be good to ally with corporations who in their organizations deal with mental health issues arising from stress, depression etc. in order to help change the attitude, the stigma surrounding mental illness. She also suggested connecting with other advocacy groups such as the CMHA (Canadian Mental Health Association) in order to lobby for rights and reduce stigma, as well as to connect to politicians and corporations.

> One of the big statistics, one of the biggest forms of mental illness in the corporate world is stress linked...people under stress cause 50% of the industrial accidents in the work world. And if we want to change the attitude about mental health we have to get the people in the corporate world...talking. (1381-1386)

> And the Canadian Mental Health Association was, in fact was started by a consumer named Clifford something...but they are nationally recognized and respected by a lot of people so if you want to know how to get to the politicians or get to the corporate world, that's a stepping stone. (1421-1425)

**Peer support: crisis support, safe spaces and recovery orientation.** The women added

to the list of programs ones that would have peers provide support services. It was suggested

initially that a phone list be set up for members who wish to use peer support when they are

going into a crisis. When someone is afraid that they are becoming unable to cope they could

call their support members. These would be members that they know and who have been

through training at the SHG.

> A: That whenever you need support that there are two or three people that you have like a
> phone list that you can call on.
> B: Is that like peer support?
> A: Ya, and not, it's people who are peers, meaning somebody who is in the same...
> B: Who's been there. (1072-1079)

The Self-Help Group has been developing ideas for a safe house. A safe space for people to

be able to experience their pain, to work through the difficult emotions which other people are

not able to handle, and to go through their psychosis if that is what they wish to try to do. As

one of the women said, "It's your psychosis dammit, you should be allowed to go through it!"

(750). This house would be staffed by trained peer counsellors and support workers. They

could bring in people with the appropriate training to provide treatments such as bodywork,

relaxation and meditation, music and art therapy etc.

This service would provide peer support and counseling with meetings that both raise

awareness of the narratives of resistance and allow people to speak and share without fear of

judgment and condemnation. Role models of those who have significantly recovered would

inspire others and provide much needed information on what is useful for recovery.

In the meeting where I brought my findings back to the women's group one of the women

wanted to add to what was said. She was wondering when it is appropriate to intervene in a

person's life when they were apparently on a self-destructive path. She had recently witnessed

a friend become very ill as a result of his addiction to nicotine. Her question was would it be

appropriate to work harder to help the smokers who use the psychiatric system to quit? She

talked specifically of how the staff at Riverview used cigarettes as way to modify behaviour, and was this not wrong.

Her other concern was that mothers in the system were losing their home support. There are cutbacks to homemaking services and that this may lead to more relapses and actually cost the government more in the long run. She also talked of how she believed this was a very positive time for consumer/survivors; that there was a pulling together of people which is bringing out a stronger, more united voice which will hopefully lead to changes.

When we went over the narratives of resistance, the women at the meeting responded to the statement, "...We're saying things that dare not be said elsewhere." (885) They said that if they brought out any of these narratives with their mental health professionals they would be, "slapped down." They were afraid of speaking their minds. It was clear that there was no room to freely discuss alternative views in the system.

**Chapter 14**

**Discussion Of Findings From The Focus Group Interviews**

In the focus group interviews, the men and women both agreed with the issues that arose from the one-to-one interviews. In their focus group interviews they extended these issues with their own viewpoints and added a few more.

The findings from the focus groups show that there are many similar concerns. I have interpreted these concerns in the light of the issues of power and oppression. I have developed some ideas and drawn from the literature some of the reasons for this control of people with mental health challenges and how the oppression of this system and the designation of a psychiatric diagnosis affects identity.

**Oppression: Insecure, Silenced, Powerless, and Uninformed**

Many of the points made in the groups addressed peoples' feelings of powerlessness while dealing with the psychiatric and financial aid systems. Even when they found sympathetic professionals to work with, they saw it as the result of luck and that they could just have easily encountered those who would patronize, demoralize and demean. They did not see it as their right to be provided with the best treatment or to choose the professionals they are treated by. The insecurity of their position results in the development of fear and anxiety around mental health treatments.

They spoke of being duped by professionals, that important knowledge about medications was held back, that they were not privy to information that affected them. At times they felt totally silenced, that what they had to say was discounted and invalidated because of their diagnosis. They always felt the power imbalance in the system which one man described as a caste system with them at the bottom, at the level of the untouchables in India. They also spoke about the internalized stigma, the shameful feelings that developed from being treated as a diagnosis, losing their rights, losing their identity as a person worthy to be part of society, and

being told that the best they could do was to become stable, to be managed, but never to recover.

What they described is very like how many other oppressed people speak of their experiences. The `power over', the silencing and control of information, the resistance, the fear, internalized stigma and self-deprecating views, are all aspects of oppression (Dufort & Lord, 1996). That one of the men spent two years believing that his disinterest in life, lack of energy and new symptoms of paranoia were as a result of his illness not the side-effects of medication, illustrates how damaging this oppression can be. If he had any feelings of self-efficacy to begin with, they would have been erased and internalized stigma well established by this process.

Another example from the men's group of a technique that oppresses is the humiliation of standing in line for a cheque at a welfare office. The financial aid services with their invasion of privacy and the undertone of suspicion of fraud also effectively keep them in their place. "...You feel like they can reach inside your gut or your soul." (8)

Dorothy Smith (1990), who also experienced psychiatric oppression, sees it arising from the patriarchal nature of the our social system where men's interests and views are dominant.

The standpoint of men is built into the traditions of its theorizing and knowledge; that effect is reinforced by the continued predominance of men, particularly in dominant psychiatric profession. Beyond this psychiatry reinforces the patriarchal character of locally produced order, such as families, as a routine effect of its operation. (p.132)

She continues by saying that it is not necessary to deny the validity of scientific aspects of psychiatry to recognize that control and regulation of is a part of the psychiatric agenda. Women's accounts which she uses as examples reflect the loss of credibility and control of their lives which members of the groups also reported. Family systems sacrifice members to the psychiatric system when they fail or no longer fulfill their roles, or endanger the power structure.

**Psychiatric treatments stop the anger to act.** In the groups they spoke of the damage resulting from over or incorrect medication with psychiatry's emphasis on stability at the cost of quality of life. They went further when they proposed that the effect of over or incorrect medication is to stop the natural healing processes; not allowing people to tell their narratives, to speak about and experience their pain also prevents them moving into action to make changes and begin healing themselves. Dorothy Smith (1990) analyzes how the treatments take away people's power to affect change:

> The psychiatric work of defining emotions, moods, feelings, as what has to be treated (by psychotherapy, tranquilizers, shock and so on) isolates them from prospective action, indeed seeks to `take out' (by medication and other means) people's energies, particularly rage, that press against  human obstacles for change. (p.137)

In the groups, the co-researchers discussed the ghettoization of people in drop-in centres, housing developments and other services, and the anger, dependency, and hopelessness of being at a dead-end that they fostered. The isolation created by these psychiatric services allows the energies of the users to be contained and defused. Without outlets in these oppressive situations their anger becomes internalized and there is no room and energy for self-directed change adding to people's states of depression, hopelessness, and self-destruction.

The men's concerns reflected their own fears of becoming like those in the drop-in centers, as well as their own experiences with the internalization of anger. In their discussion on homelessness and the benefits of living outside in Stanley Park or being over-medicated in Riverview, it could be seen that these men have considered what homelessness must be like, considered it as a choice to horrific treatments, and perhaps have been close to experiencing it. Without some hope for recovery, the freedom to express anger constuctively, then to move into action to work to heal themselves and become productive members of society, then all that is

left is to be contained in holding tanks. People's anguish can be medicated away and they can exist in ghettoes where it is not as visibly obvious that there is no hope, no possibility.

The men were able to discriminate and distinguish themselves from these ghettoized men without hope. They have been fortunate to have sufficient support and encouragement from family, friends and workers, and to have hope instilled from their interactions with their peers and the recovery orientation of the Self Help Group.

The groups again raised the issue that the pain they feel is not allowed to be expressed when they are over or incorrectly medicated. They said that it is only by experiencing and going through their pain that there is any possibility of healing.

I wonder about society's sanction of coercive and aggressive treatments by the parental figures of psychiatric professionals, and ask what is it that they are afraid will happen if the pain these people have is allowed to be experienced? I wonder if the over or incorrect drugging is sometimes to escape having to make changes because there is obviously something wrong, to allow people to become scapegoats for the overwhelming anxiety that pervades modern times, and free others to be components of the economic machine, not humans that need and feel and therefore cost money.

The pain felt by a hand when placed on a hot element is warning that damage will occur if left there. The purpose of pain is to warn of potential damage to the body. Viewing our society as an interdependent living system, the pain that brings people to mental health services can be seen as a warning that something is wrong in this system. The numbers of people taking Prozac in the U.S. is enormous. Forty of the states have community treatment orders, forcing people to be drugged in their homes or on the streets.

It could be proposed that a psychiatric theory which has the hypothesis that pain, disturbing behaviour, and unusual states of mind result from defective brains for which the discovery of a wonder drug is just around the corner, is an ideology which fits all too well with a corporate and

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sometimes government agenda that wants to continue operating as it has, increasing profits and reducing costs. As Marilyn Waring, a feminist economist points out, the human damage is considered just another area to profit from (Nash & Martin, 1996) and professionals and pharmaceutical companies step in to fill that role.

**We can't afford for you to recover.** The members of the groups saw the emphasis on cost reduction as a factor in funding only medication related treatments. For those of lower class and income level, cost, not the possibility of recovery, determines the types of treatment received. The economic realities of psychiatric treatment is that medication is a cheap form of therapy. Psychiatrists can spend only ten minutes with each patient to check if their medications are working, make adjustments for side-effects without having to join them in their pain. Counselling and psychotherapy are time consuming and expensive. Body work, herbal and other alternative therapies add to costs.

Present psychiatric treatment denies rights and personal dignity, reduces people to less than adult, allows minimal participation, silences voices and punishes expressiveness. It also denies the possibility of healing and recovery when it does not fit into the current ideology based on the biological hypotheses of neuroscience (still unproven) and the profit margins of pharmaceutical corporations.

Coming out of their experience of `participating' on boards and committees, the women's group voiced their suspicions that mental health professionals protect their salaries, their positions and their power when they fail to create policy which reflects the suggestions of the users of the psychiatric system. This lack of trust in professionals, in combination with economic cut-backs, leaves those affected by psychiatric services to make changes themselves. How else but to begin to set up alternative services that will supply the treatments wanted.

The men and women talked about their dependency on disability benefits and how this was a barrier to getting back to work. This dependency is reinforced by the notion that with a disabled identity stability is the goal; they must avoid the stress and anguish of risking either failure or success. This disabled identity, the stigma that supports it which emphasizes what people cannot do, the fear of relapse and the medications which render people without energy and enthusiasm, all add to the barriers to a successful return to work.

Both groups spoke of the lack of accommodations or flexibility in arrangements that could allow people to work who do have a lower level of energy, or who initially get too overwhelmed by the pressures of a regular job. They saw that people were treated as being either disabled or able, no transitional state was supported. The therapeutic benefits of work could definitely back funding for supported employment if they reduce costs by lowering hospitalizations. The supported businesses for consumer/survivors in Toronto gathered statistics that showed a significant reduction in hospitalizations for the people involved (Gadd, 1997).

**We won't need to change society if you're defective.** Alternative views about the cause of `mental illness' were discussed by the groups. In one discussion, causes were seen not to be either biological or environmental but a combination of both. Environmental factors are down-played as causes in present day psychiatry, these being seen as only triggers to a brain defect already present. Consequently, there has been less and less credibility for `talking' therapy and a lack of focus on the need for changes in the environment of the people in distress. This situation leads to an avoidance of dealing with the social and economic factors that can be determinants of emotional distress, especially in the case of people who have suffered, or are suffering from the traumas of abuse (Morrow & Chappell, 1999).

There are also the social and economic factors that contribute to the problems in living for people who have chronic mental health challenges. As is well documented, adequate and safe housing with sufficient income reduces the numbers of crises and allows people to cope with

lower dosages of medications (1999). Successful work experiences has been shown to reduce the amount of hospitilizations (Gadd, 1997).

Some members of the groups in their narratives of resistance opposed the idea that their brains were defective. They emphasized the importance of their behaviour being in response to the stress they encounter, and that their symptoms are coping mechanisms.

> Well it's just another way of coping. You know, we can only look at these things as another way. We behave because we're trying to adapt and cope to the stressors in our life. (742-752)

Many of the members feel that the issues of safety are not sufficiently addressed in the mental health system. Because of its dual role of social control agent and treatment provider, whether from the professionals' best intentions or not, the people it serves, or more accurately manages, often do not feel safe. They do not trust mental health professionals and are unable to feel the freedom to honestly express themselves. When the women were giving their feedback about the narratives of resistance they emphasized that they could never speak of these views with the providers of mental health services. If they did, they said they would risk the professionals' anger and disapproval and would be "slapped down". One woman recently told me that it is common to hear her peers advise that people should never tell a psychiatrist what is really happening. These hints of the nature of the relationship between users and providers of mental health services reinforce the complaints of the paternalism of the system which forces people to act as children or adolescents.

**We only listen to 'sane' people.** The members of the focus groups reported their frustrations of not being listened to. Dorothy Smith (1990) views this silencing as part of the function of regulation and control. She wrote that psychiatry suppresses women's stories because if they were heard and made the basis for change they would ,"...disrupt the locally established order of home and family" (p.134). Men's stories must also be seen as threatening since silencing is also used as a tool to dismiss their accounts.

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Psychiatry is a recourse for people in positions of power in a threatened local order who seek to sustain their working version of the world. In providing `objective' grounds for repudiating alternative versions, it authorizes the local order. (Smith, 1990, p.134)

This can explain why mental health professionals, with all the power that they possess, appear so threatened by the consumer/survivor movement. The movement's alternative views, if given validity, would force a whole reworking of psychiatric care with a consequent loss of power and ability to control, which may endanger the positions of mental health professionals.

**The magic of medication, profit and stability too.** The members of the groups felt responsible to take medications when they knew they needed them, but felt they should also able to reduce or eliminate them when it was appropriate. The majority were not ready to throw out the biological components of mental health challenges and did see a use for medications in their lives. However, they did object to medications being the only focus of treatment, the lack of participation in decisions of types of treatments, dosages of medications, and the lifetime sentence to their use.

**Misdiagnoses and mistreatment for the traumatized.** As one of the men said there are many people in the psychiatric system who have experienced physical or sexual abuse as adults or in childhood. There are people who have had enormous losses that precipitated their entry to the system, and people who have found they are unable to cope under the great pressures they have faced. When counselling is available only to those who have money, it could naturally be questioned if this is a class issue and those in the right economic or social bracket are the only ones deemed fit to recover.

Many have experienced traumas which they see as the roots of their present difficulties. Psychiatry's use of only biological treatments compounds the damage when it avoids looking at and working through these traumas, and in some cases actually retraumatizes with the use of coercive treatments. One problem is that people who have experienced trauma do not always

see that their past or present experiences could be a factor in their present emotional state and unusual behaviours. Denial and forgetting are strong coping mechanisms, and the repression of their feelings can result in experiences which appear to come out of nowhere.

When it is not recognized that a person with a psychiatric diagnosis is suffering from trauma they do not receive appropriate treatment. They can end up being called non-compliant (even when it is untrue) and untreatable, and are regularily forcibly hospitalized. They develop a distrust of professionals and the whole system, and feel unsafe in psychiatric care.

If people are allowed to heal from their abusive treatment, will that not open up even more the can of worms that is family and societal violence? Many studies document the large numbers of women (one study found 83%) who were abused physically and or sexually in childhood or as adults and who end up in the psychiatric system ( Morrow & Chappell, 1999). As people heal they may want to demand that those who were their abusers be brought to account for their actions. The access to only biological treatments points to the management by drugging to control the potential disruption of the local social order.

**We'll exclude those who aren't nice and don't fit.** There is also a movement to eliminate from receiving psychiatric services, some diagnoses, mostly given to women, which are believed to be as a result of traumas. This would curtail even the inadequate services that are already in place (Morrow & Chappell, 1999). Some of the people with these diagnoses do not respond well to medication therapy and deteriorate when hospitalized. They are the most stigmatized of diagnoses and the most difficult for mental health profesionals to `manage'. Because biological treatment is not effective, psychiatry is willing to throw these people out of the system, declare them not to be in the category of serious mental illness, and exclude them, rather than provide appropriate treatments which would undermine the assumption of biological determinism of mental health challenges.

When people, as they often do, self-medicate with alcohol and street drugs to reduce their pain, they can also be excluded from psychiatric services until they have recovered from their substance abuse. There is only one shelter, a half-way house in Vancouver for women who experience abuse and who have a psychiatric diagnosis. The jails, over-whelmed recovery centers and the plethora of services in Vancouver's downtown eastside attempt to deal with a constantly out-of-control situation with people who have `fallen through the cracks'.

Bradley (1991) did research of people who have a combination of problems such as homelessness, criminal activity, substance abuse and mental illness (the multi-problem client), a large proportion of whom are young adults (18-35 yrs.). He found that after deinstitutionalization many people with chronic mental health challenges dropped out of mental health care and entered the corrections system. This `transinstitutionalization' as it was called, occured because the criminal justice system is a system of default; its clients can not be passed on. In this case jail can be seen to have been a poor person's mental health facility. Up to a quarter of the people in prison at the time of this study were considered to have mental health challenges.

In his evaluation of the inter-ministerial project, Bradley found that, "...intensive case management was associated with a move towards more mental health use by multi-problem clients and less corrections use" (p.65). Just as the Assertive Care Team was appreciated by a member of the women's group because they assisted her in her daily life and by whom she said, "...you're treated like a person, a human being..." (250), the inter-ministerial project also helped multi-problem clients by moving towards them, assisting them to get what they needed rather than locking them away.

The two-tiered system is extended to a third tier when the very poorest, and the most resistant people with mental health challenges (often young adults) as well as other problems, end up in the judicial system instead of being cared for by psychiatric services. If psychiatry's

function is to maintain social order it is understandable that those who are non-compliant, or treatment resistant will be allowed to fall out of the protection of their control, move to the systems that are overtly punitive, the institutions of correction, and/or to a life of self-destruction on the streets.

**Different Culture, Different Treatment.** In the women's focus group there was a discussion of the cultural attitudes to someone with mental health challenges. Because one of the women came from India, where there is an acceptance and community care for those facing these challenges, she was able to bring out the differences in attitude and stigma.

In older cultures, health and mental health "...is applied to communities or families rather than just individuals..." and involves "...harmonious relationships all round in body, mind, and spirit" (Fernando, 1995, p.31). The women blamed the individualism of Western society for people with mental health challenges not being adequately cared for by their communities. This lack of community solidarity was seen to permit abuses to occur while in their communities people are neglected and hidden away, are managed only by enforced medication, or cannot find any appropriate treatment because they are excluded from services, fall through the cracks and/or enter the correctional system.

A new transcultural psychiatry proposed by Fernando (1995) uses culturally determined explanatory models and views mental health as being linked to distress and coping in relation to family, political and social systems. This gives individuals a socio-political-cultural context rather than one only based on psychopathology. Fernando (1995) states that with this perspective,

> instead of disorders of thought, belief, relationships, behaviour, etc. being analysed as
> personal illness, we would be identifying problems in thinking, problems in relating, etc., and
> analyse these in terms of their meanings in a multi-systemic framework (p.203).

This 'relativistic multi-systemic approach' is suggested as way for psychiatrists to drop an "...illness model while leaving a sound base for psychiatric practice" (p. 203).

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**Cross disabilities: Angry with no place to go.** Interestingly, in the light of the women's concerns about the differences in cultural attitudes, questions about cross disabilities were completely ignored, and not returned to after the women's outrage on being called disabled had been expressed. The issues of those with more than one disability are often not talked about. With the instances of abuse being much higher for those with some form of disability it is not surprising that mental health challenges may result in addition to those that arise from the difficulties of being disabled ( Morrow & Chappell, 1999 ).

When people fit into more than one category of discrimination, the greater the effect of oppression, the more invisible they are and the less their issues are discussed. As women are already oppressed for their gender, adding a mental health challenge increases their oppression. If another category such as colour or physical disability is included the less their voices are listened to and the more their issues are ignored. For example, in a video (Across Boundaries, 1998) by a group concerned with ethnocultural mental health, one woman with mental health challenges described how she experienced being treated as if she was more dangerous just because her skin was dark. In a study of English hospitals it was shown that black patients were put under restraint and administered medication as a sedative significantly more often than white patients (Browne, 1995). The death of a black man who was given a lethal dose of an anti-psychotic and tranquillizer while being held down by police brings to the public view the effect of this racial stereotype of `mad' and `dangerous' and the role of racism in the committal process.

Feminists, in the course for their fight for liberation, expanded their view from issues just of gender to those that included class, race, sexual orientation, and etc. Activists in the consumer/survivor movement are also becoming more sensitive to issues arising from the diversity of people with psychiatric diagnoses.

There was a discussion in the women's group about the relative lack of stigma and the better services that developmentally and physically disabled people received. Their discussion showed that although people with mental health challenges can look 'normal', they may be envious of the more obviously disabled because of the compassionate treatment they receive.

Perhaps because people with mental health challenges are not easily identifiable their presence provokes more fear than obviously disabled people. The biological treatments of electro-shock and medications, especially neuroleptics, often cause impairments, side-effects which are visible (Breggin & Cohen, 1999; Faber, 1993). There are an "...enormous variety of potentially severe and disabling neurological impairmants at extraordinarily high rates of occurrence..." (1999, p.78) produced from neuroleptics. These include abnormal movements of the voluntary muscles of the body from tardive dyskinesia; painful spasms which can be disabling and disfiguring from tardive dystonia; from tardive akathisia an "...individual is virtually tortured from inside his or her own body as feelings of irritability and anxiety compel the person into constant motion..."(p.78) and which, "...in the extreme case, can lead people to suicide or to homicide" (Putten & Marder in Breggin & Cohen, 1999, p.78); finally death may be the result of neuroleptic malignant syndrome and if they do not die patients are left with, "...irreversible mental impairments as well as permanent abnormal movements" (p.79).

As Breggin and Cohen (1999) state,

> The neuroleptics or antipsychotics are extraordinarily dangerous drugs. If they were not highly profitable drugs used to control a rather helpless, stigmatized, or troubling population...these drugs would not be so freely prescribed. They might even be taken off the market. (p.82)

Sociologists, like Pilgrim and Rogers (1993), are interested in why psychiatrists take the serious side-effects of psychiatric medical treatments so lightly. Two theories, professional dominance and labelling are suggested to account for this. Labelling theorists state that a

psychiatric diagnosis automatically labels people as unimportant and unreasonable, so that their complaints of side effects are dismissed. Doctors only pay heed to their measurements of symptom reduction (1993).

In professional dominance theory, psychiatry's need for physical treatments to legitimize and raise their status in the medical model means that any problems with side-effects will be ignored or explained away. Psychiatrists also use the rationale that symptom control, and so protection of society, outweighs negative effects of psychiatric treatments. Psychiatrists attribute the lack of compliance to take medications as a sign of pathology and lack of insight (1993).

The side-effects which also serve to identify people as having mental health challenges may be unconsciously tolerated for this function even though some medications can lead to permanent damage with prolonged use and can actually be of limited use in actually controlling symptoms. This argument brings to mind a scene that I witnessed in a community mental health team staff room. A professional who worked at the team saw one of their clients interacting with members of his community. She said he was socializing easily and appeared to be well accepted by those he was with. She, and others, were outraged by the fact that he could appear so normal when the fact was when he was alone he was self-destructive; he cut himself in response to experiencing emotional dificulty. At the time I was puzzled why people were so upset. Why were they not pleased that he could easily socialize? Now it is clearer that he violated their sense of social order by appearing to `pass' as normal. Their job is to ensure that these deviants were identified, `treated', and thus controlled; how dare he cross the invisible line they worked hard to create.

**Stigma: from abjectivication to oppression.** The women in discussing the difference in stigma experienced by people with developmental or physical disabilities, saw the difference as arising from the attitude that somehow places the blame on the individual with mental health challenges. Others, as in the men's group, look at this level of stigma as arising from fear. This

stigma can be from a projection of the `crazy' side that people deny, the fear of the `dark side' that is part of every person, the shadows held down in the subconscious, that could be let loose by association with these people, that they are those demons lurking under the beds of their childhood. This fear leads people to avoid them (lock them away) and make sure they are controlled (medicated), even when it becomes an abuse of basic human rights.

Julia Kristeva, a french feminist, developed the idea of `abjection', where a person, or thing becomes an `abject', being neither subject nor object.

Abjection is an extremely strong feeling which is at once somatic and symbolic, and which is above all a revolt of the person against an external menace from which one wants to keep oneself at a distance, but of which one has the impression that it is not only an external menace but that it may menace us from inside. So it is a desire for separation, for becoming autonomous and also the feeling of an impossibility of doing so. (Oliver, 1993, p.55)

She describes the `abject' as something repulsive but fascinating which both attracts and repels. There is, and has been, a fascination with the variations of what are now called psychiatric disorders; the glimpses of heaven and hell that are reported by `mad' people. Kristeva says that, "...it is not the lack of cleanliness or health that causes abjection but what disturbs identity, system, order" (Kristeva, 1982). With this delineation, just as Smith (1990) asserts that psychiatric oppression arises from the need to protect the social order, the stigma and discrimination which fuels this oppression can be seen to be the result of this process of abjection.

Another puzzling facet of the mental health system is the insistence by professionals that the people they treat are in need of their protection and should be under their beneficient guidance at all times. This belief is held onto even when it has been shown that often their treatments can be damaging, and that empowerment, taking responsibility for themselves and being in control of their lives enables people to recover to the greatest extent possible.

This wanting to treat their patients as children or adolescents may be caused by the process of abjection. In wanting to protect themselves from the possibility of being overwhelmed by their subconscious, and becoming `abjected', perhaps professionals project this vulnerability onto their patients and wish to protect them even when it is harmful for them. Or alternatively, knowing the power of the fear that abjection creates in the general public towards those with a psychiatric diagnosis (as they have experienced themselves) mental health professionals in wishing to see themselves as good people, not the guardians of the gates of sanity, treat their patients as children in need of care rather than as deviants in need of control.

This abjection of people with mental health challenges also becomes internalized when they experience themselves as defective, shameful, and freakish, while also becoming trapped or spell-bound by the fascination with their own inner processes and unusual behaviours. This may explain why some would rather stay in psychosis even with frightening experiences and remain in their own special and fascinating creation rather than join the ordinary world and become someone who is not only not special but is seen to be damaged and inferior.

This abjection was seen by one man who noted in his one-to-one interview that often people who use the psychiatric system act as if they were adolescents, whether they are in their twenties or sixties. They are told that sexual activity is inappropriate, marriage and children out of the picture, and that they can not take full responsibility for themselves. It is reinforced that they need to be controlled and managed, and that they need the guidance of authorities to decide where and when they can go and what they can do. It is understandable that when they are treated as adolescents they become like and react as adolescents would.

The system that says these people should not take risks, should not feel their own pain, should be protected, given only small jobs, kept on an allowance, can be compared to over-protective, controlling parents. When these `adolescents' resist, try to risk and develop independence, they can be punished by either withdrawal of supports (falling through the

cracks) or by enforced hospitilizations. Is it possible to distinguish between healthy resistance and being lost in delusions, between those with mental health and those without? Perhaps not, as is shown by Rosenhan's study (as reported in Smith, 1990) where, "...the subjects...having established that their sanity was unblemished, spent time in mental hospitals in California without being detected by the staff as imposters (yet patients noticed)" (p.133)

The relationships becomes like that of a `dysfunctional' family when the professionals and family members lobby for legislation to force these wayward children to take their medicine in the community, "Take your pills and be good boys and girls." I imagine there could be far more compliance to appropriate levels of medications if the users of the system were treated like adults and given full participation in treatment decisions.

The men raised their concerns about sexuality, a subject not often brought up for those diagnosed with mental illness. " Sexuality has long been a taboo in the mental health field." (Lacombe, 1999, p.11). The biological determinism of the science of psychiatry relegates the adult expression of sexuality as problematic. Marriage and raising a family not only become `unrealistic' but morally reprehensible. Fortunately there are people who want to address these discriminatory views. A recent issue of the magazine put out by the Canadian Mental Health Association was dedicated to addressing the problems of sexuality for consumer/survivors, bringing the stigma and discrimination to light.

> The mere thought of friendships, intimacies, and sexuality creates discomfort and unease among most families, caregivers, and virtually all health professionals. However, these issues are real and central to a person's well-being, because they relate to the essence of life and aliveness. (Whetstone, 1999, p.4)

## Identity: From Psychiatrized to Recovered

In a two-tiered system of mental health, the services that can be bought by those who are economically able are under their control and by their own choice; corporations and professional

organizations provide the type of treatments that their employees want and need. The only recourse for those of the lowest incomes is to lose their power to choose and submerge their identity into one that fits the psychiatric system,

> ...You are...forced to...change your whole...perception of what is important, or what is of value." (1335)

This change of identity is similar to the one that a person undergoes when entering the hospital system becoming a patient and taking on an identity based on being `ill' and `under' care.

**How to create a psychiatrized identity.** Smith (1990) discusses whether psychiatry constructs the identity of a mental patient. She discusses other views such as those of Thomas Szasz and Thomas Scheff. Szasz sees that people in despair and misery seek help in psychiatric agencies which then construct their state and behaviour as the condition of being mentally ill. Scheff states that when people's behaviour deviates from other people's view of the standard ways of doing things, and after other agencies of control are ruled out (for example the judicial system), what is left is what he calls residual deviations. "Most people deviate in these ways. Sometimes these deviations lead to psychiatric treatment. When this happens, that individual begins to play the role of being mentally ill " (Smith, 1990, p.119) People take on this role and learn the appropriate behaviour in a psychiatric environment. As an elementary teacher for eight years I came to see the truth in the statement that children live up to the image that you hold them in. When people are in difficult emotional states I believe they can be very vulnerable to becoming what others expect them to be. A person who needs the attention of another they will do almost anything to please the other person even to losing all the intregrity of their previous identity.

One salient point that Smith addresses is that the behaviour which is called a symptom of mental illness occurs in the interaction between people. " There are always two parties to a symptom" (p.119). Just because one of them is a professional with a supposed detachment in their position as observer does not change the fact that symptoms are found in the interaction.

The interaction is also affected by the professional's judgements about the social role, character and appearance of his client, beliefs about mental illness, and the pigeon holes of characteristics of disorders from the DSM. Through this somewhat biased interaction, the behaviour of the other can be found to signify an invisible disease for which there are no physical signs (still not found in research), a mental illness.

Smith's (1990) three instructions of how to respond to a person with mental illness shows the creation of a psychiatrized identity: (1), "Find out how to see this person's behaviour as not making sense" (p.120); separate their behaviour from any context; (2), "Don't relate to this person as if you could look at the world from the same place" (p.121); avoid any form of `we' relationship; and (3), " Don't take what she says seriously. Don't make it anything you have to act upon or respond to" (p.121). For example, if the person is angry, do not get angry back or question if there is any real basis for their anger in your, or other's behaviour or from any other external stimulus. "Together these instructions suspend a person's capacity to function as a subject in creating the intersubjective order of everyday/everynight world" (p.121).

**I'm not disabled, you're the one with the problem.** There were many statements made in the two focus groups that showed the co-researchers' resistance to a psychiatrized identity; that of a person disabled by their mental health challenges. In one narrative of resistance it was affirmed that it was society that was disabled in its view of people with psychiatric diagnoses, "What is twisted is not us sisters." (1182)

The women affirmed that they are capable a lot of the time and by continuing to work on their issues will recover to a great extent. One of the women rejected the narrowing of the lens of psychiatry to only the pathological view of her experience by saying that what are sometimes called symptoms of her `illness', she often experienced as her positive qualities.

Many people are caught in a double bind in the psychiatric system. The very resistance that can free a person from a disabled identity to recover a healthy one, one which uses a more

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holistic view to incorporate their positive aspects, their strengths and abilities, can be seen as a symptom of their illness by pathologically focused psychiatric professionals. It is in peer support groups that people are able to say whatever they need to, to develop narratives of resistance and share stories that aid in the creation of a new healthy identity. Here their strengths and abilities can be acknowledged in the mutual aid process and skills developed by assisting in projects.

**On or off disability benefits, choice is the key for recovery.** In both the men's and the women's group, economic independence was seen to be important for recovery. Then they do not need to register themselves as disabled in order to receive financial assistance, a process in which many people have to overemphasize their problems and diminish their strengths.

In the women's group there was a debate on how to best to recover. The discussion reflected different levels of experience and values. Many of the members thought that to recover one must become financially independent, find meaningful work and integrate back into society away from the designation of having a psychiatric diagnosis. Acceptance of the assistance to be found in the psychiatric system and from financial services was another view of how to recover mental health.

This debate reflects the larger one between those that call themselves survivors and those called consumers. In one article, Everett (1994) describes their differences.

People who call themselves survivors feel that consumers are dupes for believing that the mental health system has any value at all while survivors are tough feedom fighters. On the other hand, consumers believe that there is no shame in working to change from within the mental health system and that in fact, the survivor brand of loud, rude criticism only delays reform (p.63)

The group members would be generally classified as consumers. I have designated them consumer/survivors, as some do consider themselves 'psychiatric survivors', and to note that

although many of them receive psychiatric services they are critical of them and recognize that they have survived very difficult circumstances, some caused by their treatment.

There is a diversity of people and their issues which have to be be taken into account and no easy answers that apply to all those who use or have used the psychiatric system. What became evident in the discussions was that at a certain point a person has to take control of their own life and decide for themselves what it is that they need in order to recover.

## Discussion of the Program Development

The programs that the people in the focus groups developed naturally arose from their experience of the psychiatric system. Reflecting the dislocation and devastation they felt at their first hospitalizations, they suggested the programs of information line and hospital outreach.

Creating places where people can be heard counters their experience of being silenced. Ensuring correct and full information is available rectifies the use of withholding information to maintain control. Even though the men do not identify themselves as radicals and would never wish to be considered such, their ideas are in line with what is needed to liberate people from oppression. On the other hand, some of the women would identify themselves as radicals, even if their radical views are only expressed to their peers.

Advocacy for alternative treatments and counselling to be funded by the psychiatric system, as well as funding to develop peer-run services, affirms the rights of the users of services to determine which services they receive. From their own experience with healing the members said that their pain needs to be acknowledged and expressed before they are able to begin to recover. This is valuable information for those who are funding and developing treatments.

Instead of wishing to isolate themselves and ally only with their peers, both the men and the women spoke of their desire to make connections with professionals who were sympathetic to their views about recovery.

The men suggested peer-run housing which could be non-threatening for people who have had bad experiences with the system, but were concerned about housing `untreated' people. The men, who mostly took medications, showed here their fears of people being out of control if unmedicated. In contrast, the women wanted mixed housing that provided integration with `normal' people in order to aid their recovery process.

I think the program closest to serving both the men's and women's needs is the one to develop supported employment. Help in developing their own businesses, or accessing programs that provide modified working conditions, would give the support they need to get off the disability benefits, and take their place as full citizens of society.

What members of the groups ask for is safe and protected environments, safe spaces for people to share their stories, experience and work through their pain on their way to recovery. Self-help groups and sympathetic allies can be instrumental in developing these environments and ensuring their members have the services that they need.

For the members of the focus groups, the issue of identity is an important one. It includes who these people became when given a diagnosis, how the loss of an appropriate social role effects them, how the descent into supposedly damaged and defective `psychiatric patients' eroded their self-worth and trust in their own powers to heal. The distress that brought people to psychiatric services is all too real, not constructed.

We have to understand that there are experiences that are overwhelmingly fearful, states of total suspension in diffuse anxiety, and conditions of profound despair and grief, and further, that there are also people with whom others cannot live or who make others afraid for themselves (Smith, 1990, p.121).

However, many of the people in the focus groups were oppressed and diminished by being treated as less than adult, told that they would more than likely never grow up and that they

must accept this 'fact' to receive good treatment in the psychiatric system. And that is what many of them have done.

Luckily they have realized that the prognoses were wrong. They have found a place to develop resistance to a 'life sentence' in the Self Help Group; by talking with each other, listening to and reading alternative viewpoints, developing narratives of resistance. They are now in the process of recovery and many will be able to lead satisfying and full lives. They know what they need for this to happen and should be listened to and supported to develop programs.

## Peer Groups: Providing Resistance and Investigating Recovery

The critical thinking that is involved in analyzing how the oppresson of the psychiatric system works and finding information about mental health not available in the dominant narrative can help to loosen the hold of internalized stigma. The barriers to empowerment and recovery are not only from the oppression in the psychiatric system, or from resultant internalized stigma, they are also reinforced by the stereotypes and misconceptions throughout society about those psychiatrically diagnosed. There needs to be freedom, the freedom that can be found in peer support and self-help groups, to keep sharing narratives of resistance, to express as many alternative viewpoints as possible in order to loosen the hold of the debilitating dominant narrative of psychiatry. When people construct narratives of their own lives they reclaim their right to be a subject and free themselves from being defined by experts, and the object of an institution's gaze. People who join together in mutual support are able to share their stories, develop narratives of resistance and let their voices be heard. From these many voices the paths and roads to recovery can be mapped out.

## Chapter Fifteen

## Psychiatry's Function of Social Control

The co-researchers, members of the Self-Help Group, raised issues about the psychiatric system which are the hallmarks of being an oppressed group (Dufort & Lord, 1996). Stigma and discrimination, control and management, as well as the psychiatrization of identity were too often part of the stories and discussions. Fortunately, there were also stories that told of the encouragement and support for recovery and the healing relationships that some people found in agencies and with mental health professionals.

## The Ostracism of Consumer/survivors

Many of the difficulties that the co-researchers reported within the psychiatric system arose from the power imbalance with mental health professionals. They were the 'experts' who did not listen to the perspective of consumer/survivors, did not share full information, or did not give them control or decision-making power over issues that affected their lives. Luckily the co-researchers reported that there are mental health professionals and some services that focus more on recovery than management and true healing relationships are possible. However, the psychiatric system itself follows an illness-based medical model which focuses on limitations and deficiencies and cannot be fully supportive of recovery unless changes are made.

By listening to what consumer/survivors say, trying to sort out the inconsistencies of what the mental health system says it is doing and how it actually treats those it is meant to serve, it becomes clearer that by medicalizing social problems, deviant behaviour and alternative views, the psychiatric system is protecting current societal norms, values and structures. An insight which occurred during the writing of this thesis is that people who have received a psychiatric diagnosis and are under the care of the mental health system are like those who were ostracized in ancient societies. Those ostracized were shunned, ignored, not talked to or listened to, because they had broken rules of behaviour that were commonly accepted in that

society. Their presence within the community, but not participating in the activities of the community, was a warning to others to behave according to the accepted rules. They were treated with fear because everyone feared being in the same position. If people broke the rule and communicated with them they would risk the same punishment. Abandonment and loneliness are terrible experiences for humans who, despite the Western emphasis on individualism, are social animals who need each other to be happy and healthy.

Ostracizing in some form or other may be thought to be necessary for societies to continue to function, or it may be a mechanism to ensure that the current norms and standards are followed and not usurped by new ones. Those who are protesting or are upset by what they see happening may be the ones to be listened to instead of being silenced. Here in Canada we have become such a pluralistic, diverse society that we may need to rethink the tendency to only support the perspective of the dominant class and its economic imperatives.

Also it would seem that people who are suffering greatly from emotional distress are in need of care and comfort not the ostracism of stigma and discrimination. But our society generally hides and denies the disturbing aspects of illness and death, and so the pain and suffering of others is avoided and hidden away.

## Only 'Sane' People Allowed

The psychiatric system is not only about the care and treatment of mental illness it is also about social control. The mandate to legally take away someone's rights and freedom is not just to protect the person or others from danger, it is also to forcibly remove a person who is disturbing others by their behaviour. Unfortunately, this means that at times people in great pain, in a difficult situation with others, or with a difference of opinion about their or other's roles or views can be deemed to be the one with a 'problem' and come under the scrutiny of psychiatry.

As stated previously, the ideology of biological psychiatry proposes that most of mental illness stems from genetic defects of the brain that are triggered by precipitating circumstances. Social and economic factors can be ignored and individuals are managed by treatments; an effective way to avoid making changes, to maintain the status quo, and to neutralize potential disruption to the local social order (Smith, 1990).

Eugenics, the control and improvement of hereditary qualities of humans, has arisen as a movement in previous decades and luckily was suppressed due to the protests by the public of the potential for human rights abuse. If there is a total acceptance that the cause of mental illness is only from genetic defects, without any weight being put on social and environmental determinants, then eugenics may take over. It may already be covertly happening with the oppression by the psychiatric system and the harmful effects of treatments.

It is an honourable aim to wish to relieve people of suffering, but to wish to neutralize by gene therapy, or control of reproduction may be in fact suppressing some part of human evolution. In the idea of spiritual crises, the awakening of states of consciousness where mystical and paranormal experiences occur may be interpreted as psychosis. Paranormal states are often reported by many people diagnosed as having a mental disorder. If these states are not dismissed as delusional, what are they and why do they occur? One explanation found in spiritual practices is that these states can occur with the opening of channels and chakras by the raising of kundalini (sexual) energy up through the body.

Another explanation for the development of psychic ability is that it is latent in many if not all human beings. When a traumatic event is occurring or is threatening to occur, or during an extraordinary experience, there can be a state of hypervigilance. The person is perceiving at the height of their awareness which may at times precipitate paranormal abilities thus increasing the person's chances of survival or opening to other levels of consciousness.

To those who have never experienced psychic states, never thought of a person just before they phone, or known with assurance that a person close to them is in danger or has just died, these reports are taken as examples of pathology. There are now scientists of the paranormal who have made many successful experiments. But without the acceptance of its possibility this body of research is denigrated and ignored by other scientists (Grof & Grof, 1989).

The proclivity to wish to eradicate all mental illness may in fact eradicate something that has not been understood in its nature. People diagnosed with schizophrenia often live in a reality where mundane occurrences are imbued with significance and meaning. Jung's theory of synchronicity "...posits that uncanny and meaningful coincidences occur and that they are an expression of an underlying force in the universe...a divine script" (Faber, 1993, p.98). Laing (1989) writes that what it means to be sane is to be not conscious of the 'unconscious', and that the unconscious, experienced by the dreamer of dreams, is connected to a far larger consciousness than sane people experience . Some cases of schizophrenia become breakthroughs instead of breakdowns and lead to full recovery and a more self-actuated personality. Those who are recognized as being very creative talk about their non-ordinary states as inspiration for their work. We may throw the baby out with the bath water if in fact it is true that how we react to a psychotic state may determine its course. The experiments in Sweden and Finland (Chp. 11 & Martensson, 1998) point to the potential for a better prognosis.

In countries where they see that mental health is about acceptance of difference and reducing the stress in society, people have much better rates of recovery for serious mental illness. Fernando (1995) believes that mental health services should work to correct the problems in society that cause stress, especially racism and discrimination in general. He writes about a mental health service in New Zealand which works with Maoris and "...designates their therapy a 'just therapy'--on the basis that justice and mental health go hand-in-hand" (p.194).

## Diagnosis of the 'Other': The Cycle of Disempowerment and Despair

Usually it is those with power and authority, those who can convince others that they are 'normal', or who can enroll allies to their perspective, who decide that it is 'the other' who needs psychiatric care. It is in relation with other people that the designation of a possible mental disorder is made.

With the swift changes in modern society, the insecurity of a shifting economy, and the ever-narrowing definition of acceptable appearance and ability, there is an anxiety throughout the population. This anxiety is also fueled by the continuing degradation of the environment, the access to instant information about wars and conflicts throughout the world with the ever-present (almost invisible we are so used to it) threat of nuclear warfare. The estimation that one out five Canadians will experience what is called mental illness reflects this anxiety. It is necessary to question if anxiety is being displaced by constructing scapegoats of marginalized people.

As was said previously, circular logic states that if someone comes to seek help or is identified as needing help from a professional, then more than likely there is an underlying disorder to be discovered and mental health professionals can find one in their behaviour robbed of context. That the context and histories of people's lives are not looked into is one clue that what is happening is social control. If control of a person is the goal, only the drug that will manage their behaviour needs to be identified. The ideology which supports physical treatments also supports the belief that people with 'damaged' brains need to be controlled and managed, and recovery is seen as a nice but unrealistic goal. This ideology sets up the situation so that the possibility of recovery is denied for those who are diagnosed as seriously mentally ill. The way they are treated leads them to learn to become passive and leaves them without hope for the future. A version of this cycle of disempowerment and despair which creates the identity of a psychiatric patient is illustrated in figure 1.

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# THE CYCLE OF DISEMPOWERMENT AND DESPAIR:

## How to create a psychiatrized person

### THE CENTRAL ATTITUDINAL BARRIER

Instructions on how to respond to a person with mental illness:
1. Observe this person's behaviour to see how it does not make sense.
2. Do not relate as if you could view from this person's perspective.
3. Do not take anything the person says seriously, or make it into anything that you have to act upon, or respond to.
4. Do not allow this person to make any decisions or do anything that requires sound reasoning.
5. Do not allow the person to take risks and keep stress levels low.
6. Inform the person that to be treated they have to accept their diagnosis and the prognosis of a limited future, and that they will probably have to take medications for the rest of their lives.

### THE PROPHECY IS FULFILLED

People become experts in being helpless patients and the central attitudinal barrier is reinforced

### THE SYSTEM TAKES CONTROL

Professionals take responsibility for the person and control of their choices

### LEARNED HELPLESSNESS
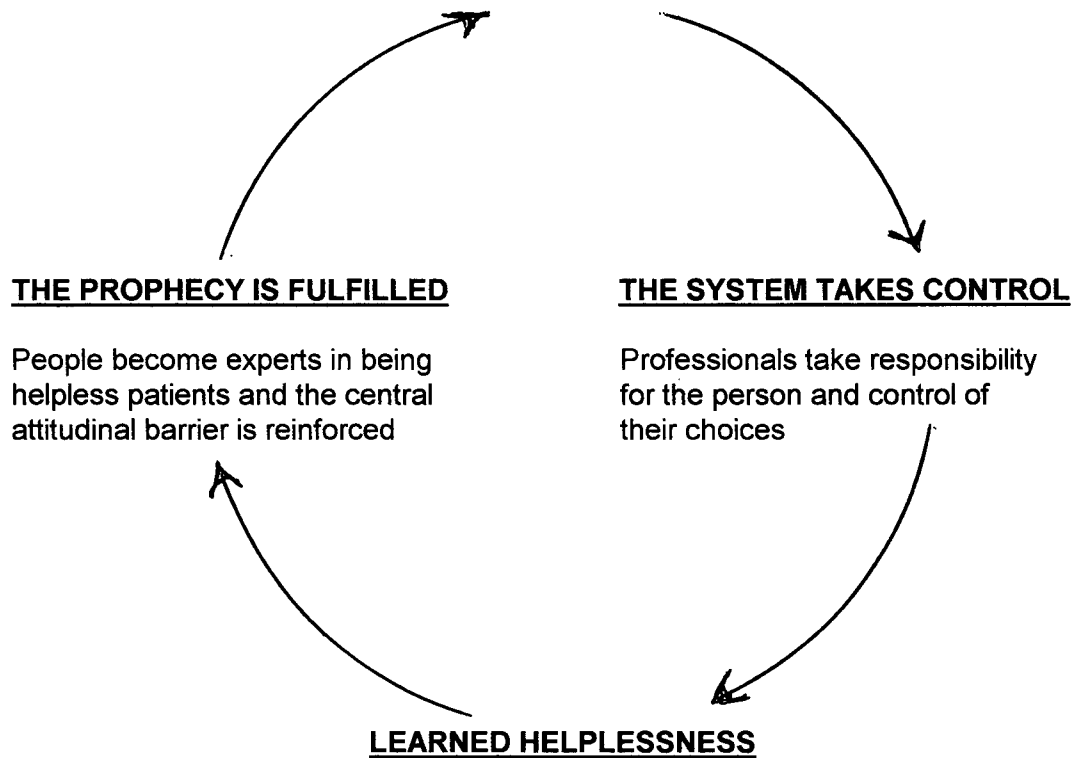
**Figure 1**                          (Adapted from: Deegan, 1992, p.12; Smith, 1990, p.120)

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People making diagnoses are exempt from examining their own biases and unconscious projections. They have a particular training in diagnosis and the support of their peers to see the pathological in their patient's behaviour. And again the diagnosis is made in the relationship between two people. If someone is given the master status[16] of a psychiatric diagnosis it is that status which determines how they are treated not their behaviour as was seen in Rosenhan's study (In Chp.14 And Smith & David, 1975).

Someone who is in great pain and distress, who is suffering from disturbing experiences, and has been shunned by those who don't understand and who are afraid of what is happening, is someone who is lonely, feels abandoned and in need of another's care and attention. If the people who are offering care make requirements and hold certain expectations it is human nature that the one in need will take on a role that their caregivers expect them to. They will be easily persuaded that what they are experiencing is due to a personal fault, a disease of their brain. Only when the treatments create more suffering than what they had been experiencing before will these people question their position.

By creating a 'sick' role and insisting on the acceptance of a diagnosis and compliance with treatments, mental health professionals may create a situation where the person can lose their ability to be a subject in action and become passive and an object in order to be treated well and not forcibly. Psychiatry of this form can then be seen to be about power and moral decision-making rather than about medical treatment (Halsasz, 1994).

## No Choice, No Recovery

From what the co-researchers said there are sympathetic professionals in the psychiatric system; the problem is that there is an insecurity in not knowing if the one assigned will be one of those. It is very difficult to change therapists or psychiatrists, and requires strength and

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[16] A master status is a designation which takes precedence over all other designations. If there is a conflict arising from two types of status, the master status is the one responded to.

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determination, not the most common qualities found in people dealing with difficult emotional states.

Some of the co-researchers thought that the services of the current mental health system were needed, especially when they were experiencing difficult states and needed the protection of a supported environment. They also saw the value of medications and an illness perspective which removed from them the responsibilities of daily life when they felt they needed it. However, because they were left in a dependent position, with their hope for a more autonomous way of live taken away, they felt they were often robbed of the possibility for recovery.

The co-researchers found medication treatment problematic when their views about dosage, side-effects and the possibility of taking themselves off drugs was discounted and over-ridden. Some talked of overmedication to control behaviour and incorrect medication because of incorrect diagnosis. They also talked about the conflict between the idea that the pain they suffered from needed to be controlled by drugs and the idea that it wasn't until their pain could be accepted and expressed that people could recover.

## Social Control in our Everyday/Everynight Lives

There is a significant body of research that shows that medications do not cure and in fact are often harmful and may at times prevent recovery, and that there are determinants of recovery which would be effective if followed by many of those who are now considered untreatable (Anthony, 1993; Breggin & Cohen, 1999; Faber, 1993; Grof & Grof, 1989; Martenson, 1998). The mystification of much of psychiatry's treatment as being therapeutic and of benefit to the recipients hides the agenda of social control. This becomes clearer when research is ignored and discredited, and explains the inconsistencies between rhetoric and actual practice. These inconsistencies highlight the idea that the hidden functions of the psychiatric system are to maintain the current family and power structures and enforce codes of

behaviour that are socially acceptable. Those who become disturbing to the social order, who have failed their roles in some way, who trigger fear, unpleasant or repressed states in others are outcast and declared to be defective and damaged. Instead of being cared for with empathy and acceptance and helped to recover as quickly as possible, they are treated in such a way that they come to think of themselves and act as if they were 'damaged goods'.

Smith (1999) writes about how the 'ruling relations', the complex of objectified social relations that organize and regulate our lives, achieve the "ongoing concerting and coordinating of individual's activities", in the "...the everyday/everynight local actualities of our lives" (p.6-7). Smith suggests that it is in our experiences throughout the day, in the actual places we inhabit, that this social control is occurring. We are in fact creating these mechanisms for social control in the conversations we engage in, the books and papers we write and read, using ideas which are reproduced from the ruling relations; those relations with the power to determine, for example by controlling the media and educational systems, the beliefs and attitudes held by the general public. The phrases and stereotypes we use in our language to connote 'madness', the feelings of fear and aversion we express towards and about 'odd' people, etc. do in fact determine how 'mad' people are treated.

## Discrimination is Fear, Stigma keeps the Distance

People who receive a diagnosis of serious mental illness are one of the most discriminated minorities. These people are excluded from society, their affliction made into jokes, their dangerousness exaggerated by media and stereotypes repeated until thought to be the truth. It is puzzling why people who are suffering great distress, dealing with unusual states of mind, frightening delusions, and often with no restfulness or peace in their lives, are people to be afraid of. Some people's behaviour appears strange and different but if they are not threatening violence, which only a very small percentage do, what is frightening about something that is not happening to us?

The fear raised originates inside of us and is not directly caused by the person, except if they are actually threatening our safety. Many say it is because these people are unpredictable, we do not know if they will or will not threaten us. A small amount of contact with people so diagnosed will assure people that most are actually timid and more likely to be a danger to themselves than others. The actual rates of violence by people with psychiatric diagnoses are less or equal to the rates of violence in the general public (Morrow & Chappell, 1999). The distortion in the media and the stereotypes shared throughout society can be seen as mechanisms for maintaining that state of ostracism which instills the fear needed to control the behaviour of people and maintain a society without citizens who dissent and promote alternative views threatening to the status quo.

When society excludes people it is usually from fear (Vanier, 1998). As discussed before the this can occur with 'abjectification'; when someone is no longer seen as subject or object and evokes an aversion which also fascinates. 'Mad' people have this quality and have been for centuries the subject of many investigations; they have been poked, prodded, paraded, and experimented on by doctors, usually men (Burstow, 1992; Kristeva, 1992; Padget, 1997).

Vanier (1998) writes that the fears we use to exclude others can be organized into the following categories: the fear of dissidents, those whose views are too threatening to the status quo, or are disturbing to our sense of order and need for a consistent base of beliefs; the fear of difference, those who don't look the same as we do, who have suffered from some experience that we do not want to imagine and who just with their presence disturb our emotional state, the 'abject'; the fear of failure, the fear of feeling helpless, not being able to cope with difference, the stranger; the fear of loss and change, the fear of losing what we have, having to move from the 'known' to the 'unknown', and being frightened of anything that reveals that life includes failure, pain, sickness and death. Vanier believes that these fears originate in childhood with

conditional love that did not value each person's uniqueness. These fears are passed on from generation to generation (1998).

Vanier includes that we move away from those who evoke fear in part because their anguish triggers our own. "Those of us with power and social standing have subtle ways of hiding our inner handicaps, our difficulties in relationships, our inner darkness and violence, our depression and lack of confidence" (p.100). He says that if we include the disadvantaged "...they will call us out from our individualism and need for power into belonging to each other and being open to each other" (Vanier, 1998, p.84).

**Chapter Sixteen**

**Resistance to Psychiatry**

**The Process of Recovery**

**The recovery vision.** There has been a recent movement based on theories of how people can recover from the debilitating effects of mental illness. Begun by psychiatric survivors, taken on by rehabilitation programs, such as those supported by the International Association of Psychosocial Rehabilitation, it provides the light that is needed for people to renew their hope, people who may have been told they never will leave the psychiatric system (Anthony, 1993).

Recovery is a term from the independent living movement denoting a person's ability to participate as fully as possible in life with the rights to full citizenship. It may not mean a return to the same state of health possessed before entering the medical system. But it does mean to live life as happily and to the fullest potential possible regardless of the symptoms experienced or the medications and treatments received (Anthony, 1993; Chamberlin, 1997; Deegan, 1996). Recovery is also about liberation; the move from an oppressed person being an object to becoming a subject is one of recovering the whole self.

Recovery is aided by self-help and mutual-aid groups who externalize stigma through consciousness raising, and who provide role models who know what it is like to be labelled a psychiatric patient. Working in these groups, people can raise their self-esteem and self-efficacy and be empowered through assisting others to recover.

The recovery process involves not only the illness with the treatment of symptoms but also the consequences of the illness. These consequences include the dysfunction from lack of work and social skills, the disability of unemployment and insecure housing or homelessness, and the disadvantage of discrimination and poverty (Anthony, 1993, p.14). Many have emerged from mental health treatment with traumatic stress responses as a result of what they have seen and suffered from in the system itself. "Sometimes recovering from mental illness is

the easy part. Recovering from these deep wounds to the human heart takes longer " (Deegan, 1996, p.96).

A testimony to recovery states that, "I, for one, have seen too many recovery `miracles' not to believe that significant recovery is possible for many people with psychiatric disabilities ", and that, "...drastic changes are needed if we wish to support people's recovery rather than hinder people's recovery" (Anthony, 1993).

**The determinants of recovery.** The following determinants of recovery have been amalgamated from several articles and reports, all but one of which are written by consumer/survivors themselves (Anthony, 1993; Chamberlin, 1997; Deegan, 1995; Fisher, 1993; Recovery--NSMHCS, 1999).

Before any work on recovery can occur, people need a certain level of security beyond just surviving; their basic needs for safe housing, physical sustenance and an adequate income must be met. This is where many concerned citizens and mental health professionals are applying their energy, but it is only the beginning of what is needed for mental health recovery.

**Hope, role models and healing relationships** all are important for recovery; there needs to be at least one person who believes in and stands by the person in need of recovery. These are universal concepts in the theory of recovery. In the consumer/survivor movement, support groups and services, all three of these determinants can be found.

**Belonging**, having a place of one's own is also important for recovery to counteract the loneliness, exclusion and marginalization that many consumer/survivors experience. Peer-run groups and services provide places to belong and to **develop a collective voice** free from judgment and stigma.

Consumer/survivors **tell their own story** and see their perspective as valid while creating their future from their dreams and aspirations. Peer support can "..help people to craft songs of

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their lives...songs and stories that are rooted in people's own words, views, perspectives, and, most importantly yearnings. This is the essence of **empowerment**" (Moxley, 1995, p.128).

Consumer/survivors need to take **control and responsibility** for their lives, as well as have meaningful, and real choices. They must be allowed, and allow themselves, to **risk** and be vulnerable as these are essential for growth and recovery. **By focusing on strengths and abilities** rather than problems, self-esteem and self-efficacy are raised in consumer/survivor groups and services.

People need to be treated as **full human beings worthy of respect**, overcoming the discrimination, stigma and dehumanization of being labelled mentally ill. Consumer/survivors deserve to be treated as **equals**; to participate and have **legally protected rights and responsibilities;** to have the potential for and the right to **full community participation and integration**. Consumer/survivor groups connecting with community leaders and organizations counteracts negative stereotypes and stigma as well as preventing mental health ghettoes.

Consumer/survivor-run groups support people to **believe in themselves and their rights**, teaching them to be **assertive** and stand up for themselves showing that they can make a difference. Consumer/survivors can learn to express themselves, their anger at their situation and use it to effect change by becoming involved in peer support and activism.

**Spirituality** has been found to be an important support for recovery. Consumer/survivors need the freedom to access spiritual guidance and counselling, and to follow the practices and religions that they choose without it being pathologized. They also find it useful to uphold, and to have upheld by those who work with them, the values of **compassion, honesty, faith and love.** It is in **cooperation, collaboration and empathy** that these values find their expression.

Consumer/survivors use a **sense of humour** to soften the tensions that arise, counteracting the suffering they experience and helping each other to cope with the daily struggles they face.

Taking themselves lightly helps avoid the dangers of becoming too serious and aids participation.

Consumer/survivors need **full access to information and resources** so that they can learn to think critically, redefine who they are, what they can do, and their relationship to institutionalized power. Knowledge is power. They also need funding for and **access to holistic treatments and therapies** which are often found useful and more suitable to the recovery process.

Consumer/survivors wish **access to education** to learn skills that **they** define as important that will help fulfill **their** goals of recovery. By participating in the planning and evaluation of programs, demanding the inclusion of their needs and desires, or by creating their own training, they can ensure that the programs reflect what they wish to learn.

Consumer/survivors **need employment and deserve meaningful, productive lives**, whether in supported employment, consumer-run enterprises, peer support, mental health work or in the mainstream work force. They need to be paid for their work and have a comfortable standard of living. "Work is a normalizing and integrating force which is fundamental to the maintenance of self-worth and self-mastery" (Ramon, 1991, p.121).

Consumer/survivors need to **initiate and/or participate in the research and evaluation** of services. At the Center for Psychiatric Rehabilitation at Boston University, they have been researching the barriers to and the resources needed for participatory action research in mental health, and are beginning to use it within their own programs (Rogers & Palmer-Erbs, 1994, p.7).

> Choice, options, information, role models, being heard, developing and exercising a voice, opportunities for bettering one's life--these are the features of a human interactive environment that support the transition from not caring to caring, from surviving to becoming an active participant in one's own recovery process. (Deegan, 1996, p.96)

Some of the consumer-controlled recovery-oriented services suggested are: rehabilitation and drop-in centres; wellness-based services and support advocacy; peer counselling and brokerage; 12-step programs and a full range of support groups; safe houses and support services for families; club houses and resource centres (educational programs and literature) (Recovery--NSMHCS, 1999).

At the National Summit of Mental Health Consumers and Survivors, the members of a workshop discussed how to promote the recovery vision. They suggested forming organizations to develop best practices of recovery; to start educational programs on recovery; to advocate for the support of recovery-oriented services, consumer-run programs, and holistic treatments; and to advocate against policy, practices and legislation that are contradictory to the recovery vision (1999).

From the determinants of recovery, for people to take full responsibility and control for their lives, they can, if lucky, be encouraged by progressive professionals, but are best supported by their peers in consumer/survivor-run organizations. The cycle of disempowerment and despair, illustrated in figure 1., can only be broken by entering into the process of recovery, another cycle where it is empowerment that is reinforced not helplessness. A version of the process of recovery is illustrated in figure 2 on the next page.

The process of recovery is accelerated when people have taken control of their lives to the extent that they are providing support for other people's recovery. This is the key to mutual-aid; that the support is mutual and that people at various stages of recovery can help each other in the process. It is in order to provide safe places for this inclusive space to occur that consumer/survivors are developing mutual-aid groups and programs. The consumer/survivor movement has been instrumental in its activism to promote the importance of these safe places.
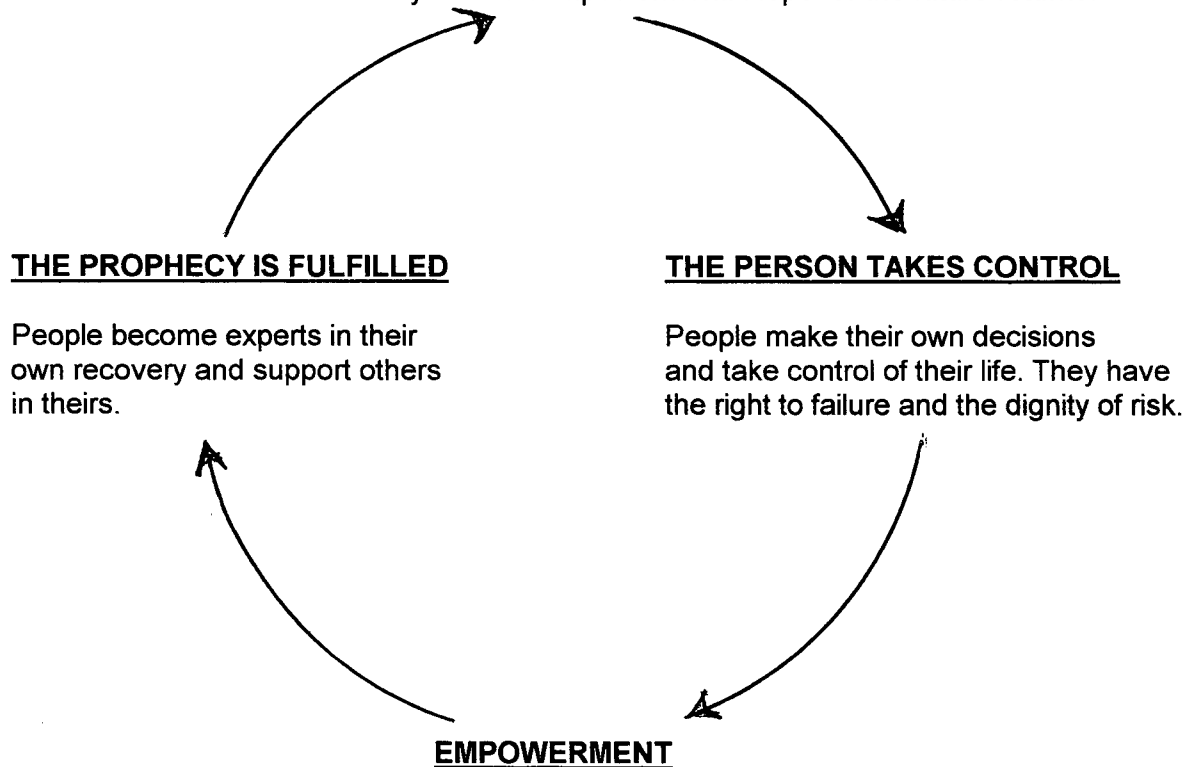
# THE PROCESS OF RECOVERY:

## How to break the cycle of disempowerment and despair

### THE CENTRAL ATTITUDINAL SUPPORT

Instructions on how people are supported in the process of recovery:
1. People share their stories and are listened to, by the telling they learn and make sense of their own and other's experience.
2. People's recovery is believed in and encouraged.
3. People are treated with respect, their diversity celebrated.
4. People are assured equal power, hierarchy is minimized.
5. People take responsibility for their lives, make their own decisions and engage in activities that they believe will aid their recovery
6. People are supported, encouraged and inspired by others who have broken out of the cycle of disempowerment. Hope for the future returns.

**THE PROPHECY IS FULFILLED**

People become experts in their own recovery and support others in theirs.

**THE PERSON TAKES CONTROL**

People make their own decisions and take control of their life. They have the right to failure and the dignity of risk.

**EMPOWERMENT**

**Figure 2**                    (Adapted from Deegan, 1992, p.12; Smith, 1990, p.120)

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## Peer Support: Co-constructing Stories of Recovery

**The *ultimate* civil rights movements** With the success of the civil rights movement people realized the effectiveness of grass roots activism and the power of combined strength. At the same time as the call for rights became popular, ex-patients of the psychiatric system had already begun to gather together to speak up against the abuses and the loss of rights that they had experienced. Through the sixties and seventies a critique of psychiatry was promoted by academics such as Foucault, Goffman, Laing, Scheff and Szasz, who promoted the view that the medical care of psychiatry was a disguised way to manage those who are excluded and the potential disrupters of society. These ideas did influence the political and economic forces of the time and set in motion the 'community psychiatry movement' (Emerick, 1996). These ideas are just as pertinent today as they were twenty years ago but do not seem to have changed as much as would be hoped about the way people are diagnosed with a mental illness or are treated when under committal, whether in a hospital ward or out in the community.

The consumer/survivor movement is a social movement which can be defined as: "...a formally organized group that acts consciously and with some continuity to promote or resist change through collective action" (Everett, 1994, p.56). Over the last thirty years many activist organizations have developed; newsletters, articles and books have been written by ex-mental patients expressing their outrage and telling their stories; there are now regular conferences where consumer/survivor groups from all over gather to discuss how and what to do; and there are web sites and chat rooms on the internet for information sharing and contact with those of similar experiences. One group calls the consumer/survivor movement the *ultimate* civil rights movement, against, what Goffman (In Emerick, 1996) calls, psychiatry's process of 'social mortification'; "The ultimate in human degradation and civil rights deprivation is the experience of being dehumanized by being officially certified and treated as 'mentally ill' " (p.149).

Consumer/survivor-run programs are gaining legitimacy and recognition in the United States. Many groups are funded to provide advocacy; California funds research and mental health services run by consumer/survivors; South Carolina has consumer/survivor inspection teams visit mental health facilities and report back to the department of health; there are consumer/survivor-run programs which have grown from drop-in centres to large organizations with budgets in the millions, who are being consulted by groups all over the country (Emerick, 1996; Mowbray et al., 1997).

Political activism is an important aspect of the consumer/survivor movement with many protests and lobbying effecting the policies and legislation in different states and in Canada. The four-point restraints, the isolation room, the forced drugging, the electroshock treatments, the over-medication by toxic drugs with horrible side-effects, are all the targets of the movement's protests and political action. Their activism has helped bring into clear focus that the basic determinants of mental health are safe, affordable housing, adequate income and meaningful activity. These at least are being addressed by many professional groups even though there are still great problems with mental health ghettoes and homelessness. The consumer/survivor movement has been effective in advocating for more protections and rights for their peers as well as in developing and supporting consumer-run services. As one activist in the consumer/survivor movement states,

> It is more important than ever that we who have mental illness not only take control of our own lives but collectively advocate for creative alternatives to traditional mental health services. In the current climate, what we fight for will exist; what we don't fight for won't. (Rogers, 1996, p.22)

**Alternatives to being managed.** In a workshop at the National Summit of Mental Health Consumers and Survivors (1999) those attending defined alternative services: "The role of alternative services is to provide peer-to-peer support by and for consumer/survivor/ex-patients

as a choice, within a broad range of services" (Alternative Services--NSMHCS, 1999, p.1).

Participants advocated for qualitative and quantitative data collection to document the value

and effectiveness of alternative services. They also decided that "...program standards, staff

certification and/or credentialing as well as program accreditation shall be designed by

consumers for consumers based upon their unique experience and knowledge and consumer

generated research" (p.3).

There are increasing numbers of peer support programs being developed, some within the

mental health system as an adjunct to professionals services and some within non-conventional

treatments outside of the regular psychiatric services. The most exciting for consumer/survivors

are programs that are developed and run exclusively by consumer/survivors. In the United

States, there are examples of programs which started as small consumer-initiated services

which are now expanding, are well-funded, into the millions of dollars, for providing peer-

supported innovative programs (See Appendix B for details of these programs). These are

successful programs which are seen as a valuable part of the mental health system by

government and mental health professionals in the areas that they are found. Not surprisingly,

they are popular because they are cost-effective (Mowbray et al., 1997).

**Benefits of the Co-construction of stories.** Some of the benefits for the consumers who

receive services from their peers are that they can relate to someone who has `been there';

who can empathize and understand without judgment; who provides a sense of hope and

inspiration; who can offer appropriate and useful ideas for recovery; who fosters independence

for decision-making and self-determination; who is flexible in services; and who produces less

anxiety than professionals (Dixon, Krauss & Lehman, 1994; Felton, Blanch, Brown, Donahue,

Knight, Shern & Stasny, 1995; Mowbray, et al., 1997)

There are many benefits to consumer providers, one of which is the increase in a positive

sense of self from providing an important contribution and role modeling recovery for others.

There is the opportunity to learn, grow, and practice new skills. They will have the chance for an improved financial situation, more life satisfaction and a reduction in the number of crises (Gadd, 1997; Trainor, Shepherd, Boydell, Leff & Crawford, 1997). Finally, they are likely to get more acceptance and respect from professionals and experience less discrimination (Dixon et al., 1994; Mowbray et al. 1997).

The benefits for professionals learning about peer support programs are that they can become more aware of the recovery process; they can change their beliefs about the negative, long-term incapacity of mental illness; they can develop a more holistic view of services by engaging in dialogue with consumers; and they can find a place to support their clients' recovery by referring them to these programs (Mowbray et al, 1997).

The overall benefits for the mental health system are that the increased involvement of consumer/survivors in policy and program development may result in a less hierarchical, coercive and a more interactive, collaborative model of service delivery. Clients may become more receptive to services they would otherwise reject. Clients may have more self-determination in their treatment; and experience respect and less discrimination. Consumers as providers may increase the voice and power for their peers and allow more effective advocacy due to collective solidarity. The combined positive effects for the consumer/providers and receivers may reduce the use of crisis services and lessen the costs of health care. Finally, the value of consumers/survivors in the communities will be raised if they demonstrate their ability to develop and run their own programs (Mowbray et al., 1997).

**Consumer/Survivors doing it for themselves.** Increasingly there is recognition that peer support in consumer-run programs is effective to, "...help consumers reduce their dependency on restrictive mental health services and improve their lives" (Rogers, 1996, p.25). In Pennsylvania, a statewide survey, "...found a direct relationship between consumer empowerment and drop-in effectiveness..." (p.25) The report also said that, "...consumer-run

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programs have gained growing acceptance in state and local governments as a valuable part of the public mental health system" (p.25).

Some consumer/survivors wish to reform the existing mental health system while Shimrat (1997) states "...that psychiatric survivors have no desire to reform psychiatry (but instead) want to replace it with varied, inexpensive, humane ways of alleviating human misery and rage" (p.63). Emerick's (1996) estimates that there are over one thousand groups in the United States with 37.5% of them "consumer" groups with an individual-change orientation, and 62.5% of them "survivor" groups with a social-change orientation. But they "...are really just two sides of the same coin..." (p.154) with the personal and collective aims developing side by side.

> The banner of self-help, and the underlying symbolism of empowerment, self-reliance, consciousness-raising, stigma-busting, and various forms of legislative advocacy and social change, establish strong subculture themes that do indeed unite *all* forms of self-help. (Emerick, 1996, p.155)

The consumer/survivor movement is slower to gain acceptance in Canada and independent groups have difficulty achieving recognition. However, as can be read in the stories of Canadian leaders of self-help groups, gathered by Shimrat (1997) in <u>Call Me Crazy: Stories from the Mad Movement</u>, over the last thirty years there have been many people struggling to make changes here. The same types of abuses as are reported in the United States are talked about in this country, with one Canadian ex-patient stating that, "...abuse and oppression is what psychiatry means by help, care and therapy" (Everett, 1994, p.62). The more educated and articulate 'psychiatric survivors' have organized and lead the Canadian consumer/survivor movement.

The establishment of self-help groups throughout the country "...in addition to providing people with a 'place to be' or perhaps, a 'place to work'...can also become fertile breeding grounds for the movement itself (Gartner, 1984) " (Everett, 1994). They have had tremendous

success in the United States, "Chamberlin (1990) describes their success as striking" (p.64). One reason why these self-help groups have been slow to develop in Canada, forwarded by Susan Hardie of the National Network for Mental Health (a national consumer/survivor organization), is that due to the Canadian social welfare and health systems, the recipients of these services become dependent, and "...the establishment of, especially, the politicized variety of self-help, can be interpreted as biting the hand that feeds" (p.64).

Everett (1994) proposes that there is a good chance for the consumer/survivor movement to be successful. She reports that successful movements promote basic liberal concepts which are already held in the philosophy of a majority of the general public. The psychiatric survivor promotion of inexpensive alternative approaches to replace the psychiatric monopoly, which many are critical of, "...is well within what are, now, rather wide and pluralistic public opinion boundaries. Liberation discourse is, in many ways, the hallmark of contemporary social movements and 'one of the most popular destructuring ideologies' (S. Cohen, 1985, p.130) " (p.66)

The mental health reform occurring throughout Canada which is placing consumer/survivors on boards and committees, has been in part a result of the participation of members of consumer/survivor groups in governments' consultation processes. There are more consumer/survivor-run projects funded through programs such as the Ontario Consumer/Survivor Development Initiative. However as Dianne Capponi (In Everett, 1994) points out "..these projects sapped the passion from the movement and replace it with eternal wrangling with government bureaucrats over in-adequate funding dollars and other complaints" (p.67). This is an example of how co-optation[17] can begin which is a danger for groups as they become more accepted, and is warned about by allies and members of the consumer/survivor movement (Rapp, Shera, & Kisthardt, 1993).

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[17] Co-optation is the process of absorption or assimilation of a group by a larger system which often the smaller group originally fought to maintain independence from.

**Canadian consumer/survivors say, "We can do it too!".** In an article about Canadian mutual-aid for consumer/survivors, the authors state that these groups provide a new world view and give hope for change for their members. The benefits they reported were help with the alleviation of problems or adaptation to chronic conditions; increase in support networks; empowerment through helping others; developing skills and potential; acquiring new skills; hope; reduction of isolation and marginalization; and access to new resources (Lavoie & Stewart, 1995).

Health care reform documents at the national and provincial levels emphasize environmental determinants of health, empowerment of populations, and expanded public participation and responsibility (Angus, Auer, Cloutier, & Albert, 1995) consistent with principles of primary health care...Clearly support groups and mutual aid groups are important ingredients of reform and renewal of the Canadian health care system. (p.9)

In the study (Trainor et al., 1997) of 36 consumer/survivor organizations in Ontario they found seven areas of activity covered by these groups (listed in descending order of prevalence): mutual support, cultural activities, advocacy, knowledge development and skills training, public education, educating professionals and economic development.

Several major impacts of these groups were discovered. All use of formal mental health services diminished for consumer/survivors after joining a consumer/survivor group, particularly inpatient days, (48.36 to 4.29), and rates of hospital admissions (2.7 to .64). "Membership in a group helps consumer/survivors either avoid, or handle in a new way, the most difficult kinds of situations, those requiring crisis services or inpatient admission" (Trainor et al., 1997, p.136).

They also discovered that there was increased involvement with the larger community and that more skills were developed for dealing with people. This was thought to be due to the consumer/survivors' participation in the support groups and the self-respect and dignity they found there which boosted their self-confidence. Another area of satisfaction was their increase

in knowledge about various aspects of services, illness, resources and rights. In the survey, respondents ranked other consumer/survivors and consumer/survivor organizations as the most helpful out of all mental health service providers and agencies (Trainor et al., 1997).

The authors of the study stated that there is not the level of support which should match the extent of the impact of consumer/survivor initiatives. The self-help and mutual-aid base to consumer/survivor initiatives is very different from traditional services and may be threatening to professionals' preconceptions. The authors suggest that both services would be optimal for a full system with self-help and mutual-aid providing the needed independence for recovery. They end by saying that, "...people coming together out of mutual concern--not for pay, nor as volunteers, but rather as peers mutually sharing their lives, without professional intervention--is the ideal of a strength-based, prevention oriented, empowering mental health system" (p.139).

In Winnipeg, Manitoba, there is a new centre for consumer/survivors called Seneca House. This is a consumer-directed residential crisis centre and is the first such facility to have been created in Canada. "Seneca House promotes personal choice and personal responsibility. It is committed to assisting individuals to become empowered in their own recovery process" (Seneca House Inc., 1999). They have trained peer counsellors and volunteers, and also provide a telephone peer support service, a crisis phone line and a mobile crisis unit.

With the success of consumer/survivor-run programs in areas of Canada and in many places in the United States, the programs may become more common and accepted as valuable parts of mental health care throughout Canada. From the experience of groups in Vancouver there is still a long way to go before this occurs.

**The uplifting support of women's stories.** Women's self-help groups reflect that knowledge is power and that women need to become assertive to take control of their own lives. "Self-help groups are reciprocal, participatory, and nonhierarchical, in sharp contrast to the traditional dominance-passivity of most physician-patient relationships" (p.21). Women

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need healing relationships and the support of other caring women who understand their experiences.

Peer support can provide a non-threatening place for women in distress to come to for assistance. Issues of diversity are addressed by providing peer support from members of many ethnic and cultural groups. The greatest advantage of this for consumer/survivors is being able to tell their stories in their mother tongue and having support from people who understand their cultural issues. In a recent research report , women reported that support of their peers was, "...what helped make the difference for them" (Morrow & Chappell, 1999, p.41), especially in groups for women who had experienced childhood sexual abuse. Recommendations by Morrow and Chappell (1999) were that "...peer support groups should be recognized and financially supported as a necessary component of the mental health service structure" (p.42)

In another recommendation about crisis services was the idea of the provision of outreach so that women could remain at home instead of being hospitalized (Morrow & Chappell, 1999). Women often report being traumatized by the treatment they received in hospital and have difficulty maintaining their family during these absences.

## Conclusion

Motivated by the oppression, stereotyping, stigmatization and the discrimination experienced by consumer/survivors in the mental health system, many are seeking other ways to find assistance for their distress. To liberate themselves from oppression they are joining in groups and raising consciousness about the political, economic, psychological and social factors in the construction and management of mental illness.

With the support of their peers, consumer/survivors are deprogramming themselves from the identity training they received in the traditional psychiatric system on how to become a chronic mental health patient. With the self-creation of an identity founded on recovery rather an illness

paradigm, consumer/survivors are able to replace internalized stigma with hope and pride in their ability to resist and take back control of their lives.

Consumer/survivors who have recovered and their allies have investigated the determinants of recovery and are promoting a recovery vision. Consumer/survivors are setting goals and developing skills and abilities that will fulfill this vision. They are providing services based on what is needed for recovery from their knowledge and experience as consumer/survivors. With the success of these programs there is an increased recognition and validation of their effectiveness, including their cost-effectiveness by other mental health and governmental agencies.

## Chapter Seventeen

## <u>The End is Just the Beginning</u>

The shift of paradigms in intellectual thinking, from one that is mechanistic and reductionist to one that is holistic or ecological, supports the change from the perspective of an isolated human struggling to survive, to groups of humans working together to build a future full of hope and possibility; a future which includes all of the inhabitants of earth, each valued for their contribution and honoured as holders of truth. This vision is in accordance with many spiritual traditions. It is the realization of our joint responsibility for each other and the movement to banish the darkness which we create in the name of progress. When we open our hearts to those that have been reviled and debased we are allowing the power of love to transform ourselves and others, we are allowing ourselves to become fully human. "Becoming human...involves a growth to freedom, an opening up of our hearts to others, no longer hiding behind masks or behind the walls of fear and prejudice. It means discovering our common humanity" (Vanier, 1998, p. 1).

## <u>How Can Social Workers Support the Process of Recovery?</u>

From the beginnings, back to the time of the settlement houses, social workers have been advocating for the rights to dignity and self-determination for the people they serve. Those who are vulnerable, the disadvantaged and the handicapped, the discriminated and the powerless have been the focus of the social worker's efforts. Those who have a diagnosis of serious mental illness need the support of social workers and the encouragement to find empowerment in a system where their freedom can be taken away and their treatment enforced.

Social workers can support the people in the process of recovering their mental health to gain as much independence and freedom of choice as possible, advocating for changes that ensure the right to self-determination is honoured. With knowledge of the current

research supporting the determinants of recovery a social worker can be more effective in advocating for empowerment within the mental health system and in the support of self-help organizations. An example of the changes possible in mental health treatment is through advocacy and mediation by social workers in the use of a health agreement; in California, as well as in other states, there is the practice of contracting the preferred treatment to be followed in a crisis situation while the person involved is relatively stable. This could improve trust in relationships with professionals and increase consumer/survivor self-determination.

It is a natural role for social workers to support and encourage the development of self-help groups and communities for marginalized people. With the increased recovery rates for those who are able to work (Gadd, 1997), the development of consumer/survivor-run businesses could be encouraged and supported by social workers. The two-tiered system of mental health pointed out by the co-researchers is of concern to social workers and their work in social justice. Those in the lower socio-economic bracket are given services that focus on maintenance and stability not recovery. Advocacy for the inclusion of counselling and non-conventional treatments in the provision of public mental health services would in part redress the imbalance. Then recovery-oriented services would not just be available to those of upper income levels.

The role of social workers both in mental health and social services is to be effective agents for the people they serve, supporting and encouraging their empowerment to take responsibility for their lives, advocating and brokering knowledge, training and resources when needed. Brokering the basic needs for mental health, safe affordable housing, adequate income and meaningful activity, is an important aspect of what a social worker can provide.

Within psychiatric and social services, social workers attempt to bring a consumer-based practice into being, advocating for human rights and freedom from discrimination.

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The views of the medical model of psychiatry and the views of the consumer/survivor movement are inherently contradictory. Psychiatry is based on the assumption of authority and expertise with a legal mandate to restrict freedom and enforce treatment. The consumer/survivor movement is based on the idea of liberation of their members from oppression and stigmatization. Social workers could work to decrease the distance between these two stances through mediation and advocacy, bringing groups together to listen to each others' stories. There is the potential for a transformation of views and practices from the sharing of stories. Systemic advocacy is appropriate to address some of the more restrictive practices of psychiatry that have the potential to be abused.

The ideas of health promotion in the field of mental health were set out in the federal government document, <u>Mental Health for Canadians: Striking a Balance</u>, in 1988 (Adult Mental Health Division, 1988). Unfortunately, the conflicts between the levels of government, involving issues of funding and jurisdiction, have reduced the progress of reform. In this document the understanding of mental health moved beyond peoples' individual adaptation to the demands of their environment to include the responsiveness of the environment to individual and group action. This focus of change from individuals to systems is shown in the following definition:

> Mental health is the capacity of the individual, the group and the environment to interact with one another in ways that promote subjective well-being, the optimal development and use of mental abilities (cognitive, affective and relational), the achievement of individual and collective goals consistent with justice and the attainment and preservation of conditions of fundamental equality (Adult Mental Health Division, 1988, p.7)

This definition implies a greater responsibility for the systems in society to respond and change in ways that promote people's mental health. It supports that the social, economic and political factors that negatively impact peoples' mental health issues need to be

recognized and addressed. The definition implies that there is an increased recognition of the determinants of and support for the recovery of mental health. The promotion of subjective well-being supports listening to the 'voices' of people, their knowledge and expertise of what constitutes well-being for them, not from mental health experts. It also moves away from the blaming of individuals and involves the communities that people live in to become part of the solution by working to end isolation and inequity.

The ideas about health promotion in mental health need to be publicized and supported as these policies are not well known in the mental health community. Social workers can play a role in reminding other professionals of these progressive policies and the need to align with health promotion. These ideas are slowly being incorporated into mental health reform, but the domination of the individual and illness-based medical model in psychiatry, and the structure of its institutions and their economic investments, may be quite resistant to changes which may threaten its current status (Stamblovic, 1996).

The new mental health policy in British Columbia is explicit about the need for the recognition and support of the recovery process. In the document, B.C's Mental Health Reform Best Practices for Psychosocial Rehabilitation and Recovery, (Calsaferri, Treherne & van der Leer, 2000) the word recovery is prominently displayed. Just as in the United States where professionals in psychosocial rehabilitation are at the forefront of recognizing, supporting and researching the recovery process (Anthony, 1993; Rogers & Palmer, 1994), here too rehabilitation specialists are promoting a recovery orientation. One of the recommendations in this document is to "incorporate the concepts of recovery and the principles of psychosocial rehabilitation into all the mental health services" (p.36). At the beginning of the document the authors make the note that

The principles of psychosocial rehabilitation form the philosophical foundation for all best practices in mental health. These principles emphasize both consumer involvement in

developing and realizing personal care and life goals and treatment and supports that

help consumers manage their symptoms and build on their strengths.

(Calsaferri et al., 2000, p.2)

The principles of psychosocial rehabilitation stated in the document include: that

consumers be involved in all aspects of rehabilitation as well as in the shaping and

evaluation of mental health services; that they are given control over decisions that affect

their lives and the ability to make choices; that their strengths and assets be recognized and

developed; that they are encouraged to connect to peers and natural networks; that hope

and belonging are essential ingredients for recovery; that practitioners use a client-centred

approach and form partnerships with consumers; that consumers have the least restrictive

living and working situations with restructured and re-educated environments easing their

integration into regular communities; and finally that they be given the opportunity to re-enter

the work force and be supported in the fulfillment of social roles from the utilization of their

strengths and abilities rather than from a focus on their impairment and treatment. These

principles are very similar to the ones that guide social work practice, suggesting that social

workers and rehabilitation specialists can be natural allies.

The best practices document recommends increasing the focus of rehabilitation on

supported education and employment. "Returning to school and preparing for and

maintaining employment is a process that helps people in their recovery" (Calsaferri et al.,

2000, p.3). They add that this process aids consumers' self-esteem and self-image and

"...counteracts the feelings of worthlessness that many people with serious mental illness

have internalized because of the social stigma attached to their disabilties" (p.3)

A section on peer support was not included in the literature review but was added to the

report from the recommendations of the working group and their expert advisors. The

criteria for successful peer support workers in rehabilitation services include that they have

accepted their psychiatric diagnosis; have a positive attitude to mental health professionals; have recovered sufficiently to be able to cope and deal with stress; have good interpersonal skills, self-worth, and motivation for improvement; and finally that they are generally stable in their personal life. One-to-one peer support and support groups are seen as valuable additions to education and work programs, as an alternative approach to those programs and as useful for all mental health services.

Some consumer/survivors are able to find the help and support they need within the mental health system and are increasingly accessing peer support as it becomes more accepted as a useful part of service provision. For those who have not been able to accept the diagnosis they received, and/or who have not been able to develop trust in mental health professionals, an alternative support for recovery can be found in self-help groups. As this research has revealed, some consumer/survivors find it helpful to be able to use psychiatric services in conjunction with peer support in an unsupervised self-help group. But there are those who do not feel safe enough to seek help from what they perceive as the potentially oppressive atmosphere of traditional mental health services. In particular, as exemplified in my findings and in the literature, it appears that people who have been abused physically or sexually, as children or adults, have difficulty finding appropriate help from services with power imbalances; where they may lose control of their lives; where there is a risk of being revictimized in coercive psychiatric practices; and where they find it difficult to develop the trust needed to disclose their abuse or to develop healing relationships. These are people for whom a safe protected environment free from fear and oppression is necessary for their recovery.

Mental health professionals, including psychiatric social workers, need to be persuaded to drop their defensiveness to some of the 'voices' of consumer/survivors whom they hear as only being critical. It is true that to really listen and act on what they say may require

changes to a powerful institution. But being allies to their liberation can also ease the difficulty of working in an oppressive system.

All the people involved in the mental health system have some experience of oppression. The tyranny of too many cases, too much work and too little time created by economic cutbacks and social control is forced on professionals at all levels of the system. If people are too busy just managing to do their job then they will not have time to be advocating for needed changes. This situation interferes with professionals' ability to do their work with the quality that they desire and leads to loss of job satisfaction. There is insufficient support for debriefing or dealing with vicarious traumatization for those who work directly with people who suffer greatly. The stress takes its toll and people harden their hearts because they cannot help as they would like to, or be allowed to admit that at times they do not really know what to do to help. Deegan (1996) writes about how mental health professionals need to resist the hardening of their hearts.

> Our job is to create environments in which opportunities for recovery and empowerment exist. Our job is to establish strong, supportive relationships with those we work with. And perhaps most of all, our greatest challenge is to find a way to refuse to be dehumanized...to be bold and brave and daring enough to remain human hearted while working in the human services. (p. 97)

Through joining forces, consumer/survivors and the professionals who recognize their own oppression, can work towards a different form of services based on the vision of recovery.

The standpoint of the members of this self-help group has revealed that there are consumer/survivors who feel that they need to resist the control and management and even the support found in traditional mental health services. For their recovery they need independence from the supervision of mental health professionals and can find support and models of recovery through the process of mutual-aid. These are the 'voices' that are not

listened to by regular mental health services. Social workers can aid the expression of their views and advocate for the support of what they say they need to recover.

The self-help movement is an effective way for groups of marginalized people to pool their resources, provide support for each other and provide a place to tell the stories which are suppressed or which they feel are unsafe to relate in other places. It is very difficult for these groups to develop more than peer support without funding. A social worker can be a liaison between self-help groups and funding agencies, and an ally to the aims and goals of the groups. "The mediating role is one that is well established in social work, and there is increasing literature...on helping networks" (Smith, 1990, p.22) Participatory research and evaluation can be initiated and supported by social workers to aid the development of self-help groups.

Forbes and Sashidharan (1997) speak about the danger of co-optation when self-help groups involve professionals in their development. The groups can be taken over by well-meaning professionals and their services mimic the treatment delivery of professional groups. Social workers need to be informed and acknowledge that the types of programs, the aspect of mutual aid, and the focus on strengths and capabilities not deficiencies are totally different from traditional mental health services; the self-help ethos[18] thrives with independence and autonomy, not with supervision.

The pervasive discrimination, stigma, and reduction to stereotypes experienced by the recipients of mental health services need to be addressed in the training of social workers. Social workers can become active in 'stigma busting' in their relationships with professionals of all sorts. Social work education needs to include the consumer/survivor perspective as well as that of the self-help movement, especially since the results from research show how important empowerment and peer support are for recovery. Representatives from

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[18] Ethos is defined as being "...the distinguishing character, sentiment, moral nature, or guiding believes of a person, groups, or institution" (Merriam-Webster, 1997, p.399).

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consumer/survivor-run organizations could be invited to talk to students about their programs and goals. Presenting research from the perspective revealed by the stories of consumer/survivors can work towards eliminating the discrimination they experience.

As many consumer/survivors, especially women, have histories of violence and abuse and are suffering from these traumas, social workers need to be aware of what is useful to help these people recover. It is important for social workers to realize the dangers of revictimization from coercive practices in psychiatric services, particularly in committal procedures and hospitalizations, and to advocate for more care and investigation of the histories and present circumstances which may reveal traumatic experiences.

The underfunding of services to assist those with histories of abuse can be seen to perpetuate the damage that abuse causes. There are school programs to educate children to break the silence of abuse, there is more freedom and support groups that allow expression about this taboo subject. But still the results of abuse can be seen in the behaviours on the streets of the downtown eastside, in the shelters for battered women and too often on the psychiatric wards of hospitals.

There needs to be more public access to information on the effects of trauma, affordable and subsidized counselling services, treatment centres for substance abuse, places for victims of abuse to go and economic support to get people out of abusive relationships. There needs to be acknowledgment that many of those lost in self-destructive behaviours are innocent of any blame and have the right to proper care and treatment.

Another area of mental health that needs to be focused on is that of multiple problems. There are those who have both a disability, physical or intellectual and a diagnosis of a psychiatric disorder. These people also have difficulty finding appropriate services and suitable supported housing. Social workers can play a role in developing the services needed and to bring an empowering perspective to their treatment.

Being aware of the transformative power of telling stories, a social worker involved with all those who experience difficulties in their identity formation can use a narrative approach to counselling. This approach can be very effective in aiding people to deconstruct the stories of disempowerment and to reconstruct stories to reflect their strengths and abilities and the process of their recovery.

With the knowledge of the effectiveness of sharing stories between professionals and the people they serve, a social worker can perform a valuable role in mediating between people stuck in their roles or positions (see Chp. 2 and Abma, 1998). The parties involved can be convinced to listen to each others' stories and hopefully be moved to transform the practices they are engaged in.

Social workers have a valuable role working within the mental health system. They remind other professionals that the people who use the services are human beings with a history and networks of friends, family and co-workers. By resisting the domination of the medical model and the ideology of psychiatry, and by publicizing and supporting progressive mental health policy and reforms, social workers and their allies can provide examples of the power of inclusion; the power to view the users of mental health services not as cases with labels but full human beings with stories of strength, ability, resistance and recovery.

**Researching the Rest of the Puzzle**

As Smith (1990) points out, in the social construction of mental illness, it is not that psychiatric intervention causes mental illness but "...that wherever it originates it takes on its particular character in the social contexts created by psychiatry. It *becomes* mental illness-- rather than something else--in that context" (p.122). She continues by revealing the ideology of psychiatry which is a "...method of superseding, substituting, and suppressing the accounts that people create out of the recollection of their experience with the accounts of professionals discourse" (p.142). By deconstructing this process for all the people

involved, a new way of looking at the people who seek help for their distress is possible. Research which uses this process would be fascinating, it could incorporate participatory methods and result in positive changes. It would be an effective continuation of the study of the discourses created and sustained through the institution of psychiatry, which includes the discourse of oppression and resistance told by consumer/survivors.

If there was a continuation of this current study by social work researchers (or others) they could next access the voices and stories of professionals, mental health social workers and others, who are connected to the Self-Help Group, or a similar group. Consumer/survivors who do not join self-help groups could also be studied. Another useful population to study for this analysis, as was seen from Jeff's example, would be consumer/survivors who are providing peer support and services within the mental health system. They would have the added standpoint of providing services to peers and viewing from the working perspective of mental health professionals. A later group to enlist could be social work educators who teach about mental health and psychiatric social work, and community development. Research which uses inquiry in its approach to studying phenomena, such as is used by Dorothy Smith in her institutional ethnographies, is well suited to explore the institution of psychiatry (Smith, 1990; Smith, 1994).

## We All Need to Recover Now and Then

The sociologist Stambolovic (1996) sees changes possible with the rise of `new paradigms' in science which challenge objectivity and propose mind as another causal reality. Reductionism and mechanistic determinism are founded on physical causality from external sources. If mind were accepted as another causal reality a human being is then seen as an open system instead of a closed one, effectively responding and choosing, and can no longer be treated as passive and needing to be controlled. By changing the present focus on dominating an object to the development of relationships, the view widens to one

where we see that if we protect others' human rights we are protecting our own. When the mind is seen as a causal reality, professionals will work in cooperation with patients; it legitimizes the patient's expertise in their own lives and the reality of their ability to affect the healing process.

Advocacy, lobbying and education of the public is needed to counter the domination of economics in the policies and practices of the institution of psychiatry in alliance with pharmaceutical companies.

The new knowledge of the body/mind system with the discovery of the molecules of emotion will increase the acceptance of non-conventional treatments for emotional distress and mental health, and hopefully warn psychiatry of the damage from over-reliance on strong medications.

Living systems theory which reveals a biological basis for the social construction of our reality, 'the bringing forth of a world', can also change how people view mental illness. It includes the view that recovery is aided by a shift from focus on individual problems to relationships and reconnection to the 'web of life', the releasing of emotions and the reconstruction or restorying of a healthy identity. The recognition of "mental illness" and psychosis as a spiritual emergency or crisis can also change the way people with great emotional distress are treated.

With the shift away from a Cartesian-Newtonian worldview there is a movement by many intellectuals towards the incorporation of the subjective and the feminine styles of accumulating knowledge; those involving cooperation, collaboration, closeness, connectedness, and empathy (Bordo, 1987). This movement is reflected in more participatory and respectful methods of research with marginalized groups. There is now an acknowledgement of the value of people's stories in how we relate to their experiences and how they structure their place in world. By listening to marginalized people's stories we

break the silence imposed on them and validate the knowledge gained from their standpoint.

Investigating from the standpoint of consumer/survivors reveals the psychiatric discourse and mechanisms of social control which determine their experiences of oppression, stigma and the creation of a psychiatrized identity. Consumer/survivors working to make changes within the psychiatric system, those in the consumer/survivor movement and working in consumer/survivor-run organizations, all can help to develop resistance to this oppression and the loss of a healthy identity. Resistance can be developed in the form of advocacy against the attitudes and treatments of psychiatry which consumer/survivors experience as not conducive to recovery and which may, at times, even be abusive and harmful.

From this research project it became clear that for some consumer/survivors there was a lack of 'safe places' to tell the truth of their experiences without fear of repercussion, to have the support of healing relationships, to share their stories and to restory their lives as people recovering their mental health. Over the last six years the Self-Help Group has been working towards providing these 'safe places' for people to be supported in their recovery.

The programs that were suggested in the focus groups to address the issues that were raised, are ones that will bring to consumer/survivors the reality of hope, possibility and recovery (see the appendix for the list). These ideas were generated from the consumer/survivors' experiential knowledge, their knowledge of what it is like to be experiencing a dissociative state or a psychotic episode, what they know would assist people in these difficult periods, and what they wish they had access to when they were suffering the most. The ideas also come from their knowledge of how the psychiatric system works, what was useful and what was missing.

The co-researchers identified gaps in the psychiatric system that they wish to fill. The lack of information for those who are first hospitalized or enter the system can be addressed

with telephone information lines and hospital outreach. The Self-Help Group can increase their programs to provide peer counselling, more peer support and crisis support. The vision of a safe house for women is becoming closer to realization and there are plans for another safe house for men. Access to non-conventional treatments is also a goal of the Self-Help Group. The development of supported employment and consumer/survivor-run businesses will aid people to have full productive and meaningful lives. The advocacy and activism was centered on two areas; one, to effect changes to potentially abusive and harmful psychiatric practices; and two, to add more humane and inclusive ideologies and practices. The issues of self-determination and full participation in decision-making were said to be the most important ones to include in current services. The importance of their inclusion is confirmed by the principles of psychosocial rehabilitation and the advocacy by rehabilitation specialists for these issues to be promoted throughout the mental health system of British Columbia.

Consumer/survivors are speaking up about what actually has helped them to recover their mental health including: resisting the creation of a psychiatrized identity, volunteer and paid work; non-conventional treatments such as bodywork, yoga, meditation and herbs, art therapy; attending support groups, and visiting various types of counsellors. The co-researchers in this research porject are intelligent, caring people who are trying to develop support for those who are just entering the system. Their work also contributes to their own continued recovery.

From my own experience of working with the Self-Help Group, the companionship of these stigmatized people has brought me humility and the insight that my middle-class background taught me to keep my distance from marginalized people, even when I was marginalized myself. I chose this time to identify myself as a consumer/survivor, someone

who had been through similar experiences to other members of the group, and join in the struggle of their group to find acknowledgement and legitimacy.

Since I began this research project, the Self-Help Group has become a non-profit society, one of their proposals has been recognized as being innovative and accepted for funding, and they are now negotiating a contract so that they will have more control over their finances. From the support of allies and the hard work of the coordinator and members, the group is being acknowledged to have the potential to improve the self-determination of consumer/survivors and aid in their process of recovery. It is the first step to the recognition that consumer/survivor-run organizations are an integral part of the future of the mental health system in British Columbia.

From becoming involved in the Self-Help Group I see that there is hope and so many possibilities for the future which I can encourage and be actively involved in; there are so many diverse people from different cultures, orientations and abilities who are telling their stories, and from their voices of experience we can map the roads to recovery for full, free and productive lives for us all.

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## APPENDIX A

## <u>Personal Story</u>

I had been at university for two years in honours math and decided I wanted to switch to psychology. I began in the fall but dropped out when I became disillusioned with the behaviourist focus of the department, with the rows of cages filled with rats and mice used in experiments (I had wanted to study humanistic psychology) and when I had to dissect a rat for a biology class. I found a job as a computer technician at the university, at a time when one computer took up the whole of one room and the programs were typed onto cards with punched holes. At this same time I was introduced to non-ordinary states of consciousness by the use of mind-altering drugs.

My initial experience with non-ordinary states of consciousness included a vision which altered my worldview. I experienced being in union with the Universe, one with God and all that is created. I knew that just as a wave is separate but a part of the ocean, I was an individual but connected to all that is. All the drama, the sadness and the joy of the world, was just a dance of God hiding from herself so that she could experience the joy of reconnection. For several months I was filled with joy at this revelation and felt at peace and connected to everything.

I fell in love and left Vancouver and my job to follow a man to his home in the interior. I began to feel less sure of myself in a role I had never played before; I didn't really know how to cook or keep a house. I became anxious and withdrew into myself. I also began to criticize myself for not being able to live up to the ideal of someone worthy of union with God.

My boyfriend brought me back to Vancouver and handed me back to my parents. I was unable to sleep with my thoughts racing all over the place. After a while I was in a full-blown state of psychosis and was experiencing both auditory and visual hallucinations. I had the common experience of feeling that the comments on the radio and television had significant meaning and were directed towards me. At this point my mother arranged an appointment with

the best psychiatrist she could find. He suggested that I needed a 'rest' which I could find in a psychiatric ward and I agreed to a voluntary committal.

Just being there was disorientating, I found it difficult to be with so many other confused and distressed people; I remember patients who were taken for electroconvulsive treatments returning with vacant expressions, a woman who saw electricity, and a man who, when I asked what he saw, drew me a picture of planets in outer space. A girl I grew friendly with told me she had swallowed a bottle of aspirin and asked me to promise not to tell; instead I decided to tell. The medications were sedating and left me with no energy, just a feeling of deadness, the hallucinations continued. The nurses, with the exception of a couple of students, appeared disdainful of the patients; some talked in front of us about how foolish we were, as if we were not there. We were taken on outings; in one, which I don't understand who thought it appropriate, we were taken to see an awful movie called "Marat /Sade".

One morning I wanted to go outside to watch the sunrise, I felt renewed by being out in nature. I realized that I was locked in when a nurse refused to allow me to go. I decided to escape and at the next opportunity I did and went to a friend's house. My old boyfriend was there and he took me back again to my parents who returned me to the hospital. I felt thoroughly defeated and just followed along. I do remember being able to use a punching bag on the ward and visualizing that it was this man who I was punching.

I returned home and was cared for by my mother. I remember feeling emotionally like a very young child, needing protection and care. I was quite depressed, but did manage to enroll myself in the university, back in the math department, and began courses. There were accommodations made so that if I was not well enough to write an exam they would arrange for me to do it another day. I continued taking medication and visiting the psychiatrist. I made it through that year. The next year the psychiatrist suggested that I move to the student residence and I re-entered the 'normal' world; just another girl with bunches of other girls, joking

and laughing over cards, studying hard and making pots of instant macaroni and cheese. I stopped taking medications and visiting the psychiatrist. I left the psychiatric system behind never to return until I became a social work student and was in a practicum with a community mental health team.

I was one of the fortunate ones; I was advantaged by being from a middle-class white Anglo-Saxon family, I found hope for a future by returning to school, and I was supported by those who believed I could recover my mental health. Over the following years I continued my recovery away from the psychiatric system; living in the country, close to the earth and exploring nature. I studied yoga and meditation, and read many books on Eastern philosophy and religion to try to understand what I had experienced. I ate and lived wholesomely in a close relationship with my husband and with many good friends. I kept at the back of my mind that I could be of use to others who had the same experience, but it has taken thirty years to actualize that idea.

I have realized that my self-identity has been as a person close to 'normal'. I felt accepted by society, even though I have always been on the fringes, because I was not involved in the psychiatric discourse, neither within the mental health system nor in the movement which has arisen in resistance to that system. I, and others I have known who have recovered their mental health, tend to stay away from identification with any group associated with mental health issues. Again, we are fortunate to have the ability to do so.

# APPENDIX B

## Examples Of Peer Support Programs

### Peer Support in Non-Conventional Treatments

An article by a consumer/survivor describes Burch House as a working alternative to traditional psychiatry. Mathew Morrissey served as an intern in this "...community for people who want to take responsibility for their own healing process, where they change to make the most of their lives" (Morrissey, 1997, p.7). The house was modeled after R.D.Laing's communities in London. For twenty years it has successfully helped stabilize people with acute psychosis without the use of neuroleptic drugs. Around 75% of residents learn to integrate their experience of psychosis into their life, manage crises and prevent relapses.

Ten clients and four interns live together in the house, with two outside staff members, a clinical and an executive director. The interns provide compassionate peer relationships, engaging in group therapy, recreational activities, yoga and meditation. Matthew wrote that, "..I can't believe that this place isn't in the forefront of people's minds...it's truly magical, in the context of what's going on in the mental health system. It's quite amazing that this place exists and that it's actually working" (Morrissey, 1997, p.8).

### Consumers as Providers Within the Mental Health System

In the Bronx, peer specialists are used in an intensive case management team. The peer specialist program is based on the values of empowerment, self-help, and people, not pathology. The advantages of peer support in intensive case management is to make contact with people who avoid the professionals, such as the homeless and those who abuse drugs and alcohol. The street smarts of those who have been in similar positions allows them to access and engage with extremely marginalized people who suffer from mental illness.

The author stated that there will only be success when the mental health system adopts and practices the core values of the healing paradigm.

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The greatest value of this program is that it raised the level of dialogue regarding the unspoken values by which professionals operate... and the problems were recast into the larger context of when and how will the mental health system accommodate to the consumer/survivor perspective. (Fisher, 1993)

In another study of consumer peer specialists working in an intensive case management program, the researchers found that these workers made a unique contribution to enhancing the quality of life for the clients (Felton et al., 1995, p.1038).

## Consumer/Survivor-Controlled Alternatives

In a publication by the International Association of Psychosocial Rehabilitation Services (Mowbray et al., 1997) there is a section on what they call consumer-controlled alternatives; services developed and run by consumer/survivors. These programs have all developed out of needs that are not met by formal mental health services. As stated by one contributor, "...in many ways the mental health system is not really a system of recovery, but rather a system of illness" (Paynter in Mowbray et al., 1997, p.156).

The editors see many benefits arising from these programs; the increase in self-efficacy and self-worth for the members; paid employment with the access to training and the accumulation of experience; the opportunity for socializing and finding support from members; and the sense of security and safety belonging to a group of peers who understand and are accepting.

Four programs are described by their founders and leaders. Each has evolved quite differently which is to be expected with the great heterogeneity of people who use mental health services. However, "...their vision statements and the values behind them are quite similar, promoting a personal empowerment philosophy" (Mowbray et al., 1997, p.123). In this philosophy it is important for consumer/survivors to have choices, to be supported and assisted as needed but to be encouraged to be independent and to do as much as possible for themselves.

The editors comment that these alternative programs,"...need well-developed business plans and/or plans for programming to meet the resource levels available...and ...evaluation systems to document their benefits and enhance their credibility and operating effectiveness" (Mowbray et al., 1997, p.124).

**"On Our Own"**

The first program in Charlottesville, Virginia, is called "on our own", named after the book by Judi Chamberlin (1979) which discussed the development of an alternative mental health system based on the values of ex-patients. The initial goal of the program was to develop a community for isolated consumer/survivors based on a peer support model of recovery.

The model included many feminist ideas: "...each person's experience is validated; members are part of an empowering society...; and members do not need to internalize negative stereotypes about mental illness, a process which belittles them into subordinate positions in society, and poses formidable obstacles to empowerment" (Silverman in Mowbray et al., 1997, p.129). They also emphasized strengths and capabilities rather than problems, and a partnership between members and staff, all having had similar experiences, all travelling together towards recovery. As the director says, "We make no decisions for anyone. We teach consumers problem-solving so that they can enhance their own choices" (p.130). They are able to build trust and rapport with those alienated from traditional services.

We are all consumers, walking the same path. In fact, we often are walking in each others' footsteps. We are friends, and because of this we are far more compassionate and less judgmental than others...Instead of having preconceived notions, we as staff and community assist each consumer as an individual. (p.132)

The program began as a drop-in center, developed an information and referral service, educational workshops on medication, a care management program for their members and supported housing. The care management program, Project Together, targeted homeless

consumer/survivors. This project raised the awareness of and validated the group for other agencies who provide services to the homeless.

The outcomes of the program are that the founders and active members benefit from having learned they are capable people who can succeed; services are provided to people who do not have access to any other agencies or who avoid the regular system; and being available on the evenings, weekends and holidays helps people whose only other choice would be hospitalization.

From 150 satisfaction surveys they found that the center was close to the ideal environment for the respondents. They said that the outcome measures from this survey, the Moos' Community-Oriented Programs Environment Scale was useful to show to funding agencies. The staff use a Quality of Life interview to aid consumers, who are interested, to see what their needs are and to help staff document the issues people are facing.

One problem the director found was that the skepticism of psychiatrists about consumers being providers led them to conclude that the people providing services were not real consumers. Recovery does not fit with the present psychiatric ideology of defective brains, and some professionals view people with schizophrenia as the only true consumers.

The group next developed a program to train consumers to be peer helpers who could be hired at the local mental health centers. However the professionals at the centers only wanted volunteers not consumers as employees. But due to their success, the group was recognized as an established agency and has now been approached by the state government to put in a grant for consumer case management.

The director says that consumer-run programs are seen as more attractive now because of their cost effectiveness. But it is also being recognized that there is an increase in quality of life for members and a decrease in the use of medical services.

However, the socialization of professionals in mental health training and societal attitudes makes it difficult for them to accept that consumer/survivors can have valuable skills and knowledge in working with their peers. They found that not only professionals but also other consumers who have accepted the views of the medical model are skeptical of consumer-run programs. "Expecting consumers to change the system from within is not possible. Giving consumers their voice is the only way to change the system" (Silverman in Mowbray et al., 1997, p.139).

## OASIS Drop-in Center

The next program described is the OASIS drop-in center in Cranston, Rhode Island. This consumer-run and directed center provides the largest employment of consumer/survivors in Rhode Island. "We all prove every day that although people have disabilities, they also have abilities" (LeDoux in Mowbray et al., 1997, p.142). The group was helped to develop and gain independence by the funding from the Mental Health Association of Rhode Island whom the executive director commends for being "insightful, progressive, helpful, and not paternalistic" (p.145). The project has proven wrong the concept that mental patients need professional supervision. "There hasn't been a situation that we haven't been able to handle, and handle well" (p.146).

The group has a recovery orientation with their own definition of recovery being: "...the maximization of consumers' lives and the minimization of their illness(es) with appropriate, relevant and continuously flexible services and supports collaboratively developed and chosen" (p.146). The principles they follow are a consumer-centered focus, high expectations, normal goals, independence, respect, hope, partnership/collaboration, and plans for comprehensive, integrated, balanced and flexible service. The services are geared, "...to achieve and sustain recovery, manage crisis, and restore the consumer to the recovering state" (p.146).

The group, which is now recognized as a successful model around the country, has a budget of nearly half a million dollars and is developing new centers in the area as well as being consultants to other groups. "This is only the beginning of a better, more empowered, more recovered life for consumers" (p.147). The executive director's advice is to keep refining your dream, be flexible, move forward, never listen to the negative voices, never give up, and seek friends who share your dream.

## Rainbow House

The third program is a peer support facility called the Rainbow House in Detroit, Michigan. The house was begun and is run by persons labelled with Dissociative Identity Disorder as a safe place and sanctuary; a warm, friendly, accepting environment where they can receive and give support, and share in the running of the house. The members create what programs they wish, hiring professionals who they feel will be useful. The ownership, decision-making power, self-initiated programs and businesses allow skills to be developed and significant recovery to be achieved (Prout in Mowbray et al., 1997).

The house is a 24 hour drop-in center and provides weekly group sessions of art and music therapy as well as facilitated support groups. These non-conventional therapies are what members have found useful to their recovery and are seen as supplements to primary therapy. The members have grown and found support through networking with other consumer, mental health and professional groups. The house is now involved in outreach and consulting for other consumer-run facilities throughout the world.

> The confidence that has been built through involvement with the positive experience of being instrumental in breaking ground in a model that has caught nationwide attention has helped many consumers venture into endeavors that they formerly would not have considered (Prout in Mowbray et al., 1997, p.152).

Rainbow House was seen to be `thumbing their noses' at traditional programs which see consumers as needing professional supervision. The members replied to the criticism that the programs function as an adjunct to what is provided in the mental health system, it is peer support not primary therapy.

The approach is cost effective and the rate of hospitalizations for members is low. Before attending the house the average hospitalizations for members were two a year, each for about 14 days. Only five out of 61 members were hospitalized in 1994 with a combined total of 64 days, a significant reduction. Rainbow House is successful because it meets a need expressed by consumers for ongoing support and a place of refuge they can call their own which is not available in the mental health system. Programs embrace rather than regulate members, self-esteem and pride have grown in the accomplishments of the house.

> By placing self-reliance above compliance, and allowing consumers individually and collaboratively (to) find their way to their personal and joint goals rather than meeting expectations circumscribed for them, Rainbow House has fostered new approaches that have caught the eye of consumers, therapists, and others nationwide. (p.154)

Rainbow House members now look at the mental health system in a new light, "...that of peer providership in partnership with existing systems" (p.154). The author, a founding member, says the current narrowing of mental health services and the success of peer initiative and advocacy may mean that consumer-run programs will be a necessity rather than an oddity in the future. She also says that,

> Almost any mental health group can successfully implement a peer support group or facility. By identifying your goals, building financial and professional support, and sharing responsibilities, a supportive and empowering environment can be built. (P.154)

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## Shining Reflections

Another program, Shining Reflections, developed `The Tea Room', a consumer-run business that provides training and employment for consumer/survivors in food service delivery and business administration. The group has maintained a training and employment focus but added a therapeutic creative outlet by developing programs like Rain Voices, a sound and video production studio to document the group's projects and develop educational and anti-stigmatization materials (Paynter in Mowbray et al., 1997).

The self-expression, development of talents and voice for consumers has also been extended to a writing workshop, Words From the Heart. The writing allows the participants a release of deep emotions leading to insight and enhanced problem-solving abilities as well as being a way to tell their stories. A book of these writings has already been published (1997).

> Fundamental to our success is a commitment to peer support and to relating to people as human beings rather than as people with mental illness...Shining Reflections is part of the fabric of the community and our members are not isolated from the life of the community.
> (p.161)

The group also provides an employer advisory board to assist the employment of those with severe disabilities.

The challenges they faced were finding and training leaders, board development, maintaining momentum, and the creation of their identity as a mental health program.

> Shining Reflections...demonstrates that consumer-run organizations can fill important niches within the community, and can emerge as a peer and equal of `professional' mental health organizations. Shining Reflections is necessary to an effective mental health system. Why? Because consumer self-help is an integral part of any strategy of recovery. (P.163)

**APPENDIX C**

<u>THE ISSUES RAISED IN INTERVIEWS</u>

<u>THE PSYCHIATRIC SYSTEM</u>

<u>HOSPITILIZATION</u>

       RESTRAINT AND SECLUSION
       ENFORCED MEDICATION
       NO INVESTIGATION OF HISTORY
       OR PRESENT SITUATION AS PERTINENT
       ABUSE HISTORY IMPORTANT FOR TREATMENT

<u>DIAGNOSIS</u>

       LIFE SENTENCE
       LOST IDENTITY
       LOSS OF RIGHTS

<u>MEDICATION</u>

       LACK OF INFORMATION:
       - ON ALTERNATIVE DRUGS
       - ABOUT WHAT SIDE-EFFECTS TO EXPECT AND THE
       DEBILITATION FROM SIDE-EFFECTS
       IS THERE 'TRUE' CONSENT?
       MANAGEMENT BY OVER MEDICATION
       NO FOCUS ON REDUCING OR GETTING OFF
     HARMFUL DRUGS
       LONG TERM USE DAMAGING

<u>PROFESSIONALS</u>

       CAN BE PATERNALISTIC
       - SOMETIMES NO CHOICE, PARTICIPATION IN
       TREATMENT, INCONSISTENT
       DEMEANING
       DISCRIMINATORY
       ABUSIVE
       LOOK ONLY FOR PATHOLOGY
       DO NOT LISTEN:
       - COMPLAINT ABOUT SIDE- EFFECTS    DISCOUNTED
         BECAUSE "PSYCHOTIC"
       - FOCUS ONLY ON MEDS AND COPING,
         NOT ALLOWED TO TELL STORY
       LACK OF COUNSELING/THERAPY

## GOOD PROFESSIONALS

SEE ABILITIES AND STRENGTHS
EMPOWER THROUGH PARTICIPATION
AND DECISION MAKING
GIVE RESPECT AND COMPASSION
SUPPORT PEOPLE'S GOALS, RECOVERY

## MENTAL HEALTH SERVICES

GHETTOIZE USERS, DEPENDENCY AND ISOLATION
RATHER THAN INTEGRATION
AIM ONLY TO HELP COPING
LOW EXPECTATIONS
STABILIZATION OVER-RIDES QUALITY OF LIFE

## FINANCIAL SITUATION

DISABILITY THROUGH WELFARE SYSTEM,
- OPPRESSIVE AND HUMILIATING
NO INCENTIVES TO MOVE OFF
LIMIT OF EARNINGS
WORK CREATED TO TOP UP NOT GET OFF
NOT ENOUGH FLEXIBILITY/ACCOMMODATIONS
FOR GETTING BACK TO WORK
TWO-TIER SYSTEM:
- WEALTHY CAN ACCESS
COUNSELING/THERAPY AND ALTERNATIVE TREATMENTS
- POOR RECEIVE ONLY CONTROL BY
MEDICATIONS

## STIGMATIZATION

MEDIA AND PUBLIC STEREOTYPES, INCORRECT INFORMATION
INDIVIDUALIZATION:
- BLAME AND SHAME AND SCAPEGOATING
- NO PICTURE OF ECONOMIC AND SOCIAL DETERMINANTS

# RECOVERY

## CONTACT WITH PEERS

SUPPORT AND SHARING INFORMATION
MODELING OF RECOVERY
TRANSFORMATION OF STORY
RAISING OF CONSCIOUSNESS
- FAMILY, SOCIAL, ECONOMIC FACTORS
- WOMEN, ISSUES OF ABUSE AND VIOLENCE
- TWO-TIERED SYSTEM

## HEALING RELATIONSHIPS

TRUST AND RESPECT
BELIEF IN RECOVERY
RECOGNIZE AND ENCOURAGE STRENGTHS
COMPASSION AND EMPATHY
EXTERNALIZE INTERNALIZED STIGMA

## SAFE QUALITY HOUSING

NECESSARY TO HAVE SAFE, PLEASANT
SURROUNDINGS TO RECOVER

## ADEQUATE INCOME AND MEANINGFUL WORK

FULL RECOVERY MEANS BEING A FULL CITIZEN
HAVING ADEQUATE INCOME AND WORK ARE OUR SOCIETY'S
DEFINITION OF BEING A   FULL RESPONSIBLE MEMBER
MEANINGFUL WORK GIVES OUR LIVES MEANING AND PURPOSE

## A PLACE OF OUR OWN

NETWORK OF SUPPORT
SAFE PLACE, TRUST AND RESPECT
RECOVERY ORIENTED PROGRAMS
NON-DISCRIMINATORY ENVIRONMENTS
NEED TO GET AWAY FROM PATRONIZING AND
DEBILITATING ENVIRONMENTS

# PROGRAMS SUGGESTED TO ADDRESS THE ISSUES

### PROGRAMS THAT BRING THE REALITY OF
### HOPE, POSSIBILITY AND RECOVERY

## INFORMATION
EDUCATIONAL WORKSHOPS
TELEPHONE INFORMATION LINES
HOSPITAL AND COMMUNITY OUTREACH

## ALTERNATIVE TREATMENTS

### CONSUMER RUN PROGRAMS:
SUPPORT GROUPS LIKE ALCOHOLICS ANONYMOUS
PEER COUNSELING
PEER OUTREACH IN THE COMMUNITY
CRISIS SUPPORT NETWORK
SAFE HOUSE FOR WOMEN
- ROLE MODELS
- EXPERTS IN RECOVERY
SUPPORT GROUPS FOR THOSE WISHING TO REDUCE OR
GET OFF MEDICATIONS

### ALTERNATIVE TREATMENTS AVAILABLE:
- AFFORDABLE COUNSELING/THERAPY FROM THOSE NOT
    CONNECTED TO PSYCHIATRIC SYSTEM
- BODY WORK
- HERBAL TREATMENTS AND SUPPLEMENTS
- MEDITATION AND STRESS REDUCTION

## ACTIVISM AND ADVOCACY

### ADVOCACY:
- FOR MORE PARTICIPATION IN TREATMENT     PLANS
DESTIGMATIZATION
- DEBUNKING MYTHS AND STEREOTYPES
- ACCEPTANCE OF EMOTIONAL DISTRESS AS PART OF HUMAN
EXPERIENCE, NOT ABERRATION ( 1 IN 5)
- REALITY OF ABUSE, NEGLECT AND VIOLENCE AS
    DETERMINANTS
- DEVELOP APPROPRIATE LANGUAGE: DISABLED, DEFECTIVE,
    CONSUMER, SURVIVOR, ALL NOT ACCEPTABLE

ACTIVISM:
- FOR ACCESS TO DRUGS WITH LEAST SIDE-EFFECTS
- FOR RIGHT FOR SUPPORT TO TRY TO REDUCE AND
  GET OFF DRUGS
  LEGAL HELP WITH RIGHTS
- SUITS AGAINST SYSTEM FOR LACK OF TRUE' CONSENT
  AND RESULTING PERMANENT DISABILITIES
  FROM DRUG TREATMENT

MEDIATION WITH SYSTEM:
- FOR THE DEVELOPMENT OF HEALTH PLANS,
  ADVANCED DIRECTIVES
- FOR ISSUES WITH TEAM, ETC.
  ADVOCACY TO MAKE FINANCIAL SUPPORT MORE
  HUMANE LESS RESIDUAL AND OPPRESSIVE
  ( NOT BASED ON WELFARE)
- MORE INCENTIVES TO GET WORK

## HOUSING
DEVELOPMENT OF COOPERATIVE MIXED HOUSING,
NOT GHETTOS
HOUSING WITH SUPPORTS FOR WOMEN AND
CHILDREN, NOT BREAKING UP FAMILIES
GROUP HOUSING WITH RECOVERY  ORIENTATION,
SUPPORTED NOT MANAGED

## EMPLOYMENT
CREATION OF SELF- RUN BUSINESSES
 - SUPPORT IN INITIAL PHASE
SUPPORT FOR SELF EMPLOYMENT
FLEXIBILITY, GRADUAL ENTRY,
ACCOMMODATIONS AND AFFIRMATIVE ACTION TO
GET INTO MAINSTREAM WORK POSITIONS
MORE FINANCIAL INCENTIVES TO GET OFF DISABILITY
- ADVOCATE AND FACTOR IN IDEA THAT RECOVERY IS
POSSIBLE, NOT NECESSARILY  PERMANENT DISABILITY

## CONNECTIONS/ALLIANCES
ALLIES MADE WITH PROFESSIONALS IN SYSTEM WHO
SUPPORT RECOVERY
CONNECTIONS TO GROUPS TO LOBBY FOR CHANGES
WANTED (CMHA?)
DIALOGUE WITH CORPORATE WORLD ABOUT
STRESS AND MENTAL HEALTH, GET THEM TALKING
SEEK FUNDING FROM FOUNDATIONS AND
CORPORATIONS WITHOUT A MEDICAL MODEL AGENDA OR
CONFLICT OF INTEREST

# INDIVIDUAL INTERVIEW GUIDE

My name is Joanna Carson. As you know, I am working in a participatory action research project with the Self-Help Group. This research is a part of a masters degree in social work, and the information will be used to write a final report for the Self-Help Group.

I want to remind you that your information will be kept confidential, that this is voluntary, and that you may choose to withdraw from participation at any time during the research project.

1) Do you have any questions before we begin?

2) Please tell me about your experiences in using psychiatric services?

3) What services, programs, individuals or experiences were helpful for your recovery?

4) If there were services, programs, individuals or experiences that were not helpful, what in your opinion would have been useful in their place?

5) Is there anything else you would like to add to this interview?

If you are not a member of the Self-Help Group please give me your address and I will forward a copy of the final report to you and will welcome any comments you wish to make. Members of the Network will have access to the final report.

Thank you for your participation. If you wish to contact me or my advisors at any time please feel free to do so.