Life Stressors and Specialized Programs and Services for Parents with Serious Mental Illness from a Peer Support Specialist Perspective

by

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Abstract

Parents with a mental illness, especially single mothers, who are caring for their children are particularly vulnerable to social isolation, stress, financial hardship, and lack of resources. Prevention and strengths-based interventions, however, are rare for mothers with serious mental illness and their children. Current mental health interventions tend to focus on the individual without respect to family context and do not address parenting needs or support for both the parent and child. The literature indicates mothers with a mental illness and their children should be considered a high-risk group in need of more intensive and more frequent mental health supports. One alternative for more frequent mental health support is through the peer support specialist model. Although the peer support specialist model is a nationally recognized evidence-based practice, the research is very limited on identifying the program and service needs of parents and non-parents with mental illness from a peer support specialist perspective.

This study implemented an exploratory investigation to identify life stressors and specialized programs and services for parents and non-parents with mental illness from a peer support specialist perspective. Results of this study indicated that peer support specialists are currently serving parents with a mental illness and identified support groups for parents with mental illness and for youth/young adults with a parent with a mental illness as the highest level of need. Results also found a need for peer support specialists to be paired with individuals based on mutual characteristics of parental status and the identification of having a parent with a mental illness.

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CHAPTER I. INTRODUCTION

Families affected by parental mental illness are vulnerable to social isolation, financial hardship, and marital discord as well as increased risks for their children (Reupert & Maybery, 2007; Beardslee, Versage, & Gladstone, 1998). Recent literature suggests that parenting by a mother with serious mental illness (SMI) is two times more likely than parenting by a father with SMI (Jones, Macias, Gold, Barreira, & Fisher, 2008; Oyserman, Mowbray, Meares, & Firminger, 2000). In addition, both Abraham and Stein (2008) and Williams and Corrigan (1992) found that children with fathers with a mental illness reported psychological adjustment comparable to adults with non-distressed parents. Therefore, Abraham and Stein (2008) indicate that there is something uniquely challenging about having a mother, rather than a father, with serious mental illness.

Maternal mental health is linked to child development, level of parent-child interaction, developmental delays, and child abuse and neglect (Dickstein et al., 1998). Due to the lack of services and specialized programs to aid this population, mothers with SMI face multiple challenges when dealing with reproductive issues, parenting assistance, and custody loss, often without family support (Nicholson & Blanch, 1994). Children of a parent, particularly mothers with SMI, are likely to be involved with multiple service agencies, including both mental health and child welfare (Hinden, Biebel, Nicholson, & Mehnert, 2005). However, despite the prevalence of maternal mental illness and the risk of adverse outcomes for both mother and

child, there are very few intervention programs that are designed specifically for parents with SMI and their children (Hinden et al., 2005).

In analyses of the National Comorbidity Survey data, 68 percent of women meeting the criteria for a psychiatric disorder over their lifetime are mothers (Nicholson, Biebel, Williams, & Katz-Leavy, 2004). The onset of many psychiatric disorders occurs during childbearing years, contributing to impairment of the affected mothers (Lagan, Knights, Barton, & Boyce, 2009). In recent years, the population of parents who have serious mental illnesses has increased (Bassett, Lampe, & Lloyd, 1999). With the advent of improved services and medications, a shift from the medical model of practice to a psychosocial basis of practice, increased consumer advocacy, expansion of community-based care and decreased reliance on psychiatric hospitalization, more women with serious mental illnesses have chosen to become parents (Bassett et al., 1999). This, however, has not encouraged or motivated the mental health system to address parenting as an important issue for individuals with SMI. Even as community programs have expanded and are focusing on recovery-oriented services, including interventions that focus on psychosocial rehabilitation that address work-related skills and employment, parenting skills are still not being addressed (Nicholson & Blanch, 1994).

When discussing mental health treatment satisfaction with mothers with SMI, Diaz-Caneja and Johnson (2004) found most of the mothers are satisfied with their individual mental health treatment, however, they were not satisfied with the level of knowledge or concern for their social and family lives (Diaz-Caneja & Johnson, 2004). Mental health professionals were described as failing to acknowledge the day-to-day practical difficulties women face as parents while simultaneously trying to adhere to treatment regimens. Lack of child care, sick children, and feeling slow to respond to their children due to the medication's side effects were identified

as barriers. Mental health professionals have ignored these issues and often label mothers as non-compliant because of missed appointments (Diaz-Caneja & Johnson, 2004). The mothers provided suggestions for improvements that included home support, long term support, groups for mothers/parents with serious mental illness, support for their children that include activities outside of their home, and family friendly facility environments (Diaz-Caneja & Johnson, 2004).

Prevention and strengths based interventions are rare for parents with SMI and their children (Hinden, Biebel, Nicholson, & Mehnert, 2005). There are also very few programs and services that include early intervention and prevention strategies targeted to children of parents with a mental illness (Craig, 2004; Nicholson & Biebel, 2002). Most training programs for parents, particularly mothers with SMI, target families where the child is either in danger of being placed in foster care or the child is displaying behavior problems (Hinden et al., 2005). Services and interventions designed to help with parenting are more often found in the child welfare sector and are predominantly deficit-based and only made available when children are judged to be "high-risk" for out of home placement (Hinden et al., 2005). Mental health interventions tend to focus on the individual without respect to family context and do not address parenting needs or support for both mother and child (Hinden et al., 2005). In addition, when intervention efforts focus on either the child or the mother outside the home environment, difficulties are likely to arise (Oyserman, Mowbray, & Zemencuk, 1994). Because inpatient psychiatric treatment of a mother disrupts her marital and family relationships, interventions logically should focus on strengthening the family and preventing hospitalization (Oyserman et al., 1994).

The rationale for the development of an evidence base regarding effective programs for parents with SMI and their children is compelling (Nicholson et al., 2007). Although there has

been progress in developing specific intervention strategies to prevent the development of psychopathology in children whose parents have serious mental illness, no programs or interventions for parents with serious mental illness and their children have been rigorously tested (Nicholson et al., 2007). According to Reupert and Maybery (2007), policymakers, researchers, and practitioners need to consider not only the child or the parent with mental illness, but recognize that families affected by parental mental illness require a multifaceted approach that acknowledges all stakeholders, including the child, the parent, the family, the agencies, and society as a whole. This includes cross training of mental health and child protection workers, including a family focus in identification, intervention, and prevention (Reupert & Maybery, 2007). Nicholson et al. (2001) pointed out that many service organizations are fragmented and uncoordinated when it comes to family mental health strategies. Programs tend to focus on the client without considering the client's environment or contextual demands. In addition, program eligibility generally either serves the adult or child with the mental illness, but not the family as a whole (Nicholson et al., 2001).

Maybery and Reupert (2009) stated that addressing workers' attitudes, knowledge, and skills in family-focused care can provide a basis from which workers can engage effectively with parents with mental illness and their families. It is acknowledged, however, that this basis exists within a larger hierarchy of health care delivery. Foster, O'Brien, and Korhonen (2012) provide a family-focused framework for practice as a 'bottom-up' approach, with the recognition it exists within the context of an overall organizational approach to care. The key element of family-focused care is a philosophy of care, incorporated into practice, which recognizes the uniqueness of each consumer and family member. The family is viewed as a complete entity that includes supporting families in their natural caregiving environments (Foster, O'Brien, & Korhonen,

2012). Family-focused care aims to improve outcomes for the parent with mental illness, reduce the subjective and objective burden of care for families, and provide a preventative and supportive framework for children.

Multiple studies recommend that families affected by parental mental illness receive various foci and interventions that acknowledge all stakeholders (Oyserman, Mowbray, & Zemencuk, 1994; Nicholson & Henry, 2003; Nicholson, 2007; Reupert & Maybery, 2007; Nicholson, Albert, Gershenson, Williams, & Biebel, 2009). The scarcity of high-specificity interventions in contrast to the high prevalence rate indicate most parents with mental illness and their families are either served by less parent-specific interventions or meet their needs by "stringing together" an uncoordinated and nonspecific array of services (Hinden et al., 2006) p. 36. Steps need to be taken in order to develop a broad array of parent and child-specific intervention strategies that provide a detailed framework for a family focused approach. An initial first step should include a focus on the enhancement of existing evidence-based services that have been proven effective.

A model of care that has received much attention in the past decade is the evidence-based peer support specialist model (Bond et al., 2001; Mowbray, Moxley, Jasper, & Howell, 1997; Salzer, 2010; Salzer & Mental Health Association of Southeastern Pennsylvania, 2002; Salzer & Shear, 2002; Salzer, 2013). Peer support specialists are persons with mental health conditions who have completed specific training that enables them to enhance a person's wellness and recovery by providing peer support (National Coalition for Mental Health Recovery, 2014). Peer support specialists can work in a variety of locations, including peer support centers, crisis stabilization units, respite programs, psychiatric hospitals, and community day rehabilitation programs (National Coalition for Mental Health Recovery, 2014). Peer support can be provided

as a one on one service or in a group setting where consumers can share together in an open forum (National Coalition for Mental Health Recovery, 2014).

The effectiveness of peer support is well documented in numerous studies (Bologna & Pulice, 2011; Bouchard, Montreuil, & Gros, 2010; Cook, Copeland, Corey, Buffington, Jonikas, Curtis, Grey, & Nichols, 2010; Corrigan, 2006; Davidson, Bellamy, Guy, & Miller, 2012; Davidson, Chinman, Sells, & Rowe, 2006; Gillard, Edwards, Gibson, Owen, & Wright, 2013; Greenfield, Stoneking, Humphreys, Sundby, & Bond, 2008; Lawn & Hunter, 2008; McDiarmid, Rapp, & Ratxlaff, 2005; Migdole et al., 2011; Nelson et al., 2007; Owstrow & Leaf, 2014; Pitt, et al., 2013; Repper & Carter, 2011; Resnick & Rosenheck, 2008; Rogers et al., 2007; Sells, Davidson, Jewell, Falzer, & Rowe, 2006; Simpson et al., 2014; Sledge et al., 2011; Spirito Dalgin, Maline, & Driscoll, 2011; Walker & Bryant, 2013). In 2007, Dennis Smith, Director of the Centers for Medicare and Medicaid Services, explained in a letter to all state Medicaid agency directors that peer support service is an evidence-based mental health model of care that consists of qualified peer support providers who assist individuals in their recovery from mental illness and substance use disorders. As a direct result, state Medicaid agencies started allowing reimbursement for peer support services, which provided the opportunity for certified Peer Specialist (CPS) training programs to be developed around the country (Katz & Salzer, 2007).

Because of its documented effectiveness, certified peer support specialists are a growing behavioral workforce that is essential in recovery-oriented environments (Salzer, 2010). The concept of Family and Youth Peer Support Specialist training and certification is an emerging concept and strategy for supporting parents with a child with a serious emotional disturbance (SED) as well as young adults with mental illness (Center for Health Care Strategies, 2013). The National Federation of Families for Children's Mental Health and family run organizations have

been strong proponents of the benefits of family and youth peer support for many years, advocating for the recognition and funding of these services through state and federal dollars, and their inclusion and sustainability as part of the broader array of children's services funded through Medicaid (Center for Health Care Strategies, 2013). Specific steps have been taken to develop a national certification process to train parents who have a child with SED as parent peer providers (The National Federation of Families for Children's Mental Health, 2014). In 2009 and 2010, The National Federation of Families for Children's Mental Health collaborated with family organizations, researchers, and treatment providers to collect and organize information about the role of parent support services in Systems of Care and other settings (The National Federation of Families for Children's Mental Health, 2014). As a result, the Certification Commission for Family Support was created within the National Federation of Families for Children's Mental Health. The Certified Parent Support Provider certification defines the uniform standards and title of parents helping other parents who have children (0-26) experiencing emotional, behavioral health, substance use, intellectual disabilities, or mental health concerns. The Certified Parent Support Provider program is a unique step in developing and implementing specialized peer support services that focus on specific populations. This specific certification program, however, has not been expanded to include peer support specialist certification for parents diagnosed with a mental illness.

Statement of the Problem

Some parents with mental illness are currently receiving services from peer support specialists. Specific life stressors and specialized program and service needs are more likely to be identified by peer support specialists who are also parents. The focus of this study is the lack

of information related to life stressors and program and service needs of parents and non-parents who are served by peer support specialists.

Purpose of the Study

The purpose of this study is to collect information related to peer support specialists perspectives of specific life stressors and program and service needs for parents and non-parents with a mental illness who receive services from peer support specialists. This study examines the most frequently identified life stressors and the level of importance for specialized program and services for parents and non-parents with a mental illness from a peer support specialist perspective. This information may provide background information to help determine whether the parental status of peer support specialists is important demographic information in determining the types of life stressors and program and service needs for parents with mental illness.

Research Questions

The following research questions guided this study.

1. What are the demographic characteristics of peer support specialists who are currently employed in Alabama?
2. What is the level of need for specialized services and programs for individuals with mental illness?
3. What are the most frequently identified life stressors indicated by peer support specialist for parents and non-parents?
4. What is the importance of specialized services/programs needed that are not available for consumers served by peer support specialists?

5. What is the level of importance for specialized peer support based on characteristics of the peer support specialist?

6. Who is the most under-served group of individuals with serious mental illness needing peer support services and supports?

7. What are the biggest barriers to receiving peer support service?

Limitations of the Study

The following limitations apply to this study.

1. For purposes of this study, only peer support specialists who provide peer support services to individuals with mental illness were included in this study.

2. The scope of this study was limited to peer support specialists who are currently employed full or part-time in the state of Alabama.

3. The questionnaire is a self-report measure that captures perspectives of peer support specialists at a specific point in time.

4. Results were limited to peer support specialists within the state of Alabama.

5. Results were limited to the extent that items on the researcher-developed questionnaire reflect life stressors and program and service needs of individuals with mental illness.

6. Results were limited to the extent that there is an adequate return of questionnaires by the respondents.

Assumptions of the Study

The following assumptions apply to this study.

1. The peer support specialists participating in this study are knowledgeable of the life stressors and program and service needs of parents and non-parents who receive services from peer support specialists.

2. Items on the questionnaire permit peer support specialists to identify life stressors and program and service needs of parents and non-parents who receive services from peer support specialists.

3. Participants are able to distinguish among the life stressors and program and service needs for parents and non-parents of those they serve.

4. The researcher-developed instrument is a valid and reliable instrument for peer support specialists to use to identify life stressors and program and service needs of parents and non-parents of those they serve.

Need for the Study

Although it has been concluded that while peer support services appear to have become a popular addition to mental health services, and peer support is considered an important component of mental health care, peer support is under-researched as a service aimed at specific subsets of individuals with mental illness. Multiple studies identify the need for parent peer support programs as a key service for parents with mental illness (Bassett et al., 1999; Diaz-Caneja & Johnson, 2004; Perera, Short, & Ferncacher, 2014; Nicholson, Biebel, Hinden, Henry, & Stier, 2001). This knowledge, however, has not led to the development of specialized peer support services that link peer support specialists who are parents with other parents with mental illness in need of support. It is not known whether being a parent is an important demographic element when pairing peer specialists with consumers in need of peer support services. It is also not yet known what the essential components would be when delivering a peer support program to parents with SMI who are caring for their children.

Significance of the Study

Although the peer support specialist program is a nationally recognized evidence-based practice, the research is very limited on identifying the program and service needs of parents with mental illness from a peer support specialist perspective. Results of this study may help identify whether the parental status of peer support specialists is an important demographic factor when pairing parents with mental illness with peer support specialists. If the mutual characteristics of the peer support specialist and the consumer are found to be an important factor, the need for a peer support provider program specific to parents with mental illness may be warranted. These findings may also identify additional service needs and barriers to accessing services for parents with mental illness. Results of this study could provide researchers, practitioners, and administrators with additional insight into the issues surrounding individuals with mental illness who are parents and highlight potential new mental health services for parents and non-parents to be developed and incorporated into the current mental health service spectrum.

In addition, findings from this study may provide the information needed for researchers, practitioners, and administrators to develop specific resources and services for both parents and non-parents with mental illness in order for them to live full and productive lives. With the development of specific services to address the specific needs of parents and non-parents, individuals with mental illness may be able to overcome specific barriers to recovery and be able to fully integrate into society.

Definition of Terms

Consumer: For the purposes of this study a consumer is a person who is obtaining treatment or support for a mental disorder, also known as psychiatric or mental illness. The term

was defined by people who use mental health services in an attempt to empower those with mental health issues. The term suggests that there is a reciprocal contract between those who provide a service and those who use a service and that individuals have a choice in their treatment.

Evidence-Based Practice: For the purposes of this study, an evidence-based practice is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of the individual patient. It means integrating individual clinical expertise with the best available external clinical evidence from systematic research. Evidence-based practice is the integration of clinical expertise, patient values, and the best research evidence into the decision making process for patient care. Clinical expertise refers to the clinician's cumulated experience, education and clinical skills. The patient brings to the encounter his or her own personal preferences and unique concerns, expectations, and values. The best research evidence is usually found in clinically relevant research that has been conducted using sound methodology.

Parent Support Provider: For the purposes of this study a parent support provider is a peer of the parent that is being supported. Their relationship is based on the sharing of their own parenting or "lived experience". The "parent" in "parent support" means a person who is parenting or has parented a child experiencing emotional, behavioral or mental health disorders and can articulate the understanding of their experience with another parent or family member. This person may be a birth parent, adoptive parent, family member standing in for an absent parent or a person chosen by the family or youth to have the role of parent.

Psychosocial Rehabilitation: For the purposes of this study psychosocial rehabilitation is a therapeutic approach that encourages individuals with mental illness to develop his or her fullest capacity through learning and environmental supports and services. These services often

combine pharmacologic treatment, independent living and social skills training, psychological support to clients and their families, housing, vocational rehabilitation and employment, social support and network enhancement, and access to leisure activities.

Recovery-Oriented Services: For the purposes of this study, recovery-oriented services are provided through treatment, services, and community-based programs by behavioral health care providers, peer providers, family members, friends and social networks, the faith community, and people with experience in recovery. Recovery-oriented services help people enter into and navigate systems of care, remove barriers to recovery, stay engaged in the recovery process, and live full lives in communities of their choice. Recovery-oriented services include culturally and linguistically appropriate services that assist individuals and families working toward recovery from mental and/or substance use problems. They incorporate a full range of social, legal, and other services that facilitate recovery, wellness, and linkage to and coordination among service providers, and other supports shown to improve quality of life for people in and seeking recovery and their families. Recovery-oriented services also include access to evidence-based practices such as supported employment, education, and housing; assertive community treatment; illness management; and peer-operated services.

Serious Emotional Disturbance: For the purposes of this study, serious emotional disturbance is the term used for a group of psychiatric disorders in children and adolescents which cause severe disturbances in behavior, thinking and feeling. Some serious emotional disorders are classified as mental illnesses. Children and adolescents generally have from two to four diagnoses.

Serious Mental Illness: For the purposes of this study, serious mental illness includes persons who are 18 years-of-age or older, who currently or at any time during the past year have

a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within the Diagnostic and Statistical Manual of Mental Disorders that has resulted in functional impairment which substantially interferes with or limits one or more major life activities. These disorders have episodic, recurrent, or persistent features but may vary in terms of severity and disabling effects.

System of Care: For the purposes of this study, a system of care model is an organizational philosophy and framework that involves collaboration across agencies, families, and youth for the purpose of improving services and access and expanding the array of coordinated community-based, culturally and linguistically competent services and supports for children and youth with a serious emotional disturbance and their families. The system of care philosophy is built upon core values and guiding principles, which include the following: 1.) Family driven and youth guided, with the strengths and needs of the child and family determining the types and mix of services and supports provided, 2.) Community based, with the locus of services as well as system management resting within a supportive, adaptive infrastructure of structures, processes, and relationships at the community level, and 3.) Culturally and linguistically competent, with agencies, programs, and services that reflect the cultural, racial, ethnic, and linguistic differences of the populations they serve to facilitate access to and utilization of appropriate services and supports and to eliminate disparities.

CHAPTER II. REVIEW OF LITERATURE

Introduction

Chapter one presented introductory information regarding parents with mental illness, statement of the problem, purpose of the study, the research questions, limitations, assumptions, and significance of the study. This chapter presents a review of the literature on the topic of parents with mental illness, with a specific focus on mothers with mental illness and the needs of their children. Information reviewed includes the perceived needs, identification of current barriers to mental health services, and recommended interventions and strategies for parents with mental illness and their children.

Mental Illness and Motherhood

According to the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA), more women than men experienced a mental illness in 2011 (SAMHSA, 2011). For women with mental illness, there are important biological differences related to hormones and brain structure that may affect mental health risks, rates of disorders, and the course of those disorders (Office of the Surgeon General, 2006). Multiple government-funded research studies show that women experience the same diseases at different rates or with different symptoms, or they may experience different kinds of illness altogether (SAMSHA, 2011). Research has demonstrated that estrogen and progesterone influence brain function and stress response in women, which results in increased vulnerability to depression during times of reproductive

endocrine changes, such as the premenstrual, postpartum, and premenopausal periods (Office of the Surgeon General, 2006).

The SAMHSA Expert Panel on Core Competencies for Women and Girls in Behavioral Health (2011) discusses the family centered needs of women and their children. According to SAMHSA, specific knowledge and skills around core competencies need to be developed in order to effectively provide mental health services to mothers with mental illness. This includes: 1) The importance of the role of mothering/parenting and how it affects most women's or girls' identities, especially in regard to their perceptions of what it means to be a mother; 3) The impact of mental health disorders on children of parents with serious mental illness, and 4) The logistics associated with the roles women and/or girls have with respect to caregiving, such as housekeeping, cooking, emotional caretaking, caring for children and meeting children's needs, keeping schedules, logistics, and caring for aging parents. All of these core competencies have an impact on a woman's identity and her ability to access services (SAMHSA, 2011).

According to Joseph, Joshi, Lewin, and Abrams (1999), in the context of deinstitutionalization, women with SMI who are mothers face increased challenges and traumas in the community. Women with SMI are likely to have a history of sexual victimization or prostitution, have more unplanned pregnancies and higher fertility rates, and have less stable partnerships than women without psychiatric illnesses. According to Felitti et al. (1998), there is strong evidence of a causal link between violence-induced neurological damage, the use of self-medicating measures, the adoption of health risk behaviors, and consequent chronic disabling health morbidity and early mortality. "Treatment as usual" that does not address trauma and the impact it has on mothers with SMI is associated with continued symptomology, custodial loss of

children, and continued cynicism regarding recovery on the part of consumers (Office of the Surgeon General, 2006).

Identifying the Experiences and Needs of Mothers with Mental Illness

According to Nicholson, Biebel, Hinden, Henry, and Stier (2001), most of what the public knows about mothers with serious mental illness usually appears in the news media. The accounts are tragic events in which a mother has severely injured or killed her children. There is a general assumption that mentally unstable mothers are dangerous and unable to care for their children (Nicholson et al., 2001). Unbeknownst to the public is the fact that these types of media events are rare. There are parents with serious mental illness successfully raising children and participating in family life without incident (Nicholson et al., 2001). However, it is important to address the needs and experiences of mothers with SMI who struggle with parenting roles so that they can receive the proper support they need (Nicholson et al., 2001).

The Meaning of Motherhood

Unfortunately there has been minimal qualitative research conducted to identify the experiences and feelings of parents who have a serious mental illness (Bassett et al., 1999). In addition, there has been little examination of mental illness' effects on the experiences of parents themselves (Benders-Hadi, Barber, & Alexander, 2013). A few studies, however, have focused on identifying the experiences and feelings of mothers with serious mental illness. Sands (1995) interviewed low income, single mothers with SMI to collect information on their feelings towards motherhood. The women stated motherhood was central to their existence, giving their lives meaning and focus. They also desired normalcy for themselves and their children. In other studies, women with SMI have identified motherhood as a central force keeping them involved with treatment, a key outlet for expression of feelings of care and concern, and a valued,

normative social role (Benders-Hadi, Barber, & Alexander, 2013; Carpenter-Song, Holcombe, Torrey, Hipolito, & Peterson, 2014; Montgomery, Tompkins, Forchuk, & French, 2006; Oyserman et al., 2000).

In a study by Benders-Hadi et al. (2013), 24 mothers in an inpatient large state psychiatric hospital in suburban New York were interviewed to develop an understanding of the characteristics and needs of this population. More than half reported being the primary caretaker of their children. Survey and focus group data revealed how important the role of motherhood was in giving purpose to their lives and helping them remain on track with treatment recommendations. Most of the mothers reported that they did not feel their mental illness had any effect on their ability to be a mother, while others indicated stigma presumes people with mental illness will inevitably be bad parents.

In an ethnographic pilot study, Carpenter-Song et al. (2014) interviewed three urban, low-income, African-American mothers diagnosed with serious mental illness over the course of a year to understand their lived experiences. A small sample size was used in order to achieve an in-depth case study. The findings indicated that the mothers had little to no involvement from the biological fathers. All three of the women rarely discussed their illness and viewed treatment with ambivalence. Most of the discussion involved struggles with everyday life including violence, loss, lack of safety, and financial insecurity. All three women experienced physical and sexual trauma and faced daily strains of financial insecurity. One woman attributed her depression and drug addiction to her traumatic childhood and took medication to ward off anxiety attacks brought on by the stresses in her life. Family life was the main focus for the women. Being a mother and the everyday work, worry, and joys of raising children brought meaning to their lives. The women took an active role in their children's upbringing and strove

to be a better mother in order for their children to have a better life than they did. All of the women were raising their children with little support from others. Faith in God was a constant source of solace and strength for all of the women in the study. This study highlights the need for family-centered supports, especially when the family is marked by a history of violence, deep poverty, and isolation (Carpenter-Song et al., 2014).

Montgomery et al. (2006) also explored the meaning of motherhood with 20 women with serious mental illness ranging in age from early 20s to late 30s. Sixteen mothers were living with their children, and of the four not living with their children, all had ongoing contact with them. The findings reflected the mothers' wishes to have meaningful relationships with their children. The core concern for this group of mothers was keeping close to their children. "Keep close" was a phrase used by some mothers to represent the purpose of their mothering behaviors. Mothers wanted a "bond so strong that it can't be broken" (Montgomery et al., 2006, p. 23). Keeping close was described as the way it was supposed to be no matter what had happened, or might happen, in illness. Keeping close to the children consisted of three categories; appearing normal, creating security, and being responsible. Watchfulness involved mothers' interpretation of the responses of others towards them. Their watchfulness allowed them to survive or to sustain their connections with the children.

Mothers derived notions of what was expected of them based on their interpretations of the ideal. Alice, a mother of two children, longed to be "perfect" (p. 23). Instead of sleeping at night she would read parenting magazines that reinforced her mothering. Claiming an identity as a good mother rested on the moral attributes of altruism and relentless commitment to their children. Placing the children's needs and interests ahead of their own affirmed them as mothers, while also affording them the opportunity to role model "appearing normal" (p. 23) for the sake

of the children. The women described living in chaos because of their illness and the ideal image of motherhood ironically served to become their undoing. The ideal image highlighted the fact that their mothering practices were "never good enough" (p. 23), intensifying their efforts to appear normal. Hence, the mothers became caught in a constricting downward spiral of either/or dichotomies – good/bad, strong/weak, patient/intolerant, happy/sad, talking/yelling and mother/witch. The mental illness undermined their efforts to appear normal, resulting in uncertainty about how to keep close.

In an effort to keep close with their children, the mothers described their mental illness as "a living hell", "cruel", "isolating", "unbelievable", "overpowering", "failure" and "unpredictable" (p. 23). The illness disrupted the purposefulness of their mothering practices and required mothers to strategize in order to keep close. Keeping close, while simultaneously keeping illness away from their children, involved mothers choosing pretenses that would imitate ideal representations of an appropriate mother. Mothers subverted their authentic identities by masking, censoring speech, doing mother work, and seeking help. The mothers intended to hide the illness and make it invisible. By portraying symbolic representations of the ideal mother in response to their perceptions of a situation, the mothers believed they were protecting the children (Montgomery et al., 2006). In addition, they were immunizing themselves against the effects of illness and were able to sustain closeness, but only to a point.

Montgomery et al. (2006) concluded from this study that in order to address the needs of mothers with SMI, it is essential to recognize their responsibility in the context of adversity. Such recognition would support the mothers' efforts to create meaningful relationships with their children. From the stance of the suffering, healthcare professionals would be required to shift their clinical lens from illness to the mothers' total life situations. For the mothers, an expression

of compassion from the listener enabled them to share their intimate struggles for the self-awareness needed for reconciliation of being a mother. To them, compassion meant that the listener appreciated their difficult choices in the midst of limited resources, their lack of affirmation, and their heightened sense of shame. This enactment of compassion required that healthcare professionals accept the mothers' difference, as opposed to judging them. When mothers in this study perceived a lack of that acceptance, they usually provided only the facts related to the signs and symptoms of their illness. Acknowledging their difference and the importance of their strategies of pretenses may foster the development of caring relationships built on the value of creating mothering possibilities sensitive to their situation.

Mowbray and Oyserman (1995) also explored the capabilities, challenges, and what motherhood meant to women with mental illness. Three overall themes about the meaning of parenthood emerged: the joys and delights associated with parenthood, parenthood as promoting personal growth and development, and parenthood as stressing. Most of the women mentioned positive feelings produced by their children's mere existence, rather than from what the children achieved or produced. Children represented a larger goal outside of the mother's own functioning. Several mothers indicated that their children were a strong motivating force in their own recovery. About 30% said that having children had kept them off drugs and/or off the streets. Similarly, many women indicated that having a child in itself was one of their greatest life pleasures. One woman stated it was one of her wildest dreams to become pregnant, while another woman stated having children made her the happiest person on the face of the earth. Thus children serve as resources by providing pleasure and also by providing a sense of purpose and worth and a sense of filling an important adult role (Mowbray & Oyserman, 1995). Mowbray and Oyserman (1995) emphasized that motherhood is traditionally an important social

role and one that women with a serious mental illness can attain. Therefore, it is critical that we learn more about these women's own conceptions of motherhood and their goals as mothers.

Bassett et al. (1999) explored women with mental illnesses experiences and feelings concerning their role as parents and how the mental illness has impacted that role. The study aimed to examine their perceptions of mental health services and areas in need of improvement. A number of themes were identified, which include fear of losing custody of their children, trauma of hospitalization, the stigma of having a mental illness, the isolation from family and friends, the need to be able to access community support services, the need for consistent staff, and the relationship they share with their children. From these themes, Bassett et al. discussed possible future directions for mental health services and community support services. This included development of the following:

Parenting programs. The mothers felt the need for education but also found a need for being able to "meet with people who are in the same boat and understand where I am coming from". They felt that it was important to have mental health service input in the group. They felt that mental health services should be sympathetic to their needs and understand some of the difficulties that they face due to mental illness. Mental health promotion and prevention is increasingly being seen as providing a framework for building better public health.

Links with other community agencies. The mothers felt that it is helpful to be linked into other community agencies, both governmental and non-governmental, that would be able to support them in their role as parents. They felt that this should begin while they are in-patients and then should continue once they are discharged. Case-managers could

take a more active role in this area. Information needs to be given when things are going well rather than being given when they are in crisis.

More supports in the community. A number of mothers commented on the shortage of resources in the community. Many had difficulty getting the help they sought in mainstream community services due to large waiting lists as well as location and timing of services. The mothers commented on the lack of respite care available to them when they were in crisis. Mothers that had access to this respite care found it most valuable and reassuring.

Education of families and communities. This is an area where mental health services need to join forces with consumers and caretakers to educate family members and the community at large regarding mental illness and the ability of the women with mental illness to care for their children. The mothers felt that once people knew they had a mental illness, they began to treat them differently. This was most distressing for them and undermined their confidence in their parenting role. The mothers also felt that the judicial system was weighted against them in residency and contact cases. They felt that the community needed to learn about "real" mental illness rather than Hollywood's kind of mental illness. It is necessary to work towards giving those with mental disorders more public and political attention so that they become better understood, less discriminated against, and have better access to general community life.

Acknowledgment of the existence of their children by the mental health service. So often children are not considered when people are admitted or discharged from hospital. Admission procedures need to include information regarding women's life roles and any concerns that they are experiencing in this area. Discharge planning needs to occur from

the beginning of the woman's inpatient stay, with closer working links between child and adult mental health services, in-patient services, and community services.

Custody as a Concern

The Bassett et al. (1999) themes mentioned above have also been identified in other research. The fear of losing custody is a significant theme for mothers with mental illness that has been found in numerous studies (Barrow & Laborde, 2008; Lagan, Knights, Barton, & Boyce, 2009; Nicholson & Blanch, 1994). Nicholson and Blanch (1994) interviewed twenty-five women with serious mental illness to examine areas of need with regards to relationships and community support services. Qualitative data revealed that mothers perceived the mental-illness related stigma to be an obstacle to maintaining custody of their children. In addition to the stigma, mothers in crisis were more likely to lose custody of their children if they had poor support networks (Lagan, Knights, Barton, & Boyce, 2009).

For mothers with SMI experiencing custody issues with their children, Hinden et al. (2005) acknowledged that children cannot remain in an environment that is unsafe, but stressed that findings indicate family disruption and custody loss can have devastating consequences for both parents and children. When removal occurs, separation affects both mother and child (Hinden et al., 2005; Lagan et al., 2009). Mothers experience grief, loss, and exacerbated symptoms (Hinden et al., 2005). Outcomes for children in out-of-home placement are comparatively poor in several crucial developmental areas, including language acquisition, emotional and social adjustment, mental health, academic attainment, and physical health (Lagan et al., 2009). Outcome studies show that removal of the child may be immediately pragmatic, but in very few instances does it produce a productive response (Lagan et al., 2009). It is not a lasting solution in guarding against risk (Lagan et al., 2009). Fox (2009) described guilt

following her for years for not being able to provide a major parenting role for her daughters. Fox (2009) states:

> Instead of encouraging and helping me to see and care for my young daughters, treatment providers viewed me as incapable of managing the stress of motherhood and discouraged me from taking a main caregiving role. I saw my girls on weekends when I could, but I missed out on many events in their lives. (p. 193)

Parents who have a serious mental illness are victimized twice according to Fox (1999). First they experience a devastating neurobiological illness through no fault of their own, and then they find themselves at risk of losing their children because they are viewed as permanently flawed and incapable of being an adequate mother (Fox, 1999).

Because of added scrutiny from society, there is a low threshold for inadequacy, which makes it difficult for the mothers who are symptomatic to prove they are competent parents (Lagan et al., 2009). Policies to promote speedier processes for the removal of children from the home and identify out of home placements may have an unintended discriminatory effects by singling out parents who have a serious mental illness to automatically be included on the fast track for termination of parental rights (Ackerson, 2003). Mothers living with a psychiatric illness are significantly overrepresented in protective care proceedings relative to the population prevalence estimate for psychiatric illness (Lagan et al., 2009). After the passage of the Adoption and Safe Families Act (ASFA) of 1997, some states have listed parental mental illness as grounds for not providing reasonable efforts to reunify a family (Kaplan, Kottsieper, Scott, Salzer, & Solomon, 2009). As a result of the ASFA, parents with mental illness face additional barriers within the child welfare system. This is despite the lack of evidence linking parental mental illness with a heightened risk of abuse or neglect (Kaplan et al., 2009).

According to Ackerson (2003), women who are mothers with a serious mental illness are caught in this gap between child welfare and the mental health system. The two systems differ in how they view mental illness and who is considered their responsibility. The mental health system has viewed the mental illness as an individual issue and has focused treatments and intervention strategies around the individual without considering the broader family context (Ackerson, 2003). The child welfare system usually intervenes when there is an "at-risk" placement outside of the home and utilizes assessment methods to recommend termination of parental rights that do not distinguish serious mental illness and those with other types of behavioral health problems (Ackerson, 2003). Inadequate linkage between mother-infant services and psychiatric care serves to widen the gap between what is required and what is available for supporting the dual needs of mother and child (Lagan et al., 2009).

In a small survey of women experiencing an acute hospital admission in the U.S., only 20% still had full custody of their children (Joseph et al., 1999). Similar findings have been documented in other research (Diaz-Caneja & Johnson, 2004). One mother participating in the *Living with Under Fives* program expressed her feelings by stating, "I'm just worried that the children's father might have something against me and take my children away from me. That's another fear I have. That…the loss of my children. I worry about that every day" (Bassett, Lampe, & Lloyd, 1999, p. 600). Diaz-Caneja & Johnson (2004) conducted a qualitative study with twenty-two women with serious mental illness and found that every mother in the study identified losing custody of their children as a main fear. The mothers viewed statutory agencies as decision makers when it came to whether or not their children should be taken away, and they did not feel that the agencies were interested in other types of parenting interventions or parenting support.

Implications of Trauma and Victimization

In addition to the fear of losing custody of their children, mothers with SMI are also more likely to deal with personal issues that include past trauma and victimization, with the prevalence of victimization among samples of women with SMI in published studies ranging from 53% to 97% (Nicholson et al., 2001). Symptoms and coping strategies associated with trauma histories may interfere with successful parenting, and mothers may have difficulty trusting their own assessment of their child's needs and their ability to meet those needs (Nicholson et al., 2001). The mothers may also have difficulty developing healthy relationships with mental health professionals. This, along with trying to cope with psychiatric symptoms, can be extremely overwhelming for the mother (Nicholson et al., 2001). It is important to remember that mothers with SMI who have had trauma and past victimization may need additional supports to develop a physically and emotionally safe environment for herself and her children (Nicholson et al., 2001).

Cogan (1998) interviewed 25 women to examine what difficulties within relationships they may have needed support and how well these needs were met by community services. The results showed that many women needed help with trauma related issues. These include emotional abuse within relationships (80%), different forms of sexual abuse (56-68%), accessing information about contraception, pregnancy, and sexually transmitted diseases (60%), and child custody issues (77% of mothers). The purpose of this specific study was to raise meaningful research questions that may precipitate more women-centered and effective treatment approaches.

Relapse, Hospitalization, and Mental Health Services for Mothers

Mothers with SMI also worried about relapse and hospitalization for multiple reasons. Not only does the illness itself create a sense of anxiety regarding stability and adherence to treatment, it also created a sense of anxiety with regards to the children's well-being and care (Bassett et al., 1999). Powell (1998) provided a personal account of her mother's hospitalization.

> It was 6 weeks before my mother returned home. I visited her once at the State hospital. My mother and I cried through most of the visit. To my mother, being in a State hospital was like being in an abattoir. Before the visit ended, she gave me a monkey she had made out of socks during one of her therapies. I kept this monkey for many years. Later, it reminded me of the pain I experienced seeing my mother in the hospital. She appeared very different when she returned. She moved slowly and she had gained weight. Her eyes appeared dazed, her speech was slurred, and at times her hands trembled. I tried extremely hard not to be afraid of her, but I did not know this person who used to be my mother: The mother who made me laugh when we watched television together, the mother who listened to music and danced with my friends and me, the mother who combed my hair for school each day, and the mother who made sure I was safe at night did not return home. She was no longer exuberant, and enjoyment seemed foreign to her. She appeared numb to the world that she felt had destroyed her life. From this time forward, my life was no longer the same. Somehow we became symbiotically united, and I knew that I would always need to take care of her in some way. (p. 176).

Fox (2009) stated that treatment providers missed out on a powerful motivating factor in her life. If they had valued her role as a mother, they may have been able to harness the motivation to see and care for her children. Fox goes on to state that if treatment providers put the same amount of

energy into supporting parents with a mental illness as they do trying to protect the person from the stress of this role, the rewards for all would be enormous.

Providers have yet to realize the importance of the mother's relationship with their children. This is a major motivating factor for mothers with serious mental illness (Blegen, Hummelvoll, & Severinsson, 2012; Diaz-Caneja & Johnson, 2004; Bassett et al., 1999). When interviewed, the vast majority of mothers expressed strong positive views about motherhood (Diaz-Caneja & Johnson, 2004). Mothers with SMI indicated that although the struggle with their mental illness depleted their energy and took up their attention, their children's needs for them as mothers were experienced as a powerful motivation to continue the struggle (Blegen, Hummelvoll, & Severinsson, 2012). However in treatment situations, mothers were obliged to prioritize their mental illness instead of the children's needs for proximity, attachment, and good mental health (Blegen, Hummelvoll, & Severinsson, 2012). This led the mothers trying to balance their own emotional difficulties, needs, and the demands of the treatment against their children's needs in each specific situation (Blegen, Hummelvoll, & Severinsson, 2012).
Six mothers described having children as a central incentive to recover and remain well, and obtaining the goal of maintaining parental responsibilities motivated the mothers to participate in treatment to prevent relapse (Diaz-Caneja & Johnson, 2004).

In a study conducted with women hospitalized at an inner-city, state-funded facility serving persons with severe mental illness, Joseph et al. (1999) found that all of the mothers felt that continuing to mother their children was important. Approximately half of the mothers described themselves as needing help in dealing with their own sadness about their children and wanted help to successfully maintain relationships with them. An important association between recovery-related constructs and parenthood have been overlooked by researchers, which may

show parenthood is positively associated with measures of hope, activation in treatment, and perceptions of recovery (Bonfils, Adams, Firmin, White, & Salyers, 2014).

Stigma and Misperceptions as Barriers for Mothers with Mental Illness

Stigma is the distinguishing factor between mental illness and heart disease, diabetes, or cancer (Nicholson et al., 2001). Smart (2009) stated that people with mental illness have been identified as among the most devalued of all people with disabilities. This stigma causes other members of society to distance themselves socially from individuals with mental illness and provide less emotional support (Smart, 2009). According the Substance Abuse and Mental Health Services Administration (2012), stigma leads others to avoid living, socializing, or working with, renting to, or employing people with mental illness, especially serious mental illness, such as schizophrenia. This leads to low self-esteem, isolation, and hopelessness for the individual with mental illness.

Nicholson et al. (2001) stated that stigmatizing beliefs and bias for women with mental illness are compounded even more by ignorance and misinformation about mental illness, pregnancy, and parenting. One of the single most pervasive factors affecting access to and participation in services for mothers with mental illness is the stigma accompanying the mental illness (Nicholson et al., 2001). Fear of losing custody, negative comments, and social isolation contribute to the mothers' resistance to seek treatment and continue participation in treatment services (Nicholson et al., 2000). In addition, according to Ackerson (2003), this bias and stigma has led the professional community to assume that parenting is not highly valued by women with serious mental illness. Therefore, outcomes for children and their mothers are compromised by ignorance and misinformation about mental illness, pregnancy, and parenting (Ackerson, 2003; Nicholson et al., 2001).

Stigma by mental health professionals is documented through research in numerous countries, including the United States, Brazil, Switzerland, Germany, England, and Australia (Courtis, Lauber, Costa, & Cattapan-Ludewig, 2008; Hugo, 2001; Lauber, Nordt, Braunschweig, & Rossler, 2006; Lepping, Steinert, Gebhardt, & Rottgers, 2004; Rao, Pillay, Abraham, & Luty, 2009). Although research is lacking in the area of mental health professional stigma and bias specifically towards women, or more specifically, mothers with mental illness, some of the research studies depicted women with mental illness in vignettes to assess attitudes towards people with mental illness (Hugo, 2001; Lepping et al., 2004).

Because stigma causes other members of society to distance themselves socially from individuals with mental illness, mothers with SMI express fear that people will find out about their mental illness and treat their children differently (Bassett et al., 1999). The mental health system has contributed to the stigma and stereotyped expectation that women with SMI are single, live alone, with parents or in supported accommodations, and do not have children (Diaz-Caneja & Johnson, 2004). In addition, the mental health system has not adequately acknowledged the possibility that women with SMI can parent successfully (Bassett et al., 1999). Many agencies which work with families affected by parental mental illness tend to have a singular and/or negative focus when defining their client base (Reupert & Maybery, 2007). Information is not routinely obtained about whether adults with mental illness have even given birth to a child, the ages of their children, where they are living, or who is caring for them. Parents with mental illnesses are also not routinely asked questions about their family (Mowbray & Oyserman, 1995). In a study conducted by Benders-Hadi, Barber, and Alexander (2013), 20% of the mothers surveyed in an inpatient psychiatric hospital setting had no mention of their children or motherhood role in treatment plans, despite clinicians' acknowledgement of this role

in other sections of the medical records. For the other 80%, there was mention of motherhood in treatment plans, but in about half of this subgroup, it was only noted but not elaborated upon. The fact that there is no consistent documentation of parenting status at this facility emphasizes the lack of acknowledgement of the motherhood role, and that parenting remains a forgotten role in the lives of patients in the mental health system (Benders-Hadi, Barber, & Alexander, 2013).

Although the likelihood that parents comprise a significant percentage of the inpatient or outpatient population, traditional programs, like ACT or PACT case management services, do not encompass the needs of adults as parents (Nicholson et al., 2001). The lack of services for both mother and child is compounded by the fact that the majority of State Mental Health Authorities (SMHAs) are unaware of the parenting status of the adult clients receiving public sector mental health services (Nicholson, Geller, Fisher, & Dion, 1993). From a national survey of SMHAs Directors regarding programs for mothers with mental illness, only 31 percent of SMHAs collected data on the parenting status of female clients and only 20 percent had policies regarding parenting for women receiving services (Nicholson et al., 1993). Less than one fourth of states require providers to formally assess the parental status of consumers and/or offer special services for parent consumers with serious mental illness (Biebel, Nicholson, Geller, & Fisher, 2006).

According to Mowbray and Oyserman (1995), administrators and practitioners must increase their awareness of parenting as a significant treatment and rehabilitation issue for women with SMI. Mowbray and Oyserman recommend developing collaborative community linkages and implementation of specific training programs for staff. Health and human agency workers also lack the skills and knowledge necessary to identify, refer, and/or intervene appropriately with different family members (Reupert & Maybery, 2007). In a study that

addressed workforce capacity to respond to children whose parents have a mental illness, Maybery and Reupert (2006) found four categories of barriers identified by workers when responding to patients about parenting and working with children. The first barrier included parental sickness and lack of insight into the mental illness. The second barrier related to the child in terms of accessibility as well as the workers' perception of the child's unwillingness to engage in discussions regarding his or her parent's mental health. The third barrier included lack of resources and time, not being part of the worker's role, and a lack of appropriate knowledge and skills regarding children and their parents with mental illness. Lastly, workers reported a barrier relating to the patient-worker relationship, fearing that including discussions about parenting and child-related issues might result in disruption to the patient-worker relationship. Maybery and Reupert recommended a two foci training for adult mental health workers; the first pertaining to parenting responsibilities and the second focusing on the child/children of the parent with the mental illness.

Expectations of the mental health system should also include assessments that capture information on whether women have children and their care arrangements (Mowbray & Oyserman, 1995). Mowbray and Oyserman (1995) suggested that intake data include assessments of mothers' strengths, not just deficits, and the meaning of children from the mothers' perspectives. Additionally, mothers with SMI face numerous hardships including inadequate housing, child care, and lack of social, emotional, or instrumental supports. These issues must also be addressed along with barriers to program participation and attainment of parenting goals (Mowbray et al., 1995).

Most of the literature that discusses parenthood by individuals with mental illness takes on a negative view due to concerns regarding the possible detrimental effects on children

(Ackerson, 2003). The focus of mental health literature has been parental pathology with little to no research on the assessment of parental competencies by women with serious mental illness (Ackerson, 2003). Adults with mental illness are often presumed to be incapable of parenting successfully and are at high risk for child welfare involvement and custody loss (Hinden et al., 2005). Studies from the 1980's found that mothers diagnosed with serious mental illness were more uncertain about their infant's needs, provided less social contact, were less involved with their infant, and less able to create a positive emotional climate (Oyserman et al., 2000). These results, however, were taken in the context of an era where newer medications, including the new antipsychotics, were yet to be developed. Other studies in the early 1990's echo many of the results from the 1980's as they provide information on the deficits of the mother and the impending risk of the children placed in their care (Oyserman et al., 2000).

Stigma not only exists in the professional community, but it also exists in many families of mothers with SMI. Lanquetot (1984) states, "I have been teaching inpatient children on the children's ward of Bellevue Psychiatric Hospital in New York City for 13 years, and yet I'm still wary of revealing the nature of my mother's illness. When I tell my friends about my mother, even psychiatrist friends, I regret my openness and worry that they will find me peculiar" (p. 467). Children's desire for a sense of normalcy contributes to the feelings of shame and fear that are part of the stigma associated with SMI. According to Lanquetot (1984),

> Feelings of shame and fear overwhelmed me in those early years, shame that my friends would find out that my mother was 'different' and fear that I would be 'different' too. The fear of being like Mother must have prevented me from studying ballet and piano seriously. My mother played the piano and danced, and she was schizophrenic. If I played the piano and danced, I would be schizophrenic also. (p. 468)

According to Diaz-Caneja and Johnson (2004), social isolation and stigma continue to be a recurring theme in multiple qualitative studies with mothers with serious mental illness. In semi-structured interviews with mothers with SMI who described their experiences, views about services, and needs for support in parenting, fourteen out of twenty-two women stated that stigma associated with mental illness created or exacerbated problems (Diaz-Caneja & Johnson, 2004). One woman states, "When you go to a play club or evening club with your children, you make friends with somebody and you can't say I have mental health problems because they would run away. They would say I don't want anything to do with her because she has mental health problems" (p. 476). Mothers also stated having concerns for their children. They were afraid their children would be rejected and ridiculed because of their mother's mental illness. Powell (1998), an adult child of a mother with a mental illness describes her feelings of stigma towards her mother and states:

> I learned to live two lives, the life with my mother and a more superficial life in the community.... No family member would talk about her condition. It appeared that they wanted her medicated and paralyzed... I soon followed my family's strategy. My mother became a secret that I learned to avoid exposing in order to protect the two of us from being scrutinized...In my mother's community, no effort was made to explain mental illness to family members. The effort focused instead on medicating the patient without treating the entire family, a strategy that perpetuated the lack of support and understanding in this particular community. (p. 176)

In a qualitative grounded study conducted by Perera, Short, and Fernbacher (2014) in Melbourne, Australia, nineteen mothers with mental illness were interviewed to determine their experiences, challenges, family relationships, and types of supports from services and families.

The participants spoke of broken relationships with partners, ex-partners, or family members. Several participants reported family members holding negative and stigmatizing beliefs about mental illness, while other participants indicated family members being the cause of past trauma and violence in their lives. This study emphasized the need for social support and an understanding from service providers that family relationships have implications for the type, quality, and level of support mothers receive from families, which may mean they do not have the support they need (Perera, Short, & Fernbacher, 2014).

Parents of adults with SMI can also contribute to the stigma of mental illness by avoiding the topic and denying the fact that their adult child may have a serious mental illness. In Lanquetot's (1984) personal account she describes her grandparents' denial:

> Mother was withdrawing more, spending the entire day lying on the bed, sleeping or doing exercises. She rarely left the house except to go next door to rant and rave at my grandmother while my grandfather stood nearby, patting her on the back and saying, 'Bonnie, my dear little Bonnie, everything will be all right'. Since neither of my grandparents would admit that their dear little Bonnie desperately needed help, we children could say nothing…We were afraid to talk about mother's behavior to our grandparents. They wouldn't admit that mother was mentally ill. (p. 469)

Children of Mothers with Serious Mental Illness

When discussing the needs of mothers with serious mental illness, it is necessary to include in the family context the needs of the child (Friesen, Katz-Leavy, & Nicholson, 2011). Very little attention is given to the children of mothers with SMI (Friesen, Katz-Leavy, & Nicholson, 2011; Nicholson et al., 2001; Nicholson, Cooper, Freed, & Isaacs, 2008; Riley et al., 2009). While no national data exists on the prevalence of children affected by parental mental

illness, if 22% of the general adult population in the U.S. qualifies for a psychiatric diagnosis each year, then the number of children affected is likely to be in the millions (Hinden et al., 2005). Most of the research, until recently, had focused and adopted a deficit view of children and young adults who cope with a parent's mental illness and has classified these young adults as "at-risk" for a variety of psychological problems (Nicholson et al., 2001). Several studies have focused on young adults to examine psychosocial outcomes for adult children including adult attachment issues (Duncan & Browning, 2009; Ackerson, 2003). Previous research studies have found that in families where a parent has a SMI, the child is also more likely to exhibit emotional or behavioral problems (Hinden et al., 2005).

Several decades ago, systematic observations established that children of parents with SMI were more likely to develop disorders themselves (Rutter & Quinton, 1984). Prevalence rates of disorder among children of parents with SMI have been found to be several times higher than that observed for children from the general population (Rutter & Quinton, 1984; Tebes, Kaufman, Adnopoz, & Racusin, 2001). In addition, it has been found that children of parents with SMI are more likely to be exposed to multiple risk factors, including familial and psychosocial risks that impact health and well-being (Erickson, 1998; Goodman, 1984; Minde, 1991). Despite these risks, many children are resilient and do not experience behavioral or emotional problems, or psychiatric symptoms (Tebes et al., 2001). According to Tebes et al. (2001), research has consistently shown that a significant portion of children with parents with SMI appear to exhibit enhanced adaptation in response to the increased role demands required in such adverse family circumstances. A child's risk for problems in adaptation may have less to do with parental mental illness, but rather with vulnerability processes that take place within the family and its immediate social environment (Tebes et al., 2001). Five areas that have garnered

empirical support are the following: Diminished family financial resources, social network constriction, impaired performance of parenting tasks, increased familial stress, and disruption of the parent-child bond (Tebes et al., 2001). Tebes et al. also found that reductions in family stress are most likely to be associated with reductions in child symptoms and problem behaviors; whereas enhancements of the parent-child bond are likely to be related to increased child competencies. It is suggested through these findings that interventions aimed at enhancing the parent-child bond may be most beneficial when they strengthen mutual feelings of attachment and caring between parent and child.

Mowbray et al. (2004) examined the psychosocial outcomes for teenage children of parents with serious mental illness that included academic, social, or behavioral domains. Methodology included cluster analysis and testing predictors of cluster membership from mother's clinical history and family contextual variables. Clusters included Socially and Academically Competent, Anxious and Depressed, Average/Adult-Oriented Youth, Delinquent/Peer-Oriented, and Isolated/Non-Conformists. The social contextual variables showed more and stronger relationships with cluster assignment than did the mother's clinical characteristics. Cluster assignment was not significantly related to mothers' diagnosis or hospitalizations or to years of maternal separation. Drug and alcohol abuse history was significantly related to cluster membership, with the Delinquent/Peer-Oriented cluster having mothers who reported more problems with substance use. The variables from the family context domain that significantly related to cluster assignment are similar to those predictors of resiliency. This is congruent with other research that stresses the importance of children having access to resources and supports beyond the mother to serve as an external anchor against the mother's likely instability and inconsistent parenting (Mooney, Oliver, & Smith, 2009).

Mowbray et al. (2004) found that resilience is multidimensional and suggests that pre-intervention research is needed to analyze clusters of risk factors at the personal level, rather than just the variable level. One intervention cannot assure positive outcomes for all individuals from an at-risk population, and some individuals with multiple risk factors may need several sequential or simultaneous interventions (Mowbray et al., 2004).

Research that focuses on attainting the needs and viewpoints of children and adult children of mothers with SMI is scarce (Foster, 2010). Because of the lack of empirical studies that specifically examine the nature of ongoing relationships between young adults and their mothers with SMI, Abraham and Stein (2008) examined young adults' self-reported felt obligation toward their parents, psychological symptoms, global psychological well-being, and interpersonal loneliness in three types of families: Families with mothers with SMI, families with fathers with SMI, and families with two non-distressed parents. The study found that felt obligation towards mothers to maintain contact, provide assistance, and be self-sufficient was equal across all three family types. Within families with a mother with a mental illness, young adults reported more psychological symptoms and interpersonal loneliness than the other two family types. However, higher scores of felt obligation to maintain rituals and contact with mothers were significantly associated with higher self-reported psychological well-being and reports of less loneliness. The general pattern of correlation is similar to previous research by Williams and Corrigan (1992) that suggested aspects of social relationships may mitigate the psychological adjustment difficulties typically associated with having a parent with SMI. Given that young adults generally feel greater connectedness with their mother, having a mother with SMI may be a particularly challenging life course disruption.

Both Riebschleger (2004) and Foster (2010) explored the experience of being a child of a parent with SMI and how they have coped with their experience. Foster (2010) interviewed ten adult children using an unstructured interactive interview. Nine out of the ten had a mother with SMI. Only one question was asked: 'Can you tell me what it was like growing up with a parent with a serious mental illness?' Findings from the interviews including four essential themes: Being uncertain of what will happen next; struggling to connect; being responsible; and seeking balance. The adult children described having a sense of not knowing what would happen next and not being informed about their parent's illness from family or health professionals. This led to the children attributing the symptoms of the illness to personality characteristics of their parents. Feelings of chaos and uncertainty throughout their childhood was a common thread. The participants also describe difficulties connecting with their parents, family, peers, and friends and feeling different from other children, which led to feelings of loneliness. Participants describe growing up quickly and being responsible for day to day household activities, including emotional responsibility for the family. The feelings of overwhelming chaos, responsibility, and loneliness led participants to look for various ways to care for themselves, including activities they found comforting and secure. Feelings of needing to regain a sense of control was common and participants recognized that this was because they felt unsafe as a child. The findings from Foster (2010) are consistent with previous literature that discuss children's lack of understanding about their parent's mental illness, lack of information from health care professionals, high level of parentification or role reversal, and subjective and objective burdens to caretaking responsibilities (Abraham & Stein, 2008; Reibschleger, 2004; Williams & Corrigan, 1992).

Although there are a few studies that capture the experiences of adult children of a parent with a mental illness, there is very little research that identifies the experiences of minor children

of a parent with a mental illness. Because of the lack of research based on this population, Reibschleger (2004) conducted a secondary analysis of data generated from a previous study that reported needs of children with a parent with a psychiatric disability (Riebschleger, Freddolino, Kanaga, & Miller, 1993). The purpose of the study was to explore a 'child's eye view' of living day to day in a family that included a parent with a psychiatric disability (Reibschleger, 2004). Twenty two children ages 5 to 17 were assessed from three prevention groups located in three community mental health agencies. Most of the children lived in single parent households with parents who were Medicaid recipients. Twelve children had a mother and five with a father with a mental illness. The children's experiences were categorized into four main themes: Good days, bad days, views of psychiatric disability, and perceptions of psychiatric rehabilitation. Good days for the children were described as feeling happy, having increased attention from parents, and engaging in family communication. Bad days were described by the children as feeling worried, scared, confused, or angry, having less interaction with parents, except for yelling, and decreased completion of daily tasks (parents not getting dressed, performing household tasks, going to work).

When describing the psychiatric disability, the children discuss what it meant to them in their day to day lives. They describe symptoms of the illness in terms of 'less attention' and 'yelling'. The children also stated feeling afraid of being moved to another home or losing their parent. Only a few of the children knew the diagnostic term for their parent's illness, with most describing the illness by the behavior of the parent. In regards to being informed or educated about their parent's illness, most were never told about their parent's illness. Five children described learning about it slowly over time through comparisons with other families, while four children stated it was a family secret no one talked about or discussed with others. Only two of

the 22 children stated they discussed their parent's illness with friends. Stigma was mentioned as a concern in the context of a parent being made fun of and asking if people treat you differently because you have a mental illness.

In regards to perceptions of psychiatric rehabilitation services, most of the children had limited knowledge about the aspects of their parent's treatment, including what medications their parents took. The children knew the least about hospitalization and stated they did not know why their parents had to go to the hospital. All but one expressed feeling uncomfortable with the hospital setting and lack of privacy. This study emphasized the need for increased family-based services that include child psychoeducation. Children need to have accurate information, reduced stress at home, and family-centered mental health environments for both parent and child (Riebschleger, 2004).

In a study conducted by VanDeMark et al. (2005), a descriptive profile was provided of children exposed to maternal substance abuse, mental illness, and violence. Consistent with prior research on children with multiple stressors, the majority of sampled children scored in the normal or better range for behavioral and emotional problems and strengths (Ruter, 1979, 1987; VanDeMark et al., 2005). According to VanDeMark et al., one important factor that may help explain the resiliency of these children is that they had the advantage of having parents who were willingly seeking treatment. Although the majority of children exhibited resilience, the sample of children was three times more likely to score in the clinical range on a measure of emotional and behavioral problems. Children falling in the low resilience subgroup had mothers with a greater level of mental health symptoms who had spent more days in homeless or domestic violence shelters. An unexpected finding was that this subgroup was also less likely to experience violence in their household and their mothers were less likely to report current symptoms of drug

use than children in the higher resilience subgroup. VanDeMark et al. (2005) suggested that it is possible that exposure to violence and parental drug problems introduced children to experiences that promote resilience in ways that are not evident in families that experience mental health problems.

Scherer, Melloh, Buyck, Anderson, and Foster (1996) studied how children of mothers with mental illness perceived their mothers and how these perceptions impacted the child's psychological adjustment. Their analyses indicated that children's perceptions of their mothers' mental health are significantly related to their psychological functioning. Children perceiving their mothers as manifesting symptoms of mental illness had more behavior problems, less perceived self-confidence, and less social support. Children who perceived their mothers using a more discouraging parenting style had mothers reporting more child behavior problems and less social competence. Children perceiving their mothers as discouraging also had self-perceptions of less scholastic and athletic ability, less confidence in physical appearance, global self-worth, and reduced perceptions of social support from parents, teachers and close friends. Children who perceived their mothers using more encouraging parenting skills reported feeling more confident in their athletic ability and more social support from close friends. It was also found that children of mothers with mental illness tended to perceive their mothers having less psychological distress than their mothers reported (Scherer et al., 1996).

Based on the findings, a child who is either underestimating or overestimating his or her mother's emotional distress may be missing an important and adaptive coping mechanism. Scherer et al. (1996) suggested that children can be taught to perceive and comprehend their mothers' behavior accurately, and mothers with a mental illness can be helped to identify and empathize with the effects of their emotional troubles on their children. Working conjointly by

enlisting the parents as change agents with their children may initiate systemic changes and reduce the risk status of children of mothers with mental illness (Scherer et al., 1996).

Providing strength and skills based services to children of women entering treatment for mental health problems offers an important opportunity to capitalize on the mother's motivation to change their own circumstances and to assess and concurrently provide services to their children (VanDeMark et al., 2005). Parental entry into mental health treatment offers a window of opportunity to reach out to the children who may not yet have evidenced serious problems, but who, without attention and support, are at risk for developing psychological problems in the future. It is recommended that service providers offer assessment and prevention or early intervention services to reduce risk of future subsequent problems (VanDeMark et al., 2005).

A particularly unique study by Riebschleger, Onaga, Tableman, and Bybee (2014) surveyed consumer parents in order to gain their viewpoint on what they recommend for developing psychoeducation programs for their minor children. This study deserves highlighting due to the lack of research on the parent consumer perspective regarding programs for their children. Riebschleger, Onaga, Tableman, and Bybee (2014) conducted three focus groups with 11 in each group. The consumers were ages 29-44, and the median income was $11,290 with two working full-time. Parents reported caring for a total of 34 children, aged 11 months to 17 years. The majority of parents were mothers or stepmothers (n = 27).

Recommendations on program content from the parents' perspective included learning about mental illness as a disease or real illness, including the symptoms and medications needed to manage the illness. Parents also wanted youth to learn that mental illness can be managed with active recovery and that it is important to follow the medication regime and treatment plan. Parents felt it was important to discuss genetic heritability and that is doesn't mean the children

will necessarily have a mental illness. They did, however, want to emphasize awareness and to know when to ask for help. In regards to stigma, parents relayed descriptions of stigma-related experiences. The parents felt it was important to teach youth about inaccurate stigmatized beliefs and how to respond to stigma situations. Lastly, parents emphasized youth coping and wanted their children to learn how to talk to the parent about the mental illness symptoms and ensure it includes age appropriate content.

This study provided valuable information from a parents' perspective on what they believe is important for psychoeducation for their children. The limitations of the study included a non-randomized sample with the majority being Caucasian consumers. It is important to expand focus groups to include more diversity and ensure a wide range of parents are included. In addition, the majority of parents had a diagnosis of major depression. This illness compared to schizophrenia is symptomatically different and therefore more parents with psychotic related illnesses need to be more represented. Riebschleger, Onaga, Tableman, and Bybee (2014) recommended mental health services revise their policies and procedures to include parenting within consumer oriented planning.

Personal Accounts from Children of Mothers with Schizophrenia

In a personal account from Lanquetot (1984), she discusses her feelings towards caregiving for her mother. Her grandparents made her mother "…the 'chosen one' (p 469), and her brother and herself took second place in the family, which she describes as opposite of a child's position in a normal grouping. Lanquetot (1984) goes on to say:

> We were frequently reminded that we would have to replace our grandparents as caretakers when we grew up… Having been told over and over again in our youth that it was our duty to take care of mother, my brother and I initially resented our burden. We

felt that since mother had not accepted the responsibility of her children, we should not have to be responsible for her. At that time it was difficult to admit that we actually loved our frail, unbalanced mother and wanted to help her. When we grew up, we began to understand why mother was different, and our resentment lessened. (p.471)

Cohen (1998) details her childhood experiences of living with her mother with SMI as well as her college and adult years of caring for her mother. In regards to normalcy and stability, Cohen (1998) describes what seems to be common with other adult children:

Nothing about my childhood appeared abnormal: two parents, mother home baking cookies, dad's lawyer's income adequate, lots of family values in our synagogue attending, holiday-celebrating household. Our brick, single family home sat on a Detroit tree-lined street in a safe, middle-class neighborhood. Behind the picture window and the tall blue spruce, Mother's mental illness took center stage, rendering my father, my younger sister and me bit players with no script to follow. One day I had an energetic "Mommy" redecorating the house, inviting strangers home for supper, filling the car trunk with packages she'd never open. Days later she would refuse food. Unable to rise from her bed, she'd lie curled in a fetal position, nearly catatonic. Then she would be hospitalized and I'd take over, her disease stealing my childhood. (p. 290)

Powell (1998) provides the reader with an intimate look into her life as a child of a mother with schizophrenia. Powell describes her childhood as a time of confusion, anxiety, and desperation and provides the reader with specific examples that impacted her life. Powell states:

During those few months before the hospitalization, it was difficult for my mother to remain in her work environment in a hosiery mill. Although supervisors described her as an excellent employee, she suddenly started accusing co-workers of plotting against her.

> The delusions were vague but tenacious. She had exceeded the limit on all her credit cards, and long-distance phone calls exaggerated the usual expense of the phone bill… Some discussions were cordial and reminiscent of times shared, but other calls accused people of harassing her or of being 'jealous' of her. The calls were usually made late at night or during the early hours of the morning. She was unaware of the inappropriateness of her behavior. She slept 2 to 3 hours a night and spent most of her time pacing in the house or walking up and down the road in clothing inappropriate for the weather or for societal expectations. She had developed a hostile, almost sarcastic character. By age 6, I realized that it was better to observe her behavior from afar and to remain confused about why she seemed to be having a conversation with "someone" I could not hear or see even when she was not on the phone. (p 175)

Lanquetot (1984) describes the chaos and unpredictability of her childhood while living with her mother with schizophrenia. Lanquetot gives an overview of the lifestyle she and her brothers had to endure and overcome. Lanquetot states:

> On the outside our house resembled those of our neighbors, but on the inside it was so different that there was no basis of comparison. Our house was a disaster. Everything was a mess. Nothing matched, furniture was broken, dishes were cracked, and there were coffee rings and cigarette burns clear across our grand piano. I was ashamed of our house. It was impossible to bring friends home. I never knew what my mother might be doing or how she would look. She was totally unpredictable. At best she was working on a sculpture or practicing the piano, chain smoking and sipping stale coffee, with a dress too ragged to give to charity hanging from her emaciated body. At worst she was

screaming at my father, still wearing her nightgown at 6 o'clock in the evening, a wild look on her face. (pp. 467-468)

Prevention and Intervention Strategies

An effective intervention strategy for individuals with serious mental illness is Assertive Community Treatment (ACT). This intervention has strong research support, is recognized as an evidence based practice for individuals with serious mental illness, and has a history of intensive service use (White & McGrew, 2013). White and McGrew (2013) surveyed Assertive Community Treatment (ACT) providers to evaluate team policies and practices for treating consumers who are parents. At its present state, the ACT model does not emphasize the role of parenting, nor has it been rigorously tested for its effectiveness in meeting the needs of parents with serious mental illness (White & McGrew, 2013; Bond, Drake, Mueser, & Latimer, 2001). White and McGrew (2013) found that although most ACT providers were comfortable discussing parenting issues with consumers, about 80% of providers endorsed negative or mixed attitudes about being a parent while managing a serious mental illness. Only 20% of the ACT providers offered specific programs for parent consumers. However, a few teams emerged that were more sensitive to the need of parent consumers.

In 2014, White and McGrew continued their research with ACT providers in order to examine the ACT teams to identify factors that may contribute to quality treatment for parent consumers. Parent sensitive ACT teams were found to seek out whether their clients were parents, spent significantly more time discussing committed relationships with consumers, significantly more likely to assist consumers with parent-child communication issues, and spent significantly more time discussing other parenting issues (parenting responsibilities, custody issues, parenting problems). Based on the preliminary findings, White and McGrew (2014)

recommended that providers be required to document parenting status of consumers in treatment services, providers regularly discuss parenting with consumers, perhaps during goal settings and/or treatment planning to ensure parenting needs are incorporated into the parent consumer's treatment plan, and that teams provide direct assistance with parenting needs of the consumers on their caseloads.

Through a qualitative study of programs for parents with serious mental illness and their children, Nicholson et al. (2007) found that parents with serious mental illness are likely to benefit from multimodal programs rather than narrowly defined interventions that address issues of access to essential resources and necessary parenting and illness management skills. In addition, the fact that outcomes for children and families depend on multiple factors suggests there are likely to be many opportunities for improving the well-being and functioning of both adults and children living with serious parental mental illness (Nicholson et al., 2007). However, according to Nicholson et al. (2007), these opportunities are often missed. Whereas the need is great, there are no evidence-based practices to improve outcomes for these families (Nicholson et al., 2007). Very few empirically tested parenting programs for women with mental illness and their children have been conducted (Nicholson et al., 2007). However, examining existing interventions is increasingly recognized as an important, complementary strategy for establishing evidence-based practices (Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006; Hinden, Biebel, Nicholson, & Mehnert, 2005). Researchers are encouraged to develop additional empirical studies that evaluate effectiveness over time (Hinden et al., 2006; Nicholson et al., 2007).

Although there is still a lack of empirical evidence, there have been recent developments of innovative programs for mothers with SMI and their children. Nicholson, Biebel, Hinden,

Henry, and Stier (2001) conducted a mail survey to the UMMS National Network mailing list of programs and providers of services for parents with mental illness in the United States. Results indicated there are at least 50 programs for parents with SMI, and of these, 25 "high specificity" programs were designed specifically for parents with SMI. Phone interviews with the "high specificity" programs indicated both similarities and differences. All programs shared a belief in the capacity of adults with mental illness to be parents. The programs acknowledged the needs of the parents were complex and that the current provision of services is fraught with barriers, which include insufficient and categorical funding and inappropriate and inadequate services (Nicholson et al., 2001). The providers uniformly reported that the mental health system is not well-suited or responsive to families. All of the programs shared common goals, which include addressing basic needs of the family, improving parents' coping and problem-solving skills, improving parenting skills, and enhancing child development (Nicholson et al., 2001).

Nicholson et al. (2001) also discussed program differences that reflect different developmental and funding histories, historical orientation, and design. Some programs were developed within the community mental health system, while others were developed in the child welfare system or inpatient psychiatric units. Most programs reported an eclectic, pragmatic orientation to services and treatment. Although the programs and services were extremely diverse, most fell into two dimensions: comprehensiveness and family-centeredness. The comprehensive type of program supported the multiple needs of the parents with mental illness, which includes both mental health and parenting needs. The family-centeredness programs reflect a design that serves the family as a unit, rather than focusing on the adult or child individually.

Although the goals of the programs were similar, the outcomes were diverse (Nicholson et al., 2001). Some of the programs had very specific and concrete goals, which included parent-child communication, or increasing the parent's understanding of child development. Other programs focused more on the overall functional adaptation of the parent and fulfillment of necessary adult roles. The comprehensive programs also included loftier and more global goals, such as enhancing the quality of life for all family members (Nicholson et al., 2001). In regards to evaluation, the programs reported having limited resources to collect outcome data. Most programs collected parent/child satisfaction data and clinical outcomes were captured in service plans. Standardized, objective evaluation data were not collected by the programs (Nicholson et al., 2001).

Hilton and Turan (2014) surveyed mental health and parenting support agencies in Ontario, Canada to identify the availability of parental support programs or services for parents with mental illness. Among the 119 mental health agencies, the most common parenting support service was referral to another agency (55%), while 23% offered no parenting support services at all. Most of the agencies surveyed offered at least one service, but only a small percentage offered direct services that included either parent support groups, family therapy, parent skills training, or child counseling. According to Hilton and Turan, the findings indicate that the lack of standardized programs for parents with mental illness and their children continue to remain an issue not only in the United States, but other countries as well.

Recommendations for Change

The above mentioned research studies have provided valuable information that will contribute to the development of evidence based practices for mothers with SMI and their children. Suggestions for essential key ingredients, defined as core processes, included

components that are family-centered, strengths-based, emotionally supportive, and comprehensive (Hinden, Biebel, Nicholson, & Mehnert, 2005). These key ingredients included:

- Family case management
- Twenty four hour crisis services
- Access to flexible funds
- Liaisons and advocacy
- Mediators reflecting parent-provider and provider-provider trust and communication
- Development of appropriate treatment plans
- Parent engagement and parent self-esteem/self-efficacy

Although the suggestions provided by Oyserman et al. (1994) were two decades prior, the suggestions remain relevant today and have yet to come to full fruition. Oyserman et al. suggested that the psychosocial rehabilitation framework address three key components when assessing mothers with SMI and their children. Mental health professionals, researchers, and policy makers must develop a comprehensive understanding of the following: 1) Mothers' environment, which may include addressing critical deficits of inadequate and unsafe housing, limited social networks, and lack of social and emotional supports; 2) Mothers' strengths, which includes being informed of the perspective that mothers with SMI have competencies and value the meaning of being a good parent; 3) Barriers to program participation and attainment of parenting goals (Oyserman et al., 1994). Mothers continue to be reluctant to ask for parenting assistance for fear that such requests will increase scrutiny by child welfare agencies and increase the likelihood their children will be taken from them. Mowbray et al. (1995) stated that administrators and practitioners must increase their awareness of parenting as a significant

treatment and rehabilitation issue for women with a serious mental illness. Expectations for assessments should change to include collecting information on whether women have children and their care arrangements. Intake data should also involve assessments of mothers' strengths, not just deficits, and the meaning of children from the mothers' perspectives. Given the hardships that many mothers experience, environmental deficits (such as inadequate housing, child care, lack of social, emotional, or instrumental supports) must be addressed as well as the barriers to program participation and attainment of parenting goals (Mowbray, 1995). This information should be integrated with clinical data and developed into a comprehensive plan for delivering mental health and rehabilitative services. Mowbray also emphasized the need for more attention on the mothers' feelings and needs with increased attention on relevant interventions for mothers with SMI and their children.

Considerations for Stakeholders

Nicholson, Biebel, Hinden, Henry, & Stier (2001) addressed critical issues for parents with mental illness and their children and provided steps to take for stakeholders from a consumer-researcher's perspective. Stakeholders were encouraged to consider the steps listed below when thinking about issues of parents with mental illness and their children. These steps included:

1. **Identify Adults with Mental Illness who are Parents.** Currently there is no standard method of state or national collection on the parenting status of adult clients with a psychiatric diagnosis.
2. **Recognize the Strengths of Parents.** Emphasize strengths in parenting skills and acknowledge successes of parents with mental illness.

3. **Battle the Stigma of Mental Illness.** Society, in general, still holds the false belief persons with a mental illness should not be a parent, and that they are incapable of raising and caring for a child. A key factor in treatment planning for parents and their children should include family unity. This can often accelerate recovery and improve outcomes of both parent and child.
4. **Attend to Custody and Visitation Issues.** Parents who appear in court to retain or obtain custody should be supported in preparing for court and should be encouraged to have a wellness plan. If parents lose custody, a request for a time line for regularly scheduled evaluations or progress reports of the parent should be requested. Treatment plans should outline objectives that include retaining or obtaining custody of the parent's children. How separation affects children should also be considered. When children visit their parent, cheerful and safe areas should be provided in mental health facilities.
5. **Attend to Termination of Parental Rights Issues.** Losing parental rights can be devastating for both the mother and child. Careful consideration must be given to whether terminating parental rights is in the best interest of the child. Peer-to-peer and support groups need to be developed that focus on parental custody issues.
6. **Attend to the Legal Issues of Parents.** Parents need help obtaining legal representation at a low cost, or no-cost basis if necessary. Emphasis should be placed on the need to keep families intact and the reunification of families that are separated from each other.
7. **Provide Supports for Children of Parents with Mental Illness:** Children of

parents with mental illness experience a wide range of emotions and life experiences. Children also feel shame, guilt, fear, blame, anger, and sadness, and may hesitate to bring home friends due to stigma. Children need an outlet to discuss their feelings, gather information about mental illness, and talk with other children in similar situations. Support groups specific to the needs of children need to be developed and implemented.

8. **Educate Professionals to the Needs of Parents:** There needs to be more education and training for mental health professionals, the court system, the legal system, and the child welfare system about the needs of parents with mental illness and the conditions that can exist in a parent-child relationship. Funding should be allocated to develop specialized programs that are specific to the needs of parents with mental illness.
9. **Peer Supports for Parents:** Parents with mental illness may have issues, concerns, and fears when it comes to parenting. Providing peer support groups, parent peer specialists, and parenting training can help alleviate many of the issues parents currently face alone without any supports. Additional peer supports should include 24 hour warm lines for parents to call when an issue or crisis arises. Web chat rooms, Facebook pages, Twitter, case management via text, and websites also need to be developed for parents with mental illness.
10. **Parenting as a Policy Priority:** Federal and state policy makers should place the issues parents high on their agenda. Legislation should be passed that gives parents with a mental illness equal rights as any other parent without a mental

illness. Policy makers need to realize that having a diagnosis of mental illness alone does not determine a person's ability to be a good parent.

11. **Coordinate Services for Parents:** Agencies and providers need to communicate with each other more effectively when working with parents with mental illness and their children. Coordination between agencies should facilitate the provision of more appropriate services and reduce duplication of efforts. Family unity should be the priority of all agencies and providers involved with the parent and child.

Nicholson et al. (2001) also provided specific recommendations for systems improvement. The need to obtain national prevalence data on the parenting status of adults with mental illness and their children is stressed first. Comprehensive questions must be asked regarding household composition, custody status, and care arrangements. Opportunities for subjective reporting must be provided to children of different ages and developmental stages in order to obtain information on the children's' experiences and needs. Current research must reflect the diversity of families and contemporary treatment and rehabilitation approaches.

Research is also needed in the area of child abuse and neglect among families with a parent with a mental illness. Factors that contribute to successful parenting must be identified in order to reduce risk to children. Past childhood trauma and victimization of the adult parents with mental illness must be explored further to determine the impact on their current relationship with their children. Research must be utilized to develop specific programs, trainings, and advocacy initiatives that focus on the needs and circumstances of these vulnerable families.

Systems capacity must be reviewed and enhanced to effectively meet the needs of parents with mental illness and their children. Programs and funding must be able to respond to the

needs of the entire family in a "wrap-around" approach. State mental health authorities are encouraged to take the lead in identifying clients as parents and consider the needs of the entire family as well as restructure services in order to effectively meet the needs of all family members living with a serious mental illness.

Knowledge dissemination across fields is also essential. Knowledge can be learned from other effective programs that focus on child-welfare preservation, incarcerated parents, substance abuse treatment initiatives, and public health support to families with HIV/AIDS. This information can be utilized to help inform the development of services and programs in the mental health system. In addition, knowledge obtained from the mental health system about parents with mental illness and their children must also be disseminated to other systems. Efforts need to be made to integrate and coordinate existing services to address the multiple needs of these families. If policy or program initiatives fail to take the whole family into account, any effort made will be less effective, more costly, and more fragmented.

In regards to services, Nicholson et al. (2001) suggested that current standardized programs, services, interventions, and treatment protocols must be studied and revised to overcome system-induced barriers to service utilization and treatment effectiveness. As services are coordinated, service professionals must review inter-agency agreements, MOUs, and vendor contracts to include language and expectations for family-centered, strengths-based care for parents with mental illness and their children. Replication of effective models and innovative programs including psychosocial rehabilitation strategies, ACT and PACT teams, and peer support specialists, should be applied to the domain of parenting.

In order to address stigma, training and advocacy efforts must target all systems and domains including child welfare, education and early intervention, primary care, legal and

criminal justice systems, and public health systems (Nicholson et al., 2001). Policy makers and program planners in each of these areas make decisions that impact parents with mental illness and their children. Training should be provided to child welfare workers, teachers, lawyers, providers, judges, law enforcement personnel, and health care professionals. The professionals and advocates must educate and inform legislators, policy makers, and the general public about the impact of their decisions on families with a parent with mental illness and potential cost-saving measures if agencies coordinated efforts.

In the mental health field, providers must acknowledge the significance of the parenting role for mothers with mental illness and the impact of parenting status on service utilization and treatment compliance for entire families. Mental health professionals trained in traditional adult or child programs must be encouraged to look at the family unit as a whole and consider the impact of only treating individual adult needs without addressing the issues of the entire family.

Advocates must work with parents with mental illness and their children to overcome stigma within the family. Children can be the recipient of secondary stigma and be teased or embarrassed to bring friends home. Stigma can create isolation for both the parent and the child. National advocacy networks and peer supports need to be developed and constituent groups that represent adults, children, or parents, must buy in to the needs for training and advocacy for parents with mental illness and their children.

Conclusion

Based on the extensive literature that emphasizes the need for improved services and supports for mothers/parents with mental illness and their children, it is clear this population group has undoubtedly been marginalized and disregarded as a priority for mental health and support services. It is still unknown as to whether the lack of service availability is due to

funding restrictions, lack of knowledge, lack of communication, or stigma and bias among the mental health profession. In order to move towards an integrated family-centered wrap around approach to service delivery for both mother and child, initial steps must be taken to formulate sound research practices that effectively address the needs of the mother as well as the immediate family. Moving from an individual to a family approach will take more than additional funding and training. It will also require a culture and philosophical shift that embraces the importance of serving the family, recognizing the importance of parenting, understanding the value of parenting for individuals with mental illness, recognizing the need to serve the child of the parent with mental illness, and believing individuals with mental illness have the capacity to be loving, supportive, and highly functioning parents.

CHAPTER III. METHOD OF STUDY AND INSTRUMENTATION

Introduction

Chapter one presented introductory information regarding parents with mental illness, the statement of the problem, and purpose of the study. Chapter one also provided limitations, assumptions, and significance of the study. Chapter two presented a review of the literature on the topic of parents with mental illness with a specific focus on mothers with serious mental illness (SMI) and their children. The specific experiences and needs of mothers with SMI and their children were discussed, as well as the stigma and misperceptions that serve as barriers for mothers with SMI. Specific prevention and intervention strategies currently available were reviewed and recommendations for change were also discussed. This chapter discusses the methods and procedures used to conduct the study. Information on the participants, location of participants, and the data collection instruments used are discussed. The chapter concludes with a discussion of the study design and procedures for data analysis.

Method and Procedure

The purpose of this study was to identify life stressors and specialized program and services for parents with mental illness from a peer support specialist perspective. The researcher initially explored the related research and literature on mothers with serious mental illness and their children along with recommended intervention strategies. Following a review of the literature, the researcher developed a questionnaire using survey methodology as the research design. The survey instrument was designed to collect demographic information and perception-

related information. The survey form was developed and distributed using the Qualtrics survey engine.

The researcher received final approval to conduct the study from the Auburn University Institutional Review Board in September, 2015. The researcher used two methods to obtain participant data. The first method was an email distribution asking participants to complete the survey by clicking a link within the body of the email. Next, the researcher developed an informational email that included the survey link and forwarded the email to the Alabama Department of Mental Health's Director of Consumer Relations. On the same day the Director of Consumer Relations sent a mass distribution email to the 133 existing mental health peer support specialists who are currently trained and certified. Participants were asked in the email to participate in a voluntary, self-directed online survey. Participants were informed it should take approximately 10 to 15 minutes to complete the survey. Once the participant clicked on the link included at the bottom of the email invitation, the participant was taken to the Information Page for participation in the study. On the informational page participants were made aware that their participation was completely voluntary and all data collected will be anonymous. Participants were made aware that they could quit the survey at any time with no consequences to them or their relationship to the Alabama Department of Mental Health, their employer, or Auburn University. No identifying information (name, address, or telephone number) was collected. If the participant agreed to participate after reading the Informed Consent information, the participant clicked on the "Agree to Participate" link and was taken to the first page of the survey. Sixteen participants responded to the initial request for participation.

For follow up to non-respondents, the researcher sent a reminder mass distribution email to the peer support specialists via the Director of Consumer Relations. Peer support specialists

were encouraged to participate in the survey if they had not already done so on day 10 after the survey was launched. Eight participants responded after the first follow up. The second follow up occurred on day 15 after the initial survey was launched. This follow up included distributing a paper version of the survey during a one-time in-person meeting. The timing for this follow up was based on the training schedule of participants. The researcher read the information letter and invitation script in person to peer specialists who were participating in the required peer specialist quarterly continuing education training in Clanton, Alabama, at the Alabama Power Conference Center. The researcher asked that anyone who had not already taken the online version of the survey and who wished to volunteer to participate to raise their hand to receive a paper version of the survey. Of the 72 attendees, 25 volunteered to participate. The researcher provided a manila envelope at the front of the room for participants to insert their completed survey form. Once all the surveys were completed and placed in the envelope, the researcher took the surveys to the researcher's place of residence and inputted the information into the Qualtrics software using a private and secure computer. The survey forms were stored in a locked, secure filing cabinet in the researcher's place of residence.

The third and last follow up occurred on day 20 from the date of the original email. The follow up emails included a thank you statement for those who had completed the survey and an encouraging reminder for those who had not completed the survey. Two participants completed the online version of the survey after the 3rd follow up request. After the conclusion of 30 days, the researcher closed the survey. Of the 133 existing certified peer support specialists in Alabama, 27 completed the online survey and 25 completed the paper version of the survey. The responses yielded a 39 percent response rate. Eight forms were incomplete and provided no

usable information. Therefore, the researcher collected usable data from 44 participants, which resulted in a 33 percent return rate.

Participants

Participants for this study were individuals with mental illness who currently serve as peer support specialists in Alabama. Participants were males and females who were at least 19 years of age and employed part-time or full-time as a peer support specialist. A total of 133 peer support specialists were recruited to participate. These 133 comprised the population of peer support specialists trained and certified as a peer support specialist at the present time in Alabama.

Instrumentation

Participants in this study were invited to complete a survey form developed by the researcher to collect demographic information and information related to the perceptions of the peer support specialist. Survey questions included (1) general demographic information, such as gender, race, and age group, (2) the number of consumers who received peer support services within the previous two weeks, (3) the amount of time spent with an individual providing peer support service, (4) whether peer support services are being provided to consumers who are parents or non-parents, (5) the number of consumers who are parents served per week, including the number of single mothers and fathers currently caring for their children, (6) type(s) of life stressor(s) for consumers who are parents and for consumers who are not parents, (7) and types of specialized services/programs needed, but not available for consumers currently receiving peer support. Open-ended questions included (1) ways that consumers are identified to receive peer support services, (2) the biggest barrier to receiving peer support service, (3) the greatest service/program need for consumers who are parents, and (4) the most underserved group of

individuals with serious mental illness needing peer support services and supports. All open-ended questions provided space on the survey form for participants to write their responses.

The level of need for specialized services was assessed using a Likert-type scale with values ranging from 1 to 10, with 10 indicating the highest need and 1 indicating the lowest need. The types of services being assessed included (1) parents with mental illness support groups, (2) money management/financial planning classes, (3) transportation services, (4) peer meet-up groups for socializing and recreation activities, (5) support groups for children of a parent with mental illness, and (6) supported employment programs.

Responses to determine the importance of specialized peer support services were measured using a three-point Likert-type scale, with values ranging from 1 to 3 with 1 being not important, 2 being somewhat important, and 3 being very important. Types of specialized peer support services included (1) peer support based on age, (2) peer support based on parental status, (3) peer support based on having one or more children with a mental illness, and (4) peer support based on having a parent with a mental illness.

Instrument validity was established by a panel of experts which included the Consumer Relations Director for the Alabama Department of Mental Health, the Coordinator of Adult Mental Illness Services for the Alabama Department of Mental Health, two community mental health executive directors, and a researcher. The panel of experts established face and content validity to assure that the instrument was clear and understandable and items were representative of items to identify life stressors and program and service needs.

Design of the Study

This was a descriptive research project to collect demographic information, as well as perception-related information for individuals who work part-time or full-time in Alabama as peer support specialists. Data were calculated using descriptive statistics.

Summary

This chapter presented information on the methods and procedures. Survey methodology was used to collect demographic and perception-related information from an existing pool of certified peer support specialists in Alabama. Participants included males and females at least 19 years of age who were employed either part-time or full-time as a peer support specialist. The survey form was developed by the researcher and was validated by a panel of experts. The survey form was disseminated both online and in-person. A total of 27 peer support specialists participated in the online version of the survey and 25 peer support specialists participated in the paper version of the survey. The design of the study was a descriptive research project and the data were calculated using descriptive statistics.

CHAPTER IV. RESULTS

Introduction

Chapter one presented introductory information regarding parents with mental illness, the statement of the problem, purpose of the study, limitations, assumptions, and significance of the study. Chapter two presented a review of the literature on the topic of parents with mental illness with a specific focus on mothers with serious mental illness (SMI) and their children. Chapter three discussed the methods and procedures used to conduct the study. Information on the participants, location of participants, and the research instrument used were also discussed. This chapter presents the results of the data analyses.

The current study implemented an exploratory investigation to identify life stressors and specialized programs and services for parents and non-parents with mental illness from a peer support specialist perspective. Both demographic and perception-related questions were assessed using a survey form developed by the researcher (See Appendix 1). The following research questions guided this study.

1. What are the demographic characteristics of peer support specialists who are currently employed in Alabama?
2. What is the level of need for specialized services and programs for individuals with mental illness?
3. What are the most frequently identified life stressors indicated by peer support specialist for parents and non-parents?

4. What is the importance of specialized services/programs needed that are not available for consumers served by peer support specialists?

5. What is the level of importance for specialized peer support based on characteristics of the peer support specialist?

6. Who is the most under-served group of individuals with serious mental illness needing peer support services and supports?

7. What are the biggest barriers to receiving peer support service?

Results

The results of this study are reported for each research question. The first research question was stated as follows: *What are the demographic characteristics of peer support specialists who are currently employed in Alabama?*

The first research question sought demographic information on participants. Of the 52 respondents, 8 were excluded due to incomplete survey forms or not being employed full-time or part-time at the time of the survey distribution. Forty-four participants were included in the analyses. Of the 44 included in the analyses, 26 (59%) were female, 17 (38.6%) were male, and one did not select a gender. The most common age group was 46-55 (n=17; 38.6%). Five individuals (11.3%) ranged from 25-35 years of age and 14 (31.8%) were age 56 or older. For race, 25 (56.8%) were Caucasian and 17 (38.6%) were African-American. For marital status, 15 (34%) were divorced, which ranked the highest. Thirteen (29.5%) were legally married and 11 (25%) never married. For parental status, 31 (70.5%) were parents and 13 (29.5%) were not parents. The majority of parents had either 1 (22.7%) or 2 (25%) children and only 1 (2.3%) had five or more children. The demographic data are reflected in Table 1.

The employment status of the participants was almost evenly distributed with 21 (47.7%) working full-time and 23 (52.3%) working part-time. For those working part time, participant hours worked per week were evenly distributed and represented a wide range of hours (2-30) worked. For current place of employment, the majority of participants worked for a public community mental health center (n=21; 47.7%) and 16 (36.4%) indicated "other". Places of employment for "other" included group homes, non-profit organizations, and urgent care clinics. For type of programs the participant served, 14 (31.8%) indicated residential, 12 (27.3%) outpatient, and 10 (22.7%) community day treatment. Twenty-two (50%) also indicated the "other" category. Some of the program examples indicated for the "other" category included intensive outpatient, crisis hotline, and homeless outreach. Employment data are reflected in Table 2.

The number of consumers served by the participants within the past two weeks ranged from 0 (2.3%) to 150 (2.3%) and was equally distributed. The average amount of time spent providing services to a consumer ranged from 0-10 minutes (n=3; 7.3%) to more than two hours (n=11; 25%). The majority of participants (n=30; 73.2%) spent between 30 minutes to more than two hours with an individual providing peer support services. Of the 44 participants, 36 (81.8%) stated that they provided peer support services to parents with a mental illness, and 5 (11.4%) stated the parental status was unknown. Of the parents served, 14 (31.8%) participants stated they served single mothers currently caring for their children and 11 (25%) stated unknown. Fourteen (31.8%) stated that they served single fathers currently caring for their children and 10 (22.7%) stated unknown. Parental status of consumers served by peer support specialists are reflected in Table 3.

Table 1

Demographic Characteristics of Peer Support Specialists

Variables	(f)	Percent
Gender		
Male	17	38.6
Female	26	59
Race		
White	25	56.8
African American	17	38.6
Others	2	4.6
Age		
18-24	0	0
25-35	5	11.3
36-45	8	18.2
46-55	17	38.6
56+	14	31.8
Marital Status		
Legally Married	13	29.5
Divorced	15	34.1
Never Married	11	25
Others	4	11.3
Parental Status		
Parent	31	70.5
Non-Parent	13	29.5

Table 2

Employment Characteristics of Peer Support Specialists

Variables	(f)	Percent
Employment Status		
Part-time	23	52.3
Full-time	21	47.7
Place of Employment		
Community mental health center	21	47.7

Other	16	36.4
Types of Programs Served		
Residential	14	31.8
Outpatient	12	27.3
Community day treatment	10	22.7
Other	22	50.0

Table 3

Parental Status of Consumers Served by Peer Support Specialists

Variables	(f)	Percent
Parental Status of Consumers Served		
Parents Served - Yes	36	81.8%
Parents Served - Unknown	5	11.4%
Single Mothers		
Single Mothers Served - Yes	14	45.2%
Single Mothers Served - Unknown	11	35.5%
Single Fathers		
Single Fathers Served - Yes	14	43.8%
Single Fathers Served - Unknown	10	31.3%

The second research question was stated as follows: *What is the level of need for specialized services and programs for individuals with mental illness?*

This research question addressed six different categories of need. The category of highest need was support groups/programs for children of a parent with a mental illness with a mean of 8.76 and standard deviation of 2.072; the maximum score was 10 and the minimum score was 2. The category with the second highest need was support groups for parents with a mental illness with a mean of 8.55 and standard deviation of 2.127; the maximum score 10 and the minimum score was 3. The categories with the lowest need both had a mean of 8.0. These categories were peer groups for socializing and recreation (SD=2.631) and money management/financial

planning classes (SD=2.405); the maximum score for both groups was 10 and the minimum score was 1. The level of need data are reflected in Table 4.

Table 4

Level of Need for Specialized Services and Programs

Types of Services and Programs	N	Mean	Std. Deviation
Support groups/programs for children of a parent with a mental illness	38	8.76	2.072
Support groups for parents with a mental illness	38	8.55	2.127
Peer groups for socializing and recreation	38	8.0	2.631
Money management and financial planning	38	8.0	2.405

The third research question was stated as follows: *What are the most frequently identified life stressors indicated by peer support specialist for parents and non-parents?*

This research question addressed the most frequently identified life stressors for parents and non-parents based on 18 life stressor items for parents and 15 life stressor items for non-parents. The life stressors listed for parents included medication management, anxiousness, depression, loneliness, benefits/insurance, feelings of hopelessness, symptom management, physical health issues, employment issues, housing issues, concerns about their children, custody issues with their children, conflict with spouse/partner, family health problems, legal issues, parenting skills, and two "other" write in categories. The life stressors listed most often for parents included housing (n=26; 59%), depression (n=22; 50%), anxiousness (n=21; 47.7%), feelings of hopelessness (n=20; 45.5%), and employment issues (n=19; 43.2%). For life stressors specific to parents, parenting skills (n=14; 31.8%), concerns about their children (n=12; 27.3%), and custody issues (n=12; 27.3%) were not listed as the most common life stressors. The life stressors listed for non-parents included medication management, anxiousness, depression,

loneliness, benefits/insurance, feelings of hopelessness, symptom management, physical health issues, employment issues, housing issues, conflict with spouse/partner, family health problems, legal issues, and two "other" write in categories. The life stressors listed most often for non-parents included depression (n=31; 70.5%), feelings of hopelessness (n=27; 61.4%), loneliness (n=26; 59%), anxiousness (n=25; 56.8%), employment issues (n=25; 56.8%), housing (n=24; 54.5%), and medication management (n=22; 50%). The data for the most common life stressors for both parents and non-parents are reflected in Table 5.

Table 5
Most Common Life Stressors for both Parents and Non-Parents with a Mental Illness

Types of Life Stressors	(f)	Percent
Parents		
Housing	26	59
Depression	22	50
Anxiousness	21	47.7
Feelings of hopelessness	20	45.5
Employment issues	19	43.2
Parenting skills	14	31.8
Concerns about their children	12	27.3
Non-parents		
Depression	31	70.5
Feelings of hopelessness	27	61.4
Loneliness	26	59
Anxiousness	25	56.8
Employment issues	25	56.8
Housing	24	54.5
Medication Management	22	50

The fourth research question was stated as follows: *What is the importance of specialized services/programs needed that are not available for consumers served by peer support specialists?*

This research question addressed the level of importance for three specific specialized services needed but not available to consumers served by the participants. These services included conflict management classes, parenting classes, and family support groups for parents and their children. The specialized service ranked as the highest need was family support groups for parents and their children, with 16 (36.4%) participants ranking it first. For parenting classes, 19 (43.2%) participants ranked this service as the lowest need compared to conflict management classes and family support groups. The level of importance for three specific specialized services is reflected in Table 6.

Table 6

Level of Importance for Specialized Services Needed but Not Available

Types of Services and Programs	Highest Importance (f)	Highest Importance Percent	Lowest Importance (f)	Lowest Importance Percent
Conflict management	12	35.3	9	20.5
Parenting classes	6	17.6	19	43.2
Family support groups for parents and their children	16	45.7	6	13.6

The fifth research question was stated as follows: *What is the level of importance for specialized peer support based on characteristics of the peer support specialist?*

This research question addressed the level of importance for specialized peer support consumer preferences based on characteristics of the peer support specialist. These characteristics included (1) mutual age of the peer specialist and consumer being served, (2) parents of a child with a mental illness assisting other parents of a child with a mental illness, (3)

parents assisting other parents with a mental illness, and (4) adolescents/young adults of a parent with a mental illness assisting other adolescents/young adults of a parent with a mental illness. Of the four peer support consumer preferences, mutual age of the peer specialist and consumer being served received the lowest number of ratings, with 22 (50%) participants rating the service as very important. Twenty-eight (63.6%) participants rated parents assisting other parents with a mental illness as very important. As a close second, 27 (61.4%) of the participants rated adolescents/young adults of a parent with a mental illness assisting other adolescents/young adults of a parent with a mental illness as very important. For parents of a child with a mental illness assisting other parents of a child with a mental illness, 25 (56.8%) rated this service as very important. Very few participants (0 to 3; 6.8%), rated any of the specialized services as not important. The level of importance for specialized peer support consumer preferences is reflected in Table 7.

Table 7
Level of Importance for Peer Support Consumer Preferences

Mutual Characteristic of the Peer Specialist and Consumer being Served	Very Important (f)	Very Important Percent	Somewhat Important (f)	Somewhat Important Percent	Not Important (f)	Not Important Percent
Age	22	57.9	13	34.2	3	7.9
Parent of a child with a mental illness	25	65.8	10	22.7	3	7.9
Parent with a mental illness	28	73.7	9	23.7	1	2.6
Adolescent/young adult of a parent with a mental illness	27	71.1	11	28.9	0	0

The sixth research question was stated as follows: *Who is the most under-served group of individuals with serious mental illness needing peer support services and supports?*

This research question provided participants the opportunity to write their response to identify the most under-served group with serious mental illness who need peer support services and supports. The most under-served group identified by participants (n=9; 20.50%) included individuals who are homeless, six (13.6%) participants identified youth and young adults, three (6.8%) identified individuals who are minorities, two (4.5%) identified veterans, two (4.5%) identified men, and two (4.5%) identified individuals with serious mental illness who live in rural areas. The most common under-served groups are reflected in Table 8.

Table 8
Most Common Under-Served Groups with a Mental Illness Needing Peer Support Services

Group	(f)	Percent
Individuals who are homeless	9	20.5
Youth and young adults	6	13.6
Minorities	3	6.8
Veterans	2	4.5
Men	2	4.5
Lives in rural area	2	4.5

The seventh research question was stated as follows: *What are the biggest barriers to receiving peer support service?*

This research question provided participants the opportunity to write their response to identify the biggest barriers to receiving peer support service. The main themes included lack of knowledge about peer services (n=7; 16%), lack of funds/non-billable service (n=7; 16%), lack of time to serve consumers due to the limited number of peer specialists available (n=5; 11.3%), lack of professional support (n=6; 9.1%), lack of employment opportunities for peer specialists (n=3; 6.8%), lack of transportation (n=2; 4.5%), lack of consumer willingness to receive peer

services (n=2; 4.5%), and lack of access to peer services (n=2; 4.5%). The most common barriers to receiving peer support service are reflected in Table 9.

Table 9
Most Common Barriers to Receiving Peer Support Service

Group	(f)	Percent
Lack of knowledge about peer services	7	16
Lack of funds/non-billable service	7	16
Lack of professional support	6	4.5
Lack of time due to limited number of peer specialists	5	11.3
Lack of employment opportunities for peer specialists	3	6.8
Lack of transportation	2	4.5
Lack of consumer willingness to receive peer support services	2	4.5
Lack of access to peer support services	2	4.5

Summary

This chapter presented information on the results of the study. The design of the study was a descriptive research project and the data were calculated using descriptive statistics. Survey methodology was used to collect demographic and perception-related information from 44 participants, of which 59 percent were female and 38 percent were male. The participants were almost equally distributed with employment status of either full-time or part-time. Almost half of the participants were employed at a local public community mental health center and worked in a variety of locations including residential care, outpatient treatment, and community day treatment programs. The majority of the participants (70.5%) were parents and were either legally married (29.5%) or divorced (34%).

The level of need assessed for specialized services and programs indicated that support groups/programs for children of a parent with a mental illness ranked the highest followed by

support groups for parents with a mental illness. The most frequently identified life stressors for both parents and non-parents were similar. Participants listed internal life stressors, which included depression, anxiety, feelings of hopelessness as the most common stressors for both groups. Loneliness was listed as a common life stressor for non-parents, but was not a common life stressor for parents. Only 14 participants listed parenting skills as a common life stressor and only 12 participants listed concerns about their children as a common life stressor for parents. For external life stressors, participants listed housing and employment issues as the most common for both groups.

In regards to level of importance for specialized services needed but not available, participants ranked family support groups for parents and their children as the highest importance most often with parenting classes ranked the least often. For level of importance for peer support services based on mutual characteristics, three out of four participants ranked being a parent with mental illness who serves other parents with mental illness as very important. Seventy-one percent ranked being an adolescent/young adult of a parent with mental illness who serves other adolescents/young adults with a parent with mental illness as very important.

For the open-ended questions, participants listed being homeless the most often with youth and young adults listed second most often. Almost half of the participants (n=20) listed either lack of knowledge about peer services, lack of funds/non-billable service, or lack of professional support as the biggest barriers.

CHAPTER V. DISCUSSION

Introduction

Chapter one presented introductory information regarding parents with mental illness, the statement of the problem, purpose of the study, limitations, assumptions, and significance of the study. Chapter two presented a review of the literature on the topic of parents with mental illness with a specific focus on mothers with serious mental illness (SMI) and their children. Chapter three discussed the methods and procedures used to conduct the study, and chapter four presented the results of the data analyses. This chapter addresses the implications of the findings presented in chapter four, discusses the limitations of the study, and presents suggested areas for future research.

Overview of the Study

The focus of this study was to obtain information about the perceived program and service needs for parents and non-parents with a mental illness from certified peer support specialists. In this study the researcher investigated how certified peer support specialists identify life stressors and specialized program and services for parents and non-parents with mental illness. Both demographic and perception-related questions were assessed using survey methodology. The researcher used a sample of currently certified peer support specialists in Alabama. The certified peer supporters were contacted via email and in person requesting their participation and how to participate. Of the 133 existing certified peer support specialists in Alabama, 27 completed the online survey and 25 completed the paper version of the survey. The

responses yielded a 39 percent response rate. Eight forms were incomplete and provided no usable information. Therefore, the researcher collected usable data from 44 participants, which was a 33 percent return rate. The data were analyzed using descriptive statistics in order to investigate the research questions.

Implications of the Findings

Research Question 1: What are the demographic characteristics of peer support specialists who are currently employed in Alabama?

In this study, demographic factors were assessed for peer support specialists currently employed full-time or part-time in Alabama. For gender and race, participants reflected the demographic characteristics of the overall population in Alabama, but were divorced at a higher rate (34%) than the general population (11.4%) in Alabama. For parental status, 70.5 percent were parents. This finding correlates with previous research which indicated 68 percent of women with a serious mental illness are mothers and 57 percent of men with a serious mental illness are fathers (Nicholson, Biebel, Katz-Leavy, & Williams, 2004).

In regards to employment, participants worked in a variety of settings including residential, outpatient treatment, community day treatment, and psychiatric hospitals and served individuals in both a one on one service and in a group setting. The location, types of programs served, and the number of individuals served reflect the finding of previous research (National Coalition for Mental Health Recovery, 2014).

Because it was unknown whether parents were currently being served by peer support specialists, it was important to determine a baseline for the number of parents currently receiving peer support service. Participants were asked to indicate the number of mothers and fathers served within the past two weeks in order to have a reasonable time frame for recollection. Of

the 44 participants, thirty six (81.8%) stated that they provided peer support services to parents with a mental illness. Because it is now known parents are being served by a majority of peer support specialists, this information provides a framework for future in-depth studies relating specifically to parents currently receiving or needing peer support services.

Research Question 2: What is the level of need for specialized services and programs for individuals with mental illness?

The level of need was assessed using a Likert-type scale with 1 indicating the lowest need and 10 the highest need. Of the six different categories of specialized services and programs, participants rated support groups/programs for children of a parent with mental illness the highest with a mean of 8.76. This finding validates the need for specialized programs and services for children of a parent with mental illness as indicated in previous research. Adult children described growing up with a parent with a serious mental illness as being uncertain of what will happen next, struggling to connect, feeling different from other children, and feeling lonely (Foster, 2010). The findings from Riebschleger (2004) also emphasized the need for increased family-based services that include psychoeducation and emotional support. An additional study provided feedback from parents diagnosed with a mental illness regarding psychoeducational program content for their children. The parents recommended including learning about mental illness as a disease or real illness, including symptoms, medications needed to manage the illness, and the ability to be active in recovery. Parents also emphasized the need for their children to be aware of when to ask for help, be knowledgeable about inaccurate stigmatized beliefs, how to respond to stigma situations, and how to develop positive coping skills (Riebschleger, Onaga, Tableman, & Bybee, 2014).

Support groups for parents with a mental illness received the second highest level of need for specialized programs and services with a mean of 8.55. Because participants were individuals with a mental illness, with a large majority being a parent, this finding also validates previous research indicating the need for programs for parents with mental illness that allow parents with a mental illness to meet and share information with other parents with a mental illness (Bassett et al., 1999). As indicated by Maybery and Reupert (2006), parents with mental illness need a venue to receive support from their peers in order to alleviate current barriers identified by mental health professionals when responding to individuals with mental illness and their children. In addition, single mothers with mental illness may not have the family support they need, which in turn, may require them to seek social support and understanding from peers (Perera, Short, & Fernbacher, 2014). Nicholson, Biebel, Hinden, Henry, & Stier (2001) recommended peer supports for parents because parents with mental illness may have issues, concerns, and fears when it comes to parenting. Providing peer support groups, parent peer specialists, and parenting training can help alleviate many of the issues parents currently face alone without any supports. Nicholson, Biebel, Hinden, Henry, & Stier (2001) also recommend a 24 hour warm lines for parents to call when an issue or crisis arises, along with web chat rooms, Facebook pages, Twitter, and case management via text.

Research Question 3: What are the most frequently identified life stressors indicated by peer support specialist for parents and non-parents?

The most frequently identified life stressors were similar for both parents and non-parents with a mental illness. Internal stressors including depression, anxiety, and feelings of hopelessness were common across both groups. Therefore both groups experienced the same types of internal stressors more often than other types of stressors. For parents with mental

illness, the findings are similar to previous research that indicates the day to day struggles are more often related to violence, loss, worry, lack of safety, and financial security (Carpenter-Song et al., 2014). The internal feelings of depression, anxiety, and feelings of hopelessness are also discussed in previous research where mothers with mental illness expressed distress, lack of confidence, and feeling ostracized due to the stigma of mental illness (Bassett et al., 1999).

For external life stressors, participants listed housing and employment issues as the most common for both parents and non-parents. Both housing and employment are basic life needs that are necessary for personal safety, security, and continued recovery. For children of a parent with a mental illness, the main cause of maladaptation is not necessarily parental mental illness. The risk for problems in adaptation is more often associated with diminished family financial resources and increased familial stress (Tebes et al., 2001). Therefore, housing and employment are life stressors that must be addressed for individuals with a mental illness and their families in order to avoid increased internal stressors, adjustment problems, and vulnerability within the family.

Research Question 4: What is the importance of specialized services/programs needed that are not available for consumers served by peer support specialists?

The level of importance for three specific services, conflict management, parenting classes, and family support groups for parents and their children, were ranked from 1 being the lowest importance to 3 being the highest importance. Family support groups for parents and their children ranked as being the most important (n=16; 45.7%) and parenting skills ranked as being the least important (n=19; 43.2%). The ranking of family support groups as the highest importance also correlates with the findings in research question number 2, which identified support groups for children and parents as the highest need.

The level of importance placed on parenting skills may be associated with the fact that the majority of participants, who are both consumers and parents, may not view parenting skills as a need for either those they serve or themselves. Because they have similar characteristics to those they serve, it may be difficult to be unbiased or objective when determining the importance of services. The term parenting skills may be viewed negatively by parents with mental illness as it may indicate a lack of ability to be an effective parent. This possibility needs to be explored further as research indicates parents with mental illness often feel ridiculed and viewed as permanently flawed and incapable of being an adequate parent (Fox, 1999). In addition, parenting skills may not in fact be needed to the level other services are needed because it could be an assumed need based on professional bias.

Research Question 5: What is the level of importance for specialized peer support based on characteristics of the peer support specialist?

The question as to whether peer support services need to be developed based on specific mutual characteristics of the peer support specialist and consumer being served has been raised in recent years. It was unknown as to whether peer support specialists themselves viewed common mutual characteristics as an important factor when pairing someone for peer support services. This research question addresses whether peer support specialists view certain mutual characteristics as very important, somewhat important, or not important. Of the six identified mutual characteristics, peer support specialists ranked each one as very important over 50 percent of the time. The mutual characteristic receiving very important the most frequently was a parent with mental illness assisting others parents with a mental illness (n=28; 73.7%), with adolescents/young adults of a parent with mental illness assisting other adolescents/young adults of a parent with mental illness as a close second (n=27; 71.1%). These findings indicate a need

for peer support specialists to be paired with individuals based on mutual characteristics of parental status as much as possible or feasible. The findings also indicate a need to develop specialized support programs for youth/young adults who have a parent with a mental illness. Currently, mental health services are provided to the individual with the mental illness and fail to address the needs of the whole family. This finding further validates the need for additional research to be advanced in order for specific services to be developed for the youth/young adults of parents with a mental illness.

Research Question 6: Who is the most under-served group of individuals with serious mental illness needing peer support services and supports?

This research question provided participants the opportunity to write their response to identify the most under-served group with serious mental illness who need peer support services and supports. The most under-served group identified by participants (n=9; 20.50%) included individuals who are homeless and youth and young adults (n=6; 13.6%). Because of the vulnerabilities of these two groups, it is important mental health providers develop specific strategies to develop outreach initiatives for individuals who are homeless or a youth/young adult to receive peer support services.

Research Question 7: What are the biggest barriers to receiving peer support service?

This research question provided participants the opportunity to write their response to identify the biggest barriers to receiving peer support service. The main themes included lack of knowledge about peer services, lack of funds/non-billable service, lack of time to serve consumers due to the limited number of peer specialists available, lack of professional support, lack of employment opportunities for peer specialists, lack of transportation, lack of consumer willingness to receive peer services, and lack of access to peer services. Based on the main

themes identified by the participants, it is evident more outreach and education is needed to inform individuals with mental illness about peer support services. Without adequate information and knowledge about peer support services, the effectiveness of the program becomes greatly diminished. In addition, the lack of funding greatly reduces the availability of peer support specialists and impacts the time spent with individuals needing peer support services. Policy change needs to occur at the state Medicaid level to incorporate peer support services as a billable service in order for peer support services to be available to an individual when needed.

Another theme that needs attention is the lack of professional support. Training and advocacy efforts that emphasize the value of peer support services must target professionals in all systems and domains. Because stigma by mental health professionals is documented through research in numerous countries (Courtis, Lauber, Costa, & Cattapan-Ludewig, 2008; Hugo, 2001; Lauber, Nordt, Braunschweig, & Rossler, 2006; Lepping, Steinert, Gebhardt, & Rottgers, 2004; Rao, Pillay, Abraham, & Luty, 2009), it is imperative that leaders in the mental health field develop mechanisms to alleviate professional bias towards coworkers diagnosed with a mental illness. Peer support specialists need to be able to work in an environment where they feel valued as a colleague and not separated or isolated from other employees based on stigma or social hierarchies.

Limitations

The results of the current study are not without limitations. One limitation was the sample size. The sample was limited to peer support specialists currently certified in Alabama who are either employed full or part-time. Results from this study may have been different if peer support specialists from other states or countries were included in this study along with peer support specialists who are not currently employed. In addition, participants chose to answer the

questions on the survey based on self-selection. Individuals who did not participate in this study may have produced different results. Because the sample size for participants was small, additional data analyses could not be conducted in order to compare the viewpoints of parents and non-parents or other subgroups.

A second limitation to the study included the accuracy of the data. Although the study was administered online and in-person, the results from the participants' responses depended upon honest answers. Participants also could have answered the questions in a way that would be viewed as pleasing to the researcher. Also, participants may have had selective memory and were unable to remember all of their interactions with individuals they served. For the participants who took the survey in-person, fatigue could have played a factor due to the participants completing the survey immediately after participating in training during the morning hours and eating lunch. In addition, the results were dependent upon whether the respondents understood the questions and that the questions reflected the life stressors and program and service needs of individuals with mental illness. Lastly, bias could have played a part due to the fact the participants also had a mental illness and were asked to determine the needs of individuals with a mental illness that they served. Participants also may have self-selected to participate based on the topic of the survey, which could have skewed the results.

A third limitation to the study included time constraints. The study was open for a period of one month and the results reflected the perceptions of the participants at a particular point in time. Additional research is needed at different points in time to address this limitation. Lastly, the questions on the survey were limited in order for the survey to be completed within a reasonable time frame. All possible answers were not accounted for which adds rigidity to the survey instrument. Additional questions regarding parents with a mental illness and their

children need to be explored further and different methods of asking the questions need to be developed.

Recommendations for Future Research and Practice

The research for this study focused on certified peer support specialists currently employed full or part-time in Alabama. The focus of this study was to obtain demographic and perception related information to determine the life stressors and program and service needs of both parents and non-parents with a mental illness from a peer support specialist perspective. The study was designed so it could be replicated with other peer support specialists in other environments. Although the peer support specialist program is a nationally recognized evidence-based practice, the research is very limited on identifying the program and service needs of parents and non-parents with mental illness from a peer support specialist perspective. **Therefore, additional research is needed to obtain the perspectives, ideas, suggestions, and opinions of peer support specialists as it relates to parenting needs of individuals with mental illness and their children.** Peer support specialists provide unique insight because they are peers with a mental illness who also function as a service provider. Findings from this research study indicate that peer support specialists spend more time with an individual with a mental illness than traditional service providers. This allows both the peer support specialist and the individual receiving service to develop rapport, trust, and a sense of comradery that parents with mental illness have reported as difficult to develop with traditional mental health providers (Diaz-Caneja & Johnson, 2004; Fox, 2009; Montgomery et al., 2006)

The results of this study also identified parental status of the peer support specialist as an important demographic factor when pairing parents with mental illness with peer support specialists. **Therefore, a peer support provider program specific to parents and children of**

parents with a mental illness is both needed and warranted. The results of this study also identified additional barriers, life stressors, and groups who need peer support services. Additional research is needed to explore these findings in greater detail in order to develop specific methods to address these concerns. With a continued focus on identifying the needs of parents and non-parents with a mental illness, researchers, practitioners, and administrators will gain additional insight into the issues surrounding individuals with mental illness and develop innovative mental health services that should be incorporated into the current mental health service delivery system.

Given the findings of this study, the following recommendations are summarized below.

1. **Public and private insurance payment models need to be restructured to support both the individual with a mental illness and their immediate family.** Based on the findings of this study, participants rated support services for children of parents with mental illness as the highest need and highest level of importance over other types of specialized programs and services. The current payment structure for Medicaid and other types of insurance reimbursement does not allow for the entire family unit to receive services and supports. Children of parents with mental illness are rarely identified as needing additional supports and services. This is in spite of the fact that numerous studies indicate otherwise (Aldridge, 2006; Aldridge & Becker, 2003; Hinden, Biebel, Nicholson, & Mehnert, 2005; Mowbray, Bybee, Oyserman, Allen-Meares, MacFarlane, & Hart-Johnson, 2004). Family support should be a reimbursable service for mother, child, spouse, parents, and siblings. Although individualized treatment may take into account the parent's treatment needs, it rarely addresses other issues important to her or him, including their children and how they are adapting to their parent's illness, how well

they are coping, worries about custody or ridicule from neighbors, financial worries, lack of emotional support, inadequate housing, and lack of transportation. Therefore, family services must be incorporated into the current billing structure for mental health treatment.

2. **Public and private insurance payment models need to be restructured to ensure peer support models are a billable service.** Based on the findings of this study, participants stated lack of funding for peer support services is a main barrier to receiving peer support services. The Peer Support Specialist Service Model is an evidence-based practice that has been proven effective in multiple studies. As with the Assertive Community Treatment Model, which is billable through the Medicaid Rehabilitation option and focuses on consistent, caring, person-centered relationships that have positive effects upon outcomes and quality of life, the Peer Support Specialist Service Model must also be included as a billable service. As stated in previous research, the Centers for Medicare and Medicaid Services recognized peer support service as an evidence-based mental health model of care that consists of qualified peer support providers who assist individuals in their recovery from mental illness and substance use disorders. As a direct result, state Medicaid agencies started allowing reimbursement for peer support services, which provided the opportunity for certified Peer Specialist (CPS) training programs to be developed around the country (Katz & Salzer, 2007). However, this reimbursement option is currently not mandatory or required in state Medicaid plans. Without the ability for providers to bill for peer support services, it will remain difficult for individuals with mental illness, which includes parents with mental illness, to access peer support service as part of their continuum of care.

3. **Current treatment models should be reevaluated and enhanced to address the specific needs of parents with mental illness and their children**. The findings of this study indicate a need for additional programs and support services for parents with mental illness and their children. Although current treatment models like Assertive Community Treatment have been proven to be very effective keeping individuals out of the hospital and stable in the community, priority populations have not included individuals who are the sole caretaker for their children (White & McGrew, 2013). Priority populations for these services are typically single males with a recurring history of inpatient hospitalization. However, the family unit is highly vulnerable and in need of additional attention from mental health providers (White & McGrew, 2013). Mental health services currently focus solely on the individual with a mental illness, but fail to recognize the importance of proactively addressing the psychological, emotional, and cognitive impacts of mental illness on immediate family members. Children and youth are especially vulnerable to the impacts of mental illness on the parent because the child is dependent on the parent for stability, support, and emotional and physical care. Therefore, children and youth of a parent with a mental illness, and in particular, children living with a single parent with a mental illness, must be included in the list of those considered a high priority for access to mental health services and supports. As stated by Nicholson et al. (2001), current standardized programs, services, interventions, and treatment protocols must be studied and revised to overcome system-induced barriers to service utilization and treatment effectiveness. As services are coordinated, service professionals must review inter-agency agreements, MOUs, and vendor contracts to include language and expectations for family-centered, strengths-based care for parents

with mental illness and their children. Replication of effective models and innovative programs including psychosocial rehabilitation strategies, ACT and PACT teams, and peer support specialists, should be applied to the domain of parenting (Nicholson et al., 2001).

4. **Specialized peer support programs need to be developed for parents with mental illness, with emphasis on single mothers caring for their children.** Participants in this study rated support groups/programs for parents and their children as the highest need. Parents with a mental illness, especially single mothers who are caring for their children, are particularly vulnerable to social isolation, stress, financial hardship, and lack of resources (Reupert & Maybery, 2007; Beardslee, Versage, & Gladstone, 1998). Because of these vulnerabilities, single mothers with a mental illness and their children should be considered a high-risk group in need of more intensive and more frequent mental health supports. This high-risk group needs to have access to peer support service, which should be considered an essential service in their mental health care continuum. Multiple studies have reiterated the need for parent and child specific interventions that are part of a wide array of family-focused modalities (Nicholson et al., 2007; Hinden, Biebel, Nicholson, & Mehnert, 2005; Riebschleger, 2004; Mowbray, 1995). Therefore, peer support services for parents and their children is one specific intervention that should be included in a family-oriented model of mental health care.
5. **Self-analysis of pre-existing stigmas and bias must be brought to the forefront for discussion for those in training to become mental health professionals and for those currently practicing in the mental health/rehabilitation field. Education on gender differences and parenting needs should also be integrated within rehabilitation and**

counseling courses. Participants in this study rated lack of professional support as a main barrier to receiving peer support services. Therefore, professionals at every level, including administrators and practitioners, need ongoing professional education that includes information that addresses stigma and bias within the counseling/mental health field. There is also a specific need for increased awareness on the topic of parenting, because it is a significant treatment and rehabilitation issue for women with mental illness (Diaz-Caneja & Johnson, 2004). In addition, the mental health profession remains steeped in the Medical Model, where the individual is automatically placed in a devalued group that society often considers worth much less than someone without a disability (Smart, 2009). The Medical Model ignores the individual's role function and environmental demands and automatically assumes the person with a mental illness cannot equally contribute to society or be a functioning and successful parent who can live a meaningful life (Smart, 2009). The mental health professional must move from a Medical Model mentality to a Social/Empowerment Model of disability.

6. **Technology (i.e. text messages, Facebook, online support groups, webchats) should be utilized to expand and enhance support services for mothers/parents with mental illness and their children, which includes training for families on technology utilization.** Because this study emphasized the need for additional programs and supports for parents with mental illness and their children, additional tools should be developed that are cost-efficient and easily accessible. Some of the most inexpensive but effective resources are now connected to technology. Social media strategies like peer networking, blogs, on-line support groups, twitter, and text messaging are quickly becoming common tools for communication with family, friends, co-workers, and other professional groups.

Not only is it necessary to develop in-person support groups for parents and their children, it is also necessary to develop alternate means of support so parents and their children can access from home or away from the treatment center. Having the alternate means of support increases the likelihood that the support services will be accessed and utilized (Foster, O'Brien, & Korhonen, 2012; Diaz-Caneja & Johnson, 2004).

7. **Additional research is needed in order to increase the knowledge base for effective interventions and support services for parents with mental illness and their children.** Currently, there is a lack of research into the needs of parents with mental illness and their children from a peer support specialist perspective. In addition, there are few studies that adequately research effective interventions and support services for parents with mental illness and their children (Nicholson et al., 2007). Researchers in the field of mental health must acknowledge the need for the development of evidence-based practices for this population group (Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006; Hinden, Biebel, Nicholson, & Mehnert, 2005). In order for mental health professionals to have access to evidence-based practices for parents with mental illness and their children, there must be a recognized need and desire for additional research that identifies what type of services and supports are most effective.
8. **Agencies must provide parents with mental illness and their families with the training and support needed to be effective advocates for systems change.** Advocacy has been the cornerstone for change in the public mental health system in this country. Conditions and services have been significantly improved because of advocacy and litigation of concerned individuals who would no longer accept injustice. With the strategic efforts of engaged advocates, a low priority can quickly become one of the

highest priorities. Unless parents with mental illness and their children demand services to meet their needs, it is unlikely change will happen quickly, if ever. Therefore, there must be continued advocacy from various fronts that demand parents and children receive equal treatment that meets their specific needs.

Conclusion

This study examined the perceived program and service needs for parents and non-parents with a mental illness from certified peer support specialists' perspectives. Both demographic and perception-related questions were assessed using survey methodology. The survey was delivered via email with an online survey link and in-person with a paper version during a one-time training event. Of the 133 existing certified peer support specialists in Alabama, 27 completed the online survey and 25 completed the paper version of the survey. Results of this study indicated that peer support specialists are currently serving parents with a mental illness in Alabama. Participants rated support groups/programs for children of a parent with mental illness and support groups for parents with a mental illness as the two programs with the highest levels of need. The most frequently identified life stressors were similar for both parents and non-parents with a mental illness. Internal stressors including depression, anxiety, and feelings of hopelessness were common across both groups. For external life stressors, participants listed housing and employment issues as the most common for both parents and non-parents.

Results of the study also found pairing with individuals based on mutual characteristics of parental status and the identification of having a parent with a mental illness as very important most often. This finding indicates a need for peer support specialists to be paired with individuals based on mutual characteristics of parental status as much as possible. Peer support services also

need to be expanded to reach other specialty populations including individual who are homeless and youth and young adults with a mental illness. The biggest barriers to receiving peer support services included lack of knowledge, funding, time, and professional support.

The results of this research on identifying the life stressors and program and service needs for parents and non-parents from a peer support provider perspective indicates that specific programs are warranted that are currently not available. Some of these programs include support groups for parents with mental illness and support groups for youth/young adults with a parent with a mental illness. Future research is needed to explore parenting needs in depth from a peer support specialist perspective and to further investigate the specific service barriers identified, which prevent individuals from receiving the benefits of peer support service.

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Appendix 1

Alabama Peer Support Specialist Survey

Peer Support Specialist General Demographic Information

1. Gender

☐ Male ☐ Female

2. Age

☐ 18-24 ☐ 36-40 ☐ 51-55
☐ 25-30 ☐ 41-45 ☐ 56-60
☐ 31-35 ☐ 46-50 ☐ 61+

3. Race

☐ Black/African American ☐ American-Indian ☐ Native Hawaiian/Pacific Islander
☐ White ☐ Asian ☐ More than one race
☐ Hispanic ☐ Alaskan Native ☐ Other _____

4. Marital Status

☐ Legally Married ☐ Separated from spouse ☐ Widowed
☐ Never Married ☐ Divorced ☐ Common Law/Cohabitating

5. Parental Status

☐ Parent ☐ Not a parent

6. If a parent, number of children

☐ 1 ☐ 3 ☐ 5
☐ 2 ☐ 4 ☐ 6 or more

7. Employment Status

☐ Full-time ☐ Unemployed/Looking for work ☐ Student
☐ Part-time (hours per week_____) ☐ Other _____

8. If employed, where is your current primary place of employment?

☐ Community Mental Health Center
☐ Veterans Administration Hospital
☐ Public State Hospital
☐ Vocational Rehabilitation
☐ Private Hospital
☐ Other _____

9. Type(s) of program(s) you serve (check all that apply)

☐ Day Treatment Program
☐ Consumer Run Drop in Center/Clubhouse
☐ Inpatient Hospital Setting
☐ Vocational Rehabilitation
☐ Therapeutic Recreation
☐ Outpatient
☐ Residential Program
☐ Other _____

10. Within the past two weeks, APPROXIMATELY how many consumers did you provide peer support services (ex. mentoring, coaching, connecting with resources, facilitating or leading recovery group activities, assisting with social supports, etc..) ?

Number of consumers you served within past two weeks _____

11. How are consumers typically identified to receive peer support services?

12. On average, how much time do you spend with an individual providing peer support service?

☐ 0-10 minutes
☐ 10-20 minutes
☐ 20-30 minutes
☐ 30-45 minutes
☐ 45 minutes to an hour
☐ 1 – 2 hours
☐ more than 2 hours

13. In your opinion, what is the biggest barrier to receiving peer support service?

_____

14. Do you provide peer support service to consumers who are parents? Check all that apply.

☐ Yes ☐ No ☐ Parental status unknown

a. If yes, approximately how many consumers who are parents have you served within the last two week period?

☐ _____ # of parent(s) served within the last two weeks.
☐ I didn't serve a parent during this time period.
☐ Unknown

b. Of the parents you served, how many were single mothers that currently care for their children?

☐ _____ # of single mother(s) served within the last two weeks.
☐ I didn't serve a single mother during this time period.
☐ Unknown

c. Of the parents you served, how many were single fathers that currently care for their children?

☐ _____ # of single father(s) served within the last two weeks.
☐ I didn't serve a single father during this time period.
☐ Unknown

15. What do you consider to be the <u>NUMBER ONE</u> greatest service/program need for other consumers who are parents? (Please identify only one specific service/program)

16. In your opinion, who is the most underserved group of individuals with serious mental illness needing peer support services and supports?

17. If you served individuals who are parents, for parents with serious mental illness, what are the MOST common type(s) of life stressor(s) for which you provide the most peer support service? (Check all that apply)

☐ Medication management
☐ Anxiousness
☐ Depression
☐ Loneliness
☐ Benefits/Insurance
☐ Feelings of hopelessness
☐ Symptom management
☐ Physical health issues
☐ Employment issues
☐ Housing issues
☐ Concerns about their children
☐ Other_____
☐ Custody issues w/children
☐ Conflict with spouse/partner
☐ Family health problems
☐ Legal issues/problems
☐ Parenting skills
☐ Other _____

18. For consumers with serious mental illness who are *not* parents, what are the MOST common type(s) of life stressor(s) for which you provide the most peer support service? (Check all that apply)

☐ Medication management
☐ Anxiousness
☐ Depression
☐ Loneliness
☐ Feelings of hopelessness
☐ Symptom management
☐ Physical health issues
☐ Employment issues
☐ Housing issues
☐ Other_____
☐ Benefits/Insurance
☐ Conflict with spouse/partner
☐ Family health problems
☐ Legal issues/problems
☐ Other_____

19. In your opinion, rank in order of importance (with 1 being the highest and 3 being the lowest) the types of specialized services/programs needed but not available for consumers that you serve.

__Conflict Management Classes
__Parenting Classes
__Family Support groups for Parents and their Children

20. In your opinion, rank in order of importance (with 1 being the highest and 3 being the lowest) the types of specialized services/programs needed but not available for consumers that you serve.

__Self-Help Groups
__Social Connection Opportunities
__Recreation/Exercise

21. In your opinion, rank in order of importance (with 1 being the highest and 3 being the lowest) the types of specialized services/programs needed but not available for consumers you serve.

__Housing Support
__Money Management/Financial Planning
__Employment/Education/Training

22. On a scale of 1 to 10, with 10 being the highest need and 1 being the lowest need, how would you rank the service need for the following specialized services?

Support Groups for Parents with Mental Illness
1 2 3 4 5 6 7 8 9 10

Support Groups/Programs for Children of a Parent with a Mental Illness
1 2 3 4 5 6 7 8 9 10

Peer Meet Up Groups for Socializing and Recreation Activities
1 2 3 4 5 6 7 8 9 10

Supported Employment Programs
1 2 3 4 5 6 7 8 9 10

Money Management/Financial Planning Classes
1 2 3 4 5 6 7 8 9 10

Transportation Services for Day, Evening, and Weekends
1 2 3 4 5 6 7 8 9 10

23. In your opinion, how important would it be to have specialized peer support for the following?

Mutual age of the peer support specialist and consumer being served (Ex. young adults paired with young adults; older adults paired with older adults)

Very Important Somewhat Important Not Important

Peer support specialists who are parents of a child with mental illness assisting other parents with a child with a mental illness

Very Important Somewhat Important Not Important

23 cont'd.... In your opinion, how important would it be to have specialized peer support for the following?

Peer support specialists who are parents assisting other consumers who are parents

Very Important Somewhat Important Not Important

Peer support specialists who are adolescents/young adults of parent(s) with mental illness assisting other adolescents/young adults with parent(s) with a mental illness

Very Important Somewhat Important Not Important

Appendix 2

Participant Recruitment Email

Dear Peer Support Specialist,

We need your help! Because peer support specialists are a vital part of mental health recovery services, it is important that researchers include the valued input of peer support specialists in their research studies. As a doctoral candidate in the Department of Special Education, Rehabilitation, and Counseling at Auburn University, I would like to invite you to participate in my research study to assess the viewpoints of peer support specialists as it relates to life stressors and specialized program and service needs for parents and non-parents with serious mental illness. You may participate if you are either employed part-time or full time and are age 19 years or older.

As a peer support specialist, you will be asked to complete an online survey that will take approximately 10 to 15 minutes to complete. Survey questions will include general demographic information, and viewpoints regarding specific life stressors and specialized program and service needs related to those you serve. **No identifying information will be collected**.

Survey results will be secured electronically on a password protected computer. The online survey tool used for this survey is Qualtrics. Qualtrics is a web-based survey software that allows the Auburn University campus community to easily create surveys, collect and store data, and produce reports. Qualtrics privacy statement can be found at http://www.qualtrics.com/privacy-statement and the security statement can be found at http://www.qualtrics.com/security-statement.

If you would like to know more information about this study, an information letter can be obtained by emailing me at swestonbyrd@gmail.com or szb0039@auburn.edu. If you decide to participate after reading this email invitation, you can access the survey from a link at the bottom of this page.

If you have any questions, please do not hesitate to contact me at 205-913-5949 or my advisor, Dr. Dave Martin, at 334-844-7685. I truly appreciate and value your input and your time regarding this research study.

Thank you for your consideration,

Shannon Weston, MA, CRC
Doctoral Candidate
Auburn University

LINK TO SURVEY

Appendix 3

Electronic Information Letter of Consent

The Auburn University Institutional Review Board has approved this document for use from August 25, 2015 to August 24, 2016. Protocol #15-334 EP 1508

INFORMATION LETTER for a Research Study entitled

Life stressors and specialized programs and services for parents with serious mental illness from a peer support specialist perspective

You are invited to participate in a research study to gain awareness of mental health peer support specialists' perceptions on life stressors and specialized programs and services for parents and non-parents with serious mental illness. The study is being conducted by Shannon Weston, doctoral candidate, under the direction of Dr. Dave Martin, Department Head, in the Auburn University Department of Special Education, Rehabilitation, and Counseling (SERC). You were selected as a possible participant because you are currently a peer support specialist providing services in Alabama, are age 19 or older, and are employed either part-time or full-time.

What will be involved if you participate? If you decide to participate in this research study, you will be asked to complete an online survey. Your total time commitment will be approximately ten to fifteen minutes.

Are there any risks or discomforts? The risks associated with participating in this study are minimal.

What if you change your mind about participating? Your participation is completely voluntary. If you change your mind about participating, you can withdraw at any time by closing your browser window, which will exit the survey. If you choose to withdraw, your data can be withdrawn as long as it is identifiable. **Once you've submitted anonymous data, it cannot be withdrawn since it will be unidentifiable. Data for the purpose of this study will be unidentifiable.** Your decision about whether or not to participate or to stop participating will not jeopardize your future relations with Auburn University's Department of Special Education, Rehabilitation, and Counseling or Department of Educational Foundations, Leadership, and Technology.

Your privacy will be protected. Any data obtained in connection with this study will remain anonymous. We will protect your privacy and the data you provide by not collecting any identifiable information or web IP addresses. Information collected through your participation will be used to fulfill an educational requirement.

Please note the following: There will be no cost to participate in this study and no compensation will be given to participants.

If you have questions about this study, please contact Shannon Weston at 205-913-5949 or by email at szb0039@auburn.edu or swestonbyrd@gmail.com. **If you have questions about your rights as a research participant,** you may contact the Auburn University Office of Human Subjects Research or the Institutional Review Board by phone (334) 844-5966 or e-mail at hsubjec@auburn.edu or IRBChair@auburn.edu.

HAVING READ THE INFORMATION ABOVE, YOU MUST DECIDE IF YOU WANT TO PARTICIPATE IN THIS RESEARCH PROJECT. **IF YOU DECIDE TO PARTICIPATE, PLEASE CLICK ON THE *"AGREE TO PARTICIPATE"*** LINK BELOW AND YOU WILL BE TAKEN TO THE FIRST PAGE OF THE SURVEY. YOU MAY PRINT A COPY OF THIS LETTER TO KEEP.

Shannon Weston 9/22/15

Investigator Date

The Auburn University Institutional Review Board has approved this document for use from 8/25/15 to 8/24/16 Protocol # 15-334 EP 1508

Click on the following link > ***AGREE TO PARTICIPATE***

Appendix 4

In-Person Information Letter of Consent

AUBURN
UNIVERSITY

DEPARTMENT OF
SPECIAL EDUCATION,
REHABILITATION, AND COUNSELING

(NOTE: DO NOT AGREE TO PARTICIPATE UNLESS AN IRB APPROVAL STAMP WITH CURRENT DATES HAS BEEN APPLIED TO THIS DOCUMENT.)

INFORMATION LETTER for a Research Study entitled

Life stressors and specialized programs and services for parents with serious mental illness from a peer support specialist perspective

You are invited to participate in a research study to gain awareness of mental health peer support specialists' perceptions on life stressors and specialized programs and services for parents and non-parents with serious mental illness. The study is being conducted by Shannon Weston, doctoral candidate, under the direction of Dr. Dave Martin, Department Head, in the Auburn University Department of Special Education, Rehabilitation, and Counseling (SERC). You were selected as a possible participant because you are currently a peer support specialist providing services in Alabama, are age 19 or older, and are employed either part-time or full-time.

What will be involved if you participate? If you decide to participate in this research study, you will be asked to complete an online survey. Your total time commitment will be approximately ten to fifteen minutes.

Are there any risks or discomforts? The risks associated with participating in this study are minimal.

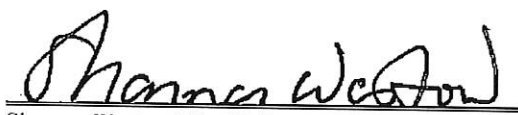
What if you change your mind about participating? Your participation is completely voluntary. If you change your mind about participating, you can withdraw at any time by closing your browser window, which will exit the survey. If you choose to withdraw, your data can be withdrawn as long as it is identifiable. **Once you've submitted anonymous data, it cannot be withdrawn since it will be unidentifiable. Data for the purpose of this study will be unidentifiable.** Your decision about whether or not to participate or to stop participating will not jeopardize your future relations with Auburn University's Department of Special Education, Rehabilitation, and Counseling or Department of Educational Foundations, Leadership, and Technology.

Your privacy will be protected. Any data obtained in connection with this study will remain anonymous. We will protect your privacy and the data you provide by not collecting any identifiable information or web IP addresses. Information collected through your participation will be used to fulfill an educational requirement.

Please note the following: There will be no cost to participate in this study and no compensation will be given to participants.

If you have questions about this study, please contact Shannon Weston at 205-913-5949 or by email at szb0039@auburn.edu or swestonbyrd@gmail.com. **If you have questions about your rights as a research participant,** you may contact the Auburn University Office of Human Subjects Research or the Institutional Review Board by phone (334) 844-5966 or e-mail at hsubjec@auburn.edu or IRBChair@auburn.edu.

HAVING READ THE INFORMATION PROVIDED, YOU MUST DECIDE IF YOU WANT TO PARTICIPATE IN THIS RESEARCH PROJECT. IF YOU DECIDE TO PARTICIPATE, THE DATA YOU PROVIDE WILL SERVE AS YOUR AGREEMENT TO DO SO. THIS LETTER IS YOURS TO KEEP.



9/23/15

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