MOTHERHOOD FOR WOMEN WITH SERIOUS MENTAL ILLNESS

by

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Motherhood For Women With Serious Mental Illness

ABSTRACT

Much of the literature about maternal mental illness makes assumptions about the problems in the relationship between mentally ill mothers and their children without the perspective of the mother's point of view. This exploratory qualitative study focused on the experiences of six mothers who were currently parents of school age and younger children, and were concurrently receiving treatment for a serious mental illness from the Greater Vancouver Health Service Society. The mothers were interviewed one or two times for approximately one hour each time, using a semi structured interview guide employing open ended questions. The interview examined the meaning to the mother herself of her role as a parent; the struggles and successes she identified; the significance of her social support network; and other aspects of her experience which have been important for her. The purpose of the study was to gain an understanding of each mother's particular situation and to explore the themes and issues raised in these mothers' stories. The data was analyzed using a narrative approach, to preserve the individuality and diversity of the mother's stories. The common themes that emerged for the mothers were: the centrality of the children to the mother's life; struggles around custody issues; the need for planning for the children in case of relapse; the need for social workers to understand mental illness; coping with children's behaviour problems; problems with the children's fathers; coping with poverty and related problems; and isolation and the need for social support. Social workers and health care professionals may use these narratives to increase their understanding of mothers who have a mental illness, and to develop policies, programs, practices, and education to improve services for these families.
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Introduction

The topic of motherhood and mental illness interests me from both a professional and personal perspective. I work at a community mental health clinic with a number of children who live with parents who have been diagnosed with a serious mental illness (generally considered to be forms of schizophrenia, bipolar mood disorder, or major depression.) I have also worked with parents who have had their children apprehended because of their mental illness. Personally, as a foster parent, I have cared for several children who had parents with a mental illness. I have observed problems for these children on many levels. Many of these problems seem to stem from unrealistic expectations, and a lack of care and support, for the mother in her role as parent. I am interested in improving services for these children and their parents.

When I began examining the literature about children of the mentally ill, I found there was a great discrepancy between the troubling situation for children that was described in the literature, and the few resources available to help families. I found very little in the literature that was useful in relation to working with and understanding the mothers of the children. Mothers were described as functions of their psychiatric diagnosis, and their struggles to maintain their families while coping with a disability were virtually ignored. From my experience in the community, I found that teachers, foster parents, and child welfare workers often lack information about mental illness, which prevents acknowledgment of the reality of the mother's situation. Compounding the problem, adult mental health workers may lack specific training which includes how to assess risk factors for children, child centered crisis intervention, and awareness of the ongoing developmental needs of children. Children who appear to be functioning well, but who are living in an unstable and distressing situation, frequently "fall between the cracks", not qualifying for services from the mental health centre, or from child protection services. At present, I am unaware of any services in Vancouver which particularly focus
on the needs of families of school age children when the mother has a major mental illness.

While the number of families with a parent who suffers from a serious mental illness is unknown, most recent studies have shown that the birth rate for mental health consumers is now about the same as the average population (Apfel & Handel, 1993; Coverdale et al., 1992). A growing number of mental health consumers are raising children, due to improvements in medical treatment, de-institutionalization, and social supports such as daycare and community programs which promote their ability to maintain custody of their children. Parenting issues are a relatively new concern in adult mental health, and there is very little literature which focuses on policy issues related to parental mental illness. Most studies addressing parental mental illness have focused on epidemiological considerations, such as the increased risk that these children may develop a mental illness. We know that stress may trigger relapse for the parents, and that chaotic family life and genetic factors may contribute to the future development of mental illness for children. Other risks for these children, such as trauma, emotional abuse, and neglect, are serious and well documented. Although the difficulties associated with these families have been a significant concern for child welfare workers, few workers are trained in dealing with the particular needs of either parents who have a mental illness or their children. It is important for policy makers to understand that both the rights of the parents and the rights of the child must be considered when designing family policies such as eligibility and mandates for children's services such as child care, and legislation in the areas of disabilities, mental health, and child protection.

When a woman with a mental illness becomes pregnant, she often immediately becomes the focus of negative, anxious attention, which follows her throughout the pregnancy and birth of her baby. Although she loves her baby, who often becomes the centre of her life, she is undermined as a mother, and the parent-child attachment is damaged, when she is given the impression that she is not the best person to care for her
child. She may suffer increased active symptoms of her mental illness, and not be able to receive the medication that helps to control her illness during the pregnancy. This mother is likely to be a single parent, living in poverty, with few resources to cope with the inevitable crises that anyone living with a mental illness is likely to experience. She may be reluctant to ask for help, because she is afraid of criticism, losing control, and possibly losing custody of her child. Both her illness, and the reality of these fears, tend to isolate her and decrease her social support.

I believe this is an important area to research because despite these difficulties, a growing number of mental health service consumers are actively raising children, due to better treatment, de-institutionalization, and raised consciousness about consumers rights to self determination. Social supports such as daycare and community parenting programs promote the ability of mental health consumers to maintain custody of their children. Many assumptions have been made in the literature which do not take these changes into account. Much of the literature comes from a positivist perspective, which attempts to apply scientific methods to investigate social problems, with the hope that they can be predicted and controlled. Most studies in this area are focused on children's problems and risk factors, but there are very few which provide insight about the mother's situation. Very few studies have based their information on the knowledge and reflections of the parents themselves. I believe that social workers need to continually explore the changing social environment, by direct inquiry into the lived experience of their clients, in order to effectively help and advocate for their clients. This small qualitative study, which seeks to understand and acknowledge a complex dimension of family life, is intended to provide mental health service consumers with an opportunity to speak for themselves in describing their own current issues and needs, and also to provide social workers with a valuable source of information.

I undertake this research from a feminist perspective. As a mother, I am aware of the prevalence of "mother blaming", and of the burden of responsibility that many
mothers face in bringing up their children. This is one of the reasons that I have chosen to focus on mother's experiences. I felt it was essential to begin an inquiry into the subject of maternal mental illness by seeking information about their experience from mothers themselves. The mothers in this study have agreed to share their perspective about their role as a parent, their struggles and successes, the significance of their social support network, and their perceptions of their own needs. While this is a very small study, and therefore doesn't address all of the kinds of situations that other mothers who are also affected by a serious mental illness may experience, I believe it does provide some interesting insight to the above questions.

Chapter one of this thesis presents an overview of definitions, history, and disability issues related to serious mental illness. Chapter two is an overview of the literature about motherhood for women with serious mental illness, primarily from medical and psychiatric studies. In Chapter three I will describe similar research studies that have looked at children who have parents who have a mental illness. Chapter four describes legal, policy and practice considerations, based on current practices in British Columbia. Chapter five describes a feminist approach to this subject, including first person accounts from feminist writers. Chapter six outlines the research design and the methodology that I used in this study. Chapter seven presents the stories of the six mothers who participated in this study, with a short discussion of the themes in each story. Chapter eight presents a summary of the main themes from the participants' stories, with references to the literature. In chapter nine I will discuss policy directions arising from the interviews, implications for social work practice, and future directions for research.
Chapter One
Definitions, History, and Disability Issues

What is Serious Mental Illness?

In this thesis, the term "serious mental illness" will be used to describe people who have a serious, continuing illness that has a significant effect on their lives. The term "mental health consumer" will be used to signify contemporary users of psychiatric services, although there is an ongoing debate among mental health consumers about the use of this term, as they differ from other consumers in that they may lack power, authority, choice, and control over their treatment. (Blackridge, 1996). It is difficult to find language to discuss mental illness that avoids objectifying and pathologizing people. I am very uncomfortable with generalizing about such a diverse group of people who have such a multiplicity of experiences, resources, and needs. I do not mean to imply that problems exist in every case, or to suggest that problems are specifically related to psychiatric diagnosis rather than complex factors.

Approximately 3% of the general population can be described as living with a serious mental illness, which refers to a long term, persistent psychiatric illness, usually encompassing the diagnostic categories of schizophrenia and related disorders, and major affective disorders, as described in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, or DSM IV. A particular diagnosis can encompass a broad variety of experiences for individuals. Appropriate medication, social support, and the availability of resources can make significant differences in the course of a mental illness. Many people do recover or have long periods of remission.

Health and Welfare Canada (1986) distinguish between "mental disorder" and "mental health problem." A mental disorder may be defined as a recognized, medically diagnosable illness that results in the significant impairment of an individual's cognitive, affective or relational abilities. Mental disorders can be managed by approaches
comparable to physical disease - prevention, diagnosis, treatment, and rehabilitation. The DSM IV states that the term "mental disorder" is a "reductionist anachronism of mind/body dualism" as there is no clear boundary between mental and physical disorders. However, the writers of DSM IV use the term "mental disorder" because they have not found an appropriate substitute (DSM IV p. xxi). A mental health problem is defined by Health and Welfare Canada as the disruption in the interactions between the individual, the group, and the environment. Such a disruption may result from factors within the individual, including physical or mental illness, or inadequate coping skills. It may also spring from external causes, such as the existence of harsh environmental conditions, unjust social structures, or tensions within the family or community. An effective response to mental health problems must therefore address a broader range of factors (Health and Welfare Canada, 1986).

People who have a serious mental illness seldom meet professionals outside of mental health professionals who actually understand the nature of their illness. Many people who are diagnosed with mental illness are able to live stable lives with support and medication. However, it is likely that a person will experience several relapses which result in crisis responses from family or the community. As well, when experiencing acute symptoms of the illness, many people will have little insight, paranoia, delusions or hallucinations, and aggressive or disorganized behaviour, and thus may be unable to access help or resources for prevention. Most studies have shown that the parental diagnosis is less important in its effect on the child than the quality of parenting, (particularly hostility of the parent toward the child,) and other factors such as poverty, quality of the marriage, etc. (Pound, 1996, p. 205).

Schizophrenia

Schizophrenia is a disease of the brain, which is diagnosed by symptoms of delusions, hallucinations, disorganized speech, grossly disorganized or catatonic behaviour, and negative symptoms, which last for at least 6 months, with the active
symptoms lasting for at least one month (DSM IV). The symptoms of schizophrenia are divided into "positive" symptoms, which means characteristics which are present, and should be absent; and "negative" symptoms, which are characteristics which are absent, and should be present. The positive symptoms include delusions, hallucinations, thought disorders, excitement, grandiosity, suspiciousness/persecution, and hostility. The negative symptoms include blunted affect, emotional withdrawal, poor rapport, passivity, apathy, social withdrawal, difficulty in abstract thinking, lack of spontaneity, and stereotyped thinking (Kaplan, Sadock & Grebb, 1994). One quarter of people diagnosed with schizophrenia recover completely, usually within two years. One quarter respond well to antipsychotic medication and do well if they continue to take the medication. One quarter respond less well to medication, have negative symptoms, and require continual care and support, such as special housing. About 15% of people diagnosed do not improve, and require asylum care. 10% complete suicide (Torey, 1988, pp.119 - 120; Mechanic, 1989.)

Children of a person with non schizophrenic parents have a 1% chance of getting the disease; if one parent has schizophrenia they have a 10-13% chance of getting the disease, and if both parents have schizophrenia, they have a 46% chance (Torey, 1988). It is suspected that the disease is not itself inherited, but that a predisposition to react to environmental influences leads to schizophrenia. The environmental influence is unknown, but may be a virus, specific dietary factors, stress, or toxins. Another theory is that there is an inherited defect in the brain that makes it more vulnerable to malfunction. Other genetic theories propose that schizophrenia may be carried on more than one gene, leading to more complex genetic pattern, or that it may be part of a larger continuum including mood and personality disorders (Torey, 1988; Mechanic, 1989).

Although schizophrenia is evenly distributed across gender, there are significant gender differences. The average age for hospitalization of women is 25, compared to 18 for men. Women have lower rates of suicide, unemployment, hospitalization, and
disruptive relationships. This may be related to later onset, as an older person may have more skills and resources to cope with any impairment. Schizophrenia is usually considered to be a more severe disease in men, measured by social life, marriage, work, suicide rate, and level of function (Torey, 1988).

**Mood Disorders**

Mood disorders are primarily disturbances in mood, rather than of thought as in schizophrenia. The two categories of mood disorders are depressive disorders, and bipolar disorders. Bipolar disorders are approximately one third as prevalent as schizophrenia, approximately 0.05% (Mechanic, 1989). A genetic predisposition is clearly established with bipolar disorder, through twin and adoption studies (Mechanic, 1989; Torey, 1988). The "manic" stage of bipolar disorder is characterized by excitement, overactivity, grandiosity, irritability, and dominance. The person may have delusional ideas and may engage in dangerous and inappropriate behaviour. The person may have episodes of mania alternating with depression, or may have a series of manic episodes, or any combination. Between episodes, a person with bipolar disorder is characteristically normal. Approximately 10% of persons with bipolar illness commit suicide, similar to the rate for schizophrenia (Torey, 1988).

Major depression is characterized by symptoms of a sad mood, crying, lethargy, irritability, self blame, self preoccupation, poor appetite, sleep disturbances, loss of interest in normal activities, loss of energy, slowed thinking, hopelessness and, often, suicidal ideas. It is much more prevalent than the other major mental disorders, and is much more gender specific: one in four women become clinically depressed at some point in their lives. For men, this is one in ten. In most people, depression lasts for about a year. For about 30% of people who become depressed, chronic depression prevents normal life. Also 50% of people who develop a major depression are likely to have a relapse. Major depression is clearly linked to external causes such as major losses, trauma, illness, and stress (Kaplan et al, 1994). While there are some studies
which support a genetic predisposition to depression, it is difficult to control for social environmental factors which influence the development of depression. However, some studies have shown that a very high number of children who have parents with unipolar depression do develop depression, which I will discuss in more depth in the chapter about children's issues.

Other serious mental disorders:

Other serious mental disorders, which range in intensity for each individual, include anxiety disorders, obsessive compulsive disorder, personality disorders, and other non specified disorders that are disabling to the person. The DSM IV also describes disorders related to alcohol and drugs, which are not specifically addressed in this thesis, although the effects on children may be very similar.

History

Women who have a mental illness have a long history of being criticized, marginalized, and stigmatized. For many years, the diagnosis of mental illness was used to oppress women, often leading to institutionalization and severe abuses such as sexual and physical abuse, medical and psychological "experiments", and forced abortion and sterilization (Caplan, 1993; Chester, 1972; Smith, 1975). Sexual behaviour in long term hospitals was denied, ignored, or quietly managed, with resulting children placed in foster homes or put up for adoption (Apfel & Handel, 1993).

The state has historically treated people who have a mental illness as incompetent child-like individuals who required "protection" which often took the form of eliminating their basic human rights. The concept of parens patriae (or parent of the country) was first used in 1700s to protect the property of vulnerable persons, and initially stressed the preservation of the property of "lunatics, idiots, and young persons" (Armitage, 1993). Thus, regarding parental mental illness, both the child and the mentally ill parent would have been regarded as requiring protection by the state acting as a parent.
During the middle ages, people with mental illness were often believed to be witches, or to be possessed by the devil, and were tortured, killed, or banned from European society. In the sixteenth century, early models of mental institutions developed. The most famous of these was Bethlehem Hospital in London, known as "Bedlam", which opened in 1547, and was notorious for wild, crowded, filthy conditions. However, most mentally ill people in Canada were not placed in institutions prior to the 18th century, and were generally assimilated into society, supported by their families. If they could not be cared for by relatives, or in private "madhouses" or church sponsored charitable institutions, they were subject to the provisions of the English Poor Law system, and indistinguishable from the poor, the unemployed, the handicapped, or other dependent people. In the mid 1800s, a reform movement called for the creation of asylums, which were envisioned as promoting moral treatment of the insane. Although the impetus of creating these asylums was to reform care of the mentally ill, the function of providing secure custody to deviant individuals became their predominant purpose. By 1850, most people with mental illnesses were isolated in asylums, which were large, overcrowded, inadequately staffed, warehouse like institutions. Another reform movement, called the Mental Hygiene Movement, attempted to improve conditions, care, and treatment of the institutionalized mentally ill during the early 1900s. It was led by Clifford Beers, a former psychiatric inmate who wrote about his own experiences in several mental institutions. The mental hygiene movement also led to an increase in institutionalization of the mentally ill, but it promoted the development of hospitals and treatment programs, rather than simply warehousing people who had a mental illness. This influenced the situation in British Columbia: in the late 1940s a psychiatric hospital, Crease Clinic, was opened on the grounds of Essondale, the B.C. asylum. At the time, the population of Essondale was over four and a half thousand inmates (Libbeter, 1994).

One of the focuses of the Mental Hygiene philosophy, which guided government policy, was the prevention of insanity through the prevention of "hereditary taint", which
referred to preventing people who had a mental illness having children (Libbeter, 1994). From the years 1933 to 1973, British Columbia had legislation called the Sexual Sterilization Act, which targeted people who "by reason of inheritance would have a tendency to serious mental disease or deficiency" (Gregory, 1996). While large numbers of sterilizations were not performed in B.C., due in part to religious opposition, thousands were reported in places such as Alberta and California. This attitude of eliminating "mentally defective parenting" also resulted in the widespread apprehension of children of the mentally ill.

Until the 1970s, treatment for people with a mental illness was centered in large institutions and psychiatric wards of hospitals. People diagnosed with a serious mental illness often stayed in an institution for life. In the early 1970s, as improved drug treatments became available, community mental health centres were established throughout the United States and Canada. Thousands of patients were discharged from hospital under the policy of deinstitutionalization. In many areas, this was a very poorly planned program, as the community did not have the resources to provide service to the number of psychiatric patients requiring care (Mechanic, 1989).

In 1972, the Metropolitan Board of Health of Greater Vancouver produced a policy paper written on mental health, written by Dr. John Cumming, called The Plan For Vancouver, which resulted in the formation of the Greater Vancouver Mental Health Service (GVMHS). This plan called for setting up eight decentralized multidisciplinary Teams, accessible to all areas of Vancouver, with a narrow mandate to treat the severely and chronically mentally ill. In 1986, a Family and Children's component was set up. This service has a mandate to respond to children, including children of adult clients, who require psychiatric assessment and treatment.

Because many mental health consumers were not able or allowed to raise their children in the past, the trend for consumers to become active parents is a new situation. Most of the research, even if ten years old, is out of date, because there have been
improvements in treatment as well as improvements in social attitudes towards diversity issues, and human rights for both people with disabilities and children. During the past ten years there has also been a significant increase in the development of the "consumer" movement in mental health, which has meant the creation of self help organizations, the assumption of advocacy roles for consumers, and increased power for consumers in decisions affecting treatment and incarceration. Consumers demand that they be seen as "people with abilities, not just diagnoses" (Bachrach, 1996). In British Columbia, the Mental Patients Association, established in 1971, was one of the first of two original patients rights and advocacy movements in North America. Other B.C. advocacy groups include the West Coast Mental Health Network, Unity Housing, the B.C. Mood Disorders Association, B.C. Schizophrenia Society, the Coalition of People with Disabilities, and the Canadian Mental Health Association.

**Disability Issues**

Disabilities associated with mental illness come from more than one source. Disability issues for people with a mental illness can be described as primary, secondary, and tertiary (Bachrach, 1996). "Primary" describes the effect of the symptoms of the illness - which may include such disabilities as lethargy, strange behaviour, lack of insight, and disturbances in social relationships, hallucinations, paranoia, and disorganization. "Secondary" disabilities result from the person's negative response to his or her own illness: for example, anger at the illness; loss of self identity connected to the feeling of being a "patient"; fear; and isolation. These disabilities persist even when the primary symptoms have disappeared. "Tertiary" disability refers to societal reactions to mental illness, and is evidenced by barriers, stigma, inadequate housing, poverty, unemployment, and marginalization in society. Other examples of tertiary disability include service fragmentation, in which mental health consumers are often excluded from services, or in which services designed for this population are inadequate and inferior to mainstream services. Bachrach (1996) notes that these three categories of disabilities are
separated only in theory, but actually overlap continually for the individual. Children are also injured by all of these categories of disabilities when present in their families' lives.

The next two chapters will primarily describe the clinical literature that relates to mothers who have a mental illness, and their children.
Chapter Two

Literature About Mothers With Serious Mental Illness

In this chapter I will give a brief summary of some of the research that has been published about mothers who have a serious mental illness. The literature quoted is primarily from the fields of psychology and psychiatry, and the “medical model” point of view is predominant in the published literature about this topic that I am presenting in this chapter. In Chapter Five, which is about feminist concepts, I will present more broadly based literature that is not so clinically oriented.

In a study of 36 research articles for the years 1983 - 1992, specifically relating to parenting and related experiences for women with serious mental illness, Carol Mowbray, Daphna Oyserman, and their co-researchers (1995) found major gaps in the research base. Many of the studies used small convenience samples, over-representing white and married women. Most used research participants from inpatient psychiatric settings, rather than individuals with a psychiatric history who are currently functioning in the community. This sampling strategy may have biased results to emphasize problems and dysfunction, or conversely may have omitted study participants with less acceptable behaviour who were not involved in treatment programs. Very few of the studies included the mothers' perspectives on issues of pregnancy and parenting:

No research study was identified which sought to understand the meaning of pregnancy and childbirth from the perspective of the mother herself. Research must go beyond measures of anxiety levels, fears, problematic maternal attitudes, etc., to find out how the mother perceives her own status and feels about her infant. Research has ignored the positive aspects of parenting for women with a psychiatric history ... yet, client anecdotes reveal pride in having taken care of someone else and the motivating force that resumption of parenting can have for attaining wellness. Clinical notes suggest that becoming pregnant can bring about a rallying of resources for patients and be a positive event. Thus, understanding pregnancy and childbirth experiences must incorporate the perspective of the mothers themselves. From this perspective, it may be possible to uncover personal strategies and get information on the ways in which
natural support systems can intervene... The extent to which social supports function to mediate the relationship between serious mental illness and problems during pregnancy and after childbirth should be explored. (Mowbray et al, 1995, p. 35)

While the number of families with a parent who suffers from a serious mental illness is unknown, most recent studies have shown that the birth rate for mental health consumers is now about the same as the average population (Apfel & Handel, 1993; Coverdale et al., 1992; Miller, 1992). A number of studies surveyed by Mowbray et al. (1995) showed that women with serious mental illness are likely to be sexually active, to engage in casual sexual encounters more frequently than stable sexual relationships, and to have children. Schab, Clark, and Drake (1991) found that clients with mental illness placed a high value on parenting, and perceived the mental health system as insensitive to their needs as parents.

Apfel and Handel (1993) described the losses suffered by women with severe mental illness as a result of voluntary and spontaneous abortions, stillbirths, and neonatal deaths as well as loss of custody of their children. They describe the value of parenting as a positive experience for the mothers, as an opportunity to order one's life, overcome stigma, and experience an emotionally rich and rewarding role.

Many research studies longitudinally compared children of schizophrenic mothers with children whose mothers have other psychiatric disorders or who do not have psychiatric diagnoses (eg. Sameroff et al., 1984; Weintraub, 1987). These studies found that the degree of symptoms, the mother's social competence and role functioning ability, single parent status, and the availability of an alternate caregiver contribute to the outcomes. Sameroff and associates found that social status was also important in the outcome for children.

Sands (1995) studied parenthood among women participating in a community residential program for mothers with severe and persistent mental disorders and their children. She found that the mothers identified motherhood as a central life experience
that gave meaning and focus to their lives, and affirmed their normalcy in the community. However, the mothers experienced many struggles associated with maintaining custody and caring for their children. In comparison with a control group of low income single mothers in the same neighbourhood, the mothers who had a mental illness were less open to discussing their children's emotional, behavioural, and learning problems, and less likely to complain about stress or any aspect of parenting. This may have reflected the past losses these mothers had experienced, and their fear that they would lose their other children.

Many mothers who have a serious mental illness are single, or have little support from their partners, who are likely to have a mental illness as well (Gopfert et al., 1995; Mowbray et al., 1995). One study showed that 66% of women diagnosed with schizophrenia had a spouse with a major mental illness, 42.4% with schizophrenia (Oyserman et al., 1994). Other research has shown that the spouse is likely to have a personality disorder (Mowbray et al., 1995). Many women who have a mental illness also cope with violent husbands and high rates of child abuse by partners (Fisher, 1996; Riddington, 1989). Mothers with a mental illness are likely to experience marital separation, and resulting loss of income, stigma and shame (Hatfield, 1996).

Much less has been researched about fathers who have a mental illness, and the effect on children. Men who have a mental illness are less likely to be in stable relationships, and seldom maintain access to their children. A majority of men with a serious mental illness never marry, while a majority of women do marry (Mowbray et al., 1995). Husbands of women with a serious mental illness frequently become depressed as well, and divorce is common (Grunebaum & Cohler, 1982).

**Family Planning and Birth Control**

Coverdale, Aruffo & Grunebaum (1992) looked at the family planning needs of women with a chronic mental illness. They found high rates of unplanned pregnancies for these women, due to lack of education concerning family planning and birth control,
problems with memory and cognitive abilities, and low self esteem among women which contributes to failures to use birth control. They also found that psychiatrists often did not take patient's sexual histories, or identify patients at risk of unwanted pregnancies. In a study they conducted of 80 female outpatients at a community health centre in the U.S., one third of the women who said that they did not want to become pregnant had not used contraceptives at the time of last intercourse. In two similar studies mentioned in this article, over half of the respondents did not use contraceptives although they did not want to become pregnant. The researchers also found that the majority of patients had not received minimal gynecological care, such as pelvic examinations, during the past three years. They recommended that family planning programs would be best provided within the outpatient clinics at mental health centers.

Psychotropic Medication

Many women undergo remission of psychosis during pregnancy, although some women continue to require medication to maintain their stability. As well, women with mood disorders may encounter increased risks of depression or mania during pregnancy. Goldberg, (1994) reviewed over five hundred articles on the use of psychotropic drugs during pregnancy and lactation. He found that no controlled studies had ever been done in pregnant women to truly prove their safety, but that it appeared that most, but not all, currently used psychotropic drugs were relatively safe for use during pregnancy. Although he advised against any use of drugs during the first three months, he stated that the physician must consider the potential risk to the mother and fetus of harm caused by the mother's behaviour during psychotic episodes or severe depression. All of the current "antimanic" medications were associated with particular risk to the fetus. Goldberg also found that all psychotropic drugs are secreted into milk, and he advised mothers using medication to avoid nursing their infants unless they fully understand the risks and benefits in their particular case. No studies about how mothers who have a serious
mental illness feel about the use of psychotropic medication during pregnancy and post partum have been undertaken (Mowbray et al., 1995).

**Custody Issues**

Many mothers who have a mental illness are not caring for their children. A recent study by the Mental Patients Association in Vancouver (Judas, Niles, & Woodward, 1997) found that of 51 women who responded to a survey to help the agency develop services for mentally ill women and their children, 52% were mothers, but few were actually raising all of their children. 27% of the respondents had given up some of their children for adoption; 19% had children apprehended by social services; 16% lost custody to relatives; 19% did not know where their children were; and 26% of the respondents had never had custody of some of their children. The mothers in this study said that lack of adequate finances and housing, lack of social and emotional support, too much stress, and fear of authorities taking away their children, were their most significant difficulties as parents. (This study is also referred to on page 21.)

Mowbray et al. (1995) reported that from 60 - 75% of mentally ill mothers were likely to lose custody of their children, based on a survey of a number of American studies. However, loss of custody may not mean loss of caretaking responsibilities, as the mother may live with extended family or have regular contact with the children (Mowbray et al., 1995). We also do not know what kinds of relationships the children in alternate care arrangements (foster care, extended family, adoption) are able to continue with their parents, how this affects their relationships later in life, and what factors mediate to create the best situation for both the children and the parents. The fear of losing custody may create a climate in which parents may not feel safe to discuss their concerns about parenting, as many have already lost custody of some of their children or have been threatened with the loss of their children when they have an acute episode of their illness.
Parenting concerns

In the mental health system, which operates on the "medical model", focused only on the patient, rather than the family or community, there is usually no differentiation between the mother's needs as a patient, her needs as a parent, and the child's needs (Grunbaum, 1993). Parenting is often seen as a constructive "vocation" for the mother. The actual complexity of the role is minimized, possibly because it is not well understood by clinicians. The children of people with a mental illness have been referred to as "The Invisible Children" (Fraiberg, 1978) because clinicians seldom inquired about the health of the children, and very seldom saw them. In a study of adult files in Denmark, almost all of the file recordings about the patient as a parent reinforced the importance of the parenting role for the adult patient. There was no consideration of the actual experience of the children (Grunbaum, 1993). In North America, a group of researchers interviewed over one hundred psychiatric patients who had school age children, and found that clinicians generally had no contact with the children (Vanharen, La Roche, Heyman, et al., 1993). This silence about such a core area of a mother's life may be interpreted by these mothers as a message that they should not expect that their illness will affect them as parents, and if it does, they should not discuss their problems openly. Considering the impact that mental illness had on the parenting issues described by the mothers in my study, it is clearly an important area to address in treatment. (Note: all of the participating mothers told me that they did feel that they could discuss parenting issues with their therapists at G.V.M.H.S., but a similar study done by a Vancouver advocacy organization (Judas et al., 1997), found that mothers said they received little support as parents from therapists or other health care professionals.)

Studies have found that the parenting skills of depressed mothers were not significantly poorer than those of single, impoverished mothers (Bartha, 1996, p. 123). However, parental inattentiveness, due to symptoms of the illness or side effects of medication, have a very negative influence on some of the children in the families that
were studied. For example, there is a high rate of childhood accidents in this population, as shown by Gelfand & Teti's study (as cited in Bartha & Concalves, 1996, p.122).

The UCLA Family Stress Project, conducted by Dr. Constance Hammen and colleagues, was one of the largest studies about mothers with mental illness. It was based on 1,000 interviews with mothers and their children, as well as reports from teachers and therapists. The study examined psychosocial variables affecting three groups: mothers with a psychiatric diagnosis of unipolar or bipolar depression; a control group of "normal" low income mothers, and a group of mothers who had severe, chronic, debilitating medical disorders. They found that children who tended to be doing poorly in school, or who showed signs of unhappiness or mental illness, shared similar risk factors of chronic stress, maternal depressed mood, and family disruption, regardless of whether or not their mothers were mentally ill. They concluded that the diagnosis of mental disorder, in itself, was not primary problem in these families. (Hammen et al, 1987).

Coping with Children's Behaviour

Much of the literature has focused on risk factors for children (e.g. Anthony & Cohler, 1987; Beardslee et al., 1993; Feldman, et al., 1987). The predominant disturbances found in the children are serious depression and behaviour disorders such as oppositional defiant disorder and conduct disorder (Anderson and Hammen, 1993; Keller et al., 1986). Conduct disorder is characterized by serious behavior problems such as school avoidance, substance abuse, violence, criminal activities, and antisocial behaviour. It has not been a particular focus of research to examine what it is like for these mothers to deal with these difficult children. Interactional approaches have looked at how "expressed emotion" (which refers to high levels of negative emotions expressed at home) is related to the subsequent development of mental illness in the child (Schwartz, et al, 1990). It seems likely to me that it would also be very stressful for a parent in treatment for a mental illness to deal with "expressed emotion" in the form of constant power struggles and negativity in their relationship with their child. Despite
many studies supporting the link between stress and relapse for psychiatric patients, there are few or no programs to support parents with a mental illness. It seems that parents who have a mental illness, and therefore may be very vulnerable to stressful home situations, are living with disturbed children who are also subject to environmental stressors related to poverty and poor housing. Research is needed to explore the efforts made by these parents to get help for their children, and the effectiveness of resources available to them. In particular, I wonder whether there is a dynamic that begins with resistance to criticism and that leads to a fear of ultimately losing custody of the children, and finally results in a lowering of trust in professional agencies. In this progression, help may be unacceptable to the mother when it is most needed.

Family, Professional, and Social Support

Studies have shown that during pregnancy the social contacts of mentally healthy women increased, while support for mentally ill women did not (Mowbray et al., 1995). During pregnancy, many women with a mental illness receive inadequate prenatal care (Oysterman et al., 1994; Seeman, 1996). These studies were American, and the situation may be different in Canada where there is universal medical care. However, there may be conditions related to the mental illness which prevent women from receiving adequate prenatal care, including psychiatric factors such as lack of insight, confusion, and paranoia, and social factors such as homelessness. Depression is also experienced by many women after childbirth, which may be more serious and complicated for women with a psychiatric history (Mowbray et al., 1995; Silverman, 1989). This may increase the likelihood that these mothers may withdraw from their support network, and require more outreach. Laura J. Miller (1992) described a number of shortcomings in the general health care of women with a chronic mental illness, including: failure to assist with family planning; failure to observe worsening mental health during pregnancy; inadequate planning for child custody; lack of access to services; and omitted pelvic examinations. Miller also described the necessary components of a system to provide
comprehensive and coordinated care for pregnant women who have a mental illness. These included assessment of adaptation to the pregnancy and ability to care for an infant; somatic and psychotherapeutic treatment; parenting skills training; family planning services; outreach; and close liaison with obstetric services. Miller described a Chicago area collaborative program called the Thresholds Mothers' Project as an example of a program which implements these components.

The previously cited study by the Vancouver Mental Patients Association (Judas et al., 1997), which surveyed 27 mothers with a mental illness, found that the mothers reported very low levels of satisfaction with emotional, family, and community support, but even lower ratings of satisfaction with professional support. The mothers reported that their family doctor gave the most support, (although this was minimal) and that their psychiatrist, therapist, and social worker gave very little support.

**Trauma and Patients' Backgrounds**

A recent study at Riverview hospital of patients on two wards (Fisher, 1996) found that many of the patients had parents who had a psychiatric history (over 30%). One finding of the study was that high levels of trauma were described by the participants: 58% of the women and 23% of the men had been sexually abused before age 17, and 38% of the women and 36% of the men had been physically abused before age 17. Half of the female respondents had been physically and sexually abused as adults. While this study provided information about the trauma experienced by patients in families where so many of the parents of the participants were mentally ill and/or addicted to substances, it did not describe whether there was a difference between patients who had had mentally ill parents and patients whose parents did not have a psychiatric history. No questions were asked about whether the respondents had any children themselves.

The Mental Patients Association study found that 44% of their sample had grown up in families where one or both parents were mentally ill, and that these women
described a range of childhood experiences ranging from physical abuse to total ignorance by the parent (Judas et al., 1997).

Concerns Related to the Diagnosis

The diagnosis of a particular mental illness is not an absolute indicator of a particular person's experience, any more than the diagnosis of cancer or diabetes describes the many possibilities of a particular individual's responses and experiences. Researchers who have compared mothers who have different diagnoses have shown contradictory results, depending on their focus, and probably the particular individuals in the study. Grunebaum et al., (1982) found greater disturbance in children of depressed mothers, and less disturbance than expected in children of schizophrenic mothers. This could be re-interpreted to imply that women who have an episodic disorder, such as recurrent schizophrenia, which may become acute and require hospitalization at times, but which can generally be managed with medication, have a different experience of parenting than women who have a severe depressed mood, with accompanying feelings of hopelessness and near-total depletion of energy. It is also possible that children may cope better with acute parental illness than with chronic illness.

Beardsley and MacMillan (1993) developed a protocol for clinicians to follow to address the concerns of parents who have a serious mood disorder. It includes: (1) assessment of all family members; (2) cognitive teaching about mood disorders, risks, and resiliencies in children of parents with mood disorders; (3) the development of a link between the cognitive teaching and the family members' life experiences; and (4) enhancement of the family's understanding of the illness and the development of plans for the future based on the increased understanding.

In her article about mothers with schizophrenia, M.V. Seeman (1996) addressed the following themes: (1) Pregnancy may be unplanned, and women with schizophrenia may not receive adequate prenatal care. (2) The mother may be particularly vulnerable to postpartum psychosis. (3) While mothers may be very deficient parents while psychotic,
it does not follow that they cannot parent adequately much of the time. Mothers with schizophrenia are often better served by the provision of regular homemakers and house help and other relevant support than by the removal of their children to foster care. (4) Parenting classes or groups are important. They teach mother about developmental milestones and provide peer support, time away from the responsibility of child care, instrumental assistance and psychological guidance. (5) The mother may have a problem with communication of feeling, and may benefit from behavioural rehearsals and training in expressing emotion, especially positive emotions. (6) Patient education groups which help patients monitor their medications, and deal with side effects, etc. if neuroleptic side effects interfere with parenting. (7) Treatment approaches should include outreach if the mother is isolated or extremely suspicious. (8) A response should be made to children if they appear to be affected by exaggerated fear. (9) Impulses to anger and aggression may arise precipitously and are very difficult to predict because they arise from fears which may have an irrational base. (10) Communication is frequently disturbed in schizophrenia, and mothers may have difficulty expressing thoughts and emotions, forgetting words or intents, getting distracted, being led off topic, or initiating conversations. This may cause more problems as children grow older. Therapeutic support and cognitive - behavioural training may be helpful to the mother. (11) It is often difficult for parents with schizophrenia to bridge to school and community organizations. Seeman states that a comprehensive treatment approach would involve individual and group therapy, family counselling, carefully monitored pharmacotherapy, attention to income supplementation, adequate housing, vocational assistance, educational upgrading, social and life skill training, with an emphasis on general health and meaning off life issues.

Assessment of Parental Functioning

Assessment and identification of needs for both parents and children in families where there is parental mental illness is essential for the provision of adequate services.
There is a difference between 'involving' and 'depriving' aspects of parental mental disorder for children. 'Involving' refers to involving children in the parent's symptoms, either by enacting the parent's delusions or abnormal fears, or by being incorporated in the parental delusional system. 'Depriving' refers to the parent who is unable to show emotional warmth or any other, even negative, affection and who may be severely depressed and unable to provide the child with any stimulation. Whether these situations should cause alarm depends on their severity. (Gopfert, 1996, p. 291) Gopfert cited the following list of questions developed by Oates in 1984 as helpful in assessing problems and their severity:

1. What is the quality of functioning of the parent during remission? Are there any significant residual negative or positive symptoms or any inability to respond to the needs of others, particularly children?
2. How long are any periods of remission in comparison to the duration and frequency of actively disordered life phases?
3. Does the patient comply with prophylactic medication and treatment?
4. How early or late does the patient (or relatives) present when an acute exacerbation of symptoms occurs?
5. How much family/community support is available in times of crisis or when the parent cannot function properly, but is not ill enough to be admitted to hospital? How much of a secure and familiar environment can be provided for the child should the parent need admission?
6. Is there intense conflict in the parent's family or closer support system, centred around child-care issues?
7. How helpful are the professional services with all these issues?

I have included more information about parenting assessment in Chapter Four, in the section about implications for practice.
Specialized programs for Mothers and Children:

Several studies reported on joint hospital admission programs which allowed mothers to bring their very young children with them to a psychiatric ward. (Grunebaum, et. al.,1975; Grunebaum & Cohler, 1982). These programs had a goal of supporting the mother as a parent by improving her mothering skills as part of her treatment, and maintaining strong bonding and attachment between the mother and child. These kinds of programs have generally been discontinued due to improvements in treatment resulting in much reduced hospital stays (Grunebaum & Cohler, 1982).

Some programs in the community have been described in the literature (Cohler, Stott & Musick, 1996; Jenkins, 1996; McKay & Pollard, 1996; Schuff & Asen, 1996; Rubovits, 1996; Zemenchuk, Rogosch & Mowbray, 1995). These programs and demonstration projects aim to optimize the mother-child relationship through improving parenting skills, and addressing the cognitive, emotional, and social development of the child. They range greatly in resources. One program, Project Child in Providence, R.I. (Rubovits, 1996) provided extensive services for approximately 25 families including home visits, mother-baby school, a lunch program, social club for adults, stimulation groups for toddlers and preschoolers, transportation and community liaison. Staff at Project Child included a part time psychiatrist, a developmental psychologist, three full time Masters level clinical social workers, and a clinical receptionist. Another model of a community program, described by Jenkins (1996), provided a community coordinator who oversees a volunteer program in an ordinary house, run primarily by the mothers themselves, with few outside resources. The coordinator arranges for new mothers to be paired up with another mother who attends the centre, who will bring her there and support her until she and her child are settled. Twenty four hour phone links are also arranged between members. The center provides non judgmental acceptance and peer support for mothers with a mental illness. Parenting and personal development programs are available on a voluntary basis to members.
Another approach to the special needs of families with serious parental mental illness is described by D. McKay and J. Pollard (1996) as the community support model. This model promotes an interactive, holistic approach, in which professionals adopt more flexible roles to support informal caring networks in the community. The model seeks to broaden understanding and healthy opportunities for families within the larger community. The components of the model are:

- An informal network of caregivers, educators, and mental health professionals who are willing to work with families to identify and use resources in the families' communities.
- A mechanism for quickly and easily bringing together parents and all concerned professionals to plan proactively for the children.
- An attitude of trust for all the players.
- A belief in proactive interventions.
- A willingness to set aside considerations of potential pathology when dealing with the children of mentally ill parents.
- A willingness to set aside professional roles and carry out tasks that may be unrelated to one's accustomed role.
Chapter Three

Literature About Children of the Mentally Ill

This section of the literature review is an overview of research that has been conducted about children who have a mentally ill parent. In most of these studies, the "parent" has actually been the mother. It is important to bear in mind at the beginning of this section that not all psychiatrically ill parents are inconsistent or ineffective at parenting, and not all children of psychiatrically ill parents are impaired or unable to cope (Silverman, 1989).

A major focus of the research about children who have a mentally ill parent has been on risk factors for the development of future pathological symptoms in children. (e.g. Anderson & Hammen, 1993; Anthony & Cohler, 1987; Beardsley & MacMillan, 1993; Feldman et al., 1987; Grunebaum et al., 1975; Weissman et al., 1984). This research shows that the children have a higher than average risk of developing a major mental illness at some point in their lives, although they will not necessarily develop the same illness as the parent. Children with a parent with schizophrenia are generally considered to have a 10 - 15% chance of developing schizophrenia. If both parents have schizophrenia, the chance is reported by most studies as around 40% (Torey, 1988; Silverman, 1989). This research shows that the majority of children of people with schizophrenia do not develop schizophrenia; and that the majority of parents whose children develop schizophrenia do not have schizophrenia. Children who have parents with serious mood disorders have a 20% chance of also developing a serious mood disorder if one parent is ill, and 50% if both parents have mood disorder (Silverman, 1989). (Note: this research did not address children who have single parents, where the child would spend most of his or her time with that parent.) Other studies which looked at gender issues found that 40% - 50% of adolescent daughters of parents with an affective disorder developed major depressive disorder by age 17. (Keller et al., 1986; Weissman et al., 1984). Although most children will not develop the same illness as their
parent, most researchers agree that at least 50 - 75 % of the children whose parents have a psychiatric illness demonstrate serious adjustment reactions to the parental illness (Feldman et al., 1987; Hammen et al., 1987). There is a particular high risk of the child developing serious depressive, oppositional, and conduct disorders (Anderson & Hammen, 1993; Keller et al., 1986).

While the cause of schizophrenia is unknown, current theory suggests that certain individuals have a vulnerability which, when acted upon by stressful environmental influences, promotes symptoms. Factors such as poverty, neglect, physical, sexual and emotional abuse, and trauma add to this risk, and are well documented (Anderson & Hammen, 1993; Beardsley & McMillan, 1993; Goldstein, 1986; Silverman, 1989). In some cases, living with a psychotic parent may be considered a trauma in itself, as the changes in the parent can be profound and greatly upsetting to the child (Hatfield, 1996).

In their recent article on mental illness and parenting capacity, Christina Bartha and Luis Concalves (1996) found that children of the mentally ill do more poorly in all areas of adjustment than children of parents who are not ill. Like children in the general population, the children of parents with a major psychiatric diagnosis have even more problems when they have also been exposed to unstable, unsatisfactory parenting.

Different researchers have found different levels of risk to children if their parents have particular illnesses, but there is a lack of consistency in these findings. Bartha and Gonclaves (1996, p.121) found that: "the offspring of the mentally ill who have fared the most poorly are the children of parents with schizophrenia. The adjustment of children of parents with affective disorders has been found to be more variable: some present at least as poorly as children whose parents suffer from schizophrenia, while others present more favourably" R.G. Sands also cited researchers who agreed that the most dysfunction in children was associated with mother's diagnosis of schizophrenia (Samaroff, Siefer & Zax, 1982; Webster, 1992; as cited in Sands, 1995). Other researchers (Hammen et al., 1987; Weissman et al.,1984) have found that
the highest rates of childhood disorder correlate with unipolar major depression. Most researchers have concluded that the risk for children is not dependent on the diagnosis of the parent, but is related to the presence and severity of symptoms which interfere with parenting, as well as the presence or absence of a caregiving/support system to provide for continuity of care for the child. All serious mental illness have features which would tend to cause the parents to present a distorted view of the world to the child, to cause the parent to become emotionally unavailable to the child, and to lesson the child's ability to know what the world will be like from day to day (Pound, 1996).

**Early Research**

The early literature about children with seriously mentally ill parents focused on very disturbed children who showed serious behavior problems and childhood psychosis, and sought to understand biological causes (Anthony, 1974; Rutter, 1979). Garmezy (1971) and Grunebaum & Cohler (1982) studied vulnerable children to discover precursors to later pathology. This "high risk" research began to identify factors which contributed to pathology and emotional disorder, including stress. Garmezy converted his data to show that a high percentage of children functioned adequately and symptom free. He called these children "Invulnerable Children" and focused his subsequent work on learning about how these children cope with adversity. His research identified a number of protective factors, or circumstances that help people resist the potentially negative influences of parental mental illness: positive temperament factors; gender (girls being less vulnerable than boys); the presence of one warm, supportive parent; the absence of severe criticism of the child; and a positive school environment.

Rutter (1979) identified six familial risk factors: severe marital distress; low social status; overcrowding or large family size; paternal criminality; maternal mental illness; and placing children in foster homes. He also identified some protective factors: the presence of at least one stable child-adult relationship; a stable and cohesive family climate; and the acquisition of cognitive and social skills that help survival under stress.
This research allowed a focus on prevention, which encouraged the development of intervention programs for high risk children. It reinforced the need for psychoeducational support groups for these children.

Bleuer (1978) was another early investigator of the effects of parental mental illness on children. He followed 184 children of schizophrenic parents over a 20 year period. He found that 5% of the children he studied developed schizophrenia over this period. (Note: this figure is lower than that commonly found in other studies, which may be due to the narrow definition of schizophrenia which Bleuer used). Many of the children became socially competent adults, although they had low self esteem, and poor intimate relationships. He stated that: "One has the impression that pain and suffering has a steeling - a hardening - effect on the personalities of some children, making them capable of mastering their lives with all its obstacles." He also observed that many of the successful children became unhappy adults, and were never fully free of their memories of their difficult childhoods.

Anthony (1975) identified some emotional consequences for children who had a parent with a serious mental illness: hopelessness, insecurity, lack of self confidence, and low self esteem. He also contributed to later studies about resiliency and "invulnerable children."

Another area of early research was in developmental ego psychology (Erikson, 1963; Freud, 1937; Piaget, 1952.) Anna Freud wrote a case study about her patient Jean Drew, who had been brought up by a seriously mentally ill mother with an "incomprehensible mixture of love, hate, and overwhelming injustice." She became an outstanding student, and a well adjusted adult. Freud wrote about her inquiry into the basis of her client's resilience, finding that the girl did receive enough positive feedback from her mother when she was not ill to allow her to develop a healthy ego. Piaget, whose own mother was mentally ill, developed a framework of child development which described the child as an active agent in his or her environment. Erikson developed a
model of male developmental stages which took into account social, cultural, and historical forces and their effect on the tasks of individual development.

**Resilient Children**

One area that has been extensively investigated is the coping process of resilient children who appear normal in spite of serious family problems. A number of researchers have studied the qualities of resilient or "invulnerable" children who have psychiatrically ill parents (e.g. Anthony and Cohler, 1987; Watt, Anthony and Wynne, 1984). This research described a number of indicators which contribute to better outcomes for the child, including: more than one caretaker; a healthy or non-disturbed parent or significant influence who was able to support the disturbed parent and model appropriate behaviour for the child; later onset of the parent's illness; fewer siblings in the family; fewer recurring episodes of illness in the parent; protection from isolation with the ill parent; and brief episodes of parent's illness rather than chronic illness (Anthony & Cohler, 1987; Watt, Anthony & Wynne, 1984). This research looked at innate "ego strengths", "abilities", and "intelligence" which it found "primarily in families with higher social status." However, the "resilient" children were found to primarily use denial as a defense, to have less caring relationships, and to have problems with intimacy as adults.

Other researchers have also found that it is not clear how these "invulnerable" children fare later in life: "It is possible that their heroic efforts on behalf of their ill parents are achieved at the cost of excessive preoccupation with the other's internal state in adult relationships and of compulsively driving the self... leading to the possibility of being exploited and taken for granted, and eventual demoralization and depression" (Pound, 1996, p. 211).

The literature about resiliency explains how important school is for children. Schools provide the opportunity for children to develop dependable attachments, to learn social skills, to form relationships with healthy adults, to take part in activities which are both physically challenging and fun, and to develop skills in academic and artistic areas.
These are all factors which increase children’s resiliency, and provide the groundwork for a healthy future. Teachers, social workers and counsellors who work in schools can employ resiliency theory to greatly assist all children who have family difficulties.

**Effects on Children**

Children who have parents with a psychiatric illness may suffer from a lack of nurturing, a lack of support for developmental tasks, social isolation, threats to their own reality testing, confused feelings about the parent, and a general confusion and possibly shame, about mental illness (Anthony, 1974; Rutter, 1966). The child experiences a disturbing change in the parent and a profound sense of discontinuity and unpredictability. The child may be neglected and experience the parent's emotional withdrawal as rejection, or they may feel blamed by the parent's behaviour. The child may be confidante to, or possibly a participant in, the bizarre and frightening psychotic fantasies of the parent (Anthony, 1974).

Although each child will be affected in a unique way, the literature has consistently shown that many children of the mentally ill suffer developmental delays that cause them to be disturbed in many areas of their functioning, including the lack of opportunity to develop sufficient psychological structures, such as a sense of safety and security, positive self-esteem, positive expectations of relations with others, and a reliable ability to control strong impulses and behave in socially adaptive ways (McRae, 1996). The risk for children is not dependent on the diagnosis of the parent, but is related to the presence of symptoms in the ill parent, as well as the presence or absence of a stable caregiving support system to provide for continuity of care for the child.

Children may experience cognitive, emotional and or behavioural dysfunction as a result of being raised in an environment of recurrent crisis and inconsistent parenting. Andrews, Brown, & Creasey (1990) found that daughters of mentally ill women who developed a psychiatric disorder in adolescence or early adulthood reported very high levels of physical and sexual abuse by fathers or stepfathers. Parental suicide and suicide
attempts are also issues for children. People who have a mental illness may also have decreased energy and motivation, impaired work performance, diminished school performance and self care, insomnia, anorexia and weight gain, and drug and alcohol abuse. All of these factors are serious preconditions for the neglect of, and trauma to children. The most common effects on children are conduct disorders, personality disorders, and depression (Anderson & Hammen, 1993; Beardsley et al., 1990; Feldman et al., 1987; Keller et al., 1986).

Long standing parental illness has more serious effects on children than brief episodes. Over 5 out of 10 of the children of parents who suffer from an affective disorder for over one year show substantial dysfunction, including depression and anxiety, physical health problems, behavioural problems, and health risk behaviours such as smoking, drinking, and drug use, compared to less than 1 out of 10 in controls (Pound, 1996). One of the major patterns of the child's response to the parental illness seems to be the child following the parent into depression or developing a behaviour disorder as a reaction to it. Girls are more likely to develop depression than boys, and nearly half of the daughters of depressed parents developed a major depression by age 17, compared to about 20% of boys (Keller et al, 1986; Weissman et al, 1984). On observation, boys are seen to respond to their depressed parent's anger and unhappiness with aggression, while girls are more likely to try to take care of the parent (Pound, 1996, p. 207).

Children who take on a caregiving role in the family, taking care of their ill parent and the household, may be described as "parentified children". They sacrifice their need for care and nurturance, and do not have the opportunity to complete childhood developmental stages because of their burden of caregiving (Brown 1989). These children are seldom offered help or counselling, because they do not meet the criteria of "emotionally abused" or "disturbed", and they are frequently good enough at caregiving that they do not appear "neglected". It is important to consider the damage that may be
caused to children, particularly girls, by such unreasonable expectations, and to look at
differences in gender in expressions of emotional distress in children, with a view to
being more sensitive to the distress of female children. For example, male children tend
to act out more, meeting service criteria, while female children often do not "act out", but
internalize their anger and emotional abandonment issues. West & Keller (1991)
described a typical pattern as "painful loneliness" where the child masks her feelings of
frustration and anger by becoming bound to her mother by the need to take care of her.
The child experiences a conflict between her own right to be taken care of vs. the fear that
ev en expressing that need would weaken her: "The role of caregiver, although it meant
denial and frustration of her attachment desires, removed her from the more feared reality
of helplessness and lack of control" (West & Keller, 1991).

Barankin and Greenberg (1996) identified the following protective and pathogenic
factors affecting adaptation in children:
1. factors related to the parents illness: diagnosis; comorbidity with parental personality
disorder or substance abuse; chronicity; age of child at onset of parental illness.
2. factors related to the child: biological (i.e. intelligence); genetic; temperment;
general health; self concept/competance; interpersonal relationships; relationship
with well parent.
3. factors related to family functioning: marital discord; communication style;
expression of affect; availability of social support; socio economic status.

Debra MacRae (1996) cited a quotation from Farber and Egeland (1987, p. 254)
which emphasized that children of the mentally ill did not show a consistent or typical
personality profile of abused children: "It is not surprising that there is no predictable
pattern of maladaptation, considering that the abusive situation and "abusive
environment" are highly varied from one case to another. " Although each child will be
affected in a unique way, the maltreatment literature has consistently shown that these
children suffer developmental delays that cause them to be disturbed in many areas of
their functioning, including the lack of opportunity to develop sufficient psychological structures, such as a sense of safety and security, positive self-esteem, positive expectations of relations with others, and a reliable ability to control strong impulses and behave in socially adaptive ways (MacRae, 1996, p. 142).

**Adult Children**

Mona Wasow (1995) reported that the most frequent present feeling expressed in her qualitative study of 20 adults who had had mentally ill parents was sadness for the tragedy and waste of their parents' lives, and also for their own lost childhoods. She found that, in general, these people felt very strongly that professionals had ignored their childhood helplessness and fear, and that they believed they had been harmed by policies of keeping families together at all costs. The adult children also had wanted professionals to know about their existence, and to make a greater effort to help them to survive the chaos and neglect in the household. They were also very concerned about stigma and prejudice against mentally ill people. Wasow cited another study by Lefley (1985) of eighty-four mental health workers who have a family member with a serious mental illness. Most of the adult children said that mental health workers did not recognize the extent of their pain or their burden in dealing with their mentally ill parent. (Wasow, 1995, p. 27). It is interesting that the participants in this study were mental health workers themselves - it raises the possibility that the caretaking skills that were learned as children may be valuable career options later in life.

While there have been very few studies documenting the mother's experience, there have been a number of studies documenting the remembered experiences of adult children of the mentally ill. Bonnie Dunn interviewed nine adults about their experience growing up with a mother who was diagnosed with psychosis. The themes that emerged were abuse and neglect, isolation, guilt and loyalty, grievances with mental health services, and supports (Dunn, 1992).
In a recent book by Dr. Diane T. Marsh and Rex M. Dickens (1995), for the Siblings and Adult Children Network of the National Alliance for the Mentally Ill (in the U.S.), siblings and adult children describe their experiences during childhood, adolescence, and adulthood very powerfully. One contributor, who describes "losing a lot of years" due to her attempts to cope with her mother's illness, states: "When they treated my mother, why didn't they treat me? Why didn't they treat the whole family?" She particularly describes the pain of her father withdrawing, becoming angry, and blaming her mother for being "lazy". As well, her sister and brother developed a serious mental illness, and she still feels guilty about not being a good enough caregiver for them when they were children, although she was just a child herself. Another important family theme described in this book is the personal impact for adult children, particularly for women, of continuing to be responsible for caring for their ill family members throughout their life cycle.

This theme of deep wounds to self esteem is repeated in another first person account of growing up with a mother who had a serious mental illness by D. Roberts, in a recent collection of articles about parental mental illness edited by M. Gopfort (1996). She writes that "being denied the necessary adult attention left me with the feeling that I did not deserve it, as if I had no right to ask to be cared for" (Roberts, 1996, p. 189). Roberts goes on to state that she felt let down by the adults who might have noticed, and intervened, when she was a child.

Jane Marlowe wrote a chapter in Gopfort's book about her own experience growing up with a mother who had a serious mental illness and required repeated hospitalizations. She describes the process in which she became the main caregiver for her mother while still a child: "As I got older my domestic chores increased and I became Mum's main carer, Dad being more the provider. I stayed in to keep her company, I took her shopping, I went with her to out-patient appointments, I counselled her and I took her on outings. By taking on these tasks, it was harder to leave when the time came. I was
asked to do things, and I felt responsible. If I hadn't who would? I didn't want her to be abandoned in hospital. I had not choice." (Marlowe, 1996, p. 101) When she left home and went to university, she started a self help group for people who had grown up with a parent who had a mental illness. Through this, she became connected to a larger organization in England called Young Carers. She wrote that thinking of herself as a young carer helped her to realize and appreciate how much she had done to support her family, and disassociate herself from feeling responsible for failing to cure her mother. She described the common response to children in a similar situation who are labeled "at risk" and are directed to inappropriate services aimed at "problem" children rather than "problemed" children, who need services and support. She wrote the following list of rights, which she has put forward as a suggestion for guidelines for policy under the Children Act in Britain:

Young Carers have the right to:

1. Have someone to talk to in confidence.
2. Have access to good information that is age-specific and the possibility to ask questions that will be answered sensitively.
3. Have an advocate to be there when required, for example, when visiting hospitals, when a compulsory admission takes place.
4. Have respite.
5. Have distraction and fun.
6. Share experiences with others who share similar circumstances.
7. Have positive adult-led input to influence their development as children and young people.
8. Have a choice to care or not to care. e.g. do chores, stay in with the patient, counsel patient, negotiate with professionals, administer medication, and so on.
9. Receive support, guidance and training in relevant care skills.
10. Be able to stay at home, backed up by good support networks and not have to go to state care.
11. Have access to good adult education, as often school years are preoccupied by caring and stress, with education becoming secondary.
12. Be supported by workers from their own ethnic and cultural group.
13. Have access to flexible services that are supportive and not interventionist in their approach.
14. To be able to change and develop the young person / Carer role in the family, i.e. to be able to renegotiate their position continually.
One way to ensure that Young Carers have choice is to ensure the patient in the family is cared for as if there were no children in the home (Marlowe, 1996).

In her recent book about families of the mentally ill, Victoria Secunda (1997) interviewed 75 adults who had been children and siblings of people with a mental illness. She described the following key themes and issues:

- Fear of breaking down.
- Arrested development.
- A skewed sense of “what’s normal”.
- Deferred dreams.
- Fear of failure.
- Guilt.
- The grief that never ends.
- Dual identities.
- Difficulty with intimacy.
- Fear of having children.
- Setting limits.
- Isolation and loss.
- Unfinished family business.
- Searching for meaning.
- Patterns of reaction.

Secunda analyzed the impact of parental mental illness for children at different stages of their development, and the psychological mechanisms of defense that children use depending on their psychological makeup, their behaviour as a reflection of family rules, and their temperament. She also described how the parents character and temperament may “fit” or clash with the child, producing relatively few problems, or serious consequences. She found that there was a lack of help for children from other members of the immediate and extended family, and a “stunning lack” of professional intervention to help the children.

Local Research

There have been several attempts to respond to this problem in British Columbia. In 1980, a demonstration project was initiated through the School of Social Work, which focused on children’s therapeutic needs (Amacher, 1980). A psychoeducational group for children is also offered in Chilliwack, B.C. through the B.C. Schizophrenia Society.
(Lees, 1995). In 1990 a project was undertaken by Lynda Campbell for the Greater Vancouver Mental Health Service Society to review the situation of children of adult clients of the agency. This survey found that 261 clients had a total of 422 children. An average of 66% of the children had no contact with the mental health teams. The study did not define what "contact" with the child actually meant in terms of family and individual work. The largest proportion of children (37%) were those whose parents had a diagnosis of schizophrenia. Of these children, 76% received no service. Children of depressed parents comprised 24% of the total number of children, and of those, 54% had no contact with GVMHSS. 15% had parents diagnosed as "other" and 63% of those children received no services; 12% had parents with a bipolar disorder and 76% received no services; 12% had personality disorders and 62% received no service. This research showed that the children of schizophrenic parents received significantly less service than did children of depressed, bipolar or personality disordered parents (Campbell, 1990.)

Several groups have subsequently been offered through G.V.M.H.S using Campbell's model, but there is no ongoing program for this population at the agency.

The research did not determine whether the parents received any support, education, or counseling related to their role as parents, or whether the partner of the ill parent may have received counseling services in relationship to the children's needs. It would have been interesting to find out what type of help or treatment that was requested by the children or parents, whether the children and parents may have had contact with other counseling services in the community, and the extent to which the respondents had maintained custody of their children.

Interventions to help children

There are fewer studies which focus on the effectiveness of intervention strategies to help these children. (e.g. Silverman, 1989, Goldstein, 1986). Interventions are described as primary preventive efforts which lower risk, such as enhanced support for all family members and effective treatment post partum; and secondary prevention,
which provide a response to developing problems, such as assessment and treatment for children with diagnosable conditions.

Grunbaum & Gammeltoft (1991) studied children of chronically ill schizophrenic mothers in Denmark, with documentation from psychiatric hospitals, consulting child specialists, and other health professionals. They found a number of serious problems in the professional involvement with the children, such as a lack of knowledge about developmental needs of infants and small children; continuation of ineffective support in a situation that was dangerous to the child; mistaking anxious attachment patterns for autonomy; inability to provide professional attachment figures because of the mother's inability to accept the children's involvement with other persons; lack of knowledge and experience with schizophrenia, particularly lack of symptom recognition; unrealistic expectations of professional support services; service planning based on dealing with immediate crises rather than long term needs; and psychiatric recommendations which did not differentiate between the mother's needs as a patient, her needs as a parent, and the child's needs. The authors commented that the problem of protecting the mother's rights as a parent at the same time as safeguarding the child against the harmful effects of the mother's severe mental illness may not have an adequate solution. They recommended that a thorough assessment of parenting capacity of the parents be performed at the earliest possible moment; that a permanent professional intervention team be established; that support services staff be well supervised; and that foster parents are well supported and treatment provided to the child (Grunbaum & Gammeltoft, 1991).

Many of the research studies address the area of therapeutic and preventive interventions for children of psychiatrically ill parents. Anthony (1975) suggested that children be taught coping skills to help them survive a difficult family situation. Silverman (1989) found that it was most important to identify and treat parental mental illness early, before the family and children are negatively affected. He also advocated increased social support in schools, although he states that it is important to ensure that
there are no negative side effects from labelling children "at risk" for psychopathology in developing preventive programs. Cohler & Musick, (1984) advocated programs which develop children's skills and competencies, using natural neighbourhood social networks. Marsh (1992) wrote about the importance of recognizing the developmental stage of the child in considering any intervention, and discussed how parentification of the child poses risks for the children. Stiffman, Jung & Feldman (1988) evaluated the living arrangements, behaviour, and skills of 306 children with seriously mentally ill parents, who they referred to as the "Web children" using the metaphor "caught in the web of parental mental illness." They proposed an interactional model which first considered environmental stressors and second, personal coping skills. They found that not all children were at risk if they had strong coping skills, or if the environment was protective. In situations where there was a hostile, unsupportive environment for children, they found that alternate living arrangements such as foster care or care with relatives were correlated with better child behaviour and fewer problems.

Mona Wasow (1995) found that the adult children she interviewed described the following needs for children, which could be a basis for helpful intervention:

1. Children need adequate substitute child care.
2. Children need to be told, repeatedly, that they are not to blame for the parents illness.
3. They need information about serious mental illness on an ongoing basis appropriate for their developmental level.
4. They need guidance in learning new ways to think about and cope with the parent with a serious mental illness.
5. They need support and encouragement for activities and interests outside the home, and every possible resource for success at school.
Werner & Smith (1988) found several indicators that contribute to better adjustment, including more than one caretaker; a healthy or non disturbed parent who was able to support the disturbed parent and model appropriate behaviour for the child; later onset of the parents illness; fewer siblings in the family; fewer recurring episodes of illness in the parent; and brief episodes of parent's illness rather than chronic illness. These factors clearly point to the need for a stable support system for the children, and protection from isolation with the ill parent. Often, this is accomplished with the well partner or the extended family.

As part of a research project for the Greater Vancouver Mental Health Services Society, Lynda Campbell (1990) developed a psychosocial treatment group for children of the mentally ill which addressed seven issues underlying the symptoms manifested by children who had mentally ill parents, as identified by Shachnow (1987):

1. Overwhelming anxiety is predominant and is related to the unfamiliar and frightening behaviour characterizing the parental mental illness.

2. Separation anxiety is evidenced in relation to both the physical absence of the parent as a result of hospitalization and to the child's awareness of the parent's detachment from them.

3. Guilt is found to be pervasive for children. The egocentricity characteristic of children leads them to assume responsibility for the parental illness because of what they perceive they have done or failed to do.

4. Fear that the parent will never get better is an issue for these children. This fear is exacerbated with repetitive and chronic illnesses. Children also fear that something will happen to the well parent.

5. Ambivalence towards the ill parent is generated from the anger these children feel regarding the loss of the parent through hospitalization, emotional remoteness, and/or the parent's inability to fulfill the practical aspects of the parental role.
6. Children experience embarrassment about the behaviour of the ill parent. This becomes more predominant with a child's increasing age and with the degree of a parent's manifest symptoms.

7. Children have concerns about their own mental health. Identification with the parent is normal. This fact coupled with attitudes associated with the stigma of mental illness leads to questions for the children about their susceptibility to parental illness. (Campbell, 1990; Shachnow, 1987).

Shachnow found that "individual, group and family interventions have been tried and compared, but positive results over time have only been reported for the one-to-one supportive therapy relationship (Shachnow, 1987, p. 68). She emphasized that the observation that each "coper" had an empathic adult available may give direction and hope to providing services to children at risk."

There are many books and articles, which I have not included in this literature review, which focus on support for caregivers and relatives of people with a mental illness. Typically, these books do not address the situation for children. For example, in a popular handbook When Someone You Love Has a Mental Illness, (Woolis, 1992), the author has included a section of only one and one half pages, plus a table, for "special concerns of siblings and children." Similarly, the book Surviving Schizophrenia, a Family Manual, (Torey, 1988) has only three or four paragraphs which address the situation of children growing up with a schizophrenic parent. As well, I have not found that these books explain the particular problems that mentally ill parents face in raising children, or the support they may need from their extended family.

In summary, while the studies I have referred to in this literature review have shown that children of the mentally ill are at risk for developing serious emotional and behaviour problems, the research seems to ignore many of the related factors which add to these problems. Interventions with this group of children typically happen only at crisis. These interventions during a crisis may confuse and threaten the security of a
child, and include multiple placements in different foster homes, changing schools, etc., and may actually increase behaviour problems. The research also does not specifically address the situation of children living in single parent families, where the custodial parent, who is almost always the mother, has a mental illness: many of the comments refer to the mediating influence of the other parent, who is usually not present in the families who participated in this study, or the families I have worked with.
Chapter Four

Legal, Policy, and Practice Considerations

The situation of children being raised by parents who have a serious mental illness raises questions about two groups of vulnerable people: balancing these concerns is difficult. While there has been an increasing emphasis in Canadian society on social responsibility for the care of children who have been abused and neglected, the problem has been generally understood to be caused by harmful, "bad" parents, who are responsible for physical, sexual, and emotional abuse to their children, and who may therefore be "punished" by intrusive social services, or apprehension. This way of understanding the problem promotes a climate in which children who are disadvantaged because of a parent's disabilities, such as chronic pain, major depression, or illness of an episodic nature such as psychosis, are often overlooked because the risk of negative responses, such as apprehension of the child, prevents the parent from asking for and accepting help. There is a basic injustice in this for both the parent and the child. The past government policies of providing residual services after a crisis, rather than long term preventive services, needs to be replaced with adequate services based on the real on-going needs of this population.

Efforts to Assist Children

Children in vulnerable families require resources such as day care, homemakers, higher welfare payments, better housing, and medical care (Callahan, 1993; Swift, 1991). Respite care is also needed by many families, and could be a valuable "safety net" for the children. Arrangements which promote respite and foster care in the home of a relative may be important for some families, and if this is part of a care plan for the children, an adequate support allowance and provision for additional expenses such as relief for the caregiver should be provided.

The most common recommendation for family treatment is for counseling and treatment for mothers (Beardslee & MacMillan, 1993; Mowbray et al., 1995; Oysterman
et al., 1994). This usually entails the development of methods to restore mothers to an "adequate" level of functioning. Most often a parenting education model is used, providing counseling and emotional support for the mother or for both parents. New policies which promote planning for the child by the parent when he or she is well, in case of relapse of the mental illness, may be important in helping these families through crisis periods.

If the child does not exhibit clearly disturbed behaviour, he or she will seldom receive individual treatment from mental health services, or additional support services from other agencies. These services are mandated to provide counselling services to families with children exhibiting severe emotional problems, but may not be able to provide helpful treatment to children of adult psychiatric clients, who may not display severe symptoms, and who require ongoing practical support, rather than a short term approach addressing an acute problem or crisis. It is also difficult to maintain access to these children if the parental illness is manifested in paranoia regarding involvement with professionals, or if the family moves prevent continued involvement in long term treatment. It has been repeatedly shown that therapeutic gains with families where a parent has a serious mental illness are lost when treatment is discontinued: "The important point is to offer these services indefinitely, with no end point in sight" (Test & Berlin, 1981).

There is generally a low level of knowledge about parenting and family issues among mental health practitioners, as evidenced by problems in discussing family planning and sexual health issues (Coverdale et al., 1992) or the tendency of health care workers to neglect the subject of children and parenting issues entirely (Vanharen et al., 1993). Mental health workers do not have specific training which includes how to assess risk factors for children, child centered crisis intervention, and awareness of the ongoing developmental needs of children. In particular, adult oriented workers seem to over estimate the resilient qualities of the children, and misinterpret unhealthy relationships,
such as anxious, insecure attachment patterns, as healthy attachment. There may also be
a low level of knowledge about parental mental illness among nonpsychiatric
professionals such as child protection workers, teachers, and foster parents. This lack of
knowledge may create a climate in which parents may not feel safe to discuss their
concerns as many have lost custody of their children or have been threatened with the loss
of their children when they have an acute episode of their illness.

There is a great discrepancy between the serious situation for children described in
the literature, and the few resources available to families to help them. There are no
services in Vancouver which focus on the particular needs of families of school age
children where the parent has a major mental illness. There is a project funded by Greater
Vancouver Mental Health Services which addresses the needs of adult clients with
infants and young children, but this is a very limited project, accepting fewer than 10
families at a time, for families who are clearly identified as attachment disordered. Parent
education services, such as Project Parent, accept parents with a psychiatric diagnosis,
and provide helpful support and education. The extent of use of these supports for this
population is not known. As well, we do not know what are barriers to using these
community supports.

Parents who have a "dual diagnosis" of mental illness and a mental handicap are
eligible to receive services for the mentally handicapped, which may include parent
education and support. While there have been past problems, as outlined in the Gove
Report (Gove 1995), these services will now be provided through the Ministry of
Children and Families, which may improve communication and provide a
multidisciplinary approach to meeting the needs of these children. The Ministry of
Children and Families will also coordinate services for children whose parents have a
"dual diagnosis" of substance abuse and mental illness.
Social Policy Responses

Representation Agreements

New adult guardianship and related legislation has introduced representation agreements which may help parents in planning for their children's care in case of relapse of their mental illness. This allows the parent, in a stable emotional state, to make a plan for the children to be implemented if the parent becomes acutely ill. One legislative model will be representation agreements when the law is proclaimed. Bill 48 - 1993, The Representation Agreement Act, is a new law which is not in effect yet, but which has been in the implementation period for several years. During this time, the effects of the proposed legislation have been studied, and a Community Coalition for The Implementation of Adult Guardianship Legislation has formed to co-ordinate community input.

Section 9 of the Representation Act allows the adult to authorize the representative to hold expanded powers. For example, the adult may authorize the representative to physically restrain, move, or manage the adult if necessary and despite the objections of the adult; and manage the adult's business and affairs. The purpose of this legislation is to provide a mechanism to allow people to plan in advance how decisions will be made if they become incapable of making decisions independently, and to avoid the need for the court to appoint people to make decisions for those who are incapable of making decisions independently. Section 9, (1) (f) of the Act allows for the representative to make arrangements for the temporary care, education and financial support of

(i) the adult's minor children, and

(ii) any other persons who are cared for or supported by the adult.

This legislation allows for recognition and respect for consumer involvement in decision making, and promotes options such as the recognition of informal support networks that may function as alternate family supports. It may be argued that with improvements in
the adult guardianship legislation, the Mental Health Act, which provides mechanisms for
the committal of mentally ill people, is no longer necessary, and in fact, segregates and
discriminates against mental health patients (Gordon, 1993). Some of the women who
participated in this study had developed informal forms of representation agreements,
which will be discussed in the research findings chapter of this thesis.

The Gove Report and the Creation of a Unified Ministry of Children and Families

The Gove Inquiry was commissioned in 1994 after a five year old boy, Matthew
Vaudreuil, was killed by his mother. Many attempts to provide services to the family
failed to provide for his care and safety. Judge Thomas Gove held extensive hearings
around the province to determine the obstacles which prevented effective help to be given
to Matthew. He found that the system was fundamentally flawed, particularly in its lack
of a child centered approach, and in the difficulties of coordination of services provided
contained 118 recommendations to reform the delivery of child protection services to
children, with the philosophy that the interests of the child should take precedence over
the interests of the family in the area of child protection.

The Gove Report was followed by The Report of the Transition Commissioner,
Cynthia Morton. In response to her report, services for children have been re-organized
under the Ministry of Children and Families in British Columbia. This will integrate
mental health services for children with other services for children such as child
protection, alcohol and drug services, the attorney general, and childcare. It is uncertain
how these changes will affect this client group. It may enable resources to be accessed
more quickly for this group of children, and promote better coordination between mental
health and child welfare. However, it may separate mental health services for children
and adults, which may now be able to use a multidisciplinary team approach to coordinate
treatment for some families.
The Morton review panel will continue to review all child deaths in the province, and will also review cases which appear to involve serious gaps in services for children. As well, the provincial Ombudsman Dulcie McCallum will review the province's implementation of the 118 recommendations of the Gove Report into child protection services. (Ombudsman to review, 1997).

Child Abuse

All children in British Columbia are protected by law from abuse, neglect and harm or threat of harm by Bill 46, the Child, Family and Community Service Act (1994). Children of the mentally ill are provided the same protection from physical and sexual abuse and neglect as all other children in the province. The legislation now includes the category of "emotional abuse", which was not included in previous acts in British Columbia. Although children may be emotionally injured by living with parents who have a mental illness, and require assistance, they may not "fit" the current definition of "emotionally abused" in terms of requiring protection. (Note: we may not wish to define all emotional injuries to children as "emotional abuse", but this label is necessary to protect some children, and may entitle the child to receive certain services provided by the Ministry of Children and Families.) The current legislation in British Columbia defines emotional abuse based on an assessment of disturbance in the child's behaviour. The definition of emotional abuse in the act is specified in Part 3, 13 (2): "A child is emotionally harmed (by the parent's behaviour) if the child demonstrates severe:

(a) anxiety, (b) depression, (c) withdrawal, or (d) self destructive or aggressive behaviour." This definition of abuse depends entirely on a professional assessment of child behaviour, which allows the Ministry to intervene to help children who exhibit these behaviours, but does not intervene to help children, who might for instance be living with a psychotic parent, and might not exhibit these particular behaviours at the time of an investigation. Many children in emotionally abusive situations adopt a "parentified child"
role rather than "acting out" behaviour. They may also appear to be compliant and loyal, due to insecure attachment and separation anxiety.

The Gove Report states that the definition used of emotional harm in the new act is inadequate to protect children in a chronically abusive situation: "The restricted scope of the Child, Family and Community Services Act does not protect a child in Matthew's situation where even before being demonstrated by the child's behaviour, harm was predictable and inevitable" (Gove, 1995, p. 219.) The act appears to state that the harm must have already occurred. The Gove Report suggests amending the act to read: "if the child is, or is likely to be, emotionally harmed by the parent's conduct."

The Morton report recommends that the circumstances of emotional harm should be amended in s.13 (1) (e) of the Child, Family and Community Services Act to include likely to be harmed by the parent's conduct (Recommendation # 79). The Morton report states:

Many studies have noted that children in greatest need of intense intervention are those growing up in persistent or concentrated poverty and social dislocation, or are in families which are homeless, or have a mentally ill, alcoholic, isolated or drug addicted parent. We know that interventions can help children in these circumstances. We know how to prevent damage before it occurs. It is neither productive nor cost effective to withhold services until these children show signs of desperate behaviour (p. A - 46).

**Assessment of parental functioning**

Assessment and identification of the quality of care for children in families where there is parental mental illness is important in providing an adequate response to the needs of the family. However, there are many complex issues about who is responsible for providing such assessments, the assessor's skills, values and biases, where the
assessment will be undertaken, and whether such assessments are actually meaningful in identifying the needs of the family, or whether they may even represent a negative form of pathologizing the mother and/or the child.

Steinhauer (1991) described the predominant clinical dilemma: Does one risk leaving the child in a marginal parenting situation in order to provide the parent every opportunity to improve, or does one risk permanently removing the child, which in the long run may be equally detrimental? Rob Poole, an adult psychiatrist, wrote an article about similar dilemmas and paradoxes that he has personally encountered in treating patients who were parents. He states that “Where there are issues of parental mental illness, the family courts may turn to adult rather than child psychiatrists to provide expert opinion regarding care and control of children, decisions which, once made, may be difficult or impossible to revoke. In so far as one is giving an opinion about the effects of mental illness per se, this is appropriate enough. However, general adult psychiatrists cannot give a truly expert opinion on parenting skills” (Poole, 1996, p. 5). Poole suggested that in such situations, the adult psychiatrist resist the pressure to make statements about parental capacity, and rather act as an advocate for the patient, explaining the reality of the illness to the court if necessary, including the likelihood that the patient will recover from acute episodes of the illness.

The Toronto Parenting Capacity Project, as described by Bartha & Concalves (1996) is composed of a multidisciplinary team of mental health and child protection professionals. They have developed a set guidelines for nine specific areas of parenting function, as follows:

- Guideline 1: Current stressors
• Guideline 2: Child’s developmental progress
• Guideline 3: Predominant pattern of the child’s response to the caregiver
• Guideline 4: Observation of current parenting ability
• Guideline 5: Impulse control
• Guideline 6: Parental acceptance of responsibility
• Guideline 7: Problem behaviours affecting parenting ability and capacity
• Guideline 8: Parent’s manner of relating to society
• Guideline 9: Parent’s use of clinical interventions

These guidelines are meant to focus on strengths as well as areas of concern. Issues of bias and countertransference (where the professional experiences personal reactions to the situation) may be addressed and managed with the team approach used at the centre.

Risk Assessment:

The B.C. Ministry for Children and Families is now using a risk assessment instrument which provides a comprehensive risk assessment and sets out a time frame for action in child protection cases. (The Risk Assessment Model for Child Protection in British Columbia, B.C. Ministry for Children and Families, 1996.) This model includes standards to evaluate risk factors related to parental influence, including parental mental and emotional ability. The risk assessment tool includes several categories to assess the needs of children of the mentally ill. This tool provides an initial checklist to assess and prioritize safety concerns. If a significant safety factor is identified, a comprehensive risk assessment is conducted, which has several categories which assess parental influence, including physical abuse / neglect of the parent as a child, mental / emotional ability to care for the child, and developmental ability to care for the child. Other scales assess the relationship of the child to the parent in terms of trust vs. anxiety, the child's mental health, the family ability to cope with stress, the availability of social supports, family interaction, and history of abuse and neglect. It is likely that the comprehensive risk assessment will make a difference in detecting serious problems for children living with
mentally ill parents. At present, the risk assessment tool does not include a specific parental capacity assessment tool, which would consist of a set of guidelines to be used to assess the quality of parent/child interaction, and the ability of the parent to care for the child. Parental capacity is assessed using unstandardized methods by various professionals, such as psychiatrists, psychologists, and clinical social workers. The key factor with both risk assessment and parental capacity assessment is the training and experience of the evaluator. At present, there is some concern because different evaluators may be applying different standards. As well, the courts have placed varying degrees of importance on these evaluations (Mossof, 1995; Whittemore & Ogloff, 1994). I will address this area again in the section in this chapter about legal issues.

Child Advocate

The office of the Child Advocate was created by the Child, Youth and Family Advocacy Act on Sept. 1, 1995. The Child Advocate has authority to "ensure that the rights of children, youth, and their families relating to designated services are protected and their views are heard and considered." The Gove Report recommended that the role of the advocate be modified so that it applies only to children and youth, and families only when it promotes the interests of the family's children. While this office has not publicly addressed the dilemmas that parental mental illness presents for children, it may hold potential for resolving some of the difficult cases where children's interests conflict with their parents, particularly when there is no one to speak for the child.

Family Centered Case Conferences

The Child, Family and Community Service Act includes a section outlining a procedure for cooperative planning and dispute resolution, through family conferences. This section of the act has not been proclaimed as yet. However, the elements of family conferences are a classic example of good social work practice, and child welfare and mental health workers have been working toward using the principles of family centered case conferences for several years, as outlined in the report for the Vancouver Child and
Youth Committee, *When the Bough Breaks: Coordinating the Planning for Services to Children, Youth, and Families in Vancouver* (1993). The goal of the family conferences is "to bring together the range of natural supports and formal service providers to meet the self-identified needs of the family and children in a manner that is both enabling and empowering to the family." It also provides an opportunity to bring in new supports, and to formalize helpful relationships. This model could be very useful to families where the mother has a serious mental illness. It could provide an opportunity for sharing information, planning, and dealing with problems, with the respectful inclusion of the mother and the children (if they are able to participate.) The Killarney Project, which was an interministry community development project sponsored in part by G.V.M.H.S., successfully developed an effective model of family centered case management that was used in several cases with mothers who had a serious mental illness (Gingell & Gilbert, 1992).

In the literature, Gopfert (1996, p. 297) cites Halevy-Martini et al. (1984) and Ruhf et al. (1984) in describing a family centered case conferencing model:

The power of a carefully convened group, which is not just the family, aims to shift control back into the network to enable its members to own their part in the problem and find different solutions to those currently attempted. Networking overcomes the artificial and often dysfunctional split between assessment and intervention, and it works well with seriously mentally ill patients. Network therapy requires enough members who are positively and constructively engaged with the parent.

Creative approaches to case conferences can help to build a committed support network for the mother and child. The child needs a number of people who know about how things are at home, and who can offer practical, knowledgeable support. The mother also needs knowledgeable, supportive people in her life who can answer questions about
the children, give her a "reality check", and can help her organize resources when needed.

Legal Issues

In her article Motherhood, Madness, and the Law (1995), Judith Mosoff, a lawyer who has built her practice representing clients at a large mental health facility in Toronto, described how Canadian law affects mothers with psychiatric disabilities. Her thesis is that the simultaneous operation of child protection law, mental health law, and the power of the psychiatric paradigm almost inevitably severs the relationship between mothers with mental health histories and their children. (Note: Mosoff is referring to her own professional experience here, which is primarily with mothers who have a serious illness requiring hospitalization.) By psychiatric paradigm, I assume Mosoff is referring to both the history and structure of mental health services, and the widespread effects of the social stigma of mental illness. Mosoff analyses legal issues in two areas: legislative statutes, and judicial decisions.

- **Legislative statutes:** Mental health statutes are based on the assumption that mentally disordered persons may be a risk to themselves or others. Child welfare statutes address parental risk to children’s well being. Under these statutes, both children and mentally disordered persons are seen to have limited legal capacity. Mosoff states that “If these women are perceived by law to be like children, they are not likely to be perceived by law as capable of taking care of children” (p. 113).

Under the British Columbia Child, Family and Community Services Act, section 59 (1) states: “On application, the court may order that a child or a parent of a child
undergo a medical, psychiatric or other examination.” The act does not specify by whom
the application can be made, for what purpose, and at what stage of the proceeding. Child
welfare statutes are intended to protect children, not to prosecute the parent. Therefore, a
criminal standard of proof is not required, which Mosoff believes may have negative
implications for parents who have a mental illness, because of the prevalence of social
disapproval and stigma towards people with a diagnosis of mental illness.

Mosoff describes four similarities of legislative schemes: (1) the responsibilities
of the state to provide care if there are concerns about safety to self or others; (2) the
implications of a “crisis”, which allows the state to use special powers prior to a legal
process; (3) intrusions into privacy, which allow psychiatric records to be admitted to
child protection hearings, leading to what she describes as an enormous reliance on
psychiatric evidence; and (4) the notion of best interests, which leads to the issue of who
decides what is in the best interests of the person deemed incapable of decision making.
There is a hierarchy of degree of agency of the person allowed in these cases, depending
on whether the authorization of “best interests” is obtained by a substitute of the person
arranged for when the person was fully capable; by standing in the shoes of the person; or
by acting in the best interests of the person.

Judicial decisions

Mosoff found that where the mother had a psychiatric disability, child protection
cases tended to be overwhelmingly decided against her. In Mosoff’s sample, 29 of the 47
cases were unsuccessful (the mothers lost custody), 8 could not be categorized, and 10
were successful (mothers maintained custody). The mothers had court imposed
conditions in all but one case.
Mosoff found that judges tended to defer to the opinions of psychiatrists in deciding cases where the mother had a mental health history. The particular opinions sought from the psychiatrist were usually how long the mother's problem is likely to last, how independent the mother is seen to be as a parent, as well as the type and amount of support she would need" (P. 131). Psychiatric opinions are grounded in a medical model of disorder, which assumes that disability originates with impairment, and that the psychiatrist's view of treatment predominates over the mother's view. For example, missed counselling appointments are brought up in court, when the counsellor thinks that counselling should continue, whether or not the mother believes that the counselling is helpful, and regardless of the difficulty that attending such counselling may be for the mother, who may have to juggle child care, transportation, and related expenses. Refusing to take medication is a frequently mentioned reason for removal, as is "resistance to treatment".

Mosoff cited a case where a mother diagnosed as manic depressive was counselled to stop taking lithium during her pregnancy because the drug could harm the fetus. She consequently developed shakiness and mood swings after the birth of her child. The psychiatrist recommended her child be placed in care until her symptoms could be stabilized. Without any objection by the mother, the child was apprehended and found in need of protection. When the mother eventually withdrew her consent, the court decided that there was no need to make a fresh finding of the need for protection, and that it was in the child's best interests to be permanently apprehended in order to be adopted. In this case, the mother had cooperated with her psychiatrist's advice concerning treatment, and also with the legal process, but she lost her child. If she had not
cooperated with her doctors and continued to take lithium through her pregnancy, or had objected to the child’s care while she stabilized, the result would likely be the same.

Mosoff’s main objection seemed to be the patriarchal structure of deferring to the doctor, psychologist, or psychiatrist as “expert”. She stated that, “As a result, women with mental health histories often lose their children to the state through some combination of persuasion, legal process, consent, and threat.” She recommended that judges act as they do on other matters and scrutinize the evidence of experts in child protection cases with the same rigor as they would in other proceedings.
Chapter Five

Feminist Stories and Ideas

As a woman who has been active in the feminist movement for over twenty five years, I wanted to ground this study with a feminist theoretical perspective. I found the following definition of feminism useful:

Feminism represents an effort to understand how gender, race, class, ethnicity and sexuality are constructed in social contexts of power, thereby dismantling hierarchies of privilege. Feminism is about locating the subjugated voice, about questioning hegemonic "knowledge" and "truths". It is about examining gendered voices and silences. (Laird, 1995).

In undertaking to write this thesis, I wanted to examine why mothers voices had been left out of so many of the studies I read about families with maternal mental illness. The lack of the voices of mothers in the research is an issue for feminist investigation. Nan Van Den Bergh points out that "As social workers, we need to ask the extent to which the practice models and the theories that guide our interventions have been derived by listening to the voices of our clients" (1995).

Maternal mental illness is not a comfortable subject to address, for many reasons. There is a risk of mother-blaming, labeling, stigmatizing, and creating negative reactions rather than stimulating an open dialogue. On one hand, there is a group of women and children who have a long history of being criticized, marginalized, and stigmatized, and whose social relationships reflect their experiences of oppression. This history must be well understood so that these women's struggles against historical and present oppression can be recognized and acknowledged. On the other hand, there is a prevailing social blindness to the reality that all women may not be able to fulfill the current socially constructed role of a "good mother."

As discussed earlier in the literature review, many mental health service consumers are raising children. This is due to changing attitudes, better treatment, de-
institutionalization, and supports such as social housing, daycare and community parenting programs. Many of these programs in the community which support mothers and children, such as daycares, family place drop-ins, and transition houses, are a direct result of feminist organizing efforts.

**Feminist writing**

This discussion is informed by feminist writers who addressed the topics of women and mental health and women as mothers early in the feminist movement. A number of feminist writers have written about their own experience with a mother who had a mental illness. Barbara Joyce (1975) wrote in an early feminist collection of essays which addressed feminist issues in psychiatry, that

As an adult, I understood my mother's impossible task - that the family structure is set up so that the children cannot look elsewhere for fulfillment. So I felt that it had something to do with a lack in me, and I learned how to feel guilty for that lack, and I learned how to feel worthless. As my nurturer, my mother did not properly nurture me. I therefore perceived myself as not worth nurturing...I now know her desperation for peace in a domestic structure designed to police her. It is understanding how a love she felt for one man had so completely changed her life as to be always determined first by her husband, and secondly by her children - with her own needs seldom met. It is understanding how she could scream and tear her hair for want of a day without family pressure or worries. (p. 189).

Joyce, who described her own experience as a psychiatric patient, came to believe that both her mother's mental illness and her own were caused by the contradictory expectations and "double binds" that they experienced.

I learned that the phrase 'a good mother' is a contradiction in terms. A good mother raises her children in complete happiness; in other words, she has good children. One rule is, 'a good mother never leaves her child alone.' What this ensures is not the goodness of mothering but a constancy of policing the child and the constancy of policing the mother through her role as supervisor. So I learned why my mother went crazy: she went crazy trying to be a good wife and mother. I learned that society was driving her crazy with its impossible demands, and there were no alternatives for her. It soon became apparent to just why I too had been driven mad. I was supposed to be preparing through my role as the good wife, to be a good mother. There seemed to be no alternatives for me either" (p. 190).
Gloria Steinem, who lived alone with her "crazy" mother from age 10 to 17, described her mother as: "a loving, intelligent, terrorized woman who tried hard to clean our littered house whenever she emerged from her private world, but who could rarely be counted on to finish one task. In many ways, our roles were reversed: I was the mother and she was the child. " (Steinem, 1983, p.130.) In her analysis, she notes that her family "blamed " her mother for her mental illness, while they tolerated and excused her uncle, who also had a mental illness. She questions her mother's lack of treatment, which she believes was connected to an assumption that mental illness was part of her mother's personality, as well as to a fear of mental institutions because of negative media depictions. In her balanced, compassionate story about her life with her mother, she comments that, "Perhaps the biggest reason my mother was cared for but not helped for twenty years was the simplest: her functioning was not that necessary to the world."

Linda Gray Sexton wrote an enlightening autobiography about her childhood called: Searching For Mercy Street: My Journey Back to my Mother, Anne Sexton. (1994). In it, she states: "Just as I do not see her as a victim or a monster, I do not see myself as a victim of abuse or a monster of revenge either. The rich yet troubled relationship my mother and I shared is too complicated for labels as simplistic as these. " Linda wrote about her relationship with her mother very openly and honestly, so that we are able to see both the extreme pain of her dependence on a mother who was often not emotionally available to care for her needs as a child, and the deep connection and love that did exist. In describing her need to "exorcise", or to take control of "the demons inside", Linda maintains her loyalty to her mother by describing empathy rather than anger as her dominant emotion. She describes the anxiety and heightened vigilance that many children might feel when living with a mother with a mental illness: " While only nine times did she actually go so far as to attempt suicide, there were many more hospitalizations than that and these were preceded by warnings: that vacant look in her eyes; twirling her hair until it snarled; crying and not being able to stop; frozen
desperation. All this brought me nauseated anxiety. Like an old woman with arthritic bones who can predict the weather, I learned to anticipate my losses." (Sexton, 1994, p. 33.) Although Lynda's mother was a famous and highly respected poet, she could not escape the blaming and critical attitude toward mothers in our society: "My mother's worst transgression ... lay in the fact that by becoming mentally ill - and both branches of the family viewed this illness dubiously - she had rendered herself incapable of caring for her children, whose protection and guidance were - to my grandmother - a decent woman's main responsibility in life." (Sexton, p 30.)

In her analysis of Motherhood as experience and institution, Adrienne Rich critiques the structure of the nuclear family under patriarchy, and discusses the power relations of parent-child relationships as: "Often simply a reflection of power relations on patriarchal society." She describes the abuses which can occur because of this patriarchal power structure: "The child ... is a piece of reality, of the world, which can be acted upon, even modified, by a woman restricted from acting upon anything else except inert materials like dust and food." (Rich, 1976, p. 38.) In situations where the mother has a distorted sense of reality, caused by a mental illness, this dynamic can become magnified. In her chapter called Violence: the Heart of Maternal Darkness, Rich tells the story of Joanne Michulski, a woman who clearly had a mental illness with psychotic features, who was entirely responsible for the care of eight children, and murdered the youngest two children. "Aware that the situation was deteriorating, Michulski (the father) stuck to his decision to "keep the family together" - that is - to leave his wife all day long responsible for eight children. At no point do news accounts or interviews suggest that there was any attempt to get household help, or to offer her any respite from her existence as 'wife and mother'. And perhaps she would have refused" (Rich, 1976, p. 258).

Rich describes the expectations laid on women with children as "insane expectations" and asks whether psychiatry would have asked Joanne to adjust to
motherhood, or incarcerated her. She describes Joanne Michulski as a scapegoat, who had endured the "violence of the institution of motherhood" for nineteen years, and it seems that the most precious thing in her life was, in fact, her children. Rich comments that: "the scapegoat is different from the martyr; she cannot teach resistance or revolt. She represents a terrible temptation: to suffer uniquely, to assume that I, the individual woman, am the "problem." Rich's portrayal of Joanne Michulski may be seen as patronizing in the sense that she does not credit Joanne with the ability to change or seek help for herself, and so she appears to minimize the horrible crime which she committed. However, the point she makes about women who live in untenable and dangerous situations, and therefore become scapegoats when a tragedy occurs, is still very relevant today.

In British Columbia, we have recently seen a similar kind of "scapegoating" in the case of Verna Vaudreuil, the subject of the Gove Commission (1995). Verna was found by a court to be guilty of killing her five year old son, and was sentenced to four years in jail. A comprehensive inquiry led by Judge Thomas Gove explored, in minute detail, every aspect of the systems that contributed to the state of affairs that led to this "isolated, unique" act. (Note: this kind of act is not unique, but is actually a common occurrence in British Columbia, as evidenced by other cases investigated by the Morton Commission.) The report shows us that Verna was mentally handicapped (perhaps from a childhood injury), severely mentally, physically, and sexually abused, and that she experienced many moves, many foster homes, and many losses. At the age of nineteen, when her child-in-care file was closed, Verna was considered to be incapable of independent living. She had a baby a year later, with an abusive and impulsive man, and subsequently had extreme difficulties both in caring for her child, and in maintaining any kind of structure or safety in her lifestyle. Verna was often described as "anxious" and "distracted" and was clearly emotionally disturbed as well as disabled. She lived in an environment beyond the common understanding of the word "neglect": for example, there
are numerous references to piles of rotting garbage full of maggots and dog feces on her kitchen floor. However, there is only one record of a brief (three week) mental health involvement, which addressed "parenting skills" rather than other psychiatric concerns. While the Gove report noted that almost all of the interventions directed toward the family focused on Verna, the interventions actually provided only sporadic attempts to teach parenting skills, for a number of years, with no sign of improvement. There was no plan which included a realistic assessment of Verna's needs as an individual or as a mother, and no provision to ensure that Mathew was even safe, much less emotionally healthy, considering the clear lack of nurturing care that he received. This story very clearly shows the entrenchment of social beliefs that mothers "should" be entirely responsible for the care of their children, even if the mother's disabilities and lack of positive role models clearly prevent them from providing adequate care. This does not mean that mothers should not be called to account for their behaviour, or that it was inappropriate for Verna to be sanctioned for her cruel treatment of her son.

**Care Issues**

Many feminists have addressed the issues about the emotional connection, and the labour involved with caregiving. (Baines et al., 1993: Graham, 1983). Caring for a child is very hard and constant work. It entails not only hard physical work (cooking, cleaning, and running after) but emotional work (adjusting to constant changes as the child develops, creativity, dealing with noise and clutter, lack of both privacy and control over time, and reconciling issues from one's own childhood.) It also involves many losses, associated with isolation, diminished social identity and status, lack of privacy and time, and financial hardship and, in many cases, poverty. Yet social attitudes reinforce the caring role for women as a privilege and an obligation: all women "should be" mothers. However, for women with a mental illness, this caring role may be highly valued, and often unavailable. bell hooks states that poor and marginalized women may find parenting one of the few interpersonal relationships where they are affirmed and
appreciated. (hooks, 1984, p. 135.) This has been found in research with mentally ill mothers (Mowbray, 1995; Sands, 1995; Schwab, et al, 1991).

**Feminism and the Mental Health System**

Many feminists have written about how psychiatric labels may promote sexism, racism, heterosexism, ableism, classism, and ageism (Becker & Lamb, 1994, as cited by Brown 1994; Caplan, 1995; Kaplan, 1983). Diagnosis is generally seen by feminists as reflecting the worldview of the dominant class.

Laura Brown, a feminist therapist, wrote about the neglect of feminists to address issues of diagnosis, except to critique the legitimacy of diagnostic labels. She argued that there is a need to develop "feminist diagnosis" which would involve the therapist and the client to work together jointly to develop organized hypothesis about the nature, origins, and meanings of a client's distress. She stated that the entire complex process for making sense of experience is diagnostic, and may also include mainstream diagnosis. She also stated that in feminist diagnostic thinking, large, overarching categories of classification become less important than precise and complex delineations of each experience within a given social context. Personally, I think that developing the idea of "feminist diagnosis" would allow for other issues in women's mental health to emerge, such as access (and barriers to access) to the safest and most effective treatment for women with mental illness.

The danger with psychiatric diagnosis is that the person may be conceptualized as the diagnosis, such as considering a person to be a schizophrenic, a borderline, or a manic depressive. Brown comments that, "Whenever I note my own careless participation in this process, I am provided with evidence of the power of diagnostic terminology and how easy it is to exchange critical thinking for a quick and apparently simple way of conceptualizing a complex human being." (Brown, 1994). Feminist theories are strongly opposed to the creation of models of a "normal" human being, because of the different degrees of resources and privileges available to people under patriarchy.
Many feminists are critical of psychiatry as a patriarchal institution, which disempowers women. Bonnie Burstow (1992) wrote in her radical feminist critique of psychiatry that the concept of "mental illness" is "illogical, unscientific, and almost unintelligible." She points out that there can be brain diseases, such as Alzheimer's, which are observable and treatable, but that many "mental illnesses" arise from disorders in the power relations in Western society. This has also been suggested by Szasz (1974) who described mental illness as a metaphor which resulted in enormous psychiatric control and oppression of people suffering from emotional difficulties. Burstow accused modern psychiatry as serving the interests of "patriarchal capitalism, which has little tolerance for differences, believes in quantification and control, and seeks to imprison, infanitilize, correct, or incapacitate those who deviate from the assigned roles."

She goes on to say "Psychiatry today is the misogynous institution it always was. The psychiatric family is the ultimate backup for the patriarchal families of origin and of marriage and the ultimate enforcer of patriarchal norms." She quoted from Statistics Canada (1988) as reporting that 64% of Canadian women have mental disorders, compared with 36% of men. Women outnumber men as "patients" by about that number. This difference speaks to the greater oppression of women and male hegemony. The great majority of psychiatrists are male, while nurses and social workers are female. Burstow states that women who are defiant and resistant are "blamed, punished, and may be physically damaged with "treatment". Sexual abuse is part of this male violation of women. This article promotes the view that women's experiences have been, and continue to be distorted by the history and social construction of mental illness.

Longitudinal British studies found very high percentages of depression in mothers of young children - 30% of mothers in an outer London borough were found to be depressed during the past month, rising to 40% where the children were behaviourally disturbed (Pound, 1996). The author of this study commented that:
We had not expected such high rates of distress in mothers, of difficult behaviour in children, and of unsupportive marriages. At that time many denied that such a high proportion of mothers really were suffering distress, since there was a general acceptance that being at home with children ought to lead to contentment and fulfilment (p. 203).

As mentioned in the literature review, the prevalence of depression in women and girls is very high. For example, 40% - 50% of adolescent daughters of parents with an affective disorder developed a major depressive disorder by age 17 (Weissman et al., 1984). These findings demonstrate that mental illness is a political as well as a medical issue, and an important area for feminist attention.

Mother Blaming

Another issue that concerns feminists is mother blaming. Usually the mother is the only one investigated for psychopathology or contributing to the child's problem. This is a logical assumption if you assume, as is often the case, that the mother is the primary caregiver, but it begs the questions of why she is the only caregiver. Van Den Bergh cautions that "searching for commonalities among women provides ammunition for oppressors, in the sense of categorizing women." (Van Den Bergh, 1995). There is an unquestioned assumption that the mother is the problem. In a study by Caplan and Hall McCorquodale (1985) of clinical journal articles, 72 different kinds of psychopathology were attributed to mothers in the 125 articles reviewed, and 82 % of the articles attributed the child's pathology to the mother's activity.

Neglectful mothers

The issue of child neglect is important in this discussion because it is one of the most common reasons that mothers who have a mental illness lose custody of their children. Calahan (1993) discusses how feminists would look at the entire picture differently, asking why a woman, particularly a mother with a disability, would be blamed for a problem rather than provided with the support and options to be cared for herself,
and also ensure proper care for her children. In her article about child neglect, Karen Swift (1991) states that virtually all of the people accused of neglecting children both historically and presently are mothers. Virtually no one has examined the issue from the perspective of the women's lives: "The almost exclusive focus on mothers makes it appropriate and in fact essential to take up the issue of neglect from the perspective of women, the lives they lead, and their actual capacity to do the work of caring." Swift suggests that when we look at the problem from the mother's perspective, we may see:

(1) Children who are upset and difficult to manage, due to moves, foster care experiences, and other losses and changes.

(2) Ongoing scrutiny and criticism when the children are in her care. Support workers may testify in court against her.

(3) Only crisis oriented interventions. Since the child welfare mandate does not include protecting children from poverty or helping the mother enrich her own life, the case will be closed until the next crisis.

Swift comments that:

The kinds of questions asked in research on neglect conform in many respects to a positivist model. Neglect is presented as an objective social category which needs to be carefully identified and counted, and for which definite causes, effects and hopefully, treatments can be found. The resulting range of knowledge is limited, by the standards of a critical approach, in that it leaves out almost entirely the social contexts and processes related to the visible appearance of neglect.

While concerns about child neglect are the surface reality; underlying these concerns are themes concerning: (1) The traditional relationship between the state and the private family which is crucial to the way we think about caring for children. The social work response is characterized by contradictory mandates to both help the family and to exercise authority over negligent mothers; and (2.) The gendered division of labour through which mothers become the primary and often only providers of care for children.
The care of children by single mothers poses additional concerns because there is no backup (Swift 1991). The solutions she proposes are: a collective approach which promotes collegiality rather than hierarchy; "taking care of" without threatening affection and love; involving fathers, and particularly more research to find out more about abandonment by fathers; and care for caregivers as a legitimate value in its own right. She states that, "We will have achieved some success in child welfare, I would argue, when a reasonable standard of care can be provided children without the necessity of impoverishing, stigmatizing, and coercing mothers to do the caring work." (p. 267).

In her article about feminist approaches to child welfare, Marilyn Callahan (1993) states that the more disadvantaged the mother or caregiver, the more disadvantaged the child. Callahan states that one must consider the impact first of womanhood, then of motherhood, and then of motherhood, class, and culture. "As long as parents, in particular mothers, are viewed as having the prime responsibility to provide for and protect their children, then terms like child neglect and child abuse discredit them. The issues that feminist child welfare addresses require other terms: caring work, community safety, hungry kids, women's wages, and many more." Callahan says that a feminist response to neglect would be to provide care and resources - not to punish. She states that children suffer because their mothers are assigned to their care, yet do not have the power or resources to provide for or protect them. "Women's behaviour toward their children is better understood in term of their powerlessness than their perversity." Callahan described a center in New South Wales, which uses a feminist model to create an extended family for women who need support and respite as parents. At Bernardo's Waverly Centre, natural mothers form a non-hierarchical team with foster mothers and social workers to make major decisions involving the care of their children. The foster mothers are considered to be like aunts or sisters to the natural mother. I think that this type of model would be very valuable to mothers who have a mental illness. However, the family problems caused by parental mental illness may not be fixed by support,
respite, training, etc., but may also require medical intervention: compliance with effective medication; insight into the illness process; and agreement with treatment.

I believe that it is essential to look beyond the individual and to use more imagination and creativity to allow for better solutions. Why can't long term support be a right and an empowering resource for both mothers and children? Why does the neglect of these children have to become so severe before a crisis response is made? Why couldn't mothers who are diagnosed with a chronic illness (of any kind) be eligible for appropriate housing, which could have a support system that they desired in place in case of relapse of symptoms? I support the position stated by bell hooks, that feminists must address both the issue that children have a right to effective child care by parents and other caregivers, and that isolated women should not have to exclusively provide that care (hooks, 1984). Why aren't there more opportunities to provide very good care for both the mothers and the children, including emotional care? Because of cuts in funding, and political attacks on women and children, (as described by Sidel, 1996 and Baxter, 1993), it is difficult to put a new awareness of need on the social welfare agenda. A feminist, transformative vision is required, which would value and affirm the value of family relationships, provide support for people to take care of each other in many models beyond the nuclear family, and create a helpful, creative discussion to the questions I have posed above.
Chapter Six

Research Design and Method

As information related to the subjective experience of mothers with a serious mental illness has been generally ignored in the literature, this study was designed as a qualitative, exploratory investigation of the parenting experiences of mothers with serious mental illness. In this chapter, I will describe how I developed this research project, and the process I used to interview the six mothers and to understand and share what I have learned.

The study was undertaken from a feminist perspective, which is committed to describe, explain, and predict phenomena within the context of women’s oppression (Chernomas & Rainonen, 1994). While there are many models of feminist research, (Devault, 1993; Fine, 1992; Reinharz, 1992; Stanley & Wise, 1990) they share the perspective that each participant’s experience is viewed as a valid source of knowledge, and that knowledge is created within a collaborative process between the researcher and the participant (Olesen, 1994). The relationship between the researcher and the participant is considered essential to the quality of the information, and the power dynamics in this relationship must be addressed in the research (Oakley, 1981). Feminist research is designed to be useful and accountable to the participants, and to be oriented to the empowerment of women through social change (Reinhartz, 1992; Riger, 1992). Feminist research is based on a distinct ethical position, involving trust, empathy, nonexploitive relationships, a critical analysis of power structures, and a commitment to giving voice to the participants (Oakley, 1981; Reinhartz, 1992). Denzin and Lincoln,
who edited a comprehensive reference work about qualitative research, endorse a research position of commitment to a feminist ethics that stresses personal accountability, caring, the value of individual expressiveness, the capacity for empathy, and the sharing of emotionality, within a model of collaborative, trusting, nonoppressive relationships between researchers and those studied (Denzin & Lincoln, 1994).

Qualitative research fits with a feminist perspective because each participant’s perspective is viewed as a valid source of knowledge for the researcher (Stanley & Wise, 1983). A qualitative methodology was used because it is considered to be the most effective approach to learning about participants’ life experiences, as it allows for story telling and free interaction between the participant and the researcher, and offers opportunities for clarification and discussion (Reinhartz, 1992). Qualitative interview research is the first stage in developing an understanding of the problems or contradictions faced in the everyday experiences of a marginalized group. A thorough consideration of the marginalized perspective can be the basis of further inquiry grounded in that understanding (Smith, 1987). Qualitative studies must specify the techniques and methods that were used, the experience and qualifications of the researcher, and the assumptions which undergird the study (Patton, 1990).

**Personal Statement:**

As a mother and foster mother, I have a well grounded understanding of the struggles that are faced by all parents. Several of the teenage foster children who came to live with me were in care because of parental mental illness, and I tried to care for them in the spirit of offering a kind of sisterhood or extended family to their parents, even
when circumstances prevented direct contact. It was important to both me and my husband for the children to be well connected to their natural families, and to have as much knowledge as possible about their parents’ illness. These children had been greatly neglected while in the care of their parents, although their parents were trying to do their best to care for them. This contradiction was very confusing to both the children and their families. As a professional social worker, I have worked with families and children for the past five years as a member of a community mental health team, and I have witnessed many cases of similar neglect, where a parent who has a mental illness has not met the basic needs of her children, but the expression of parental love and concern is paramount. As a committed feminist, I am interested in new paradigms for ending the oppression of both women and children. I believe that many of the dilemmas I have described in this thesis could be resolved if we listened to and honored the voices of wise women - great grandmothers, grandmothers, sisters, aunts, and mothers themselves. My hope is that by listening to the stories of the mothers who participated in this project, we can learn more about their strengths as well as their difficulties. With this knowledge we may be able to provide better assistance to children as well as parents who suffer from the effects of parental mental illness.

**Sample**

In this study, I sought out participants who had direct and personal knowledge relevant to the study question, and who were willing and able to share their experiences. Such a purposive sample is typical of qualitative research (Sandalowski, 1995). The study was open to any mothers who were caregivers of preschool or school age children.
and who attended either of two Community Mental Health Teams operated by the Greater Vancouver Mental Health Services Society (G.V.M.H.S.) There were no other criteria relating to age of the mothers or children. The mothers were given information about the study by their therapist, (Appendix A) with a phone number to call if they were interested in volunteering. Mothers experiencing acute symptoms or crisis as perceived by their therapist were not interviewed. The number of participants was limited by the amount of time available to the researcher, rather than a number which would adequately represent the field of participants’ responses. The criteria for “serious mental illness” was not specified by the researcher but was implied by the mandate of the community mental health service, which is “to provide treatment to the seriously mentally ill, mainly with psychotic disorders and those disorders which lend themselves to a multidisciplinary approach” (G.V.M.H.S. policy handbook, 1996). No further screening for diagnosis of the mental illness was done, and health records were not accessed, as consistency in diagnosis was not an issue addressed in the study. Study participants were told the name and nature of the study, which allowed them to consider whether or not they would like to be involved in the study. Mothers were chosen because the experience of mothers and fathers is different in our society, and while the experience of fathers is an important area for further research, it was not within the practical scope of this small study to consider both mother’s and father’s issues. Mothers are usually the primary caregiver of their children, whether or not they have a mental illness, whereas fathers with a mental illness are usually not the primary caregiver (Mowbray et al., 1995).

The sample consisted of six participants, which is considered to be an adequate number for a descriptive, case oriented analysis (Morse, 1994; Sandelowski, 1995).
Demographic information regarding the participant’s age, children’s ages and gender, and family composition were taken during the interview. All of the participants were low income as defined by Statistics Canada. Two were married, and were supported by working spouses. The remaining four received disability benefits from the provincial government. None of the mothers worked outside the home. Two of the mothers had emigrated from non English speaking cultures. The mothers ranged in age from 36 to 44, and the children ranged in age from 2 to 21. One participant had three children, two participants had two children, and the remaining three participants had one child.

Data Gathering Methods

Each participant was interviewed for approximately one hour, one or two times, using a semi structured interview guide (Appendix B). Semi structured interviews are considered best in situations where there are limited opportunities for interviewing, as they allow for variations in participants’ responses, and similarities to allow for comparative analysis of the data (Bernard, 1994). The questions were developed from an article by Mowbray, Oyserman, Ross, and Zemenchuk (1995) which points to gaps in the literature about the meaning of parenting from the perspective of women with a serious mental illness. The gaps were: (1) how the mother feels about her status and feels about her child; (2) positive aspects of parenting; (3) personal strategies; and (4) support systems.

The research questions addressed these issues, and also inquired into current struggles and relationships with professional workers. The questions were designed to flow from the most concrete (describing the qualities of the children) to the most abstract
(what do mothers who have a mental illness need from health care professionals?) It was hoped that this progression of questions would promote engagement and lessen anxiety. However, the interviews were primarily structured on the informal interaction of myself and the participant, and discussions frequently veered from the planned questions. This is an expected part of exploratory qualitative inquiry (Bernard, 1994; Kvale, 1996). Three of the interviews were conducted in the participant's home, and three were conducted at the mental health team offices, at the choice of the participant. All interviews were audiotaped and transcribed. The transcripts, as well as the narrative that I had constructed from them, were returned to the participants for review, and a further conversation was initiated to obtain feedback and any further comments. I hoped that this process would create a dialogue of shared interpretation between myself and the participants, as outlined in Kvale (1996), and result in the co-creation of a narrative story that the participants agreed to share. However, while the participants agreed to the language I used to describe their stories, for the most part they did not wish to engage in this process at any length.

I did not ask to meet the children, and met only one or two during the interviews. Data from my contact with the children are not included in this study, but may well be the focus of a future study.

As the purpose of the study was to uncover and describe the participant's perspectives on their own life experiences, interviews with the participants were utilized as the sole method of data collection (Marshall & Rossman, 1995). A consideration in research interviews is what the participant's view is of her participation: one part is the
meaning of the story to the narrator herself; the second is the meaning of the story to the narrative interaction. It is essential to consider the perceived audience that the participants believe themselves to be addressing with their stories (Borland, 1991). In order to provide the participants with sufficient information about myself and the proposed use of the data so that they could make an informed opinion about what they wished to share about themselves in the interview, I discussed my roles as a graduate student and mental health professional working with families and children at the G.V.M.H.S. team. I am not sure to what extent power issues, or other issues related to how I was perceived by the participants, affected the interview situation.

I transcribed each initial interview, which I felt was a valuable part of the research process, in that it offered me the opportunity to closely listen to the tapes and to interpret them into a textual format. Initially I was interested in recording each nuance of speech, and that may have helped me during the initial stage of engagement with the data. However, I felt uncomfortable and dissatisfied with the completed transcripts, as the language did not reflect the fluency and energy of the interviews. I also felt that the transcripts from the participants who spoke English as a second language looked particularly awkward on paper, which I was afraid could possibly embarrass or offend them. Marjorie Devault (1993) discussed the issues of transcribing spoken language, which may be clear, animated, and have significant non verbal meanings, to a written transcript, which is complicated by speech patterns, hesitations, dialects, etc. I decided that these problems with the written version of the conversation distracted from the meaning of the story which was my main focus. I also felt that I was not qualified in linguistic analysis, and to attempt it would be to risk becoming overly intrusive,
judgmental, and even disempowering. Therefore, I edited the final version of the transcripts to read somewhat more smoothly, before I returned them to the participants.

Kvale discusses the dilemma of the researcher wanting the interview to be as "deep and probing as possible, with the risk of trespassing on the person, but on the other hand wanting to be as respectful of the interviewed person as possible and thereby risk getting empirical material that only scratches the surface" (Kvale, 1996, p. 156). In some cases, participants had spoken about sensitive issues, which I brought to their attention on our second contact to ensure that the use of the data was based on knowledgeable consent.

In general, the participants did not offer much feedback about the transcripts. I was concerned about the hesitation of the participants to comment on the transcripts, because I was aware that some of the stories touched on painful areas and deep fears. One person told me that she was uncomfortable about reading the transcript, and that she would like to rephrase things, as she found she did not say exactly what she meant. I responded by assuring her that there was no problem with her editing the text, and that I appreciated her doing so. Reading a transcript of one's own interaction with another person can be quite unnerving - I found this reading my own questions, and wondering about my own responses.

The second interviews were not taped and transcribed, although I did take notes. There had been a number of changes for the participants during this time period (two to four months after the initial interview), as one participant had been involuntarily hospitalized, and another had had a serious relapse. One participant did not wish to meet
with me again, but told me that she had no problems with the transcript of the initial interview. One mother brought me a card and a rose in appreciation for listening to her, another mother was pleased with the transcript and tape, and planned to share it with her family, and one participant planned to use the transcript to write her own article. I gave each participant a copy of the transcript of our discussion, as well as a copy of the narrative account that I had constructed from it. Only one participant chose to keep the tape, and all other tapes were erased. All participants were also given a small gift certificate as a token of appreciation.

Data Analysis

As the research questions were based on the need for subjective information from mothers who have a serious mental illness, and each person responded with a personal story about her experience as a mother, I found that the data emphasized the unique situation of each participant. I decided to present each case as a limited case study, (as I did not possess much of the information which would be included in a more traditional case study, such as the inclusion of other sources of information over a longer time frame) and to use a narrative framework for analysis (White, 1990; Mishler, 1986; Kvale, 1996). I believe that narrative analysis fits particularly well in the social work paradigm, because it reflects the daily experience of social work, in terms of making sense of the often limited but significant contacts social workers have with their clients, and because it respects and honors each person’s uniqueness.

The research addressed the economic and social “double binds” that mothers were placed in as they attempted to be good patients, good mothers, and stable heads of
families despite the fact that both the mothers and the children required special care at
times. Considering each story as a unique case, I tried to develop a dialectical analysis of
the conflicting demands and struggles described by each mother. Dialectics is the study
of internal contradictions, and the tension between these contradictions as a force for
change. It situates human activity in historical and human contexts, and looks for
underlying meanings which reflect basic social and economic contradictions (Kvale,
1996).

I read each transcript carefully, trying to understand it as a story in a context, and
to achieve a wholistic sense of what that person was saying. I then developed the
interview transcript into a narrative as I understood it. I added a section of comments in
which I wrote what I perceived as the central themes of each particular story, and the
reactions, special thoughts, ideas, and linkages that occurred to me. After writing all six
stories, I then went back to the transcripts and re-read them, checking to see if I had
omitted relevant facts in the story I had composed. In most cases, I had, and I was
surprised to see that even this straightforward exercise of summarizing the interviews was
highly subjective and required revisiting several times. Even now, after many re-
readings, particular things jump out at me from the transcripts which I had not initially
emphasized or had not understood in the same way. Throughout this process, I began to
understand the context and meaning of all of the interviews as a group. Finally, I
summarized the basic themes from each story, and compared them to each other and to
the literature. I then brought the stories and the revised transcripts to the participants,
with a list of the themes I had highlighted, for their feedback and to enable them to
maintain ownership of their stories.
My process of interpretation can be described as a “dialogue with the data” (Tesch 1990) or a “hermeneutical circle” (Kvale 1996). This involved a continuous back and forth process of interpretation between the parts and the whole of the text (which in this case were the transcripts and the narratives derived from them.) With each re-visitation of the interviews the meaning of each narrative and of the group of narratives was expanded and deepened. Each theme was compared and contrasted to the themes identified in the study as a whole. Three concepts of hermeneutical interpretation, as described by Kvale, were important:

1. The autonomy of the text: “The interpretation should stick to the content of the statements and try to understand what they express about the life world of the subject.”

2. The importance of knowledge about the theme, which requires reference to the interviewer’s experience and the literature to understand the nuances of the meanings expressed.

3. Interpretation is not “presuppositionless” but must involve and take into account conscious awareness of one’s own presuppositions and modes of influence. (Kvale, 1996, p. 49).

A narrative approach, which aims at obtaining a rich description of each participant's story, was used to make sense of the content of the interviews. Mishler (1986) described the many interpretive possibilities of treating interviews as narratives, emphasizing: 1. The temporal sequence; 2. The social dimension (the telling of the story); and 3. The meaning or plot. A narrative approach was particularly appropriate because it seemed more open to exploring the diversity and range in the stories and
situations of the mothers, and to understanding the meaning that the participants attributed to their life experiences. I then developed a commentary on each story, relating my own subjective impressions, interpretations and thoughts to the data in each interview. Following an analysis of themes from each participant's story, the common themes and patterns were identified and compared and contrasted. The use of this method of comparing case studies has been advocated as a feminist research method (Reinhartz, 1992). I was particularly concerned in this study about preserving the uniqueness of each situation with as little fragmentation and discontinuity as possible. In a narrative approach, the analysis and the reporting of an interview merge and result in a story to be told to the readers (Kvale, 1996).

As narrative emphasizes order and sequence, in a formal sense, it is more appropriate for the study of change, the life cycle, or any developmental process (White, 1990). People organize and give meaning to their experience through the "storying" of experience, and in that process they express selected aspects of their lived experience (White, 1990). These selected aspects reflect a number of factors, including ideology and prevailing cultural practices. The frame for these stories is a critical sociopolitical understanding informed by feminism and anti oppression/ liberating ideology. The goal is to bring the issues of child neglect, trauma and abuse into the discussion and deal with them openly in terms of power, gender specific abuse, exploitation and oppression.

The preparation of a narrative study from an interview transcript allows for ongoing creative possibilities of interpretation. The narrative can be read to allow for a deep understanding of the situation, with numerous possible interpretations. The themes
related to the content of the narrative can be further analyzed to bring out their hidden meanings, and comparisons may be discussed (Denzin & Lincoln, 1994). In their book about qualitative research analysis, Coffrey & Atkinson (1996) state:

One of the strengths of thinking about our data as narrative is that this opens up the possibilities for a variety of analytic strategies. Such approaches also enable us to think beyond our data to the ways in which accounts and stories are socially and culturally managed and constructed. That is, the analysis of narratives can provide a critical way of examining not only key actors and events but also cultural conventions and social norms.

Validity

Qualitative research is primarily concerned with achieving a deep understanding of the participants' subjective experience. Thus, concepts such as validity and generalizability etc. are understood in terms of the success of the research in illuminating the research question. Valerie Janesick (1994) describes validity as having to do with description and explanation, and whether a given explanation fits a given description. Alternately, Joan Acker, Kate Barry, and Johanna Esswold (1991) refer to the concept of adequacy, which can be achieved by making sure that the subjects' voices are heard, accounting for the investigators as well as those participating, and revealing conditions that result in the daily lives being studied.

As I am a white middle class researcher attempting to learn through establishing a dialogue with women who have been marginalized in society, I was hesitant to include my own "explanation" without further discussions with the research participants,
although the participants confirmed that the initial findings “made sense”. I was interested in offering the participants’ stories, and a discussion of the major themes I identified, which reflected my own reading and experience, and was thus “in process” and open to question. I don’t know how much trust I was able to establish during two relatively short discussions with the research participants. This unknown level of trust may have a negative effect on the validity of this study. I am also aware that there is a great variation in parents’ experiences, and do not expect that the sample in this study will necessarily be representative of the larger population. However, I did find that many of the major issues described by the participants were similar to the findings of similar studies (Judas et al., 1997; Sands 1995).

There are more questions that bear on the validity of this work. Ross & Conway (1986) are cited by Marshall & Rossman (1995) as stating that “narratives may suffer from selective recall, a focus on subsets of experience, filling in memory gaps through interference, and reinterpretation of the past.” Although the person may “fill in” missing pieces to create their story, I believe that this story is valid in the sense that it conveys the person’s construction of the events and shows the person’s understanding of them. Marshall & Rossman also caution against several other potential pitfalls in narrative analysis: (1) “The illusion of causality” - the inference that the narrators story sequencing has accurate cause and effect linkages; (2) Narrative inquiry is very time consuming and laborious and requires some specialized training; (3) A final disadvantage is its newness: it is difficult to identify standards and common definitions or criteria for good narrative inquiry. ... It is particularly useful in developing feminist and critical theory.
Ethical Issues and Confidentiality

As a feminist, I personally had some concerns about the research, as there was a power imbalance in that I was employed by the agency from which the study participants were recruited. People with a mental illness have historically been injured through the use of implicit and explicit power when dealing with mental health professionals. Mothers in particular, including the mothers in the study, have reported that power has been used against them in their ability to maintain custody of their children. I was aware that I was not interviewing the women on behalf of an advocacy group, where there would be a strong emphasis on the protection of the mother’s interests, but for an academic purpose in which there was a possibility that the information they shared could be distorted in the process of the production of this thesis either through my own interpretation, or the interpretations of others reading the completed study. Although I would describe myself as a feminist, I couldn’t trust my own position as a mental health worker, and an academic researcher, to not harm these mothers in some way, at least in their own perception. The problem I was examining seemed to have many complex and contradictory layers, as evidenced by participants who spoke about simultaneously having their trust destroyed by “helping professionals” and yet wanting these same people to hear their side of the story. This project was personally challenging, in that I was forced to accept that I wished to depict a situation that I believe requires intervention and social change, and yet the particular changes that I might advocate may be at odds with the wishes of the participants. Michael White (1990), an Australian family therapist who practices with a critical perspective of the use of power, stated that:
If we accept that we are simultaneously undergoing the effects of power and exercising power over others, then we are unable to take a benign view of our own practices...we are always participating in the domains of power and knowledge, and thus we must work to establish conditions which encourage us to critique our own practices in this domain...thus we would identify and critique those aspects of our work which might relate to the techniques of social control. (p. 29).

Because of the possibility of distortion of the information, I would have liked to have created more opportunities for discourse with mental health consumers about the findings of this study, or perhaps to have undertaken the study through a consumer organization.

In an attempt to minimize the negative situation of unequal power, I took care to discuss the issues of the purpose of the research, consent, confidentiality, contact, feedback, and participants' rights to not answer questions or stop the process, with each participant. I gave each participant a copy of the transcript to keep, as well as a copy of the narrative I had composed, and encouraged their feedback. This gave them a chance to say whether their stories had been clearly understood, and to change, add, or delete information. (Note: I regret that I neglected to offer to read the material aloud to the participants, which may have resulted in a seeming lack of interest in the written content for several participants who may have had low literacy skills.) I revised and edited the narratives somewhat after this point, so there was a point where I took charge of the information, and in doing so claimed that my own interpretation was the predominate one in this research.
I encouraged the participants to ask their therapist to discuss any problems about the research study with me, if they did not feel comfortable approaching me themselves. I did not receive any negative feedback from the therapists.

The agency has strict rules about confidentiality and I did not access medical records or have conversations with agency staff about the participants. The research project was required to pass agency screening involving gaining consent from the directors of the each mental health team, the director of research for the agency, and the director of adult services for the agency. As well, the project was approved by the UBC ethics committee as part of a research class submission.

In the following section of this thesis, I will present a version of each of the participants' stories, including direct quotes; a summary of some of the themes from that particular story with discussion, and a final overview and summary of themes based on the data. I decided to present the data in this way in order to capture the unique issues of each individual’s situation, without asking the reader to remember the details of all six stories at the end. For example, I commented on the impact of traditional Chinese cultural understandings of mental illness following the data about a Chinese mother, and I then discussed cross cultural issues in general in my final summary of themes.
Chapter Seven

Mother's Stories

In this chapter, I have written a narrative about each of the six women who agreed to participate in this project. The narratives are entirely based on my contact with the women during one or two conversations. These stories do not represent clinical case studies, but are attempts to communicate as much detail as possible in order to help the reader understand the comments and issues that have been raised by each participant. Each story is followed by a short commentary related to some of the themes in that particular account. The predominant findings and the themes that have been described by the participants overall are outlined in Chapter Eight.

(1) Jane's Story

Jane (age 37) lived in a large public housing complex, in a small, sparsely decorated two bedroom apartment. The living room was dominated by the television, which was on loudly. Jane was lying on the couch and did not get up when I came in, or offer to turn down the T.V. Jane has many disabilities: she has a mild mental handicap, physical disabilities such as severe arthritis and metabolic disorders, and a chronic mental illness. She is the single parent of a 12 year old daughter. Jane has brought this child up with almost no family support, as her mother, who is her only living relative, lives in another province. Jane clearly relies on her daughter for both care and emotional support, stating that her daughter cleans the house, makes supper, anticipates when Jane is tired or sick, and goes shopping and picks the lowest prices. Jane said that she is sometimes frustrated because her daughter controls the family purchases: “She tells me what’s good to buy, and what’s not good - but I want to get what I want, not buy other things... I’m tired of the same stuff.” However, in general, Jane is appreciative of her daughter: “She
does things without me asking ... she treats me well. She gets me stuff, or realizes when I’m tired, and she’ll do it for me... When she knows I’m tired, she makes supper and lets me have a little nap.” Jane is aware that her child worries about her mother’s health, and that she also tries to manage practical household matters such as budgeting and bill payments. However, when I asked about the impact of these worries on her daughter, Jane told me that she “also” worries about these things, rather than considering the impact of these responsibilities for a child. It seems clear that Jane depends a great deal on her child for basic care, and that she also expects her child to share her worries and responsibilities.

In return, Jane believes that she owes money to her daughter, although "she understands when I can't pay her." Just before I visited, Jane had given her daughter $185.00 and then found out that the bank had issued the money on an overdraft from the bank machine by mistake. Jane was very upset, as she had no way to pay back the money to the bank. Although this is a lot of money to give to a 12 year old, and a large percentage of the family income based on disability social assistance rates, Jane had no clear idea what her daughter might spend it on.

Jane has always been vulnerable as a mother, and she worries about the possibility of losing her daughter. Custody issues have been a painful repeating theme for her. Her daughter has been in foster care on numerous occasions when she has been in hospital. Jane described one occasion, when she was in hospital, when she almost lost custody: "I went in the hospital to get needles for my hip - I had so much pain. And one of the childcare workers came in and said, will you sign this paper? So I thought I was signing for three months. But then she was gone. Will I get her back? I signed her away." Jane was able to get legal help to get her child back that time, because she had not been able to understand the form she signed.

Jane has had many professional workers to help her with parenting her daughter,
although she said that "I mostly don't get it often enough." The professional support from Social Services and Services to the Mentally Handicapped has included daycare, teaching homemakers, and parenting education programs. At present she is not receiving any professional help with parenting. She tries to parent based on her own ideas, but she describes herself as a "medium" mother who "needs to learn more by listening to other people." Despite these parenting programs, she is clearly very limited in her ability to manage as a parent, relying on reactive rather than reflective problem solving strategies. For example, in one instance when she describes how she successfully solved a problem with her daughter, she did this by stating "I didn't like it, so I yelled at her ... until she got mad." Standing up for herself with her daughter seems to be an issue - particularly as her daughter is getting older, and showing "attitude" and "mood swings." Jane is disturbed about fights between herself and her daughter, in which her daughter pulled on her blanket when she was asleep, or "treated her like garbage." Typically, her daughter starts these fights by picking on her, hitting her, or recently by standing on her feet, and when Jane responds, her daughter yells at her and makes her feel guilty: "She starts picking fights, and then I push her away, and she gets all mad, and she yells at me, you pushed me! and makes me feel like a bad guy." On another occasion, Jane described how she tried to tell her daughter to stop standing on her feet: "I tell her to get off and she doesn’t listen until it's really sore. Then I try to push her away... and then she runs upstairs and she doesn’t want to talk to me anymore. She gets real mad. Or the other day, she was doing something. Pulling my blanket. I told her to stop, and she didn’t. I yelled at her, and she got mad and went upstairs."

These fights become worse when her daughter's friends are present: "When her friend comes over, she doesn’t listen or nothing... She talks to me with no respect or nothing." Jane has not been able to stand up to the friends yet. When asked about what she would do if the friends were acting disrespectfully as she described, Jane said she would just tell them to: "Go home. You can't act in my home like that. You'd better go
home." When asked whether they respond to this, she said, "I don't know, I haven't said it yet."

Jane does get some support from her mother, although she feels ambivalent asking her for help. She said that her mother "expects I can't do anything right." She explained that "Even if I go and get a job, my mother says 'oh, you won't last very long.' Or if I go to school, she says 'oh you won't learn any more than you can.' The same with parenting. She would never call me a good mother. Never." In spite of this pattern of constant criticism, Jane had called her mother the previous night for advice.

Jane gets no support from her daughter's father, who was physically abusive to her, and to her daughter as a young child. Jane believes he was also sexually abusive to her daughter, although he was not charged (Jane said it was "thrown away because I waited too long to tell somebody.") Despite this history of abuse, Jane finds that she tends to give in to him, and at one point tried to move back with him, but was prevented by child welfare authorities. He is still in contact with both Jane and her daughter. Jane said that, "He writes letters. He says that he's lonely, and he wants us to forgive him and take him back. But it upsets my daughter every time he writes. It makes me feel bad, because I start giving in to him, and that's what he wants, and that's not right. Because my daughter gets mad at me." Jane told me that her daughter was also sexually abused by a second boyfriend of Jane, who lived with them, and who was found guilty and sent to jail last year. Her daughter did not receive therapy after this incident.

On the second interview, Jane told me that she had been recently been involuntarily hospitalized because she had been becoming paranoid and psychotic. Her daughter had dealt with her increasingly disturbed behaviour for over a week, but had not called for help until Jane said she might harm both her daughter and herself. Jane was distressed because her daughter had planned a summer holiday to the city where her mother lived, and so Jane would be left alone for several weeks. Jane's daughter physically pushed Jane, who is very large woman who seldom gets off the couch, to a
neighbour's home, and called an ambulance. The ambulance took Jane to hospital and left her daughter with a neighbour, who was known to me because she also has a serious mental illness, and had resigned custody of her own children. Jane's daughter stayed there during the time her mother was in the hospital, and returned home when her mother was discharged. Jane's mother's therapist did contact Jane's daughter and alert the Ministry of Children and Families when Jane was committed to hospital. They decided that she was safe with the neighbour. No additional supports were put in place when Jane returned home, and there was no counseling arranged for Jane's daughter. Neither Jane or her daughter requested help.

Discussion:

Jane described the struggles she coped with as a mother as: money and budgeting; adolescence; medication which makes her very sleepy; housing in which she is unable to physically go upstairs to her daughter's room; fights and power struggles with her daughter; her critical mother; her daughter's father who continually writes asking for forgiveness and a second chance; and loneliness and isolation. Maintaining custody is a major issue, because there is always the possibility of a medical crisis. Despite these things, Jane has been able to stay in one place for the past four years, to get consistent medical treatment for herself during that time, to prevent further abuse of her daughter during that time, and to maintain a somewhat fragile sense of order. Jane answered most of the questions in the interview with one sentence answers, and had no answers to questions such as what she would like health care workers to understand about her situation as a parent. Despite these silences, which I interpreted as signifying her feelings of vulnerability as well as a preference to deal with concrete concepts, Jane reported that she is very happy as a parent, although it has been very hard work.

A strong theme in Jane’s story is the extent that she depends on her daughter for her own physical care, as well as for help. It seems apparent that Jane depends on her
daughter for emotional support as well, and so she is greatly let down when her daughter seems to be abandoning her to spend time with friends, or when she is angry or irritable.

Almost all of the professional support available to this family has focused on Jane. Her daughter has not had consistent professional support or counseling, such as childcare workers or therapy. She has been in foster care on several occasions when Jane was in the hospital, she was in daycare when she was younger, and she has been included as the focus of parenting education programs, but her needs have generally been ignored. The present dynamic, in which this girl actually hurts her mother, is not being addressed except by short term programs which attempt to teach parenting skills to Jane, who may not be able to change the power imbalance as her daughter surpasses her energy and intelligence. Jane's daughter appears to be at risk as she enters her teenage years, unless the family is able to access preventive services. One constraint seems to be Jane's fear that she may not be able to maintain custody of her daughter, which prevents her from asking for help, and causes her to minimize problems when talking to professionals. Another is that Jane depends on her daughter for physical care, and these care needs would have to be met elsewhere before her daughter can achieve independence from her role as caregiver. The strengths of Jane as a parent seem to be in her stability in terms of being home all the time, her accepting, gentle personality, and being quite predictable in a quiet, low energy, way. Jane sees raising her daughter as the central focus of her life, and describes herself as a happy and responsible parent.

Like Jane's daughter, many children of the mentally ill adopt a "parentified child" role in the family, taking care of their ill parent, and the household. They sacrifice their need for care and nurturance, and do not have the opportunity to complete childhood developmental stages because of the burden of caregiving (Brown, 1989). These children are seldom offered help or counseling, because they do not meet the criteria of "abused" or "disturbed in behaviour" and they are frequently good enough at caregiving that they do not appear "neglected" either. They also frequently reject supportive
services, as they may be afraid of exposing their own weakness and vulnerability (West & Keller, 1991). However, this pattern of attachment can have serious consequences for the child, as they may become unable to form attachments in their life in which they receive, as well as give, care (Bowlby 1969). Both Jane and her daughter have been injured by violent and abusive men in the past. Even when Jane's daughter was sexually abused, and the perpetrator was sentenced to a jail term, she did not receive therapy. This may have been because access to counseling programs for children usually requires a concerted effort by the parent. Jane's daughter has to worry about Jane's emotional as well as physical well-being, as is evidenced by the story of Jane's recent hospitalization, where Jane was apparently reacting to her daughter leaving her alone for three weeks. Jane's daughter seems to be expressing anger as well as a desire to control her mother with her abusive behaviour, and the fact that this is happening with no intervention is harmful to both of them.

Jane's story also brings up the situation of parents who have a mental handicap, in our increasingly complex urban society, where simple neighbourhood and community supports are often lacking. Children such as Jane's daughter, whose parents do not effectively explain or mediate their experience in the world, are subject to a kind of cultural deprivation, which often contributes to poor academic achievement. New approaches to "mediated learning" have been developed in social work as well as education in recent years. The literature shows that many parent child issues emerge at latency, when the child surpasses the intelligence and social capability of the parent, but problems can be ameliorated by the strategy of reducing stress and bolstering social supports (Tymchuk, 1992). In particular, long term involvement of family workers who have training to work with parents who have mental handicaps has been found to be important (Tymchuk, 1992; Valentine, 1990). There are a number of proposed changes in British Columbia, as services to the mentally handicapped are now delivered under the Ministry of Children and Families. This is further discussed in the policy section of this
thesis.

This story illustrates for me how both children and parents can be neglected if the criteria for services is based on "protection from abuse", rather than "need". It is not clear that Jane abuses her daughter, or neglects her, as they have a home and a degree of stability. It is clear that both Jane and her daughter require ongoing support to maintain safety, and to add energy to their family system. For example, it seems apparent that Jane depends on social workers to restrict her involvement with her exhusband or other partners who might abuse her child. Much of the support has been in the form of parent training for Jane, rather than adequately supplementing her efforts to meet her daughter's needs with child care and family support workers. Rather than being a source of guidance for Jane throughout the many developmental stages of her daughter's growth, the parent training has been defined as short term and has been arbitrarily withdrawn when Jane did not improve, or during periods of relative stability. This approach has probably lowered Jane's self esteem as a parent; minimized the value of the care that Jane's daughter requires and deserves; and has not provided a sufficient safety net for Jane or her daughter.

(2) Holly's Story

Holly (age 36) lived in a newly built apartment for people with disabilities, full of light, colour, children's drawings, toys, a piano, and interesting and beautiful objects. She was quite willing to meet with me, and had a friend present for the interview. Holly described her situation as the mother of a four and a half year old daughter who had very severe allergies, and required expensive treatments and continual monitoring. Holly has had a difficult time coping with both her daughter's serious medical condition, and her own mental illness. She says that since she has been getting better, her daughter has also improved. Holly moved to Vancouver from the Toronto area when her daughter was a toddler, and initially had no support network of family or friends. She had no contact
with her child's father, who she described as a dangerous man.

Holly described the time when she first asked for help with her daughter. She felt that she was getting "really, really sick" and phoned child welfare services for help. They took her daughter to a foster home for one night, but were concerned about the child's medical condition, and took her to the hospital. Holly said that she "really crashed at that point, because they were accusing me of not taking care of her ... and she was under a doctor's care." Holly's daughter was kept in the hospital for several weeks for assessment, and Holly was committed to a psychiatric hospital against her will. She said that she had no idea about how ill she was - but that she felt "very crazy - and in reality, I was very crazy." However, at the time, she believed that the services that were in place to help her were making her crazy. During the time Holly was in hospital, her daughter remained in hospital with her allergies. After her release, Holly returned home, feeling "paranoid, devastated, hopeless, just a disaster." She began cutting her arms as a parasuicidal gesture, and then she overdosed on pain medication and was hospitalized again. She remembers her feelings at the time that:

I believed, and I know the difference today. But back then I felt that they were out to crucify me, because I was a bad mother, and that I shouldn't have this child, because I couldn't look after her in the way that she needed to be cared for.... and they were better at it. They were offering me services, such as respite care, and I thought that that was a service so they could keep their eyes on me, and on her ... So even though they were offering services that, to the normal person, would seem a support, that's not how I perceived it at the time.

Holly became more ill, and describes this as a ladder, where each stage was worse than the last. She began to cover up and lie about her illness, and her daughter was repeatedly apprehended and returned to her. She said that during that time, "I was telling social services that I was fine, and I was jumping through every hoop they put up, to the point of going to a drug rehab centre, which was not helpful to me at the time."
Apparently the child welfare workers diagnosed the symptoms of her illness as a drug problem, and Holly felt unable to tell them that that was not her problem. "It seemed to me that they wanted to put a label on me, and fit me into a box, and treat me as if I was the label, and everything was supposed to be O.K... The problem was, they continued to label me, and I didn't fit into the box." Holly's child was returned and apprehended several times during a short period. On one occasion, Holly described how horrified she was about the idea of her daughter returning because she wasn't ready. At that time, she was seriously suicidal, and worried that she might also involve her daughter in her suicide plans. Yet she continued working very actively for her daughter to be returned to her.

Holly says that from her present perspective, she understands that her workers were not at fault: "I don't hold them really to blame, because I refused to tell them all the things that were going on for me, because when I did tell them once in a while what was going on, I was immediately certified and my child was apprehended."

Holly describes her relationship with social workers as the most important variable in her ability to cope with accepting help for herself and her daughter. One social worker "definitely instilled a belief that services were set up for people like me." Another helpful worker "took the time to talk about my illness, and what it meant to me." This worker also allowed her to sign short term care agreements for very short increments of time, which allowed her to feel that she had some control of the situation. She remembers another worker who she absolutely hated, to the point of planning violence against her (although she does not believe she would have had the capacity to carry out her ideas.) Holly found that she was greatly helped by an in-home parenting worker, who
came in twice a week, and took the time to get to know her: "She was getting connected to me, even though I was trying very hard not to be connected to her." Holly said that:

When she first came, I was really afraid of her, and of course didn't trust her, because I didn't trust anybody...I felt like I was under a microscope... but shortly after I did some basic testing on trust issues, and she passed, so I would let her in a bit more. A year ago, she would come into my house, and I would be lying on the couch, because I couldn't move very much, and she would say, now would you walk to Safeway with me to get some food, you probably need some food. She'd come in and water the plants, take away the dead leaves, tidy things up... There were days when I'd say, get out of my house! I'm keeping it my way! Stop touching things and opening the blinds! But she was quite a force - she actually took the time to get to know me.

This worker pushed Holly to put more energy into finding effective treatment for her mental illness. Finding the right medication was the turning point: "Through the experience of medication, the realization that came to me was that I could have walked around the world three times in my bare feet, and I could never have got the feeling that I was able to get through the pills."

Although Holly has been in a stable remission of her symptoms due to treatment, she has worked out a Ulysses agreement to plan for her daughter in case she does become ill again. She has distributed this plan to everyone in her support network: her mental health worker, her family doctor, child protection services, and emergency services. Everyone who would be involved if she were to become sick signed it. Holly says, "It's not a legally binding agreement. It's kind of like a handshake agreement. But I happen to believe in a handshake agreement. And these people, I think, have signed their name in good faith. And hopefully, I will never have to find out..."

I was not able to complete the second interview with Holly for several months, because of my own work schedule, although we did have telephone contact about her story as it appears here. During that time, she had a relapse and her Ulysses agreement was used. Holly had stopped taking her medication, isolated herself, stopped eating, began to live in a state of panic and fear, and was losing touch with reality. Her two
therapists at the mental health team were familiar with these symptoms, which were also listed in the Ulysses Agreement which they had helped Holly create. They told her that they intended to set up a meeting, as planned for in the agreement. Holly was vehemently opposed, as she was paranoid and believed that people wanted to harm her. However, she had previously agreed that she could not change the agreement without a six month process, in order for it to be useful when she was in such a state. The use of the agreement pulled in her outside support team of friends and family, and allowed them to talk about what was going on, and how they could work together to help her. The agreement gave Holly's listed friends permission to talk to her therapists, but only to discuss what was needed at the time. Retrospectively, Holly does not feel that her confidentiality was broken. She related one story about how her friend had talked to her therapist, and then shared with her the information that the therapist had given her, which helped Holly trust the process. She commented that the involvement of her friends "forced" her to get well. Her two close friends both had mothers who had bipolar disorders, and she believes that helped them understand how to help her. Holly said she was never "threatened" with the apprehension of her child during this episode, although it was suggested that she could have support from the Ministry of Children and Families if she needed it.

Holly realizes that the episode was very hard on her daughter. She found that her daughter's allergies became worse, and that she regressed behaviourally. Holly said that "She was scared that I would go away, or that she would go away. I reassured her that someone we knew who was close to us would care for her. " Holly had people in her safety net who understood how to take care of her daughter's special needs. As well, her mother was visiting from out of town, and helped take care of her daughter. Holly still feels an intense guilt about the effect her illness had on her daughter. She realizes that her daughter still feels a need to protect her, and is not able to talk to her about how she feels about what happened. She has now arranged for counseling for her daughter.
through a private agency. She will have to pay about $40.00 a month for the counseling, which she believes is very reasonable, but also represents "a weeks groceries."

Holly states that treatment with the proper medication made the most difference in her recovery. However, in both of the episodes of illness she described, she had chosen to stop taking her medication, which caused her illness to worsen very quickly. This seemed to be a critical problem for Holly that requires greater awareness and comprehension: why did she stop taking the medication? Was it a symptom or a cause of the relapse? The area of medication is very controversial and will be discussed in further detail in the summary.

Holly plans to continue to review her agreement every six months, and has some changes she would like to include such as being prevented from driving if she is not able to drive safely. Retrospectively, Holly is horrified that she would do dangerous things like driving her car with her child with her, while she was ill.

Holly commented that "Making the Ulysses agreement was definitely a good thing to do, even though at the time it's the last thing you want to do. It is very hard to use, but with much less regrets... using the Ulysses agreement is part of accepting my illness, rather than ignoring it."

One of the striking features of Holly's story is how difficult it was for her to try to cope with her young daughter, with no organized support system. As Holly experienced acute symptoms of psychosis and paranoia when she became ill, she also became increasingly unable to access the resources she and her daughter needed. There is a contradiction between the social expectation that it is normal or right for women to be solely responsible for bringing up children, often in poverty, and the rights of children to effective child care, a variety of healthy role models, and a secure place in the community. (hooks, 1984, p. 140). This is not intended to criticize mothers, who are doing their best to meet the needs of their children, but to recognize the risks when any child is totally dependent on one person. The professional help that Holly received
helped her to develop a stronger support network, including friends who understood her daughter's special needs and who could also make decisions for her when she was not able to make them.

The development of this network also helped Holly and her daughter in many ways break out of their isolation and the accompanying risk factors. As well, "intrusive" services such as the in-home parenting program provided by the Ministry of Children and Families, while apparently resisted at the time, was greatly appreciated by this mother in retrospect. In hindsight, she also appreciated professionals keeping her daughter safe from herself, when she was actually putting her child at risk. Resources such as day care, homemakers, social workers who understand mental health issues, disability income, better housing and medical care have been critical for Holly and her daughter.

There is clearly a need for a community response of care and support for both the child and mother when the mother has a chronic mental illness. However, it is difficult to maintain access to these children if the parental illness is manifested in paranoia regarding involvement with professionals, or if many family moves prevent continued involvement in long-term treatment. Assisting parents to develop a plan for the child in case of relapse of the mental illness, may be important in helping these families through crisis periods. This story contrasts the difference between a co-ordinated approach to one in which critical things are neglected or unnoticed. The Ulysses agreement helped provide a safety net around Holly and her daughter. I will discuss this type of agreement in more detail in the policy chapter of this thesis.

3) Cindy's Story

Cindy (age 40) is an enthusiastic single mother of an 18 month old child. She describes her daughter as a happy, extroverted little girl who loves to sing and dance, and play any type of game. She describes herself as a really devoted mother, who wants to do her best. This is evidenced in that she is still nursing her daughter. The only parenting
problem she mentioned was that her daughter often wakes up five or six times during the night, and so Cindy has never slept through the night since her daughter was born.

Cindy receives little support from her own parents and sisters, who do not live in Vancouver. She also does not receive financial or practical support from her daughter's father, who she described as a kind person and an excellent musician, but also undependable and an alcoholic. He frequently visits, and Cindy encourages him although she wishes that he would plan ahead, rather than dropping in whenever he wants to. Their child is mixed race (he is black) and Cindy would like her daughter to have strong connections to his side of the family. She often phones his mother in Chicago to update her about her granddaughter.

Cindy is engaged in therapy and is very proactive about accessing resources. At present, she is involved with the mental health centre, daycare, family place, the public health unit, Alanon, a weekly single mothers group, and an intensive parent education project. She has attended two parenting classes, and she is considering enrolling her family with Volunteer Grandparents. She has homemakers come in 12 hours per week to give one-to-one care to her daughter. Cindy clearly views herself as a person with disabilities, who deserves and is entitled to help. She says that, "You know, I'm looking at completely changing the way things were done compared to how they were done when I was a kid." She recognizes that she needs support to do this. Although she alluded to serious problems in her childhood, she views her family of origin with insight and generosity. However, she is clear that because she missed a healthy childhood, she needs to have it modeled, and that she needs feedback from "normal" people about how she and her daughter are doing. She believes that her daughter needs another model at times as well:

I think it's important that (my daughter) has a break - that she has a caregiver who's not anxious, and can devote some time to her so that I can pull myself together a bit more ... because I'm sure it's not great for her to be around me
when I'm stressed out. And some people who don't have that issue don't understand how debilitating it can be.

Cindy describes one of her difficulties as "just dealing with the sort of dual diagnosis problems - the illness, and the post traumatic stress disorder that I have, so that's why I'm seeing a counselor right now. I'm also applying for disability, so I think those things might help to acknowledge - it's not just a regular mom, a regular single mom." Cindy feels that if her disability is recognized, it will be validating, and prevent criticism from acquaintances and family members who criticize her for not working in the labour market as well as parenting. She also feels that with the disability recognized she will be able to move into a better, safer neighbourhood.

Cindy feels that it is important for her to have a therapist to help her with her own issues of childhood abuse, and commented: "Sometimes it's really hard when you have a child who is the same age as you were when you went through a hard time as a kid." She has found that being a parent helps with her mental illness in some ways, because even "when every action is difficult ... kids ignore all that and have fun anyway, so it really helps. And just to have to do all those basic activities really helps to keep me focused. Cindy feels that the routine she maintains for her daughter is healthy for her as well, because she previously did not consider herself the kind of person who would be content at home: "I'm not really a homemaker. I'm not really the kind of person who would stay home, and cook and clean, and do all that kind of stuff if I didn't have a child." The support system she has created for herself as a parent is much broader than she had before. However, she still identifies isolation as her biggest stress, and she commented:

I think people really do understand this they just don't do anything about it. And I think, in a normal mother, it's difficult. I think if you have grandparents and a family, and stuff, it makes it easier. But if you have family problems, and a lot of times illness problems, and you have difficulty with anxiety and all those things, anyway, that keeps you from getting out in the community, the isolation just compounds those things, and those things will make you feel more isolated. And that's the thing I'm really struggling with these days.
Cindy expressed some concern that most of the people she knows are in 12 step groups, or are other single mothers, and "everybody is in crisis most of the time." She would like to be involved with "normal parents" to find out how many of these concerns are normal:

The single moms group helps with that, because I was talking about some of my concerns about socializing, and somebody else in the group said, I don't have any of your issues, and I still have problems with this. So it sort of put it in perspective for me, you know? I am learning that some of these things are normal, and some of them are to do with my illness.

Cindy was also highly critical of herself for not meeting her own standards at times as a parent. Like all of the mothers in the study, Cindy is concerned that her illness will interfere with her ability to care for her daughter, to the extent that she could lose custody of her. Like Holly, she wants to develop a formal agreement so her wishes will be respected regarding care for her daughter should that ever happen.

At our second interview, Cindy appeared tense and exhausted. She seemed glad to see me, though, and made some tea. She said that she had not had a good week. The one good thing was that her application for disability status had been accepted. This meant that she would have a stable income, and she would be eligible for better housing. However, this also meant that she would be out of the workforce for a long time, receiving a low fixed income. While she had enough to live on now, when her daughter graduated and moved away from home, she would not have enough to live on. Cindy realized that her income now depended on her daughter, and said that she had worried all week about what would this mean for her future.

Cindy had some observations and suggestions that she wanted to share in this research project, as follows:
1. She would like a much more concrete, skills oriented focus in the parent education group she attends. She finds it difficult to share on a personal level in a group with unclear boundaries, and different people attending each week.

2. She believes there is a need for more resources such as parenting education and support for parents. She believes that parents should not have to ask - such programs should be provided automatically. This would make it much less stigmatizing and easier to accept. She also thinks there is a need for more parenting drop ins where you can learn parenting "by osmosis", and she commented that, "You can't expect parents who haven't been nurtured or loved to be able to give (nurturance) to their children." She is also concerned about whether there would be any follow up for some parents in the group who don't seem to be able to focus on their children, or who are having other serious problems.

3. She believes that present standards of childcare minimizes children's needs for individual care, especially the caregiver/child ratio for under three year olds.

4. She believes that there are many people, including herself, who are "disenfranchised". People with disabilities, mothers, and unemployed people, primarily need a sense of belonging in a community.

5. She suggests that one housing model that might be successful for mothers who have addictions or episodic mental illness would be if they could live in a suite with a healthy family, where the child had the run of the house, and the family had a responsibility to monitor the well being of the mother. If there were problems, the child could move upstairs until the mother was well enough to care for him or her. The idea of essentially creating an extended family for parents who have a mental illness is very interesting, and it would be useful to explore whether this has been attempted in other areas, and how such a program could be designed.

Cindy described receiving a number of supports based on her entitlement for disability status. She clearly believes that her work as a mother is valuable and that both
she and her daughter deserve assistance. She has taken an active role in learning new skills as a mother. She has also arranged for alternate care for her child to compensate for her areas of disability. Cindy describes the process she has engaged in as a mother as creative and healing on many levels. She seeks affirmation that her parenting is, in fact, "normal", and that she is bringing up her daughter well.

(4) Maria’s Story

Maria, (age 44), lives with her husband and three children: sixteen and fourteen year old girls, and a nine year old boy. She describes being a mother as the most important thing in her life, and said it gives her "a great feeling." She has found her husband and children to be very supportive to her as she struggles with serious depression:

We both help in the home, but since sometimes I don't feel that good, he helps out a lot, and the kids help out a lot too. Like he takes them to the community center for swims, and he takes them shopping too, because during Christmas time I had all these anxiety attacks... and I felt it was too much.

Many of the parenting problems Maria describes seem to be common cross cultural issues for parents whose children are growing up in a different society from the parent's own childhood experience. Maria is worried about the differences in how her children are growing up: "I've done my best to bring them up the way I was brought up. I think it's the times that have changed." She commented that children in Canada seem to mature earlier than in Fiji, and know more about sex, while she was very sheltered. Her main worry is that her kids will get "wilder" and not be safe. Maria relies on her husband to help her with parenting. Usually it works out well, but sometimes the couple have arguments about managing the kids. Maria says she is more flexible than her husband, who makes rules and expects to be obeyed. Maria sees herself as more concerned about
maintaining open communication with the children. Maria said that she was very close
to her own mother, and that is how she learned to be open and talk problems out.

Maria is recovering from what she describes as a deep depression over the past
two years, where she withdrew completely and was unable to function at all. " I had put
myself in a shell. I wouldn't go out, I wouldn't do anything. " This was precipitated by a
number of stressors, such as an injury at work, losing her job, losing her disability
benefits, and moving from Toronto and finding the cost of living in Vancouver to be very
high. She believes that her husband and children understood and "felt it with me".
Because of the stressful economic situation they all had to forego new clothes and needed
items. Looking back, she says that : "The kids were really there for me ... They used to
talk to me, and say, 'Mommy, you don't have to worry.' They'd force me to get out of the
house. And my husband is a cook, so he'd do the cooking. Plus my girls like to cook too,
and they used to do their own laundries and clean up." Maria said that her doctors in
both Toronto and Vancouver called in her children and talked to them about her illness.
Maria found this to be very helpful: " They found it really hard when suddenly I got sick
like that. I don't know - it's not something physical that's wrong? ... but then, with my
mind? So he told them what was wrong." Being open about her illness with her family
helped her process of self acceptance and recovery:

I used to be ashamed ... of what was going on with me. That I didn't want to
open up. But I found that by doing that, I was hurting myself more, and I was
going deeper and deeper. When my daughters knew that I had depression
problems, we could deal with it much better than hiding it ... they encouraged
me more, too, that I shouldn't be ashamed.

Maria is satisfied with her treatment at the mental health team as a mother, and
suggests that groups for children who are coping with parental mental illness may be
helpful for some families.

Maria and her husband maintain traditional roles in their marriage, but there have
been some changes as her husband has adapted to the family's needs during her illness.
He is willing to participate in household work and doing things with the children. They make an effort to eat together, and participate in some activities together as a family. Manners are important in the family, and both Maria's husband and her children thank her whenever she does something for them. Maria is usually the parent who handles any social problems with the children, such as skipping school. She was unable to do this when she was acutely depressed.

Maria was the eighth child of ten, and she greatly misses her large extended family, but she has been able to create a caring network around herself and her family through her church and ethnic community since she has been feeling better.

Maria believes that her problems are normal responses to stress - that her depression was a response to external stressors which were out of her control, and that her current problems with her children are due to "changes in the times" and cross cultural issues familiar to many parents in her ethnic community. She feels that her problems are actually less severe than many of her friends. Maria expects to make sacrifices as a mother, and she feels that the expectations on her are reasonable. She states that:" the children come first, never mind what happens ... I know I have needs too, but they're pushed aside."

**Discussion:**

Maria emphasized the value of her health care providers calling in her husband and children, and explaining her illness to them. While this is not yet standard clinical practice, there has been a consistent theme in the literature that this type of information sharing and further counseling should be available for children, whether or not they exhibit symptoms of emotional disturbance. The affected parents condition should be explained to each family member at the level appropriate to that member, in order to strengthen and reinforce each child's perception and emotional differentiation from the parent's illness (Beardsley & MacMillan, 1993).

Maria's story highlights the problems of parenting in a situation where the
children are growing up with cultural values and expectations that differ from their parents. As her mental illness became more serious, Maria perceived that her children were at risk of becoming too wild without her mediating influence. As the mother, she believes she is responsible for the transmission of appropriate cultural behaviour and attitudes, particularly to her daughters, and her depression has largely prevented her from fulfilling this obligation for a long period. Her mental illness also affected the roles of other members of the family, in that her husband and the children have assumed a stronger caregiving role for her and for each other, but along with this, the children demand greater independence than the parents feel comfortable with. Maria found herself following her daughters' leadership, and began to develop a goal of a more consensual relationship between herself and the children. As Maria had help and support from her husband, she did not worry about losing custody of the children when she was ill. Maria describes an openness in both her family and ethnic and religious community, in which they supported her rather than criticizing or stigmatizing her. When she reflects on the stress she was under at the time that she lost her job after a work related accident, it makes sense to her that she would have developed a serious depression, and this belief in an externalized rather than internalized cause of her depression has helped her to normalize the experience, and gives her hope for recovery.

(5) Alice’s Story

Alice (age 38) is a Chinese woman from Malaysia. She is caring for her five year old son, and her thirteen year old step daughter. Although Alice is married, she is entirely responsible for the care of both children, and she receives no support as a parent from her husband or other friends and relatives. She has not had any acute episodes of her mental illness since her stepdaughter arrived, but she is having many problems coping with the children. She has also begun to examine the personal losses she has suffered, in terms of
career, relationships, and personal growth, due to her long struggle to maintain her mental health. Alice recalls that when her son was born, she needed a lot of help and education:

I was weak, I wasn't feeding him. And mainly, I didn't know how to deal with a baby. I didn't know the techniques of tending to him, and also handling my own mental illness. Because I was on medication. So when I look back now, the first two years of motherhood, it wasn't a very rosy picture.

Alice attended an intensive parent infant program for about 6 months, which provided parenting education and support. The program workers helped her to apply for daycare three days each week. This has greatly helped, as it provides an enriching experience for her child as well as respite for Alice. Alice also changed her medication two years ago, because she was sleeping too much with the previous one, and described herself as being like a "zombie". The new medication has helped her feel "much more alive" and able to see things differently. Alice says she has a good relationship with her son at present, and particularly enjoys quiet activities with him such as reading and playing board games.

Alice has a more problematic relationship with her stepdaughter, who is her husband's daughter from a previous marriage. Her stepdaughter arrived in Canada three years ago, having grown up with her paternal grandmother in a village in China. Alice commented, "She's scary actually, and it poses a challenge for me... Because I don't know if I'm mature enough in the sense of dealing with a teenager." She is bothered by her stepdaughter's "overbearing attitude", and finds it difficult to tolerate living with her. Alice repeated several times during the interview that she is not well bonded with her stepdaughter: "She hopes I will be as close to her in some way, but our personalities are quite different. I think it's the personality thing that's keeping us apart." Alice has found it very difficult to care for this girl since her arrival: "My younger child is the only one I am close to... because around that age group I can handle ... but around a burgeoning
thirteen year old, into the teenage years, I am not sure if I can find the emotional capacity to handle her." Alice does not feel that she can do anything to decrease the distance between them at present: "Maybe when she reaches maturity, say at twenty and beyond, maybe we can have a sort of a bond." Alice understands that her stepdaughter has unmet emotional needs, but she sees a conflict between meeting her step daughter's needs and meeting her own needs: "What she needs right now is someone to be behind her, and support her, but right now I'm fighting for my own self. I need help."

Alice's husband and his daughter believe that both Alice's and Alice's sister's mental illnesses are caused by a visitation from the spirit world, or possibly possession by a demon. This is deeply disturbing to Alice, and adds to her emotional isolation. She described her husband's beliefs:

Sometimes even now, my husband will say that this happened because my third brother died, in the sense as the Chinese say, a virgin. So when he died, over 24 years ago, he didn't have an experience of fulfillment as a human being, so his spirit won't be at rest. So that's why it reverberated into us, the two daughters - that me and my sister have this mental illness. My husband keeps telling my mom to go back home, and put a tomb over that graveyard, because when he died, she didn't have enough money to buy the casket, and now grass is growing over the grave. They believe that if my mother does the proper thing, maybe I and my sister will be well.

Alice is very lonely in her marriage, and states that she does not expect or receive any emotional support, or practical help around the house, from her husband: "All that he told me is, I can only support you in the area that I can to my own ability - and that's the financial...so now the burden is on me - to get some emotional support - because I don't get any emotional feedback from him." He comes home from work after the children are asleep, is sleeping when they get up in the morning, and is gone before they come home from school. He spends weekends with his friends. Alice does not feel that she can ask for anything from him for herself, and they have not considered any form of relationship counseling.
Alice receives most of her emotional support from the children:

They are very supportive of me, and they understand my emotions. I explained a lot about my mental illness, and also my battle with my diabetes. And they're very good. My little boy enjoys cutting my medicine for me at night, with a splitting machine.

Alice has also involved the children in decisions about her use of the medication, and interprets it as "supportive" when they suggest she reduce her dosage: " Both of them say every Sunday, you don't need to take Rhisperidone, which is a mental illness medication. And I've been taking very little. They've been very supportive in that way."

The children have never seen Alice when she has been acutely ill. However, Alice describes her sister, who visits quite often, as exhibiting more disturbing behaviour, such as yelling and hysteria. Alice believes that the oldest child thinks that Alice will be like her sister, and that she has negative and judgmental opinions about both of them because they are not directly related to her. It is difficult and painful for Alice to be the main support person for her sister, when they are both subjected to the stigmatizing beliefs of her husband's family members.

As an intelligent woman who has never been able to complete her education or develop a career, Alice feels that the mental illness has been a personal disaster: " I tell whoever that is putting this on me, why? All these past fifteen years, the best, the prime of my life, has been taken away." In a different light, Alice said that "maybe the mental illness is just an illness that I have to handle, and so far I handle it quite good." In some ways, she feels that her lonely years of battling mental illness have also given her resiliency and strength.

Alice believes that when mothers in her situation have a relapse, a response from mental health professionals is important to ensure that the children are safe, secure, and
well cared for. As well, she would like counseling for the children, to "let them know they are not abandoned... because they feel that mom is the closest to them, and if she's gone, they feel, oh, who's next?"

Discussion:

Alice's story brings up her isolation as both a person with a mental illness, and as a mother, which is similar to the themes of other participants in this study. She did not discuss concerns about her ability to maintain custody of the children, or planning in case of relapse, but she did describe feeling overwhelmed with the constant demands of caring for two children.

I was particularly struck how differing cultural beliefs have added to Alice's unhappiness and isolation as a mother. In many ways, she seems to be bridging the distance between the old world, as typified by the rural Chinese upbringing of her husband and step daughter, and her own experience of finding her primary source of support at a modern western mental health clinic. Alice's personal experience, as a sophisticated Malaysian woman, is also greatly at odds with the rural upbringing of her husband and stepdaughter. While Alice seems to have reached a degree of acceptance of her own mental illness, she is forced to deal with her husband's very different understanding of it. In their article about common Chinese beliefs about health care, Magdalene C. Lai and Ka-Ming Kevin Yue (1990) state that the Chinese are more likely to explain the causes of mental illness in terms of external factors or events, including supernatural forces such as evil spirits. They may not accept talking about problems as an acceptable form of treatment. Mental illness in particular may become a family secret, regarded as a stigma and shame on the family. (Lai & Yue, p. 81). Other writers have stressed the importance of understanding intra ethnic diversity and the avoidance of stereotyping while considering the impact of cultural beliefs about mental illness. (Lee, 1986; Kleinman & Lin, 1981.) As well as conflicting belief systems, the impact of adjusting to a very different society, including language, education, and work differences,
has affected everyone in Alice's family. This has complicated her relationship with her children, particularly with her stepdaughter who has had to undergo an enormous adjustment in the past three years with little sympathy or support from her father or from Alice. The situation that Alice describes, in which she feels oppressed by the expectation that she care for her stepdaughter, particularly as an emotional obligation that she "care about", rather than simply provide physical care, and in which she also relies on her five year old son to be her primary source of emotional support, is likely to result in serious problems for both children in the future, and is also likely to maintain or increase Alice's feelings of guilt, loneliness, sadness, and inadequacy.

(6) Carol's Story

Carol has two daughters who have almost grown up: one is eighteen, and the other is twenty two. They have recently moved back to live with her, after being separated from her since they were five and two years old. The children were removed by a social worker who was responding to Carol's request for a homemaker: "At that time, I asked for a homemaker to come in, because I had just started my psychotherapy, and I was very drugged on medication, and I couldn't supervise the children properly. " The social worker offered her a homemaker, with the condition that Carol had to be out of the house when the homemaker was there. Carol was unable to agree to this: "I said, no way, I'm not going to. Because I'm sick, for one thing, and I felt it was an imposition on his part. So I said no and he said, well, fine, I have to take the children then. That was the end of it. I fought for a little while, and he called the police."

The children were in foster care for about a year. Although Carol has thought deeply about it, she says she doesn't really know what caused the apprehension of her children. However, she says:
In a way it was a saving grace, because the children were out of a very risky situation with me. Because I'd take my pills in the afternoon, and half an hour later I'd be asleep. I could not stay awake. I drank coffee, I smoked cigarettes, I went for walks, I took showers, I did everything to try to stay awake, and I could not stay awake. So the kids had to be somewhere where they could be supervised. And it just broke my heart.

Carol was able to visit the children in the foster home quite a bit, but felt resentful about losing her control of decisions about them. She said that "I felt O.K. until they started chopping my kids hair off, and cut off her baby curls, and stuff like that, without asking me."

After a court battle, the children were placed with their paternal grandparents (because of their father's alcoholism, although he lived with them.) At the time, Carol thought it was better for them to be with family, but now she regrets this, as the children were abused throughout their childhood physically, sexually, and emotionally by their father.

Carol's exhusband left her when their second baby was 3 months old. He was an alcoholic, engaged in extramarital affairs, mismanaged the household income, and was abusive to Carol. Carol moved in with her mother, who supported her for the next four years. Carol's mother was a widow, with two other children to raise, and Carol eventually moved out on her own with her children because of the stress on her mother. She lived in a small community near Vancouver in a cabin with inadequate heat and poor bathroom facilities. She said that: "I tried to get housing from B.C. Housing, and they wouldn't accept my application. If they had seen the environment that I was raising the children in, they would have changed their minds."

Carol feels that because she had a diagnosed mental illness, she was given no options by social services, and she was effectively silenced as a mother. "I had to bite my lip a lot. And because of my credibility as a mental patient, I don't think I would have had a hope in hell of getting the children back." Carol believes that she would have been
able to look after the children once she adjusted to the medication - a matter of a few months. A social worker who understood psychiatric issues would have made a significant difference. She also believes that if she had been able to get a homemaker who could help with household work, and a babysitter so she could socialize and take part in rehabilitation programs, she would have been able to manage bringing up her children.

Carol describes her relationship with her children as the major focus of her life, even when she didn't have much access to the children for so many years: "The fighting went on for years and years and years. It was very draining. It puts a hold on your life - in the sense that you can't totally devote yourself to a job, school, or practically any other kind of activity". She describes expending a lot of energy in just trying to "make it" between visits. The visits themselves were very stressful, because she lived on a disability allowance for a single person, and so she didn't have the resources to feed and do things with the children when they did visit. At times social services would give her extra money for food for the children, when she was on good enough terms with her exhusband's family to plan for the visits. But often, the plans fell through, or the children would have unscheduled visits when it was convenient for the other family. Carol describes herself as always being there for her children, filling in the gaps, and being available for them to talk to when they needed someone.

Both Carol and her husband had a history of serious mental illness in their family of origin. Carol's father committed suicide after lengthy psychiatric involvement. Her husband's sister had a serious mental illness, and his mother attempted suicide. However, both families viewed mental illness as entirely caused by circumstances in the environment, and avoided any open discussion of psychiatric problems.

For a number of years, Carol has been running a support group for mothers who have lost their children due to their mental illness. She comments that:

"The amount of devastation that happens when someone becomes mentally ill is humungous. It's not necessarily the fault of the person who's ill, or the family, but it
causes a great rift in the family. I've seen it happen." The support group came out of work done at a service organization for mental patients, and an advocacy group where Carol volunteered. Both organizations had informally found an unaddressed need to support consumers who were struggling with the loss of their children. Carol says that attendance at her groups is dropping off now, and she believes that fewer mentally ill mothers are losing their children permanently.

Carol describes her children as being profoundly affected by the difficulties and trauma they have experienced. Her oldest daughter, at age twenty two, has lived with her for the past three years in an apartment subsidized through a housing society for mental patients. She is still dependent on a living allowance from Carol's mother. Carol says her daughter is " pretty volatile - she just jumps at every opportunity to be angry, as a result of the environment she was living in, and she doesn't understand that most people aren't that way." Carol believes this anger is related to the apprehension: " She was the eldest when she left me, and she can recall practically to the day what went on. " Carol's youngest daughter has also recently returned to live with them, after failing in the private boarding school she attended, because she couldn't concentrate on her work. Carol is hoping that she will be able to return to the boarding school, because it has provided excellent opportunities for her in the past, such as a trip to Europe with the school band.

Carol also describes positive things in her children's lives, such as their musical talent. However, she repeatedly states that she is still terrified that she may lose them again. At an age where most young women are focused on individuation and leaving home, these two young women are just beginning to recognize their connection and dependence on their mother. Carol feels she is able to talk to her children about the abuse they experienced, but they have not laid charges or undertaken therapy.

Carol said that she has never had much personal support: "There's been no one who could understand, except a boyfriend or two." Recognition from her daughters, such
as an "official best mom" valentine card, is very meaningful to her. She views her mother, who had initially been supportive, as now too preoccupied with her own life to pay attention to her problems, or how she is feeling. Rather than receiving support, Carol says, "I've put up with criticism from just about everywhere." Carol also feels that people in her life have unreasonable expectations, such as her mother telling her she should get a job, without any understanding about her readiness in terms of her mental health. Carol said that: "People expect me to be fluid and ever-bending. I can't always do that."

Discussion:

Carol's experience of losing her children on the first and only visit from a social worker happened over fifteen years ago, when there were fewer supportive policies to maintain families in distress. As well, there were fewer effective medications, and worse side effects associated with the medications. The social worker's lack of understanding that Carol was actually ill, and not able to leave the house so that a homemaker could come in, reflects the predominant social stigma at that time about mental illness. This stigma is also apparent in that she was not engaged in decisions about the care of her children. Although Carol admits that the children were not safe with her, she believes they would have been safe when she was stable on medication, within a year. Ultimately, the children were placed with their paternal grandparents, who previously had minimal involvement in their lives, with no monitoring of their abusive father. Although Carol had only occasional contact with them, she regards parenting as her primary occupation since her children were born.

For many years, Carol has organized and run support groups for mothers who have lost custody of their children due to their mental illness. Until recently, this was by far the largest percentage of mothers who have a mental illness (Mowbray, 1993; Judas et al, 1997). She has been able to use her own painful experience to understand the need for mothers to have a place to meet each other, share stories, and develop friendships.
Groups for parents who have lost custody are rare. The experience of losing custody of one's children is shaming as well as traumatic, and these parents often grieve the loss of their children for their whole lives, with no one who really understands or shares their pain. There are many gaps in the literature about custody issues: especially treatment for parents who have lost custody of their children. As these mother's stories show, mothers who lose custody are likely to regain it in the future, or to have a significant relationship with the children when they grow up, and so help for the mothers with dealing with lost custody is likely to have future benefits for both the mothers and the children. Because the problems related to parental mental illness have so many descriptions, such as “marriage breakdown, neglect, abandonment, emotional abuse”, we do not have accurate figures to show how many children are in care because of parental mental illness, or how many are in the care of one parent and prevented from contact with the mentally ill parent in private custody arrangements. We also do not have an accurate understanding of the numbers of people with a serious mental illness who are currently parenting, or who have lost custody either permanently or temporarily. Certainly maintaining custody, or dealing with lost custody, was a major issue for most of the mothers who participated in this study.
Chapter Eight

Research Findings

Summary Of Themes

When I reflected on what I had learned from these stories as a whole, I found that the following themes stood out in these women's accounts of their experiences:

(1) Children as central to life.
(2) Benefits of motherhood.
(3) Care issues.
(4) Struggles over maintaining custody.
(5) Isolation and the need for social support.
(6) Planning for children in case of relapse.
(7) The need for social workers to understand mental illness.
(8) Problems with the children's relationships with fathers, father substitutes, and mother's male partners.
(9) Cross cultural issues in understanding family and health care needs.
(10) Helpful services and supports, and constraints to accepting help.
(11) Poverty and related problems.

In this chapter, I will discuss what I learned from the study participants about these themes, with some references to the literature. It is my hope that illumination of the central experiences of these mothers will promote new ways of understanding and supporting both the mothers and their children.

1. Children as "central to life".

All of the mothers who participated in this study described their children as the central focus and purpose of their lives. This was true for Carol, who lost custody of her children early in their childhood, as well as for the mothers who were entirely responsible for the care of their children. The mothers greatly valued their role as caregiver, and
found satisfaction in caring for their children. Without exception, the mothers said, in some manner, that they would put aside their own needs if necessary to meet their children's needs: "I think the kids come first, never mind what happens. I mean, I know I have needs too, but they're pushed aside" (Maria).

With the exception of Alice, who expressed her unhappiness about being expected to take care of her stepdaughter, these mothers did not express ambiguity about being a parent. In a similar qualitative study of ten mothers with mental illness, the researcher found that mentally ill mothers expressed fewer problems about loss of freedom, stress, and parenting difficulties, and less ambiguity about their role as parents, than a similar group of low income mothers (Sands, 1995). Schwab, Clark, and Drake (1991) also found that parents who had a mental illness placed a high value on parenthood, and that even parents who had lost custody continued to focus their lives on seeing their children. This may imply that the meaning of being a mother is more positive to women who have a history of being denied this role (Mowbray et al., 1995), or that parents who have a mental illness consider themselves to be too vulnerable to openly discuss the difficulties they may be having with their children (Apfel & Handel, 1993). It may also imply that this group of mothers receives more actual benefits from their relationship with their children than other groups of mothers.

2. Benefits of motherhood.

The mothers in this study brought forward a number of benefits that they personally experienced from their relationship with their children, and their role as a mother.

The work of raising children provided meaning and a vocation in life. The mothers took pride in their children. They made many comments such as the following:

Jane: “When I hear people say, she’s such a wonderful girl - I know I must have done something right.”

Maria: “It’s a great feeling when you know your kids are good kids.”
Alice: “I try to be the best I can be with my parenting skills. You know, when they are growing up, and they have learned the things they need to know for the betterment of the person? Then it reflects on me too, that maybe my parenting skills are doing some good.”

Another benefit was the reciprocal love and pleasure the mothers shared with their children. Jane stated, “I’m really happy, because I always wanted a kid.” Alice spoke of her joy in having her love for her child reciprocated: “One day, my boy said, ‘Mommy, you are a perfect mother.’ That gave me a big boost.” Carol said, “It’s marvelous, having them around. We get along really well, the three of us. And they tell me everything about everything - I feel that’s a real compliment.”

The children also provided companionship to their mothers. Many of the mothers talked about their greater experience of isolation before they had children, although having the children did increase social isolation for some mothers. Only one mother had an adult partner who was an active support in her life. The other mothers described their children as their primary relationships. Alice described her reliance on her children, rather than her husband, for support with her daily struggles with her illness. Jane described a situation where she really has very little social interaction except with her 12 year old daughter, and she clearly depends on her daughter for care and companionship.

The children gave their mothers important personal feedback. Maria said, “My kids encouraged me too... they think I still look young. I consider myself old now, but they think I’m still young... We change clothes now - they don’t like my clothes, I like their clothes!”

Some of the older children provided actual caregiving services to the mother, such as shopping, cooking, cleaning, etc. Jane said that her daughter shopped, and usually cleaned the house and cooked dinner after school. Maria said that she doesn’t know what she would have done without the children’s help with cleaning, cooking, shopping, and laundry during the time that she was depressed.
The children also acted as cultural interpreters, bridging to the outside world, and interpreting and teaching their mothers about this society. This was illustrated by Alice’s comment: “The children are an instrumental part of my life, and open me up to see the different perspectives.” Maria said that her daughters would force her to do things, and get out of the house, and that she was always learning new things from them.

The children provided an important link for mothers who tended to withdraw and disengage from relationships. The mothers said that they had been personally enriched by their involvement with their child’s network of friends, alternate caregivers, and extended family. Holly was able to find friends who actually made a formal commitment to help her and her daughter through difficult times. Cindy described her relationship with her child’s paternal grandmother as very nurturing and supportive to both herself and her child: “If I want to cheer myself up, I’ll phone and talk to her grandma, because she’s a darling.” Jane said that the in-home parent workers who come to her home are “sort of company” and give her good ideas. Holly said “I had a worker come into my home twice a week, almost daily, actually, because our relationship was really good. It was a really positive experience.”

Raising children also encouraged the mothers to examine their connection to their own families, and allowed them to develop a new way of being in the family. For example, Jane was in frequent telephone communication with her mother about issues around raising her daughter, which helped her to maintain her relationship with her mother. However, Jane also believed that she was a better mother to her child than her own mother had been to her, and this gave her a sense of success and pride, and profoundly changed the negative story she had been brought up to believe about herself and her own potential.

Being a mother helped these women achieve a respected role in the society, and a place in the community. It also gave them an opportunity to share their common experiences with other mothers. Carol created a meaningful role for herself as a group
facilitator and advocate for other mothers with a mental illness who had lost custody of their children. Cindy talked about how important it was for her to connect socially to other mothers: “I’m hoping to get more involved with a coffee group for mothers, which would just be social, a place to get together and talk. I think, the more moms I meet, the more people I have - the more I’m going to find somebody that I can go for coffee with and visit back and forth. That’s part of my goal, every time I go to a group - am I going to find somebody like that?” Maria also talked about how much she enjoyed the company of other mothers: “When the weather was good, my son was into soccer. There were other mothers with their kids too, so we would all go for lunch or something. We would get together - it was fun.”

Holly described how her relationship with her daughter provided motivation to keep herself well. She has been much more stable since she became a parent, and she talked about how her commitment to her daughter helped her to accept treatment that she might have otherwise rejected. Cindy said she had never kept a regular schedule until she had to care for her daughter, and that she had benefited from her new routine and more organized home life as well. These mothers said that they were also motivated to develop a network of friends and family, who helped them through difficult times. They were also able to access professional helpers who helped them maintain stability because of the needs of their children, such as homemakers who cared for their children, but also helped to maintain their household, which helped with matters such as preventing eviction. Child protection social workers also helped maintain stability by checking in, organizing preventive services such as parenting support, and ensuring that adequate standards of child care were provided to the children.

Being a parent entitled the mother to benefits such as family housing and increased income from welfare and disability payments. While this was accompanied with increased responsibilities, the mothers seemed to feel that their situation was preferable to the situation of single women with a mental illness.
3. Care Issues:

The mothers in this study described a number of concerns about the care of their children. The first area of concern were problems directly related to symptoms of their mental illness interfering with their ability to take care of their children. The mother's symptoms included withdrawal and self isolating behaviour; loss of the ability to concentrate and to remember; loss of ability to maintain caregiving functions such as shopping and cooking; distorted perceptions of reality; paranoia; and suicidal and/or homicidal ideation. These symptoms confused and upset the children, and interfered with the mother's ability to keep them safe. The mothers felt that effective medication made the most difference in their ability to care for their children. However, the mothers also had concerns about the side effects of medication, especially excessive sleepiness. Most of the mothers, who had little help with their children from the family, felt that there was a danger that they might neglect their children when they were ill. However they were concerned that outside professionals would take away their control rather than assisting with and arranging for supplementary help. It was very important to the mothers to be in a central place in relationship to their children, even if they needed to use alternate or supplementary help at times to ensure they were cared for properly. Some of the mothers described the importance of supplementary care for their children, not just for physical care, but also for a healthy role model for the children, and a break from the stress of being with their ill parent. Cindy stated that, "There's been days when I was so anxious, just to get through the basics was a big deal... That's why I think it's important that my child has a break... That she have a caregiver who's not anxious, and can devote some time to her so that I can pull myself together a bit more, but also so she gets a break."

4. Struggles over maintaining custody:

Fear about losing custody to either the natural father or the Ministry of Children and Families was a major concern to the four participants who were single mothers.
Three of the participants had their children placed into foster care, either by agreement or apprehension during episodes of illness. While this was very painful for the mothers, in retrospect, they all expressed relief that their children had been protected and cared for. It seemed to me in listening to these stories that the alternate care for the children was often inadequate, because it was provided during a crisis, when little was known about the special needs of the children. Holly described her own battle with herself, in terms of the need for planning for the care of her daughter when she is ill, because she knows she will resist outside intervention when she needs it most. In her ill state, she thought of the apprehension of her daughter as a "bad thing" or punishment, but afterward she had more insight about her daughter's experience, and understood the reason that her daughter had been removed from her care. Jane described her shock when she realized that she had "signed her daughter away", but she was able to find a lawyer who helped her regain custody of her daughter. Carol described her experience of losing custody of her children a number of years ago, when it was much more common for children to be apprehended from mothers who had a mental illness. Her children were brought up in her ex-husband's family, although he had not been involved with their care previous to their apprehension. Unfortunately there was no monitoring of their care, and both children were allegedly abused by him.

The level of concern about custody matters among these mothers seemed to depend upon the mother's age at the onset of her illness, the age of her children, the availability of a supportive partner, past experiences, and stories she had heard. The fear of losing custody was a motivating force for some of the mothers in accessing supportive services, such as daycare and parenting courses, which they described as helpful.

5. Isolation and the need for social support:

All of the participants in this study spoke of experiencing periods of extreme loneliness and isolation. As described earlier, serious mental illness tends to cause people to withdraw from social interaction. Neighbourhoods and communities tend to shut out
support for the mentally ill person. As well, many women find that motherhood, which sharply contrasts with the relative freedom and independence of single life, promotes isolation, particularly for single mothers.

All of the women in this study had made a move away from their extended family which increased their isolation. I did not learn the reasons for these moves in my research, although it would have been interesting to understand what each person was attempting to leave, and what she was attempting to create for herself and her children in the new situation. Maria and Alice had immigrated to Canada and had successfully mastered English, but were affected by adjustment problems in a culture with differing values and customs from their childhood experience. Jane had moved far away from her only living relative, her mother. Holly had moved away from her family and friends in Toronto when her daughter was a toddler. Carol had lived in an isolated rural setting immediately prior to the apprehension of her children. Cindy had moved to the city from a smaller centre on Vancouver Island.

Jane, Carol, Holly and Cindy did receive some support from their extended family, particularly from their mothers. However, they all described negative or ambiguous feelings about accepting help from their families. Jane felt that her mother was very critical of her, and disliked consulting her, but did so anyway, partly because she seemed to have no one else to call. Carol's mother was currently sending money to support her children, but Carol said that she felt criticized, unsupported and misunderstood by her mother. Holly's mother had helped significantly during Holly's last episode of illness, but Holly said that she found it very stressful to have her mother visiting at the same time that she was sick, and she was also very disappointed that her mother had not seen her during the past year and a half when she was well. Cindy did not feel there was much potential for support from her parents; she had alluded to serious childhood difficulties. She did feel that she might receive some support from her sisters
if they lived in closer proximity, but that they were preoccupied with their own lives, and unlikely to be a strong support for her.

These mothers were more likely to receive social support from friends. Jane has two or three friends in the low income housing project where she lives, but her friends have serious problems themselves. Holly has developed a network of friends who are understanding and supportive, and have agreed to formalized roles in her Ulysses agreement. It is interesting that her closest friends both have mothers with mental illness. Cindy also takes the need to develop a support network seriously, and has made many contacts in the community with support groups, parenting programs, and community organizations. However, she said that she still feels isolated and not around enough "healthy" people. Carol has friends and a supportive boyfriend, but still feels isolated as a mother. Alice seems to rely on her therapist at the mental health team for personal support, and does not seem to receive emotional support anywhere else in her life except from her children.

6. Planning for children in case of relapse:

Holly had designed a "Ulysses agreement" in order to make arrangements for the care of her child in case of a relapse. A Ulysses contract is written when the writer is stable; it is not legally binding but provides a reference for care if the person becomes psychotic. It refers to the Greek hero who ordered his sailors to tie him to the mast and not to change course even if he ordered them to do so in response to the Siren's song. The agreement was very reassuring for Holly, and helped her workers, friends, and family assist her and her daughter when she did have a relapse. A legislative model for Ulysses contracts is set out in B.C. Bill 48 - 1993, the Representation Agreement Act, which is in an implementation period before it comes into effect. This act will provide a model for the development of Representation agreements, which could be promoted by social workers to assist parents who have a mental illness. I have included further information about the Representation Agreement Act in the policy section of this thesis.
The other mothers in the study did not have specific plans, and were not as clear about what they and their children would need to cope with a future relapse. Working together with mothers to develop such plans could be an important and empowering practice in therapy.

7. The need for social workers to understand mental illness:

The study findings imply that education about parenting issues is important for adult mental health workers, and that education about mental health and disability issues is important for children's workers in child care, education, counseling, and child protection. All of the participating mothers, who attended the community mental health teams, felt that their therapists were interested in their children and parenting concerns. This may reflect the design of the study, as the participants were informed of the study by their therapists, which may have promoted the selection of participants who had good relationships with their therapists. However, it is not known whether the therapists working with the mothers at present understand the risks for the children, or the nature of attachment difficulties which may result from the manner in which the illness interferes with the ability of the parent to provide care and control. None of the 10 children of this particular group of mothers received counselling from the family and children's component of the mental health team, although Jane's daughter had been included in several children's social skills groups in the past.

Some participants did mention poor relationships with mental health workers in the past, stating that previous workers had not understood their situation as mothers. Jane, Holly, and Carol also reported that they had problems with child protection social workers who did not understand their mental illness. Holly stated, "My social worker has no idea about mental illness, what that is, and what that means, and that someone can still be a loving human being, and be mentally ill ... That was what was missing - the human component." Holly described a social worker who had more knowledge of mental illness being able to say to her, "We've talked before, and these are the things
you've said you do when you are not well. To me, it looks like you're doing these things. Maybe you need some extra support." Social workers need to understand that clients who have a mental illness are struggling with social realities such as poverty and discrimination; symptoms of the illness such as distortions in their own perception and thoughts; and problems which may be related to side effects from medication. Social workers who have any contact with this population must have up to date information in order to help these clients, as illustrated by the following quote:

No matter how humane, loving, and well intentioned, social workers who do not have knowledge about the illnesses and their treatments will fall short in helping mentally ill people. In addition, social workers must be aware that the number one need of families of the mentally ill is knowledge (Hatfield, 1979).

Mona Wasow (1991) wrote about the deficits in social work curricula regarding mental illness, and the serious consequences of those deficits. The era in which social workers were trained (and the area in which they were trained) influences their thinking: for example, social work education in the early sixties emphasized psychodynamic theories including family causality, whereas more recent training will include up to date information on a biomedical model. Wasow states that enormous strides have been made in the past twenty years in understanding mental illness, but in social work education "the biological component of the biopsychosocial model is usually missing." Wasow quoted her colleague Rapp (1983) who stated that mental illness raises critical social work issues in curriculum planning in schools of social work. These issues include: the importance of outreach; the need to consider the family; environmental interventions and issues; the understanding that changes in the client are gradual and incremental and that the client generally experiences frequent setbacks; the need to see and feel things from the client's perspective; legal and political issues; the need for long term services and a continuum of care; and an understanding of the powerlessness and
discrimination directed against chronically mentally ill people and the difficulty of gaining neighbourhood acceptance.

8. Problems with the children's relationships with fathers, father substitutes, and mother's male partners:

Three of the study participants (Holly, Jane, and Carol) said that their children had been seriously abused by their respective fathers. Jane and her daughter still received letters from her daughter's father, asking her to forgive him and let him move back with the family, although contact was restricted by child welfare authorities. Carol's children told her that they had been abused by their father, although their grandparents were the legal guardians because of their father's alcohol and drug problems. Holly had no contact with her child's father, and described him as dangerous. These mothers did not receive any form of financial support for their families from the children's fathers. Cindy did not receive financial support or help from her alcoholic ex-partner, but she did not perceive him as a threat. Alice did receive financial support, but did not receive any other form of assistance in raising the children from her husband. Only one mother, Maria, of the participants in this study, received both financial support and help with the children and household from her partner.

I had the sense that no professional attention has been given to these men who so profoundly neglected their responsibility to their children. As a society, we seem to be remarkably silent about men who are violent and abusive within their families, and men who abandon their responsibility to care for and raise their children.

9. Cross cultural understanding of family and health care issues:

Cross cultural concerns complicated the family adjustment to the mental illness for two participants. Maria was able to find helpful connections as a member of the Fijian community in Vancouver, and found that talking to other Fijian mothers helped her to put her own struggles with her daughters in context. Maria mentioned her struggle to raise her children according to her cultural values, when there were aspects of Canadian culture
which seemed to threaten those values. The possibility of losing control of her children, when she was unable to respond to them in the way that she believed was necessary, was very frightening for her. In Alice's situation, the cultural issues were complicated by the nature of her blended family. Her husband and step daughter shared cultural beliefs about mental illness which were at odds with her own beliefs, and were harmful to her recovery. Her husband also held a cultural belief that as a man, his primary obligation was to work to support his family, even if he was almost completely absent from the social and emotional life of the family. In both of these cases, it would be important for social workers to consult with cultural advisors, and gain as much knowledge as possible about the cross cultural dimensions of the problem, in order to provide effective help with these issues. For example, this might include strategies to include Alice’s husband in a problem solving process.

It is important for social workers to learn as much as possible about the cultural practices of the communities they work with. However, it is also essential to avoid generalizing about anyone's experience, or making assumptions about the resources in a particular community. Gopfert et al (1996) developed the following list of questions to consider when assessing community resources for families with parental mental illness, which I thought may be useful for discussion with clients:

1. What is a "community's" culture and how does it fit with that of the parent and family?
2. What is the cultural distance among various families in the community?
3. What is a community's attitude to children and/or mental illness?
4. How much does a "community" see itself as responsible for the rearing of children and their welfare? What would likely happen if a child as seen to be in severe distress publicly or if a parent were seen to be in need of assistance?
5. Is there a "community", i.e. a stable core of culture -carrying people or is there lack of "community"?
6. How much are professional services integrated into this fabric of "community"?

7. How organized is this "community" and are there people who consider themselves as responsible for its welfare (i.e. community leaders/ elders)?

10. Helpful services and supports, and constraints to accepting help:

Some of the mothers described their experience as parents as an opportunity to connect to the community in a new way. They wished to use "normal" community supports, rather than specialized programs. None of the mothers reported particular problems in accessing any programs they wished to be involved with because of exclusion due to their mental illness. Jane, Holly and Alice had found group daycare beneficial for their children, both as respite, and as an opportunity for the children for socialization and stimulation. Cindy had used homemakers for the same reason. Alice, Jane and Cindy had attended intensive parent education programs, such as Project Parent, and Jane and Holly had received in-home parenting services. Jane had received help from teaching homemakers when her child was younger. Cindy attended Family Place drop in programs, where she met other mothers in the community, and had an opportunity to informally talk to the staff and other mothers about parenting concerns.

Several mothers felt that their children might benefit from talking to health care workers about their illness, and possibly taking part in a group for children of the mentally ill. Holly had arranged for counselling for her daughter through a private counselling agency. Carol had not found that existing services met her need to meet other mothers who shared similar experiences of losing their children due to a mental illness. She started a support group through a mental patients advocacy centre, and over the years she has organized and facilitated a number of similar groups, which have provided valuable social contact for mothers who have a mental illness.

Constraints to accepting help were primarily related to conditions caused by the mother's mental illness, such as fatigue, anxiety, paranoia, and cognitive distortions. At times when the mother's mental state was fragile, it was very difficult for her to ask for
and accept help. The mothers said that their primary need at these times was effective
treatment, and adequate care for their children.

11. Poverty and related problems:

None of the mothers who participated in this study were gainfully employed, although Maria had worked in the past prior to her illness, and Cindy had professional training and had worked prior to her pregnancy. Holly, Cindy, Jane, and Carol received GAIN disability allowances. Alice and Maria were supported by their husbands. The mothers were concerned about being unable to provide for their children's needs on a low fixed income. Holly expressed her frustration with not being able to afford the cost of her daughter's special diet because of her low income. Cindy described the dilemma she was caught in, where on the one hand she was relieved that she had been granted disability status, as it gave her more security, slightly more income, and less outside criticism and pressure to work. The disability status legitimated her actual experience of how her illness had affected her capability to support herself. However, on the other hand, Cindy was anxious about the possibility of an indefinite future on a very low fixed income. Her total income now depended on her daughter, and if for any reason her daughter could not reside with her, or in the future when she moved away, Cindy could not see herself managing on the level of income she would receive as a single person.

The problem of poor and unstable housing is related to low income levels. Cindy lived in a small apartment in an area where she did not feel safe. She hoped to move into housing for people with disabilities. Jane lived in a public housing complex where she had security and affordable rent, but had many social problems with other residents. She was also unable to go upstairs in her apartment because of her arthritis, which created problems in her ability to supervise her daughter. The other mothers in this study were satisfied with their housing arrangements. Holly lived in subsidized housing which she liked, Maria and Alice rented homes, and Carol lived in an apartment.
partially subsidized by a Mental Health Housing Agency which also granted a subsidy to her adult daughter.

Residential programs for chronically mentally ill adults generally exclude children. A major recommendation from the study done by the Mental Patients Association (Judas et al., 1997) was the development of inclusive housing for mothers with a serious mental illness and their children. They suggested that housing be organized for parents where continuity of care for the child could be organized if the parent needed to be hospitalized. This was described as a helpful idea by the women who participated in the study.

There are several alternatives in Vancouver for housing for people with disabilities, through the B.C. Housing Management Commission, housing societies, and cooperatives. As several of the mothers in this study stated, belonging to the category of "disabled person" allowed them to access affordable housing that was preferable to their previous housing. As the housing options for single women on low incomes are few and inadequate, this is one area where the mother's quality of life likely improved. However, one of the mothers in this study articulated her distress when she realized that her standard of living and her ability to afford the kind of home she wanted to live in actually depended on having her child living with her. If children and mothers are separated because of mental illness, they are both vulnerable to losing their home.

In conclusion, the women who participated in this study identified a number of significant themes which provided me with a much greater understanding of their experience as mothers coping with a mental illness. I found some of the themes much easier to pick out than others, and in particular I appreciate the help of my thesis advisors in pointing out that I had initially focused almost exclusively on the losses and stressors attached to mothering, rather than the benefits of mothering for this group of women. When I re-focused my attention to the mothers' accounts of the benefits of being a mother, and of the positive relationships these mothers described with their children, I
found that my perspective changed. I realized that, in comparison to many single women who have a mental illness, these mothers may actually receive much more support, from their children, from friends and extended family members, and from services designed to support the family. The mothers had actually made very few negative comments about their experience as mothers. The theme of most of the negative comments was disappointment that the child had somehow let down the mother as a friend and companion, at times. The mothers were more concerned about how their illness might potentially interfere with their ability to maintain care and control of their children, or even that they might inadvertently injure their child. In the next chapter, I will discuss some of the implications of these findings, as well as the limitations of the study and directions for future research.
Chapter Nine

Discussion and Implications

In this chapter, I will explore the implications for theory, policy and practice, and make some suggestions for further studies, based on the research findings.

Theoretical implications:

This research project was undertaken with the feminist value of respecting and valuing women’s perspectives about their own experiences. I learned a great deal from this project, and believe that the knowledge gained from interviewing these women is both legitimate and important. One of the reasons I chose to focus on the experiences of mothers in this thesis is because the existing literature had almost entirely left out direct accounts from mothers themselves about their experiences. I felt that the absence of mothers’ voices typified an attitude of simply “writing off” the importance of women’s personal accounts of their experiences as mothers, and as mental health consumers. Feminist research has a goal of bringing forward stories of women’s experience from the margins, and of actively working to include women’s voices in all forms of social dialogue. This study thus conforms with the approach taken by Karen Swift (1995), a feminist social worker, whose theoretical work about child neglect included mothers’ accounts of the way their caregiving capacity was affected by experiences in their life, including trauma, poverty, illness and disability, and poor housing. Swift proposed asking mothers about the cultural and social issues that were important to them, and developing programs together with them to address those issues. In the process of doing this research, I found that engaging in a discussion with this group of mothers gave me a completely different understanding of the questions I wanted to address than I would have reached if I had viewed these women as passive victims, or as “problems” themselves. I came to see these mothers as active people engaged in a struggle with a serious illness, and with oppressive institutions and practices, and I began to appreciate their achievements and their difficulties.
Many of the findings of this study were consistent with other feminist studies of mothers' issues, particularly issues that affect single parents and low income mothers (Baines et al., 1991; Callahan, 1993; Swift, 1995.) These mothers were affected by low status, problematic relationships with men, including violence and child abuse, lack of education and job opportunities, and economic hardship. They were also affected by relationships with both the child welfare system and the health care system, in which they described their position as mental health consumers as stigmatizing and disempowering.

Feminist theory has provided ways of examining the burden and unrecognized labour of motherhood (Baines et al., 199; Rich, 1976; Rossiter, 1988). Feminism has opened up a social discussion of the expectations of the role of motherhood, the complexity of the role, the ideology of motherhood as contrasted with the reality, and the idealization of motherhood and how that affects women. Feminists also separated the concepts of “caring about” and “caring for”, and conceptualized how a mother might deeply “care about” her children, but be unable to do the work of “caring for” them (Graham, 1983). Understanding the work involved with mothering promotes recognition of the needs of children whose mothers are not able to do this work, and presumes that problems will result if this work is not done. As well, feminists question the “ideology” of motherhood, which implies that motherhood is the only way for women to find fulfillment and achieve a valued and respected place in society.

The women in this study described motherhood as both a beneficial and fulfilling role. They spoke of enrichment, joy, and the positive connection they experienced with their children, rather than such issues as loss of identity, isolation, and unpaid labour. They benefited from their role as mothers in a number of areas, such as receiving companionship and care from their children, and more assistance in maintaining a stable living situation. Motherhood also provided these women with motivation to continue with treatment, and to focus on maintaining a healthy lifestyle. The fear of losing custody of their children was a much more common theme than the pain and worry of raising
them. Some feminist writers, such as bell hooks (1984) have described the meaning of motherhood for marginalized women in similar terms.

The women who participated in this study also brought up other issues that have not been clearly addressed by feminist theory, such as problems that arise due to deterioration in mental health, and negative relationships within families. Feminism has been informed about multiple oppressions that women experience, in terms of class, race, age, and sexual orientation, but there is still much silence about the stigma of mental illness. As well, feminist theory often overemphasizes social construction theories of mental illness, which state that intolerance and oppressive social conditions are the primary causes of mental illness, and that treatment for mental illness is often a form of oppression (Burstow, 1992). This theory, while grounded in history and not to be discounted, underplays the need for effective treatment for women with a psychiatric illness, including women’s right to access effective psychiatric treatment, which includes free access to newer and more effective drugs, and updated therapies. The study participants clearly said that medication was essential in helping them cope with their illness, and that there was still a scarcity of professional knowledge about the course and treatment of mental illness outside of mental health services, which made their contact with the outside professionals more difficult.

Working on this study caused me to reaffirm my commitment to feminism, because I believe that the goals of feminism represent the kind of social changes that are necessary to end silences about oppression, to resist the unravelling of our social safety net, and to endorse a transformative vision for the future. In the book that she edited about feminist social work practice for the National Association of Social Workers, Nan Van Den Bergh (1995) said that feminists look at the whole picture, not just the psychological aspects, and described the feminist viewpoint as “integrative, holistic, and ecological.” I think that this viewpoint provides a sound theoretical framework for the social changes that would benefit the families described in this study.
Implications for policy and practice:

As I worked on this project, my reading, conversations with the participants, and informal discussions with co-workers, raised my awareness about issues which affect social policies and social work practice.

I hope that this research has shown that mental illness is an important area of knowledge for social workers, and should be included in social work curriculums. This should include information about the nature of serious mental illness, and treatment issues such as the use of medications. I have observed that social workers in the field frequently have false impressions about the efficacy of various medications, and little knowledge about side effects, but are in positions where they sometimes make rules about medication compliance for clients. As well, mental illness is often wrongly conceptualized as requiring short term interventions and treatment, when it is more likely to cause chronic problems for the person with mental illness and other members of that person’s family (Secunda, 1997).

No agency is particularly responsible for ensuring the wellbeing of children of mentally ill parents. Concerns about serious physical and sexual abuse must be reported, but concerns about emotional problems, school failure, and ongoing moderate neglect are rarely reported or followed up on by child protection workers. Community mental health workers may see the adult client regularly, but may not be aware of problems experienced by the children. There are many "grey areas" in working with parents who have a serious mental illness, which may result in ethical dilemmas such as whether to report "suspected" child protection concerns. The therapeutic relationship with the parent is often destroyed if the adult therapist is involved with child protection concerns, especially if the therapist must testify against the client in court. Clinicians who work with adults with severe mental illness generally do not have the training or experience to know whether children are at risk, particularly of emotional abuse. Multi disciplinary teams may provide opportunities for adult workers to consult with child and family
therapists, but often the adult worker is isolated, and not sure what the extent of the problem for the child really is. The therapist is not able to find out collateral information about the well being of the child without consent of the parent, unless it is a clear case of child protection. The therapist is also reluctant to discuss the client with other systems (e.g. school, daycare) because safety from stigma and discrimination cannot be guaranteed for the client. However, decisions to report concerns are often left up to the therapist, and are a responsibility that they may perceive as potentially harmful to their relationship with their client. (Note: I am not referring to cases of clearly reportable neglect and abuse, but to cases where there may be a number of risk factors present.)

Once concerns have been voiced, the child welfare system often does not intervene quickly and effectively to help children with chronically ill parents when early warnings of distress, recognizable to mental health professionals, arise. Help is more likely to be delivered during a crisis, as was described by several of the research participants. I found that it was very valuable to discuss with mothers their retrospective opinions about these urgent situations, and it was reassuring to find that the mothers greatly appreciated interventions which had supported their children. The findings in this study about care issues, and about the need for planning in case of relapse, are particularly relevant for clinicians to discuss with their clients before an urgent situation arises.

Another aspect of clinical care that can be problematic is the right of the client to confidentiality, which may prevent a therapist who is aware of the client’s difficulties from discussing them with concerned family members, including the children. For example, a teenager living with a parent who has attempted suicide may not be told about the attempt or the underlying mental illness if the parent refuses consent. Parents have the right to refuse to allow mental health counselors to discuss any aspect of their mental illness (including that they have been diagnosed with a mental illness) with their children, even when the children are clearly affected by their parent’s illness. In many circumstances, the grandmother or another family member is caring for the children, and
yet there is no mechanism to provide counseling support for them or to even update them on the mental status of the parent. The mothers in this study had variable responses about the idea of sharing personal information with their children and the children’s caregivers. Maria brought her children in to meet her health care providers, and wanted them to learn about how her illness was affecting her. Holly came to an agreement with her therapist, based on trust, to share information with people in her support system according to the degree that they needed it. She also arranged for her daughter to go to a counsellor, although she chose a different agency the clinic which she attended (which had a children’s counselling department.) Jane simply assumed that her daughter already knew about her illness, and may have been surprised to find that this was probably not true if she had not been included in a specific psychoeducational group or program for children.

The literature supports a family support approach which is flexible and continuous, as the needs of the family vary with the illness. Unfortunately, the present system often works primarily on reaction to crisis, rather than prevention or long term support. It also emphasizes the delivery of services to individuals, rather than a family approach, so one child in a family may be seen as requiring assistance and the other children may not be included. The Ministry of Children and Families does have resources to provide short term assistance for the child, and longer term supports such as respite care, foster care, parenting programs, homemakers, and one to one child care workers. However, this system can be described as underfunded and overworked, and therefore resources may be limited, and available only to children who show serious signs of abuse or neglect. Child protection social workers change frequently, and do not follow clients when they move out of an area, making continuity of care difficult. As well, parents in acute stages of their illness often reject supports, as paranoia, irritability, and withdrawal are part of the illness. This can cause gaps in the support network of children just when they most need help.
Parenting classes and programs are often offered as solutions to all parent child problems. Most of the mothers I interviewed had participated in parent education, but they were quite non committal about the benefits. It remains unclear whether the parents have, in fact, found these classes helpful, or whether they are designed to meet the needs of this group of parents. There is usually no follow-up if a parent is not competent to complete the program, due to the mental illness. Many of the mothers told me that they had attended a number of parenting classes, but this did not address their need for ongoing support, and for ongoing connection to more intensive help when needed. Mothers and children should be involved in the evaluation of these programs.

It was a clear finding from this study that attention to parenting issues should be included in all treatment plans for parents. Even if clients lose custody of their children, support and counseling are needed to adjust to the loss and to explore the possibility of getting the children back. Parents may need parenting education, respite, or assistance for their children. They may need advocacy, practical help, or simply recognition of the additional stress and responsibility they carry as parents.

All issues around the lack of employment opportunities and economic and social marginalization of people who have a mental illness have a profound effect on their children. Poverty is a serious and well documented risk to children’s health. Housing issues also require attention. Many families live in subsidized housing projects, which often add a number of additional social problems for the children to deal with. It is necessary for children who are already at risk because of parental mental illness to live in a healthy environment. If the family tends to move frequently, a great deal of effort should be made to ensure stability and continuity in their "professional family" through such approaches as regular meetings and family centered case conferences.

Jane’s story, in particular, brought up the need for psychiatric and emergency departments to consider the needs of dependent children when a parent is admitted. An attempt by the hospital social worker should be made to find a person in the family's
network, (well parent, close friend or relative, community social worker) who can help the children understand the parent's hospitalization, ensure the children are properly cared for, assist in the decision as to the appropriateness of visiting, and liaise with other agencies as required. Under present hospital policies, patients are admitted for shorter times than in the past, or not admitted based on hospital priorities. While discharge plans consider the resources in the community to help the patient, there is usually no advocate for the children to represent their needs and concerns, particularly if the children have been staying with neighbours or relatives, rather than in care of the Ministry of Children and Families.

If the children are placed in care, the caregivers should be given clear information about the parent's illness and the likely effects on the children, in order to help the caregivers provide the best possible care to the children. The children should be able to speak directly to a mental health counselor about their feelings and anxieties as soon as possible, if they wish. If the parent is seriously injured or dies from suicide, an immediate outreach response should be made to the children and their caregivers. Again, the question is: who is responsible to provide this response?

Counselling should be available for children, whether or not they exhibit symptoms of emotional disturbance. The affected parent's condition should be explained to each family member at the level appropriate to that member: "The goal of individual and group therapy for children is to strengthen and reinforce each child's perception and emotional differentiation from the parent's illness." (Beardslee & MacMillan, 1991). However, intervention directed only toward counselling the child is not effective. It may put a child in an emotionally unsafe situation where she is not safe to reveal neglect or abuse, because such disclosures may threaten her home, and result in self blaming as well as blame by other family members. The counselling of children must be backed up by parallel work with the parents.
Daycare and school programs were stabilizing and enriching features in the children's lives. They provided important opportunities for these children to develop relationships with peers and with healthy adults. As well, they helped children develop social skills, physical fitness, personal interests, and written, verbal, and artistic skills. These skills have all been found to be linked to resiliency in children (Anthony & Cohler, 1987).

It seemed clear that the children in several of the families who participated in the study were responsible for providing companionship and care for their mothers in a caregiving role which went beyond normal reciprocal exchanges in healthy family life. Psuedo adult expectations of children who have mentally ill parents is well documented in the literature, particularly from the accounts of adult children. The findings from this study could be used as a beginning step in identifying the mothers’ needs currently fulfilled by the children, and developing services for these mothers which would reduce the pressure on the children to be caregivers. I believe that we need to think about what the Young Carers in Great Britain demanded: that their parents be taken care of as if they were not in the home (Marlowe, 1996).

Professional education about families where there is parental mental illness should be available to educators, health and mental health care workers, teachers, child protection workers, and family doctors. As well, current research should be widely disseminated in the community, and used to inform program development and policy.

Limitations of the Study, and Further Directions for Research:

There are several limitations in this study which point to the need for further research. One was the small number of participants in this study, due in part to limits on the time available to me as a graduate student. As well, the participants were all recruited from one agency, and were probably influenced by my role as a worker in that agency. I believe this can be shown by the finding that the results of this study differed in some significant ways from a study undertaken by the Vancouver Mental Patients Association,
a consumer advocacy organization (Judas et al., 1997). (Some of these differences may also be accounted for by the different research methods employed in the two studies.) It is clear that a larger and more diverse sample of women from other agencies would have increased the strength of this study. While I attempted to include a discussion of the cross cultural issues which affected the study participants, a larger sample representing various cultures would be necessary to reinforce any findings which attempted to generalize beyond the individual’s stated experience. Another limitation was the relatively short contact that I had with each participant. I believe that a similar study organized over a longer time period would provide a greater depth of knowledge.

I hope that this study will encourage others to explore this subject through research. I believe that the following directions for research would be useful:

- A grounded research study of mothers experience, involving a larger sample group.
- A longer term study which could seek deeper information by engaging with participants over the material for more sessions, with a goal of co-authoring the written version of the story with the participants.
- Long term case studies, including collateral sources.
- Qualitative research with health care professionals to determine their areas of concern in providing appropriate services to this group.
- Qualitative research with children, youth and adults who have parents with a mental illness, to learn from their experience in British Columbia and Canada.
- Quantitative research to find some accurate numbers such as the number of births to women who have a serious mental illness, correct statistics about custody, the number of mothers with serious mental illnesses who are actively parenting, and their use of services in the community.
- Research at hospitals about the children of people admitted to adult psychiatric wards.
• A qualitative study about family and neighbourhood support networks, including grandmothers, aunts, friends and neighbours, who provide practical help to these families.
• Studies about the effects of medication on pregnancy and breast feeding, and the concerns that mothers have about these effects.

Conclusion

I set out in this study to learn about mothers' perspectives about their experience as mothers. I experienced some degree of trepidation that I might inadvertently upset the research participants, or not portray their situation accurately. This study was exploratory, and I didn’t know what I would find out in these conversations. The findings did not neatly fit with my previous assumptions, and it was initially very difficult for me to hear all of the themes these mothers spoke of, and reflect them in this thesis. Often my professional contact with families where there was parental mental illness have been during a crisis, and the predominant stories of the crisis have been told by the voices of other professionals in the support system. It was enlightening to learn more about the reality of the participants' lives, particularly their retrospective accounts of how they made it through a crisis and came out on the other side. This study gave mothers an opportunity to reflect back any part of their experience that they wished to share.

These women told me that they appreciated having the opportunity to tell their stories. They told me that it was difficult to bring up their children, but that they received many benefits as well, in the pride, love and joy they felt about their children, the support they received from their children, and the value of the support network and extended family that came along with the children. The literature review told me that while a large number of women who have a mental illness have children, there is a general lack of knowledge about these mothers. There is some literature which describes the problems associated with maternal mental illness, and a few descriptions of clinical interventions to help children in certain situations. The fact that a balanced presentation of this issue is
absent in the clinical literature is, I believe, an indication of the lack of attention to parenting and childcare issues in general, in clinical work with the mentally ill. The trend in much of the research I surveyed seemed to be to address particular clinical issues without reference to social factors and the lived experience of chronic mental illness for both the parents and the children.

My own experience tells me that we have a long way to go to address this problem. We need to bring families and community members into the conversation - we won’t be able to do everything that needs to done without them. We have to get these stories out, and not to be afraid to discuss these issues with consumers, who have even more essential knowledge than we do, and who also have personal stories about their own childhoods, and what they wish had happened for them.

In conclusion, these families are not well served by the residual concept of providing services based on crisis intervention and child protection concerns. They require services based on the child’s right to services and supports needed for healthy development. The provision of services based on protection concerns involves attaching blame to the parent, rather than providing help for both the parent and child. Offering services through the concept of abuse rather than disability precludes many children who are in chronic, but not acute difficulty from being able to access services which may be important to them.

The absence of mothers’ voices in the literature adds to the blame, guilt, shame, stigma that the mothers experience. My hope is that by sharing these stories which have been shared with me, social workers will begin a different kind of conversation with their clients about their experiences as mothers. While these women described some feelings of pain, fear, and guilt, they also expressed deep love and hope for their children. I was very moved by the courage of all of the women who participated in this study, and I learned a lot from their stories. I hope that these stories can help to inform policy discussions, program development, and further research.
References


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