DECONTEXTUALIZING MOTHERHOOD: EXPERIENCES OF MOTHERS WITH SERIOUS MENTAL ILLNESS AND THE RESPONSE OF THE PROFESSIONAL SYSTEM

by

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Abstract

As more women with mental illness have the opportunity to become parents, there has been growing recognition that mental illness may present unique challenges to parenting. The purpose of this qualitative study was to describe the experiences of mothers with serious mental illness and identify the factors at the family, service, policy, and societal levels that women perceived as influencing their experiences. This study used a grounded theory approach and collected interview data from mothers with serious mental illness (n=9). Findings from the study suggest that women’s identity as a mother and the support they receive as a result of their mothering role can positively influence the mental health of mothers with mental illness. The study highlighted the interconnected collection of factors that codetermine the structure of mother’s lives. In particular, it examined how the professional system, including the health care, mental health, and child welfare systems, is involved with and influences the experiences of mothers with mental illness.
Table of Contents

Abstract ................................................................................................................................. ii
Table of Contents ................................................................................................................ iii
List of Tables ........................................................................................................................ v
List of Figures ....................................................................................................................... vi
Acknowledgements ............................................................................................................. vii
Chapter One – Introduction................................................................................................. 1
  Background .......................................................................................................................... 1
  Research Rationale ............................................................................................................. 2
  Purpose of the Study ........................................................................................................... 3
Chapter Two – Review Of Literature ................................................................................ 5
  Overview of the Chapter ...................................................................................................... 5
  I. Introduction ...................................................................................................................... 5
     Increased Opportunity to Parent ..................................................................................... 5
     Women and Mental Health Research ............................................................................. 6
     Defining Serious Mental Illness ....................................................................................... 9
  II. Research on Mothers with Serious Mental Illness ........................................................ 11
     Research on Mothers with Serious Mental Illness ........................................................ 11
     Available Demographic Information ............................................................................. 12
     Types of Research .......................................................................................................... 13
  III. The Experiences and Needs of Mothers with Serious Mental Illness .......................... 15
     The Significance of Motherhood ..................................................................................... 17
     Motherhood and Mental Illness ...................................................................................... 18
  IV. The Health Care Experiences of Mothers with Serious Mental Illness ....................... 22
     Women with SMI in the Mental Health and Health Care Systems ............................... 22
     Inattention to Parenting Issues ...................................................................................... 24
     Health Concerns and Treatment Needs of Mothers with SMI ....................................... 25
     The Role of the Health Care System ............................................................................. 27
  Summary ............................................................................................................................. 29
Chapter Three – Methodology ............................................................................................ 31
  Overview of the Chapter .................................................................................................... 31
  I. Overview .......................................................................................................................... 31
     Rationale for a Qualitative Approach ............................................................................ 31
     A Grounded Theory Approach ..................................................................................... 33
     Characteristics of the Methodology .............................................................................. 34
  II. Research Procedures ..................................................................................................... 39
     Data Sources ................................................................................................................... 39
     Data Collection ............................................................................................................... 40
     Characteristics of Study Participants ............................................................................ 43
     Data Analysis .................................................................................................................. 43
  III. Issues of Rigor and Ethical Considerations ................................................................ 50
     Strategies for Ensuring Rigor ......................................................................................... 50
     Ethical Considerations ................................................................................................... 54
List of Tables

Table 5.1: Examples of How Service Providers Can Support Processes of Building Stability and Re-stabilizing ................................................................. 113

Table 5.2: System Features that Encourage Building Stability and Re-stabilizing … 119
List of Figures

Figure 4.1: Emerging Theoretical Framework ............................................. 63

Figure 4.2: Influence of the Professional System on Building Stability and
Re-stabilizing .................................................................................................. 95
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Chapter One – Introduction

Background

As more women with mental illness have the opportunity to become parents, there has been growing recognition that mental illness may present unique challenges to parenting. Studies have described the challenges facing many mothers with serious mental illness\(^1\), including poverty and isolation, housing and employment issues, stigma and single parenthood. These factors, in addition to widespread stereotypes and myths about mothers with mental illness and a lack of family-centred supports, often prevent women from parenting successfully. However, a growing number of mental health professionals and service providers are challenging these stereotypes and pointing out that many women with mental illness can be, and are, good parents when they are adequately supported (Supporting Families with Parental Mental Illness Working Group, 2002)

Although there are no statistics to indicate the number of women with mental illness who are parenting, studies suggest that women with mental illness have children at the same rate as the general population. Research suggests that 3% of the population has a persistent and chronic mental illness and that 1 in 5 British Columbians will experience mental illness in their lifetime (Goldner, Snider, & Mozel, 2000). Given these figures and the numbers of individuals living in the community who are undiagnosed, it seems likely that there are a large number of families who are affected by parental mental illness.

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\(^1\) In this study, the term “serious mental illness” is used to describe individuals who have a major, continuing illness that has a significant impact on their lives. A discussion of the numerous definitions and terms used to describe and measure mental illness is included in Chapter Two.
Research Rationale

In the fall of 2000, I became involved with a research project at the British Columbia Centre of Excellence for Women's Health entitled *Mothering Under Duress: Policy discourses in the context of woman abuse, illicit substance use, and mental illness.* This project analyzed current approaches to mothering in Canada as articulated through key policy documents, media portrayals, and women's experiences. In particular, the project examined media and policy discourse surrounding mothering in three areas: mothers with mental health issues, mothers with substance use issues and mothers in abusive relationships. This projected highlighted how mothers with mental illness come into contact with a wide range of public systems, including the health care and mental health system, family services, child protection, and the legal system.

During this study, I had the opportunity to speak with several mothers about their experiences as well as hear from service providers and policymakers working in the areas of mental health and child protection. As I read the literature, it became clear that, in spite of nearly fifty years of research examining mental illness and mothering, surprisingly little attention had been paid to the voices and experiences of mothers with mental illness. An examination of the literature on the parenting skills of mothers with mental illness demonstrates an emphasis on deficits and failures and focuses on the effect of mother's behaviour on the emotional and behavioural well-being of their children. In the clinical literature, discussions of mothering for women with mental illness often view motherhood as a "risk" to women's mental health or describe the potential of motherhood to be a "rehabilitative tool". From a health care perspective, most research on mothering and mental illness has focused on the perinatal period, the impact of psychotropic drugs
during pregnancy, or family planning issues, and has not examined long-term parenting issues for mothers with mental health issues. In particular, the potential of the mental health and health care system to provide support for women who are parenting has been neglected.

As more and more women with mental illness are living in the community rather than in an institutional setting and becoming mothers, questions regarding how best to support mothers and their families arise. Recently, researchers have begun to pay greater attention to the experiences and meaning of parenting for mothers with serious mental illness. However, these studies have tended to focus on individual characteristics and circumstances and have not adequately considered the influence of women’s social context on their experiences. As well, previous research on the effect of mental illness on women’s mothering abilities has focused on mothers as the object of inquiry and, consequently, as the object of intervention. Little attention has been paid to how policies and practices in various public systems influence women’s abilities to successfully parent. As yet, there has been little in-depth exploration of how broader socio-cultural and structural factors shape and determine outcomes for women, their children, and broader families.

**Purpose of the Study**

In this study, I wanted to invite women to share their experiences of mothering with a mental illness and to voice their thoughts and concerns. In addition to providing women with the opportunity to reflect on their experiences, I also wanted to explore how the greater socio-cultural and political context affects women’s experiences. The following two research questions were used to guide this study:
(1) What are women’s experiences of mothering with a mental illness?

(2) How do factors at the family, service, policy, and societal levels influence their experiences?

At the end of my first interview, as Karen and I walked to her car, we spoke about the importance of being able to speak about your experiences and having an opportunity to have your voice heard. Just before we said goodbye, Karen said: “It’s important to share our stories. But we’ve been telling our stories for a while and it’s time to act and use them.” I hope that the findings of this study provide mothers, researchers, service providers, and policy makers with information that they can reflect on, think with, and apply in their own lives and work.
Chapter Two – Review Of Literature

Overview of the Chapter

This chapter provides an overview of the literature related to mothers with mental illness. In the first section, key concepts and ideas from the mental health literature relevant to this study are presented. An overview of the evolution of research on mothers with serious mental illness (SMI) is provided in Section Two. Section Three provides a description of what is known about the experiences of mothers with SMI, including a description of the significance of motherhood and the unique, additional challenges that mothers with SMI may face. In the fourth section, research on the mental health and health care experiences of women with SMI, mother’s interactions with the mental health and health care system, and the role of these systems in the lives of mothers with SMI is examined.

I. Introduction

Increased Opportunity to Parent

The history of mental health care in Canada has paralleled that of many other countries, including the U.S., Britain, and New Zealand. Similar to other industrialized nations, most individuals with serious mental illness were cared for in provincial mental health hospitals from the mid-1800s onward. In the 1950s and 1960s, a movement towards a policy of “care in the community” emerged. The growth of the mental health consumer movement had led to the recognition that recovery from mental illness was possible and had resulted in more attention being paid to the needs of “consumers” and their families. As well, a growing awareness of the costs of long-term care and the availability of new and more effective drugs fueled the philosophy of
deinstitutionalization that resulted in a dramatic restructuring of mental health care services.

Policies of deinstitutionalization shifted mental health services into psychiatric units in general hospitals and into the community. In Canada, bed capacity in mental hospitals dropped from 47,633 to 15,011 between 1960 and 1976 while general hospital psychiatric beds increased from 844 to 5,836 (Wasylenski, Goering, & Macnaughton, 1994). Consequently, women who may have formerly spent the bulk of their lives in an institutionalized setting were now living in the community (Bachrach, 1984; Empfield, 2000). As well, the growth of the mental health consumer movement had brought increased awareness to the rights of individuals with mental illness and highlighted that parenting was a normal and important life role for individuals with mental illness. Together, policies of deinstitutionalization, improved outpatient treatment for mental illness, and the growth of the mental health consumer movement, has meant that more women with serious mental illness have increased opportunity to become parents and raise their children.

**Women and Mental Health Research**

In the 1960s and 1970s, several authors, including the well-known anti-psychiatrist Thomas Szasz (1961) and critical theorist Phyllis Chesler (1972), drew attention to the pathologizing of social problems by the psychiatric establishment. Szasz argued that socio-economic hardships in life produced stress in vulnerable individuals and that mental illness was due to the “problems of living”. Rather than being understood as a symptom of personal distress, mental illness could be thought of as a symptom of social distress. In particular, scholars highlighted the ways in which women’s lives had
been pathologized by experts in the field of psychiatry. Broverman et al. (1970) commented that women were faced with a double standard with regards to mental health. In their classic study, mental health professionals were asked to respond to questions on the nature of mental health for men, women, and humans in general. They found that the mentally healthy woman was defined by her similarity to overall stereotypes of female passivity and that a “healthy woman” and a “healthy human” were incompatible.

Chesler (1972) and other feminist writers argued that psychiatry stereotyped female behaviour in such as way that many women found themselves in a “Catch 22” situation of being easily defined as mentally ill and that women who are both close to, and depart from, the normal female role are seen as deviant. Caplan (1993) also suggested that women’s unhappiness is often blamed on their (actually non-existent) masochism; consequently, women regard themselves as sick and helpless and the real causes of women’s unhappiness remain unexamined. These authors argued that the position of women in psychiatry reflected deep-rooted conceptions of women in society and a tradition of pathologizing femininity. The growth of the anti-psychiatry movement during the 1960s and 1970s led to a greater awareness and pressure to examine issues of gender in the psychiatric establishment.

In the early 1980s, researchers began to recognize the diverse needs of individuals with serious mental illness. In 1981, Test and Berlin commented on how clinicians and researchers have, to a great extent, viewed individuals with chronic mental illness as a “faceless” and genderless population. They hypothesized that a lack of sensitivity to gender-related issues stems from a genuine yet overriding concern with an individual’s illness, which clouds the clinician’s ability to see their patients as a group of diverse
individuals with differing strengths, needs and circumstances. In their article, they drew attention to several issues of special concern to women with chronic mental illness, including marital and family roles, employment, family planning needs, sexual exploitation, and physical health needs. They described how research in these areas, including the experiences and special needs of mothers with chronic mental illness, had been almost entirely neglected. Similarly, Bachrach (1984) described how policies of deinstitutionalization have had a differential impact on men and women. She illustrated how deinstitutionalization had special effects on women in areas such as homelessness, violence, and stigma.

During the 1980s, literature on mental illness began to reflect an increasing awareness of gender issues. Epidemiological studies providing evidence of gender differences in mental health stimulated debate and discussion over possible explanations for these consistent findings (Pugliesi, 1992). Explanations for these differences have been attributed to a variety of biological, psychosocial and artefactual causes. Although biological aspects of mental illness have continued to dominate the research, gender and sex differences in mental health are now understood to be the result of an interaction of biological and psychosocial factors across the lifespan. The increased attention to gender differences in mental health also has paralleled an increasing emphasis on quality of life for individuals with long-term disabilities.

In recent years, it has become well recognized that addressing the mental health needs of women with serious mental illness requires an understanding of the context of women's lives. The 1993 report Working Together for Women's Mental Health (Federal/Provincial/Territorial Working Group on Women's Health, 1993) recognizes that
women's mental health is influenced by factors such as poverty, violence and sexual abuse, sex role stereotyping, inequities in the workplace and women's multiple workloads. The report also acknowledges that many groups of women, including women with recurrent or chronic mental illness, experience additional challenges to their mental health and well-being.

**Defining Serious Mental Illness**

Mental illness is a broad term used to describe a range of illnesses that impair a person's ability to think, feel, behave, and function effectively in day-to-day life. Some people may experience a single episode of mental illness in their lifetime, while others may experience ongoing symptoms. Statistics suggest that 1 in 5 people will experience an episode of mental illness in their lives (Goldner, et al., 2000) and that approximately 3% of the population has a persistent and chronic mental illness.

A brief survey of research on mental illness demonstrates that the definitions and terms related to mental health are evolving and subject to much debate. Definitions of mental illness reflect debate on the degree to which mental illness is believed to be caused by biological or psychosocial factors and the ways in which society determines and labels aberrant or deviant behaviour. (For example, in recent years, community mental health surveys have begun to incorporate alcohol and substance use into definitions of mental illness.) In the literature, several terms are used to describe serious mental illness, including “serious,” “severe,” or “recurrent,” mental illness; “persistent and chronic mental illness;” and “psychiatric disability.” Often, these terms are used interchangeably, creating confusion and difficulties when assessing mental health research.
Serious mental illness can be defined by a clinical diagnosis, by measuring the impact of illness on social and physical functioning, or by a combination of these two approaches. In the mental health field, two major classification systems are used to diagnose mental disorders: the International Classification of Disease (ICD) maintained by the World Health Organization and the Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association. In North America, the 4th edition of the DSM is commonly used to make clinical diagnoses. The DSM-IV (TR) distinguishes between Axis I and Axis II disorders. According to this classification, Axis I disorders, including depression, schizophrenia, bipolar disorder, and anxiety disorders, are considered major illnesses.

Because a clinical diagnosis generally does not capture the range of experiences and abilities that an individual may have, a combination of diagnostic and impairment criteria often are used to define serious mental illness. For example, the B.C. Mental Health Plan states: “Generally, illnesses such as schizophrenia, manic depression, and bipolar disorder represent the most serious mental illness; however, it is acknowledged that there are others for whom medical risk and impairment, regardless of diagnosis, determines their mental illness as ‘serious.’” (B.C. Mental Health Plan, 1998: 92). Other definitions of serious mental illness include a criterion describing use of mental health services for a specified period of time (e.g., Axis I disorder combined with utilization of mental health services for a period greater than one year). For the purposes of this study, the term “serious mental illness” (abbreviated as SMI) is used to describe individuals who have a major, continuing illness that has a significant impact on their lives.
II. Research on Mothers with Serious Mental Illness

Research on Mothers with Serious Mental Illness

During the 1970s and 1980s, the academic literature paid attention to mothers with mental illness in two areas: (1) epidemiological studies of the treatment needs of women who suffer from postpartum psychiatric disorders and (2) outcome studies of children with mothers with SMI. Until the 1990s, very little research was concerned with the experiences of mothers themselves. In a report on gender-sensitive mental health services, a consumer consultant attributes the paucity of research on the demographics, issues and service needs for mothers with psychiatric disabilities to a “failure to recognize that marriage and parenting are normal roles for adults, regardless of illness or disability” (Women and Mental Health Working Group, 1996: 7).

In 1993, Apfel and Handel published the first comprehensive book discussing motherhood for women with serious mental illness. In their introduction, they comment on the stigma and myths surrounding child bearing amongst women with serious mental illness. Based on research and clinical experience from the perspective of mental health professionals who work with patients who become parents, Apfel and Handel acknowledged the importance of sexuality, reproduction, and parenting in the lives of women with SMI.

In the past decade, researchers and service providers have become more interested in the experiences of parents with mental illness. Although research on parenting and mental illness has begun to address issues for fathers with serious mental illness (Nicholson, Nason, Calabresi, & Yando, 1999), research on parents with mental illness has tended to focus on mothers with mental illness (Styron, Pruett, McMahon, &
Davidson, 2002). Research suggests that women with mental illness are more likely to marry than men (Mowbray, Oyserman, Zemencuk, & Ross, 1995) and are more likely than men to be actively involved in caring for children (Nicholson et al., 1999). As well, the later onset of some mental illnesses for women (e.g., schizophrenia) means that women are more likely than men to become parents prior to the onset of SMI. Thus, it appears that women with serious mental illness are more frequently coping with the challenges of motherhood in conjunction with their mental illness.

**Available Demographic Information**

Although Statistics Canada initiated the first national survey on mental health in 2002, national or large-scale survey data describing the prevalence of adults with mental illness who are parents is currently lacking. Studies estimate that 3% of the population has a persistent and chronic mental illness (Goldner et al., 2000); however, it is impossible to estimate the number of women with serious mental illness who are also mothers. Few studies on mothers with serious mental illness have been conducted in a Canadian setting and it is difficult to extrapolate rates from small non-population based samples. For example, in a sample of 28 Manitoban women living with schizophrenia, 13 had no children, 8 had raised or were raising their children, 6 had lost custody of their children and 1 had lost custody of a child and was raising another child (Clarke, Chernomas, & Chisholm, 2001). In a study of 51 women conducted by the Mental Patients’ Association in Vancouver (Judas, Niles, & Woodwards, 1999), 52% were mothers, 27% had given children up for adoption, 19% had their children apprehended by social services, 16% had lost custody to relatives, 19% did not know where their children were, and 26% had never had custody of some of their children (these categories were not
mutually exclusive and women responded affirmatively to multiple questions). A survey conducted by the Greater Vancouver Mental Health Service found that the majority of women in contact with mental health teams in the Vancouver and Richmond area lived alone with a child or children (Peters, 1999).

Other research on mothers with serious mental illness suggests that women with SMI are likely to be sexually active, frequently have children and are often carrying out child care responsibilities (Mowbray et al., 1995). It is now believed that women with serious mental illness have fertility rates similar to the general population rate (Apfel & Handel, 1993; Coverdale & Aruffo, 1989; Mowbray et al., 1995; White, Nicholson, Fisher, & Geller, 1995) of 1.52 children per woman (Statistics Canada, 2002).

Types of Research

The majority of the research on mothers with serious mental illness has focused on describing the circumstances, stressors, resources, and service needs of mothers with serious mental illness. In 1995, Mowbray et al. (1995) published a review of 36 studies on motherhood for women with SMI conducted between 1983-1993. The majority of these studies focused on issues during pregnancy, childbirth, and the postpartum period, and did not examine long-term parenting issues. Mowbray et al. comment that one of the limitations of studies on mothers with SMI is that they often have relied on small, clinically-based, predominantly white and middle-class samples of women. Most studies used research participants from inpatient psychiatric treatment settings rather than individuals who are currently living successfully in the community. They acknowledge that this form of sampling bias has led to an emphasis on maternal deficits and problems. Mowbray et al. also critique the methodological rigor of many of the studies included in
their review by citing a number of methodological shortcomings, including the lack of representative samples, comparison groups, standardized instruments, and assessment techniques. Although the bulk of the research suggests that psychiatric disability in the early stages of motherhood can be stressful for both mothers and infants, many of the findings were disparate and not replicated across studies.

Nicholson et al. (2001), in a review of studies in the U.S. over the past ten years, also comments on the limited generalizability of more recent research. Although the scope of research has expanded in recent years to examine the experiences and meaning of parenting for mothers with SMI and parenting issues beyond the postpartum period, most studies used small samples, were cross-sectional in design, and produced primarily descriptive findings. In most of the studies included in the review, the study participants were recruited in hospital, clinic or other treatment settings (Joseph, Joshi, Lewin, & Abrams, 1999; Mowbray & Oyserman, 1995; Nicholson, Sweeney, & Geller, 1998a, 1998b; Sands, 1995).

One study using a larger sample (n=379) recruited low-income women from a primarily ethnic minority background in the public sector (Mowbray, Oyserman, Bybee, & MacFarlane, 2002; Mowbray, Oyserman, Bybee, MacFarlane, & Rueda-Riedle, 2001; Mowbray et al., 2000). Other studies used larger samples from administrative databases (Kelly et al., 1999) or rehabilitation center populations (Ritsher, Coursey, & Farrell, 1997). Most of the participants in these studies were recruited from the public sector, were poor, single (divorced, separated or never married), and were African-American or from other ethnic minority backgrounds (Nicholson et al., 2001). As a result, little is known about the experiences of mothers across class, ethnicity, and a range of illnesses.
Prior to 1995, very few studies considered the meaning of parenting for women with serious mental illness and did not use methodologies that incorporated the perspectives and experiences of mothers themselves. Studies exploring the experiences of mothers have used survey methods (Dipple, Smith, Andrews, & Evans, 2002; Joseph et al., 1999; Mowbray et al., 2001; Mowbray et al., 1995; Mowbray et al., 2000; Ritsher et al., 1997), qualitative methods (Bassett, Lampe, & Lloyd, 1999; Mental Health Action Research and Advocacy Association of Greater Vancouver, 2002; Nicholson et al., 1998a, 1998b; Wallace, 1992), or a combination of both (Mowbray & Oyserman, 1995). Studies using survey methods have been limited by the concerns described above, while the qualitative studies have used thematic or content analysis methods to analyze data collected using focus group, short answer, or one-to-one interview methods. Although these studies have provided useful descriptions of some of the issues facing mothers with serious mental illness, they also have had a number of methodological shortcomings or have been limited in their ability to elucidate the intersections between mental illness, mothering, and the context of women’s lives.

III. The Experiences and Needs of Mothers with Serious Mental Illness

Several authors have commented that mothers with SMI have needs and experiences that are common to all parents (Nicholson et al., 2001; Nicholson, Geller, & Fisher, 1996; Nicholson et al., 1998a; Sands, 1995; Wallace, 1992). However, mothers with SMI also face unique, additional challenges, especially in the areas of custody loss, effects of stigma, and managing their illness.

Like other parents, mothers with SMI require sufficient economic resources, access to safe and affordable housing, transportation, low-cost or free recreational
activities for families, and support for safe and dependable child care. However, research has
demonstrated that it is often difficult for mothers with SMI to meet these basic needs.
The relationship between mental illness and poverty has been well established through
epidemiological studies and the majority of individuals with SMI live in poverty.
Mothers with SMI are likely to be living in poverty and must deal with financial and
other stresses associated with living in poverty such as difficulty in paying for basic
necessities such as food and clothing (Kellington, 2002; Mental Health Action Research
and Advocacy Association of Greater Vancouver, 2002; Mohit, 1996; Morrow &
Chappell, 1999; Mowbray et al., 1995; Mowbray et al., 2000; World Health
Organization, 2001).

In addition to financial hardship, many mothers with SMI live in less than optimal
housing. In British Columbia, individuals with SMI experience numerous challenges in
affordable housing (Mental Health Action Research and Advocacy Association of
Greater Vancouver, 2002; Morrow & Chappell, 1999) and other research describes
mothers living in substandard housing in neighborhoods where they had safety concerns
(Mowbray et al., 2001; Mowbray et al., 2000; Oyserman & Mowbray, 1994). Mothers
with SMI tend to be single parents (Mental Health Action Research and Advocacy
Association of Greater Vancouver, 2002; Mowbray & Oyserman, 1995; Mowbray et al.,
2001; Peters, 1999) and have limited social networks (Bassett et al., 1999; Miller, 1997;
Mohit, 1996; Mowbray & Oyserman, 1995; Nicholson & Blanch, 1994; Oyserman &
Mowbray, 1994; Ritsher et al., 1997). Research on women with mental illness has
demonstrated that women with mental illness are more likely to have experienced
domestic violence and childhood sexual abuse (Cogan, 1998; Goodman, Rosenberg, Mueser, & Drake, 1997; Mullen, Martin, Anderson, Romans, & Herbison, 1993). As well, many mothers may be overwhelmed with other concerns such as obtaining food for her family or acquiring housing (Mowbray et al., 2000).

The Significance of Motherhood

In addition to the significant stresses many mothers with SMI face while raising their children, recent studies examining the meaning of parenthood for women with SMI also have paid attention to the positive benefits of mothering, including love, purpose, identity, and support as the children become adults (Clarke et al., 2001). In one survey, half of the women described positive emotional consequences when asked, “What changes has motherhood brought to your life?” One-fifth described positive behavioural consequences of motherhood such as giving up drugs or ending bad relationships; 6.5% described positive changes in dealing with their own mental illness, and 10% described enhancements of their status or social role. Only 10% of the mothers responded with descriptions of negative consequences of being a mother. Common negative responses related to the circumstances surrounding being a low-income mother, such as financial worries, or concrete changes, such as loss of free time (Mowbray et al., 2001).

Most studies described parenthood as an experience promoting personal growth and development for women. Motherhood was viewed as a central life experience providing a sense of purpose and worth. Children were seen as a source of pleasure in their lives and often served as a strong motivating force in their own recovery (Bassett et al., 1999; Mowbray & Oyserman, 1995; Sands, 1995). One study described how children remain central to mothers who have lost custody of their children. For mothers who have
visiting rights, seeing their children was an important focus in their lives. For mothers without visiting rights, it remained important to talk about their children or incorporate them into their lives in some way (Schwab, Clarke, & Drake, 1991). Although often accompanied by many stresses, motherhood is an important role for women with SMI, providing many rewards and positive effects.

**Motherhood and Mental Illness**

Three areas of particular concern to mothers with SMI include (1) stigma (2) custody issues and (3) mental illness management.

**Stigma**

Several studies have reported that women with SMI perceive stigma as affecting their experiences of mothering (Bassett et al., 1999; Cogan, 1998; Greaves et al., 2002; Kellington, 2002; Morrow & Chappell, 1999; Nicholson et al., 1998a). Prior to pregnancy, women with SMI already cope with widespread negative attitudes and stereotypes about people with mental illness. In general, societal attitudes towards women with SMI appear to be that they should not be parents and that individuals with mental illness are incapable of raising and caring for a child. Mothers with mental illness are often stereotyped as irrational, unpredictable and physically dangerous (Greaves et al., 2002). Stereotypes of people with mental illness as violent contribute to the assumption that mothers with mental illness are violent and may abuse their children.

Cogan (1998) found that most mothers in her study perceived stigma as influencing whether they were allowed to maintain child custody. One woman described feeling as if she was “on trial” and was perceived to be guilty of incompetent parenting until proven otherwise. When a woman with SMI becomes pregnant, many immediately
assume they will be unable to care for the child. The additional stress of having to prove oneself fit to parent can serve to motivate or discourage mothers with SMI. In a study by Nicholson et al. (1998a: 638), one case manager commented, “From the outset our clients have to prove they’re able to parent, unlike everybody else who is able to assume they can parent until proven otherwise.” In addition, people also may hold parental mental illness responsible for children’s problems.

Custody Issues

The issue of custody loss is an area of particular concern and importance for mothers with SMI. Although rates of custody loss for women in the general population are low (i.e., less than 1%), custody loss estimates for women with mental health issues range from 60-89% (Joseph et al., 1999; Judas et al., 1999; Mowbray et al., 1995; Thomas & Tori, 1999; Thomas, Tori, Wile, & Scheidt, 1996).

Loss of custody may occur in a variety of ways. Custody loss may occur at birth or after caring for a child or children for years (Dipple et al., 2002). It may occur through voluntary placements when women are in the hospital, through involuntary removal or apprehension by social services, or as a consequence of divorce (Dipple et al., 2002; Nicholson et al., 1998a). Custody loss also may include loss of visiting rights to children who have been adopted or placed in care (Schwab et al., 1991). In some cases, custody may be given to extended family and women may still have contact with the children or have care-taking responsibilities (Mowbray & Oyserman, 1995).

Several studies report that the fear of losing custody prevents mothers with SMI from acknowledging problems or requesting services (Bassett et al., 1999; Coverdale & Aruffo, 1989; Greaves et al., 2001; Hearle, Plant, Jenner, Barkla, & McGrath, 1999;
Worry about potential loss can increase the stress of mothering and lead to increased psychological distress (Nicholson et al., 1998a).

Once mothers with SMI have lost custody, they often find it difficult to regain custody and mothers struggle with maintaining contact with their children (Dipple et al., 2002; Greaves et al., 2002; Mental Health Action Research and Advocacy Association of Greater Vancouver, 2002; Sands, 1995). Conflicts may arise when a mother knows her child or children are being placed with a relative, grandparent or partner with whom she does not have a positive relationship or who may have been abusive to her in the past. In addition, several studies have reported cases where custody has been awarded to partners who do not have a diagnosis of mental illness, but are less able caregivers (Greaves et al., 2002; Nicholson et al., 1998b). Visits may be stressful for both mother and child and mothers may feel jealous of their children’s relationship with grandparents or other family caregivers (Nicholson et al., 1998b). Nicholson et al. (1998a) describe how a mother’s recovery may be compromised if she is not permitted contact with her children and other studies describe how children remain central in the lives of parents with SMI who have voluntarily or involuntarily relinquished custody (Joseph et al., 1999; Nicholson et al., 1998a; Schwab et al., 1991). In one study, women who relinquished custody (74%) felt that custody relinquishment was less painful when the mother was permitted visitation rights (Thomas & Tori, 1999).

Several studies have shown that women who are dealing with the loss of custody of their children and the stigma of relinquishing custody experience grief, anger, anxiety, depression, suicidal ideation, guilt and shame (Kellington, 2002; Nicholson et al., 1998a;
Sands, 1995; Thomas & Tori, 1999). Custody loss results in a change in a mother’s relationship with her child as well as a loss of her identity as a mother. Women who lose custody of their children due to mental health problems also must cope with the stigma of being perceived as an “unfit” or “bad” mother. The loss of custody may cause long-term negative effects and unresolved grief and many women spend years or the rest of their lives struggling with the experience (Clarke et al., 2001; Kellington, 2002; Nicholson et al., 1998a). When mothers involuntarily or voluntarily relinquish custody, there is often little support provided to women and their children to cope with custody loss (Greaves et al., 2002; Kellington, 2002). Other studies have described mothers with mental illness as having difficulty accessing information about child custody issues and needing legal help (Cogan, 1998) as well as requiring assistance in dealing with their grief (Joseph et al., 1999).

Mental illness management

In addition to the “normal” stresses of parenting, mothers with SMI also have to invest additional time and energy to managing their illness. In addition to managing their busy parenting schedule, mothers with SMI must obtain services and treatment, and build relationships with service providers. In some circumstances, the needs of mothers may conflict with those of their children. For example, some mothers with SMI may choose not to take medication or refuse to go to the hospital, in order to continue caring for their children (Empfield, 2000; Nicholson et al., 1998a). Mothers also report not taking their medication because the side effects or overmedication may impair their ability to parent. Women may choose not to take medications during the prenatal period because of concerns over their teratogenic effects (Mowbray et al., 1995).
Many mothers with SMI struggle to disentangle the "normal" stresses of caring for children from the symptoms of their own illness. Mothers also may worry about the impact of their illness on their children (Mowbray & Oyserman, 1995) and specific illnesses such as schizophrenia may provide challenges to successful parenting (e.g., responding to non-verbal cues). Mothers also may have concerns about how to discuss their illness with their children. In addition, they may worry about becoming hospitalized and being unable to care for their child during their absence (Greaves et al., 2002; Nicholson et al., 1998a).

Although not extensively discussed in the mothering literature, studies have shown the existence of co-morbid health conditions among individuals with mental illness. Research has demonstrated that it is common for two or more mental health problems to occur in an individual, (e.g., mental illness and substance use) (Kessler et al., 1996; World Health Organization, 2001), and other studies document the high rates of co-morbidity among individuals with mental illness (Felker, Yazel, & Short, 1996). Several studies note that mothers with SMI also may face challenges with their physical health (Mowbray et al., 2000) and substance use issues (Mowbray & Oyserman, 1995).

IV. The Health Care Experiences of Mothers with Serious Mental Illness

Women with SMI in the Mental Health and Health Care Systems

Women with SMI, including mothers, have a wide range of health care needs, some related to issues specific to women (e.g., pregnancy and the postpartum period) and others associated with general health issues. However, it has been argued that women with SMI are an invisible population within the health care system (Caroline & Bernhard, 1994). In a study of women living with schizophrenia, women reported feeling that the
health care system focused on their illness and they were invisible as women (Clarke et al., 2001). In the literature, studies on health care issues for women with SMI have mostly been limited to reproductive health, in particular family planning issues. Overall, these studies have shown that women with SMI do not receive adequate information regarding contraception, pregnancy and other aspects of sexual health (Chernomas, Clarke, & Chisholm, 2000; Coverdale & Aruffo, 1989; Miller, 1992; Rudolph, Larson, Sweeny, Hough, & Arorian, 1999). In one study, half the women reported an unmet need for information on sex related issues. Medical professionals, such as doctors and nurses, were rated as most helpful while mental health professionals and others were rarely mentioned (Cogan, 1998). It has been suggested that clinicians tend to underestimate rates of sexual activity in women with SMI and that inaccurate stereotypes about sexual activity in women with SMI may be a major contributor to this problem. A study examining family planning issues for women with severe and persistent mental illness found that even though clinicians reported that a large fraction of sexually active women were not thought to be using birth control, many clinicians had not discussed birth control with their patients (McLennan & Ganguli, 1999). While clinicians reported that they knew the sexual activity status of the majority of their patients (93.5%), substantially fewer had knowledge about birth control status (69.0%).

Several American studies have described how women with SMI also may not receive adequate prenatal care (Kelly et al., 1999; Miller, Resnick, Williams, & Bloom, 1990; Mowbray & Oyserman, 1995). A population-based study of the association between psychiatric diagnoses and adequacy of prenatal care in California between 1994 and 1995 found that women with psychiatric diagnoses were twice as likely as women
without diagnoses to receive inadequate prenatal care (Kelly et al., 1999). This study found an association between psychiatric and substance use diagnoses and poor prenatal care even after controlling for known risk factors. A study examining the admission of pregnant women to the psychiatric unit of an urban hospital found that most women did not receive prenatal care until the third trimester and the researchers noted a high rate of involuntary admission, homelessness, and substance use in their sample (Miller et al., 1990). The authors believed that physicians and staff could have made better use of the opportunity presented by brief hospitalization to provide obstetric care.

**Inattention to Parenting Issues**

Many women report feeling as if they are seen through the prism of their mental illness and are not seen as a whole person or as individuals with particular issues and problems (Chernomas et al., 2000; Kellington, 2002; Ritsher et al., 1997). For mothers, this may mean that issues related to parenting are often overlooked or minimized in treatment. Research has demonstrated that parenting status is rarely considered in treatment planning. Several studies have shown that parenting status is rarely recorded in medical records (Dechillo, Matorin, & Hallahan, 1987; Dipple et al., 2002; Mowbray et al., 1995). An American study surveying state mental health departments found that less than one-third collected data on whether their clients had children (Nicholson, Geller, Fisher, & Dion, 1993). The authors suggest that service providers tend to focus on who will be caring for the patient, not whether the patient will be caring for someone else.

Some studies have found that women do not feel free to discuss their fears and concerns around parenting with health care providers. Clinicians may focus more on other pragmatic goals such as staying sober or finding employment and may avoid
discussions about parenting problems, thus, inadvertently minimizing the importance of parenting issues (Mowbray et al., 2001; Schwab et al., 1991; Women and Mental Health Working Group, 1996). Some health care providers may focus on the “deficits and the assumed or real inadequacies of parents with mental illness, rather than their strengths” which “contributes to a cycle of hopelessness and a view of the ‘helping’ relationship as adversarial.” (Nicholson and Henry, cited in Nicholson et al, 2001: 15). For women who have lost custody of their children, clinicians may not provide adequate opportunity for mothers to voice their grief. As well, clinicians may feel torn between being an advocate for a woman who wants to regain custody or increase visiting rights and feeling responsible for the welfare of the children (Schwab et al., 1991).

**Health Concerns and Treatment Needs of Mothers with SMI**

Treatment approaches that focus exclusively on clinical assessment of symptoms and medication management and fail to account for the fact that their patients are parents who live within a greater social context may result in poorer treatment success rates or reduced adherence to treatment recommendations. Chernomas et al. (2000) suggest that providers who do not contextualize their treatment plans in the lives of their patients may contribute to their diminished quality of life, self-esteem and sense of control (Clarke et al., 2001). Several areas of concern for mothers with SMI have emerged in the literature. These include the effects of psychotropic medications during pregnancy and breastfeeding, the effects of medications on parenting abilities, and the fear of child apprehension and problems with accessing child care as preventing women from seeking help for serious mental health problems.
Many women worry about the use of psychotropic medications during pregnancy and breastfeeding (Mowbray et al., 1995; Nicholson et al., 1998a; Ritsher et al., 1997). During pregnancy, many women are confronted with the dilemma of continuing to take their medications and risking their own mental health or exposing the fetus to perceived harmful effects (Clarke et al., 2001). Women may unnecessarily decide to stop taking medication during pregnancy if they do not feel comfortable talking with mental health or medical providers about their medication options during pregnancy. However, decisions regarding the continuation or discontinuation of psychotropic medication during pregnancy may be challenging for both health care providers and mothers as there is often little conclusive evidence regarding their safety (Altshuler & Szuba, 1994; Miller, 1997).

Nicholson et al. (1998a) described how the negative outcomes of failed treatment plans (that often ignore the mother’s goals, identity, or responsibilities as a parent) are frequently attributed to the mother’s non-compliance with treatment. Several studies report problems related to medication regimens, especially in cases where mothers have identified overmedication or inappropriate medication as preventing them from caring for their children (Kellington, 2002; Nicholson et al., 1998a). For example, a mother who needs to get up early to send her children to school may not take medications that make her lethargic in the morning. Difficulties identifying or finding adequate childcare also may be a barrier to seeking treatment, keeping appointments, or adhering to treatment regimens (Mowbray et al., 2000; Nicholson et al., 1998a). One study reported one-third of mothers had experienced a separation from their children of more than a month within
the past year and finding childcare was identified as a difficult “hassle” by about half of
the mothers (Mowbray et al., 2000).

The fear of custody loss also may prevent mothers from seeking help with mental
health problems or prenatal care (Empfield, 2000; Hearle et al., 1999; Kellington, 2002;
Morrow & Chappell, 1999). Denial of pregnancy among women with SMI is sometimes
reported in the literature and is often related to fears of losing custody of the baby
(Empfield, 2000; Mowbray et al., 1995; Nicholson et al., 1998a). In order to avoid the
stigma and grief associated with anticipated custody loss, women may choose to deny
their pregnancy.

The Role of the Health Care System

Although mothers with serious mental illness come into contact with several
different publicly administered systems (e.g., child protection, legal, social services), the
health care system has an important role to play in supporting women in their parenting
and helping them deal with issues that arise due to loss of custody.

While parenting supports and services are more often provided through the child
welfare system rather than the health care system (Greaves et al., 2002; Nicholson et al.,
1993), many mothers hold negative perceptions of the child welfare system and are
reluctant to ask for assistance. In one American study, nearly 40% of mothers gave child
welfare caseworkers one of the highest hassle ratings, which may have reflected fears
about losing custody (Mowbray et al., 2000). As well, many mothers view parenting
programs negatively (e.g., didactic, boring, irrelevant, or culturally inappropriate)
(Nicholson et al., 2001; Nicholson et al., 1996; Sands, 1995).
However, health care providers often are perceived as an important source of support in the lives of mothers with SMI. In an American study of 379 mothers with SMI (Mowbray et al., 2000), the majority of participants described the mental health services they received as “somewhat helpful”. While 44% of the participants identified their mental health service provider as a general source of support, only 20% described their mental health service provider as someone to provide support and advice about being a parent. In another study, 74% of women reported that the staff members at their rehabilitation center made them feel “respected” or “like an equal” while 25% felt they were treated like “a child” or “just another case”; 78% reported that their psychotherapist made them feel “respected” (Ritsher et al., 1997). In several other qualitative studies conducted in Canada, mothers report how individual health care providers can have a positive impact on their ability to cope with a situation and were appreciative of their support and understanding (Kellington, 2002; Mental Health Action Research and Advocacy Association of Greater Vancouver, 2002; Morrow & Chappell, 1999).

Although mothers with SMI often report good relationships and experiences with their health care providers, several Canadian studies also describe difficulties women have in obtaining services and a lack of structural supports to help them in their parenting (Kellington, 2002). Women report difficulty in accessing services; they feel the need to “prove” their need for services and may go to extreme lengths to obtain them (Chernomas et al., 2000; Cogan, 1998; Greaves et al., 2002). Mothers with SMI may be reluctant to share the true extent of their situations with health care providers because they are worried that the information may be used against them and result in their children being removed from their care. Women describe the system as being mobilized around risk and
not prevention (Greaves et al., 2002). Services are fragmented and it is difficult to find information about available services. A Manitoban study identified the period following a hospital stay as a period of transition requiring more supports than are currently available (Women and Mental Health Working Group, 1996). Mothers also described feeling constantly threatened by the removal of services that they currently depend upon (Kellington, 2002).

Mothers with SMI also report that they are unable to access special services such as a registered psychologist or alternative therapy because only psychiatrists are covered under the Medical Services Plan of BC (Kellington, 2002). It also may be difficult to obtain the services of a psychiatrist in a timely manner (even during an acute crisis period) because of wait lists (Mental Health Action Research and Advocacy Association of Greater Vancouver, 2002). The cost of most psychotropic medications are covered if mothers receive extended medical benefits through the Ministry of Human Resources. However, those who rely on private pensions, Canada Pension Plan, or those who are employed, must pay for their own medications. The cost of many medications may be prohibitive, particularly as most mothers with SMI live in circumstances of economic hardship (Mental Health Action Research and Advocacy Association of Greater Vancouver, 2002).

Summary

As more and more women with serious mental illness are living in the community and becoming mothers, questions regarding how to best support mothers and their families arise. Past research has demonstrated the significance of parenting for women with SMI and has identified a range of factors and characteristics associated with mothers
with SMI. Research from a health care perspective on mothers with serious mental illness has extensively examined family planning issues and the perinatal period, but has not examined long-term parenting issues for women with serious mental illness.

Although researchers have begun to examine women’s experiences of mothering with a mental illness, little is known about the interactions between women’s experiences and broader determinants of health. In particular, there are at least two important processes that merit further exploration. First, based on the experiences of mothers with SMI, what is the impact of mothering on the well-being of women with serious mental illness? And, secondly, what are the processes through which broader, structural factors influence women’s experiences of mothering and mental illness?
Chapter Three – Methodology

Overview of the Chapter

This study examined the experiences of mothers with serious mental illness. Chapter Three is divided into three sections and describes the methodology selected for this study. In the first section, an overview of the grounded theory approach and characteristics of the methodology used in this study is provided. The methods used in the collection and analysis of data are described in Section Two. This section provides a description of procedures used for recruitment and sampling, as well as the systematic techniques and procedures used in the collection and analysis of data. Issues of rigor and ethical considerations are discussed in the third section.

I. Overview

Rationale for a Qualitative Approach

Researchers have yet to comprehensively examine the factors that shape the experiences of mothers with mental illness. Quantitative research in this area has been critiqued for its methodological shortcomings and limited generalizability. Qualitative studies have provided some insight into the meaning associated with parenting, but have been primarily descriptive in nature. While previous research has identified what issues are of concern for mothers with mental illness, these studies have not moved beyond description to explain or understand how such factors shape women’s experiences. Researchers also have not adequately conceptualized how contextualizing features of women’s lives (e.g., poverty, single parenthood) and structural factors (e.g., policies, societal attitudes, health care delivery) intersect with mental illness to affect their experiences of mothering.
In order to more fully understand the experiences of mothers with mental illness, a research design was needed that was able to describe the range of experiences that mothers with mental illness face as well as attended "to a variety of contextual variables, including women's perceptions, attributions of meaning, relationships, caring responsibilities and preferences for interaction in the health care field" (Crooks, 2001: 14). Qualitative methods can help enhance the researcher's understanding of the context of events as well as the events themselves. An analysis of the context of women's lives, including a description of factors at the family, service, policy, and societal levels that mothers perceive as influencing their experiences, helps to move inquiry beyond description and towards more explanatory and conceptual levels.

In addition, qualitative methods can be used to construct or develop theories or conceptual frameworks and to generate hypotheses for future research. Although intended to be exploratory rather than explanatory, this study aimed to further our theoretical understanding of the intersections between mothering and mental illness. In addition to identifying the factors that influence the experiences of mothers with mental illness, the current study sought to develop hypotheses and an emergent theory regarding the ways in which these factors shape and determine outcomes for women, their children and broader families. A theory that leads to a more complete and complex understanding of women's experiences, in addition to providing a conceptual framework for future research and practice, can provide a basis for decision-making at both a clinical and at a program and policy level.

The development of a theory, which seeks to describe and explain the experiences of a group of people, should be informed by the perspectives and experiences of those
people. In the recent past, mental health research has been dominated by a biomedical model and an emphasis on determining the genetic and biological causes of mental illness. Consequently, the voices of mental health consumers and the experiences of individuals with serious mental illness were neglected. With the growth of the consumer movement and of the issuing critical examinations of clinical psychiatry, greater attention is now being paid to the voices of mental health consumers. However, many studies still provide individuals with mental illness with limited space to describe their experiences and needs. As well, few studies on mothering and mental illness have taken women’s stories as their starting point. Qualitative methods have often been used to give voice to those that are otherwise rarely heard. The methodology selected for this study provided an opportunity for women to speak in their own voice without conforming to categories and terms imposed on them by others. In addition, the particular approach adopted in the current study also provided a means of developing a theory that describes the range of factors that influenced women’s experiences and attempts to account for the similarities and differences in their experiences and outcomes.

**A Grounded Theory Approach**

The current study used a grounded theory approach. The grounded theory method was initially developed by Glaser and Strauss in 1967. In addition to the two major approaches/schools to grounded theory described by Glaser and Strauss and subsequently by Strauss and Corbin, other scholars have extended the use of grounded theory to additional applications and incorporated theoretical perspectives from other fields. The grounded theory approach used in this study draws upon the methods of analysis delineated by Strauss and Corbin and adopts a constructivist/feminist approach.
Characteristics of the Methodology

*GT is rooted in symbolic interactionism and a post-positivist tradition*

Grounded theory (GT) has its epistemological and ontological roots in symbolic interactionism. Symbolic interactionism (SI), a theoretical school in sociological social psychology, stresses the symbolic nature of human interaction, linguistic and gestural communication. SI focuses on the meanings that people attribute to events through experience or interaction. The social world is interpreted or experienced, multiple realities exist and knowledge is co-created. SI emphasizes human interaction between the psychological and sociological levels and that these interactions are dynamic and processual, not static. “Grounded theory is a method of uncovering the basic social and structural processes of a situation at both the symbolic and interactional levels” (Wuest, 1995: 127).

*GT develops theory that is firmly grounded in lived experience*

Grounded theory aims to further understanding by describing underlying social and psychological processes. It attempts to account for social psychological influences as well as individual issues of meaning and experience. GT is concerned with experiences of everyday life and “allows for the voices of participants to be heard as they tell their stories” (Keddy, Sims, & Stern, 1996: 450). It recognizes that participants are experts about their experiences and that subjective experience is a valid source of data. “Basic tenets of symbolic interactionism reflects an ingrained respect for persons’ subjective interpretation of social experience as a source of knowledge...” (Wuest, 1995: 128). The purpose of the grounded theory method is to create a theory that resonates with people’s lived concerns, fears, and aspirations and to develop a theoretical account of general
features of a topic while simultaneously grounding the account in empirical observations or data. Wuest states: “Theory that is so heavily grounded in the personal or practice experience cannot be dichotomous with it.” (1995: 128)

Theoretical sensitivity and the use of the constant comparative method

The principle of theoretical sensitivity and the constant comparative method are two distinctive features of grounded theory. During the collection and analysis of data, GT uses the principle of theoretical sensitivity. Strauss and Corbin describe sensitivity as “the ability to respond to the subtle nuances of, and cues to, meanings in the data” (1998: 35). Hall and Callery (2001: 263) state: “Theoretical sensitivity reflects the investigator’s ability to use personal and professional experiences and the literature to see the research situation and data in new ways”. Theoretical sensitivity provides techniques to question and challenge assumptions and biases and to “break through” to discover new concepts, categories and relationships.

The constant comparative method of collecting and analyzing data involves the use of various analytic tools to move back and forth between the data and the emerging categories to discover and determine the presence, variation, and absence of patterns. By constantly comparing abstract ideas that emerge during data analysis with the raw data, the findings remain closely grounded with the experiences of study participants as expressed in their own words. The constant comparative approach provides a way to systematically code and organize data into a conceptual model that incorporates a system of checks and balances to ensure that findings are not exclusively biased towards preconceived ideas, but are “grounded” in the raw data as provided by study participants.
Extending Grounded Theory: Incorporating a Constructivist/Feminist Perspective

Grounded theory, as originally described by Glaser and Strauss and later by Strauss and Corbin, is rooted in symbolic interactionism. Although symbolic interactionism is part of the post-positivist tradition, it has been argued that Glaser and Strauss, and later Strauss and Corbin, still adhere to certain positivist traditions (Charmaz, 1990, 2002). Traditional approaches to grounded theory have tended to emphasize control, prediction, and objectivity (Charmaz, 1990, 2002; Hall and Callery, 2001). Often, interview and participant observation data are considered reproductions of participants’ realities and reflect facts about a knowable world. As well, the researcher remains separate and distant from research participants and objectivity is believed to result in a more rigorous research product. For example, Strauss and Corbin discuss the constant interplay between the researcher and the research act and the fine balance that must be maintained between objectivity and sensitivity.

> Objectivity is necessary to arrive at an impartial and accurate interpretation of events. Sensitivity is required to perceive the subtle nuances and meanings in the data and to recognize the connections between concepts. (Strauss & Corbin, 1998:42-43)

By describing ways of reducing the intrusion of subjectivity into the analysis, Strauss and Corbin do not acknowledge the social construction of data. Rather than acknowledging that researchers define what is happening in the data, Strauss and Corbin assume researchers discover what is happening in the data (Charmaz, 2002).

Several authors have described how adopting a constructivist approach and acknowledging the social construction of data can make grounded theory more rigorous (Charmaz, 1990; Hall & Callery, 2001; Keddy et al., 1996; Wuest, 1995, 2002). In particular, feminist scholars have contributed to the development of a constructivist
approach to grounded theory by consistently challenging the positivist canon of objectivity and recognizing that subjective experience is valid data (Cook & Fonow, 1991). As well, they have challenged the traditional divide between the researcher and research subject and described how the knower is subjectively linked to what can be known. While Strauss and Corbin describe the product of a grounded theory study as a framework that can be used to predict or explain phenomena, a constructivist/feminist approach to grounded theory results in an explanatory model that describes how social experience is constructed and takes into account multiple realities within the social structure.

Beyond Theoretical Sensitivity: Reflexivity and Relationality

Hall and Callery (2001) examine the concept of theoretical sensitivity and examine the limitations of traditional approaches to grounded theory. "Theoretical sensitivity refers to the researcher's manipulation of the data to yield explanations that best reflect the reality that is being apprehended. It is not intended to critically examine the researcher's effect on data construction" (Hall and Callery, 2001: 263). Hall and Callery argue that extending our understanding of theoretical sensitivity and incorporating reflexivity and relationality into criteria of rigor can provide opportunities for developing a more rigorous grounded theory. As well, Lather (1991) describes the importance of examining the junctures between researcher and researched and data and theory to better understand how data are created within a study.

Hall and Stevens (1991, quoted in Wuest, 1995: 135) state: "It is the deliberate, thoughtful assessment of how researchers themselves participate in creating and interpreting research data that is the mark of adequate feminist inquiry." By increasing
self-reflexivity and developing an awareness of how researcher values permeate inquiry, theoretical sensitivity can be extended from an ability a researcher has to recognize and manipulate the data to an awareness of how the values of the researcher permeate the collection and analysis of the data. A constructivist/feminist approach acknowledges that researchers have a set of disciplinary assumptions and theoretical perspectives that they bring to the use of grounded theory methods. Wuest (1995) describes how a feminist perspective can have a sensitizing effect on the research process by providing a set of "sensitizing concepts." Wuest quotes Glaser (1978) as describing the "sensitizing nature of the researcher's previous education and practice "forms guidelines and reference points that the researcher uses to deductively formulate questions that may then elicit data that leads to inductive concepts being formulated later." Hence, a feminist perspective may influence what is observed or discussed during data collection and analysis. Charmaz (2002) describes: "If researchers make their sensitizing concepts more explicit, they can then examine whether and to what extent these concepts cloud or crystallize their interpretations of data."

A key contribution of feminist methodology is the recognition that research is embedded in existing gendered relations of power. A feminist perspective also may increase recognition of how relationships of power and trust affect the data being collected (relationality). Recognizing that data is generated from people in a relationship opens up opportunities for greater reciprocity and collaboration during the research process. Strategies for increasing relationality and reflexivity are described in more detail in the later section on rigor.
II. Research Procedures

Grounded theory is characterized by the simultaneous and ongoing collection, categorization and interpretation of data, purposeful sampling of study participants whom can illuminate the phenomenon under study, and the ongoing use of measures to ensure the rigor of the study.

Data Sources

This study was based upon the assumption that the experiences and perceptions of mothers with mental illness are necessary for understanding and identifying the factors at the family, service, policy and societal levels that influences their experiences. Data sources for this study consisted of interviews with mothers with mental health issues (n=6) and secondary analysis of interviews with mothers with mental health issues from the Mothering Under Duress Project (n=3). In order to be included in this study, women must have met the following criteria:

1. have been diagnosed with a serious mental illness (which included conditions such as schizophrenia, bipolar disorder, major depressive illnesses, substance abuse disorders, and personality disorders)
2. be over 18 years of age and residing in British Columbia
3. have had contact with the health care system within the past 5 years
4. were currently living in the community (i.e., women who were currently hospitalized were not eligible)
5. speak English.
Data Collection

Recruitment

Mothers who participated in this study were recruited through various organizations that provide support and treatment for women with mental health issues. I contacted individual service providers to develop a recruitment strategy appropriate for each agency. The service provider either provided information about the project through their networks or spoke individually with women who met the study eligibility criteria. Service providers were asked to distribute an information sheet on the study to interested study participants. Rather than directly approaching individual women, interested participants were asked to contact me regarding participation in the study. As the study progressed, women also were recruited through word of mouth.

Theoretical Sampling

This study used a form of purposeful sampling called theoretical sampling where study participants were selected on their ability to illuminate the phenomenon being studied and to further the development of the theory. Theoretical sampling is not like probability sampling where the objective is to obtain a sample representative of the population in order to maximize generalizability. Individuals are deliberately selected based on whether they have direct and personal knowledge of some event and the ability to communicate this information to others. Sandelowski (1995: 179) states that “the ‘logic and power’ of purposeful sampling lies primarily in the quality of information obtained per sampling unit as opposed to number.” In theoretical sampling, events, incidences, and experiences are being sampled rather than people per se. Sampling is
case-oriented and not variable-oriented so that it is possible to increase our understanding of the diversity of a particular case.

At the start of the study it was hypothesized that women with different diagnoses (e.g., affective versus psychotic disorders) and women from different socio-economic backgrounds would have considerably different experiences. As little is known about the range of mother’s experiences, effort was taken to include women with a diversity of experiences in terms of diagnosis, socio-economic backgrounds, custody status of children, and age (variational sampling). As the study progressed, sampling occurred on analytic grounds. In order to examine variation on a theoretical construct, participants were deliberately selected according to the theoretical needs of the study.

Interviews

I conducted unstructured, in-depth, face-to-face interviews with nine mothers with mental illness. The interviews provided women with the opportunity to share their experiences and to express their point of view. The interviews were conducted in a location and at a time that was convenient and safe for both the study participant and myself. The interviews were conducted either at the home of the participant or a small classroom at the university.

During the interviews, I asked participants to tell me about their experiences of being a mother and having a mental illness. The original interview guide was developed based on a review of the literature and in consultation with my thesis committee. At the end of the interview, participants were asked demographic questions. Following the interviews, I made notes regarding general impressions about the interview, including
content, body language, and setting. On average, each interview took one and a half hours to complete and produced 20 single-spaced pages of transcribed data.

In the interviews, most women began their story by talking about when they first experienced mental health problems. Women had holistic understandings of their health and described how social, economic, and biological factors influenced their mental health. Women described the general lack of understanding surrounding mental illness and the challenges of mothering. Most women did not differentiate between the health care system and the rest of “the system” (e.g., child welfare, income assistance, mental health). As the interviews progressed, I began to get a sense of which questions “resonated” with women and modified the interview guide accordingly. For example, I eliminated questions specific to interactions with health care providers and focused on interactions with service providers wherever their location. Subsequent questions were based on the information that women shared and became more specific as analysis progressed. As the interviews progressed, I shifted from an exclusive focus on services, supports, and the health care system to include discussions of their perceptions of the “system” and how stigma related to SMI intersected with mothering.

All of the interviews were audiotaped and subsequently transcribed. In order to ensure the confidentiality of the mothers participating in the study, all identifying information was removed from transcripts and study participants were assigned a pseudonym. Informed consent forms were stored in a locked filing cabinet and transcripts and file names do not include any personal identifiers. At the end of the project, audiotapes will be erased.
Characteristics of Study Participants

The women involved in the study ranged in age from 28-56. Three women had one child each. Two of the women had two children, two had three children, one woman had four children and one woman had one child and was eight months pregnant at the time of our interview. The age of the children ranged from 3-25 years. All of the women in this study had been coping with mental health issues for more than five years. At the time of the interview, five of the women were parenting alone and six were receiving income assistance. Three of the women had had one or more of their children apprehended and lost custody of their children for a period of time ranging from a couple of days to five years. One women lost custody of her eldest child and gave up her twins at birth to family members. Two women lost custody of their children following divorce. Three women had full custody of their children. Three women had been diagnosed with bipolar disorder, four women were coping with depression, one woman had been diagnosed with schizophrenia, and another with schizo-affective disorder.

Data Analysis

"Coding represents the operations by which data are broken down, conceptualized and put back together in new ways. It is the central process by which theories are built from data." (Strauss and Corbin, 1990: 57)

The analysis of interview data began after the initial two interviews were conducted. Analysis, theoretical sampling, and data collection was an iterative process. In this study, the collection of interviews and the analysis of data occurred concurrently. Over a period of three months, I interviewed six women about their experiences as mothers with mental health issues. Analysis of early interviews influenced later sampling decisions and the modification of the interview guide. In the later stages of analysis, I
Grounded theory uses both deduction and induction in data collection and analysis. It is inductive in that it moves from empirical incidents to theoretical concepts, and deductive in that it applies these concepts in the coding and sampling of data. Coding refers to "the process of identifying persistent words, phrases, themes or concepts within the data so that the underlying patterns can be identified and analyzed." (Morse & Field, 1995: 241) Coding is the process of assigning a conceptual label to an incident, event or happening. Strauss and Corbin describe three types of coding procedures: open, axial, and selective coding. The application of these three types of coding to the analysis of interview data in this study is described in detail below.

Open Coding

In open coding, the purpose is to "open up" the data by generating preliminary categories. In this study, I began open coding after the initial two interviews had been conducted. I read through each transcript several times in order to develop visual familiarity with the data. As I read the transcripts, I underlined key ideas, made notes in the margins, and highlighted rich quotes or "gems." As well, I identified "dross", or information not relevant to the study objectives, and excluded it from the coding process. I commenced line by line coding by assigning a code to each new idea represented in the raw data.

Line by line coding of the first two interviews resulted in an initial list of fifteen broad codes. I deliberately limited the number of preliminary codes to ensure the manageability and abstractness of the codes. For example, I placed incidents describing

returned to three of the interviews with mothers that I conducted during the Mothering Under Duress project. The use of this data for secondary analysis is described below.

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“feeling supported” and “recognizing the importance of support” under the broad code of “experiencing support.” Code names described process at both the micro and macro level, reflecting the dynamic and evolving nature of the concepts contained in the

Example of Open Coding

Sample of raw data from transcript

Well, it was the crucial decision in my life. Totally without a doubt. The crucial decision in my life. Was I going to go ahead with this pregnancy thereby affecting three lives? Or was I going to abort this fetus and continue along the lifestyle that I was sort of just vaguely maintaining? I was maintaining but once I had hit the wall and I knew I wasn’t 100%, ah, taking ownership of my illness. Now I see that. I was just vaguely aware of that at 30. Anyway, time marched on for two weeks, crucial hell. I thought you know I can’t bring myself to having this abortion because I can’t ding myself forever that I am not going to have a child. It was like I couldn’t say no to motherhood. And it had been presented to me medically that this could be a last chance. I made the decision to go ahead with the pregnancy. I went ahead and I was — the overriding feeling was terror actually. It wasn’t thrilled, it was terror. (Karen)

data. Glaser (1978) describes two processes contained in the data: the basic social psychological process (BSPP) and the basic social structural process (BSSP). Code names describing a BSPP generally ended in “—ing” (e.g., remaining well), while code
names describing a BSSP generally ended in "-ion" (e.g., *decontextualization*). This approach to coding helped to ensure that both psychological and social aspects of the data were included in the analysis.

**Axial Coding**

As coding proceeded, I modified or grouped the initial fifteen codes to form broader, more abstract codes. Axial coding (coding occurring around the axis of a category) refers to the procedures by which data are put back together in new ways after open coding, by making connections between categories. In axial coding, I grouped and classified open codes into broader categories by comparing codes for similarities and differences. For example, I grouped the open codes "Using available resources," "Looking for a 'good' health care provider," "Having expectations (of the system)," "Playing the system," "Accessing preventive services" under the broader category "Seeking/Pursuing help." In this way, the subsumed open codes became the properties and dimensions of more general conceptual categories. During this stage of axial coding, I used the qualitative data software program *Nvivo* to facilitate data management and category development.

I began writing about emergent categories during the initial stages of coding. Conceptual definitions for each of these preliminary categories included (a) summary of the meaning of the code, (b) theoretical hunches about the links between codes, and (c) best examples from the data (so-called "gem" quotes). These conceptual definitions formed the basis for decisions regarding future sampling and the modification of the interview guide.
Example of conceptual definition for preliminary category

"Being open"

This code describes the importance women place on openly talking about their mental illness—within their families, with their GP, with other parents and teachers. In family circumstances, mental health problems may not be discussed and children may not understand what is happening to their parent. This may be further complicated by certain mental illnesses, e.g., depression, where mothers will "cut out" their children and loved ones as they try to cope with their illness. Although women do not use the words "stigma" and "shame" (used extensively in the mental health literature) when describing the lack of openness about mental illness, they do talk about a lack of understanding from family members and other parents. Similarly, one woman describes a similar need for openness when discussing the challenges of parenting.

Example of a "gem" from raw data:

"...if I had been able to, say, bring my child or children at that time into some sort of therapeutic relationship with me, um, then I could have kept my avenues of communication open with them instead of cutting them out in my depression." (Karen)

Throughout analysis, I kept an ongoing record of theory development, decision-making about selective and theoretical sampling, shifts in interview questions, and ideas about the connections within the data. As I coded subsequent interviews, earlier categories were compared to new raw data and tested for "fit". Through constant comparison, the properties of categories and the relationships between categories were confirmed or modified. This ensured that the emerging framework was grounded in the data. The coding of new interviews and the process of writing about the developing categories continued in an iterative process.
Selective Coding and the Development of a Theoretical Framework

Selective coding is “the process of integrating and refining categories”(Strauss & Corbin, 1998: 143). Following axial coding, categories are grouped and connections between categories established. In thematic and content analysis, the analyst finds themes in the data but the connections between them are not usually developed in detail. In grounded theory, it is assumed that there is one central or a set of central social psychological or social structural processes occurring in a situation that accounts for all the data. “In a grounded theory analysis these linkages [between categories] would be clear. Through the process of attending to the data and looking for interactive components … connections can be made among the many themes, culminating in a multifaceted, compact, integrated theory, that rings true to the members of the study group.” (Keddy et al., 1996: 451)

As analysis proceeded, relationships between categories emerged and a conceptual model was developed. As I identified the central social processes describing the phenomenon under study, I also identified conditions in the data accounting for variation in women’s experiences. During selective coding, I used diagrams extensively to illustrate and capture analytic thoughts about relationships and patterns in the data. The drawing and re-drawing of schematic diagrams was a useful way to visualize the developing theoretical framework. The final framework consists of a set of concepts connected with arrows, which indicate the linkages and the direction of the relationship between concepts. The results of this study are explained in an emergent theory that describes both women’s individual experiences of mothering with a mental illness (the basic social psychological process of anchoring) and the response of the professional
system to mothers with mental illness (the basic social structural process of managing complexity).

Analysis of secondary data

Three interviews from the Mothering Under Duress project were used as an additional data source in this study. During selective coding, I used these interviews to further refine and expand categories and concepts as well as to “test” the emerging theoretical framework. Several scholars have described the advantages and limitations of using secondary data (Hinds, Vogel, & Clarke-Steppen, 1997; Szabo & Strang, 1997; Thorne, 1994). Three major concerns in the use of previously collected data are ethical considerations, the “goodness of fit” between the previous and new research question, and the secondary researcher’s degree of familiarity with the context in which the data was collected.

The purpose of the Mothering Under Duress project was to examine policy and media discourses surrounding mothering and mental illness. As part of this project, I conducted a series of interviews with mothers with mental illness. Women in this study were asked to tell their story and to describe their experiences of mothering with a mental illness. During the original interviews, women gave their permission to be re-contacted if opportunities to use their interviews in a future study arose. With the support of the B.C. Centre of Excellence for Women’s Health, where the original study was conducted, I re-contacted women and obtained their consent to include their interviews in a new study. During this re-contacting process, I also spoke with women about the findings of the Mothering Under Duress project and shared research reports and summaries with them.
Although each project used different methods of analysis, both the *Mothering Under Duress* project and my thesis research were interested in the experiences of mothers with mental illness. In both cases, in-depth and exploratory interviews were used to provide women with an opportunity to share their experiences and perspectives. As I conducted the original interviews, I was familiar with the original context in which the interviews were conducted and analysed. I also had access to the original audiotapes, interview transcripts, field notes, and interview summaries. As well, two of the researchers from the *Mothering Under Duress* project were members of my thesis committee.

III. Issues of Rigor and Ethical Considerations

Strategies for Ensuring Rigor

The evaluation of a quantitative study often entails the discussion of internal and external validity, reliability, and objectivity. As the purpose and design of qualitative studies are quite different than quantitative studies, several scholars have developed a variety of criteria or strategies for ensuring the rigor or “trustworthiness” of qualitative research. Many authors have proposed a range of creative and adaptable procedures designed to make the research process explicit (Devers, 1999; Marshall & Rossman, 1999). Commonly used strategies for rigor address the auditability, confirmability, credibility, and fittingness of a study (Morse & Field, 1995). As well, as discussed previously, an acknowledgement of issues of power and trust in the researcher-participant relationship and the social construction of data holds potential for increasing the rigor of a grounded theory study (Hall & Callery, 2001). In this section I list some of the
procedures undertaken in this study to ensure trustworthiness of the findings as well as a brief description of their role in ensuring rigor.

1. Developing an audit trail.

As the study progressed, I kept systematic and detailed documentation (both hard copies and computer files) of analytic procedures (i.e., decisions, choices, insights) to ensure an understanding of the logic of the research process and to increase the credibility of the findings.

2. Use of an open-ended interview style.

During this study, I used an open-ended interview style to provide participants with the time to reflect and provide detailed descriptions of their experiences in their own way. I also asked women if there were areas that I had overlooked, questions I had failed to ask, or if there was anything else they felt was important for me to know.

3. Member checking and validation of findings.

Member checking provides opportunities for participants to comment on whether they feel the research accurately reflects their experiences. Lather (1991) describes how this also may have the effect of contributing to a growing sense of collaboration. In this study, I interviewed one woman whom I had interviewed earlier to see how my findings "resonated" with her. I also interviewed two service providers who work with mothers with mental illness to solicit their views on the validity of my interpretation and findings. Two members of my thesis committee who were familiar with the content area and earlier interviews from the Mothering Under Duress project also were able to comment on the fittingness of the emergent theory with the existing data and literature.
4. Creating opportunities for reciprocity during the interview process.

Relationality refers to issues of power and trust between the researcher and researched. One component of relationality requires an acknowledgement that data are generated between two people in a relationship. Interviews are an interactive process requiring reciprocity on the part of the researcher. Lather (1991) states: “Reciprocity implies a give and take, a mutual negotiation of meaning and power.” Traditional approaches to interviewing instruct interviewers to avoid self-disclosure by deflecting personal questions and resist commenting in a way that might bias the direction of an interview. This type of interviewing practice is inherently hierarchical in nature and ignores how the researcher inevitably influences the nature of data collected (Oakley, 1993).

I attempted to create opportunities for reciprocity by being open to investing my own personal identity in the relationship. For example, before and after the interviews, I provided women with the opportunity to ask questions about the research project and answered any personal questions that may have arisen. Many women were interested in hearing about preliminary findings as well as the research process itself. When women were interested, I shared copies of their audiotapes and the interview transcripts with them. As well, following the interview, I sent each woman a note thanking them for their participation, described how to contact me if they had any questions or concerns and indicated that I would keep them informed on the progress of the study. At the time of the interview, I took field notes on how I felt women responded to me and how this may have influenced the course of the interview (e.g., my appearance, age, being childless, student status, education). However, it is important to acknowledge that it is impossible
to eliminate imbalances in the researcher-researched relationship: "[t]he final shift of power between the researcher and the respondent is balanced in favor of the researcher, for it is she who eventually walks away." (Cotterill, 1992, cited in Wuest 1995: 131)

5. Linking quotes to definitions.

As an emerging grounded theory justifies itself by providing a detailed and carefully crafted account of the area under investigation, I attempted to use in-depth description to demonstrate how the processes and interactions described are embedded in the data. By demonstrating how the findings emerged from the data, this increases the credibility of the findings.


I tried to avoid theoretical imposition during analysis by searching for disconfirming evidence. Rather than ignoring data that "didn't fit," I examined cases that did not fit the pattern to elicit variation and refine the emerging theoretical framework. For example, at one point during analysis, I realized that all the mothers I had spoken with who had lost custody of their children had not relinquished custody voluntarily. It became important to speak with at least one mother who had relinquished custody voluntarily to see whether this affected the development of the emerging theoretical framework. The strategy of searching for disconfirming evidence seeks to increase the fittingness and credibility of the findings.

7. Reflective journal keeping and peer debriefing.

These strategies were used to increase my own self-reflexivity. "Reflexivity means 'to reflect upon, to examine critically, and explore analytically the nature of the research process.'" (Fonow and Cook, 1991, quoted in Wuest 1995: 135) Through journal
writing, I kept a record of my experiences, feelings, and biases and how they might influence the work. Following interviews and at various stages in the writing process, I spoke to colleagues about my reactions to the interviews and the interview data. This type of self-reflexive activity created an awareness of how my values permeated inquiry and influenced what was critiqued or described.

Ethical Considerations

The principles of reflexivity and relationality guided the selection and development of the methodology and methods used in this study, particularly in the development of interview procedures. Relationality requires an attention to issues of power and trust while reflexivity contributes to the consideration of the effect of the research process on research participants and the researcher. As many of the women in this study were in marginalized or vulnerable positions, it was important to ensure that women’s participation in this study did not result in harm to themselves or their families. For example, women were identified as potential study participants in conjunction with a service provider. This procedure ensured that women were capable of giving informed consent and would be able to receive support following the interview, if necessary. As well, during the interviews, women were assured of the confidentiality of their interview data and were able to choose to not answer certain questions and discontinue with the interview. An application to conduct a secondary analysis of the data from the Mothering Under Duress Project (UBC Ethics Certificate #B01-0017) and additional interviews for this study was approved by the University of British Columbia Human Subject Committee on August 30, 2002 (Certificate of Approval #B02-0158). A copy of this
application, which further outlines the procedures used in this study, is included in the appendix.
Chapter Four – Findings

Overview of the Chapter

In Chapter Four, the experiences of mothers with mental illness and the factors at the family, service, and policy levels that shape and influence their experiences are examined. The first section provides an overview of the context of mothering with mental illness. In the second section, the individual-level process of anchoring and the system-level process of managing complexity are introduced. These two concurrent processes are used to describe the relationship between mothering and mental illness and the response of the professional system (comprised of, among others, health care, mental health, welfare, child protection, and family services) to women, their children, and broader families. In the third section, the process of anchoring is developed in greater depth. Using illustrations from women’s stories, this section describes women’s experiences of mothering with mental illness. In the fourth section, the process of managing complexity is used to examine the policies and practices that influence and come to bear on the experiences of mothers with mental illness. Building upon the experiences of women described in the previous section, this section explores how the professional system responds to mothers with mental illness. Lastly, in the fifth section, the interaction between these two processes is examined, as well as the ways in which policies and practices in the professional system influence outcomes for women, their children, and families.

I. Background to the Findings

Each of the nine women’s stories included in this study is unique and demonstrates the diversity of women’s experiences. The mothers in the study came from
different social locations, possessed a range of abilities to function, and came into contact with a number of different systems and sectors. Most women in this study had some degree of contact with the health care system or the mental health system as a result of their childrearing responsibilities and their own mental health concerns. As well, many mothers in this study had contact with the Ministry of Children and Family Development (including child and youth mental health, child protection, and foster care), the Ministry of Human Resources (income assistance through welfare or disability payments), and programs offered locally through health boards, family services, private services (e.g., counseling) and non-profit groups. In this study, the term "professional system" is used to refer to this assortment of public, private, local and provincial services, supports, and systems that women encountered.

The Organization of the Professional System

In Canada, the provision of mental health services is the responsibility of the provincial government. Physician services for mental health conditions (e.g., general practitioner or psychiatrist), psychiatric hospital services, and many community mental health services are publicly funded through the provincial Ministry of Health Services. Other supports and services for individuals with mental illness, such as housing and income assistance, are administered through other provincial ministries or municipalities.

Women in this study were able to access psychiatrists and other medical services through the publicly funded health care system. Women who met specific service criteria accessed additional mental health services (such as clubhouses, support groups, and weekly visits from an inter-professional mental health team) through regional community mental health programs. Services such as psychological counseling and alternative
therapy fell outside the public system and were available to women on a limited basis. However, many women were able to access counseling or support groups through community services or non-profit organizations. In B.C., administrative responsibilities for supports and services for mothers with mental illness often fall into a “void” between the Ministry of Children and Family Development (MCFD) and the Ministry of Health Services. Mothers in this study also came into contact with other sectors such as housing and the legal system, where the unique needs of mothers with SMI are often not acknowledged.

**Policy Changes Affecting Mothers with Mental Illness**

Women in this study had differing degrees of contact with the professional system over a wide range of time periods. However, many of the women I spoke with were directly affected by policy changes made by the provincial government over the past several years. In 1995, the B.C. government began a program to reduce social spending. While the professional system has traditionally emphasized treatment over prevention, reductions in social spending have significantly impaired the ability of professionals to provide any prevention services while simultaneously taxing their abilities to provide basic treatment services. As a result, many support and service agencies have developed stricter mandates that limit who is able to access publicly funded supports and services. In addition, since the Gove Inquiry in 1995, the child protection system has become increasingly child-centred with “the safety and well-being of the child” as “paramount concerns,” contributing to a system that tends to emphasize the surveillance of mothers over support for families (Greaves et al., 2002). More recently, in April 2002, the provincial government announced cutbacks and a reassessment process for people with
disabilities. These major changes have meant that thousands of people with disabilities, including mental illness, no longer qualify for provincial disability benefits (Brossard, 2003). These recent policy changes contributed to the context in which women in this study accessed and received services and supports.

II. Overview of the Emerging Theoretical Framework

In this study, mothers with mental illness described their experiences of mothering, their experiences with mental illness, and the relationship between mothering and mental illness. This study began with women’s stories as a starting place and led to the development of a theoretical framework that describes women’s experiences of mothering with a mental illness and how the professional system responds to mothers, their children, and their families. This emerging theoretical framework consists of two concurrent processes. The first process, called anchoring, describes women’s individual experiences of mothering with a mental illness. The second process, managing complexity, describes how the system responds to mothers with mental illness. The interaction between the individual and system-level processes provide an emerging conceptual framework (Figure 1) for understanding the family, service, and policy-level factors that influence and determine outcomes for women, their children and broader families. These two processes are influenced by and embedded in a socio-cultural context that will be discussed in greater detail in the next chapter (Chapter 5).

Individual Process: Anchoring

In their stories, mothers described the relationship between their mental health and their identity as a mother. The Canadian Oxford Dictionary defines an “anchor” as “a person or thing that gives stability or security.” The process of anchoring describes the
ways in which a woman’s identity as a mother influences her mental health. For example, Carrie explained how her mothering kept her “grounded”:

I think maybe [being a mother] has affected me but in a positive way. I don’t know, I feel like having a child -- and soon to be children -- keeps me grounded … It’s a good reason to continue to live and there is always — there is always somebody there for me to, that needs me. For example, being pregnant has kept me alive. I was seriously contemplating suicide and thinking about death seriously and then I thought — you know, no, I can’t [commit suicide]. (Carrie)

In the following sections, I use other examples from women’s stories to demonstrate the process of anchoring. Building stability and re-stabilizing are two components of the process of anchoring. Building stability describes how women strive to be the best possible mother within their individual circumstances and the strategies they use to create an environment in which they feel supported in their parenting and in managing their mental illness. Mothers strived to minimize the impact of their mental illness and other life circumstances on their lives and the lives of their children and family. However, many mothers experienced numerous challenges to building stability. Some of these challenges were related to their mental illness while others were related to life circumstances. Hospitalization, custody loss, and child apprehension were major events affecting women’s lives. If women felt supported during these events, they were successful in maintaining stability. However, for many women, these events served as disruptions to the process of building stability. Although not all the mothers in this study experienced a disruption due to mental illness, mothers who experienced one of these destabilizing events described how their lives and their relationships with their children were disrupted and the impact this had on their mental health. Mothers described how they subsequently experienced a process of re-stabilizing or coming to a new place of stability. Re-stabilizing refers to the process by which mothers re-develop or maintain
relationships with their children as well as cope with the impact of a disruption on their life, mental health, and the lives of their children and family. The concepts of building stability and re-stabilizing, the events that intervene between these processes, and the conditions that influence these two processes will be elaborated on in Section Two.

System Process: Managing Complexity

The process of managing complexity describes how the professional system attempts to meet the needs of mothers with mental illness and refers to the tendency of the professional system to separate multifaceted individuals into manageable components. Managing complexity is comprised of three sub-processes: simplifying, decontextualizing, and adapting. As mothers with mental illness have diverse needs and abilities and enter the system in numerous ways, service providers must assess women’s situations before providing support, treatment, or a combination of the two. Often, policies and mechanisms in the system simplify or decontextualize the complexities of women’s lives. Adapting refers to how individual service providers tailor system policies and practices to better meet the needs of individuals. The concept of managing complexity and its sub-processes are described in Section Four.

The Interaction between Individual and System Process

The two processes of anchoring and managing complexity interact and operate concurrently. When the system is successful in managing complexity, the system supports the processes of building stability and re-stabilizing. If the system in unable to manage the complexities it is confronted with, then the system may contribute to de-stabilizing events or hinder re-stabilizing. The ability of the system to successfully adapt to individual circumstances can result in better outcomes for women and their families.
The interaction between these two processes and how the professional system influences the experiences of mothers with mental illness is discussed in Section Five.
Figure 4.1: Emerging Theoretical Framework

System Process: Managing Complexity

Individual Process: Anchoring

Building Stability
- Contextualizing treatment decisions
- Finding appropriate support
- Preventing disruptions

Intervening Events
- Hospitalization
- Apprehension
- Custody Loss

Re-stabilizing
- Re-establishing relationships
- Remaining involved in parenting

- Simplifying
- Decontextualizing
- Adapting
III. Anchoring: Building Stability and Re-stabilizing

Anchoring describes the process in which a woman’s identity as a mother influences her mental health. Many women in this study described how their identity as a mother made them “stronger”, more “focused”, and provided an additional incentive to remain well (or even alive). Women often referred to the everyday acts of providing care for their children as something that helped them move beyond the self-described “darkness” that is often associated with severe depression and other types of mental illness, as the following quote illustrates:

... even when I was depressed and [thought I] couldn’t get out of bed, I could get out of bed for [my daughter]. Like, she was my bottom line. I could get out of bed and I could drive her to hockey at 5:00 in the morning. I could make sure she did her gymnastics or her tap dance or whatever. I could sit with the other mothers when I felt like I was in a fog, because I forced myself. (Karen)

Not all mothers in this study were able to care for their children. For example, some mothers were unable to obtain or regain full or partial custody of their children or chose not to have custody of their children. However, it remained important for all women in this study to develop or maintain relationships with their children. For some women, being a mother, regardless of their custody status, was described as the only stabilizing force in their lives. In their roles as mothers, women were presented with additional opportunities for personal growth and healing, became better connected to services and supports in the community, were able to engage in an important adult role and develop meaningful relationships, and were able to develop new skills for managing their mental illnesses. In the following section, women’s experiences of mothering with a mental illness are described using illustrations from women’s stories.
Building Stability

Becoming a mother and coping with mental illness were two major threads that were central in shaping women’s lives. All the mothers in this study described the ways they worked to remain well and to minimize the impact of their mental illness and other life circumstances on their lives and the lives of their children. Building stability describes the process in which women strive to develop a foundation in which to be the best mother possible within their individual circumstances. It describes the strategies that women use to create an environment in which they feel supported in their parenting and in managing their mental illness. Often, women did not differentiate between strategies for remaining well as an individual and remaining well as a mother-child dyad or family. For most women, their identity as a mother underlay their efforts to cope with or manage their mental illness.

As with other mothers, women with mental illness strive to provide a stable and healthy environment for themselves and their families. However, women with mental illness also must address additional issues related to their mental illness. The process of building stability for women in this study also meant balancing the challenges presented by mothering with the challenges presented by their mental illness. Women described how their role as a mother influenced treatment decision-making, how supports affected their ability to parent and manage their mental illness, and how they worked to prevent disruptions to their lives and the lives of their children and families.

Contextualizing treatment decisions

Women in this study described how their roles as mothers influenced their decisions regarding medication and how they valued treatment approaches that were
family-centred. *Contextualizing treatment decisions* describes how women consider their children when making decisions regarding treatment.

Most mothers indicated that they had stopped taking any medications while they were pregnant. Mothers reported few mental health difficulties during their pregnancy and several mothers felt their mental health was comparatively better throughout their pregnancies. For most women, the decision to stop taking medications was "cut-and-dry" and based on not wanting to risk possible harm to the fetus. Lara described "I wasn’t on anti-depressants during my pregnancy; I chose not to be. I didn’t want to take any chances on harming my child in any way. They don’t have conclusive studies for sure whether it’s safe or not, so I went off." In most cases, women who consulted their health care providers felt they received the information they required to make appropriate decisions regarding their treatment. However, Carrie who stopped taking antidepressants prior to trying to conceive described how several health care providers repeatedly offered her anti-depressants during her pregnancy. Eventually, her psychiatrist helped her to find an alternative to medication.

They are all quite happy for me to go on medication...[but] I have been very adamant about not wanting it [medication]. I asked the obstetrician for information [on the risks] so she looked and she found stuff for me on the internet and I asked the psychiatrist and he found some stuff for me. Actually the psychiatrist gave me an article saying to take fish oil, Omega 3 for depression. (Carrie)

Women described how their children influenced their decisions regarding medication. Sophie discussed how she continues to take medication that she would otherwise like to try to stop taking and has learned how to better manage her anxiety and other symptoms to help herself stay well and able to care for her son.
I want clonazepam when I get anxious and I tend to take excessive amounts, but I have had to learn, really learn, not to do that because it could ruin my chances to keep [my son]. (Sophie)

Carrie recognized that she might need to resume taking medication after her child is born and discussed how she would feel guilty for not being able to breastfeed.

But they will be keeping a sharp eye on me and basically if I do start suffering from post-partum depression or any, whatever, I mean I will go on medication and I will stop breast-feeding. And then of course I will deal with the guilt of that but better to be alive. (Carrie)

Several mothers described how their mothering responsibilities were not always considered a priority in treatment decision-making and that their health care providers tended to focus on specific treatment goals such as effectiveness of medication. Maya described how her medications make her tired and make it difficult to wake up in the morning.

... they just want to make sure that the meds are working. They never ask if it is affecting anything. I mean I keep telling her it is making me too tired. I find it hard to wake up in the morning with them and they are like “Try taking it at different times.” It’s all still we are trying to find out what’s working and what’s not working ... I am like this right and I am playing video games with my son and [he’s like] “Are you okay, mom?” and I am “uh huh, uh huh.” “I think your pills are working too much.” He knows and I know they are working too much, they are just overpowering. (Maya)

Women also discussed how services that were more family-centred would have been appreciated. Karen discussed how she would have valued an opportunity to bring her children into therapy with her.

If I had had help, if I had been able to, say, bring my child or children at that time into some sort of therapeutic relationship with me, then I could have kept my avenues of communication open with them instead of cutting them out in my depression. (Karen)
Finding appropriate support

Each of the mothers in this study described needing a combination of practical and emotional supports in order to remain well. *Finding appropriate support* refers to how mothers strive to develop a supportive environment in which they are able to manage their mental illness and care for their children.

As the supports available to women varied and women had different needs and circumstances, there were few supports that all women in this study shared or found helpful. Some mothers valued support groups for either single mothers or groups focused on specific illnesses (e.g., mood disorders). Other mothers appreciated one-on-one contact with counselors and service providers as it provided an opportunity for healthy contact with another adult or to address issues specific to their needs. Several mothers relied on their family or an extended support network for emotional and practical support or to provide them with time to meet their own needs. Mothers in the study who were single mothers described finding themselves dependent on the services in the public system because they did not have extended family support or the financial resources to find services outside the public system (e.g., counseling services, yoga and relaxation classes, alternative therapy).

Several mothers described the process of looking for support or assistance as "a constant search" and were unable to obtain the services they needed to keep themselves and their families well. Mothers described how the availability of support services varied from area to area. Often, available services were difficult to access, were limited with respect to their availability, or did not meet their specific needs (e.g., there may not have been a program in their area targeted at mothers with mental health issues). Women also
felt that the programs they would find helpful were not available, so they “made do” with what was available. Selena described difficulty in finding a program that would help her learn to deal with her problems and not “just take the pills” that she did not perceive to be helpful. Carrie commented on the inappropriately short duration of many programs as well as the guilt she experienced when she signed up for a program with limited space.

I phoned up looking for a support group on the North Shore. There is nothing for starters. But, they told me “Oh, in October, we are starting one up for six weeks.” I was like “Hurray, cured in six weeks!” Right. [laughter] Like a support group for six weeks. And you have to sign up. There are twenty spots available and you have to sign up because otherwise someone else will get the spot. In other words, I am taking someone else’s spot right. (Carrie)

Several mothers commented on the difficulties of finding long-term or emotional support. Lara described the need for an ongoing support system that she can access before she becomes desperate.

Unfortunately that was the only place, there’s nothing available for me here, except for on emergency basis through the mental health centre, which is not really what I need. I’m on a waiting list for therapy. The only kind of therapy I can get covered is psychiatric, and um, I’ve been on a waiting list for almost a year now...I mean, what I need is emotional support, that’s what I can’t seem to get a hold of. (Lara)

Several women also described how the process of looking for support was often exhausting, stressful, or disappointing. Although Sophie said she felt well supported, the fragmented nature of the system meant that she received support through several different community organizations and different areas of the public system. She described how managing her appointments and multiple service providers often created stress. She said, “[I] get very stressed when I have too many appointments with too many different people.” Women also described the importance of family members and friends who were willing and able to advocate for them when they were unwell.
Preventing disruptions

Women in this study described the importance of stability in their lives and their efforts to minimize the impact of their mental illness on their children. Women emphasized the importance of preventive services in averting crises and assisting them in maintaining a stable family environment. As well, they commented on how current changes in the system were perceived to adversely affect families by keeping them “one step away from crisis.” Preventing disruptions describes the strategies that women use to minimize the impact of their mental illness on their lives and to avoid disruptions such as hospitalization and apprehension from occurring.

Women identified preventive services (e.g., respite services, on-going counseling or professional support) as one of the most important resources in assisting them in preventing disruptions, especially major disruptions like hospitalization. Several mothers commented on the perceived availability of preventive services. Judith described the essential role that preventive services provided in helping her to avoid hospitalization. She also described how recent cutbacks to funding for preventive services have adversely affected mothers with mental illness.

... those [preventive] resources that were in place for us, for the most part are not readily available to people [anymore]... So people were providing us with preventative care in terms of preventing you from being hospitalized ...we were very, very lucky and the sad thing to me is, [we] shouldn’t rely on people’s luck and timing. You know, it should really be [different]. Those resources if they were essential for me then, they are probably essential for another mom who is out there now coming home with a new baby. (Judith)

Several mothers suggested that it was only possible to obtain services when a crisis occurred.

So the way it is, is that you pretty much need for everything to fall apart, or something drastic to happen, before you get the help. I mean we need to prevent
things to get to that place ... that’s where the focus needs to be right...I think instead of just having programs and help in place to deal with crisis situations, there needs to be preventative maintenance going on more. (Lara)

Women described how they experienced enormous stress as a result of no longer being able to depend upon finding support or assistance because of the widespread discontinuations of mental health and social services. Mothers felt that services were only available on an emergency basis and/or expressed frustration about the fact that many “non-emergency” services had wait lists. Those mothers that could access formal supports described feeling as if their need for the service was being constantly (re)-evaluated, so that cost-cutting measures could be made to remove the supports that were no longer perceived as absolutely necessary. Selena described, “It’s a constant thing where they put in home support and they take it out and they put it in.” Lara stated:

... it causes me constant stress, constant stress ... we fight constantly for the help that I need... I just don’t need it. I mean the whole idea of this is to take strain off of me [laughs]. The whole idea is to support me so I am better able to parent this child (Lara)

For mothers with limited social support and/or financial resources, the need for preventive resources was made more acute by the fact that they were not able to rely upon family members or friends or afford childcare if they became unwell. Single mothers in this study described being “constantly on guard” against the possibility that their mental health would deteriorate to a state where they would be separated from their children. Several mothers made “safety plans” by arranging for childcare in the event of hospitalization. Maya and her son discussed their “safety plan” and her son knew to call a friend who would take him in before Maya would seek professional intervention for her mental health problem. Maya explained:
If you don’t have a safe plan then the government steps in and they are supposed to be there to help your family but really all they do is rip it apart and it takes you years and years and years of healing and years and years of getting the trust back. (Maya)

Judith discussed the importance of stability and how not ever having to experience a disruption, such as hospitalization or apprehension, has affected her own well-being and that of her daughter:

I really still don’t think people realize, if a parent can stay out of the hospital for those preschool years it makes a huge difference to the child’s development and sense of well-being. My daughter is now 7 [years old] and I haven’t ever been hospitalized. We have had some rough spots but I have never been hospitalized; so, she hasn’t really experienced that level of trauma. (Judith)

She attributed the resources, such as respite care and weekly visits from the mental health team, as being key in preventing her from being hospitalized.

The strategies involved in the process of building stability resulted in a healthier environment for women and their families and demonstrates the connections between a women’s role as a mother and her mental health. The following section describes the events and contexts that may cause this relationship to be de-stabilized and the process of re-stabilizing and finding a new place of stability.

**Intervening Events**

Hospitalization, child apprehension, and custody loss were major events affecting women’s lives. Although many of these events were directly related to their mental health, numerous other facets of women’s lives influenced and contributed to their occurrence. In addition, many women described how, in many cases, the professional system had a role to play in preventing or precipitating events. Not all women in this study experienced one of these major events. As well, women’s experiences of these events varied greatly. Several mothers experienced hospitalizations related to their
mental illness that lasted from one week to several months. Two mothers lost custody of their children following divorce and one mother was unable to regain custody from her child’s father following hospitalization. Four mothers had their child or children apprehended for varying lengths of time ranging from a few days to several years.

In some circumstances, these events can assist some women in remaining well. When women were well-supported, events such as hospitalization could help women to build or maintain stability. For example, when Carrie was hospitalized for a week, it provided her with the opportunity to be in a supported environment and to focus on her own care. During her hospitalization, other family members cared for her daughter. Most women, however, experienced these events as disruptions with de-stabilizing effects. Judith, for example, did not have extended family support; therefore, hospitalization would require her to be separated from her daughter and her daughter to be placed in foster care. For Judith, maintaining stability was equivalent to preventing hospitalization.

Mothers who experienced a disruption to the process of building stability described how everyone (including themselves, their children and broader family) was de-stabilized. Women described how these disruptions affected their relationships with their children, precipitated other life events (e.g., changes in living situations, break-up of relationships), and had an impact on their mental health. The relationship between women’s identity as a mother and their mental health was evident when women described the impact of real or potential disruptions. For example, Karen discussed how she felt fortunate to have had the economic resources to afford childcare while she was hospitalized. When discussing the possibilities of permanent custody loss, she stated that she would not have survived the loss:
I'd be dead. There is no question. That is why— it is such a major concern-- that community services have to up the ante in terms of consumers who have children. Well, for one thing, it may save the consumer's life. It's part of child protection as far as I am concerned. (Karen)

Women described how losing contact with their children adversely affected their mental health. Nora described how the loss of her children was directly related to a suicide attempt following hospitalization and loss of custody.

I went to stay with my mum and dad when I got out of the hospital that time. I had a suicide attempt at Easter. I tried to commit suicide... because he had taken the kids to Vancouver... I just felt really left out, really sorry for myself and so I tried to kill myself. And then they really thought I was whacked, you know? (Nora)

Eventually, most mothers in the study also experienced a process of re-stabilizing. Karen described:

It takes two years to recover [from a hospitalization]. I mean for me anyway. It's not just the hospitalization; it's all the things that led up to the hospitalization and then post hospitalization integration, coming to terms where you had shattered your life and then you had to pick up the pieces. (Karen)

The following section describes the process of re-stabilizing following a disruption.

Re-stabilizing

Events such as hospitalization, apprehension, and custody loss were disruptions in women's lives that changed their relationships with their children, altered their life patterns, and affected their mental health. Following a disruption, women must cope with the trauma of separation for themselves and their children, re-establish relationships, overcome the loss of time that may have occurred, and address the challenges presented by their mental illness. The process of re-stabilizing refers to how mothers re-develop or maintain relationships with their children as well as cope with the impact of a disruption on their life, mental health, and the lives of their children and family. It also refers to how
women come to terms with a change in their identity as a mother. Nora described learning to cope with losing the full custody of her children.

I tried coming back [to work]. I came back for half days for a while. And I just couldn’t manage, because it really took me a long time to get over not having my children there with me. Like tucking them in every night, do[ing] all that stuff. Like it took me about a year to get over, to get used to that...It’s really hard to lose your children, not that I’ve lost them but the full-timeness of it. (Nora)

Although the period of time it takes to re-stabilize after a disruption varied, life patterns and relationships did not usually return to their “pre-disruption” state. In the following section, women’s experiences with re-establishing relationships and their efforts to remain involved in parenting are described.

Re-establishing relationships

Disruptions affect relationships within the family and with service providers. Following a disruption, mothers must re-establish relationships with their children, family, and other child caregivers. Mothers described having to “undo” many things when their children were returned to them or when they returned home from the hospital. Maya described the abuse her son experienced while in foster care and the difficulties of re-establishing a relationship with her son:

It disrupts my life and puts distance between us. And like I said he has only been home since September ... I am still expecting my five year old to walk in that door but he is nine [now] and, I don’t know, it’s weird. (Maya)

Even when mothers chose or approved of their children’s alternate caregivers during their absences, re-establishing relationships with their children and within the family was difficult after a separation. Nora described “sort of gradually re-establishing a different routine with them.” Maya had recently obtained full custody of her son but was working to obtain joint custody of her daughter:
I have to go through the courts all over again now just to see her. But my hopes for my daughter is that we can have, I would be happy with even one weekend a month so that her and [my son] can sit and play and fight and do what brothers and sisters do. You know, um, he misses her … (Maya)

Sophie’s son was apprehended when her family doctor called social services and said that he was concerned about Sophie. Sophie described her current relationship with her family doctor as not being “too much different” than before her son was apprehended but said:

I certainly wouldn’t confide in him [my doctor] as much now as before. Just not worth the risk… I am usually—I am just very cautious of who I get help from, very cautious. And it doesn’t take me two times to get comfortable with the person. It takes me a long time to actually trust the person and really get into things but I don’t just off the bat tell my whole life story. (Sophie)

The process of re-stabilization can have short- and long-term effects on both mothers and children. The mothers talked about the different ways they try to help their children understand and re-stabilize after these disruptions. Sophie discussed how her 16-month son was breastfed up until five minutes before he was apprehended by social services. At the time of our interview (two years later after her son’s return to her care), she reported that her son continued to need significant amounts of reassurance and security, particularly when going to sleep because, as she explained: “he is still scared that he is going to be left or taken away or something.” Karen described the “mystery” that surrounded her hospitalizations while her children were growing up and how she and her husband had avoided discussing her hospitalizations with her children. Now that her children are grown, she was trying to be more forthright and open about her illness to help her children make sense of her absences.
Remaining involved in parenting

The women in this study described the strategies they used to remain involved in parenting, regardless of whether they regained full custody, had joint or no custody at all. Following her divorce, Karen lost custody of her son when he was eleven years old. She discussed the importance of finding housing where she could bring her child for occasional visits. Seven years after losing custody of her son, she discussed how she speaks with her son every night by telephone and how they have developed a close relationship over the years (despite geographical distance). When Sophie’s son was apprehended, she was able to maintain contact with him and his foster parents until her mother was able to take custody of him.

Actually in order to get hold of the caregiver that had my son I had to phone [social services] after hours and they phoned her and she [the caregiver] phoned where I was. But when I first talked to [the caregiver], we agreed that she would phone in the morning each day throughout that weekend and she would phone in the morning, at lunch, dinner and at bedtime just to let me know how he was doing and she did. So it worked out. (Sophie)

However, Sophie described how she learned at a later date that she could have requested supervised visits with her son during his time in foster care, but the option was never suggested to her. Sophie stated that it was very important that her mother had custody of her son until she was able to regain custody. Because her son was in the custody of her mother, Sophie felt she was better able to visit and remain involved in parenting.

Although many of the women reported receiving little support to deal with the challenges of being separated from their children, Sophie recalls how her mental health worker supported her through the process and helped her get into a supported environment, which also meant that she did not have to remain at home surrounded by her son’s belongings.
Grace described a positive experience where she was provided with many options on how she could remain involved in the lives of her twins. After their birth, she was able to visit her twins in foster care for the first six months and she described how this helped her accept that she was not going to be able to care for them:

So, I had a Caesarean and I had the babies. Of course, the welfare came up the first day and said “Well, Grace, you’re not keeping the babies, right? Don’t think that you can keep them.” Cause they knew that I would want to keep them. But they know that I can’t keep them because I’m a dope addict right, I’m hooked on drugs. And so I said “well, are you going to take them away?” “Well, we’re going to take them away but we’re not gonna take them away right away. We’re going to let you spend time with them, go visit them for an hour every week for as long as they’re in the foster home you can do that. And you can help pick who’s going to adopt them right.” And so I thought, well, I felt good about that. You know, because they weren’t just born to me and then just taken out of my arms. I got to be with them right. And I got to see them and I got to go in the nursery and I got to change their diaper. I got to hold them. So, it meant a lot to me, right. (Grace)

At the time of the interview, the twins were 1½ years old and being raised by Grace’s stepmother. Grace emphasized how important it is for her to speak with her children, receive photos, and be provided with updates on how they are doing, even though she remains unable to take custody of her children.

Maya described how all her attempts to maintain contact with her son while in foster care were thwarted and her role as a mother was not valued:

And all the toys that I bought him over the last 5 years, I have spent over $1,000 on toys, none of them came home. They all got thrown in the garbage as soon as he got them from me. And that hurts. (Maya)

Later, when she had supervised visits, she expressed her frustration at the inflexibility and scrutiny within the process.

I was so pissed off that it was supervised visits. Because he wasn’t taken away because I was a bad mom. [He was taken away] just because I have a mental illness. They supervised me. I had an hour visit once a week with somebody with their notepad writing down everything that I say to him, everything he says to me and everything we do together and hands it into the social worker. And it’s like,
walk on eggshells or what. You are scared to blow your nose because you know they are going to write that down too. They closed the meetings down because my dog had fleas and they stopped the meetings for about three weeks until I could prove to them that the dog didn’t have fleas anymore. (Maya)

She described her anger at how her supervised visits with her son were stopped because her dog had fleas. Later, during one of their visits, her son appeared with a black eye. When she learned from her son that he had been hit while in foster care, she challenged the social worker and he was moved to another foster home.

The process of re-stabilizing is a continuous process as women strive to make sense of their experiences and the effect of being a mother, regardless of custody status, on their lives. As well, a disruption may have long-term effects that are never completely erased:

So, it is still obviously [at] a place where it’s really hard. It’s really hard. I am already, I am 56 now. I am still dealing with it. I am 7 years divorced…He was 11 when I moved out and now he is 18. That is a whole lifecycle to me and I am still dealing with it. (Karen)

Conditions Influencing Building Stability and Re-stabilizing

Women’s experiences of mothering were influenced by numerous factors, many unrelated to their mental illness. These factors stemmed from individual circumstances and the greater socio-cultural context in which women found themselves parenting. Women identified conditions that they perceived as influencing their ability to build stability or re-stabilize. These conditions included social support, challenging life circumstances, and discrimination resulting from their mental health status.

Social support and isolation

Women described the importance of being able to rely on family or an extended support network when they were unwell and how this contributed to maintaining stability
or re-stabilizing. Carrie described being able to reach out for help and being able to count on other people. “In my sort of more normal moments I will reach out to friends and to my mom and ask for help and advice. And I can count on other people. Like I am not one of these people who will stand alone always and think I have to do it by myself and I can do it best. So I will ask.” When Carrie was unwell, she described how her mother or partner would advocate for her. Conversely, Nora described how she would have benefited from an advocate to support her in finding a job and navigating the legal system following her hospitalization and separation from her husband. Two mothers had developed a formal Ulysses agreement\(^2\) to use in the event of their hospitalization. However, an advanced planning process is not always feasible when women do not have a strong support network in place. Judith stated:

> Well I haven’t got a Ulysses agreement because there isn’t really anybody to provide long-term care for her [my daughter] if I was to go to the hospital. I do have some sort of rough plan of what I could do and some people that could sort of help on an emergency basis. The problem is that most of the people I am relying on are single mothers and their circumstances change. (Judith)

> Although mothering can assist women in making connections with other people, supports, and resources in the community, women also commented on the general lack of understanding that exists about mental illness and how this made it challenging to connect with other parents. Two of the mothers discussed how the lack of understanding about mental illness in society resulted in them feeling excluded from other parents, both in terms of activities that other parents do or being unable to form friendships or bonds

\(^2\) A Ulysses agreement is named after the Greek mythological hero who asked his crew to tie him to the mast of his ship so he could resist the call of the Sirens. A Ulysses Agreement, or advanced planning process, allows women to create an informal agreement with child welfare, community supports, and their own personal support network regarding the care of the children should they become unwell.
with other parents. Mothers felt uncomfortable disclosing their mental health status to other parents.

There are very few people you can safely tell that you have a mental health issue. I don't hardly ever say that I am bipolar. I mostly say that I am depressed because mostly people can kind of empathize with somebody being depressed – they've felt down – than they can with somebody ... people sort of extrapolate [being bipolar] with I'm schizophrenic .... So I don't talk to them about my anxiety disorder because again that is something people don’t understand very well. So it's kind of like, depression or something, people can understand. Having low energy, people can understand. But, you know, it is challenging because I – even something as simple as a child care exchange, I can't participate because I don't have the energy. (Judith)

Sophie said of her parenting groups, "I mean I feel out of place going to them. Because everyone else seems so normal." Because she did not feel comfortable confiding her mental health status, she felt unable to connect with the other mothers.

I am dealing with different issues and all these other people look so much more together in their life. ... I don’t talk to the other moms hardly because I feel out of place...they probably don’t have brain problems like I do ...I don't think they would understand and I don’t think they would know what to do with the information. (Sophie)

Judith describes how coping with exhaustion and lack of energy due to her depression prevented her from participating in certain activities with other parents.

I mean basically because you can't consistently participate in a whole bunch of activities that normal healthy parents can participate in, you become excluded right? (Judith)

Stress from challenging life circumstances

Women described how other circumstances in their lives created additional stress and challenges to managing their mental illness. Often, these circumstances precipitated or contributed to the occurrence of disruptions. Several mothers described how poverty and struggling to make ends meet adversely affected their ability to care for themselves by creating additional stress and providing fewer resources and less time to address their
own health needs. Women also described how certain life circumstances could be more
overwhelming than their mental illness. Grace described how issues arising from her
substance use outweighed her mental health concerns. Women described how unstable or
difficult relationships and the impact of past abuse as a child or from an earlier
relationship adversely affected their ability to cope with their mental illness. Several
women also reported how their interactions with the professional system often resulted in
additional stress rather than support.

Women described strategies for self-care and the importance of minimizing the
impact of other life circumstances on their mental health. Women reported seeking
additional support around issues such as past abuse. Judith described the importance of
respite care in providing her with a break and time to focus on her own well-being.
Sophie and Judith both valued having their children in day care during the day as it
provided them with a way of coping with their anxiety and exhaustion. In turn, they felt
better able to care for their children.

Discrimination

Several women described how having a psychiatric history presented challenges
to maintaining or regaining custody. Following apprehension or custody loss, mothers
described having to counter stereotypes about mothers who have a mental illness. Maya
and Sophie described having to prove themselves fit to parent in order to regain or
maintain custody of their children. For example, prior to the birth of Sophie’s son, her
son’s father reported her to the Ministry of Children and Families as being an “unfit
mother.” Sophie described how the Ministry had been involved in her life before her
son's birth and the long process of proving herself, "with a lot of hard work," as a good mother.

Maya described the attitudes she encountered from the courts, social workers, and foster care system. After her son was removed from her care when she was hospitalized, she fought to regain custody of her son.

I fought for five years to get my son back. The only reason that he was gone so long was because I have a mental illness. And they didn’t think that I was capable enough of living on my own and raising him. I had to live here almost a year by myself before they gave me custody. (Maya)

While her son was in foster care, she commented:

I wasn’t allowed to know their phone number or where they lived because I might kidnap him. You know, they think you have a mental illness, [so they think] she is just “right out there.”

Maya had been unable to obtain joint custody or visiting rights, supervised or otherwise, to see her daughter because her daughter’s father and his lawyer portrayed her as incapable of parenting. “He told my lawyer that I abandoned [my daughter] and that I am not allowed to be near her because he is scared that I am going to take her back.”

For Karen and Nora, their divorce resulted in a loss of custody. Both of them were concerned about their medical records being used in court to introduce the idea that they were mentally unfit to mother. When Karen and her husband divorced, her husband threatened to expose her psychiatric history.

...even though my lawyer said ‘This is bullshit, Karen, people listen now. They listen to the other side of the coin and you will not be ding-ed on the basis of your psychiatric history because you have been getting help. You have made every effort, da da, da, da.’ I still didn’t believe her. (Karen)
Similarly, Nora described how her husband began divorce proceedings while she was hospitalized and that she was discouraged by her lawyer to pursue a formal custody arrangement.

Yeah he started the divorce proceedings, so then I got a lawyer, and went to the lawyer and he said his lawyer [her husband’s] had said, if I had tried to get the children, they would bring up all my medical records, and so I just said “oh never mind then.” I was so intimidated that I didn’t do that. I thought I couldn’t handle the kids anyways, I thought I was absolutely useless. (Nora)

Three years later, she has managed to see her children on a part-time basis and although she would prefer the security of a formal custody arrangement, she says “I know I can’t fight him through the legal system because he’ll just make it look like I’m really a bad person, and then the kids will be involved… like I just think, you’ve got everything, you’ve got the kids, and what more can he take away from me, and I know if I try to fight him in court, I’ll end up getting sick again and I don’t want that.”

**IV. Managing Complexity: Simplifying, Decontextualizing, and Adapting**

In Section Three, women’s experiences of mothering and mental illness as well as some of their individual experiences with the system were described. In the next section, the ways the system responds to women and their children are further explored. Mothers in this study had varying degrees of contact with the professional system. Individuals come to the attention of the professional system in numerous ways and with diverse needs and circumstances. In particular, mothers with mental illness came into contact with a number of different areas of the system, had different experiences and social locations, possessed a range of abilities to function, and required different kinds and levels of support. The process of *managing complexity* refers to the tendency policies and practices in the system to reduce or separate multifaceted individuals into
manageable pieces or components that it can “handle” or make sense of. In Section Four, the components of the process managing complexity, simplifying, decontextualizing and adapting, are described.

Simplifying

Mothers with mental illness come into contact with the professional system in different ways. The diverse ways in which mothers with mental illness entered the system and their differing needs and abilities reflects the complexity that women present to the system. Simplifying refers to the ways that system practices and policies assess and make sense of women’s situations, “move” or refer women to services, supports and other parts of the system, and how the services that are available to women are determined. System level strategies for simplifying include labeling, generalizing (“lumping”), prioritizing, and opting for “simple” solutions.

Mothers in this study described how a label or diagnosis is required to access supports and services. For mothers with mental illness, a diagnosis can assist in providing understanding of her symptoms as well as facilitate the provision of helpful and effective treatment and/or support services. However, mothers in this study also described how being labeled with a mental illness diagnosis can have a stigmatizing effect. Selena had been coping with chronic depression for most of her life, but as she had never been “officially” diagnosed, she found it difficult to obtain services. While acknowledging the possible negative effects of having a diagnosis of mental illness, Selena described her uncertainty about whether having a diagnosis would help her get the services she needed. When asking her doctor to fill out a disability form, her doctor said: “I can’t fill this out for you because you don’t have a, say, a “title” for you…. He said it’s harder to get help
because you’re not labeled.” Judith described how her daughter was assigned a general label of “global adjustment disorder” so that she would be able to obtain support regarding her mother’s mental health. Judith stated:

She doesn’t really have an adjustment disorder. She is a normal, healthy, resilient, happy child... [Having a diagnosis] doesn’t necessarily mean the child really has any problems nor does it recognize that children that have mentally ill parents are going to need supports. (Judith)

In addition, several mothers commented on how the system tends to “lump” large groups of people together in one category and ignore individual differences. Rather than being used to identify families that are vulnerable or in need of additional support, many mothers suggested that the label of mental illness was used punitively. Women in this study reported that mothers with a mental illness were not seen to have differing abilities to function or requiring different levels of support depending on their personal and financial resources. Instead, mothers with a mental illness were “lumped” or treated as if they were all the same. Many study participants suggested that, because they had a mental illness, it was assumed that they would be inadequate mothers until they proved otherwise.

As described in the previous section, many women in this study characterized the child welfare system as being focused on protection, rather than support for mothers and their families. Several women commented on the current economic climate, a political emphasis on cost reductions, and how the system prioritized or provided resources only when an individual was very ill or when a crisis occurred. However, most study participants suggested that the provision of preventive services would save costs in the long term as it could prevent them from being hospitalized and/or their children being placed in foster care. The focus on protection also deterred women from asking for
needed support because they feared their children would be apprehended. Selena asked for help repeatedly from social services but was told that they were unable to help her unless she was physically abusing or harming her children. She said:

You have to have child protection “issues” to get that [support] approved. If you have child protection issues then you have to look at your children being removed. (Selena)

Although cutbacks to social spending meant many supports were short-term, mothers in this study also commented on how it seemed that certain “simpler” supports were more readily available or provided as options. Concrete and finite solutions, which they perceived to be less expensive, tended to be offered more readily. For example, medication was perceived to be advanced as a feasible and effective treatment, rather than costly, long-term psychotherapy; programs designed for individual stress management were emphasized while the structural causes of stress were ignored (e.g., poverty); and, programs for individuals requiring less intensive forms of support (e.g., self-help groups) were more easily accessed. When Selena was able to access 12 visits of counseling, she was told on her second visit that her problems were too complex and that 12 visits of counseling would do more harm than good. She was told that she was “a black hole,” meaning that she was hopeless. Because Selena’s problems were complicated and not readily resolved, the system did not have the resources or ability to address her needs. Instead of addressing the root of many issues, the system was perceived to have to “opted” for short-term and temporary solutions, rather than addressing the complex nature of current problems or preventing future problems from arising.
Decontextualizing

As the professional system is comprised of different sectors (e.g., health care, family services, mental health), individuals are often viewed through a particular lens. Decontextualizing occurs when only one aspect of an individual (e.g., mental health or parenting) is considered or when individuals are treated outside the context of their lives. Decontextualization can occur at a service level when individual service providers fail to appreciate women’s experiences and social location or pay attention to women’s mental health needs but ignore her physical health needs (or vice versa). Decontextualization also can occur at a structural level when mothers and children are viewed separately and when services are divided across the professional system (e.g., mental health, addictions, family services, housing).

Women in this study felt that the system was focused on the well-being of children and did not pay adequate attention to how a child’s well-being depended on the well-being of the parents. For example, Judith described the relationship between a healthy mother and healthy child:

I felt better about myself and I could provide better for my child [when I have those supports] and I think that that is what they don’t get. A mother who is cared for and energized and can feed her children and can basically take care of her home is going to be a better mother. (Judith)

Studies examining the child welfare system demonstrate how the system holds the child’s “best interests as paramount” and ignores the interconnections between children and their mothers and fathers (Greaves et al., 2002). Sophie said:

I always ask myself – why do they call it the Ministry of Children and Families? I always feel like all they care about is the child. They don’t care about the moms, the dads, they don’t care about the family. Why do they call it the Ministry of Children and Families? It doesn’t make sense. (Sophie)
While the Ministry of Children and Family Development is centred on the well-being of the child, women described how mental health services are often patient-centred and not attentive to the mother-child dyad. Karen emphasized how children cannot be taken out of the equation when developing treatment plans for a mother, as “kids are your body.” She argued that this was particularly important when children needed “guideposts” for understanding their parent’s illness or when children were involved in the system for other reasons.

The divide between mental and physical health in the health care system is another way in which women felt the system decontextualizes individuals. Women described the segregation of services and policies between physical and mental health and how this divide was supported by the knowledge and attitudes of health care providers. Mothers reported being treated for their mental health problems but having their physical health problems ignored or vice versa. Mothers attributed this inattention to both the knowledge and attitudes of individual service providers and to the divide between psychiatry and other specialties. For example, Judith described the lack of integration between psychiatry and maternity.

I mean my stay in the maternity ward was really— I wouldn’t say that they had any expertise in terms of dealing with mental health issues, even though they do have a psychiatric, you know, component to their hospital. So they really weren’t prepared to deal with [mental health issues]. (Judith)

Karen described how her “holistic” general practitioner ignores her mental health concerns.

I have a doctor now. I had heard he was very holistic and was into vitamin supplements and stuff ... This guy has got blinkers on. My last hospitalization was out in Peace Arch Hospital for mania and he still hasn’t-- he never asks me. I have to tell him. I have to ask him. (Karen)
As described in Section Three, mothers in this study felt that the system prioritized physical health concerns over mental health concerns. They described how it was more difficult to have their mental health concerns addressed although the system mobilized quickly when they had physical health concerns. Lara described how she received respite care after hurting her back but could not get respite care to assist her in managing her mental health and caring for her child.

*When I hurt my back, I was injured so I got major respite [care] and in-home help, and because I needed it. Because that was viable. I mean they don’t know, there’s very little understanding [about mental illness].* (Lara)

The lack of understanding regarding mental illness and the way the system differentially treated physical and mental health concerns resulted in study participants feeling that their mental health concerns were ignored or unconnected to their physical health.

The division of services in the system (e.g., family services, mental health, child protection, welfare, housing, addictions) often means that an individual is rarely treated as whole. As well, service providers may not pay sufficient attention to the circumstances and context of individuals. Women in this study described how service providers who were able to look beyond a label of mental illness were better able to provide appropriate support. They mentioned being appreciative of service providers who were parents or had made an effort to learn about parenting. Judith described how her doctor was sensitive to the challenges of parenting and coping with poverty.

*I had a really good family practice doctor who had small children and he was a wonderful source of support … he had a really good understanding of the impact of poverty on top of all those, basic parenting challenges. So he was very, very supportive the year or two that we had him.* (Judith)
Conversely, Carrie described calling Mental Health Services at a public health unit and being told that there was no service available to help her. Because the worker on the other end of the phone did not ask about her specific needs and circumstances, Carrie did not know there was a program specific to her needs (i.e., pregnant women with a diagnosis of mental illness).

Anyway so I went back—I had come home for the afternoon—and I went back to Magnolia House and I told them what had happened and she [nurse] phoned the same people and found out some other stuff. Like I found out there is an organization there, right there, for women, which is free, which is for pregnant women or women with children. I mean I didn’t say I was pregnant but still whatever, like she could have asked. Like what are your circumstances? (Carrie)

Individuals with complex problems or problems that spanned different parts of the system presented challenges to the system. As Karen indicated, in order to address mental health concerns, it is important to look at the whole individual “because it is never just one thing.”

And it was only then that I realized that she didn’t see me as a whole person...this therapist only zeroed in on one thing in my life and that was my bad marriage...you must regard that whole individual because it isn’t one facet of one’s life or two or even three. (Karen)

The process of decontextualizing means that the system has limited ability to address multiple problems simultaneously and has the tendency to narrow in on one problem that it is most able to understand and treat.

Adapting

Adapting occurs when system-level practices and policies are tailored to meet individual needs and circumstances. Individual service providers engage in adapting when they interpret system policies and practices to better meet the needs of particular groups or individuals. Adapting is most likely to occur when there are no clear
guidelines for treatment or practice, when resources are scarce, or not fully available. When service providers are able to successfully adapt system policies and practices individual circumstances, this results in better outcomes for women and their families.

While the process of adapting can provide women with the support and resources specific to their circumstances, this also resulted in wide variability in practice. As there still appears to be little understanding of mental illness by many service providers, in mental health and the general system, and different providers are constrained by various policies and practices, there was no system-wide approach to mothers with mental illness. Women’s stories demonstrated how there seems to be little consistency across practice. For example, across cases in this study, the steps leading up to an apprehension varied considerably as did the supports offered following apprehension, depending on the resources available. For example, Sophie was not provided with all the information she needed when her son was apprehended and was not able to have supervised visits in the days following apprehension. In other examples, some mothers had the opportunity to develop a Ulysses agreement, while those in other circumstances were not presented with this option. This resulted in the perception that the supports received by mothers depended as much on the abilities and inclination of service providers to offer help as it did on the needs of mothers.

Several mothers commented on how they worked with their service providers to “adapt” solutions to their unique circumstances. Many mothers described the challenges in determining what treatment or medication regimen worked best for them. In the mental health field, there is a lack of standardization in diagnosis and treatment, partly because there are many unknowns. Many mothers in this study described the challenges
of identifying their mental illness and working with their service provider to find an
effective medication that did not result in unbearable side effects. Judith described how
she and her doctor were attempting to find medication and develop strategies so that she
could better manage her anxiety.

The doctors and I don’t know what the neurochemistry of it is, so we’re just
throwing something at it to basically counteract things in the neurochemistry. But
it’s, because we don’t really understand what is making me so anxious, what is
making me hyper alert, we can’t really even give me a medication that, you know, works really well. (Judith)

Women described how they found “pockets of understanding” where service
providers were knowledgeable about the many facets and forms of mental illness. Judith
recalled speaking with a social worker shortly after the birth of her daughter. The social
worker believed that a parent with a mental illness could be a good parent.

And she [the social worker] gave me the foresight and gave me that belief that
having a mental illness didn’t mean that I couldn’t be a good parent and it was the
same as other disabilities like being a quadriplegic or being a parent having MS,
or being a parent with diabetes, or being a parent, you know, [with mental illness]
wouldn’t prevent you from being a good parent. (Judith)

The ability of service providers to tailor practices and develop individualized strategies
for each mother was limited by the knowledge of individual service providers, rigidity in
system policies and practices, and the amount of time service providers had available to
tailor their practice for individual women. Mothers described how supports and services
varied from one area to the next and the process of finding supports was complicated by
system fragmentation, service disorganization, and the temporary nature of many
supports. Maya described how the attitudes of her mental health workers varied across
geographic locations. In one location, she was told that she would not be able to regain
custody of her children, while her service providers in a neighboring municipality believed that she was fully able to parent and advocated for the return of her son.

...my mental health worker, Anne, has been there 100% since I moved to [municipality]. When I lived in [a neighboring municipality], nobody. Nobody helped me. Everybody was against me. Even my mental health workers were against me. They were like you are a mental health patient, you are not going to get your son back. And they believed it. (Maya)

Service providers who had a comprehensive understanding of supports available in each community were able to refer mothers to appropriate services, prevent mothers from doing unnecessary legwork, and advocate for mothers when in a crisis situation. However, mothers in this study also commented on how service providers’ abilities to advocate for women were limited by constraints in the system. For example, physicians no longer had the discretion to decide whether an individual required a nutritional supplement.

They’re limiting what doctors can do now. For instance, we may lose our dietary allowance. A long time ago it was at the doctor’s discretion to write a letter to increase your dietary allowance. So, now the Ministry of Human Resources has decided. It’s not up to doctors to decide. (Judith)

Through adapting, individual service providers were better able to meet the needs of mothers with mental illness and this contributed to better outcomes for women and their families. However, while the “pockets of understanding” that women encountered were appreciated and were seen as an example of promising practices, adapting also meant that the system was perceived to be inconsistent and unpredictable. Although women spoke favorably of individual service providers, they also commented on the lack of a coordinated system-wide approach.
V. The Interaction between the Professional System and Mother’s Experiences

As described in Section Three, women’s identities as mothers underlay their efforts to create an environment in which they felt supported in managing their mental illness and in their identity as mothers. Although women drew upon their own personal, social and financial resources, they also interacted with and, in many cases, relied upon the professional system to assist them in building stability and re-stabilizing. When mothers felt they received the support they needed, both physical and emotional, most mothers in this study reported feeling able to provide their children with a healthy and supportive environment or being able to successfully maintain relationships with their children. In this section, some of the ways the professional system influences outcomes for women and their families. Figure 2 illustrates how the policies and practices in the professional system are able to support or hinder building stability, prevent or precipitate disruptions, and support or hinder re-stabilizing.

Figure 4.2: Influence of the Professional System on Building Stability and Re-stabilizing
Women felt that practices and policies in the system tended to decontextualize individuals and resulted in mothers being viewed as separate entities from their children. The influence of a woman’s identity as a mother on her mental health was often ignored. When mothers felt that their children were supported or being well cared for, women also felt supported. By supporting mothers in their parenting and by taking into account their parenting role during treatment, service providers also helped mothers manage their mental health.

Many women described how the process of finding appropriate support through the professional system also created additional stress. Women described requiring a variety of supports such as respite care and on-going emotional support in order to remain well. Many women described how supports prevented a crisis or disruption from occurring. Women felt that the removal of preventive services as a cost-cutting measure and the availability of supports only in times of crisis created unwarranted stress and had an impact on the well-being of the family. As supports were only available in times of duress, this created a cycle in which women would access certain supports, have the supports removed and then things would gradually build up into a crisis until women were again in a position to access support. In addition, the focus on protection, not support or prevention, deterred women from asking for needed support when a crisis occurred because they feared their children would be apprehended.

Many women described the process of looking for support as stressful and exhausting. Lara said, “If I didn’t absolutely, absolutely require this support, I would have nothing to do with it [the system], it’s that stressful.” Several women described how helpful it was to have an advocate or service provider who was familiar with available
supports to assist them in accessing supports. As well, the fragmentation in the system meant that many women had to juggle multiple appointments and numerous workers. The stress created by finding support resulted in less personal resources being available to women to remain well and cope with life circumstances.

Although numerous circumstances can lead to a disruption, in some cases, policies and practices in the system can precipitate a disruption by needlessly apprehending a child. Regardless of the cause, the professional system is able to support or hinder the process of re-stabilizing following a disruption. Women who received emotional support or who were provided with the opportunity to make decisions regarding their children's care following apprehension were better able to re-stabilize following a disruption. As well, the system was able to assist some women in developing strategies, such as accessing preventive supports or developing an advanced planning procedure, to prevent future disruptions. Other women who were unable to access information regarding their children following apprehension or who were discouraged from formal custody arrangements following divorce and custody loss because of their psychiatric history experienced greater challenges to re-stabilizing.

Adapting, or the ability of individual service providers to tailor system practices and policies to meet individual needs and circumstances, often led to better outcomes for women and their families. Women reported how they found support and understanding from service providers who realized that mothers with mental illness were not all the same. While adapting meant that some women were able to find "pockets of understanding," others were confused by seemingly illogical and inconsistent policies and procedures. After requesting support, one of Selena's four children was placed in
voluntary foster care and Selena was given a psychiatric evaluation. Prior to the evaluation, she took her son home and questioned the rationale behind the foster care placement:

What was that evaluation for? Was that just to take my kids away? Were you trying to prove that I was a terrible person or something? Well, I said, that if I'm not good enough to be a parent to one, then take all four of them. Don't leave me with three, if there's something so seriously so wrong with me. (Selena)

Often, women perceived the system to be acting punitively and creating further destabilization rather than supporting them in a way that was viewed as helpful. Selena stated: “I think if they listened to the people and didn’t think that they were all the same that would be a big thing.”

Summary

Many studies have attempted to describe how a woman’s mental health may influence her ability to mother. Other studies have described how mothering is often a stressful experience for women with mental illness and may have negative consequences (e.g., Mowbray et al., 1995). However, many women in this study, while acknowledging the challenges of mothering, also described how being a mother has had a stabilizing effect on their mental illness.

In this study, anchoring refers to the process in which a women’s identity as a mother influences her mental health. Regardless of their actual involvement in the act of mothering, women perceived being a mother as strongly influencing their mental well-being. In addition to being anchored by their identity as mothers, women were also anchored by the support they received in their parenting or that resulted from their roles as mothers.
The process of managing complexity describes how the professional system responds to mothers with mental illness. It refers to the tendency of the system to reduce or separate multifaceted individuals into manageable pieces or components that it can “handle” or make sense of. Managing complexity encompasses the mechanisms, policies, and structures that influence the ability of the system to address the needs of mothers with mental illness. While simplifying and decontextualizing reflect the way the system attempts to universalize its practices and policies, adapting is the means by which service providers interpret and apply the tenets of the system to meet the needs of individuals.

In this chapter, women’s stories highlight the diversity of experiences, abilities, strengths, and needs of mothers with mental illness. And, although this diversity can present complexity and challenge the ability of the professional system to respond to mothers with mental illness, the capacity of the professional system to adapt to individual circumstances and to support women in their identities as mothers can contribute to the creation of stability for women, their children, and families.

I mean there’s such a variety of mental illness, like, let’s face it. But say for someone like me, with severe reoccurring depression, if I can have what I need to, support-wise, then I can be okay. And I can, you know, I mean I’m not living it up or anything, but I can function well enough to give my daughter a safe loving home environment, and the things she needs and that’s well, that’s the most important thing in my life to me, is my daughter’s well being. But I’m not superhuman, I can’t do it all myself without help. I mean it’s like if I had diabetes or something and I couldn’t get any insulin, so then how would I be able to take care of her right? (Lara)
Chapter Five – Discussion

Overview of the Chapter

Chapter Five consists of four sections. In the first section, I explore the socio-cultural context of women’s experiences of mothering with a mental illness by drawing upon literature examining the ideology of motherhood and societal attitudes toward mental illness. In the second section, I return to the concept of complexity and how women’s diverse experiences and abilities present challenges for the professional system in addressing their needs. In this section, I make suggestions regarding how the health care system can better respond to mothers with mental illness. In the third section, I discuss some of the conceptual and practical challenges for meeting the needs of mothers with mental illness at a macro-level. In the last section, I describe some of the limitations of this study and possibilities for further research.

I. Intensive Mothering, the Panopticon, and the Scrutiny of Mothers with Mental Illness

Socio-cultural Context of Mothering and Mental Illness

While all mothers have concerns about whether they are adequate parents, mothers with mental health issues often feel that they face unique challenges based on “invisible things.” Socio-cultural values regarding mothering and popular notions of mental illness combine to create assumptions and stereotypes about mothers with mental illness. Values about mothers with mental illness, embedded at the family, service, policy, and societal levels, formed the context in which women in this study lived as mothers. In this section, I draw upon the literature examining socio-cultural attitudes and understandings of mental illness and mothering as well as the experiences of women in this study. In addition, the Foucauldian use of the metaphor of the panopticon is
suggested as a metaphor for understanding how the broader socio-cultural context may influence women's experiences of mothering with a mental illness.

**Societal Attitudes Toward Mothering and Mental Illness**

Many of the mothers in this study described how they felt that others perceived them as "dangerous," "defective," or "incompetent." Women described the general "lack of understanding" concerning mental illness among their family, friends, service providers, and general society. Research has documented the stigma associated with mental illness at a number of levels (World Health Organization, 2001). Discrimination, particularly in the areas of housing and employment, is common and many individuals with mental illness have described the self-blame, shame, silence, and feelings of mistrust that are inherent to coping with mental illness (Hinshaw & Cicchetti, 2000).

Research also has examined societal attitudes towards mental illness by examining media portrayals of individuals with mental illness. Depictions of people with mental illness as violent and criminal are common (Olstead, 2002). Although the majority of individuals with mental illness present no danger to others, the media often portrays people with mental illness as individuals who are not in control of their impulses and likely to harm or kill themselves or others. For the general public, television, newspapers and the Internet may be the only source of information on mental illness (Prior, 1999). One study described how, even for people with personal experience of mental illness among family or friends, media images eventually dominated their perception (Philo, 1996, cited in Prior, 1999).

These ideas contribute to the notion that individuals with mental illness are distinctly different from members of the general population. Depictions of mothers with
mental illness in the media portray women as dangerous and unpredictable (Greaves et al., 2002). The conditions and circumstances surrounding their mothering are rarely mentioned and women’s actions are attributed solely to their mental illness. As well, women who treat their children poorly are often immediately believed to be mentally ill. These beliefs are reinforced by the fact that mothers with mental illness only come to the attention of the media and policymakers when women are in adverse situations (Morrow, Johnson, & Nathoo, 2003). This selective vision promotes the idea that all mothers with mental illness are “bad” mothers and incapable of mothering.

**Ideology of Motherhood**

In a review of the past decade of scholarship on motherhood (1990-1999), Arendell (2000) describes “intensive mothering” as the prevailing ideology of motherhood in North America. Although the idea of one mothering ideology has been criticized in light of research demonstrating numerous arrangements, practices and cultural contradictions in mothering, intensive mothering has remained the normative standard, both culturally and politically. Sharon Hays, in her book *The Cultural Contradictions of Motherhood*, describes how society’s concept of “socially appropriate mothering” revolves around “intensity.” Mothering is an intensive activity in terms of time, energy, and money (Hays, 1996). “Childrearing is child-centered, expert-guided, emotionally absorbing, labor intensive, and financially expensive” (Hays, 1997: 288).

Mothers who digress from this ideal of motherhood often have their ability to mother questioned or scrutinized (Wallbank, 2000). Mothers, such as single mothers, welfare mothers, or lesbian mothers, are the subjects of deviancy discourses on motherhood. Mothers with mental health issues also deviate from the dominant ideology
at a number of levels. As mothers with mental illness are often single mothers, they challenge the ideal that child-rearing should occur within the context of a heterosexual, nuclear family. Mothers who receive income assistance either through welfare or disability payments are not able to invest enormous amounts of money in their children. As well, women with disabilities are questioned regarding their ability to care for another individual because they themselves are seen to be dependent on others (Grue & Laerum, 2002).

In particular, Mosoff (1997) describes how the ideology of motherhood presents unique challenges for mothers with mental illness. Mothers are expected to be autonomous and unselfish. A good mother should place the interests of their children above their own and is not seen to be a subject with her own needs and interests (Arendell, 2000). However, mothers with mental illness must meet “the conflicting requirements of being a ‘good’ mother and a ‘good’ patient” (Mosoff, 1997: 237). In order to remain well, women must expend time and energy on meeting their own mental health needs. But, by being a ‘good patient,’ mothers with mental illness divert attention and personal resources away from their children. Hays describes how “the mother’s day-to-day job is, above all, to respond to the child’s needs and wants” by being aware and reacting to a range of subtle cues and signals (Hays, 1997). For many mothers with mental illness, their illness may prevent them from meeting their child’s needs in a socially acceptable way. A single mother may be seen to present a “risk” to her child and a single mother receiving welfare payments may be seen as a “double risk.” Mothers with serious mental illness who meet both these criteria may have to face “layers of stigma” as they stray from societal ideals of motherhood.
The Metaphor of the Panopticon and the Climate of Scrutiny

Several mothers in this study reported feeling defensive or threatened for no apparent reason or feeling as if other family members, service providers, or society in general, are scrutinizing or judging them. Carrie described this feeling as follows:

So I could tell you, in all honesty, I have never hurt [my daughter] emotionally or physically. You know. None of that stuff. But you are scared anyway. Sometimes you feel on the defensive before, like, for no reason. Just because you suffer from something like a mental illness, you are scared, like are they going to see me as unfit or incompetent to look after my child. (Carrie)

Foucault’s model of the panopticon provides a metaphor for understanding how the broader socio-cultural context creates a climate of scrutiny for mothers with mental illness.

The panopticon (all-seeing place) was an architectural design for a prison developed by Jeremy Bentham in the eighteenth century. The panopticon consisted of a central observation tower surrounded by concentric cells. The tower was designed so that each prisoner was unable to see the guards in the tower. Guards could potentially observe all the cells simultaneously, but prisoners would not able to tell if they were being watched. Consequently, through continual observation or the illusion of continual observation, people would discipline their own behaviour to avoid the receipt of externally imposed punishment (Foucault, 1984).

Foucault used the panopticon to describe how normalization, rather than coercion, could be used to discipline people. He described how people can exert power over others and through power structures that operate without actually actively administering punishment as a form of control. “Power is not hierarchical, flowing from the top down, but everywhere local.... patterns of power established with families interact with patterns
of power in institutions and throughout the social body” (Fillingham, 1993). Scholars have used the panopticon to describe how people police themselves because they feel they are always being watched. As well, the panopticon can be useful in understanding how the dominant culture can shape norms or shape an individual’s worldview.

Unlike more overt methods of ensuring conformity, the origin of this gaze is invisible and ambiguous. Duncan (1994) argues that the panoptic gaze “is enstructured into many forms of media—magazines, film, newspapers, televisions, books, radios—and functions on many levels – textual, institutional, psychic, and so on.” For mothers with mental illness, the “psy” disciplines, popular culture, and the media play important roles in establishing and dispersing norms of behaviour, particularly in the realms of family and social policy (Mosoff, 1997; Wallbank, 2000). Discourses produced by psychiatrists, psychologists, and social workers provide expert and technical information on mothering and mental illness. These discourses in turn are shaped by popular understandings of mental illness and mothering.

The Gaze of the System

Social values about mothering and the ability of mothers with mental illness to mother are embedded at the family, service, policy, and societal levels. In this study, several women commented on the feeling of surveillance when accessing supports. Indeed, many structures and policies within the professional system have a degree of scrutiny built into them. Within most communities in British Columbia there are a variety of parenting programs offered through the Ministry of Children and Family Development (MCFD). If child protection issues arise, workers in these programs may be required to report to court. Thus, there is an element of scrutiny built into the provision of support via
these programs. As well, in situations where child protection issues may exist, the MCFD workers may provide more intensive supports or programs with more restricted mandates. Workers may develop a contract with individual mothers outlining specific goals (e.g., ability to respond to child’s cues, attendance at specific day care, or child’s participation in day care). These contracts may emphasize goals such as promoting mother-infant attachment and may not reflect mother’s needs or goals. As White (1996) suggests, requesting or receiving support through the child welfare system may be a “poisoned chalice” where services provide coercion, censure, and surveillance rather than support.

Mothers in this study also described how the professional system is selective in whom it chooses to assess and seems to be overly interested in appearances. Sophie discussed how her son has never been at risk or in danger from her, yet she felt that she is “always scared that they are going to come and take him away.” She described an incident that occurred at one of her parenting groups.

...one parenting group that I go to, two facilitators have the time to phone my social worker and said [my son] wasn’t drinking from a bottle and he hadn’t had a wet diaper for a number of hours. First of all, [he] was breast-feeding. And he had a cold. And my social worker got this big meeting together and said that [my son] isn’t thriving and he’s not happy ... And the social workers aren’t even—they are not with you 24 hours a day so how can they [say that?]. And neither are these other people. (Sophie)

She expressed her frustration at the system that seems focused on appearances and not interested in helping families. Karen also described how appearances make a difference. As she had family support and financial resources, she never became involved with social services:

... looking from the outside in, we were all doing very normally well [laughs]. Like nobody knew all these repercussions and permutations and the-- it just looked on the outside like a sort of yuppie couple going ahead and having a kid (Karen)
Mothers in the study described how the system has a narrow gaze. The attention of the system is drawn to particular mothers only when a crisis occurs or when its attention is drawn to a particular case by an outsider (e.g., neighbor, physician, teacher). If things appear normal or if a family is “shielded” from the system by family support or financial resources, then the gaze of the system passes over a family. Single mothers and mothers receiving welfare payments receive greater attention due to greater contact with the professional system and the perception that these mothers present a greater risk to their children. With each layer of stigma, or deviation from societal ideals of mothering, women are placed under greater scrutiny.

Mothers also may internalize the panoptic gaze. They may internalize societal attitudes toward mothering and engage in self-surveillance. “The overwhelming power of these norms extends to the point where the participants carry the gaze of the dominant culture with them” (Quiring, 1999). Mothers in this study who had limited contact with social services or did not have fears of custody loss often engaged in self-scrutiny when describing their mothering in relation to what they felt was “good mothering” practices. Women in this study reflected on their mothering and their perceptions of being a good mother in numerous ways. Some of the mothers felt guilty for not always being emotionally or physically available for their children or not being able to be a “supermom.” Carrie stated:

I don’t feel like I give as much as I could or as much as – like I would like to be different and I would like to be more and I would like to be “supermom,” you know. I think a lot of people who have depression anyways are like that. You know perfectionists and would like to be super this and super that. (Carrie)
Other mothers described how caring for their children sometimes meant that they did not have enough energy to focus on their own needs. As well, several mothers described feeling as if they had to go to great lengths convince others that they were a good mother. Sophie described a period of time when her son was unable to sleep. “I would sleep on the floor in his room until like 2:00, 3:00 in the morning … [laughter] I am a patient mom. I don’t think any other mom would do that.”

II. Managing Complexity

The Heterogeneity of Mothers with Mental Illness

Mothers in this study came into contact with several different sectors of the professional system. Mothers entered the system in numerous ways and used a diversity of supports. In many ways, the diverse needs and abilities of mothers with mental illness presented challenges to the system. Because they often have complex problems or issues that span different parts of the system, mothers with mental illness do not fit in a predetermined “slot,” creating difficulties for the system as it attempts to address their needs. In particular, the heterogeneity of mothers with mental illness contrasts with the policies and mechanisms in the system that attempt to simplify complexities in order to efficiently provide support and treatment.

Like most systems, the professional system examined in this study has developed strategies to encourage objectivity, consistency, and efficiency. One strategy used by the system to prevent inconsistencies in the assessment of “at risk” families by different workers is the development of a risk assessment model used by child protection workers. However, because this assessment tool was developed for use in assessing all families, its accuracy in assessing the situations of individuals with mental illness is questionable.
Rather than accurately assessing "risk" for children whose parents have a mental illness, this tool may contribute to the "lumping" of mothers with mental illness and the perception that all mothers with mental illness are the same. The Child Protection Risk Assessment model, while considering the emotional and mental state of the parent, is not sensitive to families where a parent has a mental illness. As the checklist conflates mental illness with emotional and mental state, this often means that individual understandings of mental illness influence the outcome of the checklist (Greaves et al., 2002). In addition, a checklist approach cannot always be sensitive to the variable nature of mental illness. For example, a diagnosis of "depression," can describe a wide range of abilities to function. A checklist also may not fully capture an appreciation of the cyclical nature of many mental illnesses where there may be long periods of wellness alternating with periods of illness. Hence, mental illness is not easily simplified or codified using "objective" tools designed to remove uncertainty about a client's mental health status or to accurately evaluate "at risk" situations.

Mothers with mental illness do have unique needs, but they also may have more in common with other mothers than they do with each other. The academic literature, particularly studies examining the impact of parental mental illness on child outcomes, has a tendency to "lump" mothers with mental illness together. Many view diagnosis alone as reason for concern. However, the actual impact of parental mental illness varies with duration and severity of illness, age of children and mother, and the supports and resources available to them. As Pound (1996) describes, parenting quality is more important than parental diagnosis when examining the impact of parental mental illness on a child. In a recent study, Mowbray et al. (2002) found that specific mental illness...
diagnosis was not an independent or useful predictor of parenting problems or strengths. Chronicity, current symptomatology, and community functioning mediated the relationships between diagnosis and parenting stress and parenting satisfaction. Mowbray et al. suggest the importance of assessing the status of mothers with mental illness rather than assuming problems or a need for intervention. For many families, parental mental illness is the greatest challenges they cope with and may have a large impact on their well-being. But, often, as seen in this study, mental illness may not be the only challenge that women must deal with. For some mothers in this study, the additional challenges of single parenting, a poor marriage, or coping with poverty interacted with or directly influenced their mental health; often, these challenges outweighed their current mental health needs.

Multiplicity of Supports

Mothers’ diverse needs and abilities influenced the type, intensity, and duration of supports they needed and there were few supports that all mothers found helpful. Some women in the current study required support around their parenting; others needed support around their mental health issues; and others required support for both. Women in the study often had challenges finding specific supports to meet their needs. Mothers with mental illness “fell through the cracks” and were not acknowledged by the professional system as a population requiring extra support. Most women reported that there were no programs or supports available for mothers with mental illness in their community. System fragmentation, variability in community programs, and the narrow mandates of many programs also presented challenges to accessing supports.
The heterogeneity of mothers with mental illness presents challenges to developing appropriate interventions and supports. Some women who need additional support in developing their parenting skills may find parenting programs helpful while others may find them didactic. Other women may value parenting programs as they provide opportunities to overcome isolation and connect with other parents. Programs specific to the unique needs of mother with mental illness may be incredibly helpful for some women, but irrelevant to others who may require one-on-one counseling around non-parenting issues (these supports indirectly influence their parenting abilities).

Programs designed to support mothers in other “high risk” circumstances may be well-suited to support mothers with mental illness if their mental health concerns could also be addressed (it is quite likely a women with mental illness who is parenting may also be coping with poverty or isolation as well). The recognition that mothers with mental illness may require additional support and the subsequent widening of the narrow mandate of several programs and supports (e.g., respite services) may be another approach. The development of appropriate programs and supports requires balancing the provision of programs with narrow mandates (e.g., supporting mothers with schizophrenia) with programs with wider mandates (e.g., mothers in other “high risk” circumstances). While the former may address the unique needs of a particular population, the latter has the potential to address a women’s mental health, parenting, and other needs. The diverse needs, experiences, and abilities of women with mental illness mean that no one specific intervention will address the needs of all mothers with mental illness.
“Missed Opportunities” in the Health Care System

Although some mothers in the current study had a greater degree of contact with other public systems, the health care and mental health systems were the only systems that all women had contact with. However, most mothers in this study did not describe their health care providers as a source of support around their parenting or described the lack of awareness of their mothering role in treatment decision-making. Women also described how health care providers in fields outside of mental health had very little understanding of their mental health or how mental illness may interact with other health needs.

Research has described how health care providers often focus on patients or clients and do not consider individuals with mental illness in the context of communities and families. The health care system tends to treat individuals as “patients” and not as “persons.” Nicholson et al. (2001) describe how this may mean that parents’ efforts are overlooked or undermined. More importantly, lack of awareness of the context of mother’s lives may result in “missed opportunities” to provide support to mothers with mental illness. Nicholson et al. describe each health care encounter as an opportunity to connect parents with mental illness with other resources in the community, offer emotional support, or provide parenting information.

Mothers in the current study described several qualities of health care providers that they found helpful. They appreciated health care providers who acknowledged their parenting role, who were aware of the resources and services in the community, and had knowledge of parenting challenges. Health care providers provided a human interface between mothers with SMI and the policies, practices, and procedures of the system.
Mothers in this study also acknowledged how health care providers were “gatekeepers” to numerous services or were instrumental in referring them to certain services. Although women may have been managing “just fine”, health care providers who were sensitive to the context of their lives were better able to meet women’s needs. Ultimately, health care providers who supported women in their parenting also supported women in managing their mental health (and vice versa).

Table 5.1 Examples of How Service Providers Can Support Processes of Building Stability and Re-stabilizing

- Reinforcing the belief that mothers with mental illness can be good mothers (countering stigma)
- Contextualizing care by considering the role of mothering in a woman’s life, her past experiences, and other life circumstances in treatment decision-making (looking beyond label of mental illness)
- Addressing issues regarding continuity of care and encouraging integrated case management and other similar practices where appropriate (overcoming system and service fragmentation)
- Providing options and decision-making power, especially when there are no clear guidelines or standards of practice
- Becoming familiar with range of supports offered in community in order to refer mothers to appropriate supports (source of information)
- Providing a source of emotional support for mothers who have lost custody of their children and supporting mothers in developing new relationships with their children (supportive presence)
- Facilitating access to services and programs (advocacy)
III. Beyond “Pockets of Understanding”: Towards A System-Wide Approach

I know someone who went through a very serious depression and she is probably still quite depressed. And, you know, pulled her daughter out of school and said she was home schooling her which she wasn’t effectively doing and yet what can I do? Who do I call where this woman is going to actually get support? I can't call the Ministry of Children and Families because if they believe the situation is serious enough they will take the children away which further exacerbates a bad situation --she herself doesn’t recognize that she is experiencing a depression. She’s afraid, if she admits that to a healthy person, she might lose her children. (Judith)

This quote illustrates how many mothers view the professional system as punitive or unhelpful and potentially damaging. As well, it raises the issue of individuals with mental illness in the community who are undiagnosed and who may need additional support. While some women in this study described the “pockets of understanding” they found to support them in their parenting and in managing their mental illness, others found the system unsupportive. The next section raises potential areas or possibilities for change and offers some thoughts on restructuring at a systems level to enhance the abilities of the professional system to meet the needs of mothers with mental illness.

Opportunities for Intervention

Research has shown that the population using mental health services does not fully represent the population experiencing mental health problems. For the majority of the population, there are numerous barriers to using mental health services. As well, the professional system has limited abilities to address the needs of the general population. In many cases, a mental health diagnosis may not be helpful or may be damaging if effective supports and treatment are not available. Families that appear to be functioning well often do not receive attention. Some mothers may not receive support from the system because their circumstances are not “serious” enough while other mothers feel
they receive unwarranted attention because they are perceived as a “risk.” Many mothers in this study felt that the emphasis in the system on protection, and not on support or prevention, deterred women from asking for needed support. Rather than receiving support to cope with their mental health issues or resources to assist them in parenting, women in this study often found that the system created additional stress or acted punitively by removing their children from their care.

Moving away from an emphasis on risk and scrutiny opens up other possibilities for providing support to mothers with mental illness which may contribute to preventing disruptions and building stability. In particular, the interrelationship between mothers and their children may provide additional opportunities for supporting mothers and their families. Several women in this study described how they felt supported when the needs of their children were met. Conversely, when they felt well-supported, they were better able to care for their children. The mother-child dyad has the potential to be stronger and more resilient than an individual. As well, a dyad may present more opportunities to develop effective interventions or meet the needs of families. Nicholson and Biebel (2002: 169) state:

As there are many mediating and moderating factors in the relationship between parental mental illness and children’s functioning, there are many avenues for preventive and rehabilitative interventions with children, parents, or both. Because maternal and child well-being are interrelated, addressing the clinical issues of one is likely to make a positive contribution to both.

**Extending Mental Health “Treatment”**

In this study, it became clear that the majority of factors contributing to mother’s mental health status fell outside the purview of the health care or mental health system. This suggests the need for an expanded concept of support and that the “treatment” of
mental illness may require strategies not usually considered part of the health care system.

There is a wide array of treatment options available for treating mental illness. These include individual, group, family psychotherapy, medication, behaviour modification, alternative therapies, or a combination. Although there are many options, these options are not equally available to all individuals. Not all health care providers are familiar with all options and the availability of these services may be limited by geography. Although medication and psychotherapy have been shown to have similar effectiveness, studies have demonstrated that most individuals who come into contact with the health care system are more likely to receive medication than psychotherapy or counseling. Indeed, services such as psychotherapy and counseling are available either on a limited basis or not at all through the public system. Options that would be helpful to many mothers with mental illness, such as counseling or therapy approaches that are family-centred, are rarely available or funded through the health care system. This may reflect the dominance of the biomedical model in the health care system or financial constraints (i.e., psychotherapy is more time and money intensive in the short-term), or both. Regardless, many women in this study described the importance of medication in treating their mental illness, but also described the range of socio-economic factors that influenced their mental illness.

The range of systems that mothers encountered in this study indicates how mental health needs are not easily compartmentalized and influence many aspects of an individual’s experiences. In this study, the process of building stability was used to describe the strategies mothers with SMI used to develop a foundation in which to be the
best mother possible within their individual circumstances. As described earlier, supporting the mental health of mothers also requires supporting them in their parenting. But the process of building stability is not limited to actions that directly influence a women’s ability to manage her mental illness. Given the range of factors that affect a mother’s mental health (and consequently her parenting abilities), it also may be necessary to support them in diverse areas, including relationships, sexuality, coping with past abuse, or developing spirituality. Many mothers in this study described long-term emotional support to be as important as practical support.

Reducing stress in the social environment or altering the structural factors that may contribute to mental illness is rarely considered as “treatment” for mental illness or is secondary to more individualistic approaches. For most women in this study, their individual circumstances and the stressors in their social environment greatly affected their ability to build stability or re-stabilize following a disruption. The material, personal, and social resources available to women influenced their ability to manage their mental health and parent. Mother’s mental illness presented challenges to remaining employed and having an adequate income. Conditions resulting from living in poverty exacerbated women’s mental illness. Following custody loss, women’s circumstances affected their ability to recover, regain custody, or remain involved in parenting. Several mothers described the importance of housing and employment as resources that gave them the opportunity to care for their children and/or remain involved in parenting following custody loss. Income, social support, and housing were all important in determining whether mothers were able to meet their own needs and the needs of their
children. Thus, “treating” mental illness also requires equal attention to be paid to the structural factors that influence mental health and parenting circumstances.

Research has demonstrated strong correlations between mental illness and substance use, mental illness and poverty, mental illness and past abuse, and high comorbidity between mental illness and physical health issues. As mentioned in the previous chapter, mental illness is “never just one thing.” The overlap between these areas presents challenges to a system that often targets a specific problem or is not able to address multiple, interrelated problems at once.

Different Models of Caregiving

In our society, the heterosexual nuclear family is the model around which politics, policy, and law revolve (Fineman, 1995). This dominant model of family and the ideology of motherhood contribute to the notion that mothering and caregiving can and should occur in a particular way. In our society, there are few variations of motherhood permitted. Several authors have examined how families which fall outside of prevailing ideological constructs of what constitutes a complete or real family are responded to with the presumption of inadequacy and the guarantee of supervision and intervention (Fineman, 1995; Wallbank, 2000).

For mothers with mental illness who are not able or have chosen not to care for their children, there is little support provided to them to cope with the grief that may follow these decisions. In addition to coping with the stigma of mental illness, many women may have to cope with the stigma of losing custody of their children or having been determined “unfit” to parent. Women in this study described the importance of remaining involved in parenting regardless of their custody status. The recognition that
mothering and nurturing can be performed in different ways (e.g., possibility of part-time parenting) could result in different relationship models that would provide mothers with mental illness greater opportunities to remain involved in parenting. As well, this would result in the recognition that a “good outcome” for women and their families can mean different things. In circumstances where women are unable to care for their children, a “good outcome” may mean creating an environment in which women can maintain contact with their children if they choose or supporting a woman if she decides she is unable to care for her children.

Table 5.2: System Features that Encourage Building Stability and Re-stabilizing

<table>
<thead>
<tr>
<th>System Area</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Custody and Access</td>
<td>Assisting mothers in maintaining contact with children either through full or partial custody or visitation rights; developing different models of mothering or family</td>
</tr>
<tr>
<td>Income support</td>
<td>Ensuring that mothers have adequate resources to care for their children (e.g., adequate housing, food)</td>
</tr>
<tr>
<td>Health services</td>
<td>Expanding notions of mental health “treatment”; increasing availability of psychotherapy through public system</td>
</tr>
<tr>
<td>Scope of care</td>
<td>Providing opportunities to bring children into therapeutic care; emphasizing a family-centred approach rather than “best interests of the child”</td>
</tr>
<tr>
<td>Support and services</td>
<td>Providing support without scrutiny or threat of child apprehension (non-punitive); increasing availability of preventive- versus crisis-oriented support; widening mandate of general services to address unique challenges of mental illness</td>
</tr>
</tbody>
</table>
IV. Re-contextualizing Mothering and Mental Illness

In the research literature, the two terms “mental illness” and “mothering” are generally associated with the recognition and belief that mental illness has a detrimental effect on women’s mothering practices. The diverse experiences of mothers in this study suggest the importance of examining other contextualizing features of women’s lives that affect their mental illness and mothering. For many mothers, their mental illness was just one of several factors defining their identity and influencing their mothering. Further research on mothering and mental illness may need to reconceptualize and problematize the question that is being asked. An exclusive focus on mothering and mental illness may perpetuate the idea that mental illness and mothering are strongly interrelated (they may be related but influenced by numerous other factors) and may further decontextualize women’s lives. If mothers with mental illness do have many things in common with other mothers, as has been suggested in the literature, developing effective interventions for this population may require a combination of approaches rather than one or two specific “magic bullet” interventions.

Contributions of this Study

The purpose of this study was to highlight the intersections between mental illness and mothering. This study provided an in-depth examination of the context of mothering with a mental illness. It demonstrated the interrelationship between a women’s mental health and her identity as a mother. It suggests that the act of and identity of mothering can have a positive influence on the mental health of women with mental illness. The study highlighted the interconnected collection of factors that codetermine the structure
and meaning of mother’s lives. In particular, it examined how the professional system is involved with and influences the experiences of mothers with mental illness.

**Limitations**

Although the purpose of a qualitative study is not to produce findings that are generalizable to the general population or the population under study, this study was limited by a small sample size. In particular, sampling procedures, resources, and time constraints prevented greater variation in sampling.

This study used principles of theoretical sampling. In theoretical sampling, study participants are chosen based on their ability to illuminate the phenomenon under study. As little is known about this area of study, I chose to use a sampling approach that would capture great variation in mother’s experiences. As this study progressed, the diversity and range of women’s experiences emerged and it became evident that a number of factors and contexts are important in understanding mothering and mental illness. This study was able to hint at other factors that influence mothering and mental illness (e.g., single parenting, socio-economic status, family history), but I was not able to fully capture and explore all these dynamics. Additional interviews would have been able to capture greater diversity in circumstances and contexts.

Sampling procedures also limited the range of experiences captured in this study. As mothers were recruited through service providers, mothers who are undiagnosed or do not access mental health care services were not included in this study. In particular, mothers of different ethnic backgrounds are underrepresented in mental health services. Mothers in this study represented a relatively “well” segment of the population with serious mental illness. As well, the mothers I spoke to were all B.C. residents and the
majority of their experiences with the professional system occurred in B.C. Although many policies and practices are common across the provinces, specific changes in the British Columbian government in the past five years are reflected in this study.

**Potential for Further Research**

In addition to capturing other dynamics such as single parenthood and ethnicity that intersect with mothering and mental illness as described above, this study suggests several areas for further research.

1. **The experiences of mothers with mental illness**

   This study identified numerous areas that are important in understanding women’s experiences of mothering and mental illness, but which could only be examined briefly in this study. These areas include the impact of poverty, substance use and other co-morbid health conditions, past abuse, and stress from interacting with the professional system.

2. **The experiences of fathers with mental illness**

   Fathers with mental illness have received little attention in policy and the media and are a neglected area of research. Although many of the issues that fathers face are similar to the challenges that mothers with mental illness may experience, there also are several major areas that may result in very different experiences. For example, men have different experiences in the mental health and legal systems (among others), often parent with another individual, and must meet different societal expectations regarding appropriate fathering.

3. **Different models of mothering and foster care**

   Like women in the general population, not all mothers with mental illness are able or willing to be the primary caregiver for their children. Research examining different
models of caregiving, foster care, and mothering would provide better understanding of how women who do not have full custody of their children can remain involved in parenting in a way that benefits mothers, children, and alternate caregivers.

4. Intersections between mothering, mental illness, and the legal system

Many mothers in this study reported a lack of support from the legal system when negotiating custody arrangements. Often, custody loss occurred following periods of illness and several mothers were discouraged from pursuing custody or a formal custody agreement on the basis of their psychiatric history. The role and potential of the legal system in supporting women in maintaining relationships with their children is an area that could be further explored.

5. Identity and mothering

Although there is a substantial body of literature examining mothering and identity, little is known about how experiences of mental illness may intersect with mothering and identity and how this might vary with race and ethnicity.

6. Responsibilities, expectations, and abilities of the professional system

What is the ability of public systems to respond to individuals with particular concerns? How can a system be both flexible to individual circumstances and apply its policies universally? What is the role of service providers as intermediaries between the faceless “system” and individuals?
Conclusion

This study examined the experiences of mothers with serious mental illness and supports the belief that mothers with serious mental illness can be, and are, good parents. The purpose of this study was to illuminate the contexts in which mothers with mental illness parent. This study suggests that the context of women’s mothering is not always considered in a clinical setting or at a policy level. Women’s stories described their encounters with “pockets of understanding” and provided examples of promising practices. By extending our understanding of the experiences and contexts of mothering for women with mental illness, I hope that this study is able to assist and challenge us to consider a range of possibilities in the development of practices and policies to better support mothers with serious mental illness and their families. As this study was grounded in mother’s stories, it seems appropriate to close with an excerpt from a study participant.

Maybe because people have a mental illness is that they treasure certain things in life so much. You know, I mean, I am sure there are a million people out there who have got two kids and they don’t [laughs], it’s just part of the norm. They come along, they expected to have two children. They expected to do all this. They expected it. I didn’t expect it. It’s like you get so totally thrilled that you have got this opportunity of being human. (Karen)
Bibliography


Devers, K. J. (1999). How will we know "good" qualitative research when we see it? Beginning the dialogue in health services research. *Health Services Research, 34*(5), 1153-1188.


<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. Where will the project be conducted (room or area)?</td>
<td>James Mather Hut, Rm.13</td>
</tr>
<tr>
<td>19. Who will actually conduct the study and what are their qualifications?</td>
<td>Ms. Nathoo will be conducting the interviews. Ms. Nathoo has previous experience conducting interviews in this area and with this population, as she was employed as the interviewer/research assistant on the original Mothering Under Duress project. As an M.Sc. student in Health Care and Epidemiology, she has received training in conducting qualitative research and has research experience in women's health. Ms. Nathoo's data collection and analysis will be supervised by her thesis committee members, including Jean Shoveller (Assistant Professor, HCEP), Joy Johnson (Professor, Nursing) and Marina Morrow (Research Associate, BC Centre of Excellence for Women's Health).</td>
</tr>
<tr>
<td>20. Will the group of subjects have any problems giving informed consent on their own behalf? Consider physical or mental condition, age, language, and other barriers.</td>
<td>No, all research participants will be competent adults capable of giving informed consent.</td>
</tr>
<tr>
<td>21. If the subjects are not competent to give fully informed consent, who will consent of their behalf?</td>
<td>N/A</td>
</tr>
<tr>
<td>22. What is known about the risks and benefits of the proposed research? Do you have additional opinions on this issue?</td>
<td>This research carries minimal risk to study participants. The purpose of the project is to understand the experiences of mothers with mental health issues. In order to ensure the confidentiality of the mothers and key informants participating in the study, all identifying information will be removed from research records, no identifying information will be published in any work arising from the research. Interviews will be conducted in a location and at a time that is convenient and safe for both the interviewer and the study participant.</td>
</tr>
<tr>
<td>23. What discomfort or incapacity are the subjects likely to endure as a result of the experimental procedures?</td>
<td>Study participants in the interviews may experience mild emotional distress from recounting their experiences. Immediate referral for counselling or additional information will be provided in these cases (in the Lower Mainland, Mental Health Emergency Service, 604-874-7307).</td>
</tr>
<tr>
<td>24. If monetary compensation is to be offered to the subjects, provide details of amounts and payment schedules.</td>
<td>Mothers who participate in the study will be offered a $25 honoraria to compensate them for their time and incidental costs. No honorarium will be provided to the key informants.</td>
</tr>
<tr>
<td>25. How much time will a subject have to dedicate to the project?</td>
<td>1-2 hours</td>
</tr>
<tr>
<td>26. How much time will a member of the control group, if any, have to dedicate to the project?</td>
<td>N/A</td>
</tr>
</tbody>
</table>
## Data

### 27. Who will have access to the data?
Ms. Nathoo (M.Sc. student, HCEP), Jean Shoveller (faculty advisor, Assistant Professor, HCEP), and members of the thesis committee, Joy Johnson (Professor, Nursing) and Marina Morrow (Research Associate, BC Centre of Excellence for Women’s Health) will have access to the data.

### 28. How will the confidentiality of the data be maintained?
Once initial contact with study participants has been made, study participants will be assigned a pseudonym and no personal identifiers will be included in the reports of the findings. Informed consent forms will be stored in a locked filing cabinet in the James Mather Hut, Rm. 13). Tapes will be erased at the end of the project and transcripts and file names will not include any personal identifiers.

### 29. What are the plans for the future use of the raw data beyond that described in this protocol? How and when will the data be destroyed?
NOTE: Original data for a given study should be retained in the unit of origin for at least five years after the work is published or otherwise presented (if the form of the data permits this, and if assurances have not been given that data would be destroyed to assure anonymity). No specific plans for the use of the raw data are presently known. Consent for keeping the data will be secured at the time of data collection. Transcripts will be kept indefinitely.

### 30. Will any data which identifies individuals be available to persons or agencies outside the University?
No.

### 31. Are there any plans for feedback to the subject?
Interested participants will be provided with a project summary, copy of the student's thesis or published reports of the research.

### 32. Will your project use:
- [x] Interviews (Submit a list of the questions);
- [ ] Observations (Submit a brief description);
- [ ] Tests (Submit a brief description).

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138
33. Funding Information

Agency / Source of Funds: There are no operating funds associated with this project.

- Internal
- External

Funds Administered by:
- UBC
- VHHSC
- SPH
- BCWH
- BCCH
- BCCA

UBC or Hospital Account Number:

Status:  
- Awarded
- Pending

Peer Review:  
- Yes
- No

Start Date (YY-MM-DD):  
Finish Date (YY-MM-DD):

34. Who will consent?

- [X] Subject.
- [ ] Parent or Guardian. (Written parental consent is always required for research in the schools and an opportunity must be presented either verbally or in writing to the students to refuse to participate or withdraw. A copy of what is written or said to the students should be provided for review by the Committee.)
- [ ] Agency Officials.

35. In the case of projects carried out at other institutions, the Board requires written proof that agency consent has been received. The Request for Ethical Review may be submitted before agency approvals have been obtained. Please specify below:

- [ ] Research Carried Out at a Hospital - Approval of hospital research or ethics committee.
- [ ] Research Carried Out at a School - Approval of school board and/or principal. Exact requirements depend on individual school boards. Check with Faculty of Education committee members for details.
- [ ] Research Carried Out In a Provincial Health Agency - Approval of Deputy Minister.
- [ ] Other - Specify:

36. Questionnaires (Completed by Subjects)

- Questionnaires should contain an introductory paragraph or covering letter which includes the following information. Please check each item in the following list before submission of this form to insure that the instruction contains all necessary items.

  - [ ] UBC Letterhead. The covering letter included with this application must be on letterhead. A photocopy of the letterhead is OK.
  - [ ] Title of Project.
  - [ ] Identification of the Investigators, Including a phone number.
  - [ ] A Brief Summary that indicates the purpose of the project.
  - [ ] The Benefits to be derived.
  - [ ] A Full Description of the Procedures to be carried out in which the subjects are involved.
  - [ ] A Statement of the Subject's Right to Refuse to Participate or Withdraw at any time without jeopardizing further treatment, medical care or class standing, as applicable. Note: This statement must also appear on explanatory letters involving questionnaires.
  - [ ] The Amount of Time required of the subject.
  - [ ] The Statement that if the questionnaire is completed it will be assumed that consent has been given. This is sufficient if the research is limited to questionnaires; any other procedures or interviews require a consent form signed by the subject.
  - [ ] An Explanation of how to return the questionnaire.
  - [ ] Assurance that the Identity of the subject will be kept confidential and a description of how this will be accomplished; e.g. "Don't put your name on the questionnaire."
## Consent Forms

37. UBC policy requires written consent in all cases other than those limited to questionnaires which are completed by the subject. (See item #36 for consent requirements.) Please check each item in the following list before submission of this form to ensure that the written consent form attached contains all necessary items. If your research involves initial contact by telephone, you do not need to fill out this section.

- **UBC Letterhead.** The consent form included with this application must be on letterhead. A photocopy of the letterhead is OK.
- **Title of the Project.**
- **Identification of investigators, including a telephone number.** Research for a graduate thesis should be identified as such and the name and telephone number of the faculty advisor included.
- **Brief but complete description in lay language of the purpose of the project and of all procedures to be carried out in which the subjects are involved.** Indicate if the project involves a new or non-traditional procedure whose efficacy has not been proven in controlled studies.
- **Assurance that the identity of the subject will be kept confidential and description of how this will be accomplished, i.e. describe how records in the principal investigator’s possession will be coded, kept in a locked filing cabinet, or under password if kept on a computer hard drive.**
- **Statement of the total amount of time that will be required of a subject.**
- **Details of monetary compensation, if any, to be offered to subjects.**
- **An offer to answer any inquiries concerning the procedures to ensure that they are fully understood by the subject and to provide debriefing, if appropriate.**
- **A statement that if they have any concerns about their rights or treatment as research subjects, they may contact Dr. Richard Spratley, Director of the UBC Office of Research Services and Administration, at 822-8598.**
- **A statement of the subject's right to refuse to participate or withdraw at any time and a statement that withdrawal or refusal to participate will not jeopardize further treatment, medical care or influence class standing, as applicable. Note: This statement must also appear on letters of initial contact. For research done in the schools, indicate what happens to children whose parents do not consent. The procedure may be part of classroom work but the collection of data may be purely for research.**
- **A statement acknowledging that the subject has received a copy of the consent form including all attachments for the subject's own records.**
- **A place for signature of subject consenting to participate in the research project, investigation, or study and a place for the date of the signature.**
- **Parental consent forms must contain a statement of choice providing an option for refusal to participate, e.g. “I consent / I do not consent to my child’s participation in this study.” Also, verbal assent must be obtained from the child, once the parent has consented.**
- **If there is more than one page, number the pages of the consent, e.g. page 1 of 3, 2 of 3, 3 of 3.**
- **Include a version date on the consent form.**

## Attachments

38. Check items attached to this submission, if applicable. Incomplete submissions will not be reviewed.

- **Letter of Initial Contact.** (Item 16)
- **Advertisement for Volunteer Subjects.** (Item 16)
- **Subject Consent Form.** (Item 37)
- **Control Group Consent Form.** (If different from above)
- **Parent / Guardian Consent Form.** (If different from above)
- **Agency Consent.** (Item 35)
- **Questionnaires, Tests, Interviews, etc.** (Item 32)
- **Explanatory Letter with Questionnaire.** (Item 36)
- **Deception Form, including a copy of transcript of written or verbal debriefing.**
- **Telephone Contact Form.**
- **Other, Specify:**
Experiences of Mothers with Serious Mental Illness - Interview Guide

Preamble
In our discussion today I am interested in hearing about your experiences of mothering and your experiences with the health care system. I’d like to hear about how you think having a mental illness has affected your experience of mothering and your thoughts and recommendations on how the health care system can better support mothers……

Opening Question:
I’d like you to start at the beginning. Please tell me about when you first learned you were pregnant. (OR Please tell me about when you first had mental health problems).
- What happened? What were your circumstances?
- Was your mental health affected?

Interview Topic Areas:

1. What kinds of services or agencies have you been involved with? What kinds of supports have you received?
   - How have your experiences affected your expectations of the (health care) system? Have your experiences affected future decisions to seek health care? How?
   - Has the fear of custody loss influenced your decisions to seek care?
   - Have you had difficulties finding or obtaining services? (lack of information, wait lists, not covered by MSP, appropriate services)

2. In what ways do you think having a mental illness has affected your mothering?
   - Do you think that having a mental illness has affected your mothering?
   - Do you think being a parent has affected your mental health?
   - What kinds of strategies have you used to manage your mental illness and motherhood? What would help you in doing this better?
   - How have you balanced your own needs with the needs of your children?

3. Have you ever lost custody of your child(ren)?
   - What was this experience like?
   - Who did you seek support from?
   - What, if any, kind of support did you receive after loss of custody?
   - What would be/would have been helpful to you?

4. Do you see your health care provider(s) as a source of support for parenting issues?
   - Do you feel comfortable discussing your fears and concerns around parenting with your health care provider(s)?
   - Has your role as a mother been considered in treatment decisions or follow-up planning? (Psychotropic drugs during pregnancy or while...
Experiences of Mothers with Serious Mental Illness - Interview Guide

breastfeeding, effect of medications on parenting abilities, discussing MI with children)

5. Do you feel that societal attitudes towards mental illness have affected your experiences? (stigma)
   • Do you think that people see mental illness differently from physical illness?
   • Do you think that people's understanding of mental illness has affected your experiences?
   • Do you feel that people understand you/the impact of your mental illness?
   • Do you feel that people have stereotypes about mothers who are coping with mental health issues?

6. Thinking back on your experiences or encounters you have had with the health care system as a mother with a mental illness, have there been certain individuals or service providers who have been particularly helpful?
   • Can you describe these individuals to me? What did they do or say that you perceived as helpful?
   • Was there discussion about parenting (or custody issues)? How would you describe this discussion?
   • Were you given the support you needed, information, referrals...?
   • Did you get the response/assistance you wanted/needed?

7. In your opinion how could the health care system respond better to mothers with a diagnosis of mental illness?
   • What works in the system and what doesn't?
   • Which health care providers are in the best position to assist mothers?
   • What needs to be done to help health care providers understand the issue of mental illness better?
   • What needs to be done to help health care providers develop better skills to help and support women?
   • What kinds of programs or services do you think would be helpful?
   • What would be/would have been helpful to you?

E. Wrap Up

Is there anything else you would like to tell me about?
   • Is there something you would like to tell me that I haven't asked?
   • Is there something you feel I should know?

Before we finish, I would just like to ask you a few questions that will help give a sense of the women I've spoken with in this study. For example, on average, the age of women, number of children women have, etc.
   • How old did you turn on your last birthday?
   • How many children do you have? How old are they and where do they live?
Experiences of Mothers with Serious Mental Illness - Interview Guide

- What was the highest level of education that you completed?
- What was your total income for this past year before taxes and deductions? I don't need an exact amount, just the general category, e.g., less than $10,000; $10-20,000, etc.
- If asked to describe your ethnicity, culture or religion, how would you do so?
- at some point during the interview, remember to ask about “official” diagnosis

Do you have any questions you’d like to ask me?

Thank you for taking the time to talk with me about your experiences....