SUPPORTS AND BARRIERS EXPERIENCED BY PARENTS LIVING WITH MENTAL HEALTH ISSUES

Kezzia J. Bullen
B.A., Concordia University, Irvine, 2004

Katherine S. Metoyer
B.A., California State University, Sacramento, 1999

PROJECT

Submitted in partial satisfaction of
the requirements for the degrees of

MASTER OF SOCIAL WORK

at

CALIFORNIA STATE UNIVERSITY, SACRAMENTO

SPRING
2009

SUPPORTS AND BARRIERS EXPERIENCED BY PARENTS LIVING WITH MENTAL HEALTH ISSUES

A Project

by

Kezzia J. Bullen
Katherine S. Metoyer

Approved by:

Committee Chair

Susan A. Taylor, Ph.D., MSW

4/30/09

Date

Students: Kezzia J. Bullen
Katherine S. Metoyer

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Susan Talamantes Eggman, Ph.D., MSW Date

Division of Social Work

Abstract
of
SUPPORTS AND BARRIERS EXPERIENCED BY PARENTS LIVING WITH MENTAL HEALTH ISSUES
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This thesis was completed in collaboration between Kezzia Bullen and Katherine Metoyer. Each collaborator was involved in every aspect of writing and completed half of the interviews. Ten therapists with a Master's level degree or above were interviewed to obtain their views of the supports available and barriers faced by the consumer parents they serve. They identified internal and external barriers that affected consumer's ability to effectively parent and access needed supports. A review of literature available on consumer parents' needs, along with organizational changes and barriers to accessing services by those parents was highlighted. Also included is a history of mental health services including federal and state legislation supporting the trend for consumer involvement in all aspects of mental health service delivery.

Committee Chair
Susan A. Taylor, Ph.D., MSW

DEDICATION

Dr. Sue Taylor
Excitedly proclaimed
Just get 'er done, girls
And plant your seeds

Victoriously
Under the sun

ACKNOWLEDGEMENTS

I want to thank all my friends and family who supported me through this journey and allowed me to neglect them for months and months. Thank you to all the social workers at my field placement who understood the Pain of Thesis. I want to thank my collaborator, Kathy Sue, for keeping me on task when I was distracted by people watching at Starbucks and for keeping the humor alive even in times of "stress brain". Thanks to Ashtan "Face" for having me miss three weeks of classes for your birth and false alarms. You can always make me smile with those saucer eyes and giggle. Thanks to Joey "Jo Jo Potatoes" for making me miss classes once in my last semester. Despite both of your efforts to make me fail out of the program...I made it. There were many moments of Déjà vu but we made it through. –Kezzia Bullen

Thank you Lord for giving me hope and empowering me to use my life experiences to pass this hope on to others. Thank you Daryl for your patience and sacrifice, not only for the last two years, but over the last several in my pursuit of a new career path. We made it. Thanks to all my family and friends who provided support and needed breaks that helped me deal with the stress of going back to school at my age. Finally, thanks to my thesis partner, Déjà vu, for all of her entertainment and snacks (Go Girl) that kept me going when I wanted to scream. We did it! --Kathy Metoyer

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Chapter 1

THE PROBLEM

Introduction

Having a cousin who is a consumer parent in Sacramento County who without receiving support services eventually lost custody of her children influenced Researcher A's decision to research this problem. Her cousin was diagnosed with Bipolar I disorder and took lithium for years before becoming a parent. She began to self medicate with alcohol because she could not take her medication while pregnant with her second child and eventually replaced alcohol with Methamphetamines. This led her to losing her informal familial supports and eventually to the loss of custody of her children. Lack of support for her from professional agencies, such as Child Protective Services (CPS) was another determining factor in Researcher A's pursuit of this research.

Researcher B became aware of the need for supports and services for consumer parents in her role as an intern with Placer County Children's System of Care. During this internship, Researcher B became aware of several examples of consumer parents having their children placed into foster care because of mental illness. Lack of support for parents, along with focusing on the child only, were some of the barriers faced by these consumer parents that Researcher B observed.

In hopes of learning a new perspective as to why consumer parents face barriers to accessing necessary supports and services, both researchers applied for and were chosen to be members of the Mental Health Services Act Stipend Program at CSUS. As members of the stipend program, they learned of how meeting consumer parents' needs

and helping them to overcome barriers to services could lead to successful parenting. This added knowledge about consumer parents' need for supports, as well as the barriers they face, coupled with personal experience has led these researchers to explore this problem.

Statement of Collaboration

This thesis was completed in collaboration between Kezzia Bullen and Katherine Metoyer. Each collaborator was involved in every aspect of the writing. Each collaborator completed half of the interviews and data collection.

Background of the Problem

In the past few decades, deinstitutionalization and community based rehabilitation and support programs have increased the likelihood that women with serious mental health issues will be parents and will raise their children (Oyserman, Mowbray, Meares & Firminger, 2000). Assorted new opportunities and challenges for people with mental health issues came with the deinstitutionalization movement. People gained the freedom to experience parenthood. Nearly ½ of the women and men in the United States report a lifetime prevalence of a psychiatric disorder. (Kessler, 1994 as cited in Nicholson, Biebel, Hinden, Henry & Stier, 2001). Thirty percent report the prevalence of at least one disorder in the previous 12 months (Kessler, 1997 as cited in Nicholson et. al., 2001). Sixty-six percent of these women and over fifty percent of these men are parents (Nicholson et. al., 2001). The impact of parental mental illness on the family life and children's well-being cannot be overstated (Nicholson et al, 2001).

Deinstitutionalization's intention was to ensure that people experiencing mental health issues would be in charge of their own care. Deinstitutionalization was a result of federal legislation dating back to 1963 and implemented through state legislation. Aftercare or follow-up care services were under-funded; therefore, people experiencing psychiatric disabilities were lacking services to help them assimilate back into mainstream society. For many years, advocates have been calling for services that include the person with the psychiatric disability in his or her treatment planning.

Several studies declare that stigma accompanying psychiatric disabilities is the single most pervasive factor affecting consumer parents' access to services. Stigma surrounding psychiatric disabilities is preventing people from accessing appropriate services (Children, Youth and Family Consortium, 2003). Stigma prevents people from getting treatment and generates erroneous beliefs that parents with psychiatric disabilities are unable to parent successfully (Nicholson et al, 2001). The Substance Abuse and Mental Health Services Administration website (Substance Abuse Mental Health Services Administration [SAMHSA], 2009) claims that the stigma of psychiatric disabilities and the pervasive assumption that consumer parents will fail keep many parents from seeking help. While stigma is the largest barrier that consumer parents face, lack of culturally appropriate providers, limited insurance coverage, fear of losing custody of their children, limited availability of information, and location and access to services are also great concerns.

A sizable number of women experience a serious mental health issue either before or after pregnancy, with the risk of onset remaining elevated in the early years of

parenting. Post-partum depression occurs in five to 9 percent of women and is not considered in the risk of serious mental health issues. Being a mother of a child aged zero to five increases the risk of mental health symptoms such as anxiety and depression while disorders are more likely when mothers are stressed and caring for multiple young children. Women with serious mental health issues tend to have a greater number of children, and begin their parenting earlier in life than women without serious mental health issues. Women dealing with a serious mental health issue are at an increased risk of both poverty and raising their children as single parents. They are more likely to experience marital and familial discord and trauma which only adds to the difficulties they and their children face. Parenting can also be a positive and motivating experience. Mothers with serious mental health issues state that parenting is the central force keeping them involved in treatment, an outlet for feelings of care and concern, and a valued, normative social role. Many qualitative studies have had women with mental health issues explain the significance of having children, the struggles of maintaining or obtaining custody of their children, and the need to achieve normal lives for themselves and their children. (Oyserman, 2000)

Statement of the Research Problem

Consumers began to live in communities and become parents. Living with a psychiatric disability can create a more challenging parenting experience. As more consumers become parents it is necessary to look at the barriers faced and community supports available to consumers to become successful parents. In communities, there is a lack of available services that are specific to consumer parents' needs. The services that

are available continue to be difficult to access due to lack of knowledge about them, stigma surrounding accessing them, and the ability to access them due to active symptoms.

Purpose of the Study

This study aims to gather information on therapists' perceptions of the barriers and supports needed for consumer parents. It is hoped that the information gained from the study will be beneficial for therapists and their work with consumer parents by establishing a larger view of the barriers faced and the support necessary to keep consumer parents successful. By establishing this larger view of the barriers faced by consumer parents, therapists will be given a tool to help consumer parents break these barriers down.

Theoretical Framework

The founder of attachment theory, John Bowlby, supported a family systems perspective and used this to shape his attachment theory. He realized that children grew up in large family systems and their relational problems and interventions should be viewed with that perspective. In 1949, he wrote one of the first papers on family therapy. In it he stated that even the most dysfunctional family has a strong desire to live together in a healthy way and that working with the entire family system would hold hope for successful interventions (Marvin, pgs. 3-27).

Bowlby (1969) explains attachment as a "lasting psychological connectedness between human beings." He further states that the earliest bonds between children and their caregivers have a tremendous impact through their entire lives. The early

experiences between a child and his/her caregiver construct the child's sense of self and whether or not they are deserving of attention (Cretzmeyer, pps. 65-68). This sense of self or internal working model has the function of protecting children from a range of dangers while they learn the skills to protect themselves (Marvin, pps 6-7). Bowlby (1988) described three different patterns of attachment which are central to the child's psychiatric development. Secure attachment is the first pattern which maintains that a child feels confident that their parent will be consistently available and responsive during adverse or stressful situations. The second pattern, anxious-resistant attachment, results when a child feels unsure about their parent's responsiveness or availability. Anxious-avoidant attachment is the third pattern that occurs when a child is in need of comfort or protection and the parent constantly ignores or rebuffs them. (Cretzmeyer, pps. 65-68).

Psychologist Mary Ainsworth expanded on Bowlby's work. Based on research she conducted, she described four major behaviors of attachment; secure behavior, avoidant behavior, anxious-ambivalent behavior and disorganized behavior. These behaviors of attachment in childhood continue into the attachment and relational styles of adulthood. (Alexander and Warner pps. 241-245) Main and Goldwyn (in press) linked attachment styles to an adult's parenting style (Alexander and Warner pps. 241-245).

Murray Bowen's Family Systems Theory suggests that individuals cannot be understood in isolation from one another, but as a part of their family. Bowen describes the family as an emotional unit and uses systems thinking to explain the complex interactions within the family. He further notes that the family is a system in which each member has a role to play. Members of the system respond to each other in a certain way

according to their role. Bowen also states that the nuclear family emotional system and its problems are defined by four relationship patterns; marital conflict, dysfunction in one spouse, impairment of one or more children, and emotional distance. When family tension increases, each spouse may externalize his or her anxiety into the relationship. Each tries to control the other, and each resists the other's attempts at control. An unequal balance of power creates dysfunction in one spouse when family tension increases. This increased anxiety level may lead to development of psychiatric, medical, or social dysfunction (Bowen, 1978).

Impairment in one or more children may lead to the parents focusing their anxieties on that child. With more focus being placed on that child, the child focuses more on the parents. This leads to the child being more reactive to the needs, attitudes and expectations of the parents. Emotional distance patterns are seen when the intensity of relationships in the family increases causing people to distance themselves even at the risk of becoming isolated. Depending on the relationship patterns, family members may experience different levels of dysfunction (Bowen, 1978).

Bowen's belief that the family is a system in which each member has a role to play emphasizes the importance of consumer parents and their role in the family. He strongly suggests that individuals be looked at as part of the family unit not in isolation from one another. As the families of consumer parents are looked at as a whole, relationship patterns can be discovered. It is within these relationship patterns, that family dysfunction may be developed. Helping consumer parents, along with society, understand these relationship patterns and supporting them in their role in the family can

empower them to face the barrier of being looked at in isolation apart from other family members (Bowen, 1978).

In addition to the above theories, it is important to note the use of a strengths perspective when working with and assessing consumer parents and their families. "Practicing from a strengths perspective means that everything you do as a helper will be based on facilitating the discovery and embellishment, exploration, and use of clients' strengths and resources in the service of helping them achieve their goals and realize their dreams (Saleebey, 2002, p.14)." The strengths perspective calls for therapists or social workers to focus on the strengths of consumers and use them to ameliorate any concerns to achieve a better quality of life. The strengths perspective assumes that all people, groups, communities and families have strengths and that the therapist or social worker does not know the upper limit of the person's ability to change and grow and must take their goals seriously. It also holds that trauma, abuse, illness and struggle may be harmful but also may be areas of challenge and opportunity. The strengths perspective states that consumers are best served in collaboration and that every environment has resources. (Saleebey, 2002).

The strengths perspective includes principles of empowerment, resiliency, hope, healing and wholeness. Empowerment is the intent and process of helping consumers, families and communities to discover and disburse the resources and tools within and around them. Resiliency is a person's ability to rebound and overcome adversity and should be expected from consumers by social workers. "Hope is crucial to recovery, for our despair disables us more than our disease ever could (Leete, 1993, p.122. in Saleebey,

2002, P. 253)." Healing is intrinsic and contains both wholeness and resiliency of the consumer when faced with a disorder, disease or trauma (Saleebey, 2002).

The strengths perspective demands that the therapist or social worker see the consumer, their environment, and their current situation in a different way. Rather than focusing on the deficits, concerns, or problems the focus turns towards possibility and hope. If a strengths oriented practice is used then the social worker can expect changes in the character of the work and the relationship with the consumer (Saleebey, 2002).

Definitions

Consumer-Persons that have accessed or currently access any mental health service. In America this term is used to convey the hope of one day being able to practice active consumerism in relation to mental health services (Deegan, 1997, p.12).

Consumer parent-Persons that have accessed or currently access any mental health service that also have biological or adoptive children.

Mental health issues-Symptoms of any DSM-IV TR classified disorder experienced in any degree.

Psychiatric disability-preferred term used in recovery-oriented literature to describe the difficulties, functioning, significant impairment, disturbances, commonly experienced by people with a DSM-IV TR classified disorder.

Mental illness- According to the DSM-IV TR, it is a manifestation of a behavioral psychological or biological dysfunction in the individual.

Recovery- learning to cope with the effects of their psychiatric disability and to reach their highest possible level of functioning (Anthony, 1993).

Recovery model-Overarching model of change which can incorporate empirically validated therapies and which makes use of common factors such as hope, personal empowerment, respect, social connections, self responsibility, and self determination (Reisner, 2005).

Consumer driven- Services that are individualized and responsive to consumers and their needs. Consumers and/or their family members are involved and dictate the treatment plan and services for the individual.

Therapist- a clinician that possesses a Master's Degree or higher in fields related to psychology, social work and counseling.

Assumptions

Assumption is that consumer parents need services and supports and that there are barriers to needed supports. The recovery model is the best practice when working with person with psychiatric disabilities. Therapists interviewed will gain insight from the summary of findings to better inform their practice with consumer parents. Therapists will further disseminate the information given to them to their colleagues promoting the need to remove barriers to services.

Justification

Discovering the supports available and barriers faced by consumer parents will provide therapists with needed information to inform their practice with consumer parents. Therapists will gain a wider knowledge base regarding consumer parents and their needs. This knowledge will assist in the primary mission of the social work profession to enhance human wellbeing and help meet the basic human needs of all

people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty (National Association of Social Workers [NASW], 2008). Consumer parents are vulnerable and have been oppressed by stigma placed upon them by society. By enhancing consumer parents' capacity and opportunity to change and to address their own needs, one element of the NASW's (2008) core value of Dignity and Worth of the Person will be accomplished. This study's goal is to bring awareness regarding consumer parents' needs and barriers to services to therapists who may in turn share it with colleagues. It is hoped that this will be the beginning of an opportunity for consumer parents to be supported in their search for services.

Limitations

This project only gathers information from qualitative interviews with therapists who work with consumer parents and not from the consumer parents themselves. Therefore, some of the consumers' specific needs for support and barriers to services may be undiscovered. Further research which involves interviewing consumer parents is needed to discover these needs and barriers firsthand. Information gathered about available services and supports are specific to Sacramento and Placer Counties. Consumer parents' need for supports is explored in this study, yet recommendations to meet these needs are not given. Although barriers to services are also explored, ways to overcome the barriers are not provided.

Chapter 2

REVIEW OF THE LITERATURE

Introduction

Implementation of mental health services around the world, the nation, and state have evolved into more of a focus on consumer involvement in the process. Participation in the Mental Health Services Act (MHSA) stipend program by these researchers has confirmed this focus and has increased interest in the topic researched for this project. This chapter will examine the history of mental health services to demonstrate how legislation has influenced a shift from institutions determining treatment, to a drive for more consumer involvement in the ways that services are provided. The history of mental health services is varied between countries and ideologies. Many countries embraced a holistic consumer driven and community-based way of practicing long ago. The United States, in particular, California has recently begun to integrate consumer informed practice into its mental health service delivery and treatment system. (Mental Health Services Act [MHSA], 2004, New Freedom Commission, 2003).

The literature review will investigate four areas. First, the history of mental health services internationally and nationally will be examined. Next, national and state legislation will be explored to ascertain the government's role in supporting consumers and their family members. Recovery model programs for consumers will be discussed. Consumer parents' needs and recommendations for organizational changes to meet these needs, will be outlined. Finally, resources available for consumers, parenting beliefs, along with supports and barriers to services for consumer parents will be reviewed.

History of Mental Health Services

The World Health Report (2001) renewed emphasis on the following three principles that were laid out by the UN a decade before: there shall be no discrimination on the grounds of mental illness; as far as possible, every patient shall have the right to be treated and cared for in his/her own community; and, every patient shall have the right to the least restrictive or intrusive treatment (pp. ix). To help implement these principles, it was recommended in the international report that communities, families and consumers be involved in the policy design, programs, and services. Self-determination along with the need for information about medication and other treatment as well as services to facilitate active community participation were mentioned. In addition, the report emphasized an end to stigma and discrimination, improved laws and public attitudes, removing barriers to community integration, and the need for alternative, consumer-run services. These themes that have emerged in the last 30 years of consumers beginning to articulate their visions of services they need and want (World Health Report [WHO], 2001, pp. 56).

From the Second World War forward, there has been an international trend of deinstitutionalization of persons with psychiatric disabilities (Norman, 2006). While this trend can be traced back to decades of advocates working to change mental health policy in the United States, there were specific policies enacted that began the shift of services being provided by states to the federal government for responsibility for mental health services. More recently, policies were enacted that supported states and communities in providing services to consumers and their family members.

The National Mental Health Act of 1946 was one such policy that allowed the federal government to enter into the mental health arena. On July 3, President Truman signed the National Mental Health Act of 1946. The Act provided for the first time in U.S. history a significant amount of funding for research into the causes, prevention and treatment of mental illness which led to the establishment in 1949 of the National Institute of Mental Health (NIMH) (Mental Health America [MHA], 2006, pp. 2).

The mission of NIMH was and is still is to transform the understanding and treatment of mental illnesses through basic and clinical research, paving the way for prevention, recovery and cure (National Institute of Mental Health [NIMH], 2009). The NIMH was dedicated to bring about the demise of public mental hospitals and to substitute in their place a community oriented policy (Grob, 2005). Grob (1995) explained that deinstitutionalization had a positive connotation in the 1970s. "The term referred to the discharge of long-term psychiatric patients from obsolete custodial mental hospitals that had seemingly outlived their usefulness" (Grob, 1995, p. 1). This deinstitutionalization has led to people receiving psychiatric services outside of hospitals and in the communities. Psychiatric rehabilitation is defined as an individual developing to his/her full capacity and becoming successful and satisfied in the environment he/she chooses with as little involvement as possible by professionals (Anthony, Cohen, & Farkas as cited in Norman, 2006). It was this drive for community-based services that led formerly institutionalized patients and a psychiatrist to establish Fountain House, the first 'clubhouse' in New York in 1948. "The 'clubhouse' was intended both to provide

immediate refuge and to help its members regain a normal life" (Macias, Jackson, Schroder, & Wang, 1999).

Goldstein (2008) noted how the establishment of the Fountain House encouraged world-wide expansion of the clubhouse model; now numbering over 400 clubhouses in 30 countries. The clubhouse model came at a time when severely disabled psychiatric patients were being released from institutions and scattered into the community (Schlicksup-Curdt 1998, as cited in Di Masso, Avi-Itzhad, & Obler, 2000). Clubhouses offered these individuals a place to live, a feeling of belonging, and a belief that they were needed in the larger community. According to Norman (2006), the clubhouse model is a method of rehabilitation where people suffering from mental health problems organize themselves to create change. Individuals, known as *members*, in the clubhouses setting are 'intentional' community members that can and will achieve their life goals when provided opportunity, time, support and fellowship (Jones, as cited in Norman, 2006). Being a member of a 'clubhouse' meant the members had rights and choices. They had the right to choose the type of work they wanted to do and to choose the staff worker they wanted to work with (Macias et al, 1999). Having this right to choose and be involved in the decision making process of their treatment, was echoed in The New Freedom Commission Report (2003) submitted to President Bush in which, "nearly every consumer of mental health services who testified before or submitted public comments to the Commission expressed the need to fully participate in his or her plan for recovery" (p. 27).

Legislation

Federal.

Federal and State mental health policies were enacted to support deinstitutionalization and provide community-based mental health services for individuals suffering from mental health issues. The first President's Commission on Mental Health, in the mid 1950s, called for a shift from an institution-based public mental health system to a community-based system. This report led to the Community Mental Health Centers Act of 1963 and to deinstitutionalization (Friedman, 2003).

The Community Mental Health Centers Act of 1963 (CMHA), provided Federal funding for community mental health centers (CMHCs). Facilitating early identification of mental health symptoms, offering preventive treatments to diminish the incidence of mental disorders and prevent long-term hospitalization, and providing integrated services to people with severe mental illness in the community was supposed to be accomplished by these CMHCs (Grob, 1995). This gave states the initiative to plan and implement such systems.

The President's New Freedom Commission Report of 2003 emphasized recovery and rehabilitation. Its intent was a transformation of the delivery of mental health care. This would be accomplished through consumer and family centered services and treatments with choices of treatment options and providers. Focusing on increasing the consumer's ability to cope with life's challenges, and emphasizing recovery and resilience, rather than just managing symptoms were also deemed necessary for transformation. A recovery model offering options in treatment, housing and

employment and other supports to help people with serious mental illness take charge of their lives was an emphasis in the report. Further, the report defined recovery as, "the process in which people are able to live, work, learn, and participate fully in their communities" (President's New Freedom Commission Report, 2003, pp. 1).

State.

In June 1999, the U.S. Supreme Court in *Olmstead v. L.C. and E. W.,* ruled against the state of Georgia rejecting the state of Georgia's appeal to enforce institutionalization of individuals with disabilities. The high court upheld that mandate, ruling that Georgia's department of human resources could not segregate two women with mental disabilities in a state psychiatric hospital long after the agency's own treatment professionals had recommended their transfer to community care. On June 22, 1999, the U. S. Supreme Court ruled in the case *Olmstead v. L.C. and E.W.* that the "integration mandate" of the Americans with Disabilities Act requires public agencies to provide services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities" (p. 2). Disabled people segregated in institutions have used it to require states provide services in the community (Cornell University Law School, 1999).

In 2000, Donna Shalala, Secretary of the U.S. Department Health and Human Services ordered states to follow the 1999 *Olmstead* ruling. Following this, President Bush created the New Freedom Commission on Mental Health and charged them to study the mental health service delivery system and then make recommendations enabling adults with serious mental illnesses and children with serious emotional disturbance to

live, work, learn, and participate fully in their communities (New Freedom Commission's Report, 2003). California's Mental Health Master Plan (CMHMC) tries to do for California what the President's Commission has done for the nation. PL 106-310 re-authorized the Community Mental Health Services Block Grant and reaffirmed the requirement that each state must have a mental health planning council in order to receive the block grant. The Planning Council is mandated by state law to provide oversight of the public mental health system, to advocate for adults and older adults with serious mental illnesses and children and youth with serious emotional disturbances and their families, and to make recommendations regarding mental health policy development and priorities (California Department of Mental Health [DMH] 2009).

CMHMC pointed out that there were approximately 600,000 adults, older adults, and children and youth that need mental health treatment that were not receiving it (DMH, 2009, p. V). In November 2004, voters in the state of California passed Proposition 63, the Mental Health Services Act (MHSA). Expanding and transforming California's county mental health services systems was the purpose of MHSA. Six components of building a better mental health system to guide policies and programs were addressed by MHSA: community program planning; services and supports; capital (buildings) and information technology; education and training (human resources); prevention and early intervention; and innovation (2004, pp. 2-3). California's State Department of Mental Health (DMH) contracted with county mental health departments to develop and manage the implementation of its provisions (DMH, 2009). Section 7 part D of the MHSA (2004) stresses that

> planning for services shall be consistent with the philosophy, principles, and practices of the Recovery Vision for mental health consumers: 1) to promote concepts key to the recovery for individuals who have mental illness: hope, personal empowerment, respect, social connections, self-responsibility, and self-determination; 2) To promote consumer-operated services as a way to support recovery; 3) To reflect the cultural, ethnic and racial diversity of mental health consumers; 4) To plan for each consumer's individual needs (MHSA, 2004, p. 5).

Recovery Model–Consumer Driven Services

Goldstein (2008) tells of a town in Geel, Belgium that in the early 1200's was perhaps one of the first to demonstrate what a recovery community looks like. Started in response to overcrowding in the churches of the day, the townspeople of Geel opened up their homes for individuals with mental health issues. Persons with mental health issues were visible members of the community. This program still operates today, providing homes for individuals with mental health issues, as part of a comprehensive system of mental health services whose goal is community integration. Goldstein (2008) suggests that for a community to be a recovery community it should meet the following criteria:

- Acknowledges the human needs of those with mental illness
- Responds to those needs by providing social opportunities and meaningful work in the community
- Accepts those with mental illness as members of the community
- Shows flexibility in programs and approaches in order to address individual needs of clients (p. 1)

According to Goldstein (2008), there are many programs in the United States that have had particular success in meeting some or all of these criteria. Gould Farm in Monterey, Massachusetts was founded in 1913 as a therapeutic community for people

with mental health isseus. It provides a community where residents can work and learn new job skills. Spring Lake Ranch started in Cuttingsville, Vermont in 1932 was modeled after the Geel, Belgium community model with community integration as one of its goals. Broadway Housing Communities, Common Ground, Community Access, Compeer, Inc, and Fountain House are some of the recovery communities established in New York (Goldstein, 2008).

The Village Integrated Service Agency in Long Beach, CA was built on an integrated services approach which means that they provide all the services and support individuals need to lead lives of greater independence in their community. Most significantly, having integrated services was identified as the approach for serving adults with mental health issues in the Mental Health Services Act, enacted in 2005. As one of California's greatest mental health reforms, the Act creates systems of care for adults, youth and children built on recovery principles and practices (Mental Health America [MHA], 2006).

Anthony (1993) describes recovery as a deeply personal process of changing one's attitudes, values, feelings, goals, skills, and/or roles. Living a satisfying, hopeful and contributing life even with limitations caused by mental illness is recovery. According to Mowbray, Nicholson and Bellamy (2003), recovery values are as follows:

- All persons, no matter the severity of their psychiatric disability, have the capacity to grow and change-the value of hope.
- The involvement and empowerment of consumers' rehabilitation services is essential to effective services and good quality programs—the value of partnership and self- determination.
- Services must build their own supportive communities and also assist consumers to integrate into normal life of the community at large and to utilize informal support networks—the importance of relationships.

- Services help consumers to themselves develop the experience and skills to compensate for their illness and to cope with the demands of everyday life—the importance of interdependence and of doing and learning together (Hughes, 1994 as cited in Mowbray, Nicholson & Bellamy, 2003).
- For optimal functioning, individuals need to feel they are engaged in meaningful activity, based on shared consensus between personal and cultural values (Beard, Propst & Malamud, 1994 as cited in Mowbray, Nicholson & Bellamy, 2003).
- A recognition that all problems that psychosocial rehabilitation need to address do not reside within the individual (Deegan, 1994 as cited in Mowbray, Nicholson & Bellamy, 2003); there is a need for societal change in many areas. (pg. 111)

One of the values of psychosocial rehabilitation asserts that a consumer should and can have successful outcomes in the larger community in any role they choose. To achieve this outcome more effective services need to address the unique experiences every consumer faces.

Women have been found to develop psychiatric disabilities later in life than men. This could explain the reason that women tend to have better social skills, employment and educational success and are more likely to become parents. Women tend to face barriers such as family and childcare responsibilities, self-esteem, and abusive and/or addiction-maintaining relationships; when accessing services. Goals for overcoming such barriers must be developed by the consumers themselves (Mowbray, Nicholson & Bellamy, 2003).

Consumer Parents

Needs.

According to Nicholson, Biebel and Katz-Leavy (2004) two-thirds of adults who meet criteria for a psychiatric disorder are parents. Research indicates that these parents

face the same day-to-day stress of other parents but have the added challenges that accompany a psychiatric disability (Nicholson, Sweeney & Geller, 1998, p. 635). Consumer parents and their families face many vulnerabilities; among them are family separations and disruptions due to psychiatric hospitalization of the parent and Child Welfare System (CWS) involvement (Mowbray, Oyserman & Zemencuck, 1995). Consumer parents are seen as being incapable of effectively parenting and are at-risk of CWS involvement and custody loss based solely on there psychiatric disability (Hemmens, Miller & Burton, 2002). While children need to be kept safe, custody loss and family disruptions have major implications fiscally, (i.e. foster care and residential care), and emotionally for parents and their children (Hinden, Biebal, Nicholson, & Mehnert, 2005).

Parents that are living with mental health problems have needs on multiple levels. Their caretaking and that of their children often falls to the parents' spouses, partners, parents or other children. According to Cook and Steigman (2000), parents with mental health problems need service delivery with the following seven principles. The first principle is an ongoing availability of services with no exclusions or time limits. Next, the family also needs to be the focus of the services. Thirdly, the services need to include a mix of rehabilitation, treatment and support. Service delivery needs to have sensitivity to the stigma associated with having mental health problems is the fourth principle. Fifth, the importance of the parents' concerns in seeking and accepting assistance regarding the custody of their children needs to be included in service planning. The sixth principle, that parenting is the foundation on which consumers can build their recovery. Lastly,

collaboration among all the agencies including health, mental health child welfare and others is necessary (Cook and Steigman, 2000, pp. 21-22).

Cook and Steigman (2000) state the following comprehensive services for parents dealing with mental health problems are necessary. Case management services are vital to linking the entire family to the following appropriate services. Assessment of parenting strengths and needs is necessary to drive the referrals for services. Peer support, self help, and parent mentoring opportunities are shown to be critical in meeting the needs of consumer parents with other people who have experienced similar struggles. Parent and child development education help the consumer parent to build their parenting skills and tools. Medication management is a component to helping consumer parents recover. Basic needs in the form of housing support and vocational rehabilitation may also need to be addressed for the family to become or remain together. Supported education or training may need to be a part of obtaining a job or achieving some of the consumer parents' goals. If a parent has lost custody of their children then counseling and support will be necessary for that specific issue. Other services that need to be available are family planning, crisis and respite care, trauma and abuse counseling, foster care support and linkage, substance abuse treatment, marital and family counseling, assistance with child's school issues, advance directive planning and support, and benefits and public entitlement counseling (Cook and Steigman, 2000, pp 21-23).

Nicholson, Sweeney and Geller (1998) conducted a study on mothers dealing with a mental illness. The researchers conducted focus group with the mothers themselves and with case managers that worked with the mothers. In the conversations with both the

consumer parents and the service providers, Nicholson et al. found four sources of conflict for the mothers. Stigma of mental health problems was the first source of conflict found. The mothers felt like they were judged by people in the general society for becoming mothers when they had mental health problems. These mothers felt an added stress of having to prove themselves as fit parents. Since there is a stigma against people with mental health problems, the problems their children were having were blamed on their mental health issues if the child's issues were part of normal adolescence. A second source of conflict found, was the day to day stresses of parenting that are coupled with the stresses of dealing with mental health problems. Many mothers expressed that they often have difficulties knowing when they are experiencing symptoms of their psychiatric disability or the normal stresses of parenting. Many women stated that they would feel guilty and wonder if they have raised their children appropriately while dealing with their mental health issues (Nicholson et. al., 1998, pp. 637-638).

Another source of conflict identified by the consumer mothers in the focus groups was the management of their mental health problems. Consumer mothers tended to put their children's needs ahead of their own. The guilt they felt led them to ignore their own needs that may have lessened their symptoms including time alone or sleep. One mother stated that her medication slowed her down so much that she was not able to keep up with her toddler. Although the mothers experienced stress and possibly an increase of symptoms, having to care for their children served as a motivation for recovery. One mother reported that she may not be able to get out of bed for herself, but would and had

to care for her child. Lastly, many consumer mothers may have concerns regarding the custody of or contact with their children, especially in times when they have to be hospitalized (Nicholson et al., 1998, pp. 639-640).

Mental health issues may make it more difficult to mange the role of parenthood, but services could make considerable differences in the consumers' functioning as a parent. These services should include good clinical care, symptoms management, appropriate assessment and goal setting, and access to rehabilitation services such as parent skills classes and parent support groups. These rehabilitative supports have been long neglected until recently (Nicholson & Blanch, 1994). The mental health system needs to address these rehabilitation needs in order to serve consumer parents effectively. Consumers continuing to have children with or without support and lack of attention to these needs will continue to place children at risk for behavioral and mental health issues (Silverman; 1989, Grunbaum & Gammeltoft, 1993 cited in Nicholson and Blanch, 1994).

Rehabilitation efforts must focus on the context of parenting, formal and informal supports, as well as individual skills and knowledge (Oyserman, Mowbray and Zemencuk, 1992 cited in Nicholson and Blanch, 1994). To appropriately address service needs, case managers and therapists need to attend to such topics as parenting skills, childcare resources, concerns about child's functioning and how to answer their questions about their mother's psychiatric disability, safe and secure housing, money management, interpersonal relationships and communications, and leaving abusive partners (Mowbray, Nicholson & Bellamy, 2003).

Organization Recommendations

As the WHO paved the way for the United States legislation for mental health services, England paved the way for awareness of how consumer parents need to be served by organizations (WHO, 2001). In England, nearly thirty three percent of people with mental health issues are parents. Changes in mental health public policy over the past twenty years have led to more adults with mental health issues living in the community. As an additional result of these policy changes, more children are living in a household with a parent with mental health issues and more parents with mental health issues will be experiencing the stresses of parenting. Consumers in recovery are advocating for improvements in mental health services that will help with consumers' inclusion in the larger community (Revans, 2008).

The most common stressors for English consumer parents were inequality and poverty. Consumer parents are often in poverty because they are unable to work. A lack of community supports especially culturally appropriate services were identified as impacting consumer parents and their children. Children were impacted by parental depression because the parenting became either too intrusive or withdrawn. Children and spouses of consumer parents often experience complex loss. Complex loss is when a person is physically present but is "lost" due to the symptoms of their mental health issue. This is a stressor for children because secure attachment is vital in promoting and maintaining resilience (Revans, 2008).

Resilience factors are generally focused in three categories: individual factors, family relationships, and ecological dimensions. Resiliency is developed from a sense of

security, recognition of self-worth, the experience of control over one's immediate environment, and the experience of multiple social roles. A consumer parent's resilience is bettered by satisfying employment, good physical health and professional, community and personal support. Identification of family's strengths and resilience is critical for intervention planning (Revans, 2008).

Triseliotis (1980 as cited in Hetherington & Baistow, 2001) stated that child care policies across Europe have recently been changing to reflect the priority of keeping children with their birth parents whenever possible. When children are not able to be cared for by their birth parents, for example if their parent is hospitalized, then they should be cared for by the extended family and ensure a connection to their parents (Triseliotis, 1980 as cited in Hetherington & Baistow, 2001). This shift towards maintaining the relationship between children and their parents requires a larger involvement of various service providers within the family. This calls for an increase in communication between adult and child systems (Hetherington & Baistow, 2001).

Hetherington and Baistow (2001) conducted a part of a comparative study with researchers from various European countries to see the differences and commonalities in their social work practice to better ensure the communication necessary between adult and child systems. They created a case story and asked professionals from different areas of the United Kingdom, including England, Northern Ireland and Scotland, what their responses to the family would be. The authors found some universal services and responses as well as differences. They then analyzed the information gathered to find the most helpful practices to change systems particularly in England. They found factors that

led to good outcomes for consumer parents and their children. These factors included that informal communications were more successful than formal meetings in building trusting relationships which led to increased collaboration between the family and social worker. English participants noted very little opportunities for informal contact. Resources and social support at an earlier stage with a family often led to a higher level of functioning for the family as well as less services and resources overall for the family. It is also important that professionals share information between mental health and child welfare agencies. The mental health professionals surveyed shared that they did not know how to work with the children and child welfare professionals stated that they had difficulties in focusing on the parents and their mental health problems. Professionals in all United Kingdom areas that worked in an agency that served both children and adults were much better prepared to work with a family where parents had mental health issues. These professionals reported much more success with families (Hetherington and Baistow, 2001).

Having both universal and targeted services are necessary in working with families that have parents with mental health issues. Targeted services such as support groups and hospitalization need to complement universal services such as medical healthcare and education (Hetherington & Baistow, 2001). French participants described multidisciplinary child welfare teams as one way to create such a wide variety of individualized services (Cooper, 1995 as cited in Hetherington & Baistow, 2001). Participants in Scotland emphasized the importance of schools and school-based medical

services as part of the services to support families while English participants rarely mentioned these services (Hetherington & Baistow, 2001).

Resources Available

Community based.

The Community Mental Health Centers Act of 1963 called for mental health services to be available in the community and accessible to people who need them. Every community has different services available depending on the needs of their citizens and the amount of funding available. Hinden, Biebel, Nicholson, Henry and Katz-Leavy (2006) researched components of services that made them successful for consumer parents. They interviewed directors of programs that served consumer parents and their families. Strengths-based and family-centered approaches were identified as crucial to the success of the service. Parent education and support whether it was formal or informal and case management were the two most critical and essential components of all the programs surveyed (Hinden et. al, 2006).

Faith based.

The Salvation Army provides food, clothing shelter, and financial assistance in many communities. Youth camps, drug and alcohol rehabilitation and disaster relief are among many other social services that Salvation Army provides to communities around the nation. Salvation Army is one of many faith-based organizations that offer social services (Salvation Army, 2000-2008).

Some churches may require that a person is from the congregation or promises to be in order to provide assistance. The Anti-Defamation League states that charitable

choice provisions have been put forth as a solution to the very real problems associated with delivering social services. Charitable choice provisions require the government to give religious institutions an equal footing when it seeks bids and grants contracts for the private-sector provision of government-funded social services. These provisions may have help exclude some people from receiving services because many charitable choice plans have been put forth without adequate safeguards to ensure that religious activity is not a part of service delivery (Anti-Defamation League, 2001).

Government services.

In California, with the passage of Proposition 63, The Mental Health Services Act (MHSA), in November 2004 many of the programs and concepts merged that the Systems of Care Adult and Older Adult Program Policy Unit helped develop in preceding years. Programs that had been developed were able to become permanent programs with the support of MHSA funds and federal program funding. The California Department of Mental Health administers a number of programs for adults. The programs' services are directly provided at the local level by counties and their contract providers (DMH, 2009). These programs and services can be located by using the Network of Care for Mental Health, which is an online resource guide for mental health services in California (Network of Care for Mental Health, 2009).

Women with severe mental health issues are almost three times more likely than other mothers to come to the attention of the Child Welfare System (CWS) or to lose custody of their children. CWS involvement may involve completion of non-voluntary services to have custody of their children returned. In-home preventative services, such

as life skills, parent education and case management, are intended to prevent the removal or re-removal of children from their parent's custody and to increase family functioning (Park, Sullivan & Mandell, 2006). Biebel, Nicholson, Fisher and Geller (2006) found in their survey of State Mental Health Authorities' (SMHA) programs, policies and procedures that many had not addressed the needs of consumer parents. This is disheartening because a majority of consumers have the role of parent as well. The percentage of consumers that are parents in the future will remain steady or increase; the lack of response from SMHAs will result in missed opportunities for wellness and recovery for consumer parents and their children and will lead to poor outcomes (Biebel, Nicholson, Fisher & Geller, 2006).

Parenting

Grusec, Hastings and Mammone (1994) outline how a person's cognitions and relationships form the way he or she parents. They believe that a parent's cognitions; specifically feelings of self-efficacy and about the child's behavior; are influenced by the parents' culture, experience with children, and relationship schemas. Cultures and communities convey many messages about parenting. Goodnow (1985) suggested that culture is the primary source of information about facts of parenting including developmental stages, specific parenting techniques and goals of parenting. Child-rearing experiences of parents will add to their belief system. Goodnow continues, stating that more specific beliefs may change depending on parents' experiences with their children. Thoughts about parents' own competence and effectiveness are prone to

change based on the feedback from parent-child interactions (Goodnow, 1985 as cited in Grusec et al., 1994).

Parent's self-efficacy is also determined by the relationship schemas that they possess. These relationship schemas dictate every interaction they have with others including their children. The thoughts that parents have when they are talking and relating to their children should be similar to any other close relationships including spouses and friends. These cognitions include expectations for behavior of others and relative control of the social interaction. Parents' cognitions and feelings about their social relationships create a relationship schema which determines the parent's cognitive, behavioral and affective reaction to a social situation (Grusec, Hastings & Mammone, 1994).

McKellar, Pincombe, and Henderson (2009) describe the transition into parenthood a major life event that many parents find themselves unprepared for. Unrealistic expectations of the ante partum period can cause significant distress for parents. When a parent's experience does not live up to the idealized version, women can be left feeling like a failure while fathers contend with uncertainty and a sense of inadequacy. McKellar et al. suggest that if parents are adequately informed about what they should expect they will have a more positive experience during the ante partum time that leads to confidence and an ability to better master the new role of parent (McKellar, Pincombe, and Henderson, 2009).

Support for Consumer Parents

Mowbray and Oyserman (2004) in their article, *Parenting Self-Construals of Mothers with a Serious Mental Illness: Efficacy, Burden and Personal Growth*, discuss the importance of the relationship between a mother and child in women with serious mental health problems. They stress the relationship between a mother's view of her efficacy and symptom frequency. If a mother believes that she is a good mother and has confidence in her parenting there is an increase in positive parent-child interactions and a decrease in the frequency of symptoms. A woman that has a self-construct of positive parenting that includes parenting warmth and nurturance experiences less parenting stress (Mowbray et al., 2004).

Oyserman, Bybee, Mowbray and Kahng (2004) interviewed women that were parenting children ages 4-16 and had a mental health diagnosis. The women suggested that being a mother was central to their identity. The researchers found that positive parenting self-constructs did in fact promote parenting behaviors and styles known to be encouraging of positive outcomes for children (Oyserman et al., 2004).

Zemencuk, Rogosch, and Mowbray, (1995) found in their research of 48 mothers in state psychiatric hospitals that social support networks were vitally important. Most women's social support networks were dominated by family members. Non family members were included but in a much lower rate. Over 75% of the women included their children in their support network. The types of supports described varied from emotional support to advice to child care assistance. The majority of women were satisfied with their support network even when supporters provided stress as well (Zemencuk et al., 1995, p. 77).

Most women did not perceive any difficulties with their children. However, of the women that perceived difficulties with their children, much of the difficulties were due to negative control from her mother and inadequate living situations. While the women in this study faced considerable parental difficulties and risk factors including having given birth at a young age, poverty, unplanned pregnancies and single parenthood, most maintained parenting responsibilities and many displayed an authoritative parenting style which is generally considered the most adaptive. Overall the authors found that while many serious mentally ill women are mothers their treatment plans rarely if ever include goals or services with, for or about their children (Zemencuck et al, 1995).

Barriers to Services

Hearle (1999) declares that fear of losing their children can keep parents from acknowledging problems and requesting services. He connects this fear to the stigma of mental illness and the assumptions made by society at large about individuals with mental illness, i.e., that they are incompetent, violent or potentially dangerous. (Hearle et al., 1999; Nicholson, 1996 cited in SAMHSA National Information) Not only does this stigma create fear, the stigma of mental illness and the pervasive assumption that parents with mental illness will fail keep many parents from seeking help. The stigma accompanying mental illness is the single most pervasive factor affecting parents' access to services (SAMHSA, 2009). Nicholson et al. (2001) suggests that the impact of stigma prevents people from getting treatment, sustain myths that people with mental illness do not have children, generates erroneous beliefs that parents with psychiatric disabilities are unable to parent successfully, and removes the potential for program development.

In a series of policy briefs on mental health and families at the University of Minnesota (2003), location of services for consumers was also noted as a barrier to treatment. Not only was the location a concern, but lack of culturally appropriate and qualified providers in rural areas were said to make it almost impossible to obtain treatment. Limits through insurance causing parents and their children who have mental health problems to have to go to different providers, and parents fearing losing their children so they avoid seeking help were additional barriers to treatment referenced in the policy briefs (Children, Youth and Family Consortium, 2003).

In May 2005, focus groups were established by Virginia Ross and other community engagement staff from Vancouver Coastal Health. One of the goals for the focus groups was to have parent-consumers identify and present their strategies and solutions for more accessibility and support in the mental health system. As a result, it became clear that few participants had comprehensive knowledge of services available to them. There was no one place where everyone could get the same information. Participants expressed concerns that service providers lacked support for them as parents and this was a barrier to people's access and use of services. Many parents spoke of their constant fear that if they admitted to struggling with depression their children would be taken from them. They also acknowledged that they felt there is a silent prejudice against parents with mental illness (Vancouver Community Mental Health Services, 2006)

This prejudice against parents with mental illness was also discovered by San Mateo County Mental Health Services (2005) when they conducted over 100 focus groups and community meetings (which included consumers, family members, and

community members) to obtain information that would help them in designing programs to meet the needs of Latino consumers in their county. Information from the focus groups suggested that stigma about mental illness prevents many people from seeking mental health services; and people lacking a basic understanding about mental illness were barriers to treatment. Culturally specific barriers were also discovered and discussed during the San Mateo County focus groups. Fear of being called "loco" or of being shamed within the community were seen as a result of the stigma behind mental illness that deters Latinos from seeking mental health services (Latino MHSA Summary Report, 2005).

While their study was specifically focused on the Latino population of San Mateo County, much of their findings support those of the above mentioned studies. For example, Consumers, family members, and providers were most consistently dissatisfied with access to services. Services were identified as confusing, impenetrable and sometimes lacking compassion. Stigma and embarrassment were identified as major barriers to care. Technology such as computers and automated phone systems were seen as a barrier by some consumers. Location of services was a final barrier to care noted. Those who lived in coastal areas described that public transportation was time consuming and indirect (Latino MHSA Summary Report, 2005).

Summary

Over the last several decades, legislation and policies have been implemented that determined where and how mental health services would be provided. Deinstitutionalization was in response to overcrowded and poorly run state mental

hospitals. One of its goals was for people experiencing mental health issues to be in charge of their own care and to be served in the community. More recent legislation has been implemented in California in hopes of giving consumers the ability to design their treatment plan. The recovery model became prevalent with its emphasis on consumer driven services. Hope, empowerment, and self-determination are values of this model resulting in consumers being better served. Unfortunately, there continues to be barriers to services and lack of supports for consumers in achieving the care they want and need.

Stigma, as well as location of and access to services continue to be barriers that are faced by consumers seeking treatment. In addition to these, consumers who are parents face more specific barriers such as, stress of proving that they are a fit parent, pressure of parenting while dealing with mental health issues, and fear of losing custody of their children because of their mental health issues. Further research is needed in order to understand the supports and barrier faced by consumer parents.

Chapter 3

METHODS

Introduction

An advantage of qualitative research is that it contains rich multiple facets and provides a deeper understanding of the underlying meaning that would not be possible by quantitative data analysis (Professional communication, March 2008). Qualitative data analysis aims to capture the richness and complexity of lived experience (Alston and Bowles, 2003). Qualitative data analysis consists of three stages; data reduction, data organization, and interpretation. Data reduction is where data are coded, summarized, and categorized in order to identify important features of the topic being researched. Data organization is the process of assembling the information around themes and disseminating the results. The identification of trends and explanations which lead to conclusions which can then be tested through additional research is the interpretation stage (Alston and Bowles, 2003).

Exploratory research is undertaken when little is known about an area (Alston and Bowles, 2003). Alston and Bowles state that exploratory research identifies the general terrain of a topic and its important themes and issues and is generally a precursor to more detailed research. Non-probability sampling is generally used with exploratory research and qualitative research. It is not intended to be representative of the entire population and its ability to be generalized is limited. This sampling method is useful when information is sought in a new area. One method of non-probability is snowball sampling. In snowball sampling, a 'typical' case is contacted and interviewed. The

participant is then asked to recommend others that might fit the research; this is continued until the sample is considered to be complete and saturated (Alston and Bowles, 2003).

Research Design

This study was designed to gather information regarding therapists' perceptions of the barriers faced and supports necessary for consumer parents. A qualitative, exploratory research design with face-to-face interviews was used. An exploratory design was chosen because there is limited literature and research available regarding consumer parents and their experiences in seeking services. Snowball sampling, a non-probability sampling method, was used to gain access to therapists that would otherwise be unavailable to the researchers. While the information obtained through this method will be limited in generalization of research results, the insights gained will benefit the participants and the consumer parents they serve.

Subjects

Participants in this research study were comprised of therapists who work with consumer parents and their children. As was previously mentioned, participants were recruited using a snowball sampling method beginning with therapists at the researchers' current internship agencies. Participants then provided referrals to other therapists working with a similar client base. To be included in the study, participants must have obtained a Masters Degree or higher. Researchers interviewed ten participants. Therapists were not offered any inducements for their participation in this study.

Instrumentation

The interview included eleven open-ended questions which were designed to gather

information regarding therapists' perceptions of barriers and supports their clients face as well as parenting skills and resources their clients have used. Each therapist was asked five demographic questions about their experience, training and practice setting. (Appendix B) Face-to-face interviews were conducted at off-site locations determined by each interviewee and lasted approximately 30-45 minutes. Interviews were tape-recorded unless the subject declined to be recorded. Notes were also taken during the interview. All tape-recorded interviews were transcribed and coded for analysis.

Data Gathering Procedure

Consent and confidentiality were explained to each participant individually and in person. Participants were asked to sign an Informed Consent Form (Appendix A) prior to beginning the interview. Individual participants were given the right to withdraw from participating at any time during the interview process. Each interviewee was assigned a participant number, beginning with the number one and ending with the final number of participants in the study. No names will be used in the data collection process.

Data was obtained through personal interviews with therapists working in various practices settings. Interviews were tape-recorded and notes were taken concurrently. Data collected through tape recorded interviews was transcribed and coded for analysis. Notes taken were used to supplement tape-recorded information. Recordings of interviews, along with researchers' notes, will be stored in a locked container to be placed in one researcher's home with only researchers' having access to material. Data was analyzed to discover any commonalities and themes among the experiences expressed by the therapists interviewed regarding supports and barriers experienced by consumer

parents. Aggregate information gathered regarding the needs of consumer parents will be shared with the participants.

Protection of Human Subjects

The Division of Social Work's Committee for the Protection of Human Subjects at California State University, Sacramento approved the proposal "Supports and Barriers Experienced by Parents Living with Mental Health Issues" on February 17th, 2009. The research approval # 08-09-091 was assigned and interviews began on February 23rd, 2009. Each participant signed an informed consent form prior to completing interview. (appendix A) This study was classified as no risk because the information obtained came from professionals working with vulnerable consumers and not the consumers themselves. The therapists that volunteered for the study did not experience any discomfort necessitating their termination of the interview.

Chapter 4

FINDINGS

Introduction

This study was conducted in hopes of gaining a new perspective as to why consumer parents face barriers when trying to access necessary supports and services. Ten therapists with a Master's level degree or higher were interviewed during the months of February and March 2009. A consent form (see Appendix B) was signed by each therapist which included an agreement to be audio-recorded. Interviews lasted approximately one half-hour and consisted of five demographic and eleven open-ended questions (see Appendix B). Questions were grouped into the following six categories: demographics, psychiatric issues, parenting, barriers, supports, and additional comments.

Demographics

Each of the ten therapists reported having a Master's level degree or higher in fields of Social Work, Psychology, or Marriage and Family Therapy. Three of the ten therapists are Licensed Clinical Social Workers, one is a Licensed Marriage and Family Therapist, and the remaining six therapists are working towards obtaining licensure. Therapists averaged eleven years of overall experience in the mental health field; three of the ten had less than ten years of experience, while the remaining seven had ten or more years of experience. Five therapists currently work in a public setting with the other 5 working in a non-profit setting. Ages of therapists ranged from 27 years old to 64 years old.

Table 1
Demographic Information of Therapists

#	Gender	Degree/ License	Years of Experience	Current Employment Setting	Age
1	F	LMFT	11	Public	33
2	F	LCSW	22	Public	50
3	F	MFTi	7	Public	64
4	F	MA	5	Non profit	26
5	F	LCSW	5	Non profit	30
6	F	PsyD	10	Non profit	33
7	F	MSW	17	Public	38
8	F	LCSW	17	Public	40
9	F	MA	10	Non profit	43
10	F	MSW	6	Non profit	27

Psychiatric Issues

Types of psychiatric issues seen by therapists in the consumer parents they served included both Axis I and Axis II diagnoses from the DSM IV-TR. All of the therapists stated that they saw depressive symptoms in the parents they served. For example, Therapist 5 stated,

> I can speak largely from the 0-3 population that I serve and the parent and caregivers of that population; depression was number one mental illness we saw from the parents; Bi-polar Disorder; PTSD and Anxiety are common; talking to the parents about depression, it was the most common difficulty they had during their pregnancy.

Additionally, Therapist 7 said she saw, "a lot of depression; parental demands workforce or societal expectations that a lot of parents have checked out from their parenting responsibilities and become depressed as their children's behavior tends to act out."

Consumer parents with Anxiety Disorders and Bi-polar Disorder were seen by six of the ten therapists surveyed. For instance, Therapist 1 stated,

> Are you asking diagnosis specific? Anxiety, I have a parent who is actually taking medication for that, depression. I also see a lot of either drug and alcohol abuse, some of it harder than others on some parents so a lot of alcohol, also Bi-polar. I have two parents that have personality disorders; one that I um she's borderline. She had a lot of traumatic events that occurred as a child. Both of her parents were she thinks murdered, but they committed suicide, murder suicide and she came home and found them dead and she has major issues with that. And then another one who actually ended up giving up her kid so I only know about what I've heard about her so she's very Borderline.

Five of the therapists conveyed they saw parents with personality disorders, specifically mentioning Borderline Personality Disorder. Therapist 8 answered, "A lot of Depression, Anxiety, mood disorders, Bi-polar, Borderline Personality Disorder, Narcissistic Personality Disorder." Substance abuse issues were identified by four of the ten therapists. As evidenced by Therapist 4 stating, "Bi-polar; ADHD; Depression; borderline intellectual functioning, it not psychiatric but it affects parenting; recovering alcoholic and cocaine addict."

Psychotic disorders and Post-Traumatic Stress Disorder (PTSD) were seen by three of the ten therapists. Therapist 10 replied, "I've had some Schizophrenic parents, a lot of psychotic issues; Bi-polar; Dissociative Identity Disorder; PTSD; Depression; Domestic Violence; a little bit of everything"

Therapist 6 added,

> A lot of PTSD, Anxiety Disorders including Obsessive Compulsive, Panic Disorder with Agoraphobia, Generalized Anxiety Disorder, Depression is a big one, Bi-polar Disorder and axis II, Borderline Personality Disorder, Dependent Personalities. I did have a parent who had some psychotic symptoms with PTSD; mostly it seems to be Depression and PTSD here and some flavors of Bi-polar

Two therapists reported working with consumer parents who were dealing with Domestic Violence issues. One of them, Therapist 2 replied, "There's a wide variety of issues. Depressive symptoms, a lot of anxiety, a few psychosis, Substance Abuse, Domestic Violence, Personality Disorders; a majority would be in the borderline arena."

Denial, Attention Deficit Hyperactivity Disorder (ADHD), Dissociative Identity Disorder, Development Delay and other mood disorders were each seen by at least one of the ten of the therapists. Therapist 3 illustrated one of these by stating, "A lot of Substance Abuse with psychiatric issues; denial; Anxiety; Depression." Therapist 9 demonstrated another by her answer, "We see a lot of psychiatric issues; Schizophrenia, Bi-polar; Borderline moms; Depression; it's getting worse; were seeing a lot more."

Parenting

During the interview process, several themes emerged regarding the parenting abilities of the consumers affected by the above psychiatric issues. One of them being that as parents' symptoms increase, their ability to parent effectively decreases. Therapist 3 supports this by responding, "they have a total impact; trying to deal with child's issues without being able to deal with their own issues. Often parents are developmentally behind child; really impacts the respect for the parent." Therapist 1 further illustrated this theme by stating,

> Well I don't think they're thinking clear half the time; a lot of them go off their emotions, and what is learned from their family dynamics. I think Anxiety and Depression leads to more chaos, so if they have more chaos the kids' issues become greater, so it's more of the parents because they are depressed the kids act out even more because they get anxious and get on the kids the kids don't know how to handle that, so they end up acting out. I also think with substance abuse their priority isn't to parent; I think a lot of them don't know how to parent.

Several therapists, including the above respondent, described how consumer parents' depressive symptoms can affect them physically; leaving them without the energy to care for their child's needs, provide adequate supervision, or respond to their child's cues. This physical effect is noted by Therapist 4 stating,

> Significantly; person's ability to be aware of their impact on their environment and their children and be receptive to other's needs; functioning is decreasing, not

able to parent, don't have the energy to make dinner to clean, to get kids in bed, to discipline.

Therapist 5 also portrays this theme by saying,

> From an infant mental health perspective, Depression can impact the infants emotional development; if the parent is suffering from Depression and has a lack of responsiveness, facial cues; the parent may be missing the infant's cues as well as the infant child not getting feedback from parents can result in the child having more a flat affect, not babbling, cooing or initiating circles of communication; language gets impacted; trust and secure attachment.

Therapist 6 added that,

> It significantly affects their ability to productively parent depending on how they're currently treating their mental health issues. Like with Depression and some that cycle with Bi-polar or Depression illness, as they get more depressed they're unable to participate in services as well. In PCIT (Parent Child Interaction Therapy) parents become less reinforcing and shoving down a lot more, kids respond and try to get their attention, a lot can be negative or they try to do positive things and take care of their parents, parentified kids. In general, it affects their parenting and being able to be consistent on a daily basis.

Finally, Therapist 10 expressed,

> It affects everything they do with their child; schizophrenic parent even if they're medicated they have flat affect, poor recognition of what kids cues are. Overall, they don't have a lot of empathy and have difficulty responding to their children

> even when they're medicated. Depression-flat affect not interested in child; Bi-polar, up and down. Sometimes they like the kids sometimes they don't. There's not a lot of follow through.

An additional theme expressed by the therapists was a lack of availability along with lack of structure. Therapist 7 believes that, "They're not available, lack of supervision issues lack of structure results in juvenile justice system for their children, school trouble."

Another theme portrayed the belief that if parents are open and willing to seek treatment the negative impact on their ability to parent decreased. Therapist 2 explains how consumers' psychiatric issues affect their parenting,

> Negatively, depending on the kind of treatment they're willing to accept. Some parents are really open to receiving therapy and medication support; it might be wrap-around services, FFT (Functional Family Therapy), TBS (Therapeutic Behavior Services), any kind of services. The more open they are to receiving help, the less there's a negative impact on their parenting. The more they're willing to stay committed to working through the issues makes a big difference.

Therapist 9 further explains that,

> If parents with mental illness are not in treatment or taking medication, in my opinion, they are not as connected to their children. A Schizophrenic mom is going to be different than a Borderline mom. There's a lot of disconnect in the parent-child relationship.

One final theme discovered during the interviews was that dealing with psychiatric issues led to inconsistent parenting. This was touched upon by several therapists' responses. Therapist 8 clarifies that it,

> Depends on the disorder. Anytime you're trying to deal with your own mental illness, it leads to inconsistent parenting and when you have inconsistent parenting, kids get mixed messages and don't know how to behave what way. So there's that aspect of it, but I think there is a transmission of that disorder sometimes if you're depressed and have low self-esteem a lot of times you transmit that to your child via the way you think about yourself and the way you perceive yourself and possibly the way you speak about your children because if you're not happy and you're not experiencing any happiness in your life you're unable to dig that up for your kids.

Parenting skills.

Therapists recommended a variety of parenting skills necessary for consumers to be successful in parenting. A need for individualized programs for parents and families to obtain these skills was indicated by therapists 2, and 8. Therapist 2 responded, "that's hard to answer. Can't do a generic parenting class. Parent project program targets a certain population and needs to be individualized programs, depending on what the issues are, to children and family can be helpful." Therapist 8 responded,

> Interactive parenting; PCIT; so hard to sit in a classroom and teach parents how to parent; DVDs; large group setting doing role playing; real life situations; has to be

interactive; how to praise children, need to be caught doing good all the time; how to consequence.

In addition, Therapists 3 and 5 suggested that teaching of these skills begin early in the child's life and include early childhood development information. Therapist 3 stated, "early childhood education is critical; begin starting a pattern of behavior with child and when they catch on, it's hard to pull them out of it; nurtured heart approach, learning how to manage their children without all negative re-enforcers, lose-lose situation." Therapist 5 stated,

> Learning how to read child's cues; sometimes as a therapist we'll come to the home and talk with the parent about noticing some cues that their child may be giving them. Sometimes they're misinterpreting and interpreting, a child literally has their arms reaching out for a hug and it's going right past them. So helping, kind of being the voice for the child, so they can realize what their child is trying to communicate to them. Understanding normal child development and expectations. Sometimes expectations are too high or too low; realizing when a child is biting, what's normal infant development for a child to start biting when they are getting their teeth versus biting to harm the parent. Sometimes the parent's own self-esteem; they may be projecting a lot of their insecurities onto the child. Learning how to read cues; learning how to play and follow the child's play.

Along with the above listed skills, therapists suggested that consumer parents begin to think long term. Therapist 7 declared,

> Understanding why they parent; have to do it because it's going to benefit child; thinking in short and long term, how is this going to impact my child instead of thinking how am I going to resolve this problem now; things get carried too far and can't reel children back in.

Consumers being aware that they need parenting skills and that these skills are necessary for them to be successful in parenting was noted by Therapist 4 stating, "awareness makes the big difference; knowing that they need skills; that there are such things as parenting skills that they can learn; what re-enforcement is; what punishment is; how to shape behavior in a child; having appropriate expectations."

Specific parenting skills needed for successful parenting were recommended by several of the therapists. Therapist 9 recommended the following skills,

> PCIT (parent child interaction therapy); PRIDE skills, praising the child describing what they're doing to enhance the relationship; learning how to redirect; active ignoring; I recommend that they read positive parenting; remain calm when you're upset so the child learns not to get sucked into the parent's drama

Therapist 6 recommended, "behavior skills, positive reinforcement, PCIT skills, ignore minor behaviors, parents escalate and they get mad and then feel bad that they yelled at their kids, redirect, step back, remove privileges, time out."

Therapist 1 recommended,

> One thing I think about is support. I know it's not a parenting skill per say, but I think they think they're alone out there. Their peers are usually the same level

> emotionally so I don't know if they are learning from one another. They need to learn to be consistent, set clear boundaries and expectations and follow through. Follow through would be the biggest out of all my parents. They say one thing and do something different a lot of times. It's easy to let the kids go out even though you punished them for the weekend.

Before these specific skills can be acquired by consumer parents, Therapist 10 believes,

> We teach a lot of parenting skills; sometimes they just don't get it. You can teach and teach them, they don't get them. They practice when you're there, but when you're gone they don't do it. You have to address their mental illness before they're going to develop any parenting skills; if they're not medicated or getting any services; you can't address their parenting skills because if you're going to lie in bed all day you're not going to practice them anyways.

Programs.

Therapists were asked about the existing, available parenting programs in the local area and their effectiveness specifically for consumer parents. Therapists 3, 4, 6, and 7 stated that the current programs were ineffective in educating consumers about parenting. Therapist 3 responded,

> Parenting in hospitals; when you have a newborn they have educational type things; PCIT is the one that gets into individualizing. The effectiveness of that is that we put them in a therapeutic situation and other factors come into play. One

> parent said 'that I've been through the CPS parenting classes four times, I could teach it.'

Therapist 4 responded, "CPS-hospitals; they're not individualized; they've repeated parenting classes several times they can teach it. Generalized. Educational."

Therapist 6 responded,

> No, I don't. They're helpful, I think they do get some info from it but a lot of our parents struggle with cognitive ability and anxiety so you get them in a class and throw a bunch of information at them. It doesn't generalize out into the public. They're just getting this information and some aren't absorbing the information. It's easy to tell someone how to do something, but actually showing them how to do something and having them practice is different. Their individual kids are different; parenting classes are not specific. Kids that have significant history, someone needs to be there to assist the parent in implementing some of the things that have been taught to them if they even remember them. The retention isn't that good.

Therapist 7 responded, "I don't think they are; they throw everybody into a bunch and say here's the curriculum. You're either a successful parent because you can do it or a failure because you can't"

Of the ten therapists, 5, 8 and 9 think that the existing parenting programs are effective in teaching parenting skills to consumers. Therapist 9 clarified, "I do think that they are effective. Some of the parents have court ordered classes. Once class is over they go back to their old ways; classes are too short-term." Therapist 5 clarified, "Family

resource centers are trying to broaden parenting classes for different cultures and languages; how to respect multi-cultural parenting. Parents gave good feedback from Rancho Cordova Family Resource Center parenting classes." Therapist 8 clarified, "I do; everybody wants parents to learn; is that person open to it; if the teacher is engaging the class is successful."

Therapists 1, 2, and 10 said that the existing parenting programs can be effective. Therapist 1 explained,

> I think they can be sometimes. I had a parent that's done Parent Project and done all these different things and are a little higher functioning than some of the other parents I have. They have alcohol related issues and they still have a hard time setting limits. They've done programs. It's easy for someone to teach you; no one's in the home to help them follow through and apply them. Even if I go in and doing family therapy once a week, I will say here's your chore chart lets do x, y and z and they do two days out of the chart. I'm not going to be there everyday to have them do it. It's up to them to decide if they're going to do it or not.

Therapist 2 explained, "some are, some are not; depends on parents; depends on the problems the families are experiencing." Therapist 10 explained, "Birth and Beyond can be helpful. They need professional mental help; parenting classes can be helpful to an extent; parenting support group."

Barriers

Internal.

Therapists listed a plethora of emotional barriers that many consumer parents face in their daily lives. Many families have no support systems in place and this leads to isolation as Therapist 7 explained, "because there's not a lot of support systems in place, a lot of families are so isolated. Parents have isolation; don't have an outlet to deal with their emotional issues; things kind of go sideways."

Therapists 4 and 6 said many of the consumer parents they work with have CPS involvement and have a fear of losing custody of their children. This fear often leads to a lack of trust with CPS social workers and other involved agency staff. Therapist 4 described, "affect regulation; knowing when you're angry and being able to control it; knowing when you're sad, angry. Trust issues with CPS; always feeling like CPS is swooping in. Vulnerability." Therapist 6 described,

> Fear about losing their kids; not supposed to see spouse that has to do with abuse. Struggle with the letting go or not letting go of the relationship and nervous or anxious that they're going to get caught. Struggling just to get schedules, emotional stuff gets in the way of them being productive. Lots of missed appointments because they can't focus or are sad. They're anxious so they're missing things left and right.

Worrying about finances is another emotional barrier faced by consumer parents as reported by the following therapists. Therapist 2 reported,

> I don't know what that means. A depressive parent, if they're not working on the issues and getting treatment for them because their depressive symptoms are so horrible they can't get out of bed. Financially, people don't feel like they can get the treatment they need. Stigma around mental illness and using the word mental illness causes that to continue. Don't want others to know they're having difficulties especially if it's a mental illness. Sometimes people grow up in families that say we deal with our own problems, don't seek help. Substance abuse. They want help; can't ask for help. Anxiety disorders; can't get out of the house to get to the services and we need to go to the house if they'll allow us to.

Therapist 9 reported,

> Financial struggles affect their emotions gets them depressed because they're wondering how am I going to feed my children this week. I see a lot of parents running on empty not having enough emotional support or resources in the community so they tend to be more isolated.

Therapist 3 reported, "Financial anxiety; fears; lack of self-esteem; lack of education-understanding where child is developmentally; social skills." Therapist 1 thinks that the consumer parent's inability to regulate their emotions may interfere with their ability to access community supports. Therapist 8 supports this thought saying that if a parent is motivated they won't have this internal barrier. Therapist 1 responded,

> I don't understand that question. I have one parent that is I believe has lower functioning. I don't know if I would say they are developmentally delayed, but they are borderline intellectual functioning two of them. I would say that when it

> goes to daily life they don't react as well to things. When they're at work, both of them do convalescent home work or cleaning or caring for older people. They don't have very good social skills both of them go on the computer a lot. They don't know how to model to their kids how to do anything outside the house a lot. I think with anxiety, I think in particular this one mom I have she gets so concerned and worried about the minor things that she doesn't even function and she'll write emails and emails about what is going on in her mind and the next day she'll be fine because she got it all out. She gets so worked up about things. I don't know how she is at her job, but I know from the emails I receive from her you can see how she can escalate in her mind.

Therapist 8 responded,

> Not having any happiness or joy; hopeless; don't see that things are going to get better; they see barriers; they see the things we ask them to do get some treatment; get some therapy; take medication; see an inability to work through barriers.

Therapist 10 explains some of these barriers further,

> I've had parents cut; I've had a little bit of everything. If you're in bed crying all day you're not actively participating with your kid. The young kids need their parents to be there; they use the TV as a babysitter; they're not really present for their kids; they don't want to interact with their kids half the time.

External.

Lack of transportation was given as the most significant external barrier in consumer parent's ability to access local services or supports. Therapist 10 concluded,

"It's difficult to get to them; a lot of barriers are in place if you miss an appointment." Therapists 2, 4, 7 asserted that an additional barrier was a lack of community resources and awareness of available community supports. Financial eligibility guidelines and compliance policies of agencies were other external barriers noted by Therapists 1, 2.

Supports

Community supports.

The therapists listed community supports that are available to consumer parents. The mental health services available seem to be focused on and driven by the family. Therapist 8 listed, "parent project; FRC (Family Resource Centers); Sierra Family Services; private therapists; Pacific Educational Services." Services are delivered in a variety of ways included home, school and community-based. As reported by Therapist 1,

> 26.5. They have family therapy. There's referrals in the community, like the family resource center. I have some issues with some of the families that are very, I think it's a culture thing they don't want to go anywhere in their small town, so they want to be referred to the next town. They would rather drive 20 minutes to another town than people know that they're having family issues at home. I think being in small town effects people being honest about what's going on.

Therapist 9 furthers this point by saying, "CHR (community health representative) goes out to family and tells them about resources-housing-rent-utilities-community events." The available services were also culturally and faith-based when necessary. Therapist 6

spoke of, "WIC (Women, Infant and Children), food services, CPS parenting classes, after-school programs, Asia pacific community center." Individual mental health services were seen as lacking but this may due to the fact that all therapists interviewed worked in a children's system. Therapist 10 listed, "Medi Cal; psychiatric services; AOD (Alcohol and Other Drugs); limited counseling services; have to transport themselves and their children on the bus; sometimes they don't have money for the bus."

Case management services were also available from both community and government based agencies. These agencies were listed by Therapist 4, "CPS, Volunteers of America" and Therapist 7, "Family Resource Centers, parenting groups through PCOE (Placer County Office of Education), parenting a special needs child or adolescent; I think there's room for more supports." Basic needs such as food and housing were identified as having community services to meet those needs. Therapist 2 stated that it, "depends on community. Own support systems; family, church, Family Resource Center, food banks. I think there are a lot of resources available they don't know how to get to them." Consumer support groups were also identified by Therapist 5,

> A great program for the young population is the Birth and Beyond Program which is a home-visitation program for parents with children 0-5; and it's paraprofessionals who come to the home and visit the parents. It's the number one link because parents with mental illness are less likely to get out of the house, have the resources to get out of the house, to want to get out of the house to seek these services. This service comes to their homes and often becomes a referral

source; Birth and Beyond often refers to the Infant Mental Health if the parent's mental health is affecting the child. NAMI-consumer to consumer support." Educational systems from elementary to community colleges were seen as sources of community supports by therapists 3, "early childhood education is available in community college; seems to take courage for parents to admit they need help."

Effectiveness.

Only one of the ten therapists declared that the available supports for consumer parents were effective. Therapist 5 said, "Yes. It links parents to counseling and financial services, specific resources." Whilst several of the therapists, 1, 4, 8 and 10, reflected that the effectiveness of the supports was dependent on the parents' willingness and openness to receive services and their follow-through. Therapist 1 explained,

> We also have RAFT, and FFT and we have resources for them; we have family support counselors. The biggest thing about effectiveness for supports is willingness. If you don't have willingness from a family and buy in as well then it's not going to work. I feel like a lot of the parents have good ideas but they get so overwhelmed because it means its changing their behaviors, who wants to change, even though they say they want to do the work that has to go into it, they don't or maybe can't because of what their emotional issues do.

Therapist 4 explained community supports,

> Have been effective, their structure have been good for him. He has been very motivated to sober up through Volunteers of America. If parents are open to

changes, services can be effective. Parks and recreation center has been helpful, things for kids to join, low cost activities in the communities.

Therapist 8 explained that community supports are, "only effective if parent wants classes. Parents can attend every single parenting class but that doesn't mean they took in what the class was teaching." Therapist 10 explained that community supports are effective, "when they're used. Psychiatric services can be helpful once they get stabilized on them. It's not effective if parents aren't following through."

Five out of ten therapists deemed the available community supports as ineffective. For example, Therapist 2 revealed that,

> St. Vincent de Paul helps with housing and food, but certain rules that they have to follow that are sometimes difficult for them to follow and they end up getting kicked out of it. People that are systems savvy, the supports are helpful because they know where to go. No, people don't know where to get services. Consumers do not know where to get services.

Furthermore, Therapist 3 stated that, "what I hear from parents is, 'I've tried this and I've tried that and it hasn't helped.' They're ineffective or not enough specificity or variety." Additionally, Therapist 6 mentioned,

> Some are some aren't; hard to get; economy problems less services. Parents with mental health issues get limited therapy through CPS because they have too, but they feel like they're being watched, unable to participate openly. After school programs are effective. Parenting, no, a couple of times only; they need to actually practice these skills.

Therapist 7 offered the following reasons why the supports are,

> Not as effective as they could be; I think it ask parents to be something they're not. A lot of parents don't have a high sense of authority and they're not going to follow through with that and it sets them up to feel like a failure as a parent. I think we need to have some more parenting starting from where a parents is and drawing on their strengths instead of trying to make them the parent we want them to be.

Finally, Therapist 9 answered,

> No, they don't utilize them. Parents that are really paralyzed by their symptoms don't. Depends on the individual and what's going on in that parent's life at the time. I have a mom who's agoraphobic so she's not going to go anywhere.

Satisfaction.

Satisfaction with community supports was said to be dependent on consumers' engagement in and desire for services. Therapist 1 maintained that,

> I would say some do, and some don't. I guess the ones that are engaged and they feel like they have a connection with whatever the support is whether it's a family support counselor or if its going into the community and going to a group, its getting them there, they're connected they do. They have the fear because they heard someone else went there cause it's a small town then they don't want to go.

Therapists 5 asserted that, "home based services they are satisfied with." Therapist 6 said, "school ones yes. Food closets yes. Psychiatric support, no and therapists through CPS, no." Therapists 3 acknowledge, "most of them not. Every now and then I get a

parent who is totally grateful for everything that's been given to them but that's rare." Therapist 4 simply said, "no." Therapists 2 claimed,

> The ones that are systems savvy do. Having parent advocates who know the resources; they can help other parents navigate the system. And, we also have youth advocates to help the youth. Those with CWS cases not satisfied because they don't want it.

Therapist 7 replied, "fifty/fifty." While Therapist 8 said, "overall." Therapist 9 stated, "yes. Absolutely!" Therapist 10 reported that it "depends on parents follow through."

Accessibility.

In response to the question of whether or not consumers were able to effectively access community supports, Therapist 5 replied, "in the home yes. Transportation can be a barrier. Agoraphobia." Therapist 6 declared, "no! Transportation. For some with anxiety, it's overwhelming to contact the places and ask for help and have to go there. Therapist 8 claimed that

> with child welfare we'll pay for it. Transportation is a barrier; public transportation. If parent is motivated; they have to find some type of internal motivator; and no, Spanish speaking classes aren't available because the need isn't great enough for an entire class.

Therapist 9 answered, "Transportation is a huge issue," that keeps consumers from accessing services. Therapist 10 stated, "I don't think so. It's difficult to get to them. A lot of barriers are put in place if you miss an appointment. Transportation.

Therapist 3, responded,

> They have to have a resource person who can show them how to access services. Most parents are computer illiterate. Some take the initiative; the more educated parents do; the less educated parents need to be led by the hand in general; sounds like I'm stereotyping.

Therapists 4 stated, "parents need to know that the supports, resources and activities are there. Not that up to date online and parents may not have access to on-line. More marketing of resources." Therapist 7 believes that, "for the most part. If they're not involved in a system of care knowledge not out there in community." Therapist 1 replied,

> I think that they are able, they have transportation most of them. I don't know if emotionally, because of their own stuff going, on if they're able to really go to them and do them. I have a family that had RAFT that said they wanted RAFT, but they couldn't follow through; they couldn't change behavior so in a month they were closed. It's there and they have tried but because they don't have the follow through it doesn't really go anywhere, so they'll know about the family resource center but they don't call. They have the ability to there's just something, may be it's their own issues. They don't want it to be about them they want it to be about the kids.

Therapist 2 said,

> Yeah; Some barriers to getting to some of the services such as rules at agencies. Don't income qualify. Maybe there's people that really, really need help but

> because they make that much too much money they don't qualify for services such as health care.

Gaps in Services and New Ideas

Having a mentor, someone who's been in their same shoes, other parents that they can relate to, or an individual coach, were types of resources reported by therapists interviewed. Therapist 1 recommended, "having someone who's been in their same shoes to explain." Therapist 3 believes, "Alta regional needs to reach out to parents or respond to parents. More places like mentors follow through the day with parents until it becomes natural for them. Compassionate non-judgmental non-systemic stuff; individual." Therapist 6 suggests,

> More community groups that have childcare available for them where parents can access. Other parents that they could relate to. Transportation services. Information more available to parents. Advocates for support to help them find out how to access what they need. PCIT and help them practice their skills.

Therapist 7 said, "smaller groups; individual coach working with them." Therapist 2 recommends, "Parent support group; as economy gets worse need to come up with ways to be consumer friendly taking the stigma away from asking for help." Therapist 8 suggests, "Interactive parenting class for teens." Participant 4 states, "CPS has been a support for some families. Make it where CPS can be more supportive by having lower case loads to like 10 kids they have to know. 211 information line for resources." Participant 10 responded, "psychiatric services with Medi Cal. Only see psychiatrist once a yr. Transportation services would be good. Seeing psychiatrist more often."

Additional Comments

Most of the therapists' additional comments were restating information already recorded above regarding barriers to services. For example, Participant 2 commented, "It's a cultural thing that we have that you should be able to take care of your own. You should be able to take care of yourself. Being able to get the word out about what's available." Therapists 3 commented,

> The schools were more aware of the resources because the school is the first connection the parents have with the community; that's the one they're comfortable with the one they don't feel stigmatized with; they rely on them for info. and direction If the school could be the resource person or the churches-parents go here freely for advice ready to receive; if you bring them into a community or county office there's walls and barriers coming in with them-not receptive to that environment. Families that have had a lot of experience with CPS, connect 26.5 therapists to CPS and put up walls.

Therapist 4 recommended, "Talk to other directors of other programs." Therapist 8 commented,

> County mental health services are getting cut and cut; hard to get services for parents unless they're in absolute crisis. They have to have a high level of diagnosis; you can't just have anxiety and go to adult system of care for mental health services.

Therapist 7 commented, "I think a lot of hospitals are good with the younger ages, but school age to adolescent there's a lack of support there. More community based programs at community center or library that have more age appropriate classes. Therapist 1 said,

> One thing I think there is still the stigma in mental illness. A lot of parents, if I was to say to them you seem to have some anxiety around that, depending on their space they can become very defensive and not follow through on anything. They want their kids. They would rather have their kids than deal with their own stuff.

Therapist 5 suggested, "a group for maternal depression and the challenge of getting people there. A support group for new mom's with mental illness." Therapist 6 replied,

> transportation is a huge barrier for them to ask for support. Case managers that are able to help parents get the resources they need. We don't want to hold their hand all the way they need to do this stuff on their own, but they do need a little bit of help. Parents that are struggling with mental health issues; I think the more we can provide them with some support like case managers or transportation the better we can help them.

Therapist 9 said, "The biggest limit is transportation. Therapist 10 declared, "change the whole Medi-Cal system!"

Summary

As a result of interviewing therapists that serve consumer parents, these researchers gained a new perspective of the barriers faced by consumer parents and supports and services that are available to them. Psychiatric issues, along with their

effect on parenting, barriers to services and, available supports were explored. Several overarching themes were discovered by these researchers during the analysis of the data and will be further explored in Chapter Five.

Chapter 5

SUMMARY, CONCLUSIONS, RECOMMENDATIONS AND IMPLICATIONS

Summary of Data

The purpose of this study was to gain information that would be beneficial for therapists in their work with consumer parents, by establishing a larger view of the barriers faced and the supports necessary to keep consumer parents successful. During the interview process, many psychiatric issues were seen by the therapists as impacting the day to day lives of the people they served. Depression was seen most often and interfered dramatically with the parent-child relationship. The symptoms of depression, including low energy, flat affect and inability to read their child's affect, made it more difficult for the consumer to successfully parent. Inconsistency, as a result of consumers' mental health symptoms, was seen as a major barrier to effective parenting. Consumers were physically affected by their mental health symptoms and the side effects of medications, which often led to consumers' lack of availability and supervision of their children and their needs.

Current parenting programs were generally not successful in teaching consumers the specific parenting skills needed to overcome the aforementioned barriers. Several suggestions were given by the therapists that would increase the success of these programs to help them meet the individualized learning needs of consumer parents. Local supports to help consumer parents keep custody of their children were reported as lacking. The supports that do exist were seen as difficult to access because of eligibility guidelines, financial restraints, and lack of awareness about services available.

Several internal and external barriers were faced by consumers who are parenting. They were impacted both emotionally and by the stigma. Stigma is a very real barrier that consumer parents face each day from general society and some service providers as well. Gaps in services as well as accessibility were noted as additional barriers to services for consumer parents. Openness and willingness to receive services positively impacted the consumers' ability to parenting effectively. Their apparent lack of willingness may be attributed to fear of the stigma they may face for reaching out for help.

Conclusions

Living with a psychiatric disability creates a more challenging parenting experience due to the day-to-day stress of being a parent and the added pressure of dealing with mental health symptoms (Nicholson, Sweeney and Geller, 1998). For example, Therapist 3 stated "trying to deal with the child's issues without being able to deal with their own [psychiatric issues] affects consumer parents' parenting a lot." Due to deinstitutionalization and community-based services more consumers are becoming parents and raising their children (Oyserman, Mowbray, Meares, & Firminger, 1999). It is necessary to look at the barriers faced and community supports available to consumers to become successful parents.

There is a lack of available services that are specific to consumer parent needs. Services that are available continue to be difficult to access due to lack of knowledge about them, stigma surrounding accessing them, and the ability to access them due to active mental health symptoms. Therapists 2, 4, and 7 asserted that an additional barrier

was a lack of community resources and awareness of available community supports. Consumers are continuing to have children with or without these community resources and supports; a lack of attention to their specific needs will continue to place their children at risk for behavioral and mental health issues (Silverman, 1989, Grunbaum & Gammeltoft, 1993 in Nicholson & Blanch, 1994).

Therapist 1 confirmed that there is still stigma surrounding mental health issues even among professionals in the field. Not only does stigma create fear, the stigma of mental health issues and the pervasive assumption that consumer parents will fail keep many of them from seeking help. The stigma accompanying mental health issues is the single most pervasive factor affecting parents' access to services (US DHHS, SAMHSA, 2005). Nicholson (2002) suggests that stigma prevents people from getting treatment, sustains myths that consumers do not have children, generates erroneous beliefs that consumer parents are unable to parent successfully, and removes the potential for program development. Compassionate, non-judgmental service providers along with reducing the stigma around asking for help were ideas for creating successful parenting by four of the therapists interviewed.

The language of the recovery model and psychosocial rehabilitation involves non-judgmental, strengths-oriented and hopeful terminology. In interviewing therapists from different settings and educational backgrounds, a difference was seen in the overall language use. Generally, the therapists in the non-profit but more medical settings tended to use more deficit, symptom focused language in their responses. For example, "I've had some Schizophrenic parents, a lot of psychotic issues; Bi-polar; Dissociative Identity

Disorder; PTSD; Depression; Domestic Violence; a little bit of everything" and "We see a lot of psychiatric issues; Schizophrenia, Bi-polar; Borderline moms; Depression; it's getting worse; were seeing a lot more". In the public, more recovery focused settings, therapists tended to use more strengths and ecological based language. For example, "There's a wide variety of issues. Depressive symptoms, a lot of anxiety, a few psychosis, Substance Abuse, Domestic Violence, Personality Disorders; a majority would be in the borderline arena."

Hetherington and Baistow (2001), found that resources and social support at an early stage with a family often led to a higher level of functioning as well as less services and resources overall for the family. A majority of the Therapists interviewed, conveyed a lack of preventative and tertiary services available that may decrease a family's stress and crises. Therapist 8 spoke of the current financial climate where mental health services are getting cut especially at a county level making it difficult for consumer parents to receive services until they are in an absolute crisis.

Lack of transportation was given by therapists as the most significant external barrier in consumer parents' ability to access local services or supports. Therapist 10 concluded that,

> It's difficult to get to services and a lot of barriers are in place if you miss an appointment at local agencies. Many agencies have policies that limit the number of missed appointments a person can have before they are told they can no longer use the resource.

Getting to appointments and accessing services is made difficult by the local transportation system because there are often no direct routes to social service agencies resulting in extended commute time. It can be difficult for a consumer parent to use public transportation when they have to switch buses or even modes of transportation.

National and state legislation was created to address the concerns of persons dealing with mental health issues. Areas of concern that were addressed include stigma, service availability, and knowledge of available services. Lack of funding often limits the full implementation of the well intentioned legislation and policies.

Recommendations and Implications

In support of recovery model values of self-determination; empowerment; hope and community-based services, these researchers recommend that further research be completed with consumers as the participants. This will provide firsthand knowledge about the barriers faced and supports utilized in the consumers journey of parenthood. We also recommend that professionals in the mental health field receive training to create an awareness of how language can impact the well-being of the consumers they serve. This awareness can lead to an increased use of recovery-oriented and strengths-based practice.

According to Cook and Steigman (2000), parents with mental health issues need service delivery with the following seven principles; an ongoing availability with no exclusions or time limits; the family needs to be the focus; includes a mix of rehabilitation, treatment and support; has sensitivity to the stigma associated with having mental health problems; values the importance of the parents' concerns in seeking and

accepting assistance regarding the custody of their children; sees parenting as the foundation on which consumers can build their recovery; and collaborates with all agencies including health, mental health child welfare and others is necessary. Hetherington and Baistow (2001), add that informal communications were more successful than formal meetings in building trusting relationships which led to increased collaboration between the family and social worker.

Limitations of the Study

This study is limited in its ability to generalize the information gathered to the larger population due to its use of a non-probability sampling method. The sampling size was small because the availability of participants that met the study's criteria was limited. As a result, information obtained is narrow in scope. Therapists were interviewed to mitigate any psychological harm to consumer parents. Therefore, results are the opinions and experiences of the therapists about consumer parents and not the consumers themselves. While the researchers provided therapists a summary of the information obtained regarding supports and barriers, the intention was only to gather this information and not to provide solutions. Additionally, no male therapists were interviewed. The therapists spoke mostly about women that were consumer parents and the researchers assumed that most of the consumer parents are women. The needs of men that are consumer parents were minimally addressed, although, they are nearly as likely as women to become consumer parents.

Awareness of the need for supports and resources for consumer men and women who are parenting is only the beginning. These needs are best met with consumer-driven,

community based services as pointed out by state and national mental health reports and policies. Strategies are needed to help consumers overcome external and internal barriers they face in attempts to access services. Increased education and training regarding individuals experiencing mental health issues who are parenting will help reduce stigma.

APPENDIX A

Consent to Participate in Research

You are being asked to participate in research which will be conducted by Kezzia Bullen and Katherine Metoyer, who are graduate students in Social Work at California State University, Sacramento. The purpose of this study is to gather information on therapists' perceptions of the barriers and supports needed for consumer parents.

You will be asked to participate in an interview consisting of 5 demographic questions about yourself and 11 open-ended questions about the consumers you work with. The interview may require up to one hour of your time. You may choose not to answer any of the questions for any reason.

It is hoped that the information gained from the study will be beneficial for you and your work with consumer parents by establishing a larger view of the barriers faced and the supports necessary to keep consumer parents successful.

All results from this study will be kept confidential. The researcher will record and take notes during your interview. You may choose not to be recorded; then only notes will be taken. Recordings and notes will be stored in a locked container which only the researchers having access to. Tapes, digital recordings and notes will be destroyed once interviews are completed and data is collected and analyzed.

You will not be compensated in any way for your participation in this study. You may choose to end the interview at any time. You have the right to withdraw from this study at any time.

If you have any questions about this research, you may contact Kezzia Bullen at
or by e-mail at or Katherine Metoyer at
or by e-mail at You may also contact our thesis advisor Dr.
Susan Taylor by email at or by phone at

Your participation in this research is entirely voluntary. Your signature below indicates that you have read this page and agree to participate in the research.

I agree to be audio recorded during interview: ☐ Yes ☐ No

_____ _____

Signature of Participant Date

APPENDIX B

Questionnaire

Demographic questions: **Participant number:**_____

○ Male ○ Female ○ Other
Type of degree: _____
Years in the field:_____
Practice setting: ○ Public ○ Non profit ○ Private
Age:_____

Interview questions:

What types of psychiatric issues do you see in the consumer parents you serve?

How do you think that these psychiatric issues affect their parenting?

What emotional barriers do you see the consumer parents you work with face in their daily lives?

What parenting skills do you think these parents need to be successful?

What community supports are in place for these parents?

Do you feel that the supports are effective? If no, what would make them more effective? If yes, why are they effective?

Do the parents seem satisfied with the community supports they utilize?

Are they able to effectively access community supports available to them? Why or why not?

What types of resources or supports do you think should be created that may benefit consumer parents in becoming more successful in parenting their children?

Do you feel that the existing/available parenting programs are effective for consumer parents? Why or why not?

Is there anything else you would like us to know that can help us in identifying barriers and community supports available for consumer parents?

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