MENTAL HEALTH CONSUMERS’ PERSPECTIVES ON TRADITIONAL MENTAL HEALTH SERVICES VERSUS PEER-RUN SERVICES: A QUALITATIVE STUDY

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ASHLAND UNIVERSITY, 2012

Carla Edlefson, Ph.D., Dissertation Chair

The purpose of this study was to examine mental health consumers’ perspectives on traditional mental health services versus peer-run services. Three mental health consumers, a family member of each, and a mental health worker of each were selected using purposive selection and were interviewed one time each about traditional mental health services and peer-run services. Several themes emerged in addition to traditional mental health services and peer-run services, including alcohol and other drugs (AOD), family issues, boundaries and ethics, and medication issues. I found that these mental health consumers preferred traditional mental health services over peer-run services. The limitations of the study included the small sample size and purposive sampling which could affect validity. Future research directions should include the connection between mental health consumers and AOD and the effectiveness of peer-run services as an adjunct therapy for mental illness.
DEDICATION

I would like to thank Jesus my Lord and Savior for giving me the strength to complete this dissertation. I would like to thank the two most awesome people in this world, my parents Don and Pat Harley; you are my strength, my courage, and my hope. If it were not for my parents, I would never have had the ability and support to have completed this project. I would also like to dedicate this project to my friends Chris Nedrow-Carr, Deborah Zuercher, and Tina Swartz for their encouragement and support. Thank you to my family and friends for supporting me through this endeavor.
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CHAPTER I

Introduction

This dissertation is a report of interviews with individuals identified as having a mental illness, their family members, and mental health workers. The focus was on the perceptions of all those involved with regard to experiences with peer-run services and traditional mental health services. This study was based on direct interviews with the participants and their answers to the semi-structured interview questions. The first chapter of the report provides a background of the study, the research problem, the limitations of the study, and an overview of methodology. The chapter ends by noting the limitations of the study and defining the key term of peer-run services.

Background of the Study

Individuals with mental illness in America have faced many challenges over the past century. Mental illness has gone from being deemed as demonic possession, poor character, and being caused by poor parenting to now being understood to be a complex combination of the biological and the psychosocial. Much of this change has come about due to the advent of the disease model of mental illness and the creation and systematic utilization of newer and better psychotropic medications.

Individuals with mental illness were once shunned and institutionalized, often in poor and inhumane conditions. Individuals with mental illness were invisible members of fringe society which drew little attention from the public or the government. Today, the
bulk of even the most ill individuals live in the community, sometimes with significant assistance from community mental health centers. I have seen the families of individuals with mental illness often carry a huge burden by allowing them to live in their homes, taking them to their mental health appointments, and following the ups and downs of the disease of mental illness. Legislation is in place to mandate services in the community for individuals with mental illness with the focus of avoiding hospitalization except in the most extreme cases. Over the past few decades, large scale residential facilities have become defunct, with most mental health advocates favoring community-based services.

This change did not come about easily; a long struggle against the stigma of mental illness, including assumptions held by the mental health professionals placed in positions of helpers, took place. Many mental patients advocated for themselves and others to bring about change. Individuals involved with grass-roots efforts lobbied the United States government for better care in the community and the deinstitutionalization of state facilities. Often advocates and their allies came together and formed peer-run services which were an adjunct to, or even a substitute for, local mental health services. These services include self-help groups (i.e. Alcoholics Anonymous, or Narcotics Anonymous) which can be seen as a rejection of traditional psychiatry in favor of peers healing each other through understanding and support.

The Research Problem

The main research question addressed in this dissertation is what are the experiences of individuals living with mental illness, as well as family members and mental health workers, as they interact with peer-run services and traditional mental health services?
Subsequent questions involve (a) how do mental health consumers view their involvement in their traditional mental health treatment?  (b) What are their views on mental health legislation and deinstitutionalization?  (c) Do our participants act as consumers-as-professionals? (d) How do families provide support for family member who has mental illness?  (e) What part do advocacy and peer support play in their lives?  How do they view the consumer-as-professionals’ movement?  (f) How do the mental health workers view their participation in treatment?  (g) What part do drugs and alcohol play in the lives of these individuals?  (h) Do these individuals with mental illness experience personal empowerment when interacting with their services?  (i) What part do medications play?  Are boundaries and ethics relevant?  (j) Have the participants experienced discrimination?  and (k) What hopes for the future do the participants have?  All of these questions are important for the study because they provide a rounder, deeper, more complete perspective of the participants.  Overall, the purpose of this study is to listen to the voices of these individuals and gather a more complete picture of what it is like to be involved in the mental health system.

Many studies involving individuals with mental illness have been conducted over the past several decades.  Often, the participants of these studies have indicated that they have not felt that their voices were heard (Barnes & Wistow, 1994; Watts & Priebe, 2002).  This dissertation is significant because it attempts, through the very words of the participants, to give voice to not only the experiences of individuals with mental illness who utilize peer-run services, but also to hear from their families and mental health workers.  Every attempt was made to allow the participants to express their true feelings and opinions in a non-threatening environment.  The participants were asked specific
questions and allowed to expound on their thoughts and subjects
relevant to their lives. Additionally, the results of the study were shared with the
participants in order to enhance reliability and to give the participants the opportunity to
amend any statements they felt were incorrect.

Overview of Methodology

For this study, I decided to interview people with mental illness, one of their
mental health workers (their choice), and a family member of their choosing. The person
with mental illness had to be involved with a mental health facility and a peer-run group
of a facility. To conduct this study, I chose purposive sampling in order to capture this
specific population. One mental health center and one peer-run drop-in center (which
were linked) in a rural area were solicited for this study. The director of the mental
health center and the director of the drop-in center acted as gatekeepers when they
identified six potential participants and solicited them by giving them my research
proposals. Three of the individuals showed interest in the study and became eventual
participants.

I obtained background demographics, including age, race, and gender as well as the
person with mental illness’s self-identified psychiatric diagnosis (i.e. what they believe
is their diagnosis at this time; it may have been true, or it may have been just what they
thought to be true). Each participant was asked to sign two Authorization for Release of
Informations (a) for the Mental Health Center, for myself to be able to talk to their mental
health worker that they selected to be part of the study, and (b) for a family member of
their choosing who would also be interviewed. Each participant was asked to be
interviewed one time using an interview script that was different for participants, family members, and mental health workers (See Appendix B). The participants were each given a copy of the interview questions for their family member and their mental health worker and were asked if they had questions, which they did not (see Appendix B). The scripts were not deviated upon except to ask the person to go into more depth (e.g. “Tell me more about that”.)

The persons with mental illness interview script topics included: psychotropic medications, personal view of mental illness, deinstitutionalization, mental health legislation and policy, community support, treatment provider-client relationship, advocacy, self-help group involvement, consumers-as-professionals, the value of peer support, feeling understood by others, empowerment, ethics, and experiences in peer-run services (See Appendix A).

The family members’ interviews contained questions including history of their family member’s mental health diagnosis, symptoms, the potential benefits of traditional mental health services and peer-run services, burnout, deinstitutionalization, demographic information, the role they play in their family members’ mental illness, mental health legislation, and empowerment (See Appendix C). The mental health workers’ interviews contained questions including history of the mentally ill person’s diagnosis and symptoms, the potential benefits of traditional mental health services and peer-run services, burnout, job satisfaction, ethics, demographic information, mental health activities done with the client, deinstitutionalization, and mental health legislation.

All interviews were audio taped and all participants signed a release for audio taping. The tapes were transcribed by an independent transcriptionist. Participants names and
indentifying characteristics and features were changed. The transcribed interviews were coded for themes. I reported the final results back to the individuals to enhance understanding and validity.

Limitations

This study does have some limitations. First, because all of the participants were volunteers, there is the possibility that they may have answered a particular way in order to please the interviewer. I am also a mental health professional and this fact was disclosed; it is unknown how or if this fact affected the outcome of the study. Second, the nature of mental illness could mean that at any given moment the illness may have affected the answers given by the participant with identified mental illness, both positively and negatively. Medication changes, fluxes in mood and affect, or the chaos associated with some individuals with mental illnesses lives may have affected the results.

Definition of a Key Term

Finally, I must define the peer-run, sometimes called consumer-run, services, as it is a key term used and referred to throughout this dissertation. For the purposes of this report, peer-run services will include all services, such as self-help groups (e.g., Alcoholics’ Anonymous, Survivors of Sexual Abuse), outreach centers (e.g., centers which provide structured programming for consumers with mental illness), and drop-in centers (e.g., less formal forms of outreach centers), whose day-to-day operations are run by mental health consumers and/or mental health advocates that are separate from the local mental health systems (Bentley, 2000; Holter, Mobray, Bellamy, Mc McFarlane, &
Dokarski, 2004). Some of the day-to-day operations include the financial matters of the organization, running of groups, fixing meals, running food pantries, making and carrying out policies, management of other staff, etc. These peer-run services, although separate from traditional mental health services, often work cooperatively with the local mental health agencies. Advocacy is also a role of the service providers as well.
CHAPTER II

Review of Literature

The lives of the people with mental illness have changed dramatically over the past century. Brain chemistry, environment, and even the effects of medical disorders are all known to contribute to the likes of depression, anxiety disorders, schizophrenia, and personality disorders. Possibly the biggest advancements have come in the new understandings regarding the role of neurotransmitters in mental illness. These chemicals, including dopamine and serotonin, are linked to certain mental disorders and can be manipulated through drugs, increasing or decreasing the levels as needed. The advent of the Selective Serotonin Reuptake Inhibitors (SSRI’s) in the late 1980s has allowed millions of people to lead manageable lives while reducing, or sometimes even eliminating, signs and symptoms of depression (Kingland, 2004). Persons who had previously lived isolated lives under the stress of severe depression were able to again function in society.

Also significant was the introduction of a new line of antipsychotic medications, often called atypical antipsychotics over the past two decades (Awad & Voruganti, 2004). These drugs include Risperdal, Zyprexa, and Seroquel. Although many antipsychotics have been on the market for decades, the older drugs usually brought with them side-effects, some of which were as bad as the original disorders themselves; such as weight gain, tardive dyskinesia (a movement disorder that can be permanent even after the drug is discontinued), tremors, rigidity, involuntary limb movements, loss of
consciousness, catatonia, even death (Chiang, Klainin-Yobas, Ignacio, and Chng, 2011). These heavy side effects of medications were in contradiction with The Ohio Department of Mental Health’s Clients Rights statement that all mentally ill clients had the right to be free of unnecessary or excessive medication (The Ohio Department of Mental Health, 2007). The Ohio Department of Mental health saw the need for this kind of mandate when they would visit facilities and talk to clients. The atypical antipsychotics, although not without the flaws, weight gain being one of them, when properly administered generally leave the patient in a more functional condition. Without the debilitating psychosis, many individuals are able to reintegrate into society.

Disease Model

Medical advancements in mental health have not only contributed to the increased functionality of the patient, but the publicity surrounding the notion of a disease model of mental illness has contributed to the increased public awareness and acceptance of the mentally ill individual (Wahl, 2012). With the advent of the asylum, patients were chained to beds, subjected to types of water torture, deprived of food, and left socially isolated all in the name of treatment. Although no informed mental health professional would claim that all people with mental illness are free from mistreatment and exploitation even today, the vast majority would agree that treatment today is much less archaic. Deinstitutionalization, which I write about next, led to the advent of the outpatient mental health clinic model which is still around today. Persons with mental illness began showing up at clinics that were often run right in your average neighborhood or out of hospitals. Then, persons with mental illness were in the
community. Medical advances were happening all the time. New medications, especially antidepressants and antipsychotics were being developed rapidly. People were getting better. Maybe not normal but better. State and federal legislation became more involved in trying to defend the rights of persons with mental illness.

**Deinstitutionalization**

However, as recently as the 1950s in America, many severely mentally ill individuals were still committed, sometimes for decades, to institutions. In general, an institution housed persons with mental illness once they could no longer be managed in the community. Inside the walls of the institutions treatment varied. Mostly, they were a function of the treating psychiatrists and their treatment orientation. Some psychiatrists believed that the persons with mental illness must be medicated into a stupor. Some believed in medication and psychotherapy, some believed in Electro Convulsive Therapy (ETC) or Water Therapy. Regardless, it was the therapy of the day, and probably the worst thing one could do to treat a person with mental illness. Partially a function of no other sound treatment choices being available, state institutions were filled with thousands of patients whose illnesses were subjected to the “finest” medications and therapies of the time (Bowers et al. 2008).

Those who survived the experiences told of abuse, neglect, and substandard living conditions of the asylums. Initially, these stories were left largely unheard by authorities, but eventually both grass-roots concerns and governmental explorations of the situation led to the development of the federal Joint Commission on Mental Illness and Heath in 1955 to evaluate the broad issues of mental illness, especially the institutions *(Bloody*
Legislation Against the Poor, n.d.). The Commission eventually released Action for Mental Health, in 1961 which called for the widespread deinstitutionalization of the state hospital systems under the guise of cost savings and consolidated care (Dixon & Goldman, 2003). The book also called for massive federal investment in research, mental health awareness campaigns, and increased funds for early detection and treatment of mental disorders. More specifically, Dixon and Goldman’s report indicated that treatment should be done in the community and that state hospitals should never exceed 1,000 beds. The community treatment option was a new idea, a generalization from the usual pattern of sending persons with severe mental illness to the state hospitals.

Although many hospitals began discharging patients on smaller scales as early as 1955, psychiatric hospitals all over the United States began releasing them in mass numbers in the early 1960s (Cook & Jonikas, 2002; Mental Health Association of Westchester, 2005). Many of the hospitals were downsized or closed so quickly that patients’ belongings, paperwork, and other items of personal interest were still found in the remains of the decrepit buildings years later (Solis, 2005). Over the duration from 1955 to 1990, state psychiatric hospitals downsized from over 560,000 patients to less than 110,000 (Mechanic & Rochefort, 1990). Some of the early patients were released to their families, but often they were left to fend for themselves. Psychiatric patients no longer able to access even the minimally effective services they had in the institutions were then on the streets, creating a huge and unique homeless problem, especially in big cities. Unfortunately, the public outpatient mental health systems were not equipped to deal with the influx of persons with severe mental illness, many of whom had spent most of their adult lives in an institutional setting (Hogan, 1998).
Although some individuals were able to obtain housing and employment even without the assistance of their family or friends, a large portion committed crimes either of survival or those which constituted offshoots of the symptomologies of their mental illnesses. Theft, public indecency, disorderly conduct, and drug and alcohol abuse led many of the deinstitutionalized back into commitment of another sort: into the criminal justice system. Authors have termed this phenomenon of mental health history as the criminalization of the mentally ill (Mechanic & Rochefort, 1990). Jails and prisons were even more inadequately equipped to deal with persons with mental illness and the milieu, the mentally ill mixed with criminals, often led to additional abuse and exploitation.

According to Mechanic and Rochefort (1990), the prison setting led to increased delusions and hallucinations for those who had preexisting psychosis with themes of persecution.

Initial Mental Health Legislation

Mental health consumers, some ex-patients from state hospitals, banded together in an attempt to lobby the government to provide better and more expansive community mental health services for the people with severe mental illness (Biegel & Tracey, 1994; Frese & Davis, 1997). The call for community-based mental health care was heard by the United States government, and two important federal developments in 1963 fueled deinstitutionalization and increased services for people with mental illness: categorical Aid to the Disabled, now called Supplemental Security Income (SSI) and the Mental Retardation Facilities and Community Mental Health Centers Construction Act. Categorical monetary aid provided people with severe mental illnesses an income to
secure housing and meet basic needs. For many, this was the first time they were able to financially support themselves. The Facilities and Mental Health Center’s legislation provided the beginnings of mental health services in the community, more easily accessible to those now living outside of the institutions. This act was amended in 1965 also to provide grants for initial staffing costs for the centers (Dixon & Goldman, 2003, Lamb, n.d.; Mechanic & Rochefort, 1990).

Today, Ohio Department of Mental Health (ODMH) has put together a list of client’s rights and grievances by which all Department funded agencies must abide (Ohio Department of Mental Health, 2007). Some of these rights include the right to be treated with consideration and respect for personal dignity, autonomy, and privacy; the right to service in a humane setting which is the least restrictive feasible as defined in the treatment plan; the right to be informed of one’s own condition of proposed or current services, treatment or therapies and/or the alternatives; and the right to consent to or refuse any service, treatment, or therapy upon full explanation of the expected consequences of such consent of refusal.

Community Support

Although the legislation was a good start, as late as 1970 the mental health system was still criticized for the effects of deinstitutionalization and the gap between state hospital discharge and good, coordinated community care and support for those with severe mental illness living in the community (Hogan, 1998). This gap was not unusual when looking at deinstitutionalization efforts worldwide. In Greece, whose deinstitutionalization efforts began in the 1980s, the same large gap between
hospitalization discharge and community was found into the 21st Century (Hyphantis, 2003). Canadian deinstitutionalization efforts have shown wide variability, with some provinces coordinating community care better and more quickly than others (Sealy & Whitehead, 2004).

The National Institute of Mental Health (NIMH) in the United States responded to this gap by the presentation and execution of the Community Support Program (CSP) in the late 1970s, which brought coordinated community mental health care to the country (Cook & Jonikas, 2002; Dixon & Goldman, 2003). CSP enhanced the mental health center’s legislation and provided for not only medication and therapy for those with mental illness living in the community but for case management which could assist the people with severe disabilities with daily living skills, securing housing, navigating Social Security systems, etc. The theme of coordinated and expanded care and rights continued into other life domains as well with the passage of the Individuals with Disabilities Education Act (IDEA) to provide for special accommodations and care for children in schools, many of whom suffered from mental illness and other behavioral disorders, and the Americans with Disabilities Act (ADA) to provide for accommodations for adults in the workplace and public, and to fight discrimination of disability, both passed in 1990 (Bentley, 1994; Cook & Jonikas, 2002; Weber, 2011).

At the beginning of the 1990s, significant progress towards solidifying community care for the severely mentally ill came in the passage of the Community Care Act of 1990 in the United Kingdom (“Cascade of Change”, 1992). The act was designed to ensure mental health consumer involvement in service development and allocation decisions. Although many policies were put into place with regard to increasing consumer
involvement, the execution of these policies often fell short. For example, although mental health consumers were often involved in peripheral issues in the mental health arena, such as attending board meetings and offering suggestions, policies directly affecting clients were frequently changed without any consumer input at all. Mental health consumers often felt criticized for offering opinions and had fear due to past interactions with the mental health system. Additionally, mental health staff were frequently resistant to consumer involvement (Bowl, 1996). In the United States, this lack of collaboration fueled the passions of consumer advocate groups such as the National Alliance on Mental Illness (NAMI), which formed in 1979, to become even more vocal and active in the political arena (United States Public Health Service, n.d.).

Treatment Collaboration

More shocking, however, was the continued lack of collaboration between mental health professionals and the consumers with regard to the consumer’s actual individual treatment. Crowe, O’Malley, and Gordon (2001) found two themes emergent with regard to consumer treatment in New Zealand: lack of collaboration of staff with the client regarding their treatment and lack of staff sharing information with the client. This meant that the staff would be driving the treatment, planning goals and setting client expectations, with little or no input from the client at all. Similar themes have been found in research in the United States and, most interestingly, Chinman and Allende (1999) found that mental health staff often underestimated the degree to which consumers wanted to be involved in their own treatment. This may sound ironic since most mental health treatment is voluntary, meaning the consumer has actually come to the clinician
for help. The Ohio Department of Mental Health’s Community Clients Rights Statement states that clients have the right to be active and informed participants in their service plans (Ohio Department of Mental Health, 2007). Thus, the clinician should do whatever it takes to involve the client in participating in treatment planning.

Often, and disturbingly, clients will passively agree to treatment (Carpenter & Sbaraini, 1996). This means that clients, many of whom are severely compromised both cognitively and emotionally, are not really offered treatment options but told by treatment providers, including doctors, nurses, therapists, and case managers, what their treatment will entail. The client, either due to incapacitation, feelings of emotional or power inadequacies, or both, will simply not disagree or offer any input at all, and the clinician does not question this lack of input into the treatment. According to Carpenter and Sbaraini, those who work as mental health providers should be aware of these issues; however, time constraints in gaining treatment consents, insensitivities to clients’ needs, or simple disregard for clients’ rights can lead to the continuation of the passive agreement to treatment.

Advocacy and Self-help

Some clients are spurred into advocacy work due to poor experiences with the mental health system (Chamberlin, 1998). This advocacy can be for themselves or in reference to their fellow mental health consumers or family members. Often, mental health advocacy takes the form of clients working with self-help organizations such as support groups, club houses, or drop-in centers (Mowbray, Robinson, & Holter, 2002; Trainor & Shepherd, 1997). Of these services, club houses and drop-in centers will be
the focus of this paper. Both club houses and drop-in centers offer consumers a safe, non-judgmental place to congregate, work on social skills and daily life skills, enjoy daily social outlets, and participate in the daily operations of the agency (Cella & Besancon, 1997; Holter, et al, 2004; Lucca & Allen, 2001). All participation is voluntary in these establishments and they are usually not formally connected with local mental health services, although they often coordinate services with the local centers.

Becoming involved in self-help services provides a sense of empowerment for the mental health consumer and also has been linked with self-reported positive life satisfaction, decreased hospitalization recidivism when support is given after hospitalization, decreased hostility towards others through anger management, and increased coping skills (Chamberlin & Rogers, 1996; Connors, Siddique, Vulpen, & Mullhall, 1998; Silverman, & Blank, 1997; Weingarten, Chinman, Tworkowski, Stayner, & Davidson, 2000). One can argue that being a part of an organization in a meaningful way, such as part of its infrastructure, daily operations, etc., can bring about a sense of pride and empowerment. Additionally, consumers have stated that they highly value the peer-to-peer relationships and help which is associated with these services, especially for their understanding and empathy toward their situations (Armstrong & Korba, 1995; Biegel & Tracy, 1994; Mead, Hilton, & Curtis, 2001; Onaga, McKinney, & Pfaff, 2000; Trainor & Shepherd, 1997). A peer who understands the workings of the mental health systems, symptoms of mental disorders first hand, and the stigma that can be associated with having a mental illness can be beneficial in offering support and peer-to-peer counseling. They are also seen as “friends” rather than part of the mental health establishment. Being closer to the situation and the consumer can lead to a consumer
more readily opening up and trusting the peer (Polvere, 2011).

*Consumers-as-professionals*

Consumers-as-professionals is a relatively new idea in the mental health field; however, paraprofessionals have been utilized in many fields for centuries. Consumers-as-professionals has been a strong initiative of the consumer movement started in the 1970s. The empathy and understanding of the peer support persons is seen as quite beneficial to many mental health consumers. However, it is important to note that training for peer-professionals is also recommended, especially to understand and keep good boundaries and to decrease any personal hostility toward mental health professionals, with whom they will most likely have to coordinate care (Bentley, 2000).

Peer-professionals do need training before they work with peers in this quasi-professional relationship (Bentley, 2000). Obviously, helping others is probably not a new notion for the peer-professional; however, in this new position they are asked to take a role that may be more neutral. For example, it may be necessary for the peer-professional to help their client understand the importance of working cooperatively with the mental health system, go to therapy, take their medication, etc. This is why Bentley stressed the importance of training, especially in decreasing hostility towards mental health professionals. Bentley presented a series of trainings to peer-professionals in a drop-in center. The trainings were designed to increase skills in assisting others and also improving personal growth in the hopes that the workers would not only be better helpers but better able to help themselves.
Mental Illness and the Family

The family context has become an interest and concern among those who study mental illness (Ludbrook & Hafner, 1998). Most individuals with mental illness live in the community and many live with their families. Thus, families are subjected to the day-to-day, ongoing course of the illness, often without much support from anyone. Families are often ignored by the mental health system and need increased support and involvement in the patient care (Jubb & Shanley, 2002). Although research has found that treatment outcomes are better if families are involved in the patient’s treatment, mental health workers still often do not collaborate with the family (Burbach & Stanbridge, 2006; Macpherson, Jerron, Lott, & Ryce, 1999). In fact, families are given more respect in cases of physical illness than in cases of mental illnesses (Kaas, Lee, & Peitzman, 2003).

Mental health workers can either increase a family’s hope or destroy it (Bland & Darlington, 2002). This can be done through words, actions, tone, timing, and mannerisms. Simply knowing what to share with a family, and how to share the truth tactfully, can make the difference between keeping hope alive and dashing it. Keeping hope alive is often complicated by the burden felt by the family caring for the individual with mental illness. Cuijpers (1999) defined the elements of objective burden as the following: disruption of household routine, the relatives’ leisure time and careers, strain on family relationships, and a reduction of social support. Subjective burden is defined as psychological consequences for the family and includes the relatives’ mental health and elements of subjective stress. Riebschleger (1991) indicated that siblings of
individuals with mental illness may go through the Kubler-Ross Survivor Syndrome stages of grief. Indeed, all families with individuals coping with mental illnesses need help in coping, grieving and finding positive treatment resources (Riebschleger, 2002). Services need to be put in place to decrease the burden, increase family resilience, and allow the family to mourn the family that is no longer there (Marsh & Lefley, 1996).

From a mental health system’s standpoint, it is reported to be important to use the family as a resource in treatment (East, 1992). The family is often closest to the patient and can report on symptomology, medication compliance, activities of daily living, etc. These reports are crucial for the mental health worker or psychiatrist to be able to assess accurately the patient and to be able to prescribe the appropriate treatment. Families often report that they are mostly satisfied with working with their CSP’s (Community Support Providers or Case Managers) (Solomon & Marcenko, 1992). This is mostly likely because the CSP is in the field, in the client’s home, and has the most contact with the client and family. In contrast, families reported they had very little contact with other mental health workers, and when they did, the contact was limited to updates on the client’s functioning or teaching about coping and crisis services (Marshall & Solomon 2004).

Families must become empowered to become collaborators in their family member’s treatment (Heflinger & Bickman, 1997). This may involve becoming the “squeaky wheel” in the mental health system in order to be heard. Additionally, there is a need for advocacy. Families are with their loved ones sometimes constantly, and they need support and must advocate for not only current care but for what will happen to the individual with mental illness after all family are deceased (Corring, 2002). Family
advocates often find themselves overburdened (Diamond, Parkin, Morris, Bettinis, & Bettesworth, 2003).

**Mental Health Policy**

 Simply involving consumers in peer-run services is not seen as adequate by mental health advocates. They argue that consumers must be involved in policy-making on the local, state, and federal levels (Hopton & Nolan, 2003; Orrin, 1997). Only when consumers are involved in all facets of mental health policy decisions will the power differentials between mental health professionals and consumers become more nearly level. No longer would the mental health providers have most of the control of the treatment of the persons with mental illness. With education, advocacy, and alliance, the persons with mental illness can begin to make solid choices for their care and take control over their treatment. McAllister and Walsh (2004) discuss that the mental health professional often does not understand the power, or perceived power, they have over the client. The authors suggest that professionals need to be mindful of these power issues and involve themselves in training to better encourage the client to take control over their care. Additionally, the notion of recovery is based upon the clients’ increasing power and responsibility in their lives and taking control (Jacobson & Curtis, 2000). Taking this control on a larger scale, then, can be argued as assisting recovery.

Advocates have reason to worry with regard to mental health public policy; managed care, lack of funds, and more stringent regulations on who can receive services leave mental health and other rehabilitative services at risk (Baron & Rutman, 1996). Services are being downsized, with mental health worker layoffs, decreased allowable mental
health board funded hospital days, and wait lists for services in high demand. Those mental health employees working in the field are usually overworked and unable to meet the full demands of their jobs as well. Both professionals and advocates alike are concerned, and it is of benefit for them to combine to make coalitions to increase their power when lobbying with local, state and federal government (McAllister & Walsh, 2004).

However, becoming involved in policy-making has even more important implications than just the personal level. Mental health parity is still not a reality in the United States. Parity in mental health means that mental health services are supported by medical insurance plans at the same level and duration as medical services. All mental health diagnoses, including those like schizophrenia that are hard to treat and often lifelong illnesses, would be covered fully as well. Health insurance companies argue that including this level of coverage would bankrupt them; however, one study has shown insurance coverage rates would, on an average, only increase 3.4% (Levinson & Druss, 2000). Although a parity amendment was passed nationally in 2001, the measure did not cover substance abuse, new companies, or those with less than 50 employees.

Ironically, the parity issue is complicated somewhat by the self-help movement. Self-help groups are seen as a cost-effective measure to deal with mental health issues; however, some would argue that legislators who overemphasize self-help as effective do so at the expense of justifying less funding for professional mental health services (Macpherson, et al. 1999). Self-help services often treat only the symptoms of mental illness rather than the underlying root of the disorders and the societal inequities impacting persons with mental illness (Riessman & Bay, 1992). Most advocates believe
that funding for both the symptoms of the illness and the root cause is necessary to bring about a complete package for mental health treatment. The combination of professional help with peer-level support can only be of benefit to the consumer.

Self-help services are often instigated by those persons with mental illness who are unsatisfied with traditional professional mental health services. Generally, satisfaction with professional mental health services varies widely by location (Sullivan & Spritzer, 1997), although it has been found to be generally positive (McCoy, Penick, Powell, & Read, 1975; Sheppard, 1993). Exactly what elements play into this satisfaction are up for debate. For example, Wakefield and Read (1998) found that consumers were mostly satisfied with services defined as affecting the mental illnesses and found less satisfaction with those identified to be dealing with their social and relational problems. Conversely, Sheppard (1993) found that 91% of consumers who identified their problems as social in nature were satisfied with mental health services and 69% who identified their problems as mental health related were satisfied with community mental health services. One could argue, however, that mental illness and social/relational problems are inevitably intertwined.

Much of the training for both professional and lay staff working with people with mental illness is focused on listening to clients’ voices. Listening to clients’ voices means really hearing and understanding what a client is saying, even if you disagree with their statements, knowing when to probe for more information, and when to drop a subject. It is a delicate balance, one that can take years to develop. However, listening to clients’ voices is crucial because it is of utmost importance to the development of their treatment (Burbach & Stanbridge, 2006). Treatment must be client-centered to draw
clients into the treatment process, to engage them. In fact, Klein, Stone, Hicks, and Pritchard (2003) found that client-centered goal development is a key to decreased dropout rates in mental health counseling. Surely, if one were to engage in counseling with goals that were not his or her own, it makes sense that he or she would not be inclined to complete the sessions.

In Europe, Van Weeghel, et al. (2005) found that consumers, professionals, and others in the community agreed that a trusting and stimulating relationship between consumer and professional, as well as individualized treatment, were regarded as the most important characteristics in good community care. These findings underscore why the consumers’ insistence that they are not being listened to is so disconcerting. Clearly, a trusting relationship in any arena cannot be established if one partner is not feeling heard. Additionally, individualized treatment cannot be developed if the professional is truly not listening to the consumer’s needs or wants and incorporating those needs into the treatment plan.

A trusting relationship is sometimes hindered in the consumer-professional relationship due to the boundaries a clinician must keep, both legally and ethically. A certain amount of self-disclosure may be appropriate on the part of the professional, but an informal relationship is inappropriate and can actually harm consumers in the consumer-professional dyad. However, informality in relationships is often appreciated by consumers. They are able to easily build up trust with those who share of themselves. This fact may relate to why consumers value interactions with peers-as-consumers in situations such as clubhouses.

So, why are clients’ voices not being heard? Ironically, the problem can begin with
the clients themselves. Clients/consumers face many barriers when it comes to making their voices heard in the mental health field and in other arenas (Barnes & Wistow, 1994; Gill, Hayes, Dickinson, Whittaker, & Gilheany, 2003). First, and maybe most pressing, is their fear of the denial of their problems by others. This fear, both at times imagined and very real, may make clients under-report symptoms or be reluctant to stand up for what they want due to the power differential between themselves and the professional mental health staff. Second is stigma. Mental health stigma, being labeled crazy, being discriminated against, being devalued as a productive person, is a long standing phenomenon. Stigma can cause a person to hide or even deny his or her illness for many years, which of course cannot best facilitate client-centered treatment. Finally, there are the symptoms of mental illness themselves. Symptoms can include psychosis, with delusions or hallucinations, negative symptoms such as thought blocking or slowing of mental processes, and medication side-effects such as lethargy. All of these symptoms can hinder a client being able to fully express, or even understand, what they want out of treatment (Gill et al., 2003).

Of course, the mental health professional has to fully understand all of the symptoms of the mental health conditions of their clients in order to be able to fully help the client understand and relate what they want out of treatment. The mental health worker must understand the stigma that still exists with regard to mental illness and combat this by being as understanding as possible and advocate for the client. More importantly, however, the mental health clinician must strive not to support this stigma through their actions or words. Devaluing the mental illness or person, thinking the person is just angry and not insightful, making fun of the person, and generally not supporting the
notion of mental illnesses as diseases are all ways a clinician can buy into the stigma of mental illness (Barnes & Wistow, 1994). Additionally, sometimes the mental health clinician has unrealistic expectations of the consumer and his/her progress (Davidson et al., 2001). Not only may the clinician expect the consumer’s mental illness to go into complete remission, but also that the consumer should lead a full life, i.e., working, completing education, family life in order, etc. Unfortunately, with persons with severe mental illness this is often not possible. The course of most mental illnesses is variable, waxing and waning, with differing impacts on the person’s life (Taylor, Gordon, Asmundson, & Jang, 2011).

Getting mental health consumers involved in their treatment even under the best of circumstances is still difficult. Mowbray, Megivern, and Holter (2003) found that there is often very little communication or coordination between other agencies, such as supported education or self-help organizations, and the formal mental health system. This may be due to confidentiality reasons; however, it is more likely due to turfing. Turfing is the notion that a client can only really be part of one system, or turf, and all other services are seen as ancillary or unneeded. Turfing can be dangerous because a combination of treatments, medication, therapy, and/or self-help, may be needed to fully serve the consumer. Isolating the client to one service is not only bad care but also feeds into the notion of the power of that system over the client to control their care. In addition, The Ohio Department of Mental Health’s Clients Rights Statement says, in part, that a client has the right to be part of one service and refuse another without fear of reprisal from treatment providers (The Ohio Department of Mental Health, 2007).

Consumers’ complaints against community mental health often surround the nature of
the interpersonal relationship between consumer and professional (Spencer, 1996). Consumers have reported feeling coerced into accepting treatment options they sometimes do not agree with or understand. Many consumers report feeling not listened to when interacting with mental health professionals (Watts & Priebe, 2002). Feeling unheard is ironic with regard to the mental health system since one of the first things mental health professionals are taught to do is to listen to the patient and gain insight from their experiences. However, professional training does not prepare mental health professionals for the required volumes of paperwork, meetings, and red-tape, which eat away at precious client time (Acker, 2010). Still, if the client is not being heard, or perceives that this is so, good treatment is not likely to occur. The feelings of not being listened to can also frustrate the client and cause the client to not trust the clinician. This can lead to an imperfect therapeutic relationship.

The Value of Peer Support

The value of peer support is part of what has fueled the consumer-as-professional movement. Indeed, peer support is the whole concept behind the self-help movement and such organizations as Alcoholics’ Anonymous (AA), women’s groups, clubhouses, and drop-in centers. Mead, Hilton, and Curtis (2001) defined peer support as “understanding another’s situation empathically through shared experiences of emotional and psychological pain” (p. 135). Elements of peer support include the following: active listening, self-disclosure, shared power and building empowering relationships, conflict management, understanding, and reflection and evaluation.

Clearly, understanding is key to the definition. As mentioned previously, lack of
being heard and understood is one of mental health consumers’ biggest complaints about the professional mental health system. To be truly understood is crucial to feel supported.

Peers learning from those who understand their experiences makes sense, and not only do those seeking help benefit but those who are the helpers often benefit as well. Armstrong and Korba (1995) found that the consumer-professionals related that hearing about their peers’ troubles benefitted their own insight into themselves. The reciprocal, informal nature of these relationships is helpful to both and fosters an atmosphere of acceptance and trust. The give and take of the relationships is essential for recovery and relapse prevention (Biegel & Tracy, 1994). Indeed, the consumer-professional is doing real work and may gain the self-satisfaction from a job well done the same as anyone else who enjoys their job.

**Empowerment**

Thus, we must conclude that inclusion into treatment equals power over treatment and, hopefully, positive outcomes to follow. Barnes and Wistow (1994) found that consumers involved in consumer mental health councils felt empowered even if their participation had no real effect on change. On this level, we are not talking about personal care; however, the reader can see the power of suggestion that just the notion of involvement can bring out feelings of empowerment.

For the purpose of this paper, I will define *empowerment* as being able to access needed information, make choices, be assertive, have positive self-esteem, the ability to think critically, learn about and express anger, feel like one is part of a group, and feel
competent (Chamberlin & Schene, 1997). The model now affords the client increased decision-making powers in treatment, collaborative partnerships with clinicians and psychiatrists, and even input into mental health program development, largely the push of the consumer movement. Clark and Krupa (2002) stated that this model can afford the client opportunities for better jobs, housing, and social status through empowering them to make their own choices. In fact, they hold that empowerment, along with feelings of competence and ongoing recovery, is necessary for clients in psychiatric rehabilitation to be successful in their treatment. The Ohio Department of Mental Health’s Clients Rights Statement says, in part, that each client has the right to consent to or refuse any service they wish (The Ohio Department of Mental Health, 2007). It is truly empowering to guide one’s treatment in this way.

**Power Differential**

Traditional mental health services have defined the client as the problem and the professional as the solution (Segal, Silverman, & Temkin, 1993). This situation sets up a huge power differential with the professional in the control, the client merely acting as a receptacle for predetermined services and, again, sometimes passive agreement to services. Not only is the situation disempowering, but clients are put into positions where they can be easily coerced into situations not in their best interest. Some power differential is inevitable in a treatment situation; obviously, the clinician does have a certain amount of power in order to prescribe treatment or medication. However, when power differential is extreme, the treatment then becomes solely of the mind of the clinician and the client is forced to follow treatment goals that are not of their own (Shaw
& Eagle, 1971). The outcome of the treatment, even if favorable, is then not truly of the client’s own.

To truly change the power differential between client and clinician, some professional-client boundaries must be broken down (Finfgeld, 2004). A more informal relationship between provider and client is needed in which power is equalized, the client is allowed increased choices, and decision-making leads to increased feelings of empowerment. As mentioned before, this is not an easy task; however, it is one that agencies and clinicians alike should strive for if they truly wish to empower their clients. Partnerships can be formed between the client and agency staff not only on the personal treatment level but also on the level of program development (Clark & Krupa, 2002). A client who is involved in developing mental health services beyond their own care will benefit from helping others. Ultimately, the clinician should strive to be a consultant for the client in situations of consumer-run services (Salzer, 1997). The clinician is there simply to help and offer advice, with no strings attached and only when asked by the client.

Clinician Perceptions

Clinician perceptions can often be a hindrance to client empowerment; however, clinicians are placed in a high-stress situation when working with persons with severe mental illness daily. Many variables are involved in why a direct careworker or mental health supervisor leaves a job. Blankertz and Robinson (1997) found that those workers who were younger, felt less job fulfillment, had more emotional exhaustion, had a Master’s degree, felt a lack of clear job path, held a previously similar job, and those who
dealt with Acquired Immune Deficiency Syndrome (AIDS) patients were more likely to quit their mental health jobs. Ironically, studies have found that money does not have overly significant meaning to mental health workers (Tang & Kim, 1999). Other studies have found emotional exhaustion and problems with role clarity related to burnout (Onyett, Pillinger, & Muijen, 1997). Burnout of mental health staff is common, leaving staff feeling overworked, and exhausted (Heginbotham, 1999). Negative self-image is related to burnout and emotional exhaustion in mental health staff (Jeanneau & Armelius, 2000). It is easy to see how these types of feelings are not conducive to good, quality client care. In fact, mental health workers are often prone to mental illness correlated with the stress of their jobs (Walsh & Walsh, 2001).

As in other jobs, some of the mental health workers’ job dissatisfaction comes from their relationship with management (Dallender & Nolan, 2002; Norman & Peck, 1999). The poor relationship may be over job duties, amount of paperwork, productivity, perceived management attitudes, etc., but all can lead to job dissatisfaction. To come to work everyday and feel not supported by your superiors can be disheartening and is likely to bleed over in negative attitudes toward or around the client in addition to negative self-image. The distrust of management can lead to a shared worker culture in which there is a loss of faith in the mental health system in general (Norman & Peck, 1999). Obviously, an entire agency which shares a negative culture can hurt even more clients than a single individual with a negative attitude toward the mental health system. However, mental health workers have indicated that contact with a colleague is one of the most rewarding parts of the job (Reid, et. al, 1999).

Another reason a clinician or direct care worker may be dissatisfied with his or her
Job is that he or she must work closely with clients, sometimes even on a daily basis, but still maintain professional boundaries set forth by the standards and practices of the agency or the state regulating bodies. This can lead to conflicting roles or role confusion (Lloyd, King, & Chenoweth, 2002). For example, a direct care worker in a residential program for adults with mental illness may spend 40 hours per week with a client in somewhat informal situations: cooking, cleaning, going to the store, or doing laundry. Although this type of situation requires less formal boundaries than perhaps a counselor-client relationship, the direct care worker and the client cannot be friends. The worker must limit the amount of self-disclosure with the client (Goldstein, 1997). The worker cannot give or accept gifts other than tokens, even for birthdays and holidays. Yet, the worker is the very person whom the client relies. The client speaks with the worker daily about important and trivial things, just as with a friend. Clearly, the roles can become easily blurred in this situation, and the worker or client may feel uneasy about actions they must or must not take. Again, we are speaking of treatment boundaries, which must be held firm at a certain level to avoid exploitation of the client (Carey, 1998).

Another problem in the mental health system is team splitting. I will define team splitting here as one or more of the direct care workers on a mental health team, working with the same client, having radically different views on the client’s treatment and acting on those views. This conflict among team members can rage for years with long-term clients, providing the client with differing styles and methods of care and often causing client confusion or even decompensation of mental status. Adding in the high turn-over rate of mental health clinicians, one client could have multiple team members trying numerous treatment styles over a period of only a few years. Team splitting and the
associated role ambiguity hinders the multidisciplinary approach needed for a client with severe emotional problems (Martin et al. 1999).

To avoid negative work attitudes, team splitting, burnout, and role ambiguity, intense and direct supervision by competent mental health supervisors is needed (Blankertz & Robinson, 1997; Lloyd et al. 2002; Onyett et al., 1997). The supervisor must be aware of the strengths and weaknesses of the workers and be able to use those to the advantage of quality client care. Most importantly, supervision must extend beyond the mere job duties of the workers. For example, supervision in mental health systems is often absorbed in the administrative details of the job: paperwork compliance, productivity, completion of treatment plans, work hours, etc. All of these elements are important and certainly relate to how the work that is being done is billed and services are reimbursed. Clinical elements are also the focus of supervision, including who is being treated with what method, the length of treatment, its effectiveness, etc. Again, this is important to ensure proper care of the client. However, the less tangible elements of the job, such as role clarification, avoiding burnout, and team continuity, are rarely addressed. Some would argue that once you address the administrative and clinical aspects of the mental health worker’s job, there is little time for other conversation. But these other elements of the job, such as worker burnout, worker support, and trust issues, must be addressed in order to provide for full and competent quality care of the client on an ongoing basis (Acker, 2010).

Actually, there is often little time for supervision at all due to the enormous amount of paperwork and productivity expectations. But to be able to construct a team which can run effectively and provide proper client care, the supervisor must address these issues.
Not only is this an issue for the direct client, but also for other agencies and professionals attempting to access services. Other service providers, including over 50% of physicians, report having trouble accessing first time appointments or emergency hospitalizations for their clients (Trude & Stoddard, 2003). Clearly, a well working agency would be able to provide proper access to services for clients and professionals who call for help.

_Ethical Concerns_

Ethics play a role in the community mental health system. Mental illness fluctuates widely over time, often with periods of remission and exacerbation (Francis, Colson, & Mizzi, 2002). The mental health worker must be careful to understand this fact and that some patients are unable to make long-term commitments, such as work or therapy groups. In fact, for some consumers just the act of committing to a situation can cause increased anxiety and decompensation (i.e., decrease in positive mental functioning). The worker must separate out what are their goals for the client versus the client’s treatment expectations for themselves in order to provide proper care (Backlar, 1997). Again, this goes back to the notion of individualized care.

Ethics also goes into simpler measures, the basics of care. Christensen (1997) found four areas of ethics of particular concern to community mental health: valid consent and refusal of treatment, coercing clients into care, scarce resource allocation, and organizational relationships. The first, valid consent and refusal of treatment, goes to the very core of mental health treatment. Does a person truly give informed consent to be treated, and does that person have the mental capacity to give consent? The answers are not always as easy as one would think. Clearly, a well informed and high functioning
person seeking out services such as counseling has been able to educate themselves enough to ask the right questions in order to give informed and complete consent. But when we are referring to individuals with severe mental illnesses, we must wonder, if the illness is so severe, can they truly give consent? Very few adults with mental illness have a guardian who can protect them and give consent or refusal of treatment. Thus, the ethical responsibility of getting informed consent is on both the client and the clinician.

Christensen’s (1997) second ethical concern, coercion of the client into treatment, is not necessarily as overt as it sounds. Certainly some clients may be “forced” into a certain type of treatment or medication and sometimes the courts even require compliance with recommendations of mental health professionals. However, coercion can be more subtle. Relating back to consent, if a person is mentally incapacitated and the clinician simply picks a therapy for them, is this coercion? What if the worker strongly pressures the client into deciding on a certain type of treatment that he feels is in the client’s best interest? Is that coercion? Again, the answers are not easy. Passive agreement comes into play with regard to this notion as well (Rothery, 1980). If a client is unable to give consent or, more likely, feels unheard by the clinician and simply passively agrees to treatment, does this constitute coercion?

The third ethical concern, scarce resource allocation, is a common problem with most community and publicly funded mental health centers according to Christensen (1997). The balance is one that mental health workers have to make every day: how to split up a small amount of resources among a large number of persons with mental illness. The ethical concern is who gets left out? Guidelines are in place to determine who is prioritized first. Certainly the sickest individuals should receive the most timely and
highest number of services to prevent tragedies. But there are always more people who
could be served, or given more services. Someone always gets left out, or at least left
with services that are inadequate in number or intensity to truly optimize their mental
health. Choosing some and wait-listing the rest is a daunting task.

Christensen’s (1997) fourth ethical concern, organizational relationships, has to do
with how two mental health workers solve disputes. The disputes are often philosophical
concerns over type of care. For example, a psychiatrist may believe that a patient needs
continued therapy whereas the therapist believes that therapy is completed. It is how
these issues are resolved that frame the ethical dilemma. Team splitting is may be a
concern in this situation and often, these issues are resolved by professional rank. In
many mental health centers, the psychiatrist has the final say on treatment issues. But is
the psychiatrist always correct? In other places such as a communal work space, a more
democratic process is utilized. In some centers, management will make the final call.
However, managers in the mental health system are often far removed from the actual
treatment and care of clients.

*The Client Experience in Peer-run Services*

Holter et al. (2004) found 31 critical ingredients essential for running peer-run
services in four basic categories: structure, process belief systems, process opportunity
role structures, and process social support. Most importantly, the study found that
consumerism, i.e., consumer control, decision-making, voluntary participation, and
respect for members by staff were crucial to a successfully run consumer organization.

But who attends peer-run services? Lucca and Allen (2001) found that although most
consumer-run services have large memberships, few members participate daily or even weekly. Generally a core group of “regulars” exist that participate often with the center or facility. Kessler and Mickelson (1997) found that about 30% of those attending self-help programs did so for substance abuse issues. Additionally, the study found that the participants were likely to be female, Caucasian, unmarried, younger, and with lower incomes. Higher levels of neuroticism were also found among those who attended self-help groups more frequently. Thus, the typical peer-run participant may be vulnerable due to socio-economic standards (i.e. their income, where they live, their ability to obtain and keep viable employment, etc.), and lack of the social support of marriage.

Chamberlin and Rogers (1996) found that the average age of a self-help participant was 40 years; half took psychotropic medications; and few held regular jobs. Thus, in addition to economic disadvantage, the typical client may have cognitive problems associated with psychotropic medication and its side-effects. However, the authors also found that over three-quarters of those surveyed responded that they were happy with their lives.

All true peer-run organizations are voluntary in nature. No one is forced to participate and everyone is free to come and go as they please. This can be a big change from typical mental health services which, as I have said before, can be coercive and overly-directive in nature. With the voluntary nature of the programs comes responsibility, though. Decision-making for the group can involve time and effort, but it is also a privilege. In the self-help groups, members can participate at all levels of decision-making and feel competent to make those decisions (Salzer, 1997; Silverman & Blank, 1997).
Self-help services and organizations differ from place to place, but some of the general characteristics of self-help organizations include that many social-recreational services are included into the day and that most of the participants found that peer-to-peer services and interventions were the most beneficial for them (Lucca & Allen, 2001; Trainor & Shepherd, 1997). Peer-to-peer support is the crux of the self-help movement. Whether at a drop-in center or other self-help group, the mutual support is key to the success of the program. With the support comes the encouragement to make decisions, the advocacy to work with the typical mental health systems, and the personal power to make real change. In fact, Weingarten et al. (2000) found that consumers helping consumers when they leave the hospital leads to a lower recidivism of re-hospitalization of 50%.

Many self-help participants liken their experiences at self-help organizations to a family system (Onaga et al. 2000). The family atmosphere allows equal participation and understanding of others in similar situations. Participants feel protected and free from violence. Additionally, knowledge can be passed down from one person to another as they move along in their journey. Flexibility was also found to be an important element in a self-help agency (Cella & Besancon, 1997). The ability to remain flexible and patient with consumers is important, especially due to the changing nature of mental illness. One day people may be able to participate fully in an activity, the next they may struggle just to get out of bed. Being understanding and having flexible rules helps those with mental illness succeed at their own pace.

The self-help organizations tend to be funded poorly and located mostly in urban areas (Mowbray et al. 2002). This is not surprising given the nature of funding for
mental health services in general. However, the fact that most services are in larger areas such as cities is concerning. People who live in larger cities are able to partake in a variety of services, although wait-lists certainly do exist. It should be noted that few minorities are found to attend these services as well. However, urban areas provide more opportunities to participate in mental health type services, both self-help and traditional service.

One of the most significant developments in client-run, client-centered mental health services has been the advent of the clubhouse and drop-in center models. As stated before, clubhouses and drop-in centers are consumer-run organizations that provide classes, including social skills, budgeting, cooking, substance abuse classes, and independent living, a daily living and working atmosphere, including daily house chores and basic upkeep of the center, and a place for consumers to congregate and gain support from each other. The target population for clubhouses consists of people with long-term, serious mental health issues, many of whom also have social skills difficulties (Mastboom, 1992). The same population is targeted for drop-in centers as well.

Clubhouses/drop-in centers are founded on a vision of shared values of the stakeholders, i.e., the consumers, local agencies, and the community at large (Moxley & Jacobs, 1992). Some of these values include the importance of the dignity and worth of all human beings regardless of mental health functioning, status, employment, or financial situation. The first recognized clubhouse was Fountain House Clubhouse in New York State, formed in 1948 (Peck, 2000). Fountain House was born out of the need for consumers to have a place for support that was separate from the traditional mental health system and the real and perceived mandating of mental health services through
coercion. Many subsequent clubhouses and drop-in centers were formed using the Fountain House model (Dudek & Stein, 1992).

Although clubhouse and drop-in centers are designed to function independently from the traditional mental systems, as many as 72% are operated as part of the local mental health or other public agency (Macias, Jackson, Schroeder, & Wang, 1999). The connection is often due to funding, as the money to run these centers is often sent from the state to the local mental health and recovery services board to be allotted to individual programs. In addition to state money, the majority of clubhouses and drop-in centers receive some sort of Medicaid reimbursement for their services. Some also have mental health staff that partner with the organization to provide Medicaid reimbursed services. The connection through funds with the mental health system is a precarious one, as it could cause a dual relationship and a set up for potential coercion; however, it is necessary to provide the needed funding for services (Mowbray & Tan, 1993). Criterion for clubhouses and drop-in centers is that services are voluntary in nature (Glickman, 1992; Propst, 1992). Members are free to come and go as they please, to participate in services they feel are good for them, and to reject services they feel are not necessary for their lives. The attitude is freeing for mental health consumers who may have experienced a push for participation in certain services, such as therapy or medication management, from local mental health clinicians. The voluntary nature of the clubhouse and drop-in centers provides consumers with the ability to form their own destinies and to use their intuition to direct their own treatment planning. However, because part of the daily needs of the clubhouse/drop-in centers are the daily upkeep of the center, those consumers acting as staff must be able to be enthusiastic in presenting the needs of the
organization and the benefits of the programming offered in order to gain participation and help without coercing the consumers into helping or participating (Glickman, 1992).

Clubhouses/drop-in centers are often based upon the Fountain House Clubhouse model (Propst, 1992). One of the most significant differences between the clubhouse/drop-in model and the traditional mental health system is the lack of separation between staff and client. In the traditional mental health system, staff and client are separated by a definite line: the staff is the professional and the client is the one in need of services. The staff are generally seen as in control, knowledgeable, and the ones who provide what is needed for the client to get better. The client, conversely, is seen more as a passive receiver of services. In the clubhouse/drop-in center model, there is little separation between staff and client. In addition to the staff being made up of consumers, all agency meetings are open to any consumer. The physical space of the organization reflects the inclusive nature as well. No staff-only areas are permitted in the clubhouse/drop-in center. Staff members and consumers work side-by-side in the work-ordered day (Macias et al., 1999; Propst, 1992).

In addition, all services must be offered to all participants regardless of level of mental illness. This differs from the traditional mental health model which provides services according to level of needs, such as case management services usually only being offered to the severely mentally disabled. In the clubhouse/drop-in center all services are equally assessable to everyone. A key service in most clubhouses/drop-in centers is case management. As many as 77% of clubhouses provide case management to their participants (Macias et al., 1999). Case management can assist the consumer in managing their mental health appointments, find housing, assist with employment.
concerns, help with strengthening social skills and budgeting, and act as a liaison with other local agencies.

The clubhouse/drop-in center case manager can work in conjunction with a client’s mental health case manager as well to increase and better service delivery. This partnership is key in providing appropriate services for the client in that the mental health case manager must be educated as to what the clubhouse/drop-in center values as far as client care. For example, some mental health professionals expect the clubhouse/drop-in center staff to control the client, i.e., make them do this or that despite the client’s wishes (Mastboom, 1992). However, the clubhouse/drop-in center case managers must make their role and expectations known, simply helping and coordinating for the client, assisting them to represent what they feel is in their best interest.

In order to found a clubhouse/drop-in center, it is important for mental health consumers to form a partnership with local and state political figures to gain support for their programs (Moxley & Jacobs, 1992). Political support is important for policy formation in favor or the clubhouse/drop-in center and to gain funding. Currently, funding for clubhouses/drop-in centers is limited, it is important for organization members and staff to educate those in power about the benefits of the clubhouse/drop-in center model (Mastboom, 1992). When money is scarce, it is important to show how it will be best spent to gain support.

A key to the success of a clubhouse/drop-in center is intensive leadership in the staff of the organization (Moxley & Jacobs, 1992). The concept of a consumer-run approach to mental health services is still relatively novel, even to those in the mental health profession. Thus, it is crucial for those in charge of the clubhouse/drop-in center to be
able to represent the organization well, including stating its values, mission, and day-to-day operations. Particularly, it is important for the leadership to be able to navigate disagreements between themselves and the local mental health agencies in a way the client’s wishes are well represented but the traditional mental health agency, crucial for the care of the client, is not alienated.

For the purposes of this report, I will be looking at peer-run services in rural areas. To define rural versus urban is a difficult task because the delineation can be relative. For example, what may be considered rural to New York City may be different to what is considered rural compared to Columbus, Ohio. Additionally, the titles or urban and rural are often dichotomously assigned, without regard to the varying degrees in between (Blank & Jodl, 1996). However, we will here define rural as a location with less than 1,000 people per square mile (United States Census Bureau, 2000). Rural areas often serve a more heterogeneous group of individuals because a few services are offered for all individuals (Blank & Jodl, 1996). However, even though there are fewer services available in rural areas for individuals with mental illness, the clinicians who are available are just as qualified to treat mental illness as those who are in urban areas (Rohland & Rohrer, 1998).

Peer-run services such as clubhouses and drop-in centers are critical in rural communities because people with mental illness can be socially isolated otherwise due to the barriers inherent in rural areas, i.e., lack of transportation, small communities, less acceptance of mental illness, less funding for services in general, lack of other clubs or social gathering places, etc. (Philo, Parr, & Burns, 2003).

In addition to few services, rural areas also encounter the phenomenon of dual
relationships more often than in urban areas (Nickel, 2004). Dual relationships, in this sense, are the boundary problems that arise when a service provider also plays another role in the life of a client. For example, a mental health clinician may see a client as a patient but also attend the same church as the client. Or a therapist may also share the same parent-teacher group as a client. These dual relationships are not ideal but are often unavoidable in a small community. Still, dual relationships are one barrier faced in providing services in a rural setting.

Although one study found that rural mental health clinicians have more experience than urban (7.3 years versus 5.5 years) and that the clinicians in rural areas tend to have more credentials (Rohland & Rohrer, 1998), paraprofessionals are often used in rural settings to fill in gaps for service providers. Paraprofessionals are those service providers who do not have degrees or credentials in mental health but are trained to work with clients in a certain capacity. The utilization of paraprofessionals can help in decreasing the stigmatization of mental illness in rural communities (Bjorklund & Pippard, 1999). The decrease in stigma can be due to the client seeing a non-professional for services as opposed to a clinician.

Conclusion

Mental health consumers who partake in peer-run services face a variety of challenges surrounding their illnesses, ranging from the side-effects of medications, the need for advocacy, the interface with the traditional mental health services, and the need to have their voices heard and understood by others. Peer-run services provide an outlet and safe haven for those with mental illness; a place where they can be themselves and
not be judged. Further research is needed to specifically address what benefit these peer-run services provide to the mental health consumer and to “hear” their voices. The life experiences of these individuals must be told in their own words to be understood by all.
CHAPTER III

Methodology

Purpose of the Study

The problem addressed in this dissertation is what are the experiences of individuals living with mental illness, as well as family members, and mental health workers as they interact with peer-run services and mental health services. The lessons learned from this study could be beneficial to the state, the local mental health agencies, and the participants of the studies alike in that they could provide insight into the actual perspectives of the mental health client, his/her family members, and the mental health workers.

In this study, I took a modernist approach to the work and the findings of the study. For example, I assumed that what I reported were accurate reflections of what I found. This is in opposite to postmodernism, which takes the stance that the researcher creates reality (Hansen, 2006). I am an traditional interviewer; I believe in reporting exactly what I see and hear. I think this is important to keep the work true to form.

In order to gain insight to my purpose, I formulated interview questions that allowed me to look at the various aspects involved. But I was careful to do more listening than talking. Seidman (2006) says that it is important for an interviewer to listen on three levels: first, to be cognizant of what the person is saying so that the interviewer is sure to have the substance of the interview material later on. Second, the interviewer is to listen for an internal voice rather than an outer voice. An internal voice has a level of
thoughtfulness to it. An outer voice is more of one that is more public and on display. Seidman says to try to get the interviewee to speak in the internal voice; this is where the heart of the matter lies. Finally, the third level Seidman says an interviewer should be aware of is listening while being aware of what is going on around you. The interviewer must be aware of the time, be aware of what has been covered in the interview and what has not, aware of how well the interviewee is holding up, etc. I attempted to do all of these steps in my interviews with the participants.

Some of these questions included in the study are as follows:

- What value have you experienced from traditional mental health services?
- What value have you experienced from peer-run services?
- What effect has deinstitutionalization had on your life?
- What types of mental health legislation are you involved in?
- Is burnout a factor in your job?
- Have you seen your family member empowered to take charge of their care? If so, how did that come about?
- What role do you play in your family member’s illness?

The Choice of the Qualitative Method and Interviews

I chose the qualitative method because I felt it was the best method to capture the answers in this study. I was interested in the participants’ meaning and of how they interacted with their world. Merriam (1998) stated that qualitative research is founded on the view that people construct their own reality and are interacting with their social worlds. She further went on to write that qualitative research can show how all the
different parts can form a whole. This is what I was interested in: the participants’
drawing a complete picture in their own words.

A second reason I chose the qualitative approach is that I wanted results that were full
and descriptive. Qualitative research provides a product that is richly descriptive in
nature (Merriam, 1998). I wanted depth and meaning to my results; the kind that only
qualitative research could provide. I wanted a way of knowing these individuals as best
as I could through the little time that I had with them.

I chose interviews because I wanted to interact with the participants in a way that I
could make a connection with them. I wanted to understand their stories on a deep level.
Seidman (2006) stated: “Most simply put, stories are a way of knowing” (p.7). I wanted
to know about these individuals and their stories. I believed wholeheartedly that these
individuals’ stories had merit and worth, and thus they were worth studying in an in-
depth fashion (Seidman, 2006). I also wanted to put the participants at ease during the
interviews for two reasons: (a) just to simply preserve the dignity of the participant and
(b), to help them feel they could trust me enough to share their personal information with
me. I did things like provided bottled water and a snack for the participants because I
knew we would be together for a while and they may become thirsty or hungry during
that time. I also dressed in street clothes as to not intimidate the participants in a way in
which they might think I was just another professional.

The one thing I wanted to avoid in conducting interviews was the idea of forming a
therapeutic relationship (Seidman, 2006). Unfortunately, the nature of the interview, the
give and take of the conversation, lends itself very easily to forming a therapeutic
relationship. However, this can be very harmful to the participant as there will be no
follow-up involved and it is an inappropriate role. I tried to avoid this situation by keeping the interview on topic and avoiding doing any counseling.

The Researcher’s Role and Management of Bias

Before describing this study, I must first explain my background and how I became interested in this topic. I am a Licensed Professional Clinical Counselor (LPCC-S) with supervising credentials and I have a Masters Degree in Clinical Counseling. I have worked in outpatient mental health settings, partial hospitalization, and residential facilities. I have been in the role as therapist and supervisor. I am currently a contracted counselor for an agency and I do both home-based counseling and in-office counseling. My patient load is approximately 80% children and adolescents and 20% adults. I work with everything from Adjustment Disorders to Schizophrenics and extreme Personality Disorders.

I became interested in this topic because I have witnessed mental health clients being treated poorly and having their rights infringed upon. Because of this very fact, I knew from the start of this study that I had to be careful about bias. I knew that I needed to examine my own thoughts about not only the questions I asked but the responses to participants’ answers to ensure I was not letting my background color the outcome of the study. Merriam (1998) warned of this in that both the reader and the researcher should be aware of their biases.

Additionally, two of the three sites where I conducted interviews had adjoining mental health centers where I had previously worked. I knew I needed to be careful not to bring in bias regarding my old employers and former colleagues. I did this by
carefully examining my thoughts and asking myself questions. Are old stereotypes coming into play? Although it is not possible to eliminate all bias, I feel I was able to neutralize most through self-evaluation.

*Internal Validity*

Internal validity basically asks, Do the research findings match up with reality (Merriam, 1998)? In qualitative research, what is being observed is how the participants are viewing their world. This can be dynamic and changing. The following are some of the methods Merriam suggests using to enhance internal validity that I used in this study:

- Member checks: taking the data and tentative explanations back to the participants and asking them if the results are correct.
- Peer examination: asking colleagues to comment on the results. For this, I asked three of my colleagues to read through a rough draft of the document and give me their comments on style, grammar, bias, use of participant quotes, etc.
- Researcher’s bias: clarifying the researcher’s biases at the beginning of the study.
- Patton (1990) talks about the importance of keeping objectivity and a clear viewpoint in order to increase internal validity. I did this by constantly asking myself questions such as, “Why am I doing this study”? and “Am I showing my personal bias here”?
- The use of rich, thick description: giving enough description so the reader will be able to tell how closely their situation matches the research situation.
- Typicality or modal category: describing how typical the person, program, or event is compared with others in the same class, so the reader can make comparisons with their own situations.
Participants

For this study, I decided to use purposive sampling (Patton, 2002) due to the fact that I was looking for such a specific group of people (i.e. persons with mental illness that did not have any history of recent psychosis so they would interview well and that these persons would be willing to participate in the study). I additionally wanted to use purposive sampling in order to select information which would provide rich cases that would illuminate the research questions. Patton (1990) states that purposive sampling is powerful because it selects information-rich cases from which a researcher can learn a great deal about the truth of his/her study.

I had to gain access to the right type of participants and explain to them the basics of the study. This was largely done for me by the director of the Mental Health Center and the director of the Outreach Center, both of which acted as gatekeepers to the subjects. Both of these individuals knew what I was looking for in a subject because I made them a list, they knew where to find the subjects (i.e. the Mental Health Center and the Outreach Center), and they were able to determine from talking to the subjects if they understood the subject of the study and I also talked to the participants about that in person.

With regard to the participants that I used in this study, I felt they were the right fit for the study due to the notion of three constructs: saturation, typicality, and triangulation. I felt that I reached saturation with the three main interviews because in asking the questions, I was generally getting the same answers (Coenen, Stamm, Stucki, & Cieza, 2011; Kerr, 2010). I felt the interviews met typicality because, in my professional opinion, they were similar to other cases I had worked with (Saldana, 2009).
The cases were really not surprising in any way. Also, I felt the participants were the right fit due to triangulation. I looked at the information from each participant, family member, and mental health worker and compared them and for the most part they matched. Triangulation also enhances internal validity (Merriam, 2001).

I decided to interview groups of three: each consisting of one person with mental illness, one of their family members (their choice), and one of their mental health workers (also their choice). I selected three mental health centers and three drop-in centers (the two being linked) in rural counties to solicit as research sites. One site (a mental health center and drop-in center) said yes and at this research site the director of the mental health center and the director of the drop-in center acted as gatekeepers by suggesting six possible participants who were persons with mental illness. Then they solicited these individuals by giving them my description of my study (See Appendix A). Three individuals volunteered to be participants in the study. All of these individuals were involved with both the local mental health center and the local drop-in center.

Background demographics were obtained from these individuals, including age, race, gender, as well as self-identified psychiatric diagnosis (meaning the diagnosis the participant felt they had at that time, whether it was accurate or not).

Three participants identified as mentally ill signed consent forms to be involved in the study with one female and two males participating (See Appendix A). They also signed Authorizations to Release of Information for me to be able to talk to their family members and their mental health workers (See Appendix C). The ages of the participants were 29 (male), 32 (male) and 49 (female). All were Caucasian and all of the consumers with mental illness reported that they were actively involved with their local community
mental health centers. All of the mental health consumers reported receiving medication management, all reported receiving therapy, and all reported receiving case management.

Three family members signed consent forms to be part of the study (See Appendix A); all three were female. One was a participant’s mother and the other two were participant’s sisters. All of the mentally ill participants signed Authorizations to Release Information (See Appendix C) to allow these individuals to participate. All three family members were Caucasian and their ages were 28 years, 30 years, and 59 years.

Three mental health workers signed consent forms to be part of the study; all three were female (See Appendix A). Two were case managers and one crisis worker (who used to be a participant’s therapist). All of the persons with mental illness signed Authorizations to Release Information to allow these individuals to participate. All three mental health workers were Caucasian and their ages were 26 years, 31 years, and 36 years.

All participants’ names and any other identifying demographic information were changed to protect confidentiality.

**Method**

I chose the method of intensive, descriptive individual interviews involving the participants in order to gather an emic perspective on the lives and experiences of the participants as they interface with issues involving mental health (Cheung, von de Vijver, & Leung, 2011; Lahlou, 2011). Qualitative designs are beneficial for studying emic perspectives (Guba & Lincoln, 1990). The approach included the ethnographic style of inquiry, where the inquirer attempts to describe a culture, including learned patterns of
behavior and ways of life. This is done through prolonged observations of the group and one-on-one interviews (Creswell, 1998). This type of indigenous approach to the material meant truly engaging the clients on an equal level and making them feel as comfortable as possible (Holt, 2011). I dressed in street clothes and was careful to not use “therapy words”. I offered each one a bottled water and a small snack as I knew we would be talking at length. I just tried to be myself. I also had to recognize the notion of subjectivity (Lincoln & Guba, 1985).

I conducted semi-structured interviews, ranging from an hour to three hours in length, with the participants. Through this, I obtained thick description of the topics through the interview process, providing a holistic look into the lives of these individuals. The interviews were audio taped and transcribed.

I coded the themes utilizing the Focused Coding Method and using suggestions from Merriam (1998). The Focused Coding Method allows a researcher to go through his or her document and look for the most frequently found codes and these create categories that, when scanning the document again, allow other relevant codes can be placed in these categories, and these create themes (Saldana, 2009). Merriam states that when coding information from interviews, it is important that the researcher simply mark the parts of the information with numbers, letters, or other symbols is that the information, being put in thematic units at the time of coding, can be easily retrieved by the researcher at a later time. Merriam goes on to say when coding data there are two levels of coding—first simply identifying the information about the data and, second, interpreting higher constructs relating to analysis. Of course, working towards analysis is certainly the higher level construct. In using both the Focused Coding Method and Merriam’s
suggestions, I initially scanned the document for themes and cut out quotes from the transcripts that I felt were relevant. Then I went through those relevant quotes, put them into themes, and looked for higher levels of analysis from those themes, which I hand wrote out. I also reviewed the rest of the transcripts to see if there was anything I missed. I determined which were the strongest themes by the number of items that I found to code for each theme and through analyzing the coding items for themes central to the significance of the study.

Pseudonyms were used to identify all participants. I presented the final results of the original transcripts back to the original participants for feedback as to the validity of the researcher’s interpretation.

In summary, for this study, I took the modernist approach. I used Seidman’s (2006) approach to listening on 3 levels: first being cognizant of what was being said, second listening to the internal voice, and finally, being aware of what was around me. I chose the qualitative method because I wanted thick, rich, descriptive material. I was interested in the participants drawing a completed picture in their own words (Merriam, 1998). With regard to internal validity, I approached that through using member checks, peer examinations, clarifying my bias, and modal category. I used purposive sampling because I was looking for a specific group of participants. I had access to these participants through the directors of the Mental Health Center and the Outreach Center, who acted as gatekeepers. To decide if the participants were right for the study I used three constructs: saturation, typicality, and triangulation (Merriam, 2001). For the
method, I chose individual interviews with semi-structured questions. Finally, I used the Focused Coding Method, coding for themes.
CHAPTER IV

Findings

The purpose of this study was to examine perceptions of those involved with regard to experiences with peer-run services and traditional mental health services. I also had several sub-questions which included alcohol and drug issues, family issues, etc. After data analysis, I was able to uncover ten major themes. With the strongest theme first, the ten themes were (a) alcohol and other drugs, (b) family, (c) traditional mental health service activities, (d) personal empowerment, (e) medication, (f) peer-run services, (g) boundaries and ethics, (h) discrimination, (i) consumers-as-professionals, and (j) what the participants would like people to understand and believe about people who have mental illness.

Deb Davis’s profile.

I would like to begin this chapter with a brief discussion about the participants with mental illness and their history of diagnosis. Deb Davis, a 49-year-old divorced mother of three, was diagnosed at about 30 years old. Short, with blond hair cut to the quick, Deb’s face was very expressive. She bounced around as we did our interview. Her sister, Tina Swartz, shared that Deb had problems since she was a teenager. Deb was on and off different medications when she was younger. She had seen many doctors. She was diagnosed with depression. Deb’s case manager, Missy May, stated that Deb’s diagnosis was Schizoaffective Disorder, bipolar type, and she had Polysubstance Abuse.
**David Joyce’s profile.**

David Joyce, a 29-year-old man, said about his diagnosis that he had Borderline Personality Disorder and Severe Depressive Disorder, moderate, “and I’m also a recovering addict from opiates.” A tall man with sparkling eyes, David often left his seat during our interviews. David wore clothes that were disheveled. David’s case manager, Jamie Dove, gave details on David’s diagnosis, including that David’s primary diagnosis was Major Depressive Disorder, recurrent, moderate, with Borderline Personality Disorder on Axis II and also an Opioid Dependence diagnosis (per the Diagnostic and Statistical Manual of Mental Disorders, Four Edition, Text Revision, [DSM-IV-TR]).

David’s 59-year-old mother, Susan Joyce, talked about his diagnoses and David’s violence towards her:

> David has never been right. I have been taking him to doctors since he was very young. When he was four or five years old, he was diagnosed with ADHD [Attention Deficit/Hyperactivity Disorder]…I’m not really sure what he is diagnosed with right now. I know he is supposedly recovering from an opiate addiction. And I think he was diagnosed as a Borderline Personality…David can be very violent. He has been violent towards me. I have filed Domestic Violence charges against him and he has gone to jail. . . .

**Mike Berry’s Profile**

Mike Berry, a 38-year-old participant in the study, said that he was 29 when he was diagnosed with Bipolar Disorder. Mike was a short man with big, brown eyes and bushy brown hair. Mike spoke softly during his interview. Mike’s case manager, Carri Ivy, 26
years old, from the Mental Health Center stated that Mike had Bipolar I Disorder, most recent episode severe, with psychotic features. She also added that Mike had many other diagnoses in the past.

Mike’s sister, 28-year-old June Best, described Mike’s functioning and his intelligence through her eyes:

…depression and kind of introvert(ed). [He] doesn’t get involved in conversations and stuff too much. He like can’t do daily things that people do like working and stuff like taking care of himself…He’s very, very sweet, very nice, super intelligent, very, very smart. I think that’s probably part of his problem too, you know…they say, there’s a fine line between genius and insanity … He’s come a long ways from like fifteen years ago…I think he pretty much hit rock bottom probably seven years ago…He was in prison and came out. And ever since I’m not sure if he was institutionalized after he came out of prison but that’s kind of when things kind of turned up…

As is evident, each one of the participants was different from the next, with different issues, strengths and needs. In the ten themes below, the differences among the participants will become even more evident.
Below is a representation of the commonalities between my three main participants and the more pertinent findings.

**Table 4.1.: Commonalities Among Participants**

**Table 4.2.: Commonalities of the Participants’ Cases**

<table>
<thead>
<tr>
<th>Categories</th>
<th>David</th>
<th>Deb</th>
<th>Mike</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants felt their families didn’t understand their mental illness</td>
<td>“Out of sight, out of mind”</td>
<td>NONE</td>
<td>“I don’t think they really understand it [his mental illness]. A lot of times they’ll want to force change or force recovery in me, and that doesn’t tend to coincide with my program for recovery.”</td>
</tr>
<tr>
<td>Participants had past AOD problems but were currently recovering from those problems</td>
<td>As far as my addiction, oh, yea, but you know you can be honest today and I need to tell them my disease so a lot of times in certain situations I will tell people I’m a recovering addict because it is something I’m proud of. “</td>
<td>“I go to NA. I started NA ‘cause I started craving again and I go to as many meetings as I can go to; that really has helped.”</td>
<td>NONE</td>
</tr>
<tr>
<td>Participants felt they were over-medicated on psychotropic medications</td>
<td>“…was on Lithium for years. Every time I would start acting out, they would up my Lithium, which made me lethargic.”</td>
<td>“I was on fourteen medications when I first came here (The Mental Health Center) and now I’m on one.”</td>
<td>NONE</td>
</tr>
<tr>
<td>Participants had positive interactions with Traditional Mental</td>
<td>“….it is a positive thing at the Mental Health Center.”</td>
<td>“Dr. Nick I absolutely love.”</td>
<td>“We try to focus him on day-to-day steps he can”</td>
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<tr>
<td>Health Services</td>
<td>Participants had positive interactions with Peer Run Mental Health Services</td>
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<tr>
<td>“I know he is doing really well at the Outreach Center and is really involved there … I know that he has been much more stable in his mental health since he has been involved in the Outreach Center.”-Susan Joyce, mother.</td>
<td>“I know she ran some of the groups and liked doing that (at the Outreach Center). That really made her feel special, important.”-Tina Swartz, sister</td>
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<tr>
<td>“….realize that we all have problems and that we sometimes can get on each other’s nerves, but I think our hearts are in the right place and [we] generally kind of solve our problems and work out our differences...”</td>
<td></td>
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<tr>
<td>Participants felt a sense of Personal Empowerment through their interactions with various services</td>
<td>“….but he did really blossom with being a facilitator of a group and taking a leadership role in the Outreach Center....”</td>
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<td></td>
<td>“Before I came here, I was in a group home for five years. It was mental illness and drug addiction. I started getting stronger and learning a lot myself and wanting more and more when I came here. Now I’ve been clean for two years....”</td>
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<td></td>
<td>“I think the self-help groups have been really good for Mike because it has empowered him to reach beyond his own circle of acquaintances and talk about mental illness and be an advocate for treatment in a number of ways on the state level.”</td>
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<tr>
<td>Participants have encountered Discrimination because of being Persons with Mental Illness</td>
<td>“If you feel uncomfortable around us, you need to move to an area that you feel safer because we’re not going to hurt you, nobody’s going to...”</td>
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<tr>
<td></td>
<td>“A girl said “the crazy people” are in here during the day. I’m sitting right there and I was totally offended.”</td>
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<tr>
<td></td>
<td>“Sometimes the people I meet, if they know that I have a mental illness or see that I am acting differently, they might avoid me and not want to talk...”</td>
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<tr>
<td>Participants talk about their experiences as Consumers-as-Professionals</td>
<td>Hurt you here but your perception is your perception…”</td>
<td>“…they’re all wonderful to me, the Outreach Center people are. When I first came, I started teaching right away. We had a class on intimidation. It got around to the director and she said I’m intimidated by Deb and I looked up at her to see if she was joking and she wasn’t. She said when I first came she couldn’t tell who was the student and who was the teacher.”</td>
<td>NONE</td>
</tr>
</tbody>
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**Traditional Mental Health Services vs. Peer-Run Services**

Traditional mental health services vs. peer-run services were not the strongest themes…..but this issue is central to my research question. Theme strength was determined through the coding method. When I coded the themes from the original transcripts, I did so by scanning the documents for themes and actually cutting out those quotes out of the transcripts and putting them in piles of similar themes. I then scanned the transcripts again and cut out any themes I missed and added those to the piles. I then
went through the piles and separated out what quotes were actually relevant to the
research and finally counted up the number of quotes in each theme pile and put them in
order from highest to lowest and that is how I determined strength.

Traditional services include psychiatric services (medication from a psychiatrist or
seeing a psychiatric nurse), counseling services, crisis management, and case
management. David Joyce’s case manager, Jamie Dove, had this to say about traditional
mental health services as they relate to David:

There is value in the traditional as far as the collaborative case management,
psychiatrist, [and] counseling, but for him, less has been better. He seems to be
more successful when we don’t shower him with housing and paying for his meds
and all that kind of stuff. Instead, we give him options and encourage him to
make choices that are in his best interest….

David Joyce thought carefully and answered slowly and completely as he explained
about his interactions with traditional mental health services:

I have a counselor out there (at the Mental Health Center), Lisa Gottfried. We
usually will work through things that I’m either struggling through and I’m not
seeming to get through….NA [Narcotics Anonymous], the twelve-step, I have Dr.
Nick. He is the best psychologist, psychiatrist, psychologist…He is the best I
have ever known because he takes time like a counselor. He wants to know what
is going on with me before we get to the med part of it and most psychiatrists I’ve
met before are really focused on just the medication part. Is it still
working?…,Then I have a case manager. I had one for two years. We were very
close. I trusted him with all my heart. He passed away at the age of thirty-eight;
that was really hard for me. But now, I have Jamie and I am finding out that Lisa is great. I’m trusting her….She’s just not Don, but that’s okay. Usually, we get together about once a week….to sit and talk and her to catch up and see where I’m at. So, it is a positive thing at the Mental Health Center.

David’s mother, Susan Joyce, had this comment on David’s traditional mental health services:

He started to make sure he always had his medication refills. He made all of his doctor’s appointments. He went to counseling and when I was allowed to talk to his counselor at that time he was doing really well in counseling. He also was working with their housing people to make sure he had a place to stay. He was just really doing well, at least for that time period.

Deb Davis, who also saw Dr. Nick, had a similar experience with him: “It was always a pill and Dr. Nick believes in a lot of talking and doesn’t dope you up.” Deb’s case manager, Missy May, explained in more detail about Deb’s relationship with Dr. Nick and other aspects of traditional mental health services:

Well, I think she has been much more stable since she has been seeing the psychiatrist at the Mental Health Center. He has got her (Deb) to go from 14 medications down to one. And she seemed the better for it….Deb told me that [Dr. Nick] actually talks to you and listens to you instead of just pushing pills on you….Now the case management part I know had helped Deb a lot. She has worked with me for a long time and we work on everything from doing basics like paying bills, making sure Deb took a shower if she was depressed, making
sure her house was clean and that there was food in the fridge. We also worked on budgeting, crisis, planning, all that good stuff.

Deb herself talked about her relationship with Dr. Nick. She was very intense during this part of the interview, with rapid speech, using her hands to make points in her dialogue:

Over the years it really was bad. Then, Dr. Morrow wanted to do shock therapy on me. He had me on fourteen medications. I just sat in a corner and didn’t even know I was alive for a year. So I asked for Dr. Nick. Dr. Nick I absolutely love. When I got out to get my own place, my family lives in Rockville, and I had to struggle whether to stay here or go to Rockville but they don’t have programs in Rockville, No. 1; No. 2, I did not want to leave Dr. Nick because I trust him totally.

Mike Berry was concise in his view of his traditional mental health services: “I’ve had positive results with them. I’m happy with my counselor and psychiatrist.” Mike’s case manager, Carri Ivy, described his interaction with traditional mental health services:

Mike is very aware of his diagnosis and their symptoms that it can involve so we work on coping skills on how to integrate into the community despite having a serious mental illness. We also try to focus him on day-to-day steps he can take to achieve his goals.

For another perspective on traditional mental health services, Mike’s sister, June Best, described what she knew about Mike’s experience:

I know he’s on medication which has helped a lot, like immensely, actually if he didn’t have he probably wouldn’t be home now. He’s come a long way from
where he was when he was diagnosed. I guess he goes to a group study, not a study but a group therapy type of thing every day. I think that is good.

Peer-run services were at the crux of this research and were the sixth strongest theme. All participants were asked, in various ways, about their interactions with peer-run services and how they felt they benefitted from them, if at all. Each of the participants’ experiences was unique and varied in degree of service and interaction. They unfolded as follows:

Mike Berry, a participant at the Outreach Center, a peer-run service, told briefly about his experiences at the center:

It has been generally positive. I realize that we all have problems and that we sometimes can get on each other’s nerves, but I think our hearts are in the right place and [we] generally kind of solve our problems and work out our differences...

Mike Berry’s case manager, Carri Ivy, had this to say about Mike’s involvement with the Outreach Center:

The Outreach Center, I feel, for Mike has been a great help. It gives him support in the community. It gives him a way to excel, because Mike has been able to really take leadership roles in the peer support and has actually, through their encouragement, gone to state meetings, advocacy programs, and [it] has really allowed him a place where he can see success relevant to his mental illness.

Mike’s sister, June Best, also lent her opinion: “I think it is a big role because that is the only contact with people he has other than my parents. That isthe only big thing he sees on a daily basis.”
David Joyce, also a participant at the Outreach Center, explained his experience this way:

I figure if the Outreach Center has not taught me anything else it has taught me how to choose, have accepted tolerance for people and learn how to get along with people who aren’t necessary…It’s good progress, believe me.

David Joyce’s mother, Susan Joyce, had a couple of comments to make on the subject of David attending the Outreach Center:

I know he is doing really well at the Outreach Center and is really involved there … I know that he has been much more stable in his mental health since he has been involved in the Outreach Center. He hasn’t had any violent outbursts in a long time. He doesn’t seem as depressed. And, if he is telling the truth, he has been clean and sober for awhile. There are good people at the Outreach Center. I talk to Amy, the director, every once in awhile. Just to check in and see how David is doing. She has had an open door policy with me and David has agreed to that. I can also call her if David is not returning my calls just to make sure he is safe. So I would have to say that David gets, yes, a lot out of going to the Outreach Center.

Deb Davis was also an Outreach Center participant. Her case manager talked about her experiences with the peer-run group:

I think that was a great motivator for her. It gave her somewhere to go, again where she wasn’t judged and where she could say I’m having a really crappy day, and I’m feeling very paranoid, or I’m feeling this or I’m feeling that, and those that she talked to weren’t just saying yeah I know how you feel and have never
walked in her shoes. To be in the Outreach Center you have to have a mental health diagnosis.

Deb’s sister, Tina Swartz, gave her input into Deb’s participation in the Outreach Center:

I know she ran some of the groups and liked doing that (at the Outreach Center). That really made her feel special, important. Amy, the director, is a nice person. I have talked to her a couple of times. She was very supportive of Deb. I think Deb got a lot of value out of the Outreach Center.

Alcohol and Other Drugs (AOD)

The strongest theme found in the interviews was alcohol and other drugs, or AOD. The fact that AOD and mental illness are linked in some way is not a new phenomenon. However, no interview question actually addressed AOD. Thus it is surprising that AOD came out as the strongest theme.

Deb Davis, who sat and bounced in her chair as she explained her experiences with AOD and NA (Narcotics Anonymous), seemed slightly manic as she said:

I go to NA. I started NA ‘cause I started craving again and I go to as many meetings as I can go to; that really has helped. It really does help. I got my thirty-day tag again ‘cause I screwed up and smoked a couple. Someone stopped over and had marijuana and I smoked a couple and I felt absolutely horrible guilty, so the next day I picked up the phone and called someone for NA and I’ve been going since.
With regard to NA, Deb’s sister, Tina, described the value of it this way:

…but she was in NA. At one point she was the secretary of the one chapter… NA really got her on the straight and narrow as far as her narcotics addiction. She relapsed a few times, and they were there for her, and she got clean right away. So I guess you could say that Deb got a lot of value out of NA.

Deb’s sister Tina looked a little nervous as she recalled parts of Deb’s AOD history:

She was also addicted to pills; I’m not sure which types but I know they were narcotics. She beat that addiction pretty much before she died…When she was on the pills she was very irresponsible. She wouldn’t pay her bills and she would get money from her payee saying she was going to pay her bills and spend it on something else. She even ended up in jail for disorderly one time. She wouldn’t call the family, even her children, and she would stay up all night and just generally not take care of herself.

David Joyce talked with rapid speech as he described his life on and off drugs. He started off by describing how drugs ruined his life: “Heroin just happened to be the last opiate that ruined my life, you know, but I was on Percocet, patches, and everything else because of my back for twenty-plus years without success.” David was involved with the Drug and Alcohol Center, which was court-ordered treatment, due to his assaults and Domestic Violence convictions. Although David felt he needed the help, he had some complaints about the Center’s protocols:

I went to the Drug and Alcohol Center for a while. But I would be accused of using and I wasn’t. One time I missed a piss test because I was at home sick. I struggle with my teeth. Using heroin for any amount of time will rot your teeth
out early. And I need false teeth. I just struggle with them over the last couple of years. I remember that day I was home sick as hell and I had a horrible toothache. I told him [the Center worker] if he brought the bottle there I would pee in it but I wasn’t going in. Of course, they think because you’re sick you have to be dope sick and you’ve relapsed, blah, blah, blah, and then you get to hear that scenario over and over instead of their trusting you or moving on.

David was a long time member of NA and believed in working the program. He appeared to receive a lot of value from attending NA. Below, David’s mother, Susan, described some of that value that David received from NA:

He says he can relate to the people that go there and often gives rides to some of the members that don’t have a way to get to meetings. He does leads, where you open the meeting by telling your story, and likes to do those. So I’d say he gets a lot out of NA, too.

Next, David, who was quite animated at the time, made some statements about NA:

We’re just now starting; there’s an NA group, Tuesdays and Thursdays at noon. So, I’ve worked out with Cathy that anybody that wants to go on Tuesdays I will be taking the group over to the NA meeting and then bringing them back so we have some drug structure in there also…and they (the Outreach Center) beat, beat, beat in my head between them and NA that my recovery must come first in my life.

David took pride in his recovery from drugs and alcohol. Next you will find some comments on David’s early recovery and his views on the Outreach Center:
As far as what the Outreach Center does, we’re a dual diagnosis group. I have been really pushing more because when I got here it was all about mental illness which is part of it, but me being a heroin addict and nobody admitting . . . I’ve gotten to know a lot of them personally. They still self-medicate with either drugs or alcohol, but they didn’t see that as being an addict. And when I first came in I struggled with the fact that I was a heroin addict and they just thought that was horrible, they couldn’t trust me, I was a big old liar.

David talked about his life in recovery and the obstacles he had to overcome, in particular prejudice, in order to stay sober. David spoke with power when discussing this topic:

As far as my addiction, oh, yea, but you know you can be honest today and I need to tell them my disease so a lot of times in certain situations I will tell people I’m a recovering addict because it is something I’m proud of. My life would never have started or beginning to feel good like it does today if I hadn’t been an addict to begin with. People are very prejudiced. They think you should lock, you know put us in prison, throw away the key, blah, blah, blah, blah, and to me that is not the answer because there are just as many drugs in prison and you’re not fixing the problem…A lot of it comes from maturity. I think I’ve matured a lot over the last few months. They say you stop maturing as soon as you pick up that drug and you don’t start maturing again until you start recovery and I truly believe that because I was a 42-year-old teenager…I work steps. My sponsor works steps…So that is the approach I take versus trying to be accusatory.
Family

Obviously, AOD issues were close to the hearts of two of the participants; however, the issue did not come up when interviewing Mike Berry, his sister, or his case manager. Also, close to the hearts of the participants, and the second strongest theme that emerged from the interviews, were family issues. Some of the subthemes that emerged from the transcripts included family member burnout, isolation, perspective of person with mental illness, family member mental health history, etc. Here I will start with Deb Davis’ experiences with her family. Ms. Davis explained a bit about her family members’ mental health:

My family used to not understand but they do now because out of nine kids, four of us have bipolar. The other three won’t take medication and my sister is in jail right now. My other sister has been in the hospital at least twenty times in the last few months, and Bobby [her brother] is always in trouble because of not paying support and [not] doing what he is supposed to be doing. The sheriff was looking for him the other day…Just now in the last three months have they, because of them watching my other sister with it and denying that she has it and two sisters and a brother denying that they have it, and it is quite obvious that they’ve been studying about bipolar, and my mom is bipolar but was never medicated. They treat me with a lot more respect now because I’m more open about it and explain what bipolar is and how it affects me, but they like it that I don’t use it as an
excuse to do drugs or do anything wrong anymore. I owned up to the fact that
yes, I have bipolar and I’ll have to live with it the rest of my life and the addiction
but I can still have a good life.

Deb’s sister, Tina Swartz, explained how difficult and frustrating it could be at times
to support Deb:

To the extent that she would let me in, I tried to check up on her and make sure
basic needs were met. This was much easier over the last couple of years since
Deb got off drugs. She has been much more stable. Sometimes I think she felt I
was treating her like a little kid, but really I just wanted to make sure she was
okay. So was I burnt-out? I’d have to say so. I was just so stressed with worry. I
would never want to go through that again…Well, I’d have to say that there were
times that I felt burned out. This was mostly when Deb was doing drugs and
when she was refusing contact with me and her children. It would become
absolutely terrifying to call and call and call and not get any answer and to stop by
her house and knock and knock and know that she was home but she just
wouldn’t open the door. Sometimes I would get really angry with her. I would
think “what gives her the right to do this to me?” It was just frustrating, you
know?

Deb’s sister and her case manager, Missy May, talked about how Deb’s behavior
affected Deb’s children: Tina Swartz stated:

Her children at one point cut off all contact with her because they couldn’t take
the unpredictability of all of it. They were just so scared for her, but they all live
out of state and couldn’t check up on her in person, and Deb wouldn’t return their phone calls.

Missy May, recalled the following about her client and her client’s children:

She has three children and I know that it was very hard for them. They have been put through a lot growing up and it was hard for them to forgive her. That’s been a very strained relationship for her. Her mom and she didn’t get along very well either; that was a very difficult relationship. I would have to say it has affected the family greatly, and it had put stress and tension on her and the family. Her oldest daughter actually had a decent relationship with her over the past year. The more clean and sober and longer she stayed, and the better she was, the more they came around. But they would often tell her about her lacking parenting skills and things and there was a lot that she had a guilt over, you know not being there necessarily, them having to be more of the parent growing up, her not being around a lot, and then her being in and out of the hospital or gone for days. But as they got to be adults they were a little more empathetic.

Mike Best was quite curt with his comment about his family members and their interactions in his life: “I don’t think they really understand it [his mental illness]. A lot of times they’ll want to force change or force recovery in me, and that doesn’t tend to coincide with my program for recovery.” Mike’s case manager, Carri Ivy, found it difficult to comment on Mike’s family because she had not interacted with them:

That’s a tough one because I have not included Mike’s family into his treatment other than I see his mom in the waiting room and wave to her, so I guess I don’t
know. They seem very caring and concerned about him, and I’m sure since they were the victims of his assaults, that certainly affected their lives.

Mike’s sister, June Best, talked about her involvement with her brother, seeing him struggle, and how it is to support a brother who lives so far away: “I try to [support him]. I don’t see him very often because I live in Nevada. He doesn’t really talk a whole lot so it is hard to converse with him…” June continued:

Well, I don’t see very much but just from [what] I feel, my parents are burned out sometimes, but you know they try to be supportive as they can. But it’s hard you know… it’s hard for me because I don’t see him on a daily basis so I don’t see the progress that he makes, and it seems to me that he’s not trying but he probably is trying. I think the situation that he’s in, he is very fortunate that he can live with our parents. He has somewhere. He doesn’t have financial troubles or anything so he’s taken care of…I mean that it’s a good thing that he has the family support that he has, but then if he was in a different situation where he has to do things then maybe he would get things done quicker. He doesn’t really have other friends or anything that I know of.

When David Joyce was asked about his family, he answered this way:

Out of sight, out of mind. I was hearing voices for a while. I went through some psychotic episodes. It turned out to be a medicine he had me on, but it was an interaction. But I was really scared. My mom didn’t believe me. It was just me “acting out” again. You know, it’s all the time away from the family and they don’t have to deal with me, my drug addiction or my [mental illness]. They don’t want no part of my recovery so I’m pretty much on my own. Mom would like to
say she supports me, but she probably will when she talks to you, but then you
know I have to look at what part I played in this too. You know, during active
addiction I stole from my mom, I lied, I cheated, you know so maybe the trust
issue is there. It is just more about a trust issue than any of the support issue. She
doesn’t trust anything I say or do. But, so, it is just where I stand. My brothers
and sisters won’t have anything to do with me. I’ve learned that being alone isn’t
always bad and I’m never truly [alone], I have God.

David’s case manager from the Mental Health Center, Jamie Dove, related this
information about David and his family through her work with David:

His mother was probably his closest support person in his life. They have a very
strained relationship. He had stolen checks and money from them, her in particular.
It’s very unstable. It’s kind of a love-hate relationship, oftentimes and that has been
difficult for him but also for the family. She has moved out of state recently, kind of
getting a fresh start . . . He and his sister[s] and brothers have had a very strained
relationship so it affects them based of kind of the instability that surrounds the way
he interacts with people. There are times when it is very much about David and that
doesn’t always go over well with his family.

David’s mother, Susan Joyce, described her struggles with her relationship with her
son in this short comment:

It is even more difficult with David because one month he will allow me contact with
the Mental Health Center, the next month, he won’t. He signs releases then he
revokes them. We are constantly fighting. I was surprised he allowed me to do this
interview. I never know with him. There is a lot of tension in our relationship.
Personal Empowerment

The fourth strongest theme in the study is personal empowerment. For the purposes of this study, I define personal empowerment as being any instance in the interview where participants were said to be doing things that were previously beyond their means; something like paying their bills on their own for the first time or holding office in an organization. The theme of empowerment is often connected to participation in peer-run services, such as the Outreach Center. Opportunities for empowerment, such as opportunities to lead groups or coordinate trips, were readily available at the Outreach Center. Deb Davis was able to relate a few instances of personal empowerment for herself:

Before I came here, I was in a group home for five years. It was mental illness and drug addiction. I started getting stronger and learning a lot myself and wanting more and more when I came here. Now I’ve been clean for two years…But I’m out on my own now. I have my own apartment. I pay my bills. I take care of myself. Dr. Nick just told me Thursday that I didn’t have to come back for two months because I was doing so well…The Outreach Center been a great God-send to me…

Deb’s case manager, Missy May, explains a continuum of activities that Deb had done that were evidence of her personal empowerment:

I suspect that her intelligence level had a lot to do with it, I really do…When she was in assisted living, she would get up and shower every day, and there were
people who wouldn’t shower unless you basically forced them in the shower. I think she saw that she could help other people and she could be a role-model. I think that empowered her to do better for herself… to set a good example and to show other people, hey, if I can do it you can do it. I think that totally just wrapped itself into the Outreach Center, and the more she went along the more empowered she felt, because everybody else was commenting on how good she did and were coming to her for advice. Hey, how could I do this? You did this, what can I do? She just continued to be built up by those around her and by doing good herself.

Deb’s sister, Tina Swartz, talked about Deb’s personal empowerment as it related to her participation with the Outreach Center and her involvement with the Mental Health Center.

Well, I know that Deb really felt empowered by her participation and work with the Outreach Center. I think she started going there about three years ago, about the same time she started at the Mental Health Center. She really enjoyed the people there and the things that they got to do, like going to the movies, to the mall, and bowling…I think that Deb took the most charge of her care when she started at the Mental Health Center and the Outreach Center. She was supported by the Lifeworks people and made connections with the Mental Health Center staff and she started to go to the doctor regularly, got a counselor I believe, and started with a case manager. She was taking her medication on a regular basis and we really saw a change in her. . . .
David Joyce’s case manager, Jamie Dove, expressed how David was empowered through his work at the Outreach Center and also through the choices he made at the Mental Health Center and beyond:

….but he did really blossom with being a facilitator of a group and taking a leadership role in the Outreach Center…He’s been empowered. Like I said in the Outreach Center when he first started there he was a facilitator for a group, he held some responsibilities. That has been empowering to him that self-esteem, self-confidence that he has had a purpose for the day and such. He is also empowered to make choices for himself. The case managers have decreased their interventions on housing; yes we will help support and work with him of course, but wanting him to make choices for himself rather than doing it for him. Empowering him by including him in treatment planning, wanting him to say this is what I want to work on, whatever it might be at that time. Empowering him to decide if he is going to come to a counseling appointment or not. I encouraged him.

David’s mother, Susan Joyce, related her ideas of David’s personal empowerment through his work at the Outreach Center and in how he took charge over his treatment at the Mental Health Center:

David has done very well at the Outreach Center. I think he feels empowered there. He does all sorts of things there. He runs groups and also helps with their transportation. I know he has planned trips for other people there, like to the bowling alley and the movies; things that they could do for fun and to just get away from the building. I know he was going to try to get on their board of
directors. It is something very important to him. He wants to be part of making the rules…Well, I would have to say that David has taken the most charge over his treatment after he got out of jail this last time and started back with the Mental Health Center. This was also about the same time he started with the Outreach Center. He started working with a case manager, it was a gentleman at the time but I don’t remember his name, and he really liked him. I think he wanted to make him happy. But I think also working at the Outreach Center gave him some self-esteem and he wanted to take better care of himself.

Mike’s case manager, Carri Ivy, was able to express Mike’s personal empowerment through his work at the self-help groups:

I think the self-help groups have been really good for Mike because it has empowered him to reach beyond his own circle of acquaintances and talk about mental illness and be an advocate for treatment in a number of ways on the state level.

Medication

The fifth strongest theme in the study was medication. Medication, for the purposes of this study, includes such topics as side-effects, compliance, reactions, differences of opinions, etc.

Mike Berry casually mentioned what medications he was on and that he felt they worked; then told me he used to not be so compliant with his medications:
I take Risperdal, Zoloft, Invega, and Lamictal. So far they have been successful at treating my symptoms…Yeah, before I was actively seeking treatment, I kind of would casually see a medical doctor for antidepressants, but I wasn’t firmly convinced that I needed them so I took them sporadically.

Mike’s case manager, Carri Ivy, related that she interacted with Mike by trying to encourage him to take his medication:

The biggest gain for my own work with Mike has been to encourage him to take medication. When I first started working with him, he would consistently go off of his medication and have a very serious increase in symptoms. Early on when I started working with him he was somewhat paranoid about medication and he thought the medication made him worse rather than better. Prior to taking medication, Mike had been incarcerated twice for serious assaults on people. Since being on medication and taking it consistently, he has not had any problems.

David Joyce’s mother, Susan Joyce, discussed his issues with medications in this manner: Later, when he was a little bit older he was diagnosed Bipolar and put on Lithium. David didn’t like that. He said the medication made him feel like a zombie. I had to force him to take it. She went on to say, “well, I think they all have helped somewhat.” The psychiatrist would help more if David would take his medications more consistently.

Finally, David had to offer this about his experience with medications:

…was on Lithium for years. Every time I would start acting out, they would up my Lithium, which made me lethargic. I think it was a tool for the doctor to keep
me in line. The reality of it was I was using drugs and I just needed to learn some tools, but it was a great possibility I was already back then like I am today.

Deb Davis had a slightly different experience with medication. Her case manager, Missy May, began by explaining the situation this way:

Well, I see Deb on meds and off meds and she tends to be more functional when she is taking some sort of psychiatric medication. So I’m going to say the psychiatrist maintaining her medication compliance was a big thing for her.

Deb Davis herself explained her experiences with medications in this fashion:

I was on fourteen medications when I first came here and now I’m on one. Of all the medications that they’ve ever tried, nothing worked, but Abilify works on me, and it’s changed my life. They put me in the hospital and weaned me off the fourteen medications. They used to tease me that I didn’t eat because I was real skinny ‘cause I ate my breakfast, lunch, and supper in pills.

**Boundaries and Ethics**

Boundaries and ethics, the seventh strongest theme in the study, are two topics that affect most social workers and counselors each day. They are impossible to avoid, and, if one does his or her job correctly, boundaries and ethics must be carefully considered in each case a social worker or counselor is involved in. In this study all the comments on boundaries and ethics came from case managers. I’ll start with the comments from Missy May, Deb Davis’ case manager. This is what Ms. May had to say about boundaries and ethics:
Well, I guess boundary-setting. You have to set good boundaries. Ethics play a big part of our job I would say. We’re teachers and we have to teach right decisions from wrong; think before you act. But at the same time you need to be very careful because I can’t push my religious beliefs on somebody else. You kind of have to watch because each person has their own faith or whatever and you have to let them go their own way but at the same time you’re there to help them live, you’re there to help them stay in the community, and it is all about helping them a lot of times develop their morals or their values or you have to allow where that person is and what their beliefs are too…I remember times when another case manager and I worked until like 7 or 8 o’clock or 9 o’clock at night and then we would be back in the morning and it would be never ending and we would get calls at home. You have to know to turn it off when you leave. I live in Centerfield so I could live right up the street from half my clients anyways so they all know where I live but it is just they come by and say hi if I’m out or whatever. It is just knowing that you do the best you can while you’re at work every day, and having no regrets, because you do the best you can. Then when you leave you know there’s always going to be more tomorrow…Yes, that’s important to avoid burn out you have to set boundaries.

Mike Berry’s case manager, Carri Ivy, talked about ethics being a daily concern and the plight of being a case manager in a small town:

[Ethics] are a daily concern. Gosh, it seems like there is a question that comes up just about every day. It’s like, okay, is this the best ethical decision I can make about this or that. Yeah, it’s on the forefront a lot. You know issues that you
wouldn’t think would play in. You know you think of the big ones, the ethical stuff, but there is all these little grey areas of ethics that have to be considered with on a daily basis actually…They’re not, especially in a smaller community like this where you’re likely to run into family members of clients you know when you go to Wal-Mart. Just indicating that you know them when you go to Wal-Mart is an ethical issue.

Discrimination

Discrimination, the eighth strongest theme in the study, is an issue that all three of the participants diagnoses with mental illness experienced in some way. Each spoke about it, and the degree to which it affected them, in brief comments. Mike Berry related that discrimination usually comes from people you know:

Sometimes the people I meet, if they know that I have a mental illness or see that I am acting differently, they might avoid me and not want to talk to me. But largely that discrimination comes from people who think they know you. There is really no reason to think that someone who doesn’t know you would suspect you have a mental illness.

Mike Berry’s sister, June Best, talked about how discrimination of her brother caused him to be less socially involved:

He’s encountered a lot of people that he’s known from years before he was ill, and then they’re like I’ll give you a call, and then they find out he has a mental illness and then they don’t want anything to do with him anymore. I think that
kind of brings him down too a bit. I guess a lot of people have a hard time understanding it. The important thing is that he can understand it. He’s told me like people don’t want anything to do with people that have mental illness...I think it kind of holds him back too in social activities and stuff.

David Joyce spoke about a mixture of sexuality and religion as they related to his experiences with discrimination:

But, I’ve been with this group before and how people look at us during vacation Bible school here. [We rent space at a church for the Outreach Center.] Well, they wanted to play hide and seek or something and they kept moving our way. Well, a lot of the people have prejudice here in the church, not the pastors or anything, just some of the people that work in the nursery, some of the older folks. We’re “the crazies.” But anyhow she asked us if we would move that day. Maybe I put too stern of a boundary down but I said no, this is our area. If you feel uncomfortable around us, you need to move to an area that you feel safer because we’re not going to hurt you, nobody’s going to hurt you here but your perception is your perception… As far as my own sexuality goes, I have had some prejudice views down here. The pastors are both very good. They all believe now it’s not a choice. I used to hate. Love the sinner, hate the sin. Well, you know what, we all sin. Adultery is one of the Ten Commandments but I don’t see anything about homosexuality in the Ten Commandments. I think it is more where my heart is. I had a priest tell me this once. He said I think God cares more about where your heart and your soul is, and that you’re a loving person, than where you put your genitals. So, you know, that kind of made it a little
lighter. But, so I’ve lived dual lives my whole life and today I’m trying to be honest and open and have that balance in life. This is who I am. You don’t have to be around me. You don’t have to like me. But, we can have some respect, especially if we have to be around each other every day.

Deb Davis talked about her experience with discrimination while attending a group that was supposed to be nondiscriminatory:

In fact, just here at the NA meeting that was held here the first Wednesday I went to it. A girl said “the crazy people” are in here during the day. I’m sitting right there and I was totally offended, and David that was just here, she did it the other night to him. She said well at least I know one “crazy person” and she put her arm around him. Someone wrote up on the bulletin board we are not crazy, we are getting help, are you? I was instantly furious.

**Consumers-as-Professionals**

One of the greatest movements in mental health recently is the consumer-as-professional movement. This is the ninth strongest theme in the study. Two of the participants had some involvement in this movement. Both felt being in this position had positive results in their lives:

David Joyce discussed his experiences about giving back to others through running groups and possibly looking at board membership:

Well, just to let you know a little bit about what I do here at the Outreach Center first. I am on the board of trustees. I drive for the Outreach Center and I run
groups for the Outreach Center. But, the group seems to like my groups best. I think it is because I have some group experience through NA. You have to keep the group under control and try to pull out of the people that don’t want to speak, you know…I don’t have the degree to back it up but I’ve just been so long in many groups and counseling and stuff that I feel like today I’m giving back. I don’t expect anything in return; I’m just kind of giving back and trying to help.

Long-terms goals: I talked to the director and told her I thought I was ready to start some schooling. I think, I’m not 100% sure yet, but I want to go into drug and alcohol counseling, possibly help. You know, eventually down the road get a halfway house here in town or a place where addicts can go when they’re detoxing, things like that. Or, after they’ve got through detox a house, because a lot of addicts are homeless, that they can come and continue to work on their recovery for so many months…Yes, I want to get more involved. Yes, I want to be an advocate.

Deb Davis told about her experiences teaching classes at the Outreach Center:

…they’re all wonderful to me, the Outreach Center people are. When I first came, I started teaching right away. We had a class on intimidation. It got around to the director and she said I’m intimidated by Deb and I looked up at her to see if she was joking and she wasn’t. She said when I first came she couldn’t tell who was the student and who was the teacher.
Finally, each of the participants lent their voice to the topic of what they would like people to understand and believe about people who have mental illness, the tenth strongest theme in the study. As evident from the participant’s previous comments, each one was very opinionated and had a unique view on life. In these final comments, the same is true and even more so as they each speak so passionately on this topic. David Joyce’s expressions on this topic included how people with mental illness interact on their medication, love, and respect:

That even the sickest of schizophrenics under the right medication and learning the right coping skills, there’s a person inside there and they can become functioning members of society. My meter of well or sick is how well do you work on your program and do you take your meds regularly and what choices are made today.

Deb Davis took on this topic by talking about respect, grief, and the fragility of life:

That they’re people. Take the schizophrenic. I’ve taught many people this. In fact, I did a group therapy with 120 cops and told them when they encounter them and they’re talking off the wall, don’t yell at them, don’t shove them around, let them say, because whatever they’re saying they’re really hearing and they believe. You should always, always have a little respect for them. If they’re violent, I can see handcuffing them and trying to control them, but if they’re not violent you don’t need to be pushing them around.
Mike Berry discussed this topic by talking about the ignorance about mental illness and about learning the “rules” of being mentally ill:

There is a lot we don’t know about mental illness and there is a lot we don’t know about persons with mental illness…Try to be I would think, yeah [understanding]. It’s really a whole new ballgame really, and sometimes the rules aren’t so clear, and a lot of the times we find ourselves struggling just to learn the rules. You have to cut a certain amount of slack because it is still a learning process for many people.

As evident from the above quotes, the participants, their family members, and their mental health case managers were all interesting, evocative individuals. Their views sometimes wove together seamlessly as one; at other times they were as opposite as the ends of the earth. Amazingly, stories of mistreatment, discrimination, drug and alcohol abuse, over-medication, suicide attempts, and violence only seem to have made them stronger individuals. Only the test of time and maturity will allow others to see how these special lives play out in the vastness of life. Unfortunately, Deb Davis will not be able to complete the journey, as she passed away during the completion of this dissertation. Or, maybe, she has completed her journey here on earth and has started a new one elsewhere.
CHAPTER V

Summary and Discussion

The findings draw interesting results. The participants, their family members, and the participants’ mental health workers spoke more frequently and in more depth about traditional mental health services in contrast to peer-run services. I could draw many conclusions from this finding.

First off, the participants may have simply been involved more in traditional mental health services as opposed to peer-run services. It makes sense with all the psychiatric, case management, counseling, vocational, and housing services available at the Mental Health Center that the participants would fill their days and weeks with more of these services rather than the limited groups, classes, and peer support offered at the Outreach Center.

Second, the participants and the others may value traditional mental health services more than peer-run services. Again, this could be for many reasons. Traditional mental health services have been in play for numerous decades; whereas peer-run services have only been around for people with mental illness for less than 50 years. And their beginnings were sparse; it took a grass-roots effort to push forward their humble beginnings. People also tend to value services they receive more of and, again, as I stated earlier, the participants of this study likely interact more frequently with traditional mental health services.

Third, traditional mental health services are more structured than peer-run services
and are thus easier to evaluate and talk about. People who utilize traditional mental health services are used to evaluating these services. They know, through outcomes measures and client surveys, how to speak their minds about their mental health services and what parts of their services are considered important, at least according to the mental health centers they attend. This may make it easier to speak about their services. Peer-run services, however, usually don’t have such a formal evaluation system and thus it may be more difficult to talk about their services in an evaluative sense (Aarons, Covert, Skriner, Green, Marto, Garland, & Landsverk, 2010; Uttaro, 2003).

One of the interesting themes that emerged important to the participants from the research was the theme of Alcohol and Other Drugs (AOD). Two of the three participants had issues with drugs and alcohol and their family members and mental health case managers spoke about their struggles and triumphs with AOD. On one hand, this theme should not be surprising; mental health issues and AOD issues are often linked (“Alcohol Use”, 2005). However, I found it interesting that I did not ask a single question about AOD and yet the participants, quite freely at times, and their family and mental health workers, all shared information about the subject. This could be for a variety of reasons.

First could be that the participants, the two that did report AOD usage, appeared to be in manic or hypomanic states when they met with me for the initial interview. Both were excessively talkative, had rapid speech, bounced in their seats, and appeared to have an inflated sense of self-esteem. Deb’s eyes were wild and she used extreme hand gestures to get her point across. David was very animated in his discussions and kept adding sayings such as “you know,” “you see what I mean.” A manic or hypomanic state would
be consistent with a current or recent diagnosis of Bipolar I or II Diagnosis. I did give the participants an opportunity to do the interview on another day, recognizing that they might not be at their best; both declined and wanted to continue. People in a manic or hypomanic state tend to be less inhibited and more likely to speak on subjects that others may consider taboo. Both of these participants spoke freely about their AOD issues.

Second, both David and Deb were in NA and AA (self-help groups, peer-run groups). These self-help groups teach their participants to be unashamed of their addictions and to speak about them whenever they can, at times to reach out to others who may be in need. I think this may be a key here as to why Deb and David spoke out so strongly about their experiences with AOD. Both were very proud of overcoming their pasts, overcoming relapses, and emerging drug and alcohol free. Not only were they proud of their accomplishments, but their families and their mental health case managers were proud of them as well. Their families and case managers talked about the participants’ struggles, their own anxieties, at times their need to distance themselves from the participants, but their ultimate joy over the participants’ successful undertakings.

Basically, having AOD show up as the second strongest theme in research I think says to my research question of participants’ perceptions of peer-run services versus traditional mental health services that participants bring much to the table when they enter a study such as this, and when dealing with mental health, AOD is always going to be a closely linked variable. Deb and David are perfect case examples. Through the small glimpses of their lives, they have allowed us to tap into unique pictures that show us they are indeed funny, quirky, decent, friendly, nice individuals who happen to have
mental illnesses and AOD issues. The two are linked. And because they are, they intertwine with traditional mental health services and peer-run services. It is just inevitable.

The issue of family, the third strongest theme in this research, was not a surprise to me as far as a theme emergent related to my research question of participants’ perceptions of traditional mental health services versus peer-run services. Obviously, family was an important theme to my participants. It has been my experience that most persons who are involved with mental health services have family who are involved with their care, or who want to be involved in their care. That is why I was not surprised when all three of my participants, Mike, Deb, and David, mentioned family and, of course, I interviewed a family member of each participant for the study. It was interesting that two of the three participants, David and Deb, had families that were somewhat involved in their care. Although Mike’s family was not very involved in his mental health treatment, they were very involved in his daily life.

Even though there has been a lot of talk and writings about the crumbling of the family unit and families in general over the past couple decades, I have experienced many families trudging in with their family member for mental health services (McGilloway & Donnelly, 2004; Moynihan, 1990). And many families are peripherally involved; this seemed to be the case with Deb and David. Deb’s sister would call her, talk to her caseworker, check-up on her when she could. David’s mother, living several hours away, still called, talked to the caseworker, came by when she was in town. Family is still strong in many parts of America, as it has been shown in this research study, and they are involved in their family member’s treatment.
Additionally, the families in this study had a close connection with the director, Lisa, at the Outreach Center. All seemed to feel that Lisa was extremely helpful to them and in keeping them connected to their kin during times of disconnect. The families had high remarks for the director of the Outreach Center and felt their family members received value from their experiences at the center.

Personal empowerment was the fourth strongest theme in the research and this should not be surprising, although it is interesting, because should not those with mental illnesses want the same things as those who do not have mental illnesses, namely: to achieve in their lives? When I look at the results in the theme of personal empowerment, I find that most of the examples of personal empowerment are activities such as acting like an employee, such as Deb did when she was living in the assisted living home, running group sat the Outreach Center, and holding offices such as being a board member in the Outreach Center. All of these activities are industrious, similar to jobs, and hold an air of achievement to them. These are all activities that these individuals should be proud of and their family members and mental health workers spoke of the activities bolstering the participants’ self-esteem.

Work is often attached to our self-esteem. What we do often helps define who we are and how we feel about ourselves. When we are gainfully employed in a position we enjoy, we feel good about ourselves. When we are unemployed and having a hard time finding work, we may have a tendency to feel less satisfied. For people with severe mental illness, who often cannot hold full-time jobs, other activities such as holding board positions or leading classes for their peers can be that all important link to helping them feel industrious and fulfill that part of their identity (Haj-Yahia, 1999).
The fifth strongest theme, medication, was not surprising to me due to my experience with individuals with mental illness. Medication is always an issue for people with mental illness. These individuals are constantly going to the psychiatrist, having their medication adjusted up, down, changed, tapered, titrated, started, and discontinued. They are often asked to keep medication journals; logs about their symptoms, medication compliance, etc. Medication has side-effects: rashes, high blood pressure, low blood pressure, double vision, sexual issues, mood changes, headaches, body aches, etc. Sometimes, just to stay sane, the side-effects of the medications are debilitating (Murphy et al. 2008).

Because of the aforementioned reasons, I’m not surprised medication was mentioned during this study: medication is a daily life struggle for people with mental illness. And much of the success of medication comes from the effectiveness of the psychiatrist. Deb and David both spoke about changing doctors and finding more success with their medications. Medication compliance strongly influences medication efficacy. Some of the family members talked about their concerns about medication compliance now and in the past. For all these reasons, medication fits quite nicely as a theme in this research study.

Boundaries and ethics were the seventh theme in the study (with peer-run services being the sixth theme, which I’ve already mentioned). I specifically asked about boundaries and ethics of the mental health professionals, so I was not surprised boundaries and ethics emerged as a theme in the research. David did make a statement about boundaries. So did Deb when she spoke about having her confidence betrayed by her doctor. Boundaries and ethics are held as strong beliefs in the mental health field;
one could say the field is built on boundaries and ethics. Mental health workers, in particular Licensed Social Workers (LSWs) and Licensed Professional (Clinical) Counselors (LPCs and LPCCs) in the State of Ohio are sworn to a Code of Ethics when they take their licensure test. Other mental health workers are bound by codes of ethics by the State according to their job title and by their employer (Brill, 2001).

Ethics also apply on a more personal-professional level. Some of the mental health workers talked about having their own code of ethics to which they aspired. This was almost an adjunct to the mandatory codes of ethics. These codes of ethics often come in handy in the grey areas of the job; where the mandatory codes, however neat and tidy they are, don’t necessarily cover.

Boundaries were spoken of by mental health professionals as lines of demarcation that had to be placed in order to do their job within a code of ethics. The mental health professionals spoke of boundaries as ways to prevent burn-out, ways to keep themselves professional in their relationships with their clients, and ways to keep themselves sane in their daily work with clients. Boundaries are certainly important when working with clients in the mental health world and in other professions as well. However, personal boundaries, those boundaries we hold between ourselves and those we work with, those we live with, and those we associate with on a daily basis are important as well to keep us well adjusted as individuals all around. It is important to keep a sense of self in our interactions with others; although there is a certain amount of blending of personalities with those whom we are close. That is why both boundaries and ethics are crucial in the mental health arena and also in our daily lives (Fisk, Rakfeldt, Heffernan, & Rowe, 1999).
Discrimination, the eighth theme in the research, was natural and expected. Individuals with mental illness experience discrimination at many levels and often. They can experience discrimination by their own family members and be shunned by the family, thrown out on the streets. They can be discriminated upon by service providers and be patronized in their servicing. They can be discriminated upon financially and have difficulty obtaining benefits. They can be discriminated upon by law enforcement and be unjustly arrested. They can also be discriminated upon by the general public and ridiculed for their illness.

The individuals in this study suggested discrimination on some of these different levels. Deb may have been discriminated upon by her children who shunned her for awhile during the height of her illness. Both Mike and David spoke of discrimination by the general public; David even had an experience of being discriminated upon by a church member. Mike has been discriminated upon by friends. All of this discrimination leads to the negativity and stigma that surrounds mental illness. The discrimination also leads to negative feelings that persons with mental illness may have about themselves (Leff, 1998).

Discrimination against persons with mental illness has progressed, however, in the past 100 years. Years ago, the mentally ill would be kept in chains, separated from society, or locked in institutions. As late as the mid-twentieth century, some persons with mental illness were kept in a back bedroom away from the rest of the “normal” family and friends. Still today, in certain circles, mental illness is spoken about in hushed voices. Education and advocacy have done quite a bit to bring mental illness out of the back rooms, but there is still a lot of area for growth.
in the realm of discrimination of persons with mental illness (Hoagwood et al., 2008).

Consumers-as-professionals, the ninth theme of the research, came from a specific question I asked of the participants. Both David and Deb answered in the affirmative that they had fulfilled this role, mostly leading groups at the Outreach Center and also acting as board members. Consumers-as-professionals is a relatively new idea in the mental health realm. It has allowed persons with mental illness to take on the role of a mental health worker; the role of teacher, advisor, and expert. And for those persons with mental illness, this opportunity provides an increased sense of self and self-esteem (Dixon, Krauss, & Lehman, 1994).

Consumers-as-professionals has a dangerous side, however. If the program is not properly supervised, misinformation may be transmitted and people can get hurt. For example, if a person with mental illness is acting as a consumer-as-professional and they are going through a particularly rough point in their own mental illness and should not be in that position at that point, but are, they may transmit misinformation, misadvise, etc. This is why the program should be handled with care and monitored well. However, overall these programs appear to benefit many individuals (Uttaro, 2003).

Finally, what the participant would want people to understand and believe about people with mental illness is the tenth theme in the research. The participants spoke passionately about this theme. They spoke about wanting others to understand that persons with mental illness were just like the others; “We are not freaks,” David said.

I believe this is all part of the human experience; wanting to feel normal and to be perceived as normal. To have our own identity, yet be closely related enough to everybody else that we fit in is understandable. Nobody wants to be the outcast. Nobody
wants to be ridiculed. People innately want to be accepted. To have some sense of self-worth is essential to life. I think this sums up a lot of what our participants had to say: please don’t judge me, just accept me for who I am.

This study does have some limitations. First, because all of the participants were volunteers, there is the possibility that they may have answered a particular way in order to please the interviewer. This researcher is also a mental health professional and this fact was disclosed; it is unknown how or if this fact affected the outcome of the study.

Second, the nature of mental illness could mean that at any given moment the illness may have affected the answers given by the participant with identified mental illness, both positively and negatively. Medication changes, fluxes in mood and affect, or the chaos associated with some individuals with mental illnesses lives may have affected the results.

Recommendations for professional practice include the following: (1) the fact that both traditional mental health services and peer-run services are valued by mental health clients and should be acknowledged and encouraged by the mental health worker; (2) giving additional time to listen to the client to talk in the initial interview is important to (a) make the interviewee feel comfortable and able to organize their thoughts and (b) helps the researcher gather a more complete and thorough assessment of the interviewee’s life and story; (3) it is important to ask questions about the interviewee’s family dynamics, the history of their mental illness, their AOD history, and their future plans; and (4) it is important to understand that many persons with mental illness have a significant AOD history and are generally willing to talk about it if you give them the time and space to do so. AOD treatment may be needed early in the course of mental
The role of family may be mixed; however, if a treatment provider can get a Release of Information to talk to family, it can be very informative. Family can provide a colorful history and useful information that can be used for treatment. Understanding that the mental health client wants to feel industrious and working as a consumer-as-professional may be a way to feel that they are contributing to the world and to themselves. The professional must be prepared to monitor medication because noncompliance, for many reasons, is rampant among mental health consumers.

Further research is needed on traditional mental health services vs. peer-run services; this research just scratches the surface, more is needed for clarification. Further research is needed on the link between mental illness and AOD usage, as this appears to be an ongoing issue for the population. Research concerning the influence of family members on mental health consumers’ compliance with treatment seems to be apparent here. Also, research on consumers-as-professionals and how they are influenced to become involved in those special programs, as well as the effects on their self-esteem deserve a further look.

On a personal level, this study has changed me. I had always thought that I really understood the lives of persons with mental illness because I worked with level every day. But I think it took related to these individuals on a more personal level to really understand what they go through and how difficult at times their lives can be. I believe that this will allow me to be more understanding, more patient, and more willing to help persons with mental illness than I was before. And I feel I will dedicate more time to advocacy for mental illness in the future.
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APPENDIX A

PARTICIPANTS INFORMED CONSENTS
A. PURPOSE AND BACKGROUND

Miss Harley in Ashland University’s Doctoral or Education Program is conducting a research study to help understand how individuals with mental illnesses view their peer-run and traditional mental health services. You are being asked to participate in this study because you utilize both of these services and can provide an unique perspective with regard to the research topic.

B. PROCEDURES

If you agree to be in the study, the following will occur:

1. You will be interviewed one or two times for approximately one hour each time.

2. One of your family members (of your choice) and one of your mental health workers (or your choice) will be interviewed one time for approximately one hour.

3. You, your family member, and your mental health worker will be asked to answer questions regarding your peer-run services and traditional services. In additional, all three of you will be asked questions about your mental illness, and other questions surrounding the topic of mental health.

4. All interviews will be audio-taped. These tapes will later be dictated.

5. All identities will be kept confidential. Names will be changed and all identifying information will be altered.

C. RISKS/DISCOMFORTS

Participation in the study will not cause any known medical or psychological harm. There are no direct benefits to you from your participation in this study.
1. It is possible that talking about your mental illness, or having your family member or mental health worker talk about your mental illness, may cause you some discomfort or upset. Crisis counseling will be made available for you if needed.

2. Some of the questions about mental health in general may be upsetting. You are free to decline from answering any question.

D. BENEFITS

The benefit to you from this study is that you will be able to share your story and have your voice heard. Additionally, the information you provide may help future mental health professionals understand the perceptions of clients.

E. COSTS
There will be no costs to you as a result of taking part in this study.

F. PAYMENT
You will not be paid to participate in this study.

G. QUESTIONS
You have talked to Miss Harley about this study and have had your questions answered. If you have further questions, you may call her at 419-747-0866.

If you have any comments or concerns about participation in this study, you should first talk with the researchers. If for some reason you do not wish to do this, you may contact the Human Subjects Review Board, which is concerned with the protection of volunteers in research projects. You may reach the board office between 8:00 and 5:00, Monday through Friday, by calling or writing Randy Gearhart, Chair, Human Subjects Review Board, 101 Gill Center, Ashland University, Ashland, Ohio, 44805. 419-207-5460.

H. CONSENT
You will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You are free to decline to be in this study, or to withdraw from it at any point. Your decision as to whether or not to participate in this study will have no influence on your present or future status as a [patient, student or employee].

If you agree to participate, you should sign below.
A. PURPOSE AND BACKGROUND

Miss Harley is in Ashland University’s Doctoral of Education Program is conducting a research study to help understand how individuals with mental illnesses view their peer-run and traditional mental health services. In addition, the study is interested in the family perspective of individuals who interact with family members who have mental illness. You are being asked to participate in this study because you are a family member of a person who utilizes both peer-run and traditional services and you can provide an unique perspective with regard to the research topic.

B. PROCEDURES

If you agree to be in the study, the following will occur:

1. You will be interviewed one or two times for approximately one hour each time.

2. You, your family member, and your family member’s mental health worker will be asked to answer questions regarding peer-run services and traditional services. In additional, all three of you will be asked questions about mental illness, and other questions surrounding the topic of mental health.

3. All interviews will be audio-taped. These tapes will later be dictated.

4. All identities will be kept confidential. Names will be changed and all identifying information will be altered.

C. RISKS/DISCOMFORTS

1. It is possible that talking about your family member’s mental illness may cause you some discomfort. Crisis counseling will be made available
for you if needed.

2. Some of the questions about mental health in general may be upsetting. You are free to decline from answering any question.

D. BENEFITS
The benefit to you from this study is that you will be able to share your story and have your voice heard. Additionally, the information you provide may help future mental health professionals understand the perceptions of family members of people with mental illness.

E. COSTS
There will be no costs to you as a result of taking part in this study.

F. PAYMENT
You will not be paid to participate in this study.

G. QUESTIONS
You have talked to Miss Harley about this study and have had your questions answered. If you have further questions, you may call her at 419-747-0866.

If you have any comments or concerns about participation in this study, you should first talk with the researchers. If for some reason you do not wish to do this, you may contact the Human Subjects Review Board, which is concerned with the protection of volunteers in research projects. You may reach the board office between 8:00 and 5:00, Monday through Friday, by calling or writing Randy Gearhart, Chair, Human Subjects Review Board, 101 Gill Center, Ashland University, Ashland, Ohio, 44805. 419-207-5460.

H. CONSENT
You will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You are free to decline to be in this study, or to withdraw from it at any point. Your decision as to whether or not to participate in this study will have no influence on your present or future status as a [patient, student or employee].

If you agree to participate, you should sign below.

__________________________________________________________
Date                              Signature of Study Participant
__________________________________________________________
Date                              Signature of Person Obtaining Consent
(Participant Informed Consent - Mental Health Worker)

“Perceptions of Mental Health Clients with Regard to Peer-Run and Traditional Mental Health Services”

A. PURPOSE AND BACKGROUND

Miss Harley is in Ashland University’s Doctoral of Education Program is conducting a research study to help understand how individuals with mental illnesses view their peer-run and traditional mental health services. In addition, the study is interested in the mental health worker’s perspective of individuals who interact with individuals who have mental illness. You are being asked to participate in this study because you are a mental health worker who works with an individual with mental illness who utilizes both peer-run and traditional services and you can provide an unique perspective with regard to the research topic.

B. PROCEDURES

If you agree to be in the study, the following will occur:

1. You will be interviewed one or two times for approximately one hour each time.

2. You, your client, and their family member will be asked to answer questions regarding peer-run services and traditional services. In additional, all three of you will be asked questions about mental illness, and other questions surrounding the topic of mental health.

3. All interviews will be audio-taped. These tapes will later be dictated.

4. All identities will be kept confidential. Names will be changed and all identifying information will be altered.

C. RISKS/DISCOMFORTS

2. It is possible that some of the questions asked you may feel breech confidentiality or answering may hurt your therapeutic relationship. You may simply decline to answer these questions.
D. BENEFITS
The benefit to you from this study is that you will be able to share your story and have your voice heard. Additionally, the information you provide may help future mental health professionals understand the perceptions of a fellow mental health worker.

E. COSTS
There will be no costs to you as a result of taking part in this study.

F. PAYMENT
You will not be paid to participate in this study.

G. QUESTIONS
You have talked to Miss Harley about this study and have had your questions answered. If you have further questions, you may call her at 419-747-0866.

If you have any comments or concerns about participation in this study, you should first talk with the researchers. If for some reason you do not wish to do this, you may contact the Human Subjects Review Board, which is concerned with the protection of volunteers in research projects. You may reach the board office between 8:00 and 5:00, Monday through Friday, by calling or writing Randy Gearhart, Chair, Human Subjects Review Board, 101 Gill Center, Ashland University, Ashland, Ohio, 44805. 419-207-5460.

H. CONSENT
You will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You are free to decline to be in this study, or to withdraw from it at any point. Your decision as to whether or not to participate in this study will have no influence on your present or future status as a [patient, student or employee].

If you agree to participate, you should sign below.

___________________________________  Date  Signature of Study Participant

___________________________________  Date  Signature of Person Obtaining Consent
APPENDIX B

INTERVIEW QUESTIONS
Interview Questions

Participants

1. What is your name?
2. What is your date of birth?
3. In what city do you live?
4. What mental health center do you use? Tell me about your services there.
5. What drop-in center do you attend? Tell me about your services there.
6. What is the nature of your mental illness? What is your diagnosis? How old were you when you were diagnosed?
7. As a person with mental illness, what has been your experience in interacting with society in general? Have you ever felt discriminated upon?
8. How do you feel about the deinstitutionalization movement?
10. What involvement do you have in mental health legislation?
11. Tell me about your experiences with traditional mental health services.
12. Tell me about your experiences with peer-run services.
13. Tell me how your family interacts with your mental illness.
14. What would you like people to know about persons with mental illness?
Interview Questions

Family Member

1. What is your name?
2. What is your date of birth?
3. What city do you live in?
4. Who is your family member with mental illness?
5. How long has your family member had mental illness?
6. How does the illness manifest itself?
7. What role do you play in your family member’s mental illness?
8. What value have you seen of traditional mental health services for your family member?
9. What value have you seen of peer-run services for your family member?
10. What effect did deinstitutionalization have on your family member?
11. What types, if any, of mental health legislation are you involved in?
12. Is burn-out ever a factor?
13. Have you seen your family member empowered to take charge of their own care? If so, how did that come about?
Interview Questions

Mental Health Workers

1. What is your name?
2. What is your date of birth?
3. Where do you work?
4. What is your position?
5. How long have you been in the field?
6. What degrees/licenses do you hold?
7. Who is the person with mental illness that you work with?
8. What is this person’s diagnosis? How long have they held this diagnosis?
9. What do you work on during your time together?
10. What value for this person do you see of traditional mental health services?
11. What value for this person do you see of peer-run services?
12. Tell me your concept of the disease model.
13. Did deinstitutionalization affect this person?
14. What types of mental health legislation are you involved in/aware of?
15. Tell me about the treatment collaboration within and outside of your agency.
16. How has this person’s mental illness affected the family?
17. How has this person been empowered in his/her journey through mental illness?
18. Tell me about the perceptions of your job? Are you satisfied? What about burn-out?
19. What role do ethics play in your job?
APPENDIX C

AUTHORIZATION FOR RELEASE OF INFORMATION
AUTHORIZATION FOR RELEASE OF INFORMATION

Regarding: [Client's Name]  [DOB]  [Last Name]  [Middle Name]  [First Name]

(Chose One)  [ ] To Release To:  [ ] To Request From:

To Exchange With:  [ ] Other:

[ ] To Request:  [ ] Organization  [ ] Individual:

Address:

City:  State:  Zip:

[ ] Current  [ ] Former

[ ] Phone:  [ ] Fax:

[ ] Communication

[ ] Narrative Summary

[ ] Psychoeducational Evaluation

[ ] Psychiatric Evaluation

[ ] Psychological Assessment

[ ] Progress Notes/Service Logs

[ ] Treatment Plan

[ ] Other:

I understand this information extends to all or any part of the records indicated above which may include treatment for psychiatric illness, alcohol and/or drug abuse, HIV test results, AIDS/AIDS Related Complex (ARC) diagnosis, and/or other communicable diseases, unless indicated below.

Exceptions or exclusions to information released:

Purpose or use for disclosure: To secure appropriate information from or release appropriate information to the above named person or organization to assist in treatment planning.

This consent (unless otherwise revoked earlier) expires (30) days from the date of authorization or if more than thirty days (check one): [ ] 90 days  [ ] 150 days  [ ] 180 days.

NOTE: This information has been disclosed to the party listed above from records whose confidentiality is protected from disclosure by State law, Section 3123.31 and/or Section 3701.24 of the Ohio Revised Code prohibits this party from making any further disclosure of it without the specific written and informed release of the person to whom it pertains, or as otherwise permitted by law. A general authorization for the release of medical or other information is NOT sufficient for this purpose.

I understand that the information disclosed is protected by law and may not be redisclosed without my written authorization, or as otherwise authorized by law. However, I understand that [ ] I and/or [ ] my family or [ ] my doctor(s) cannot control the recipient's use of the information. I hereby give my permission to release and/or obtain information about myself, my child and/or my family. Communication may be in writing and/or verbal.

[Client Signature]  [Date Signed]

[Parent/Legal Guardian Signature]  [Date Signed]

[Proxy to Client and/or Parent/Legal Guardian's Signature]  [Date Signed]

I have the right to stop this release of information at any time. Although I understand that I cannot rescind anything about information I presently said could be shared, I may want to review information shared and can withholding consent.

[Signature of Client/Parent/Legal Guardian]  [Date Signed]

visited 4/4/03
APPENDIX D

HUMAN SUBJECTS REVIEW BOARD APPROVAL LETTER
TO: Judie Harley
FROM: David Vanata, Chair
DATE: June 10, 2009
RE: Human Subjects Review Board Approval

On behalf of the Human Subjects Review Board, I have reviewed the research proposal you submitted. You may proceed with the project.

The primary function of the HSRB is to ensure protection of human research subjects. As a result of this mandate, we ask that you pay close attention to the fundamental ethical principles of autonomy, justice, and beneficence when establishing your research proposal. These ethical principles pertain specifically to the issues of informed consent, fair selection of subjects, and risk/benefit considerations.

If you have any questions, please contact me.

Sincerely,

David Vanata
Phone: 419-289-5292
Fax: 419-289-5333
E-mail: dvanata@ashland.edu