Walk A Mile In My Shoes: The Social Construction Of Mental Illness Among State Administrators And Consumer-Advocates

Paul Arthur Dragon
University of Vermont

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ABSTRACT

From 19th century insane asylums to state sponsored eugenic programs in the 20th century, the state has been an incongruous leader and provider of mental health policy and practice. Current practices that include such treatments as confinement, restraints, forced medication and electro-convulsive therapy continue to raise issues of social justice and humane treatment.

Since the 1970s a diverse group of consumers of mental health services from political and radical emancipatory movements to consumer and family initiatives have emerged to question, inform and influence federal and state policies and services. Today state administrators and consumer-advocates meet in formal settings in which they exchange ideas as they work to affect and develop mental health policy and practice. However, such exchanges have raised new questions regarding the relationship between these two groups and their ability, in light of past practices to effectively work together to develop mental health policy and practice.

The purpose of this study is to compare how state administrators and consumer-advocates perceive mental illness and how these perceptions impact policy and practice. Through a qualitative research study, the researcher compared and contrasted the perceptions of five consumer-advocates and five state administrators who are involved in major mental health policy in a rural state in order to consider how their perceptions of mental health affect policy and treatment.

This study shows an emerging relationship between state administrators and consumer-advocates but a relationship that lacks communication and trust as their discourse attempts to span the gap between their two symbolic universes. The focus of consumer-advocates on the importance of their role in battling pervasive stigma and the need for people with lived experience to be central in the mental health system can be seen as an effort to overcome a historical pattern of coercion and abuse of mental health patients by the state. The focus of state administrators to remain relevant in a mental health system in which consumer-advocates challenge the status quo can be seen as their effort to retain legitimacy as well as their historic control over the mental health system.

State administrators and consumer-advocates know that they exist in a new, shared world of mental health care and both groups agreed that the relationship between them needs to improve.
DEDICATION

This paper is dedicated to my late mother Ruth Stevenson-Dragon.
ACKNOWLEDGEMENTS

I want to express my deepest appreciation to Dr. Judith Aiken and the faculty at the University of Vermont’s School of Education, my sisters Cheryl and Donna who have always been there for me and especially to my wife Julie and daughters Eleni, Anastasia and Katya who help me to be a better person.
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CHAPTER 1: INTRODUCTION

We must try to return in history to that zero point in the course of madness at which madness is an undifferentiated experience...We must describe, from the start of its trajectory, that “other form” which relegates Reason and Madness to one side or the other of its action as things henceforth external, deaf to all exchange, and as though dead to one another. (Michel Foucault, *Madness & Civilization*, 1973 p. ix)

This study explores how perceptions of mental illness among state administrators and consumer-advocates affect current policy and practice as they work together in light of their historically asymmetrical relationship. The purpose of this study is to explore with a sample of state administrators and consumer-advocates how each group perceives mental illness and how these perceptions impact policy and practice. Consumer-advocates are defined as those individuals who have experienced or are experiencing a mental health condition and who are working formally or informally with state administrators on issues of mental health policy and practice. State administrators are defined as those individuals who are working or who have worked as top-level mental health administrators in state government. It was anticipated that the knowledge generated from this research would provide new insights and so inform how these two groups can best work together to enact mental health policy and practice. This research employed a phenomenological framework with qualitative research techniques and, in particular, semi-structured interviews to illustrate the phenomenon being examined. In this study purposeful, criterion sampling was used to select five state administrators and five consumer-advocates for a total of 10 participants.
Chapter 1 is an overview and background including the historical context that frames the study. Following this overview the problem statement, the statement of purpose, and accompanying research questions are presented. Also included in this chapter is discussion regarding the research approach, the researcher’s perspective and assumptions. This chapter concludes with a discussion of the rationale and significance of the research study and definitions of the key terminology used.

**Background and Context**

It is widely accepted that perceptions of mental illness have changed throughout history and vary according to socio-political, economic and cultural conditions. Indeed, as Foucault points out there is some point in our human history when there was no distinction or definition separating reason from “madness” (Foucault, 2006). However, very early on in Western European history, governing authorities began to separate reason from unreason and to define what it considered to be insanity from sanity and began, with unprecedented power, to control and treat those considered to be insane or mad. The state often resorted to coercion and violence to enforce the separation of the sane from the mad including the use of electro-shock, waterboarding, lobotomies, sterilizations and other methods, still prevalent today, such as forced medication, involuntary restraints, separation and seclusion (Whitaker, 2002).

Consumer-advocates have only recently emerged as a force in mental health policy and treatment. Since the 1970s a diverse group of consumers of mental health services from political and radical emancipatory movements to consumer and family initiatives began to question, inform and influence federal and state policies and services.
Consumer groups surfaced as a reaction to a history of formalized mental health treatment and the prior experience of coercion, abuse and victimization by the professional system. Consumers brought first-hand knowledge and experience of their treatment with an alternate and powerful way of providing services and supports in the community. Consumer-run groups empowered people with self-management tools based on empathy, peer identification and shared experience (Chesler, 1990; Christensen & Jacobson, 1994; Constantino & Nelson, 1995; Emerick, 1990; Gartner & Riesman, 1993; Hardiman, 2004). “It’s a thrilling time, because people with lived experience are beginning to collaborate in large numbers. They are developing their own theories, their own language about what their experiences means from the inside” (Hornstein, 2009, as cited in the New York Times, November 26, 2011).

Since national health care reform and the push for self-determination, the discourse between consumer-advocates and state administrators has converged over important policy issues like the de-institutionalization of state mental health hospitals (Zeman & Swanke, 2008). Today these two groups meet to discuss mental health services in formal and informal settings in which they exchange ideas and perceptions of mental illness and work to affect and form mental health policy and services. However, such exchanges have raised new questions regarding the relationship between these two groups and their ability to establish shared values and goals and a common understanding of what constitutes socially just treatment and policy.

In other words, how do consumer-advocates and state administrators communicate across this historical boundary in which, on one side, state administrators
have held the power and helped define sanity itself; while patients or consumers, on the margins of society, have been left and labeled with insanity? Paolo Friere (1970) reminds us that each relationship is inherently reciprocal, and that “dehumanization marks not only those whose humanity has been stolen but also those who have stolen it” (p. 26). In light of their past relationship, can state administrators and consumer-advocates effectively work together to develop mental health policy and practice? How does each group understand, think and feel about their current role and relationship in light of their tangled, imbalanced but intimate history?

Research comparing the viewpoints of state administrators and consumer-advocates is important. How mental illness is defined and treated has economic, cultural, political and moral significance for society. Today, what is medically and socially considered to be a mental illness is determined by the American Psychological Association (APA) through a system of diagnosing, with diagnoses continually being changed, eliminated, or added over time. The number of mental illness diagnoses have consistently increased from the APA’s first publication of the Diagnostic Statistical Manual (DSM I) in 1952 to the DSM V, recently completed in May 2013. The DSM has become the instrument for how society views normal and abnormal mental capacity and therefore who has access to treatment. It also determines how mental health providers and pharmaceutical companies are reimbursed. On the other hand, some consumer-advocates reject the DSM as labeling and categorizing people based on the perception of what professionals in the mental health field consider being normal. For them the DSM leads to stereotyping, stigma and self-fulfilling prophecy (Corrigan, David, & Hector, 2011).
For example, Corrigan and colleagues reported the loss of self-esteem and efficacy that occurs when an individual internalizes prejudice and discrimination.

For this study, I chose state-level administrators as one group for study because of the historic power the state has held in the field of mental health and the incongruous role it has played over the lives of people with a mental illness from 19th century insane asylums to state sponsored eugenic programs in the 20th century. Current state sponsored practices like seclusion, restraints, forced medication and electro-convulsive therapy continue to raise questions regarding medical value and ethical treatment. I chose consumer-advocates as another group to study because of their radical and liberatory history, and how they currently work within mainstream settings, typically dominated by state-level policies. The study evokes several important questions: How do consumer-advocates overcome this history of marginalization and navigate the asymmetrical relationship between themselves and state administrators? How can these two groups given their shared yet divergent histories communicate and work together? How do they each perceive mental illness and what ways do these perceptions inhibit or recover any historical distance that lay between these two groups?

There are currently two dominant paradigms in which to view mental health policy and treatment. Many consumer-advocates see mental illness through a social framework or lens that raises issues of identity and stigma, consumer rights, and social justice (Bassman, 2005; Castillo, 1997; Corrigan & Watson, 2006; Goering, Durbin, Sheldon, Ochoka, Nelson, & Krupa, 2006; Taylor, 2006; Thornicroft, 2006; Townley, Kloos, Green, Margarita, & Franco, 2011). In contrast, there is evidence that many
mental health administrators and mental health providers are more likely to view mental illness through the lens of the currently dominant medical model of mental illness rather than a social framework (Bassman, 2005). There are minimal and stronger interpretations of the medical model but the underlying approach of the medical model sees mental illness as an individually based neurobiological disease which can be approached, assessed and treated like other chronic health conditions such as diabetes and asthma. Proponents claim that the medical model normalizes mental health and reduces stigma by making it just another health condition. Furthermore, there are adherents of the medical model who argue that people who think that mental illness takes place outside of the individual as a product of social forces are placing clients in danger by employing philosophy over science and discouraging standardized diagnostic assessments, medication and other forms of medical treatment (Taylor, 2006).

There are those, including educators, social workers, as well as many consumer-advocates, who challenge this neurobiological approach to mental health claiming that it pays too little heed to the historical, cultural and philosophical dimensions of mental illness (Eisenberg, 1988). They do not accept mental illness as a completely objective phenomenon and question the implied truths of the medical model. They consider how economic, social, political, symbolic capital might interpret and construct the way we think about mental illness and how these interpretations, over time, become normative. It is in the space between these two dominant paradigms that varied perceptions about mental illness emerge to affect policy and treatment. This research explores these two dominant paradigms and how they may inform both the shared and varied perceptions of
state administrators and consumer-advocates. Figure 1 depicts a hypothetical model based on my professional experience and a review of the literature.

![Figure 1. Hypothesized Conceptual Model Relating to Perceptions of Mental Illness](image)

It should be noted that although this study looks at mental illness from a biological and social perspective it is not concerned with the etiology of mental illness but rather how mental illness is defined and interpreted by these two groups and how these perceptions affect policy and services.

**Problem Statement**

Research indicates a historical pattern of state government control and abuse over those considered to be mentally ill. In addition, the literature describes the emergence of people with lived experience, who, in their role as consumer-advocates, are now called upon by some states as well as the federal government to play a role in shaping mental health policy and practice. There is little to no research comparing the perceptions of
mental illness among state administrators and consumer-advocates and how these perceptions affect the way these two groups interact to develop policy and practice.

**Research Purpose and Questions**

The purpose of this phenomenological research study is to compare how five state administrators and five consumer-advocates perceive mental illness and how these perceptions impact policy and practice. To explore and illuminate the research problem, the following research questions were developed to guide the study:

1. How do state administrators and consumer-advocates perceive their role and the role of each other?
2. What are the perceptions of state administrators and consumer-advocates regarding the existence and causes of mental illness? How are they similar and how do they vary?
3. What are the perceptions of mental illness as a problem among state administrators and consumer-advocates? How are they similar and how do they vary?
4. What strategies do state administrators and consumer-advocates propose for treating mental illness? How are they similar and how do they vary?

**Research Methodology**

With the approval of the University’s Institutional Review Board (IRB), the researcher studied the perceptions and experiences of five state administrators and five consumer-advocates. By using a qualitative approach, the researcher compared and contrasted the perceptions of five consumer-advocates and five administrators who are
involved in major mental health policy in a rural state in order to consider how their perceptions of mental illness affect policy and treatment. A qualitative methodology was used as it is effective in discovering the “subjective understanding, interpretation, and meaning of social behavior” (Curry, Jiobu, & Schwirian, 2002, p. 18).

In depth, semi-structured interviews were the primary method of data collection in order to learn from these two groups in their own voices how they each perceive mental illness and how they each approach policy and decision-making. This type of interview was best suited to compare and contrast perceptions of mental illness and how these perceptions might interact to inform policy and practice. Edward Husserl (1932) and other phenomenologists used in-depth interviews early on to understand complex social issues (Husserl). Semi-structured interviews are also a way to get at the many sides or perspectives of truth (Crabtree & Frey, 2005; Karner, 2005; Marshall & Rossman, 2010; Patton, 2002). The semi-structured interview was set within a framework of themes that allowed me to tailor questions to the interview context, situation and people being interviewed. Coding categories were developed and refined on an ongoing basis guided by the study’s conceptual model.

The conceptual model in Table 2 depicts how each of research questions framed and informed the coding and findings.
Table 1

**Conceptual Model as a Working Tool**

<table>
<thead>
<tr>
<th>Perception of the other groups role and effectiveness</th>
<th>Positive Perception</th>
<th>Neutral Perceptions</th>
<th>Negative Perception</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perception of the existence of mental illness</td>
<td>Similar Perception</td>
<td>Mixed Perception</td>
<td>Different Perception</td>
</tr>
<tr>
<td>Perceptions of mental illness as a problem</td>
<td>Not a problem</td>
<td>Somewhat of a problem</td>
<td>A significant problem</td>
</tr>
<tr>
<td>Strategies for treatment mental illness</td>
<td>Primarily the same strategies</td>
<td>Somewhat mixed strategies</td>
<td>Different strategies</td>
</tr>
</tbody>
</table>

Each interviewee was identified by a pseudonym, and all interviews were tape recorded and transcribed verbatim. I attended meetings between state administrators and consumer-advocates to collect data through my role as an observer. I used document review including policies and newspaper articles to understand how perceptions are codified and transmitted to the public. The overall approach to this research is phenomenological as it seeks to get at the lived experience of state administrators and consumer-advocates. By telling and sharing stories through interviews this study created a space for state administrators and consumer-advocates to strengthen their purpose, efficacy and leadership while fostering dialogue, understanding and discussion between both groups (Dillard, 1995).

**Researcher’s Assumptions**

Based on the researcher's professional experience as a manager working with both the state’s mental health system and the substance abuse programs for nearly two years, two primary assumptions were made regarding this study. These assumptions are formalized in the Hypothetical Concept Model (Figure 1). First, state administrators and
consumer-advocates have different perceptions of mental health. This assumption is based on personal observation during meetings with state administrators and consumer-advocates as well as research that shows that consumer-advocates are more likely to take a social perspective of mental health. A second assumption is that the strategies among state administrators and consumer-advocates for assisting people with mental health issues are likely to diverge. This assumption is based on the literature cited in this study that shows that the consumer-advocate movement has emerged in response to a long history of state control and a perceived need for more consumer driven services.

Before this research I had both professional and personal experiences with mental health issues. I worked for two years from 2009 to 2011 as the Chief of Integrated Services for the State’s Department of Mental Health where I was responsible for integrating the policies and practices of the State’s mental health and substance abuse systems. Part of my job was to develop and convene a large steering committee that included state administrators, consumer-advocates and nonprofit community mental health administrators who would focus on the program’s implementation. During this time I had an opportunity to see and listen as state administrators and consumer-advocates discussed policy issues with each other and within their own group.

As part of my work I had decided early on to build on the recent attempts in the mental health field at both the federal and state level to increase consumer involvement. This included involvement in the design and delivery of co-occurring mental health and substance abuse services. During this time I observed and participated in discussions on policy and practice that led me to hypothesize that consumer-advocates and state
administrators approached issues of mental health differently and that these differences might be due to varied and deeply rooted perceptions of mental health which made it difficult for these two groups to share a common vision for mental health policy and services. This hypothesis was based on informal and unstructured conversations with each group as well as periodically tense discussions during structured meetings with administrators and consumer-advocates. This insight did not emerge for me as a hypothesis until I considered this research study and reflected back on my work between these two groups. It was only in reflection that I considered how strongly consumer groups felt about consumer led services along with their seeming distrust of traditional treatment services and how state mental health administrators seemed biased toward traditional treatment services and guarded in discussions with consumer-advocates. I began to realize how much mediation, accommodation and compromise actually went into my work when addressing the varied positions and perceptions of these two groups.

Based on these observations, I wanted to follow up on my experience and inquire more deeply into how history, identity and roles might influence perceptions and how the boundaries of identity, power and perception might be eased and overcome. In this next section I share personal narratives, drawing from my experiences.

The Researcher: My Place in the Study Through Personal Reflection

Be prepared to respond to concerns about the natural subjectivity of the researcher shaping the research. Again, the researcher should assert the strengths of qualitative methods by showing how she will develop an in-depth understanding of, even empathy for the research participants to better understand their world. (Marshall & Rossman, Qualitative Research, 2011, p. 253)
Professional Position August 18, 2008: One day, within my first two weeks on the job in the Department of Mental Health, I was walking through the tunnels underneath the State Hospital where there is the discomforting smell and sense of being underground. Each side of the narrow corridor is lined with small 12 feet by 12 feet rooms. The rooms have shiny new pad locks and some have technical names like “Number 4 Dispersal Pipe.” Nobody needs to tell me the history of these rooms or what they were used for. You see them and you understand.

My colleague, the Chief of Substance Abuse Services for the State, was leading me to the cafeteria. He is tall and lowers his head so he does not hit the collection of sagging wires, wrapped in duct tape, running the length of the ceiling. Remnant strands of hair cover his head and his eyes and shoulders droop at the same angle perhaps from the weight of 30 years of work in the field of addiction. He knows something about the history of the hospital. As he shared, “There are hundreds of yards of tunnels. They used to move people from building to building through these tunnels so the people in the town didn’t have to see them. There were over 1500 people here up to the 1960s.” Then, in 2009, there were approximately 60 patients. It is hard not to feel uncomfortable your first time in the tunnels. My colleague asked: “Did you know they built most of the state hospitals on hills because they thought the germs would be carried away by the wind? Go to a state hospital in any state and most likely it’s built on a hill.” The state hospital discussed in this study was not on a hill but rather at the western edge of the town, next to a large river, in a flood zone. Indeed, as we stood in this facility, a hurricane, moving up from the south, would soon flood and all but destroy this century old complex.
Personal Experience, 1972: In addition, to my professional experience, I also had personal experiences which inevitably inform my approach to this research. I grew up in Cranston, Rhode Island, home to one of the largest state hospitals in New England. It is a mid-19th century structure, vast and stony. Growing up, the hospital and prison were repositories for our fears. It was the frontier, another world where anything could happen, where chaos was the norm. We did not need the Grimm brothers to tell us scary fairy tales because our parents had the real thing right next door and could be heard telling their misbehaving kids: “You don’t want to end up there do you?” All of us know what they meant by “there.”

One day as a child, we drove down the avenue past the hospital which peers down at us from on top of the hill. It has large porches sticking out from its sides. They are encircled by metal poles giving them the appearance of immense bird cages. My father was driving. My sister and I look out the window and she points to a dozen people dressed in light, feathery hospital clothes. They are surrounded by a gelatinous and slowly twisting cloud of cigarette smoke. They shuffle and gesture reminding me of a flock of pigeons who expand and contract according to some hidden rhythm or ancient geometrical pattern when my sister says; “Hey, I think I just saw mom.”

My interest in this research is shaped by my professional and most importantly my personal experience as I consider how my mother’s mental illness and her frequent hospitalizations that informed my childhood and continues to influence who I am as a person and as a researcher. I have had until recently a one-dimensional view of my mother, finding it difficult to see past the pain and unhappiness of her life. Recently I
began to reinterpret and reconstruct my perception of her mental illness to form a deeper understanding of what I at one time considered to be a weakness or a failure. There is evidence to show that under difficult life conditions, when the oppressed have little hope of reversing a relation of dominance, resistance expresses itself in non-normative ways and manifests itself through behaviors of crime, deviance, and mental illness (Geiger, 2005). I have recently begun to hypothesize that this period in my mother’s life was a resistant strategy to emotional abuse at home – an abuse that was reinforced by a hegemonic and patriarchal society more evident in the 1970s. I began to consider my mother’s resistance in light of my hypothesis of the varied and perhaps conflicting perceptions among consumer-advocates and state administrators. Because of this personal experience, I considered how the voices of consumer-advocates manifest and evolve over time to become part of the dialectical process in which advocates and rebellious voices emerge from the margins of society to challenge and influence mainstream, traditional treatment systems. I became interested in how consumer-advocates might work with and even resist state administrators.

Recognizing and acknowledging the resistance to power, whether passive or overt, by vulnerable and marginalized groups in our society may assist, not only with the liberation of suppressed knowledge, but the creation of socially just and liberating policies. A reinterpretation of non-normative behavior of disadvantaged populations may guide us in the attempt to create models of change to address institutionalized oppression of all kinds (Geiger, 2005). In this way my mother’s story and my personal experience
and perceptions of mental illness has, at its best, informed my purpose behind this research (Dillard, 1995, p. 58).

I acknowledge that these professional and very personal experiences that informed both my purpose and insight might also serve as a liability, biasing my judgment in both the design of the study and the interpretation of the findings. In addition to the research, literature review and the theoretical orientation, I remain committed to critical self-reflection by way of dialogue with colleagues and advisors. Also, other more structural precautions to guard against bias have been taken such as the triangulation of data and inter-rater reliability checks with colleagues.

**Definitions of Key Terminology Used in this Study**

It is important to define several of the terms unique to this study and the institution and state in which it resides.

- **State Administration/Administrator**: The government agency or official who oversees and enforces State-level regulations regarding mental health services. Mental health legislation under Title 18, which guides the State in setting mental health laws. The state administrator's job is to oversee and enforce this law.

- **Consumer-advocates**: For the purposes of this study, the terms consumer-advocate, survivor and peer, as well as the meanings and standpoints they may represent are not considered reified categories but as the lived experience of people who define themselves in those roles in relation to each other and the mental health system (Morrison, 2005).
- **Consumer**: A person who accesses psychiatric services and may have been given a diagnosis from the *Diagnostic and Statistical Manual of Mental Disorders*.

- **Survivor**: Self-identifies as having survived psychiatric intervention and the mental health system (which may have involved involuntary commitment and involuntary treatment (Corrigan et al., 2011).

- **Psychiatric survivors movement**: (more broadly the consumer/survivor/ex-patient movement) actively campaign against their diagnosis, or its assumed implications, and/or against the DSM system in general.
CHAPTER 2: LITERATURE REVIEW

Is it not by confining one’s neighbor that one is convinced of one’s own sanity? (Fyodor Dostoevsky, A Writer’s Diary as cited in Author, 1965, p. 9)

The departing point for this study is that mental illness is not an objective phenomenon or thing-in-itself that is determined solely by its intrinsic nature. This study maintains that regardless of etiology people have varied perceptions of mental illness resulting from social, cultural, historical and economic factors that define and influence what society considers being a mental illness (Eisenberg, 1988). It is the perceptions among these two important and influential groups of state administrators and consumer-advocates that I will explore in this study.

Prior research in areas of mental illness and those informing it such as phenomenology, ontology and language are valuable for framing and informing this study. The specific areas of the literature most applied in this study Include: a) the definition of mental illness; b) the prevalence of mental illness; c) understanding mental illness as a social condition; d) the role of the state and the medical model in the policy and treatment of mental illness; and e) consumer involvement in mental health policy and services.

Together, these areas of literature provide a theoretical base and conceptual framework to explore and better understand how state administrators and consumer-advocates perceive mental illness and how these perceptions inform their ideas, policies and practice. By considering the ways in which mental illness may be socially constructed among state administrators and consumer-advocates we can understand how,
“the values and behavioral norms of the group become the background against which individual decisions about behavior, values, and attitudes are taken” (Chickering, 1969, p. 153). In addition, by critically examining the range and diversity of literature and voices that discuss how mental illness is defined and implemented, we can liberate the dialogue and foster democratic and more open communication within mental health policy and services.

**Defining Mental Illness**

The idea of mental illness has a long history and how it is defined and explained has varied throughout time and from culture to culture. How each culture perceives or constructs mental illness depends on their worldview. All societies seem to recognize abnormal and irrational behavior as some form of “madness” or mental illness. However what is accepted in one culture may not be tolerated in another. Hallucinations among Siberian Eskimos and fears of persecution among the Dobu are considered acceptable in those societies while they are seen as symptoms of mental illness by Western standards (Ackerknecht, 1968; Conrad & Schneider, 1992; Kiev & Francis, 1964; Rosen, 1968; Rothman, 1971; Scull, 1975; Szasz 1970; Szasz 1976). In the West, notions of madness or deviant thinking gradually turned to pathology, diagnosis and illness over several millennia of western culture and social development (McLeod & Wright, 2010). How mental illness came to be defined and interpreted would determine how people with a mental illness would be treated and thereby begin a long and tragic history of prejudice and persecution.
In ancient times, among the Hebrews, madness was considered uncontrolled and unreasonable behavior that might have both redeeming and less reputable qualities. Some deviant behavior served a prophetic role in which revered prophets imagined and expressed abnormal behavior while other deviant behavior was seen in the context of divine retribution in which the person was being punished. In ancient times, madness depended on the role and message being attributed to the deviant person as well as the perception of those around the deviant person (Rosen as cited in McLeod & Wright, 2010, p. 37).

The medical model has its roots in classical Greece and Rome where it was adopted by the educated upper class who, drawing upon concepts of rationality, saw madness as disease rather than within the generally accepted religious-cosmological framework. Romans introduced treatments which included a form of “electroshock” and restraints along with games, recreation and mental exercises which are all forms of treatment that continue in some context today. During this period Roman law asserted the power and responsibility of the state into what used to be a family matter by imposing legal restrictions on the mad and forbidding them to marry or acquire property (McLeod & Wright, 2010).

The fall of Rome led to resurgence in theology in which madness was framed by dogma within the Christian Church. Physicians were as likely as theologians to agree that mental illness was caused by God or the Devil and this eventually led to the tragedy of the inquisition that culminated in the publication of the Malleus Maleficarum (Hammer of Witches) in 1487 by two Dominican monks, Johan Sprenger and Heinrich Kramer. For
the next 200 years across Europe half a million, people mainly those who were considered mad, were punished and killed as witches (Neaman, 1975; Zilborg, 1941).

Prior to the 17th century, madness was not hidden from the public or subject to state control; however, as capitalism was emerging as the dominant economic and social model of the period, the “great confinement” of the poor and deviant began with the construction of institutions built to remove the mentally ill from the public view. These institutions also doubled as cheap, readily available labor for the wealthy (Foucault, 1965). To ensure work productivity the mad were eventually separated from the poor to protect the poor from “contagion.” Institutions began to specialize in madness giving rise to the mad house which became a lucrative business run not for medical reasons but for economic reasons (Foucault, 1965; Scull 1989). By the 18th century physicians became the gatekeepers to the madhouse providing an economic windfall to the profession even as treatment in these facilities was rudimentary, antiquated and often cruel. It was not until Phillipe Pinel’s Treatise on Insanity in 1801 that discussion of a humanitarian and moral approach was brought to the treatment of the mentally ill (Skull, 1975).

19th Century America saw the growth of the institutionalization of the mentally ill with the development of insane asylums. The legitimacy of state control and confinement of the insane was rooted in English Law which included the state’s role in ensuring peace and the public welfare along with parens patria or guardianship of a person who is declared incompetent. Gradually the asylum-building movement in the United States moved from a morality and punishment approach to a belief that, with the right environment and treatment, insanity was curable (McLeod & Wright, 2010). This state
control and development of asylums became intertwined with the medicalization of mental illness and the rise of American Psychiatry. American Psychiatry successfully lobbied for their own formalized training, approach and specialized treatment of the mentally to the exclusion of all other fields ensuring the control and prosperity for their profession (Grob, 1970).

By 1955 psychotropic drugs began to revolutionize mental health services with the introduction of major tranquilizers to treat psychotic illnesses. Pharmaceutical organizations aggressively marketed drugs like Thorazine, Resperine and hundreds of other psychotropic drugs to state legislatures and state mental health administrators for use in state mental health hospitals as a way to calm patients (McLeod & Wright, 2010). Psychotropic drugs were now widely used throughout the state mental health system as well as outpatient services and the symbiotic connection between psychiatry, pharmaceutical companies, mental illness and capitalism was complete.

For Western culture and history, defining mental illness is a dialectical process in which definitions have changed over relatively short periods of time to determine who is and who is not mentally ill and what illnesses will be covered by health insurance. Current psychiatric practice is guided by the Diagnostic and Statistical Manual of Mental Disorders (DSM), (1952), developed by the APA. The recently issued DSM 5th (2013) edition makes controversial revisions in the definition of depression, eliminating the long-standing bereavement exception for diagnosing a major depressive disorder. Proponents of the exception claim that this bereavement after a death or tragedy is normative while opponents claim that major depression and bereavement have the same
symptomology and should not be treated differently. Does bereavement have a different value or usage than depression in other circumstances? To answer this is to assume that the definition of mental illness can fall into both the empirical and moral domains suggesting, if not concluding, that mental health definitions are not free from perceptions and competing judgments (Gutting, 2013).

Foucault (1961), in his critique of modern society, claims that defining mental illness is less about scientific validity than it is about moral judgments often couched in terms of positivism and humanism that ultimately lead the "mentally ill" to "moral imprisonment." Perhaps there is no better example of Foucault’s critique regarding the subjectivity and moral assumptions in defining mental illness than the long-standing inclusion and subsequent removal of homosexuality from the DSM. In 1973, the empirical evidence, changing societal norms, and the political and monetary influence of the gay community overturned the establishment view that pathologized homosexuality. This insurgence led the APA to remove homosexuality from the DSM II (1968). A fierce counter-reaction from psychiatrists led to a new diagnosis, ego-dystonic homosexuality, which was introduced in the DSM III in 1980. This new diagnostic category was criticized by many as nothing more than a political compromise than any kind of science and resulted in the removal of the diagnosis from the DSM in 1986 (APA, 1974; 1975; 1987; Bayer, 1987; Berube, 1990; Boswell, 1980; Coleman, 1982).

Today, mental illness has emerged not only as a definition but as a branch of medical science which addresses the classification, incidence and control of disease in a population. While psychiatric epidemiology presupposes that mental disorders are
objective, discreet realities that can be identified, measured and treated, there are also
those taking a philosophical view of mental illness. These researchers call into question
any measurement particularly categorical assessments that make yes/no decisions on the
existence of a mental illness (Kesslar, 2002).

The philosophy of mental illness, also called the philosophy of psychiatry, is an
emerging field that raises these conceptual issues and unpacks the assumptions on which
mental health assessments and treatment are based (Banner & Thornton, 2008; Thornton,
Shah, & Tomas, 2009). The philosophy of mental health asks questions about how mental
illness is defined and by whom. These are the same empirical questions at the heart of
psychiatric taxonomy but seen through a different lens. A philosophical or conceptual
view of mental illness helps us understand how to approach mental illness and critique
the prevailing definition, values, laws, policies and practices on which medical treatment
for mental illness is based (Banner & Thornton).

The anti-psychiatry movement, largely fueled by the consumer movement,
emerged in last quarter of the 20th century to undermine any definition of mental illness
and pose the conceptual question by asking if mental illness is more myth than reality.
Their claim was that unlike physical illness, which can be treated medically, mental
illness can only be treated as non-medically treatable life problems (Banner & Thornton,
2008). The psychiatrist Tomas Szasz, one of the leaders of the anti-psychiatry movement,
claimed that psychiatric diagnoses are evaluative judgments rather than objective reality
and therefore preclude the need for anything that approximates diagnosis or medical
treatment (Szasz, 1970). For Szasz and others like him, there is a clear distinction
between physical and mental illness. He argues that just as physical illness is a deviation from the structural or functional integrity of the body; mental illness is a deviation from psycho-social, ethical and legal norms of society (Szasz, 1970b). Since psychiatry was an essentially evaluative function for Szasz, he concluded that mental health was more a discussion about human values rather than science. Today, however, workers in the mental health field, including social constructionists, must use the framework and the accepted definitions within the DSM along with the prevailing policies and programming if they are to be reimbursed for their services.

This is not to say there is no value to psychiatry, diagnosis or medication but it may lead us to be skeptical as there have been a myriad of changes in approach and treatment to mental illness from antiquity to modern times. In addition, the relatively recent examples of changing, adding or retracting diagnoses cited in this study provides little assurance that the definition of mentally illness can be free from subjectivity and judgments that are based on morality, economics and politics.

The Prevalence of Mental Illness

Social constructionists claim that the definitions and categorizations of mental illness are social products rather than objective realities and therefore do not necessarily represent human experience. On the other hand, those working within the medical model claim that it is possible to categorize those who have a mental illness from those that do not using specific definitions and well developed screening and assessment tools. Today, researchers rely on surveys of the general population to understand the rates or prevalence of mental illness in the general population and how many people who are
identified actually seek treatment (McLeod & Wright, 2010). Categorization for what is considered to be abnormal has a history reaching back to Roman law which included statutes that governed how the mentally ill were to be treated (Eaton, 1980). Throughout the history of mental illness people who did not conform to accepted norms were categorized mad, lunatic or Idiot. Today the APA’s publication of the fifth edition of Diagnostic and Statistical Manual places people into nearly 250 categories of mental illness (Bromet, Dew, & Schulberg, 1986).

How mental health conditions are measured in society is a source of controversy because of the technical issues like testing instruments, surveys and nomenclature as well as the existential issues regarding the nature of mental illness and what it means to be rationale and normal. Psychiatric epidemiology is a branch of medical science which addresses the classification, incidence and control of disease in a population. Psychiatric epidemiology using population based surveys looks at overall prevalence as well as subpopulations that might be at greatest risk. These surveys asking people about particular symptoms help to influence how leaders think about mental health policy and treatment. Understanding these surveys’, including their strengths, challenges and biases, is important to understanding how perceptions are formed and manifested among state administrators and consumer-advocates (Ross, Mirowski, & Goldsteen, 1990).

Psychiatric epidemiological research has had three evolutionary phases that move from an emphasis on the individual’s personal history to population based surveys. The first period ranging from 1890 to 1950 relied on key agency records, key informant interviews and direct interviews with patients. The second period from 1950 to 1980
relied on direct interviews which were bolstered by the U.S. Army’s use of the Neuropsychiatric Screen Adjunct (NSA) that was developed to screen out people with psychiatric impairment from entering the army. The third period from 1980 to present relies mainly on self-reported surveys with computer assisted statistical analysis (Dohrenwend & Dohrenwend, 1974). The first two periods were more concerned with disorder and impairment while the third mainly focuses on diagnosis.

One of the primary limitations of mental health studies in the first phase was due to prevalence estimates being based only on those who were treated. Projections based on treatment rates were then made to estimate prevalence across the population. It is now well known that most people never seek mental health treatment which means any estimates during the first phase would be underestimated (Dohrenwend & Dohrenwend, 1990).

Second phase studies were enhanced by community samples using probalistic sampling methods and direct interviewing. This method was more broad based and cost effective using screening tools that could be done by non-clinicians. However, there were considerable issues in the second phase studies particularly in regards to validity as not all diagnostic categories were addressed nor were the co-occurrence and interaction between substance use and mental illness considered. There were also additional validity concerns in this phase based on the large discrepancy of psychiatric disorders between countries. Research pointed out the error and potential negative consequences of different tools in studies between countries that showed great disparity in prevalence. For example, research in Britain showed nearly 20 times the rate of manic-depression as compared to
the US (Kramer, 1961). However, this variation was produced by different tools and methods of diagnosis and later discounted when the same assessment tool was administered in both counties revealing very little cross national differences (Cooper et al., 1972). The fact that different diagnostic tools led to different rates of prevalence in populations and across populations led to a search for reliable tools for epidemiological research. It also led to several major revisions of the DSM with increasing detail and specificity in regards to diagnostic categories.

The third phase of diagnostic tools included the development of tools particularly designed for epidemiological research. Today there are a large number and variety of assessments used for population-based research. A challenge involved in any methodology is often one of competing definitions of what a mental illness is and the variety of tools used to extract prevalence within a community. One definition or one tool may be preferred by a medical doctor, another by a social worker and yet another by a psychologist (Leighton, Harding, Macklin, Macmillan, & Leighton, 1963; Srole, Langner, Michael, Opler, & Rennie, 1962).

Mental health measures used for epidemiological research are divided into dimensional and diagnostic screening tools. There is ongoing debate regarding the advantages and disadvantages of these tools which is relevant to this study. Proponents of the diagnostic measures point to its clarity and consistency while proponents of dimensional tools argue that the medical community is motivated by status and funding to maintain the preeminence of the medical model. Diagnostic tools favor the medical approach and are based very closely on the DSM. Proponents of the diagnostic approach
argue that it is more precise, outcome focused and is necessary for insurance reimbursement and concomitant services. Those favoring dimensional tools claim that the diagnostic approach is overly prescriptive by taking a too narrow biological and disease focused approach. According to the social constructionists, the diagnostic approach disallows the potential that mental illness comes in degrees and is not either entirely present or absence but rather exists along a continuum. Dimensional tools, in contrast, provide information about an individual’s relative symptoms and look at mental health along a continuum of wellness rather than making simple yes or no decisions, as the diagnostic tools do, on a particular diagnosis like depression. Both measures, diagnostic and dimensional, are subject to concerns of both validity and reliability (Mirowsky & Ross, 1989; Robins, Wing, Wittchen, Helzer, Babor, Burke, Farmer, Jablenski, Pickens, Regier et al., 1988; Weissman, 1987).

The use of diagnostic and dimensional categories supports the idea of varied and competing perceptions among those working in and around the field of mental health. In spite of this, many on both sides claim progress in how community mental health is measured since the mid-19th century. Some would argue that the continued inclusion and growth of interdisciplinary methods, increased coordination of dimensional and diagnostic instruments and the application of computer technology may be important to better understanding mental illness within a population (Mcleod & Wright, 2010).

In terms of establishing prevalence, there are also concerns regarding reliability and validity for assessing mental health. Reliability looks at the screening tools’ ability to be consistent over time. Validity looks at the underlying construct of the tool. Reliability
is necessary but not the only component for establishing validity. Reliability is most often used because it is easier to achieve. However, an assessment tool may be 100 percent reliable and not at all valid. Community assessments have become increasingly reliable but questions of validity remain (Dohrenwend, 1995).

Detailed epidemiological studies such as the National Comorbidity Survey suggest that half of the American population will experience a major mental disorder at some point in their lives (Mcleod & Wright, 2010). Some challenge that claim based on a critique of the questions used in the survey tools that may misdiagnose the distress that is really just a normal part of life. These questions regarding symptoms have no context provided that may distinguish mental health symptoms from the normal distress experienced in life. Because people may be experiencing normal and temporary distress they may not be as likely to seek treatment which would inflate the numbers of untreated disorders (Horowitz & Wakefield, 2006). Examples of normal stress responses and not necessarily mental disorders might include depression, sexual dysfunction, anxiety disorders and drug and alcohol abuse. Policy-makers, consumer-advocates, treatment providers and pharmaceutical marketing all build on this prevalence data to advocate for their constituents or approach in order to garner more funding, medication, influence or authority.

Psychiatric epidemiologists use the DSM because of the detail in defining disorders and symptoms. However, the decision to use decontextualized, symptom-based measures in community studies assumes an uncritical acceptance of the DSM definitions. In addition, and in contrast to people involved in treatment, community-based studies rely
on structured interviews with people most of who have never been diagnosed with a mental illness. People involved in treatment have already decided that their problems go beyond normal reactions. People taking the survey without that kind of self-reflection or context may not be able to discern the difference between temporary mental health issues and a mental health diagnosis or problem. If respondents answer broad questions in a structured interview for example, regarding depression, they do not have the assistance of lay people or clinicians to explain the difference between ordinary sadness, the breaking of a relationship, or a depressive disorder. The result can be that symptoms which, neither the respondents nor clinicians would see as requiring treatment may qualify as a mental illness in a community survey (Horowitz & Wakefield, 2006). Many argue that the inflated rates of diagnoses in community surveys may undermine the true mental needs in the community while fostering a medicalization of mental illness when some results may be better explained by social circumstances (Horowitz & Wakefield, 2006).

Community surveys do not currently allow for contextualization and probing questions which may better help the respondent with their answer. This lack is no doubt due to the higher cost and resources of contextual interviews and may also be due to the advantage of high prevalence rates to pharmaceutical companies, the medical profession, policy-makers and advocates seeking more funding and services. High prevalence rates can benefit both state administrators and consumer-advocates as each seeks out more funding and avenues to justify their important work. Pharmaceutical advertisements can often focus on money making diagnoses such as sadness and loneliness, as if they were pervasive even though sadness and loneliness may also be normal components of every
day existence. Consumer-advocates like the National Alliance for the Mentally Ill point
to the high prevalence rates to express their need for more funding and also to generalize
and normalize mental illness, thereby reducing the stigma and distance between those
with a mental illness and those without (Horowitz & Wakefield, 2006).

For the purposes of this research we know that the definition of mental illness has
varied throughout history and across cultures. In the US, mental health diagnoses have
been added, changed and dropped, demonstrating that identifying mental illness is, at the
very least, a fluid process. We also know that establishing the prevalence of mental
illness across a population has challenges based on the kind of approach or tool
(diagnostic or dimensional) and challenges establishing the validity and reliability of any
chosen tool. Assessment tools are established in a particular historical, social and political
context. A society’s perception about the causes of mental illness will be reflected in the
tools and methods it uses to assess mental illness. The selection of these tools will be
based, at least in part, on power, status and economics. The many examples of how socio-
political and economic factors have influenced what is considered to be mental illness
have already been cited with many authors pointing to the subjective and transient nature
of psychological categories. The increased ability to determine what is medically or
genetically explained such as Alzheimer’s disease has only bolstered the interest in how
sociological factors and perceptions might influence mental health (Switzer, Dew,
Thompson, Goycoolea, Derricott, & Mullins, 1999). Those attempting to bridge the
medical and social divide point to the progress in sampling methodology and advances in
screening tools along with an ever growing interdisciplinary approach to mental illness
that may help to lay common ground for the varied perceptions and approaches to mental health treatment and policy.

**Understanding Mental Health as a Social Condition**

The literature reviews those social factors that influence health and psychological well-being. The literature on social factors includes research on stress, social roles and labeling, social stratification and inequity, social capital, social disorder, gender and poverty. Of particular importance is the literature on role theory, which provides a view of those factors which determine how roles such as state administrators and consumer-advocates are created and sustained. Role theory is discussed in more detail below.

According to social constructionists, reality is neither true nor objective but constructed by human interaction that over time becomes so habituated and institutionalized that it is seen as normal, objective and true. In trying to understand mental illness as a social construction, Berger and Luckman (1967) would caution those inclined to see any human phenomena as objective, independent and existing in and of itself. In this view in which all reality is socially constructed, mental illness can only be understood in the context of its ever-changing definition within evolving historical, cultural and social mores.

Understanding mental health as a social condition helps us look beyond the personal experiences of mental illness, including etiology to identify the features of society that influence and create personal suffering (Mills, 2000). Research has shown that social factors influence mental illness and that mental health is prevalent and predictable in societies with high levels of social disorder (Barrett, 2000; McLeod &
Nonemaker, 1999; Mirowski & Ross, 1992). In fact, researchers looking into social factors don’t really consider etiology or origins but rather look at the consequences of social arrangements on a person’s mental illness. The goal in the social perspective is to look at the impact society has on health rather than isolate the cause (Aneshensel, 2005). Those factors include social and economic class, race and ethnicity, gender, age and sexuality (Pearlin, 1989).

The literature, in particular, discusses the causal relationship between poverty and mental health both for parents and their children (McLeod & Edwards, 1995). There is research which argues that the effects of a stratified social class in a quasi-open society will sort people into different social classes or positions based, in part, on factors including physical and mental health, social competence, age, gender, marital status and exposure to violent and stressful situations like war. There is evidence to suggest that in the case of gender the higher levels of mental illness amongst women is not so much based on genetics or biology as social causes (Nolen-Hoksema, 1987). Sex role theory proposes that women experience mental illness more than men because their positions in society are less fulfilling and more frustrating (Gove & Tudor, 1974). Rates of distress among women are estimated by some to be 30 percent higher and cannot be dismissed as bias or differences in the way men and women emote and answer questions (Mirowski & Ross, 1995).

Stress research has contributed to the social understanding of mental health by studying how well-being is affected by the inequitable, complex and demanding social structures in which people live (Elliot & Eisdorfer, 1982; Lin, Dean, & Ensel 1986;
Pearlin, 1989). In a hierarchical, class-based system mental illness should not be a surprise but rather the expected outcome of social inequality (McLeod & Wright, 2010). Societal structure and role stratification can create stress and hardship within a variety of social arrangements (Pearlin).

There is also research that looks at the macro-economic effects on the well-being of a population. Research on the 1974-75 recession concluded that macro-economic issues increased distress scores by one-half a standard deviation during the 1973 to 1977 period. Results for high distress during this period excluded more specific, non-economic social factors that may have occurred such as marriage and child-bearing rates. Much of the change in this distress is due to changes in job characteristics, labor restructuring and other labor market experiences. Macro-economic changes impose a systemic risk that underscores the idea that well-being levels change because of macro or contextual issues and not solely because individuals are exposed to more personal, negative experiences (Tausig & Fenwik, 1999).

Researchers studying social stratification suggest that a hierarchy of credibility exists between social roles with those in superior roles seen as representing official morality while those in subordinate roles are seen as violating that morality (Becker, 1967). Researchers studying a class-based system suggest that historically superordinate groups like state administrators get to define the issues, set the agenda and determine services while subordinate groups like consumer-advocates may be challenged to get their voice heard. In this paradigm those in superior positions must legitimize or support their role by defining other roles as inferior and those in them as somehow less worthy.
Therefore subordinate positions correlate with less power, lower morality and even deviance. Status conflicts between those in superordinate and subordinate positions do arise and become caught up in competing symbols, perceptions and worldviews (Ben-Yhuda, 1990; Goffman, 1963; Schur, 1980).

There are studies that examine the public perception of mental illness and stigma. Public perception and stigma are important considerations for state administrators; consumer-advocates and treatment providers because it is thought that stigma of mental illness and concerns regarding treatment are reasons that so many people do not seek treatment (Pescosolido, Martin, Link, Kikuzawa, Burgos, Swindle, & Phelan 2000). Research also looks at the positive trends in the public perception through national education about mental illness that was incorporated into the Community Mental Health Legislation of the 1960s and 1970s. Beginning in the 1980s, consumer-advocates demanded a better understanding of mental illness, access to more treatment including medication as well as the de-stigmatization of mental illness (Pescosolido, Martin, Link, Kikuzawa, Burgos, & Swindle, 2000).

Opposing the rare positive trend, the public’s perception of mental illness are informed by the rare but highly publicized acts including the assassination of John Lennon, Son of Sam murders and more recently a series of school shootings. Feeding the popular perception are movies and the entertainment media which have depicted the mentally ill as out of control and extremely violent in movies such as Taxi Driver and Psycho (Pescosolido et al., 2000).
A social perspective of mental illness does not exclude the notion that mental illness is an experience of individuals that may be influenced in part by biology. In fact, biology and the social understanding of mental illness are not conflicting perspective but rather serve different purposes. One looks at the biological disposition and the other the social factors that affect mental illness as well as the social dynamics that define and interpret mental illness. What this means for anyone in the field or doing research is that mental illness is a complex, multilevel phenomenon which regardless of etiology must account for the perceptions of people, families, groups, organizations and governments. It is not solely a medical issue but a social one involving politics, economics and ultimately issues of equity and justice.

Understanding mental illness as a social condition must take into account the negative effect of stigma, prejudice and discrimination on the sense of self and identity for people labeled as mentally ill (Bassman, 2005; Corrigan & Calabrese, 2005; Corrigan & Watson, 2006; Fisher & Chon, 1986; Holmes & River, 1998; Oyserman & Fryburg, 2006; Thornicroft, 2006; Townley et al., 2011). Individual testimonies and accounts demonstrate how society’s approach and understanding of mental illness can shape the personal and social experiences of consumers of mental health services. Particularly relevant for this study are the past personal accounts of both service users and their relatives which demonstrate that once a person is labeled as mentally ill their decision-making ability is often called into question even by those mental health professionals providing support and treatment (Thornicroft). How will state administrators view the
decision-making ability of consumer-advocates and how will consumer-advocates perceive the decision-making ability of state administrators?

**Role theory.** Role theory is relevant to this inquiry as state administrators and consumer-advocates are two distinct groups each given the possibility if not propensity to fall into set roles defined as “state administrator” or “consumer-advocate”. The literature places role theory within the social construction paradigm and suggests that behavior is based largely on a person’s role or roles. A person’s role can help provide them with existential meaning and behavioral guidance (Thoits, 1983). According to role theory each social role comes with a set of duties, expectations, norms and rights which a person comes to conform and align (Blumer, 1969; Mead, 1934). A person’s commitment to a role can increase when they experience enjoyment in their role, feel a loyalty to others in the same role, receive rewards for role enactment or avoid punishment through role enactment (Weick, 1979a).

The literature in social construction theory discusses institutions as a collection of roles in which people, like actors, enter and exit throughout time accepting their role and the role of the institution (Berger & Luckman, 1966; Nelson & Winter, 1982). According to this theory people forget they are the creators of institutions and come to see institutions as outside of themselves and no longer within their control. In this theory, for example, state administrators may rely on a calcified bureaucracy to explain why things are done rather than view themselves as active agents for change. For consumer-advocates, they may come to see their role as one of constant opposition and therefore they may be unwilling to mediate or compromise. However, it should be noted, that in
role theory, particularly for those who have been on the margins of society, roles can also be useful in helping people develop a sense of self based on social interaction and role fulfillment (Faris, 1934; Mead, 1934).

Role theory looks at the effects of social isolation for people on the margins of society. Social isolation hypothesis contends that a mental illness can occur when people are cut off from intimate social relations over extended period of times (Faris, 1934). Social isolation is based on symbolic interaction theory and suggests that people develop a sense of who they are through interaction with others and through their role in society (Mead, 1934). In symbolic interaction, the individual perceives that he or she has been placed in a social category or role. Attached to each category are a set of behavioral expectations (Merton, 1957; Stryker, 1989; Stryker & Serpe, 1982). Role requirements can give meaning and direction to one’s existence. According to role theory, state administrators and consumer-advocates will act out their role within a set of behavioral expectations. Accumulating roles and identity can lead to a positive sense of self and well-being. However, if the person holds few social identities and a limited role in society this may lead to a sense of loss and the development to depression or a more serious mental illness (Bradburn, 1969; Gove, 1972; Gurin, Veroff, & Feld, 1960; Rose, 1962).

The idea of social capital influences the role theory. Social capital theory looks at how norms and values develop to provide group cohesion, validity and efficacy (Lochner, Kawachi, & Kennedy 1999; Putnam, Leonardi, & Nanetti, 1993). Social capital may provide a lens to view the exclusion or inclusion of consumer-advocates into the development of mental health policy and services. Social capital research focuses on how
groups with low social capital may be affected by health and other disparities (Faris & Dunham, 1965; Freeman, 1984; Leighton, 1982). There has been little research on social capital as it relates to mental health and in particular how it might relate to the consumer movement in the mental health field and how they may influence policy and practice (Kawachi & Berkman, 2001).

Role theory also looks at the impact of labeling on mental illness in which, on one hand, psychiatric symptoms are labeled as a violation of societal norms and, on the other hand, stable, enduring mental illness is considered by some to be a social role which a person is acting out. In role theory most mental disorders can be seen as acceptance of a social role with the role reflecting a corresponding status of the mentally ill in society. Once the symptoms are no longer considered transitory but permanent and the person accepts his or her role within society then he or she, as the theory suggests, will continue to work within the framework of that role. Part of this has to do with self. For example, if a person imagines himself or has been repeatedly told that he lacks self-control then during times of duress his behavior will break down. Furthermore, this theory suggests that labeled deviants may be rewarded for playing the deviant role and conforming to the stereotype. When patients demonstrate insight into their behavior and acknowledge what the physician has diagnosed they are rewarded. Conversely, when the patients attempt to return to conventional roles, he may be blocked by the provider’s sense of his illness or by discrimination (Balint, 1957; Shibutani, 1961).

There are researchers who suggest that there is an element of role playing in mental illness once people are labeled. Szasz (1961) suggests that once people are labeled
as mentally ill there is an element of role or “game playing.” In this model, people confuse the problems they are having with living with society’s image of mental illness and thereby impersonate mentally ill people to fulfill that role. Rather than willful role playing, this deviant behavior is actually a coping strategy and a way to get help from others as long as there is willing audience (Szasz, 1970b). For there to be role playing and labeling, society has to have certain beliefs regarding mental illness. Researchers suggest that stereotypes of the mentally ill are learned in early childhood and are continually reaffirmed in media and more inadvertently, in ordinary social interaction with such banal comments as “you are driving me crazy” or to the mistaken notion that former mental patients are more likely to commit violent crimes than the general population (Blake & Mouton, 1961; Scheff, 1963).

Labeling theory or social reaction theory does not necessarily view a person as mentally ill but instead as someone who, through a set of circumstances, is labeled as mentally ill and forced into a social role in which they begin to conform. Goffman (1959) discusses the public stigma of mental illness and corresponding personal conceptualization of being mentally ill which results in what he terms the moral career of the mental patient (Goffman, 1959). A moral career is when the concept of self resides more within the social arrangements and patterns of social control rather than being the property of the individual. Therefore, according to social reaction theory, the mentally ill person is a victim of society’s social arrangements.

There is a modified labeling approach that takes a more middle course acknowledging that negative conceptions of being mentally ill will lead to an image of
oneself based on how society views and treats a person with a mental illness while acknowledging that societal attitudes regarding mental illness have improved. Modified labeling theory claims that people will feel a strong sense of stigma upon entering treatment because of society’s negative perception of mental illness and that they have internalized this negative perception of what it means to be mentally ill. In this approach, people labeled as mentally ill will often initiate coping skills such as secrecy and withdrawal. The research supporting a modified labeling theory challenges the notion that labeling and stigma are inconsequential (Link, Francis, Cullen, Struening, Shrout, & Dohwenrend, 1989).

Opponents of role theory in relation to mental illness point to the lack of evidence for the systematic victimization of the mentally ill through labeling. They point to the evidence that most people who are hospitalized have a serious psychiatric condition quite apart from any societal reaction. In summary, they conclude that a person’s behavior determines the expectations of others to a much greater degree than the reverse (Gove, 1970).

One major obstacle in any social theory of mental illness is that the term “mental illness” which refers to a certain phenomenon actually prejudges the issue. The medical metaphor of mental illness presents a fait accompli by labeling it a disease. Many researchers favor the term deviant behavior to signify behavior that violates a social norm rather than pathologizing the issue with the term disease (Lemert, 1951; Goffman, 1961; Szasz, 1961).
Primary deviances include behaviors that may cause someone to be labeled deviant or mentally ill and secondary deviances include behaviors that are reproduced by being placed in a deviant role (Gove, 1970). There are many recognized violations of social norms such as perversion, drunkenness and crime but there are others governing decency and normality, which are so ingrained as to be taken for granted. These norm violations are often placed in a catch-all category like witchcraft or spirit possession in some cultures or in our society the category of mentally ill (Scheff, 1984).

In the context of role theory, consumer-advocates and state administrators come to objectify themselves in their different roles conforming to the expectations assigned to them while at the same time finding some sense of purpose and self (Linton, 1936; Merton 1957; Thoits, 1983). It is these two roles we will explore more deeply through semi-structured interviews. Of particular concern will be how consumer-advocates, as current and former service users, can influence and affect mental health services and policy after having worn the label of mentally ill and as a result, according to the literature, of having their decision-making ability called into questions (Thornicroft, 2006).

The literature supports the importance of social conditions on mental health and how structural issues in societies such as persistent violence, poverty, a high degree of social stratification and even macro-economic and political policies outside the society’s control can influence mental health and perceptions of mental health. The literature supports the importance of role playing and how the individual may fall into the role of a person with a mental illness or the role of a state administrator. The literature discusses
how perceptions of mental illness can lead to widespread stigma resulting in social isolation and marginalization. The notion that biological factors or mental illness as a medical disease is ascendant in the field of mental health. The medical model is seen as an alternative and, by some, in conflict with the social model. The perspective on the medical model of mental illness will be explored in the next section of the literature review.

The Role of the State and the Medical model in the Policy and Treatment of Mental Illness

The medical profession’s cooption of mental illness, the asylum movement and state control over the mentally ill have been aligned and mutually reinforced throughout the history and organization of mental health policy and treatment. The literature describes the medical model of mental illness as having evolved over a long period of time to become the dominant approach to treatment and care in Western society (American Psychiatric Association, 1980; Katz, 1996; Keith, Regier & Rae, 1991). The idea that you can approach non normative behavior from an illness perspective much like a physician approaches a chronic medical condition has treatment implications as well as moral, political and economic implications (Angel & Thoits, 1987; Mechanic, 1995).

The causes of mental illness can depend on the society’s worldview. In a society with a predominantly spiritual worldview, mental illness will less likely be defined as a biological illness as it is in western psychiatry. The idea of mental illness as a biological disease is a product of 2000 years of western social and cultural development. The medical model had its nascence in classical Greek and Roman thought with its rational
perspective on humanity. Hippocrates (460-377BC) based his approach to physical illness on natural causes and soon began to place madness into this natural-medical paradigm. However, much of this approach was rudimentary and based on the humeral theory, in which bodily fluids (the four humors) needed to be proportionate and balanced for the maintenance of health (Conrad & Schneider, 1992).

The medical approach was stalled in the middle ages with the collapse of the Roman Empire and, in the fifth century with the rise and dominance of the theological approach to mental illness characterized by supernatural beliefs, mysticism and mythology. There were, however, a few educated people during this period who still saw madness as a physical presence in the body. During the middle ages, trepanning became the first surgical practice which sought to relieve pressure on the brain by incising the skull to release the atoms which were believed to cause abnormal behavior (Neaman, 1975).

The Renaissance brought a rediscovery of the Greco-Roman model which along with other changes between the 16\textsuperscript{th} to 18\textsuperscript{th} century, like institutionalization, led to the dominance of the medical model and the justification of physicians as a profession most able to treat mental illness. Before the 17\textsuperscript{th} century, the mentally ill, referred to as the mad, were not hidden away but were free to roam and were taken care of by the family and the community. At this time the Narranschiff or Ship of Fools was an uncommon but since popularized method of moving the mentally ill in ships from town to town via barge or ship (Conrad & Scheider, 1992).
By the middle of the 17th century the shift from the feudal order to capitalist order led to the confinement of significant portions of the population including those who were poor and mentally ill to serve as cheap labor for this new economic system. In the late 18th and early 19th centuries physicians came to be the keepers of the asylums as medical certificates needed to be developed and authorized for those who were placed in the institution. This formalized and systemized the medical model even while less than helpful treatments such as bloodletting, dunking, purging and even castration were widespread in these asylums (Ackerknecht, 1968, p. 38).

In the 19th century asylums came to be seen as the cure for insanity and they proliferated all across the US. Mental illness became firmly rooted in the biological or medical model and many thought this disease of the brain was triggered by social factors. Having defined the cause medically but rooted in society gave practitioners and administrators hope that mental illness was curable. Part of the cure or solution was to remove people from the social cause which was society into the controlled environment of the asylum where they could receive medical care. In 1844 the Association of the Medical Superintendents of American Institutions of the Insane was established as a forerunner to the APA which became and remains the dominant political and financial body in the mental health field. The APA advocated for the medicalization of mental illness and insisted that psychiatrists were required for proper treatment (Grob, 1970, p. 312). By the late 19th century asylums had medical superintendents who served as gatekeepers and guardians (Conrad & Scheider, 1992). The medical model without any
evidence of successful biologically-based treatment had emerged to dominate the mental health field.

The rise of the asylum is deeply connected to the medical conception of mental illness. Asylums were erected in manufacturing centers like New York and Massachusetts as well as agricultural states like Vermont, Ohio, Tennessee and Georgia. By 1860, 28 of the 44 states had asylums (Rothman, 2002). The main principle espoused by medical superintendents of asylums was to remove people from the community at the first symptoms of illness. The asylum was typically an ornate, massive, architectural structure that physically declared itself as a place apart to protect, confine and treat the insane. Asylums were highly regulated and rigid environments whose predictable rhythm and order of everyday life was thought to help rid the patient of disease. The asylum introduced into western society an institution like no other seen before and one far away from the informality of the village, community or household. This strict order and separation was to become the new treatment and living condition for the insane (Rothman). From 1903 to 1950, the number of patients in state mental hospitals increased by 240 percent (from 150,000 to 512,000) a rate of growth nearly twice as large as the increase in the U.S. population as a whole (Rothman).

The community mental health movement was born out of the increasing institutionalization, the increasing costs and a growing awareness that removing people from their communities to distant hospitals may not be the cure after all. Community mental health developed out of financial concerns and an interest in providing community-based treatment using outpatient clinics and brief therapy and interventions.
It was hoped that community mental health would prevent or mitigate chronic mental health conditions and diminish the need for state mental health hospitals (Morrissey & Goldman, 1984). However, some considered institutionalization and community mental health as part of a series of reforms which tended to apply a one dimensional solution to the multi-faceted and complex issue of mental health care. Both seemed to be overly reliant on the medical perspective that tends to see mental health in terms of acute care while ignoring the long-term and complex socio-economic factors that influence mental health care.

The emergence of the Medical Model held the promise of viewing mental health like any other medical condition such as diabetes or high blood pressure. The problem with the model is that, in spite of its claims to science, it is not necessarily objective and can lend itself to interpretation (Holmes & Angell, 2001). The medical model frames medical problems in terms of cures and resolution and is based on the western narrative of linear progress through science (Cleeton, 2003). This idea of linear progression through medicine and science supported in much of the medical care literature and practice is contradicted in much of the literature and practice in the mental health field with its emphasis on patient driven care, recovery, relapse prevention, peer supports, and alternative therapies and medicine. The concern is that the medical model which is founded on the belief of progress through science may, at times be deeply antithetical to new and emerging practices in the mental health field that are not based on medication or other practices typical to medical care settings. This worldview that nearly everything can be “fixed” is often contradicted by the medical profession itself which has, at times,
conveyed the message and practice that people with mental illness are genetically unfit, morally depraved and incapable of self-regulation. For example, research has shown that the rate of mortality among people with a severe mental illness is increasing and that people with severe mental illness die, on average, 25 years younger than the general population (Mandersceid, 2006; Parks, Svendsen, Singer, & Foti 2006). Suicide and injury account for approximately 30-40 percent of these premature deaths while 60 percent of early deaths are due to chronic medical conditions, which are largely treatable in the general population (Parks et al.). These medical conditions including cardiovascular, pulmonary and infectious diseases are caused by modifiable risk factors such as obesity, tobacco use, poor nutrition and lack of exercise (Manderschied; Parks et al).

Research suggests that medical providers and support staff generally conceptualize people with mental illness as poorly organized, unable to follow treatment plans or to adequately look out for themselves. This complacency, fatalism and conceptualization of people with mental illness have deep roots in western culture (Heck, 2004; Mental Health Today, 2006).

Critics point to the potential danger of the medical approach to mental health because physicians played such a prominent role in the eugenics movement and in the forced and voluntary sterilization of the mentally ill in the US and Europe from the early 1900s until the 1960s. The German physician-legislator Rudolph Vichow’s public health movement was fused with eugenics to form the racial hygiene movement in Germany. This movement migrated to the US through the American physicians he trained. Within
the eugenics movement in the US, idealistic and respected administrators, social workers, politicians and physicians sought to purify the human race for the betterment of society (Parker, 2009). Many of these progressively minded scientists and social workers relied on oppressive methods including the forced and voluntary sterilization of the mentally ill and other vulnerable populations. There was a deeply held belief that a sterilization program would improve society and promote healthy families which would relieve the mentally ill and their families from generations of suffering (Gallagher, 1999).

There is a widespread critique that states that the medical model is not necessarily objective and can lend itself to interpretation (Holmes & Antell, 2001). The Medical Model is interwoven with the medical narrative, which frames medical problems in terms of cures and resolution which is based on the western narrative of linear progress through science (Cleton, 2003). This idea of linear progression through medicine and science supported in much of the primary care literature and practice is in contrast to much of the literature and practice in the mental health field with its emphasis on patient driven care, recovery, relapse prevention, peer supports, and alternative therapies and medicine. There is a risk that the medical model which is founded on the belief of progress through science may, at times, be antithetical to new and emerging practices in the mental health field that are not based on medication or other practices typical to primary care settings. Other challenges to the medical model include the argument that an individualistic orientation fails to take the historical and cultural context of the behavior into consideration (Duran & Duran 1995). What are implications for free will and morality within the medical model? If a person commits a crime can he or she be responsible for
that crime if there is a biological basis for their crime? If mental illness is seen as an individual disease rather than a social problem how does that affect morality, justice and equity?

The literature in the 1960s began an active critique of psychiatry and the medical model. Thomas Szasz claimed that psychiatry was a threat to civil liberties because it was used as a tool to incarcerate people and stifle dissent (Szasz, 1961). Franz Fanon, in *Wretched of the Earth* (1961) said that the medicalization of mental illness and the concomitant rise of psychiatry are used to label as mentally ill those Africans resisting French Colonialism. In Erving Gossman’s collection *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (1961), he states that institutions were created to separate those who thought differently from the mainstream to be either reeducated to the “normal” or relegated to the margins of society and the care of the institution. In Ken Kesey’s (1962) novel, *One Flew Over the Cuckoo’s Nest*, the institution could take the socially marginal and the dissident and stifle him or her through medication and surgical lobotomies. Foucault (1961) in *Madness and Civilization* pointed to the use of language and how vocabulary was used to make these categories real and come to define and separate the sane from the insane.

Allen Frances, the chairman of the task force that created the DSM IV now claims that by controlling normality the medical world has and can create, at any time, mentally ill people through new categories of diagnoses which then becomes a financial boon for the pharmaceutical industry and medical profession who prosper from these new consumer groups. Frances includes examples of three false epidemics that were created
by small changes in the definition of mental disorders including attention deficit disorder, autism and childhood bipolar disorder. Defining the elusive line between mental disorder and normality is not simply a scientific question that can be left in the hands of the medical profession or any so named expert as both groups will have tendency to expand certain disorders which hold interest for them. They may not even do this for self-serving reasons but rather from a genuine desire to avoid missing people who need help (Frances, 2010).

The medical model continues to dominate the mental health field in controversial ways. Medication is still used for reasons of control more than treatment. Thirty-six states and DC have involuntary outpatient commitment laws, which allow people to be court ordered to take their psychiatric drugs against their expressed wishes, even if they are living at home (Francis, 2010). Although the emergence of the Medical Model held the promise of viewing mental health like any other medical condition, a review of the history of mental health also traces the state’s role and the medical profession’s involvement in coercive practices toward people with a mental health condition. Recent attempts to include consumer advocacy groups, peer supports and recovery groups bode well for a more diverse, balanced and comprehensive approach to mental illness.

**Consumer Involvement and State Administration of Mental Health Policy and Services**

The struggle to end domination, the individual struggle to resist colonization, to move from object to subject, is expressed in the effort to establish the liberatory voice – that way of speaking that is no longer determined by one's status as object – as oppressed being. That way of speaking is characterized by opposition, by resistance. It demands that paradigms shift – that we learn to talk – to listen – to hear in a new way. (Bell Hooks, 1989, p. 15)
Literature suggests that leaders such as state administrators may, at times, support an unjust social agenda because they have been hired and trained into their role and, within that role, are expected to conform to the prevailing agenda of their organization (Chomsky, 2000; Rapp, 2001a). However, socially just leaders are committed to transforming oppressive and exploitive social relations through dissent and resistance if necessary (McLaren, 2000; Rich, 2001). Today how do state administrators lead in light of the oppressive history of state mental health policy and treatment? How do they view socially just policy and treatment in the field of mental health and how is their leadership seen from their own perspective and from the perspective of consumer-advocates? On the other hand, how are the current array of consumer groups born out of radical ex-patient alternative groups able to deepen the ideological argument and increase democratic action, social equity and social justice in the area of mental health policy and treatment? Are consumer-advocates authentic leaders focused on social justice or have they become coopted, depoliticized and financially reliant on the state mental health system (McLean, 2000)? How is their leadership perceived by state administrators? Are consumer-advocates considered viable partners and are they listened to and taken seriously by state administrators?

Today’s consumer advocacy has historical precedence that may go as far as back as a pamphlet published in 1620 titled, *The Petition of the Poor Distracted People in the House of Bedlam*, which attempted to raise awareness and advocate for better conditions (Brandon, 1991). One of the first consumer-survivor self-help groups to emerge was the Alleged Lunatics’ Friend Society, which was begun in England in 1845. John Perceval,
one of the founders of this early consumer group said that obtaining the cure for oneself
was an act of resistance to the system (Manderscheid & Berry, 2004). This consumer
movement like others that would come later was not without criticism. The British
newspaper, *The Times*, on March 27, 1846, noted:

> Some of the names we have seen announced suggest to us the possibility that the
> promoters of this scheme are not altogether free from motives of self-
> preservation. We think they should be satisfied to take care of themselves, without
> tendering their services to all who happen to be in the same position. (Hervey,
> 1986, p. 245)

The objectives of the Society were to reduce the likelihood of illegal incarceration and
improve the condition of asylums, to offer help to discharged patients, and to convert the
public to an enlarged view of Christian duties and sympathies (Hervey, 1986). First-
person stories began to bear witness to patients’ need to reclaim their voices and find a
way to speak their own truth (Frank, 1995). Hornstein (2002) points to parallels between
patients’ autobiographical accounts of mental illness and slave narratives, in that both
bear firsthand witness to oppressive treatment and injustice.

*In A Mind That Found Itself* (1908), Clifford Beers, in this breakthrough book for
consumer and patient rights, publicized the abuses he saw and experienced as a patient
confined to an institution after a failed suicide attempt. Beers, with the help of the
prominent psychiatrist Adolph Meyer, whose reputation allowed Beer’s book to come to
fruition would later co-found the National Mental Hygiene Committee (now the National
Mental Health Association) in 1909. Beers began a history of consumer advocacy that
has enlarged the understanding of mental illness and contributed to changes in attitudes and in the way mental health services are delivered by promoting greater self-determination (Mandersheid & Berry, 2004). Self-determination refers to the right of individuals to have full power over their own lives and encompasses concepts that are central to existence in a democratic society, including freedom of choice, civil rights, independence, and self-direction (Falck, 1988; Pierce, 2001).

The consumer advocacy literature in the 1960s and 1970s emerged to describe a diverse group of recipients who challenged the policies and treatment services in the field of mental health at both the federal and state level. These activists originally calling themselves ex-inmates or ex-patients subsequently split into two groups called survivors and consumers who now, despite continued ideological differences, have come to loosely affiliate themselves within the state mental health system under the banner of “consumer movement” (McLean, 2002).

Today consumer involvement can be part of the traditionally and professionally run community mental health system in which consumers work as paid providers within the clinical rehabilitative setting or, apropos of this study, part of client self-help organizations and consumer groups that are independent and separate from state run organizations. Research shows that many state mental health authorities encourage the hiring of consumers to work as paid providers in mental health treatment programs. However, some have argued that the hiring of consumers has often been based on “tokenism” rather than a sincere desire to integrate consumers into professional teams as
equals. This could also be due to operational issues such as poorly defined roles, policies and procedures, and workflow (Roose & De Bie, 2003).

Client self-help organizations that are independent of professional organizations typically strive for social and community change through education, training for mental health professionals, public advocacy and political organization. The values that guide consumer run organizations include member empowerment and participation, social justice, a sense of community, peer support and mutual learning. In the field of mental health many people, including social workers and medical professionals, are beginning to view self-help organizations as an important compliment to formal services provided by professionals (Swarbrik & Ellis, 2009). There is, however, less information and evidence on how effective these services are including questions regarding who they serve. Skeptics suggest that these consumer run groups do not serve those with severe mental illness but rather serve higher functioning individuals who do not meet the criteria of diagnosis, duration, and disability that characterize clients of formal treatment services. This is hard to confirm or deny since consumer run groups often lack data and reporting systems, formal assessments and admission criteria (Franskowski & Segal, 2002).

Two important federal documents have recognized the value of consumer involvement in state mental health services including the 1999 Surgeon General Report on Mental Health and the President’s New Freedom Commission on Mental Health. In 2003, the Commission said, “Nearly every consumer of mental health services who testified before or submitted public comments to the Commission expressed the need to fully participate in his or her plan for recovery. Consumers and families told the
Commission that hope and the opportunity to regain control of their lives is vital to recovery” (p. 45). The Commission stated that, “Emerging research has validated that hope and self-determination are important factors contributing to recovery” (p. 46). The Commission advocated that consumers of mental health services must stand at the center of the system of care and that consumer’s needs must drive the care and services provided. The Commission concluded that while capable and willing, consumers and families do not control their own care and that the time had come for increasing the opportunities for consumer choice in the delivery of services. The Commission argued that:

…Increasing opportunities for consumers to choose their provider and allowing consumers and families to have greater control over funds spent on their care and supports fosters personal responsibility, creates an economic interest in obtaining and sustaining recovery, and shifts the incentives towards a system that promotes learning, self-monitoring, and accountability. (p. 29)

Consumer-run groups promoting recovery challenge people’s perception about the capabilities of consumers (Anthony, 2000; Campbell, 2006a; Mueser, Corrigan, Hilton, Tanzman, Schaub, Gingerich, et al. 2002). Consumer run groups have successfully reframed calls for personal responsibility to emphasize individual choice (New Freedom Commission, 2003; SAMHSA, 2005c). Most researchers agree that it is important for state mental health authorities and treatment providers to work closely with consumer-advocates and consumer run organizations. Treatment providers and consumer-advocates provide important services to people with mental health conditions.
and both work toward similar goals. However, research has shown that collaboration between the two service systems when it happens has been problematic and it is apparent to many that there are now two parallel but separated mental health systems: one for professionally run mental health agencies and one for consumer-run agencies. The core nature of the relationship between professionals and consumer-advocates is said to be a one-way exchange of help and is similar to a provider-recipient relationship (Mueser et al., 2002). Consumer-advocates bring empathy, personal knowledge and experience while treatment providers and state mental health administrators bring technical assistance and access to networks. Collaboration between consumer-advocates and professionals is little studied, but Frese and Davis (1997) describe collaboration in four stages from lower to higher: mutual referrals, coordination, coalition and joint ventures. Much of the literature agrees and contends that coordination is important so that each group as well as consumers can thrive.

One of the values of consumer or peer support is how they help to integrate people with mental health conditions back into the community. As defined by McMillan and Chavis (1986), a sense of community is “a feeling that members have of belonging, a feeling that members matter to one another and to the group, and a shared faith that members’ needs will be met through their commitment to be together” (p. 9). It takes many to make this sense of community work and the obstacles to a sense of community can occur, according to social identity theory, when people identify with their own group and have unfavorable attitudes toward other groups. The research discusses self-verification theory which proposes that individuals seek groups that are distinguishable
from other groups because this makes their own self-views more distinctive and, thus more verifying. Research has also shown that out-group members evoke more dislike, distrust and competition than in-groups (Townley et al., 2011). In contrast, contact hypothesis is the idea that contact with another group will lead to more positive attitudes toward members of that group. However, for this to work, members must have equal status, something that may be difficult to attain when considering the historical marginalization of people with a mental illness (Townley et al.). In social capital theory there is the concept of bridging capital which is an opportunity to have normalized relationships outside of the context of the mental health system. Bridging is living among and interacting with neighbors who do not necessarily have a mental illness (Townley et al.).

Consumer-advocates working on issues of community integration face issues of stigma and discrimination toward the mentally ill. The “mentally ill” has become a category, formalized by the DSM and made real through the vocabulary and metaphors our language offers us (Bateson, 1972; Lakoff & Johnson, 1999; Linville, Salovey, & Fisheer, 1986). Additionally, community integration and issues of stigma and identity can be particularly challenging in rural communities. Illness identity is defined as a set of roles and attitudes that a person has developed in relation to the society in which they live. A study based on qualitative interviews with people with mental illness and those so called normal individuals living in four different rural communities suggest that those who accept their role as “mental patients” seem to have easier access to services, experience less stigmatization and fewer conflicts with their surroundings than those who
oppose the patient role. According to this study the definition of integration is feeling accepted as yourself (Ekeland & Bergem, 2006). Other research claims that accepting one’s role as mentally ill comes with the negative societal connotations such as incompetence and inadequacy that lead to increased stigma, poor self-esteem and negative outcomes including risk of suicide (Lysaker, Roe, & Yanos, 2010). There are researchers who claim that one method to transforming illness identity is through a narrative approach which helps people develop a meaningful story promoting confidence and agency that will help lead to recovery (Lysaker et al.). Constructing a meaningful story may help to facilitate a future-oriented aspect of identity, or the self one hopes to become and avoid becoming (Markus & Nurius, 1986). Possible selves may be rooted in past successes and failures, and they also provide a way to make sense of one’s current situation and create new ideas about who you are and who you might become (Dunkel & Anthis, 2001; Markus & Nurius).

“Identity Politics” means that people of a particular, usually oppressed category such as consumer-advocates unite and fight for political rights for their particular group (Younge, 2010). However, research findings do demonstrate that community supports for people with mental illness make a considerable contribution to an individual’s quality of life, as well as to their ability to manage everyday tasks. In addition, the presence of community supports appears to be a significant mediator of burden in families coping with mental illness. Community supports can moderate levels of emotion and bring relief to caretakers (Kohn & Wilson, 1995). Regardless of these theories, and how community may be defined, it is generally acknowledged that consumer groups should cultivate a
sense of belonging and purpose to those who might feel isolated due to their mental health status (Townley et al., 2011).

**Finding common ground.** As consumer-advocates and state administrators come together in formal and informal ways to discuss policy and treatment, the hope is that both will enter into a dialogue of mutual respect that can foster shared goals, shared values and shared accountability for customers seeking help rather than establish two parallel and divergent systems of care. For the dialogue to have purpose the two groups will need to continue to find common ground on the most controversial aspects of service and treatment that seem to point to fundamental issues and emotions surrounding choice, freedom and social justice including involuntary commitment, forced treatment and the elimination of coercion. The social justice compass seems to point toward public policy that favors a totally voluntary mental health system although the methods are not quite worked out. This direction is memorialized in basic principles of law and justice, including civil rights legislation such as the Americans with Disabilities Act (ADA). There are many hurdles including a reluctance within the disability rights world to defend with equal passion the rights and humanity of people with mental health conditions. Like most Americans, the disability rights movement may be quick to accept the historical and demonizing stereotypes that people with a mental illness are dangerous and incompetent (Hillman, 1975).

**Summary of the Literature Review**

From this literature review, one can see that much is known about the social construction of mental illness. The literature has provided a great deal of information on
the history of mental illness including varied perceptions of mental illness throughout
time and culture, how definitions of mental illness have changed, and how those changes
impact the prevalence of mental illness. The literature speaks to the stakeholders involved
in the discussion of mental illness from pharmaceutical companies, psychiatrists, medical
doctors and social workers to a broad range of consumers and advocates. We also know a
great deal about the far-reaching consequences of mental health for individuals and
families along with the broader implications it has on the socio-economic, political and
moral landscape of a society. Through the literature we better understand the institution
of mental illness and to a degree the goals, mission and architecture of the medical
profession and as well as the state in its treatment and confinement of the mentally ill.
The literature frames a discussion of ethics and social justice over the policies and
treatment of people thought to have a mental illness. The literature speaks to an overall
orientation to mental illness by asking fundamental questions about normality and
rationality and whether there is really such a thing as mental illness. However, an
argument can be made that there is a gap in the literature and much to be learned about
how state administrators and consumer-advocates perceive mental illness and how those
perceptions affect their relatively recent attempt to collaborate over policy and treatment.
The perceptions and the relationship of these two groups are of interest given the historic
power and control of the state over those considered mentally ill. The questions that the
literature does not address is how these two groups perceive mental illness and how they
can effectively engage each other to positively influence socially just mental health
policies and treatment. The voices of state administrators and consumer-advocates with

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their perceptions and their experiences of mental health and each other are missing from
the existing literature.

The literature review has helped me to understand the relatively recent initiative
to involve consumers in mental health policy and services which has resulted in
collaboration between state administrators and consumer-advocates that, to date, has not
been fully explored. The literature review has helped me understand the current
relationship of these two groups from an historical perspective and from the perspective
of power and powerlessness. The review has led me to explore ways to understand the
perceptions of state administrators and consumer-advocates and to imagine ways to
understand and strengthen the relationship between these two groups. We can learn from
listening to how state administrators and consumer-advocates describe and view their
own perceptions and experiences of mental illness. What is learned from these two
groups can inform discussion, enhance communication and perhaps help to develop
methods to foster their ability to agree on and develop more socially just and humane
mental health policies and practices. This literature has helped me construct the
theoretical model in Figure 2 providing a foundation for the purpose, research design and
methodology in following second.
Figure 2. Theoretical Model: Social Construction of Mental Illness among State Administrators and Consumer-Advocates

Conceptual Framework for this Study

The literature review along with the researcher’s own experience has contributed to developing three conceptual models to help focus and frame the research process. The first is a hypothesized model initiated by personal and professional experience of the researcher. This initial, hypothesized approach was confirmed as an idea through a review of the literature, which subsequently led to this research study. This hypothesized model assumes the researcher’s inclination and bias (Figure 1). The second is a
theoretical model, which is the foundation for the research approach including the broader questions of epistemology and ontology (Figure 2). The third conceptual model developed for this study serves as a repository for the data that was collected and is the foundation for the coding scheme. This conceptual model is the framework for reporting the study’s findings and effectively serves as a “working tool” for this research (Table 1). The hypothesized model is based on a critical approach to the use of language, accepted values and ways of thinking. A review of the literature demonstrates how the mentally ill, throughout western history, have been maltreated, marginalized and persecuted in the name of humanity, progress and even compassion. We only need to consider the eugenics movement which was active in the US, including the state within this study, through the mid-20th century, to remind us how science and progressive thinking can sometimes combine to violate the rights of people living with a mental illness as well as other marginalized populations. A critical approach helps us to unpack this history and uncover the stereotypes behind what were considered to be scientific, rationale and humane ideas.

The hypothesized conceptual model builds on personal accounts and testimonies that illuminate how negative social constructs and perceptions can operate and shape the personal and social experiences of people with mental illness. They include the sense that once labeled as mentally ill their decision-making ability is called into question (Corrigan & Calabrese, 2005; Corrigan & Watson, 2002; Holmes & River, 1998; Link, Bresnahan, Stueve & Pescosolido; Lsaker et al., 2010; Martin, Pescosolido, & Tuch, 2000; Thornicroft, 2006). Research has also shown that mental health administrators and peers working in consumer run organizations are often mistrustful of each other (Stewart, 1990;
Constantino & Nelson, 1995). In particular, research has noted that mental health
providers and administrators are often skeptical of peer lead mental health services and
are reluctant to coordinate with or refer people to those services (Chamberlin, 1990;
Constantino & Nelson, 1995; Emerick, 1995; Gartner & Riessman, 1993; Halperin, 1987;
Hardiman, 2005; Salzer, Rappaport & Segre, 1999; Stromwall, 2002). This prior
literature, along with personal and professional experience, informed the hypothesized
conceptual model becoming a catalyst to explore the role of state administrators and
consumer-advocates and their perceptions of mental illness.

The theoretical model assumes that all knowledge, including the most trivial
knowledge of everyday reality, is constructed and maintained by social interactions.
Symbolic interpretation and role theory help us examine how knowledge is constructed
through symbols and then normalized and validated within social roles (Berger &
Luckman, 1967). For the purposes of this study, administrators and consumer-advocates
are considered to have socially constructed views of mental illness that are informed and
maintained by their roles. These two groups interact to fashion, frame and eventually
legitimize policy and services that affect the lives of a vulnerable population – people
living with a mental illness.

By analyzing how mental illness is socially constructed, symbolized and defined
by groups we can better understand if and how a particular definition may gain social and
intellectual dominance. As Szasz (1973) writes, “The struggle for definition is veritably
the struggle for life itself…the one who seizes the word imposes reality on the other:
“The one who is defined is subjugated and may be killed” (pp. 24-25). The dominant
definition does not need to be true; it needs only the force of power, legitimacy and repletion to be successful.

In the social construction and the symbolic interpretative framework, words have the power to reveal or conceal and can be used to promote or demote a definition or approach (Jenkins, 1992). By exploring perceptions of mental illness among these two groups this study will ask how each group defines mental illness as well as consider the currently dominant definition of mental illness within society and how that definition gained prominence.

Social construction is part of the postmodern and critical approach taken in this study, which posits that the respected characteristics of modernity such as formal logic, science and technology are subject to interpretation. Postmodernism and critical theory emerged in the mid-20th century to provide a major theoretical challenge to traditional western knowledge systems. Postmodernism is a paradigm that helps us question claims to universal truths and dominant definitions, particularly those developed and held by individuals and groups in power. Critical theory provides a lens that can expose and deconstruct meta-narratives that continue to prevail and perpetuate myths such as those surrounding mental illness (Weiler, 1991). Each one helps us to challenge the widely accepted notion that science equals progress, that history is linear, progress inevitable, and that societies are not only knowable but continually improving. This study will make use of postmodernism and critical theory to question accepted assumptions of rationality, sanity and normalcy that contribute to their opposites manifested in the concept of the “other” as irrational and abnormal (Szasz, 1973). A phenomenological method will
provide the framework and approach to the qualitative inquiry that will be primarily based on semi-structured interviews.

There is no evidence in the literature of using semi-structured interviews to compare and contrast the perceptions of state administrators and consumer-advocates. The working conceptual model is based on a comprehensive review of the literature that helped to develop the research questions. The working conceptual model serves as a repository for the data that was collected. It is an organizing structure for reporting this study’s findings. Each category of this conceptual framework is derived from the research questions as outlined in Chapter 1. The first research question seeks to determine how state administrators and consumer-advocates perceive their own role and the role of each other. Therefore the logical conceptual category to capture responses to this question is “Perceptions of Roles.” The second research question looks at how consumer-advocates and state administrators perceive the existence and causes of mental illness and how, if at all, these perceptions vary. Therefore the second category is titled the “Existence and Causes of Mental Illness.” The third research questions seeks to uncover how consumer-advocates and state administrators perceive mental illness as a problem and how their perceptions may be similar or vary. The third category is titled “Perceptions of Mental Illness as a Problem.” The fourth research question looks at the strategies of state administrators and consumer-advocates and how they are similar and how they may vary. This category is titled “Strategies for Treating Mental Illness.” For each category, the researcher drew on the literature which resulted in the various
descriptions under each category. It should be noted that this conceptual framework was continually revised and refined.

Together the three conceptual models provide the framework to understand how perceptions of mental illness vary depending on group or social role (state administrator or consumer-advocate). The three conceptual models led the researcher to ask whether there are significant differences in perception of mental illness among state administrators and consumer-advocates and if any differences are based on distinct value systems, epistemological approaches and competing belief systems. Once this is determined it allows the researcher to ask if and how these differences might inform policy, treatment and services.
Problem Statement

Research indicates an historical pattern of state government control and abuse over those considered to be mentally ill. In addition, the literature describes the emergence of people with lived experience, who, in their role as consumer-advocates, are now called upon by some states, as well as the federal government, to play a role in shaping mental health policy and practice. There is little to no research comparing perceptions of mental illness among state administrators and consumer-advocates and how these perceptions affect policy and practice. If we do not understand each group’s frame of reference and how their perceptions compare and contrast, then we cannot determine how to help create a stronger working relationship based on mutual understanding, shared values and shared accountability.

Research Purpose and Questions

The purpose of this phenomenological study is to compare how state administrators and consumer-advocates perceive mental illness and how these perceptions impact policy and practice.

To explore and illuminate the research problem, the following research questions are asked:

1. How do state administrators and consumer-advocates perceive their role and the role of each other?
2. What are the perceptions of state administrators and consumer-advocates regarding the existence and causes of mental illness? How are they similar and how do they vary?

3. What are the perceptions of mental illness as a problem among state administrators and consumer-advocates? How are they similar and how do they vary?

4. What are the strategies of state administrators and consumer-advocates for treating mental illness? How are they similar and how do they vary? What is their capacity to work in concert and collaborate with each other?

**Research Method**

The overall approach to this research was phenomenological as it seeks to get at the lived experience of state administrators and consumer-advocates. I utilized qualitative research techniques in this study. I rely primarily on semi-structured interviews to hear directly from consumer-advocates and state administrators on how they perceive mental illness. This type of interview is best suited to compare and contrast perceptions of mental illness and how these perceptions might interact to inform policy and practice. Edward Husserl and other phenomenologists used in-depth interviews early on to understand complex social issues (Husserl, 1932). Semi-structured interviews are also a way to get at the many sides or perspectives of truth (Crabtree & Frey, 2005; Karner, 2005; Marshall & Rossman, 2010; Patton, 2002). The semi-structured interviews were set within a framework of themes that allowed me to tailor questions to the interview context, situation and people I interviewed. I used observation by attending meetings
between state administrators and consumer-advocates to collect data through my role as an observer. I also engaged in document review including papers, policies and newspaper articles to understand how perceptions are codified and transmitted to the public.

Potential Significance/Contribution to the Research

This study addressed an identified gap in the literature on the social construction of mental illness by focusing on the perceptions and roles of state administrators and consumer-advocates. While the literature review uncovered many articles relating to the etiology of mental illness and how people perceive mental illness through the medical model of mental illness or the social model of mental illness, there were no qualitative or quantitative studies that compared and contrasted the roles and perceptions of state administrators and consumer-advocates. These two groups are important because of their historic involvement and current influence regarding mental health policy and treatment. State administrators have historically defined mental illness and determined how it is to be treated. Consumer-advocates have historically been the recipients of that definition and treatment. Currently, both groups are being asked or required to work together to influence both policy and practice.

This study enhances our understanding of how these two groups approach, influence and determines mental health policy given their different historic roles and historically polarized positions of power. The information used in this study was obtained from state administrators and consumer-advocates in their own words. State administrators, consumer-advocates and other policymakers may use what is learned in this study to increase their understanding of each other’s perceptions in order to
strengthen their communication. While these two groups may continue to differ in their perceptions, this study may foster a process, program or training that may better assist them in their work and discussions.

**Applying a Phenomenological Research Approach**

A phenomenological research approach will be applied since this study focuses on the perceptions of mental illness among state administrators and consumer-advocates. Phenomenology is a method of philosophical inquiry that is based on lived experience and as such rejects the concept of objective research as a bias that has dominated Western thought since Plato (Orbe, 2009).

Phenomenology was founded by Edmund Husserl (1932) but has its roots in the philosophy of Immanuel Kant who distinguished between phenomena and numina (Hicks, 2004). Phenomena are those things that people can directly experience and interpret in their attempt to understand and numina are things in themselves thought to express some truth beyond direct experience and interpretation. As Schram (2006) states, “Phenomenological studies investigate the meaning of the lived experience of a small group of people from the standpoint of a concept or phenomenon” (p. 98).

Phenomenology is a skeptical and even radical approach to inquiry, which suggests that in our ways of knowing we should take nothing for granted (Natanson, 1973). Phenomenology rejects the notion of objective research. In Husserl’s theory of consciousness, the concept of intentionality assumes that consciousness is not in the mind but is something that is developed in relation to something else or the intentional object which it is given to the mind to describe and make sense of.
The additional but more peripheral reason for using a phenomenological approach is the role that empathy and inter-subjectivity play as part of this approach. Empathy in phenomenology refers to the ability to identify with the experience of the other making it possible to understand the intentions and emotions of other individuals. Since the focus of this research is on two different groups of people and how they may perceive mental illness, the notion of empathy and inter-subjectivity gives the phenomenological approach further credence particularly when we consider the goal of fostering more human and sociallyjust policies and treatment.

**Rationale for a Qualitative Study**

Neither a qualitative approach nor a quantitative approach to inquiry can claim to be value free or able to capture the absolute truth. Many researchers agree that any inquiry, whether quantitative or qualitative, is inherently a moral and political undertaking (Denzin & Lincoln, 2005). Given the constraints of both methods, a qualitative approach was chosen because of its ability to study issues both in depth and in detail (Patton, 2002). Qualitative research can be either exploratory or descriptive and help us understand the individual’s lived experience, the domain of society and culture and the process of language and communication (Marshall & Rossman (2010). Because this is a mental health inquiry and exploration with a long and controversial history, I believe that qualitative research helps us understand the lived experience of both state administrators and consumer-advocates as they are situated within their culture and as they are framed by language and communication.
This type of exploration reengaged this topic as a form of radical democratic practice (Peshkin, 1993). Exploring democratic practice seems particularly important as consumer-advocates emerge from an oppressive history to lend their voice to mental health policy and practice. In other words qualitative research and in particular listening to people in their own voice and understanding their lived experience can help us move beyond the static, self-satisfied and dependent democracy to a place of questioning and constructive resistance (Hardt & Negri, 2005). The varied forms of radical democratic practice have as a foundation the attempt to reconfigure liberal-democratic institutions, the role of civil society, and the importance of demands for inclusion in the political life (Laclau & Mouffé, 1985). The goal of radical democracy is not to renounce liberal, democratic society but to expand and deepen it. One small step toward this goal is to ask questions relating to power, stigma and voice particularly in regards to people living on the margins like those experiencing a mental health condition. One way to do this is through phenomenological research and inquiry. By uncovering information through interviews with state administrators and consumer-advocates we have the opportunity not only for dialogue, but also for a more deliberative and participatory process within the democratic institution of mental health care. This qualitative study and the phenomenological framework can help us understand the multiplicity of subjectivity in order to deepen democratic practice and resist hegemonic practices based on social roles.

This inquiry was implemented through semi-structured interviews, which unlike structured interviews, do not adhere to a set of fixed questions but allows the researcher to respond to new ideas as they are brought up in the interview (Galleta, 2013). I
interviewed five state administrators and five consumer-advocates. The interviews lasted approximately one hour in length and they were conducted where the interviewee was professionally located.

In addition, participant observation is a powerful adjunct to interviews. Glesne (2011) states that “through being part of a social setting you learn firsthand how the actions of research participants correspond to their words: see patterns of behavior; experience the unexpected, as well as the expected; and develop a quality of trust, relationship, and obligation with others in the setting” (p. 49). The analysis of interview transcripts and field notes were informed by an inductive process by identifying patterns in the data through thematic coding (Patton, 1980). Documents provided historical and contextual data that expanded and challenged the perceptions of state administrators and consumer-advocates while providing a more meaningful and multi-dimensional view of this complex topic (Glesne).

**Research Plan**

The research plan describes the rationale for choosing the site, the research setting, a description of the respondents, the data collection process and how the data will be analyzed. The plan also includes the limitations of the study as well as the quality assurance measures utilized to maintain the integrity of the research.

**Site selection**

State mental health administrators and consumer-advocates were chosen in this small, rural state in the Northeastern, United States because of the very active debate of the role of the state hospital in the care for the mentally ill. This debate

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1 The citations in this section are known but not listed in order to maintain the anonymity of the institution in which this study occurred.
came to a crucial turn when the state mental health hospital was decertified by the Centers of Medicaid and Medicare in 2003 following several suicides at the hospital. Since 2003 the state has tried and failed several times to regain federal certification. A vocal opposition of consumer-advocates, who long argued for de-institutionalization, then heightened their call for the closure of the state hospital by proposing an alternative community-based system of care. The opposition of consumer-advocates centered specifically on involuntary commitment, forced restraints and forced medication.

As the idea for this research was forming, Hurricane Irene hit the east coast of the US sending waters from the nearby river flooding into the state hospital complex forcing a dramatic evacuation and relocation of the patients and ultimately the destruction of the facility. In the wake of the flood, the question for state administrators and consumer-advocates was not only how to address the emergent issue of relocation and treatment but how to rebuild the system of care for those who previously needed hospitalization.

I chose this site for the study because, as a former employee of the Department of Mental Health, I had access to state administrators and consumer-advocates. During my time at this site, I had observed and been involved in meetings over an 18-month period in which state administrators and consumer-advocates interacted and discussed mental health services and policy. My position, as the Integrated Services Chief, was to help integrate the mental health and substance abuse systems at the policy and practice level in order to provide integrated services for people with co-occurring mental health and substance abuse conditions.
I chose this site because of the active role that consumer-advocates appear to play in this State and the seemingly high number of active consumer-advocate organizations. A guide published by the state mental health agency lists 71 consumer related organizations working in some way for people with mental health and substance use conditions. This guide is intended to help spread the word about the range of peer support services and help connect individuals to services in their communities.

I also chose this site because the state agency clearly prides itself in terms of engaging, supporting and working with consumer-advocates. Indeed, this state agency would seem, at least according to its vision and mission, to be worthy of study because of the professed desire to communicate and empower consumer-advocates. In other words, if communication and collaboration between state administrators and consumer-advocates was not working at this site then we might hypothesize and generalize that it was not working as well as it should at other sites throughout the country.

**Participant selection process.** In this study, purposeful criterion sampling was used to determine eligible participants; according to Patton (2002), the “power of purposeful sampling lies in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research” (p. 169). In criterion sampling, “all cases that meet some predetermined criterion of importance are explored (Patton, 2002, p. 238).

The criteria used to select consumer-advocates for this study were: (1) the consumer-advocate was a former or current user of the mental health system; (2) the
consumer-advocate was an employee of a nonprofit and in a formal advocacy role in the mental health system for at least one year. Criterion used to select state administrators for the study were: (1) the state administrator is an employee of the state mental health system for at least one year; (2) the state administrator has experience working with consumer-advocates.

Five consumer-advocates and five state administrators were interviewed for this study. Once identified, consumer-advocates and state administrators received an introductory telephone call followed by a letter sent electronically inviting them to participate in the study. This letter stated the purpose of the study, requested their participation and reminded them that this is an optional study. The letter stated that they are being invited to participate because they have been working in the mental health field and have knowledge of mental health policy and services either from the state administrator perspective or the consumer-advocated perspective. If interested, consumer-advocates and state administrators were asked to confirm their participation electronically or by telephone. Once the participant agreed they received an electronic note confirming and thanking them for their participation along with a meeting and interview schedule.

Sample. The population of the state in which the study was conducted is predominantly White. Every effort was made to achieve diversity in terms of race, age and gender which at the very least reflected the population of the state in terms of percentages. Pseudonyms were used for all study participants throughout the findings reported in this dissertation.
Data collection. This study used in-depth, semi-structured, individual interviews as the primary means of data collection as well as group observation and a review of artifacts in the form of documents that includes meeting minutes, newspaper articles, and websites. The interviews were based on the premise that those being interviewed have an important and needed perspective from which we can attain information and insight (Patton, 2002).

The interview format is semi-structured to allow for less structured follow-up questions in an effort to align with the course of the conversation and glean deeper information for better understanding. The interview sessions lasted approximately one hour, held in a private setting. Each interview was digitally recorded and later transcribed. Once transcribed, digital recordings were deleted. Written field notes were also taken during each interview. All notes and associated information were kept in a secure and locked container with every effort given to confidentiality. This locked security process also included consent forms and any releases of information.

Documents included meeting minutes, the ability to focus on how human beings make sense of their world and helps us put participant interviews into context (Bruner, 1991).

Data analysis. Data collected through interviews, observations and artifacts were compared and contrasted to understand the perceptions of consumer-advocates and state administrators from various points of view and with greater depth. In qualitative research, the goal is to find patterns and connections that are meaningful to the research (Glesne, 2011). The intent is that patterns discovered once the interviews and artifacts were
analyzed to make sense of the large amount of data and to make it readily available for others to review and make sense of (Glesne).

Coding was used in this research and categories were created and compared based on the research questions. Coding helps to conceptualize, organize and interpret the data and provides a method to reflect the data in a quantitative way (Saladana, 2012). Coding allows a researcher to make continual comparisons and to look for similarities and differences which are important for this study (Schram, 2006). Coding with the use of categories helps make sense of the data and hypothesizes how these findings may be generalized to other situations and in other locales where consumer-advocates and state administrators interact.

The responses of consumer-advocates and state administrators were gathered and sorted into themes in order to analyze the common and varied perceptions of the two groups. These themes are the basis of the findings in Chapter 4. The analysis of these themes appears in Chapter 4.

Limitations. While qualitative research provides the opportunity for a deeper and more nuanced understanding of the problem to be addressed is also exposed to biases. Brown (1996) concludes that understanding one’s biases is as high a priority as any theoretical knowledge. I did not go into this research believing that there is no bias. In fact, I agree with Mehra (2002) that one must, “Think about your topic, and ask yourself what you believe in, not as a researcher but as a human being? Do you think it is possible to be totally unbiased about a topic, to have no opinions one way or the other?” (p. 5).
I have to particularly guard against researcher bias as I consider the long and oppressive relationship that the state has had over patients and my tendency to empathize with consumer-advocates. I consider consumers informed and driven care to be a strong value that I hold. Also, as a former state employee, my experiences led me to be skeptical of the willingness of state employees to fully embrace and integrate consumer voice into its planning and decision-making process. Finally, as a person who has been affected by mental illness through my mother’s experiences, I may have developed a stronger adherence with the consumer-advocates interviewed in this study. Conversely, as a state employee for a number of years, one could argue that my role in the bureaucracy may leave me less sensitive to people seeking services.

Another bias, in qualitative research, is that the sources may not always be completely honest or credible. The main disadvantage of self-report is that people may be dishonest or deceive themselves. In addition, a bias, known as the actor–observer effect, is the tendency for people to describe or blame their own behavior on situational factors while other people’s behavior is due to their own character or disposition (Fiske & Taylor, 1991; Jones & Nisbett, 1971).

In this research there will be acknowledgement and deep consideration given to these personal biases as well as the general biases that are inherent in qualitative research. Protocols listed and considered within the methodology section will be developed and followed to minimize the bias and mitigate the risk.

**Quality assurance.** There are critics who question the rigor and trustworthiness of qualitative research. In order that qualitative research has transferability it must at its
foundation be sufficiently detailed so that the findings can allow for transferability to another setting or environment (Shenton, 2004). A critical component of transferability is that the findings conform to reality so that they are fundamentally credible and trustworthy (Merriam, 1998). In Guba’s (1981) paradigm researchers can enhance trustworthiness by (1) ensuring credibility particularly in terms of internal validity, (2) allowing for transferability or generalizability, (3) ensuring dependability or reliability, and (4) demonstrating confirm-ability meaning the results can be realized by those who are objective.

To achieve credibility and legitimacy the data was obtained from different sources or triangulated a term qualitative research has borrowed from the field of surveying in which triangulation is used for multiple reference points to determine the exact location. The primary reference points for triangulation were interviews where I explored how each state administrator and consumer-advocate understands and perceives mental illness. I do this through multiple interviews and shared the interviews, in written form, with each person interviewed to ensure accuracy. I used participant observation as a reference point in order to observe state administrators and consumer-advocates in different settings. I used document collection to understand how their perceptions are organized and reified through policies and procedures, meeting minutes and through interviews and editorials.

Patton (2002) cautions that triangulation is unlikely to arrive at consistency across data sources, the inconsistencies in the triangulation, will however help reveal a deeper meaning in the data. Towns and Serpell (2004) claim that, “Just as three dimensions give
an in-depth perspective to the eye, triangulation allows for a deeper multifaceted view of the picture under study” (p. 51).

In conclusion, to assure data quality, I used three reference points for data collection including semi-structured interviews, document review and observation. I shared my preliminary research findings with three other readers who are familiar with the framework of social construction and mental illness in order to see if these findings resonate with their own understanding of how perceptions, particularly those toward mental illness, might be constructed. I also shared the interview texts with the people I interviewed to ensure quality, intent and meaning.
CHAPTER 4: THE FINDINGS

Introduction

The purpose of this study was to explore with a sample of state administrators and a sample of consumer-advocates how their perceptions of mental health compare and vary and how these perceptions might inform mental health policy and practice. It is intended that the results of this research will help state administrators and consumer-advocates work more closely and effectively together to develop mental health policy and practice. This chapter presents the key findings from in-depth interviews with five state administrators and five consumer-advocates along with a review of documents and meeting observations.

This chapter focuses on the perceptions of mental health among state administrators and consumer-advocates by looking at four main issues: (1) the role and effectiveness of consumer-advocates and state administrators, (2) the causes of mental illness, (3) mental illness as a problem, and (4) the appropriate strategies for treating mental illness. The first part of the analysis is how each group sees itself and the other in terms of their role and effectiveness. The second part of the analysis examines causal attributions regarding mental illness. The third part explores whether each group sees mental illness as a problem and whether it is growing or decreasing. The fourth part of the analysis looks at each group’s strategies for treating mental illness. The analysis concludes by asking how state administrators and consumer-advocates can work more effectively together.
The interviews were conducted with five current or past leaders in state mental health administration and five consumer-advocates who work as leaders in organizations that provide advocacy and support for people with mental health issues. It became clear in conducting the state administrator interviews that their perception of mental health and the mental health system must be seen against the backdrop of two dramatic events; the 2005 decertification of the state hospital by the Center of Medicaid and Medicare for multiple violations of health and safety standards and Tropical Storm Irene which flooded and destroyed the state hospital leading to the relocation of patients to various places around the state. For consumer-advocates, the interviews and their perceptions were naturally influenced by their personal experience with mental health and the mental health system.

Together these findings tell a story of these two groups. The story may go like this.

For both state administrators and consumer-advocates, the current mental health system is dysfunctional. The system is broken for each group and, thus, undermines their roles and effectiveness. In this system consumer-advocates are seen by state administrators but not truly heard. They are asked to be involved only to have the involvement undermined by state administrators that don’t effectively listen or trust consumer-advocates and use funding and their authority as a way to coopt, marginalize or coerce consumer-advocates. However, consumer-advocates are divided. There are new levels and tensions within the consumer movement that may make it hard for them to coalesce around a particular message. Yet, in this system there are converging ideas among the two groups regarding the causes of mental illness as well as the strategies to treat mental illness. Both groups in this story desire to communicate but this communication must take place across a historical, political and social chasm that divides these two groups. It remains to be seen if the mental health system can be reimagined to bridge the gap and find common ground between these two groups with their separate and distinct symbolic moral universes.
The above story touches on the six findings or themes that emerged from this study: (1) dysfunctional mental health system; (2) seen but not heard; (3) a divided movement; (4) walk a mile in my shoes; (5) bridging the gap; and (6) finding common ground.

The first finding describes a dysfunctional mental health system. State administrators were unanimous that they were functioning in a mental health system in crisis or on the brink of crisis that limited how effective they could be in their role. They also described a system that took a tremendous personal and professional toll on their outlook and well-being.

In the second finding, consumer-advocates described their role in a system in which they are seen but not heard. Four out of five consumer-advocates said their role and effectiveness was marginalized by state administrators through a variety of ways either intentional or unintentional. Indeed, state administrators talked about the important role and need of consumer-advocates in the mental health system but suggested their effectiveness was compromised by having “strident” views.

In the third finding, a divided movement, all five consumer-advocates said that there was no real consumer advocacy system and that their organization functioned to varying degrees in isolation from others.

In the fourth finding, walk a mile in my shoes, consumer-advocates discussed the importance of their role. Consumer-advocates each said they felt effective in their role and that their work was very important because of the stigma still facing people with mental health issues. They described the importance of people with lived experience in
the mental health system. Also, three out of five consumer-advocates questioned the effectiveness of state administrators.

In the fifth finding, bridging the gap, both state administrators and consumer-advocates agreed that there are a variety of causes for mental illness with each acknowledging the role of biological factors in mental illness. Both groups took a holistic view of mental health acknowledging the various dimensions of mental health. However, state administrators seemed to emphasize the role of biology more so than consumer-advocates and were more likely to see mental health through an illness framework. Consumer-advocates were much more likely to focus on the social factors surrounding mental health. To reinforce this difference on the role of biology, consumer-advocates strongly expressed a need to get away from using the term mental illness. In addition, both groups thought mental illness was a problem in some way and that it is associated with a variety of social problems but were divided on whether it was growing or what factors attributed to its growth. Both groups claimed a variety of strategies when working with people with mental health conditions. All five state administrators and all five consumer-advocates supported forced medication, restraints and hospitalizations to some degree as a strategy although consumer-advocates expressed much more caution and constraint in the use of forced treatment.

In the sixth finding, getting to common ground, both state administrators and consumer-advocates agreed that there is a fundamental need for better communication when working with each other.
Each state administrator held a position of power and influence at the Department of Mental Health. Mary is in her 27\textsuperscript{th} year as state administrator. She has been doing quality assurance for the Department of Mental Health for the past 10 years. Sandy is the director of mental health services overseeing operations for the central office. Phil was the Commissioner of Mental Health for a little over one year. Nate is currently the Policy Director at the Department and Mark was the Commissioner for several years.

Each consumer-advocate is a leader in the field of advocacy or peer services. Amy is a legislator and editor of the state’s only advocacy newspaper. Dan developed and runs a statewide peer organization for veterans. Lynn is the Executive Director of a nationally known mental health advocacy organization. Wes is the Director of an advocacy organization and peer center working with people with serious mental health conditions. Mathew is the Director at a home for people with serious mental health conditions that may otherwise be in a psychiatric hospital.

**Findings for State Administrators and Consumer-Advocates**

**Finding 1:** A dysfunctional mental health system. A significant finding of this study for state administrators is that they are working in a stressed mental health system that is either in crisis or slowly emerging from crisis. This finding is highly significant because it is unanimous among state administrators (100 percent). All state administrators five out five (100 percent) indicated that the mental health system was in crisis or on the brink of crisis and that this compromised their role and effectiveness. State administrators described a system that is under resourced along with the personal toll it takes to work in such a system. Both state administrators and consumer-advocates talked about the high
turnover rate among state administrators and the corresponding problems of instability and discontinuity within the mental health system. The finding indicates a work environment in which state administrators are often dealing with emergent crises that negatively impact how effective they are in their role and therefore as a system of care. State administrators discussed the varied dimensions of this dysfunctional system. For instance, Mary did not think others in the system valued her role:

Well, if you want to know the honest truth, I don’t think a lot of other people think my job (Quality Improvement Manager) is very important but it’s essential and the reason I’m saying they don’t think it’s important is that when we had rescissions a few years ago, what had been a quality management team of six, was reduced to a quality management team of two basically… It’s been slow going. And when you’re dealing with crises like mental health has been through, especially after Tropical Storm Irene, you put out the fires first… It (quality management) was not seen as an important goal, in part, because the department functioned in perpetual crisis. (Mary)

Sandy pointed to turnover but also sees the Department as finally starting to stabilize following the storm:

The Department has been through five commissioners in four years and I think that we are making progress in stabilizing who’s doing what. We are just barely getting past the huge crisis of the closing of the state hospital due to Tropical Storm Irene which continues to have a significant impact on the mentally ill. Tropical Storm Irene turned back the clocks on the mental health system. (Sandy)
Phil talked about the nature of the crisis through the lens of his role as the new commissioner.

The system was in extreme crisis. I was the commissioner of mental health for a year but it felt like five. It was extremely intense. The house was on fire every single day no matter what you did. I didn’t have the expertise to keep going. I have strong opinions but I was swimming upstream and it felt like somebody else needs to be in this role that has the actual mental health background. I was at risk of failure because I just couldn’t go to the next step. I was told in the beginning that they did a national search and couldn’t find anybody to be the commissioner of mental health. It’s a tough job and they don’t pay enough. I do feel you need to have somebody with a clinical background because that’s what you are fighting with every single day. (Phil)

Nate talked about the federal intervention that occurred and impact that a system in crisis can have on care:

Part of the reason that people have such negative outcomes from mental illness is because the way that they act is so grating to society so we punish them and put them in a system that makes them feel like crap… It took the Department of Justice coming in to say, we’re going to sue you for a Olmstead Act violation because you’ve decimated the system so much that people are going to be stuck in the hospitals. (Nate)

Mark also talked about the extreme nature of the job and personal toll it took on him as a relatively long-term commissioner.
It took me about six months to detox from having been in that job… When I came into the job as commissioner I read books on kidnapping and survival to prepare for not being kidnapped and not being a victim. From my perspective the mental health system from top to bottom was victimized… This 120 year old hospital, which had been decertified by the federal government, was clearly not able to run in a way that was safe for patients. (Mark).

Dan, a consumer-advocate, spoke about the high turnover rate among state administrators as contributing to the marginalization of consumer-advocates. Dan specifically refers to the process of political appointments in which commissioners and deputy commissioners can change with the election of a new governor.

I think part of the problem with the state administrators is the turnover rate of leaders is kind of quick so then once you get something started, the next election, oh so and so is not commissioner anymore, so and so is not deputy, you know what I’m saying? So some people believe in the peer movement and some people don’t, so it makes it really difficult. You have to train them all over again and that can change every two to four years (Dan).

**Finding 2: Seen but not heard.** Four out of five consumer-advocates said their role and effectiveness as consumer-advocates was impeded or marginalized by state administrators. Five out of five state administrators expressed reservations over the effectiveness of consumer-advocates. Four out of five consumer-advocates spoke about the lack of support from state administrators for consumer advocacy in favor of individualized peer services. This was done through a lack of funding, funding for
individual peer services over public advocacy also called cooption by two consumer-advocates and coercion. Consumer-advocates discussed three ways in which they felt marginalized; through a lack of funding particularly when compared to professional organizations; through co-option or the implicit and explicit expectations attached to their state funding which comes with a fear of retribution; and in connection to this, the State’s promotion and funding of individual peer services over public consumer advocacy. Four out of five said their voices were muted because of their organization’s receipt of state funding. Three of five consumer-advocates charged the State with tokenism and said there was a failure to listen or to take consumer-advocates seriously. Two worried about losing their jobs if their advocacy was too strong. One cited the lack of support due to turn over in state administration. One talked about the lack of patience or receptivity once consumer-advocates start telling their story. One said the state was very supportive of her organization and did not express any concern or feeling of being marginalized.

Amy said consumer advocacy was coopted by state funding which now focused on peer services rather than consumer advocacy.

After Irene, when (the new Commissioner) came in and took over, he bought out the consumer voice. He totally bought it out and the way he did it, he bought it for a million dollars. That was the price tag and what happened is, he came and said, what would you do with a million dollars? (Amy).

Amy also spoke about the firing of an executive director from one of the state’s leading consumer-advocate organizations:
The rumor is, the word was very much with the support, endorsement, whatever, of the Department of Mental Health and the new leadership (of this organization). I think they (the Department) were ready to point to other problems to push her out, and there was an element of “she is a burr under the saddle”. Maybe not even a conscious one (Amy).

Amy continued by speaking about the pressure she felt as the editor of the consumer advocacy newspaper:

I’ll tell you when, working on this article for the September issue ...there wasn’t any doubt in my mind what I was risking, that I might get word from the board president saying, you can’t write that article. In which case would be like, oh okay, well then, you take over writing it because I’m not going to deal with editorial interference and I was very conscious of that risk. Now this issue came out and things seemed to be okay so far, and I wrote a fairly strong, I toned it down after the first draft but a fairly strong editorial about the identity crisis at the state hospital was facing and that are we abandoning, “nothing about us without us” (Amy).

When speaking about the Commissioner at the Department of Mental Health Amy said:

He is not a friend of a consumer voice and has already made a decision to cut back on the number of meetings with the transformation council which was supposed to be all about the community voice because he hears it from other places. He doesn’t think he needs to hear it again (Amy).
Amy spoke about the disconnection between the Department and consumer-advocate organizations. Her observation confirmed the finding from a review of documents on the Department’s website (see section on Document Review).

The legislature said that the Department was supposed to have a group that provided input to the commissioner… it wasn’t prescriptive in terms of meetings. It had been for years meeting monthly but it was not being used, the commissioner would come into the meetings and present updates, present here’s what we’re doing in the system, which had nothing to do with soliciting input on things that were going on. So I don’t think it was really being used in the way it was intended and then the commissioner decided that it’s taking up too much time and isn’t valued to him. Of course he’s not using it the way it was intended and so now it’s being cut back to every other month, maybe even quarterly… I think the legislation expires on it next year and he’ll probably advise that it is not needed anymore, so sometimes when you don’t have something that’s part of the infrastructure, it ebbs and flows by individual personalities. (Amy).

Amy made a point about intentionality regarding state administrators:

I don’t think there’s, a blocking. I think there’s a lack of grasping. I think we’re just a long way from people getting it and I talked for several years now about the fact that we have to create an end vision because if we don’t have an end vision, then we can’t keep our eye on the prize, because there is no prize, and we don’t know if we’re even doing things in the right direction so we’re doing these little steps where we think, okay, we’re working towards integration (Amy).
Dan talked about the lack of support for consumer-advocates.

I think this state is a little bit behind the ball on it. At first they kinda started to lead the way a little bit, but in the last four or five years, none of that got completed… (Dan).

Dan also talked about this support specifically in terms of parity in funding between consumer organizations and professional treatment organizations:

We’ve never really had adequate funding and personally I think we do a lot of work…I think they need to sit down with us at the table and be real about what’s for funding out there for peers and be a little more fair with the money that is available (Dan).

Dan said this parity is important because consumer organizations are more flexible and responsive than state supported professional, treatment organizations.

Unlike them we can actually say, listen, we need to knock the bullshit off and we need, it needs to straighten out. I think part of the problem with the mental health system and even the substance side, you’re kind of locked with those laws and what you can and can’t say. What you can and can’t share, and I think it actually hurts a lot of people’s recovery (Dan).

Dan said greater parity is needed because consumer organizations focus on the consumers unlike treatment organizations that focus more on protecting themselves than the consumer. He gave a specific example.

When I tried to talk about suicide to the Deputy Adjutant General, they acknowledge some of it but on the other hand they’re worried about their
recruiting numbers and their retention numbers because it’s a numbers games. Your budget is based on the amount of troops you have in the state. I think there’s also a big fear about suicide. Nobody wants to talk about it. When someone brings up suicide, they’ll go the other way. It’s a very hard subject to talk about. I just think that’s a problem... And the young guy we saw here in this room. I believe he’s around because the extra effort we put in to at least call him once or twice a week... are you doing all right? You make that extra little effort it makes a different sometimes (Dan).

Dan said consumer groups are more effective than professional treatment groups and provides a specific example.

I think we’re really effective. I mean, we got a lot of letters over the years. I think we got, in the last five years, six years almost, 11 suicide people that are really suicidal; all of them are still here except for one. That’s a pretty good rate...I think it’s because we are peers and we do understand it. Some of us came from being very suicidal. A lot of times people come to us first before they’ll go seek professional help (Dan).

Wes, like Amy, talked about being compromised or co-opted by State funding. He talked about the organizational change that occurred as formal funding came from the State and about the struggle within the organization between its early more radical history and its emergence as a state funded mainstream organization:

We started as a survivor movement, so essentially it was a grassroots, almost liberation type thing where people who’d been through forced treatments, electric
shock therapy, five point restraint, forced medication …over time we got recognition, grants. As we got grants, there was pressure to do certain things associated with the grants and then there was also pressure to really, a hope to be involved in forming policy and so my role has been a lot more moderate than most people (Wes).

Wes talked about his role as the Executive Director and the pressure he feels as he navigates his way between the historical roots of this consumer advocacy organization and its shift due to mainstream funding.

In my position, involved in this organization, it’s definitely; I receive a lot of flack for it. I’m sort of in the middle…I also have a tremendous amount of pressure from my organization from folks on the board and people who have been here a long time to be extremely damning of forced medication and coercive treatment and so it’s just one of those things where I’ve tried to walk the line and I don’t know if I’ve walked it well enough and I also am conflicted… So I get a lot of shit from the survivor movement when I don’t find that framework to be conducive to having a conversation or having an influence (Wes).

Wes added the potential for tokenism or the notion that state administrators need consumer-advocates to demonstrate that they had their input but may be less concerned about their views of the mental health system:

Historically we have influence, we are asked to review things and testify and do all these different things. In terms of how much of that is tokenism is hard to know. There’s always a certain fear that you give your testimony and it ends up
in the trash and then they can say check, we have peer involvement and participation, whatever. But it’s hard to know (Wes).

He also talked about the need to maintain his influence, professional role and livelihood and says that people who speak out have either courage, nothing left to lose or both:

So this is the reason I want to be confidential and everything else, is that so I as an individual ultimately want to work within the state to be involved in systems reform and have some real influence on how things look. I don’t think I’ll be able to do that if I define myself as really radical on certain issues around coercion and medication…I want to be really careful not to eliminate my opportunity to have influence by being too out about stuff. That’s that thing that takes a lot of courage or it might mean you have nothing to lose or both. I’ve got a mortgage and two kids and a family and whatever else and so it’s like I have to be employable, and all that stuff (Wes).

When asked how the consumer advocacy system compares to other states Wes said:

I think we talk a good game. I don’t think we’re better than a lot of places. I think that we really still spend the bulk of our money on business as usual. You put the money in the hospitals or community mental health agencies and then whatever crumb is left you kind of throw in the air and all the peer programs fight each other for, and that sort of creates an environment that isn’t collaborative. We’ve got a lot of competition and a lot of pressure from people to demonstrate (Wes).

Mathew talked about dangers of state funding for advocacy because of the expectations that come with it:
I think that is a real issue. How do you get around though is another question. I’m not really sure because people do need eat. There’s a real danger in it becoming a job. I think when you look at some of the hardcore original advocates; they were doing it because this is life and death for people, for themselves. You really lose something when people start getting paid. I think getting paid for providing services kind of makes a lot more sense on one level. Where does the advocacy come from? It really needs to come from people’s passion around it or otherwise it’s watered down. It’s compromised. I’m not gonna be the person who’s there like, demanding at the statehouse saying like this is my experience. I think there is some fire. People who have been doing this for decades and then get burned out and are like who’s gonna step up and take this over? I can’t do this for everyone. And I’m not sure what the answer is to that… there really needs to be the strong presence outside of the structure that continues to kind of prod and push things ‘cuz people get too comfortable (Mathew).

Mathew also suggested that there is a reason for the disconnection between state administrators and consumer-advocates that feeds into a sense among consumer-advocates of being marginalized:

There’s an element of competing priorities where one does not talk to the other, and so I think that as a state, as a bureaucracy in general, you kind of have to stay in this middle ground because you have a lot of different entities and interests that you’re having to interface with, so you can’t really go too far afield, I mean because you have to have a coherent center that you can stand. You can’t be a
different voice. There’s a certain shifting and there’s a certain kind of finessing of different things but there has to be some center to hold so there’s a level of consistency so…(Mathew).

He went on to share how at meetings with state administrators and consumer-advocates people can lose patience when listening to people with lived experience telling their story.

I sometimes go to meetings and consumer-advocates start talking and it’s like, oh man, this is, it’s going to get really inefficient here. We’re not going to be able to get anything done. As if we get stuff done by just meeting with each other. It’s kind of like, oh, this is really inconvenient to have this voice in the room and why do they have to always tell their story. That seems really selfish. I’ve shifted to where that’s actually what needs to happen. Because it’s really about the mindset and the perspective that people are holding. You have to be constantly reminded, like you’re in this other world…But there needs to be, the voices need to be more central somehow. And I don’t know exactly how that happens except by really including people and really in a central way having them be the head of taskforces kind of thing (Mathew).

Mathew talked about consumer involvement in State meetings and suggests it’s the responsibility of the State and the advocacy groups:

I think it’s pretty token and I think that there is a couple of vocal and well-spoken advocates who get asked to be on taskforces or committees and stuff like that and it’s not broad enough and you have to kind of put some on that onus is on the
advocacy movement to like really develop people, have people be effective so they can step into those roles and kind of rattle the cages a little bit. But there needs to be, I think it’s a real effort there (Mathew).

Lynn, on the other hand, is the one consumer-advocate who had nothing negative to say about state administrators or their support:

Yes I think they are really listening to what people want and need. A lot of the meetings I go to I always see them at the table and listening to what is going on. Our recent commissioner who is now retiring was really good at that. He was always there when we needed him and listening to the concerns of the people (Lynn).

This finding is significant because it contains a certain level of contradiction in that all five state administrators said that consumer-advocates should play an important role in the mental health system even as each one questioned their role and effectiveness in some way. Three out of five thought that consumer-advocates are too loud or strong in their advocacy. One of five questioned their skill level or readiness to be involved in the mental health system. Two questioned the mental health’s systems readiness to accept their view. One said some could be effective while others were not and added that their role should be limited within the mental health system. One said consumer-advocates felt the need to divulge their life stories in order to get attention. Another suggested that because of power dynamics consumer-advocates felt limited in their role because of fear of retribution. Mary tied their lack of effectiveness to their stridency:
I think they’re more effective when they are less strident, frankly. Their advocacy walks a fine line between assertiveness and stridency and I think they are more effective when they can be more in balance in presenting their positions on issues. (Mary)

Sandy is concerned that a relatively few advocates will control the narrative:

There are a few very loud voices that have very strong feelings and dare I say agendas that have had a significant impact on mental health law and on treatment. Some of which I think has been really positive. Some of which I think may not necessarily be in everybody’s best interest at all times… I think what’s concerning is that if you think about the fact that there are maybe 10 or 15 people statewide who are the consistent voices, we can’t know, we don’t have a good idea about whether that is representative of the way that the majority of folks feel and I think that’s problematic. And certainly in terms of being collaborative with the advocates, that has been truly difficult because some of the same folks who are advocates are also those that bring lawsuits and there may be some conflict there of interest essentially. And so that has, that requires a great deal of sensitivity and you know careful thought and lots of communication and transparency to the level at which it’s possible to be transparent. (Sandy)

Phil acknowledged a disconnection between administrators and advocates and touched on the lack of skill or business acumen of consumer-advocates.

I learned a lot more about mental health, especially about consumer-advocates. I learned how they felt the system didn’t really listen to them as individuals…I
gotta say there was a certain disconnect between what the peers thought really needed to happen and what the professionals thought needed to happen and it was hard to bridge that gap…You know, these mental health folks, these patients, former patients, are people that because of their illness, lost the opportunities to develop all these good business skills and stuff and so we were relying on people that didn’t necessarily have that background although more and more, as more people came out and declared, you found people that had really great skills. (Phil)

Nate acknowledged the need for peer involvement and the limits to that involvement.

Peers have to be a part of what happens around the treatment and care and support of the people with mental illness but it isn’t a good idea for peers to be involved in all aspects of care such as running and directing facilities because there are things that happen for people in which peer services may not help… I think some people are incredibly effective and I think others put a huge amount of energy into it and are very ineffective so I think it’s all over the map. I think a better assessment is how well the system is in creating a place for effective consumer advocacy to happen and how well they come in and take advantage of that. I think we’re still struggling with how to do it really well (Nate).

Mark is concerned about the public nature of peer testimonials and constraints they may have in a system in which they hold little power:

There is an oddity to me about mental health advocates in that they almost all find themselves at some point or another telling some of the most personal moments of their life, recounting them on public record, which always I find slightly
disturbing that it’s almost as if in order to get anybody to listen, they have to stand naked in front of everybody and often these are people who had very traumatic experiences in institutions so I think that has always been an issue for me but I think that to a person, every one of the advocates that I had contact with, were committed to making things better…The challenge in a psychiatric population is that you so often have people who have been abused or overpowered by, they’ve lost their civil rights, they’ve had things happen, that are legally sanctioned in terms of forced medication. And you’re asking them to speak out against that system, which could someday have them back in its hands. (Mark)

Finding 3: Divided we fall. This third finding is important because it shows that consumer-advocates are divided and some of these divisions are reinforced through state funding decisions. In this finding we see the emergence of a variety of consumer advocacy organizations. This finding highlights a divide among a newer and more professional, direct-peer service and the more traditional grass roots, direct-peer service as well as an overall division between peer direct-services and public advocacy. Two people talked specifically about the difference between professional peer organizations and grass roots peer organizations. Two people said the state is intentionally funding direct peer services over advocacy services implying that the State’s intention is to stifle the consumer voice on public policy issues. One person said it was the intention and strategy of the State to pivot away from and fund individual peer services rather than public advocacy.
Amy when speaking about the infusion of funding (one million dollars) into the Department of Mental Health for peer direct services rather that consumer advocacy said that the commissioner had bought out the consumer voice. Amy lamented the lack of consumer involvement in the process when determining the best use of these funds:

It is all about peer services and that our job isn’t consumer advocacy anymore. So all of the energy and focus of the consumer community was on the opportunities and what they could do to enhance the system and all that. So where was the voice saying, whoa wait a minute how’s this gonna work? Are we sure this is the best… there was no creative tension in the process of the rest of the redesign of the system (Amy).

Amy talked about the separation among consumer advocacy groups and particularly the separation between more professional, direct peer services which she called the “medical model perspective” and consumer advocacy. She describes the continued need for advocacy not just direct peer services through the lens of a very personal experience.

I had a very bad experience in terms of inadequate informed consent…I had real issues with what they were doing and so that was sort of my real first major advocacy effort, and it got me connected to other people in the advocacy community. I also had written several pieces. One was about Electric Convulsive Therapy that appeared in the Journal of ECT and then another that appeared in the Journal of Social Work which was exploring the tension from a consumer perspective between the self-help consumer organization types and consumer
groups that are more aligned with what some people call the medical model perspective (Amy).

The debate between the historically radical and emancipatory consumer advocacy organizations and the more current service organizations was being played out within her organization.

This organization is involved in a huge internal debate about its role providing peer services versus being an advocacy voice for consumers and to the point which its board of directors which it acknowledged was kind of a little bit of a screw up to not have a dialogue with its membership or anybody beforehand. The board of directors voted to change the name. At the annual membership meeting...There was a real outcry and rebellion and pushback and they withdrew the decision for now pending a much broader discussion…We really are at a point where we all need to be working toward the same goal which includes peer services being accepted while not losing sight of, “nothing about us without us” (Amy).

Dan talked about the difference within consumer-based services expressing disappointment at over professionalizing peer services.

I think there’s a difference between a living experience having it, and being trained for eight years in school about it. I think it’s a huge difference in perspective… I think there’s a fine line and you gotta be able to not cross that fine line. I mean we’ve had a lot of, I guess we’ve had a lot of vets that have come in and start out as a facilitator but they were going to school for substance abuse or
mental health counselor and I noticed that like in the third or fourth year, they
would change. And I was like, wait a minute. They’re having a hard time with this
peer stuff now. We can’t seem to stay in the peer mode because of everything
they learned in school (Dan).

Dan talked specifically about the training his veterans’ peer group received, the tension
that this professionalization creates even among peer groups and how consumer or peer-
based communication is different from professional communication:

There are actually three levels I’ve learned, especially in the last couple of years,
because we all went to school this past year to be certified peer specialists… Now
we’ve been training as peer specialists. It doesn’t make us professionals, but we
do have to act a little bit different, ‘cuz they’re looking up to us, they’re asking for
advice. I don’t think advice is the right word, but our guidance so you do have to
kind of carry yourself a certain way…but I don’t get, I don’t really agree with
everything the doctors are telling me, because they’re like, well you shouldn’t
swear so much. I mean everybody in the room swears. That’s the only way they
understand me. That’s how the military talks (Dan).

Dan was upset that other consumer organizations are getting more funding than his
organization:

Mental Health’s just stepped in a couple of years ago and yea, we’ll fund 8
organizations but you have other peer agencies that do equal or less work than us
and get as much as $800,000 a year. We need to sit down and talk about this a
little bit (Dan).
Liz’s comments did indicate a less than coordinated system of consumer services.

I think our paths cross. We do refer people to the other organizations and we hope they refer to us. I think we complement each other in different ways depending on what your recovery looks like (Liz).

When Liz is asked about the goals of different peer organizations she talked about the passion of some consumer organizations and the need for consumer organizations to be open.

They may be different. I think that some people are very passionate about their insights about it. I just hope that people can have an open mind about how different organizations can help in different respects (Liz).

When asked if she sees other differences between her organization and other consumer organizations she suggested that her organization is different because it is based on evidence based practice:

Maybe in the delivery system. We are a state chapter of a national organization. They have created an evidence based educational programs to help individuals affected by mental illness. Maybe other peer programs don’t have that national curriculum that they can use but they bring to the table something a little bit different (Liz).

Wes said that there is collaboration among peer groups on many topics however these may be more inconsequential or superficial.

So there’s a lot of collaboration amongst peer programs and consumers, providers, until you kind of get to the nitty gritty of a certain course of treatment
or not. What does that look like? There’s been a lot of clashing over particular issues with the new legislation that went through particularly around forced drugging and some of that stuff too (Wes).

Wes talked about the change happening from the early survivor groups to the present day organization in which he works:

We have people that have been involved for three decades or something and so there’s that resistance to change and new language and a natural distrust for new ways of doing things too. And so I think that a lot of this sort of old guard, folks in the psychiatric survivor movement feel that maybe we’re losing our values or being coopted (Wes).

Wes talked about the difference between his consumer organization and, in particular, singles out Liz’s organization:

They use a mental illness framework in all their material and most of the people who we work with won’t work with them for that reason…They really embrace the framework of like this is a disease and you have to acknowledge that and there’s no shame in acknowledging that and getting the help. A lot of people we work with say no, this is a by-product of trauma or I’ve been mischaracterized or this is just the way that I am and there’s nothing wrong with me and I don’t need to change. I need to be viewed in a more respectful way (Wes).

Mathew talked about the efficacy of consumer advocacy and considers the connections and coordination between groups:
I think there’s an aspect where people are so consumed and overwhelmed with the work that’s right in front of them, including me. There are conversations happening around coordination. There are a lot of people serving on different boards. But there’s something missing it feels like. It feels like it’s still being held in the hands of too few people, and that it is too leader driven maybe. There’s a disconnect at times between some of the leaders of some of the peer organizations and the constituency that they’re serving and that there’s some tension there (Mathew).

**Finding 4: Walk a mile in my shoe.** This finding is important because even though there is a long history of consumer advocacy, stigma is still a major concern and reason for maintaining the role and efficacy of consumer advocacy organizations. This may be of particular importance in light of the shift in funding away from consumer advocacy toward individualized peer services. All five said they were effective in their role. Five out of five people said that only people with lived experience can truly understand people with mental health conditions. Three said that labeling people as “mentally ill” is not appropriate and adds to the stigma. Three said that formalizing mental health conditions through definitions and diagnoses caused stigma. Stigma is cited by two participants as the one common denominator and unifying principle among consumer organizations. One person said stigma caused people to avoid asking for help. One talked about the particular stigma facing veterans with mental illness.

Amy spoke about the death of a prominent citizen in this State and said that stigma was partially to blame.
It just really hit me hard all over again, reading some of the things about the death of “Claire” and the fact that she felt so strongly that she couldn’t let people know because it would hurt her professionally and it just made it clear as to the depths to which stigma impairs access to treatment. I mean, it just made it so clear for people who think we’re getting past that and I feel speaking about it is another really important part of advocating for making headway (Amy).

Amy spoke about her own preconceptions and experience:

How could my life be in a place where I am in an in-patient psychiatric hospitalization and that’s that outside stigma, that whole way the world looks at it and I looked at it, and so through my own experiences and realizing as I got better that that wasn’t me, starting to read different things, just be more aware all of the debates (Amy).

Amy talked about the effectiveness of people with lived experience:

And yet we can be in recovery, even still struggling, still in treatment but be an effective advocate, so that becomes advocacy in and of it. And the simple advocacy statement that’s involved in being willing to be public about it.

She said that even though people still do not understand the role of consumer-advocates, she feels like there is progress.

I feel like people just still don’t get it. I have to step back and remind myself, no we’re really making progress and I know from external feedback that people feel that I am effective in helping making that progress (Amy).
Lynn reflected on the lived experience of consumer-advocates as a “core competency” for consumer advocacy.

What we really bring to the table is lived experience and that is really our core competency. To be able to share with other people that we understand and we know what you have been through. We talk about mental health, mental health condition mental health challenge, not so much an illness because it has a stigma associated with it (Lynn).

Dan talked about the added stigma those veterans with mental health conditions face:

I truly wish that they would listen to what us veterans have been trying to explain to them. I think the stigma out there that, because we are trained to do what we’re trained to do, I think there’s fear there. It definitely causes a stigma. Everybody seems to think the VA can take care of everything when it’s not a fact. We actually are your vets… People think they are killers, they are crazy, they are crazy vets (Dan).

Wes talked about the language that is used and how formalizing mental health issues can be stigmatizing and self-defeating.

So the way we view it, our program, it’s basically a first choice situation where we want to give value to you, whatever people find helpful, so some people find the language of “mental illness” stigmatizing and unhelpful. They want to do these things, but our general language has been to never use the word mental illness. Most of the people we work with have been institutionalized in psych hospitals. My biggest point to drive home is that we do people a tremendous
disservice by stigmatizing and formalizing mental health issues. I think that people are so worried about having diagnosis, rightfully worried, about having a diagnosis, having it follow them, having it impact their relationships and their work and everything else that people go through a tremendous amount of suffering to avoid getting into any type of system of care…so I think that if we had a situation where you didn’t need a diagnosis to receive care, we’d have a lot better mental health for everybody. It’s the hardest thing I think (Wes).

Wes talked specifically about the importance of lived experience that consumer-advocates bring to their work:

My feeling is that you just never really have empathy until you’ve experienced something that makes you have empathy. And so that’s the thing. I think that it’s like, that’s the hardest thing to do, so we always try to be telling our story, campaigns are produced, documentary, short film, and done different things like that. I think that people like to respond to a tragedy (Will).

Mathew, when asked if he feels effective in his work, talked about the effectiveness of the consumer advocacy movement:

I think so. If you look at the history of the consumer advocacy movement in the mental health field, and any movements like this, it takes people who, talking and figuring out where we can stand together and develop common language. It’s a long process of developing what that vision is and there are some people who have been doing it for decades under really trying and dangerous conditions that have been the torch bearers that have kept the momentum. So I don’t measure
effectiveness completely by has everything changed in the world because any significant change is going to take a lot of shifting underground (Matt).

Matt also talked about stigma and the complexity of receiving a diagnosis:

They can be horribly stigmatizing. I recognize there is for some people that actually are greatly relieved to get a diagnosis. I’m not really sure what to do with all that but I think there needs to be room for us to say that there’s different ways of seeing things (Matt).

**Finding 5: Bridging the gap:** This finding is significant because of the agreement on the biopsychosocial nature of mental health conditions among state administrators and consumer-advocates. It shows emerging consensus on the fundamental nature of mental illness. There was agreement among state administrators (five out of five) and consumer-advocates (five out of five) regarding the causes of mental illness; however consumer-advocates (five out of five) were more likely to stress the social factors contributing to mental health and state administrators (four out of five) were most likely to stress medical factors.

Mary talked about the diverse causes of mental illness.

It is a combination of genes, chemical imbalances in the brain and the environment. The way people live, the way they grow up, the way their parents live, what they learn as they grow up, the way their parents treat them, the way their friends treat them, any number of things (Mary).

Sandy talked about the trauma connections and the hereditary aspect of some illnesses.
I think it’s a variety of things. Also I think trauma can cause, well has a relationship to it, I don’t like the word cause. I think that there’s a genetic proclivity and a hereditary aspect to some mental illnesses such as schizophrenia. I think that illness, someone who is predisposed to illness can have a real exacerbation by using drugs and alcohol. So again, I think it’s quite complex. I think some people have truly endogenous, biologically, etiologically biologic illness and I think others may have illness that more evolved and developed from life experiences, impact on development (Sandy).

Phil is clear that he does not define mental illness as a medical condition although there may be chemical issues but more of a life condition which made his relationship with psychiatrists particularly challenging:

I wanted out of that position probably because I was not a mental health professional and I was tired of arguing with psychiatrists. I realized I would have to become one if I was going to stay in that job because there’s so much clinical knowledge you really have to have. So I don’t define mental health as a medical condition. I define it as a situation where, something’s happened in your life that has made it difficult for you to live in this current reality. They just can’t manage in this world for whatever reason and there may be a clinical component to that. I’m sure there is a chemical component to that but there’s more to it underneath. The first thing is to find out what’s bothering you and how you think we can fix it (Phil).
Nate talked about the complexity and is the only one to specifically mention the cultural component.

I think the term mental illness is very complex because it’s a really broad generalization for a thousand different issues and behaviors and norms and cultural expectations that don’t fit with kind of what we view as a society as sort of healthy behavior, pro social behavior, and so when you start to look at any one individual, there’s, it becomes very complex and kind of understanding what the issues are. I think it also is very complex trying to understand the relationship between the environment and the biology that’s going on (Nate).

Mark talked about the interconnection between genetics and the environment and mentions the early years of brain development:

I’m absolutely convinced that mental illness is about genetics to some extent. It’s about environment to some extent. It’s about what your parent’s make of the cards they got dealt. It’s what economic and social standing you’re born into, all these things can have a play, and they play out in the individual in one hundred thousand different ways, but there are some really key pieces about early brain development that are hugely impacting to people’s ability to deal with the stresses that could prevent mental illness (Mark).

This finding is important because it shows unanimity among consumer-advocates regarding the causes of mental health conditions in spite of the fragmented consumer system. Consumer-advocates spoke more at length than state administrators regarding the social factors contributing to mental health issues. One person strongly connected mental
health to one’s overall health suggesting that mental health should be integrated into healthcare. One person brought mental health back to his own personal experience with traumatic events. One talked about the continuum of mental health which we all exist within. One attributed mental health issues to social factors and in particular to get one’s basic needs met. One said that mental health conditions were connected to individual, family and community relationships.

Amy, when asked, said that there is not such a thing as mental health and “physical health” which she acknowledges as an equally limiting term. She talked more in terms of the social determinants of health.

I would say my number one goal is to really have a healthcare system that is a holistic health care system that recognizes that there is a continuum of all of our healthcare in which everything relates to everything and is integrated and that means what’s going on in the neurons in our brain, what’s going on in our environment, what’s going on in the pressures of life that affect our heart and our blood pressure and that affect our aging and affect all those things and that affect our well-being and affect our ability to have a healthy mental status. They’re inseparable and indistinguishable (Amy).

When Amy was asked about the connection between the medical model versus the social she said:

I think it’s a ridiculous fiction. Holistic health care for any kind of health conditions should not be a medical model, whatever medical model…all of health is bio-social-psycho and that’s what a holistic health care system looks at (Amy).
Amy feels strongly that mental health is connected to overall health and said that the Department of Mental Health should be integrated into the Department of Health.

I support it being joined… We will not have achieved an integrated system until we’ve eliminated the Department of Mental Health. That has to happen… the existence of a separate Department of Mental Health will always be the strongest indicator of whether we’ve achieved the vision (Amy).

Amy again mentioned stigma and labeling as an issue related to the definition of mental health and does not like the trend of reframing mental health as behavioral health.

I think it being called behavioral health traps it so much into a stigma because it is labeling it as something that’s a social stigma about behavior. So I think a lot of how it originally was defined as an illness had to do with people categorizing this person’s like weird, acting weird so we gotta do something about it. I’ve never thought of it in these terms so I’m really going kind of off the top of my head.

What do I think? I think that it is a health condition that influences a person’s ability to engage with the world in a way that makes them be able to grow as a person and interact with society… I think the term mental health condition makes it less stigmatizing (Amy).

Dan agreed that there are a variety of causes contributing to mental health conditions and talks about it from a personal perspective:

I think there are a lot of causes. My case, I had some brain damage I didn’t know about. I went through a lot of childhood abuse that I didn’t want to talk about. I had a big family, a lot of brothers so there was a lot of physical abuse there. Back
then everybody had to be the toughest and so I think it’s a combination of a lot of things can cause mental health issues. And I think some of its hereditary. My mom’s mom was in the hospital a lot for depression and stuff so I imagine something might have come down the bloodline (Dan).

Liz also sees mental health through a comprehensive lens:

I kind of look at mental wellness and that there are different degrees of a person’s wellness and your capacity to be able to function. It consists of many different things. I look at it as physical, spiritual kind of all-encompassing because if that is out of balance then your mental health gets out of balance. I kind of look at it as an overall well-being of the person themselves (Liz).

Wes sees mental health mostly from a social perspective in which a person’s needs must be met for them to have a foundation for being healthy.

We view mental health issues or mental illness as sort of whatever is left over after you responded to the hierarchy of needs. If somebody has social connection, has shelter, they are doing something they feel good about, they have access to creative pursuits and whatever, if you’re doing everything you can to make them be a happy, productive, healthy person connected to their community, and they’re still having issues, then that’s what we kind of look at…we assume that the vast majority of people have pronounced trauma backgrounds and are living in poverty and are probably dealing with multiple issues…and so we personally don’t ever use any diagnostic language unless someone prefers a diagnosis (Wes).

Wes talked about getting away from definitions altogether.
One person is eccentric and somebody else is deranged and who’s making that
decision? Is it based on their social status…? We are pathologizing human
experience as time goes on and finding new diagnoses for things that used to just
be part of human behavior… There is research in which providers, are given case
studies and they’re basically told to make a diagnosis and they’re so wildly
different that it’s just hard to take it seriously as a scientific study… I feel like the
DSM, being linked to service and to payments for a service for a care is a
disservice to people because it’s like you have to submit to diagnosis to get care
(Wes).

Mathew talked about mental health in terms of personal and community relationships.

Yea, I feel like what we call mental health conditions are disconnects in the fabric
of our relationships, whether that be in our familiar relationships, our community
relationships, one on one relationship… I think that there’s a trend within our
society that puts more and more responsibility into government and isolates
different aspects of our existence and I think that in and of itself is feeding into
what we call mental health issues because it’s creating this disconnect and
isolating people. We’re social creatures (Mathew).

Mathew sees a value in a medicine but wonders about its place in mental health:

To try to shoehorn this thing, to say that well it’s a brain thing and that’s
something broken in the brain. I don’t really buy that. I think that there could be
components of that and there could be pieces of organic dysfunction… but I think
at the core of it, you’re talking about how do people feel okay about the world
that we live in and feel okay about their life and there’s a lot of reasons to not feel okay about that and so, just to say to someone yea, of course this is going on. You’re not the only one because there’s all this stuff happening in the world. I know how you feel (Mathew).

The Bridging the Gap finding is also important because state administrators (100 percent) and consumer-advocates (100 percent) agree that mental health is a considerable problem that needs a robust system with considerable personnel and financial resources. This finding is important because each person problematized mental illness to some degree. Nobody in either group said mental illness was not a problem or that mental illness was just part of an everyday experience. Each person thought that something needed to be done about it. State administrators talked broadly about the social problems associated with mental illness. All thought mental illness was either increasing or was persistent. Consumer-advocates went on to consider the different kinds of problems associated with mental health. All five consumer-advocates said there was an increase in the number of people who have a mental health conditions but cited diverse reasons for this increase.

It is not surprising the state administrators working in the field of mental health thought about mental health issues as a problem in some way. Three administrators saw mental health as increasing and three saw mental illness as not being truly accepted by the medical profession. It is also important to note that two strongly made the connection of mental illness to violence. Two referenced the growth of mental illness was due to the proliferation of diagnoses. One cited stigma as a major problem because it seemed to
inflated the issue of mental illness as a problem in society. One person saw it as decreasing even while noting it is a serious problem.

Mary said any increase may be due to broader recognition of mental illness as well as the ability to pay though Medicaid. She said that if there is a problem it is because it does not get the same recognition and support as health care.

It’s something we have to deal with. I think it’s at the low end of the healthcare spectrum. I know incidence and prevalence rates and things like that. I don’t know if they’ve grown over time or not, so I can’t speak to that. But it’s definitely a stepchild in the health system and people overall think it’s very important and want something done about it, but they want somebody else to pay for it but that’s true about a lot of things and not just, not necessarily mental illness. I think it’s certainly over the last 10 years, the inclusion of mental health among the kinds of conditions that insurance companies have to pay for have brought it closer to, the national consciousness anyway has been rising about that as a legitimate issue.

They were more aware of it now (Mary).

Sandy talked about the increase in mental illness among the elderly, the impact of media and the continued presence of stigma and how stigma affects health care and emergency services.

I think that the number of people who are elderly and/or aging with concurrent organic and possibly mental illness who have no place to go and there’s no treatment, that population I think is increasing and I think it’s all exacerbated by a lot of different things. One is stigma, which amazingly, even after all these years,
at least I’m old, so after all these years, I’m sometimes still surprised at the level of stigma that there really is out there. And I think people are, medical systems for example, hospitals, emergency departments, are very reactive to somebody who comes in with a label of mental illness, and there’s a lot more discussion about it in the media and so on and so forth. So that I think raises the threshold, or maybe it lowers the threshold of tolerance. Therefore making it seem like we have a lot more mental illness today than we have had in the past. But if you contrast that with let’s say the number of mass shootings across the country, you know, one could say well, look at all of that. Anecdotally it would seem that that’s really increased but I don’t know that really has or whether we’re hearing more about it these days. I think the other piece is the media, social media, and how quickly we all get information and how that information as it’s transmitted, sometimes is embellished upon. Does that make sense? (Sandy)

Phil said that mental illness is a significant problem and it has to be addressed early and systemically to have an impact.

I think I’ve said enough. It’s a huge problem. What I’m learning now, in this primary care world, is how much we’re dealing with is really based on mental health issues and trauma. And I’m trying to get people to understand, if you really want to have health care reform, you gotta deal with this issue. You can do everything else you’re talking about. You can cut down return times to the hospital. You can put up a new website. You can insure everybody but if you do not address early on and effectively the mental health and emotional health issues
that people have, they are going to continue to have poor health. So that’s something (Phil).

Nate, when asked if mental health conditions are increasing, said, “Yes.” He did say that mental illness is a growing problem and can be associated with violence but said there are effective ways to mitigate this:

It’s a very complicated issue because it’s in everyone’s human nature when they feel any level of threat or danger, our first instinct is to control and to clamp down on that danger or that risk and when you’re, the easiest way to do that is to give someone medication or to grab onto them or put them into a room. People will always tend to use that unless they’re trained incredibly well and certain understand that so it’s a very challenging issue (Nate).

Mark talked about the problem through the lens of serious mental illness, violence and hospitalization.

You know when you’re dealing with people with severe psychiatric illness, you can always do better care, more informed care, more trauma sensitive care that may greatly reduce patient assaults but these folks come to these facilities because of the level of dangerousness. It is part of the reason why they got there and the unfortunate reality at this time is that the risk of harm to staff is high. The state hospital had four times the rate of injury as the next closest department, which are military affairs. The National Guard was at war and we had the highest workman’s comp claims. Staff were getting injured and undergoing tremendous levels of stress and coming back to work (Mark).
Like state administrators, consumer-advocates thought of mental illness as a problem in some way. However, consumer-advocates talked about it differently and were most likely to see mental health as being imposed on the individual by society: Three saw mental illnesses as not being truly understood and accepted by the medical profession. Two said that any growth of mental illness is due to growth in new diagnoses. One said that mental illness could be the cause of violence. One said that mental illness was the product of a violent society. One said that any growth is due to more media attention to mental illness and more openness about mental health issues in general. One cited stigma as a major problem because it seemed to demonize mental illness as a problem in society. Amy saw the growing problem of mental health linked to the growth in pharmaceuticals. It grows when the pharmaceuticals have found a new drug, but you know we do that with everything, and we forget that sometimes when we look at mental health. That it’s not just about mental health and a really easy example is the need for toddler car seats. When did all the states pass all these laws saying you had to have a kid in a car seat up to age six? Do you know when? It was when the designers and manufacturers of toddler car seats started producing them (Amy). She continued by suggesting that new drugs can be developed or over-prescribed in order to curb undesirable behavior. It’s a really fundamental important thing when we say, well some of these kids are disruptive and the other kids can’t learn and all that we need is to put them on medication to quiet them down. What are we destroying? You know the heart of creativity. But it’s important to keep it in the context also of all of medicine in the
United States, all of western medicine. We want the quick fixes of the pill. We don’t want to go out and exercise or change what we’re eating. We want the blood pressure pill, and we’re simply addressing mental health the same way. We want to fix it with a pill instead of doing the things where we work with the kid and his family to say, how we can channel these really good parts, but make it work. You’ve got to work in a real world out there (Amy).

She concluded by saying that labeling is increasing not necessarily mental health.

Well I think labeling is increasing and that’s that interrelationship because we have drugs, therefore we want to treat people with them but also we want to be fixers. We want to fix things and make it better and so we’re over-labeling them (Amy).

Dave thinks mental health is a problem that is growing because of economic factors and the co-occurrence with substance abuse.

I think it’s a huge growing problem. I think even more with the younger population now. One due to the economy, I think especially with the new type of synthetic and streets drugs that are out there. We’ve got heroin epidemic. We’re working with several vets now, Iraq Afghan vets that are in their early 20’s that are coming in all hooked up on heroin and didn’t even realize they had PTSD on top of it so it’s just making anything so much worse. I don’t know if there’s a way to categorize it but I do believe it’s a bigger problem than what’s being addressed or there wouldn’t be what 87% of the population in corrections with mental health illness (Dave).
Dave also connected mental health to violence:

I think with untreated mental illness the violence would be very high.

Schizophrenic, bipolar, even PTSD. If it’s not treated, then we can get pretty violent (Dave).

Liz thinks that mental illness is not growing as much as it is finally being recognized.

Statistics you know one in four may be affected. I think the more awareness we bring to it brings to light how common it is. If you can get people to start talking about it we can bring it out into the open and that it is a lot more common than people think. I don’t know that it is growing. It’s always been there. I just don’t think that people want to talk about it (Liz).

Liz is the only consumer-advocate to say anything positive about the DSM in suggesting the DSM can bring more awareness.

I think it (DSM) is positive. I think the more awareness you can bring to it and educate people to what it is all about then you are reducing stigma and that really helps in people’s recovery as well because there then more apt to want to get help (Liz).

Wes thinks the growth of mental illness is due to the DSM and the addition of diagnoses.

We are pathologizing human experience as time goes on and finding new diagnoses for things that used to just be part of human behavior. You look at the massive expanse of diagnosis for hyper attention deficit disorder, childhood bipolar and medication rates for children with those issues. As one particular example, you know women are often given dissociative identity disorder,
borderline personality disorder that men wouldn’t get with the same circumstances. The DSM, being linked to service is, to payments for a service for a care, all these things is a disservice to people because it’s like you have to submit to diagnosis to get care (Wes).

Wes does not see mental illness as particularly linked to violence.

In my personal experience, I’ve been here for about three years, work with about 300 unique individuals per year, I think I’m aware of two physical altercations that happened on premises, so I think about next door an apartment building, how many might have happened, and it’s hard to think that it could have been less, so I don’t think that there’s an innate connection, but I do think that a lot of people have mental health issues because of violence and they’ve survived (Wes).

Mathew said that mental illness is a problem and that it is a problem that our society has created mainly through violence.

I think it’s a huge problem. But I just think that it’s a lot broader than a diagnosis. We look at mental health conditions as the people who get diagnosed and who are kind of creating these issues, you know whether it’s with police, or with hospital, and the whole thing but I think that when we start looking at all people individually, we have a hard time living together. Collectively, I mean that comes down to what is my struggle with being a person in this world. And so that’s really what mental health condition is in my mind. It’s how do I interact with other people in ways that create hurt…We haven’t really evolved tremendously far I think in terms of, we call this thing civilization but we’re still really treating
each other pretty badly in a lot of ways and it’s a violent world. Violence is at the core of things that really creates a lot of the biggest problems, creates all problems essentially. And we all have a role in that in some form or fashion (Mathew).

In the Bridging the Gap finding there was agreement among state administrators (100 percent) and consumer-advocates (100 percent) that there should be a variety of strategies when working with people with mental health conditions and all five supported forced medication, restraints and hospitalizations to some degree as strategies for treating people with a mental health condition. Consumer-advocates were more reserved and cautious than state administrators when considering forced treatment. Each of the consumer-advocates agreed that involuntary treatment including medication, hospitalization and restraints were sometimes necessary but each agreed that it should be used as a last resort.

It was clear that state administrators saw the need for many different strategies including peer supports. However, each, even those who strongly support peer work, saw coercive treatment as necessary at times. The following are comments participants made in response to questions on strategies.

When asked, Mary talked about a continuum of services from community integration to hospitalization depending on the level of need.

Depends on what it is. It could be a combination of, I think, medication, environmental changes that can help, all kinds of supports for people when they can’t do the things they need to do for themselves. I think giving people a sense of purpose. Giving them hope. There is a large spectrum of levels of care, if you
will, that will fit a large spectrum of mental illness and the symptoms that are presented. Hospitalization for a time is at one end of it and having your own apartment and telling the community system to go do its own thing and you’re fine, that’s another end of the spectrum (Mary).

Sandy said the strategy depends on the person and the illness and readily acknowledges the use of hospitalization.

It depends on the illness, depends on the person. I think open dialogue is a really wonderful intervention and even though it’s sort of new, it’s not new at all but it’s basically involving a family in social system in treatment. I think being able to give the person receiving treatment as much involvement in determining what their goals are and how they’re going to get there. Engagement is really important. I think those are a couple of the things. I did think that some people need access to different levels of care at different times and so having a good team of people on your side is really helpful for that. So if you need to be in the hospital for a short period of time, there’s a plan in place. I think having a treatment plan that follows the person; I know I’ve been saying this for years to everybody who will listen to me. One treatment plan follows the person wherever they go so that there’s consistency (Sandy).

Phil talked about an overhaul of the system and once again mentions the need for early intervention before people need hospitalization. He suggested natural supports over traditional treatment.
I think the whole treatment system needs to take a different approach. Right now, you don’t even come to the attention of the whole system a lot of times until you hit a crisis, so you have a psychotic break and you end up walking down the Street naked or something and then the system comes and gets you and you go to a hospital, or you go to an ER and determine whether you need to go to the hospital, then you go to the hospital, then people are trying to get you to take medications and all that kind, I really think we need to intervene differently and find a way to divert people from that system and give them peace and quiet for a little while. A lot of people with mental illness, they are not dangerous. We put them in a hospital because we want to control them. Well, there’s other ways to control people that are less coercive. While we assess what’s going on and I would definitely be exploring everything but typical mental health treatment in the beginning. What is really going on in your life? What would really make a difference? And there’s plenty of literature that talks about if you just give people three weeks or four weeks of concentrated support while they work through this, lots of times, even in the serious schizophrenic breaks will decrease. The same thing, there’s literature about depression. The people with depression will work it out if you just support them and keep them safe. That’s different than putting them in a hospital so in terms of strategies; I would investigate every possibility that’s out there (Phil).

Nate thinks interventions need to be informed by science. He talked about both chemical and nonchemical interventions.
I think it really has to be informed by science but at the same time informed by personal experience and preference and the experience of other people who have gone through the same thing. I think in an ideal world you’re continually researching and examining what are the chemical and nonchemical interventions that you can do to help a person’s brain shift and put them in a place of healing (Nate).

Mark who spoke about the need for hospitalization and the connection between mental illness and violence also sees recovery and patient-centered choices as useful components.

Recovery works and patient-centered choices work. Most people have a low level of mental illness, some anxiety, some depression. Maybe mental health is not any different than getting some male pattern baldness (Mark).

When discussing coercive treatment Mary said that forced restraint has to be the last choice:

Again, that’s the thing that I think the less you use it (forced restraint), the better and the more judicious they use the better. Situations can arise. Those would I would characterize usually as emergency, but I’m not a clinician so I don’t know it all. You can’t trust me with any clinical thing. That’s a judgment call but definitely the less the better. There are ways to reduce it and we are having a trainer come up here now as a matter of fact for the staff at the state. There are ways to do without it (Mary).
Sandy, while acknowledging the need for hospitalization, does not think that forced hospitalization is the answer. She said that there can be better interventions, like therapy, in hospital settings.

Can I say one more thing about that? One of the things that I think is really missing in some of our hospital settings is therapy. We don’t do therapy anymore and I know I’m old, but there’s a place for providing therapy, whether it be psychotherapy, behavioral therapy, and cognitive behavioral therapy. I think our hospitals have kind of become medication dispensaries more than really offering treatment (Sandy).

Mary acknowledged the need for forced medication:

My views on forced medication, I have to say is that I think it’s necessary sometimes. Well, I write that Act 114 report…So I think there are situations in which that kind of medication is the only way. And the terrible thing is, in those situations too, it does not, the medication can bring them around and uncloud a cloudy mind but then they perceive the experience as bad and so there’s a payoff there (Mary).

Nate said that forced medication is a necessary evil until the system evolves:

In our current system, given the staff that we have, the competencies, the programming, I think there are situations where it is helpful. I think it is possible for us to create a system in our workforce and programs that can manage anyone, without the forced use medication but I think right now with what we have, it is a necessary evil (Nate).
Each consumer-advocate seemed genuinely concerned and conflicted as they acknowledged the need for involuntary treatment even as they spoke against it and hoped for better solutions.

Amy talked about involuntary treatment and in particular forced medication if the person’s ability to make decisions is compromised:

I think what we miss out on in the whole discussion is making a clearer understanding and distinction about the issue of having the capacity to make a decision and give consent when somebody truly doesn’t have the capacity, then in all of our health care, somebody else has to make that decision for them and, this is anonymous and all that, ‘cuz this is so easily misconstrued. The fact that it’s involuntary may sometimes have to happen because the judgment is being made that this is what the person would have wanted if they had the ability to decide and they had the ability to judge. This person cannot give their own informed consent, so somebody else has to do it, and has to do it judging the risks and the benefits and so forth (Amy).

Amy talked about her own experience and the use of an advance directive for the time when she may not be able to make competent decisions:

I did an advanced directive once although I never turned it into official legal advanced directive but I basically said, I’m a person who loves life. And so if I’m in a place where I am so desperate, in such anguish, that I feel my only option is to die, I want to die, then I can tell you right now, that’s not me speaking. That’s
not the real person I am. That’s an illness speaking so I don’t want that person to be listened to (Amy).

Amy said that hospitalization may be needed but that cannot be the goal:

There are some situations where for safety reasons, but I mean the goal in all of health care is about being able to be in your home community, whether you’re an elder person or you’re a person with a severe mental health condition (Amy).

She also spoke more generally in favor of involuntary treatment making an analogy to medical care:

I mean, restraints and seclusion and emergency involuntary medication is a whole other realm from treatment as a whole without consent. Yes, there are other circumstances where we involuntarily contain people because of an illness, because they’re a danger to other people and they’re refusing to comply such as tuberculosis (Amy).

She suggested that we would not think of involuntary treatment so differently if there was parity between mental health care and medical care. She also said that this lack of parity means we need to have additional protections in terms of involuntary treatment.

It is sort of similar to the idea of affirmative action. When you have a history of abuse and a history of stigma, sometimes you do have to protect more than. It does need to be parity plus until you really get to the place and until we’re really color blind, until we’re really illness blind. We do need additional protection (Amy).
Dave talked about his own personal experience with medications and that of his friends. He very reluctantly acknowledged that involuntary medication may be needed at times.

I’m not against medicine. I think in the beginning of my recovery I needed medicine. I’ve not been on any kind of psych meds for five years so I’ve done really well without any of it and I feel better. Physically I feel better without it, but I’m not against it. I don’t know if I’m for forced medicine but then I could see if somebody was that much of a danger, why it may be needed, but I’m not into, I don’t know if I’m a huge believer in 30 years of meds. I think there’s other alternative methods that could be used out there. Whether it’s meditation, I use a lot of that. I’ve got some people that are on acupuncture now using it. Some people are doing yoga. I’ve got a friend that’s a veteran that does Native American sweat stuff. So then, interesting ‘cuz I do have a couple of personal friends that are schizophrenic that probably will have to be on some kind of medicine the rest of their life. It depends on what illness you have I think (Dave).

Dave also sees the need for involuntary hospitalization under certain conditions:

I believe in all strategies. I think somebody’s, we deal with quite a few, actually had a female veteran that had a suicide attempt. I think hospitalization was the right thing for a while. She actually had to go into the 72 hour watch ‘cuz she wasn’t going on her own and actually us peers pushed for that with one of the doctors at a local, actually that was a local hospital and that doctor really accepted us (Dave).

Dave talked about involuntary hospitalization from a personal perspective:
I got locked up at the state hospital for a 90 day evaluation and I really don’t think I benefited from that too much… I think that really kept me away from recovery even longer. When I got that all way behind me, I said no way man, I’m not going to talk to anybody about anything. So I’m not saying no confinement, I think it’s necessary in some cases, but I think sometimes it was definitely overused (Dave).

Dave also acknowledged the need for involuntary medication:

I know a couple cases where it needed to be used, so they were safe and their family was safe and the community was safe. But it’s a really hard thing for us peers to swallow. I think because we have it (mental health conditions), it just makes it a little harder, but logically I think it does possibly need to be done, just for the safety of the own person themselves (Dave).

Lynn also acknowledged the need for involuntary treatment:

We want to be able to have zero you know seclusion; restraint there may come times when some of these procedures may have to happen. We really want the organizations that need to do this to debrief and figure out best practices and strategies so that they can eliminate and reduce seclusion and restraint as much as possible and from what I have seen the Department of Mental Health is doing an excellent job with providing education and training to be able to move in that direction (Lynn).

Lynn feels the same way about hospitalization:
There are times where it is needed. People need help and the longer you go
without getting help umm you get worse. Treatment is really important that
people get treated whatever that treatment might look like (Lynn).

She continued to say that involuntary medication and medication in general is the only
answer for people with a serious mental illness;

I think depends on where the person is the person might be very ill and they do
need medication and they might need it for a very long time and some people may
need it for a short time when they get balance in place and they get other supports
like counseling you know peer support whatever that might look like so I think
that each individual needs to figure out where that balance is for them but when
you are severely mentally ill medicine is the only answer (Lynn).

Wes talked about the tension that involuntary treatment causes among and within
consumer-advocate groups:

The most loaded issue is really involuntary confinement and forced medication.

So there’s a lot of collaboration amongst peer programs and consumers,
providers, until you kind of get to the nitty gritty of like who should have what
course of treatment (Wes).

Wes is concerned about being vocally opposed to involuntary treatment:

I don’t think I’ll be effective in the system if I define myself as a really radical on
certain issues like coercion and medication. I also have a tremendous amount of
pressure from my organization from folks on the board and people who have been
here a long time to be extremely damning of forced medication and coercive
treatment and so it’s just one of those things where I’ve tried to walk the line and I don’t know if I’ve walked it well enough and I also am conflicted (Wes).

Wes is conflicted but does think that involuntary treatment can be an appropriate intervention:

I haven’t been forced into treatment or into an institution so I do have some conflict because I do personally believe that there are situations where that stuff is life saving and helpful and I have worked with some people who have responded really well to that, that weren’t probably gonna be okay otherwise and so I think that, I don’t personally feel like we’re in a society where we’re ready to eliminate that from our system of care and I think that as long as it’s part of what we do, we need to keep communication open to be able to actually have influence and collaboration in that process (Wes).

However, Wes did show concern for process around involuntary treatment:

But I don’t think it’s as good as it needs to be. I’ve actually recently visited some folks who we work with who, who are in involuntary treatment and just had a lot of reservations about it all and did a lot of research on the statutes and you know the way that it’s set up now, anybody that’s an interested party can basically make a recommendation that a person is in need of treatment and so that can be a lay person, it can be a family member, a parent, a police officer, medical professional, whatever and the framework is all very subjective. You know the person I was visiting, we’ve worked with every day for three years and then they got hospitalized for behavior that we dealt with every day (Wes).
Mathew is conflicted but acknowledged the need for involuntary treatment at times:

I can definitely see forced hospitalization I guess is the tool that we have now, but forcing people, restricting people’s movement is what it comes down to. Forced medication? Yea, within a hospital. I’m definitely opposed to it on principle. I also empathize with what’s going on in hospitals. I still think that’s somewhat of a sellout collectively. I don’t think that we’re built the bridge to do something differently. I don’t think it’s reasonable to expect people to be going into work and have someone who’s highly assaultive and we don’t have adequate structures in place so I think it’s really an indictment of society that this is where we’ve gone with things and that we haven’t come up with something better. I think that people can be conscientious but that you lose perspective of when it’s really necessary and when it’s not and when it’s your only tool, it’s going to get overused. Seclusion and forced medications, it’s incredibly traumatizing for people who experience it and I know that people say that there’s people who say that they’re thankful that it was done to them. I haven’t talked to that person yet. So I think it’s ultimately really unhelpful for the person and for our communities, for what it does for the person in the communities. I think it’s a short term solution of a problem that’s in the moment and I think that a lot of our short term solutions are creating more problems for us down the road so we have to come up with a smarter way of doing things. But so to me I recognize that yea, there’s people who need to sometimes (Mathew).
Finding 6: Finding common ground. There was agreement among state administrators (100 percent) consumer-advocates (100 percent) that the relationship between them needs to improve. Five out five state administrators and three out of five of consumer-advocates said that the best strategy for working together is to develop better communication. Three out of five state administrators said that the relationship with consumer-advocates needs to be ingrained in the system. Three said this systemic approach can be done by hiring more consumer-advocates and one said the relationship should be mandated in legislation. All five (100 percent) consumer-advocates thought the relationship between state administrators could be improved. Four out of five consumer-advocates said greater communication and dialogue was important. Three out of five said that the state should better integrate the consumer voice into state services.

Each state administrator pointed to the need to develop better communication suggesting that, in spite of the existing opportunities and forums to interact, the communication still suffered. One administrator pointed to embedding people with lived experience into the management structure of the mental health system as a way to overcome historic and current group differences. When asked, Mary said a more trusting relationship needs to be developed:

Listen to each other. Develop a more trusting relationship. And these days of fairly widespread anti-government feeling that’s hard to come by sometimes.

People don’t like government because it’s government (Mary).

Sandy said that identifying mutual goals is important:
I think what’s working well now is having opportunities for ongoing discussion and communication. I think identifying mutual goals. Is a really important thing because sometimes I think we all forget that we actually do have mutual goals (Sandy).

Phil said that advocates or people with lived experience need to be brought into the system and not be external to it.

The most important elements of working well together is being able to have a civil discourse in a way that assumes that everyone’s trying really hard, even if they may not be. Assume that people are well meaning and that no one here is the bad guy and that we actually are even on the most controversial or difficult issues, trying to get to the same place for the most part…I’m biased because I’m part of the state, but I think we’re in a period and in terms of American history, in which people are trying to improve the system and listen to people who are the recipients and make changes because of that. There was a time, as recently as two years ago, when advocates would come in and sue and break down the doors and throw everything at you. I think the other thing we have to do is, not just walk a mile in each other’s shoes but trade shoes. We need people with lived experience everywhere, at the legislature, in the Department, in the governor’s office and running designated agencies… rather than being this external advocacy group that’s always knocking on the door saying you need to change. We need to have peers in every kind of position working, who are open about their lived
experience, you know, psychiatrists, executive directors, case managers, across the board (Phil).

Nate talked about how the system is responding to the inclusion of peer advocates:

I think we are past that stage where people think it is just something we have to do. However, I don’t think we’ve systematically implemented it in a way that makes it really meaningful for consumers. I also don’t think we know what to do with all this feedback besides sort of cringe, like here we go, we’re going to get toasted again. We don’t have a continuous quality improvement model of how we take the advocacy and the peers input and really do a lot with it (Nate).

Mark thinks that only legislation can bring consumer-advocates and peers together.

I think it’s probably legislation. For example, if you looked at Act 264, which is the act that brought education, mental health and schools together, before that act happened, everybody had their separate plan. They all thought they had the best plan, and nobody could make them come to the table and make an agreement. That act changed everything so that now they all have to work together. It took Act 264 to bring everybody be at the table. Legislation could bring peers and administrators together (Mark).

Three consumer-advocates said there was need to develop better communication and trust and three said there was a need to embed consumer-advocates in the state system.

Amy said the fundamental strategy is better communication in order to develop a sense of trust:
Gotta talk and talk and talk and talk and be willing to listen. I really believe in that
the process of debate, the process of disparate views, kind of wrestling it out.
There’s always a problem when you don’t have a level of trust that you’re trying
to get to the same place makes it harder, but you still have to keep trying (Amy).
As referenced in another finding she talked about the misuse of meetings and argues for
these meetings to be ingrained in the system:

So I don’t think the meetings were being used in the way it was intended and
then the commissioner decided that it’s taking up too much time and isn’t a value
to him. Of course he’s not using it the way it was intended and so now it’s being
cut back, maybe quarterly, whatever. I think the legislation expires on it maybe
next year and he’ll probably advise, I don’t think we need it anymore, so
sometimes when you don’t have something that’s part of the infrastructure, it ebbs
and flows by individual personalities (Amy).

Amy’s goal is to integrate the mental health and physical health systems:

Why in the world would we want to pass a bill that says we’re reforming the
mental health system? Why weren’t we reforming the mental health care
components of our health care system? We’re still endorsing it being a separate
system with care in effect. That’s how much we don’t get it. We will not have
achieved an integrated system until we’ve eliminated the Department of Mental
Health …But the existence of a separate Department of Mental Health is like the
strongest, will always be the strongest indicator of whether we’ve achieved the
vision (Amy).
She talked about the need for a consensus between state administrators and consumer-advocates on the vision:

We have to have an end vision because if we don’t have an end vision, then we can’t keep our eye on the prize, because there is no prize, and we don’t know if we’re even doing things in the right direction so we’re doing these little steps where we think, okay, we’re working towards integration (Amy).

She said the integration will improve medical care for people with mental health conditions as well as mental health care and provided a personal example:

Right now in the health care system there are physical complaints of some sort or the other being ignored. I have my sister-in-law who died of internal hemorrhaging after being sent home from the doctor who said she had a psychiatric history and it was all in her head (Amy).

She argues for an Office of Consumer Affairs within the Department of Mental Health.

I’m not that familiar with other states but I know they’re states that have been actually offered office of consumer affairs where they’re kind of more recognized as a voice in the system (Amy).

As referenced in an earlier finding Dave is looking for more of a focus on veterans and for understanding, trust and to be listened to.

Well, honestly, what’s really sad, like I said I’ve been doing this almost eight years, I want to get this politically correct, there seems to be a little, and in our case, I’m talking for us veterans, there’s a little bit of favoritism to the civilian side, and I don’t know if it is because of the stigma of us veterans being, because,
you know how people thing of veterans... We come along and ask for something or can we do something, it’s kind of heard but not really heard or we are told, okay, we’ll look at it, then you never hear back from it (Dan).

Dan said the veteran peer group could use a peer center of their own:

We just want that little piece so we can have our center and... We’re only asking for one, if you can have 13 for civilians, how about one for us (Dan).

Lynn suggested that because she is new she does not have recommendations but thinks that the state is on the right track even if there is a “ways to go”:

Because I haven’t been in this role a very long time what I’ve seen especially coming from my background in organizational improvement they are doing good I would say I know that there is definitely a ways to go but I think they are heading on the right track (Lynn).

Wes thinks there is a need for greater dialogue between state administrators and consumer-advocates:

I guess what I’d really encourage, what I try to do any chance I can, is to encourage a dialogue so that you know, we set aside our preconceptions of like, I think people really approach this with an agenda. We’re right, you’re wrong, peer good, medical bad, medication good, bad, whatever, and I think we need to just say, we’re all involved with this work because let’s give each other the benefit of the doubt, that we care about the people we’re working with, and we feel the need to be involved in helping people’s lives be better, so can we really just sort of put
aside differences in opinion, belief, method, whatever and just really ask ourselves the difficult questions of like, what do people need the most (Wes).

Wes talks about the need for greater collaboration in general and the need for incentives and accountability:

We need to create incentives that reward collaboration and really have not just accountability but accountability for outcomes, for saying that I worked with this person and it was clear that they did need psychiatric care and so I referred them to this person and there’s a way of linking to see if that actually worked and it was the right thing that was helpful and then we together get credit for having to do that (Wes).

He talked about creating a system that focuses on prevention and on the individual:

I think we’re in a system where it’s really emergency based. People are feeling the need to respond to sort of the worst situations because everything’s based on liability and money and insurance and everything else. We are robbing ourselves of the opportunity to be preventative and work with people a lot sooner before just putting out fires. I think it’d really, you have to be willing to have an individualized approach and it’s harder than having specific rules (Wes).

Wes said that if the State hired consumer-advocates that it would bring empathy and understanding into the system:

That would be the biggest change we could make. I mean, and I think, I’ve done a ton of briefings with people in the community mental health agencies and I think that’s the thing they feel the worse about. Like they wish they could talk about
their lived experience. They wish that they could infuse clinical work with that but there’s sort of protocols around boundaries and ethics and things related to how organizations work or how that code of, you know, if you’re a licensed clinician, what you’re supposed to do and not supposed to do and all of that (Wes).

Mathew said that bringing consumer-advocates into the state system is the best hope for real change:

That seems like a real change that could happen, having consumer-advocates just completely be invested and indebted in the system (Mathew).

**Findings from the Document Review of State Administrators and Consumer-Advocates**

A review of documents from both state administrators and consumer-advocates reinforces four of the findings found during the interviews. This includes:

**Finding 2: Seen but not Heard**

**Finding 3: Divided We Fall**

**Finding 4: Walk a Mile in my Shoes**

**Finding 5: Bridging the Gap**

**Finding 2: Seen but Not Heard.** During the interviews state administrators clearly expressed the important role of consumer-advocates and their desire to include them in the mental health system. However four out five consumer-advocates felt marginalized and left out of the process and one state administrator said he thought the effort to include consumer-advocates was more token than substantive and three other state administrators
generally spoke about the difficulty of including consumers for a variety of reasons. The documents cited support this gulf between what state administrators say they want to do or are required to do and how they actually include consumer-advocates in the mental health system.

**Document Source: Department of Mental Health Website Materials (commissioner letter, mission statement, meeting minutes)**

The purpose of the website is to let the public know about the mission and goals of the department, announce public meetings, post minutes to those meetings and provide links to mental health resources. Mary, the quality assurance specialist interviewed for this study, is the person primarily responsible for maintaining this website. The documents cited include a message from the commissioner along with the vision and mission statement for the department. These documents are on the homepage of the department’s website and are meant to provide an introduction to the department’s philosophy and work.

In the documents the department challenges itself to change the culture within the mental health system and embrace the concepts of recovery. According to the federal agency administration for substance abuse and mental health: “Recovery is a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential” (SAMHSA 12/22/2011).

The documents on the website embrace the concepts of consumer supports yet they talk about this from a position of helping people with lived experience succeed
rather than having them help direct the mental health system. Here is an example of this approach:

The individuals and families we support in our communities want the same things we all want: safe homes, close friends, loving relationships, good health and something meaningful to do each day. Our job is to help them succeed.

The documents express the desire and vision for people with lived experience to be in charge of their own recovery but again do not mention their role in the mental health system at large: “The Department is working toward its vision of self-determination, resiliency and recovery.” According to the website the state mental health agency engages consumer-advocates through a variety of committees including the State Mental Health Planning Council, the Transformation Council and through an initiative to build a statewide peer network.

The Planning Council is comprised of a wide range of stakeholders including adult consumers of mental-health services, family members, parents of children and adolescents experiencing a serious emotional disturbance, providers of mental-health services, advocates, and other interested members of the community. Membership on the Planning Council is through appointment by the Governor of the State, as delegated to the Secretary of the Agency of Human Services (AHS). The federal mental health block grant statute requires states and territories to establish Mental Health Block Grant Planning Councils with a variety of responsibilities. The purpose of the Planning Council is to provide a forum for the exchange of views and ideas among the multiple stakeholders of the state’s mental health community and to offer advice to the
Commissioner of Mental Health. In particular it is designed to inform the planning process, to explore the issues that impact the transformation of the delivery system, and to arrive, whenever possible, at a common understanding of planning and policy initiatives as these impact mental health services and support recovery. However, the last minutes posted for the Planning Council were from November 5, 2012. There are no minutes in 2013, 2014 and 2015. Although not noted on the website it appears from the lack of agendas and minutes that the Planning Council is either defunct or is integrated into the Transformation Council. At the November meeting there were five members of the Council present. It appears that three were from consumer advocacy organizations. The two remaining represented advocacy groups but were not consumers or people with lived experience. The guests included five state administrators.

According to the state website the purpose of the Transformation Council is to provide a forum for the exchange of views and ideas among the multiple stakeholders of the Vermont mental health community and to offer advice to the commissioner. In particular it is designed to explore the issues that impact the transformation of the delivery system, and to arrive, whenever possible at a common understanding of planning and policy initiatives as these impact mental health services and support recovery. The Transformation Council established by the legislature planned to meet regularly until the new state hospital opened in September, 2015. Based on the minutes, the Transformation Council is much more active having met seven times in 2014. It has met once to date in 2015. There were 16 people in attendance with 11 state administrators and five
representing advocate groups. Only two of the advocates are people with lived experience.

The Peer Services Workgroup is charged with expanding the coordination and quality of peer services. According to the state website existing peer services are being strengthened, new peer services are being created, and models for a peer workforce are being piloted. However, according to the state website, it looks like this group only met once, in November of 2011 and is no longer active.

**Document Source: State’s 2015 Mental Health Services Block Grant Application, Meeting Minutes and Letters**

Several documents were reviewed from the State’s Mental Health Services Block Grant Planning Council Meetings. These documents demonstrate that the State intends and is indeed required by the federal government to include consumer-advocates in their mental health policy and planning; however both the attendance as noted in meeting minutes and a letter submitted by a consumer-advocate organization shows that full or appropriate participation was not realized.

According to a review of these documents there were 30 members invited to be on the Council. Of the 30 members, one declared as an advocate, one as a consumer, two as family members and there were two members from consumer organizations who were interviewed for this study for a total of 6 people out of 30 who were not aligned with state administration or community mental health organizations. Using the total of 6 the consumer-advocates made up less than 20 percent of the total.
Based on the budget document for the block grant out of a total amount of $811,934, there was $37,576 allocated for peer-operated services and another $47,660 designated to an agency to support “other peer activities.” This agency was one of the consumer-advocate agencies highlighted in this research. This amount proportioned to consumer-advocate groups is less than 10 percent.

In addition, following the first Council’s meeting the executive director of one of the consumer-advocate organizations highlighted in this research wrote a letter to the department pointing out the gap between the consumer-advocate involvement required in statute and the actual level of involvement. In fact, the Executive Director states that she cannot fulfill the role because the Planning Council has not been provided a copy of the State’s plan. She continues that there was not “sufficient time allocated for input from Planning Council Members.” She said that during the meeting, “Some members were cut off and did not have the opportunity to voice their concerns. Others did not try because we were told that we were out of time.”

**Document Source: The National Associations for Mental Illness’s State Report Card, 2009**

The National Associations for Mental Illness’s State Report Card also reinforces the second finding. The last report card issued in 2009 gave this state’s Department of Mental Health agency an overall ranking of “C” for addressing mental health issues. It received a “C” for Health Promotion and Measurement; a “C” for Financing and Core Treatment and Recovery Services; a “C” for Consumer and Family Empowerment and a “D” for Community Integration and Social Inclusion. Six states received an overall grade
of “B”; 18 states received an overall grade of “C”; 21 states received an overall grade of “D” and six states received an “F”. The next report card is to be issued in 2016. Although this report card was issued six years ago it is unlikely in light of the interviews with the state administrators that the department would improve dramatically over these grades as Tropical Storm Irene devastated the State and by all accounts “turned back the clocks” on the Department’s work.


The article on the incarceration of people with a mental illness in the 2015 Summer issue of the State’s only consumer advocacy newspaper supports the second finding that there is a disconnection between state administrators and consumer-advocates over the level of engagement with advocacy groups and over the care that is delivered. This article discusses three lawsuits involving claims of inadequate mental health care in the Department of Corrections and also implicates the Department of Mental Health. In particular the third lawsuit is regarding a person who was supposed to serve a 21-day term for a parole violation but lost his eligibility for release as a result of disciplinary reports that were, according to the consumer advocacy group,

In large part from his disability-related behaviors, during his months in 22-hours-per-day seclusion, Patient A’s condition continued to get worse, with self-destructive behavior that included pulling out hair and “extended bouts of crying and/or screaming”.

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According to the article the consumer advocacy organization working on behalf of this person made numerous efforts to initiate conversations with the Department of Corrections and the Department of Mental Health about inadequate treatment. According to one advocate quoted in the article:

Unfortunately I do not see any reason to believe the situation will improve short of a court order…forcing the State to spend the money necessary to avoid disability-based discrimination in the form of inadequate mental health care in prison and lack of capacity to provide the most integrated treatment setting for people needing treatment and supports.

In summary, the information and documents found on the website, in documents for the Planning Council and in the Report card, support the Finding of Seen but Not Heard. The information portrays a department that talks about the need for self-determination for people with lived experience but does not proactively include consumer-advocates in mental health policy and planning.


**Topic: Interview with New Executive Director of a Consumer Advocacy Organization**

One of the strategies in *Seen but not Heard* is that the perception among consumer-advocates that the State would try to coopt consumer-advocates. In this interview a new Executive Director of a consumer-advocate organization tells of her desire not to let this happen. She states that her goal is to forcefully promote this
organization’s mission. The article quotes here as saying that she would like the public to “think of us as an independent organization and not an arm of the State.”


**Topic: Budget Cuts**

Amy spoke about the concern she had regarding retribution for what she wrote in this consumer advocacy newspaper because of State funding. Her agency, according to this article, lost at least a third of its budget for the fiscal year that began on July 1, 2015. This consumer-advocate newspaper will be reduced from six issues to three per year.

**Finding 3: Divided We Fall.** In this finding consumer-advocates acknowledged a fragmented consumer advocacy system and also the emergence of several different tiers of consumer advocacy groups.

**Source: Consumer-advocate Newspaper (2015): News, Commentary and Arts**

**Topic: Peer Boundaries**

The idea of what it means to be what are, at times, interchangeably referred to as peer, consumer-advocate or person with lived experience came up both in the literature review and in the interviews. Dan, in particular, spoke about the delicate balance between being a grassroots peer and a more professionalized peer. His concern was preserving the person to person relationship in peer services while also considering the needed boundaries. This article highlights the topic and tension. It begins by stating the need for boundaries:
If a peer takes on the responsibility of allowing someone more vulnerable to look towards them for support, it brings with it the obligation to set personal boundaries in the relationship. A boundary is something that a person identifies as the guidelines or limits on the “reasonable, safe and permissible ways for other people to behave around them”.

One participant stated one of the main issues in the discussion is not to replicate the power hierarchy that has long existed in mental health between the consumer and the treatment provider or state. This person was concerned with the suggestion that there was a “power thing” involved in being a peer. Another peer responded and is quoted in the article, “I’ve been there and it’s very important that they believe I’m a peer,” which means being equal, not holding power over someone else. The article includes that there is a need for peer training on boundaries and that role of the peer is, “not to heal or fix anyone or create the solutions for them; the point is to help bring the best out of people through their own values.”

**Finding 4: Walk a Mile in My Shoes.** A number of articles support the fourth finding regarding the prevalence of stigma and need for consumer-advocate organizations to be involved in the mental health system.

**Source:** Consumer-advocate Newspaper (2015): News, Commentary and Arts

**Topic: Stigma**

In the 2015 summer issue of the consumer-advocate newspaper we find support for both the literature review and interviews that talked about the continuing issue of stigma:
Sometimes I like to allow myself to speak only to myself. I don’t feel this is something should be ostracized for… period. Yes, I am someone diagnosed with schizophrenia and I am goddamned proud of it…Living in exile, you learn to find resources in your psyche to cope with the fear of losing your mind. Ironically, talking to myself is one resource I’ve found helpful in times of emotional deprivation…Talking to oneself does not mean a person is unaware of their surroundings. It does not mean that they do not have the coherence to engage with another person. All eccentricities can be contorted into perceived “mental illness.

Just look at the gross exploitation perpetrated by the several hundred billion dollar psycho-pharmaceutical industries, and at how this exploitation has caused an explosion in the rate of diagnosed mental illness in developed nations…All of us have a right to the mind-states we choose… or do not choose. No one should have the power to say that my differences make me less employable or less otherwise fit for society.

**Finding 5: Bridging the Gap.** State administrators and consumer-advocates expressed their mutual concern for involuntary treatment. Both groups were unanimous in that involuntary medication was at times needed but consumer-advocates remain much more reserved and cautious in the use of involuntary treatment. These articles help illustrate this finding along with how state administrators and consumer-advocates attempt to navigate the discussion on involuntary treatment.
This article reviews a legislative discussion on involuntary medication. In testimony to the legislature the nurse at the psychiatric facility refers to a patient for whom the nurse and staff has “exhausted nonemergency Intervention.” The articles say that the woman continues to escalate by, “smashing her head against the floor and attacking staff members”. According to the article the nurse is frustrated that she cannot simply administer the emergency medication but has to leave the room to do this while her colleagues are dealing with this very difficult issue to telephone and on-call physician, who agrees to prescribe the medicine that the nurse has already decided offers the best hope of relieving the crisis. The article goes on to cite an advocacy organization that disagrees with any loosening of existing rules regarding involuntary medication. In his written testimony, this advocate states that the State’s psychiatric care facilities were engaging “in an effort to retreat from patient rights.” The advocate goes on to discuss another case of a man involuntarily confined to a hospital emergency department for three weeks without ever seeing a psychiatrist, ordered to take psychiatric medications by a doctor, not a psychiatrist, who rarely if ever saw him. “For three weeks his entire world was a tiny room, segregated from other people, guarded by law enforcement, and deprived of any psychiatric care.”

The article continues that after further testimony from stakeholders, the legislative committee added a clause that identified practices “aimed at reducing the use of coercion.” The current draft bill states that “emergency involuntary medication may only
be ordered by a psychiatrist, an advanced practice registered nurse licensed... as a nurse practitioner in psychiatric nursing, or a certified physician assistant...supervised by a psychiatrist; and that a certified physician assistant... shall personally observe a person admitted to a psychiatric inpatient unit... prior to ordering emergency involuntary medication.


**Topic: Medications and the Side Effects**

In this excerpt from a commentary by a consumer-advocate we find an acceptance of medication as helpful but also concern for how they are marketed and by the side effects:

I find commercials for psychiatric medications really irritating, because they tend to avoid mentioning the actual experiences they’re supposed to eliminate. I would like to see a psychiatric drug commercial that references any stigmatized aspect of mental illness: suicide, self-injury, hearing voices, unusual beliefs, etc. The downside of the pills that make my life less unbearable is that they also make me incontinent. In doing so, they allow me to swap one stigmatized experience for a different stigmatized experience!


**Topic: Electro-Convulsive Therapy (ECT)**

In the literature review and in Amy’s interview there is discussion and concern for ECT as a therapeutic intervention. According to this newspaper article, new annual data on ECT showed an increased use in this State. According to the Department of Mental
Health in 2014, the overall number of persons receiving ECT as a treatment for mental health was the highest reported since records started being kept in 2001. The DMH report states that of all those who received ECT treatment, about 55 percent, had some degree of memory problems. The article also states that this report also claims that nearly 90 percent of patients receiving treatment with ECT reported at least some benefit, and just over 10 percent reported no change. The report notes that the Department of Mental Health Quality Management unit (the group that Mary leads) conducted site visits at two of the facilities that deployed ECT the most and ordered that ECT be administered in a dedicated treatment room which had not been the case. The article states that the Department of Mental Health developed new practice guidelines for ECT and said that a follow-up meeting is planned in 2015 with all ECT providers to share best practices and get feedback on the implementation of the new standards that went into effect July, 2014.

**Source:** Consumer-advocate Newspaper (2015): News, Commentary and Arts

**Topic:** “Shackling”

Each of the state administrators and consumer-advocates talked about minimizing forced restraints to an absolute minimum. According to the article, shackling with metal cuffs is not decreasing as was hoped. This, according to the paper, is because the Senate balked at the provision to order the use of soft restraints fearing the extra expense. Instead, the final legislation simply instructed the Department of Mental Health to report to the Legislature this year on how the transports were being carried out. The report, covering July of 2014 through January, showed wide differences in how patients were treated around the state. A consumer-advocate said he was concerned by a decision to
study the issue rather than direct the Department “to do what is necessary to assure compliance.”

**Source:** Consumer-advocate Newspaper (2015): News, Commentary and Arts

**Topic:** Proof of Danger

This article covers the Supreme Court which unanimously said that the Department of Mental Health may not keep a psychiatric patient in involuntary community treatment unless the state proves that without treatment the patient is likely to become dangerous in the near future. The court said that, “The fact is people who do not pose an imminent danger to themselves or others have a right to autonomy that includes the right to make decisions about the most personal of matters, even if those decisions are deemed by others to be profoundly ill-advised.”

**Source:** Consumer-advocate Newspaper (2015): News, Commentary and Arts

**Topic:** Long Delays in Hospital Emergency Rooms

Amy in her interview talked about the problem of bringing people to the hospitals under involuntary treatment because of the long waits and the crowded, public environment. The article states that the average number of patients held waiting in an emergency room for lack of an inpatient hospital bed has been decreasing, but remains an ongoing issue according to data from the Department of Mental Health. In the first four months of 2015, an average of 22 patients was held in the emergency department each month. In 2014, the average per month was 27. In 2013, it was 29.

Topic: Return to the Asylum?

The history, discourse and argument over institutionalization was outlined in the Literature Review. State administrators saw the value of institutionalization but certainly wanted to limit it as much as possible. Consumer-advocates more than state administrators wanted other options but in the end agree that, at times, institutionalization was needed.

This issue of the consumer-advocate newspaper reprints an article that was first seen in the 2014, winter issue of the prestigious *Journal of the American Medical Association*. The article by three bioethicists from the University of Pennsylvania argued that the era of deinstitutionalization – the closing of mental asylums – had been a failure. Subtitled, “Bring Back the Asylum,” the commentary said the situation of persons with mental illness stuck in prisons, emergency rooms and nursing homes was “appalling,” and proposed creating new models of “patient-centered, long-term psychiatric care.” The advocacy newspaper adds an excerpt from the *New York Times* opinion article that supported the *JAMA* commentary. It was written by a psychiatrist who said that the writers “argue that the ‘way forward includes a return to psychiatric asylums.’ And they are right.” The advocacy newspaper said that the articles created a “firestorm of criticism” and in turn published in this issue of the paper several rebuttals. One rebuttal from Harvey Rosenthal from the national organization, Recovery Now, exemplifies much of the critique reprinted in this issue of the advocacy newspaper:
There is little evidence that long-term institutionalization offers effective treatment. And it took away people’s most basic freedoms. In contrast, community-based services such as supported housing, mobile crisis, and peer support have decades of proven effectiveness and offer people much better lives. Montross correctly identifies problems caused by the failure to fund sufficient community-based services. But the solution is not to go back to the same failed policies of the past but rather to expand the community services that we know work. Let’s promote recovery, not lifelong dependence.

Harvey Rosenthal, *Recovery Now!*

**Findings from Meeting Observations**

I observed two meetings between state administrators and consumer-advocates. The first meeting I attended was held in August, 2015 at the statehouse. The public meeting was convened to get feedback on the Department’s Annual Plan for mental health services. There were three advocates in the meeting, five administrators from the Department of Mental Health, and five administrators from other departments within state government including corrections, vocational rehabilitation, the health department and Medicaid. There were three guest presenters and two guests including myself in attendance. The meeting started with a welcome and introductions. First there was presentation on young adults with early episodic psychosis. The administrators talked about the need for early detection and intervention. There was also a call for an ethnographic study to, “detect needs and patterns of help seeking behavior.” It was
interesting to see advocates question how the current budget was built and how allocations were made. State administrators responded that the budget and allocations are federally prescribed.

The state facilitators asked the group to identify the current strengths in the system. Several state administrators identified strengths in the system that was focused on particular state programs. It was interesting to see an advocate raise the concern about how we message mental health in terms of stigma rather than offer to identify strength. The meeting then began to address the adult mental health system. An advocate again raised concern about the budget allocations for the various programs and again was told by an administrator that there was no flexibility to make changes to the budget line items at this time. A state official from the Department of Corrections raised the concern regarding the number of “mentally ill” people in the correctional environment. He shared his concern regarding the impact of the state policy to reduce inpatient hospitalization in favor of community-based treatment. He said there was a need for a “short stepdown” from corrections to begin the transition into the community. He called this a “critical gap” in the system. A consumer-advocate then questioned the terms Seriously Mentally Ill (SMI) and Severe Emotional Disturbance (SED) as being stigmatizing. A state administrator reiterated that the Block Grant is primarily focused on the SMI and SED populations and that use of statutory language demonstrates that the State is serving these populations. The same consumer-advocate requested an update to the language in the Peer-Support section of the program. She was asked to send written comments. State administrators introduced a new results-based methodology to track performance and
“increase transparency” by issuing a scorecard on all mental health programs. Stigma is missing from draft application. Address stigma by developing more concerted efforts statewide. A second consumer-advocate addressed how we use language in our planning that can “trigger” people. She said that much of “our values are encoded in words we use”. Another consumer-advocate requested “more meaningful opportunities to provide input” suggesting that this one meeting was not enough. The meeting was adjourned by asking all group members to provide additional written comments.

The second meeting I attended was in September, 2015. The meeting was held with state administrators and consumer-advocates to discuss what they call the “Seriously Functionally Impaired”. This group is to help plan for people coming out of corrections that mental health issues but who do not fall within the State’s available funding streams. According to 2015 data, there could be approximately 50 people who met this category during the year. There were eight state administrators in attendance from various state departments and one consumer-advocate on the phone. The group discussed gaps in the system and there was a consensus that both a step down facility from corrections into the community was needed as well as forensic psychiatric unit within corrections to be able to serve the high number of people with significant mental issues that are incarcerated. In discussing the prior release of a person from corrections, the consumer-advocate on the telephone expressed dismay regarding the inability of a local mental health agency to adequately provide services to this person in the community.

It was interesting to see how the discussion in these two meetings paralleled the findings from the interviews and the document review. During the first meeting on
mental health service planning the consumer-advocates brought up the issues of language, stigma, financing and how to achieve fuller participation in mental health policy and planning. The state administrators, while not dismissive, did not answer these questions and rather put them off through a final comment such as the “budget is prescriptive” or “please send in your written comments.” This meeting did not seem to have any room for problem-solving or meaningful discussion. The second meeting did seem a bit more solution focused; however there was only one consumer-advocate joining by phone. Both meetings veered from the interviews but were similar to the document review in terms of the several references to the incarceration of people with mental health issues and the inability of corrections to provide adequate mental health services.

Both these meetings confirm perceptions of fundamental separation between state administrators and consumer-advocates due to issues of trust, communication and perception. Consumer-advocates kept coming back to issues of stigma and input but these issues were not fully engaged at least during the meetings by state administrators. These meetings confirmed the issue found in the document review and that is the profound concern regarding the number of people in corrections and the lack of adequate mental health services.

Chapter Summary

This research focused on the perceptions of mental illness among state administrators and consumer-advocates concerning four issues: (1) How state administrators and consumer-advocates perceive their role and the role of each other, (2)
perceptions of state administrators and consumer-advocates regarding the existence and causes of mental illness, (3) the perceptions of mental illness as a problem among these two groups, and (4) the strategies these two groups have for treating mental illness.

This chapter presents the findings of state administrators and consumer-advocates based on responses to semi-structured interviews with state administrators and consumer-advocates as well as a document review and meeting observations. The findings are organized according to the research questions. Individual interviews, document review and meeting notes revealed how both groups perceive mental illness.

There were six findings that emerged from this study. In the first finding, *A Dysfunctional Mental Health System*, state administrators were unanimous that they were functioning in a mental health system in crisis or on the brink of crisis that limited their effectiveness. Phil’s comment exemplifies this for state administrators.

The system was in extreme crisis. I was the commissioner of mental health for a year but it felt like five. It was extremely intense. The house was on fire every single day no matter what you did. I didn’t have the expertise to keep going (Phil).

In the second finding, *Seen but not Heard*, four out of five consumer-advocates said their role and effectiveness was marginalized by State Administrators through a variety of ways either intentional or unintentional. As Amy said:

After Irene, when (the new Commissioner) came in and took over, he bought out the consumer voice. He totally bought it out and the way he did it, he bought it for a million dollars (Amy).
In the third finding, *Divided We Fall*, all five consumer-advocates said that there was no real consumer advocacy system and that their organization functioned to varying degrees in isolation from others. Wes talked about a system of some collaboration but little if any collective advocacy:

So there’s a lot of collaboration amongst peer programs and consumers, providers, until you kind of get to the nitty gritty of a certain course of treatment or not. What does that look like? There’s been a lot of clashing over particular issues with the new legislation that went through particularly around forced drugging and some of that stuff too (Wes).

In fourth finding, *Walk a Mile in My Shoes*, we see that stigma is the driving issue for consumer-advocates. Wes sums up the connection best between stigma and a system that may help reinforce rather than reduce it:

My biggest point to drive home is that we do people a tremendous disservice by stigmatizing and formalizing mental health issues. I think that people are so worried about having diagnosis, rightfully worried, about having a diagnosis, having it follow them, having it impact their relationships and their work and everything else that people go through a tremendous amount of suffering to avoid getting into any type of system of care (Wes).

In the fifth finding, *Bridging the Gap*, both state administrators and consumer-advocates agreed that there are a variety of causes for mental illness with each acknowledging the role of biological factors in mental illness. However, state
administrators seemed to emphasize the role of biology more so than consumer-advocates.

I think some people have truly endogenous, biologically, etiologically biologic illness and I think others may have illness that more evolved and developed from life experiences, impact on development. Does that make sense? (Sandy)

On the other hand, consumer-advocates took a more social approach exemplified by Amy getting away from the term mental illness:

So I think a lot of how it originally was defined as an illness had to do with people categorizing this person’s like weird, acting weird so we gotta do something about it. I’ve never thought of it in these terms (Amy).

In the sixth finding, Common Ground, state administrators and consumer-advocates agreed that there is a fundamental need for better communication when working with each other. Consumer-advocates also strongly voice support for more participation in the system and better support from state administrators. Sandy represents the thinking of state administrators:

I think what’s working well now is having opportunities for ongoing discussion and communication. I think identifying mutual goals. Is a really important thing because sometimes I think we all forget that we actually do have mutual goals (Sandy).

Amy summed up the tension on behalf of consumer-advocates:

Gotta talk and talk and talk and talk and be willing to listen. I really believe in that the process of debate, the process of disparate views, kind of wrestling it out.
There’s always a problem when you don’t have a level of trust that you’re trying to get to the same place makes it harder, but you still have to keep trying (Amy).
CHAPTER 5: ANALYSIS, INTERPRETATION AND SYNTHESIS OF THE FINDINGS

The purpose of this study is to explore with a sample group of state administrators and consumer-advocates their perceptions of mental health. It was hoped that a better understanding of how these perceptions might compare and contrast would provide insight to foster better communication and collaboration between groups when working on mental health policy and practice. This research is important because any new insights may lead to improved services and less stigma for those with mental health conditions.

The research method was qualitative using data from in-depth interviews, document review and meeting observations. Participants in the study included five current and former state administrators and five current consumer-advocates. The data was coded, analyzed and organized first by research question and then by categories and subcategories guided by the Conceptual Framework as a Working Tool (Table 1 in Chapter 1). The study was based on the following four research questions.

1. How do state administrators and consumer-advocates perceive their role and the role of each other?

2. What are the perceptions of state administrators and consumer-advocates regarding the existence and causes of mental illness? How are they similar and how do they vary?

3. What are the perceptions of mental illness as a problem among state administrators and consumer-advocates? How are they similar and how do they vary?
4. What are the strategies of state administrators and consumer-advocates for treating mental illness? How are they similar and how do they vary?

The two analytic categories of On the Margins and An Emerging and Shared Relationship correspond to the study’s research questions. In the analysis I took the findings from state administrators and grouped them for patterns among state administrators. Then I took findings from consumer-advocates and grouped them to find patterns among consumer-advocates. For the analysis, interpretation and synthesis of the findings, having completed the in-group patterns, I searched for connecting patterns in each category among state administrators and consumer-advocates.

The previous chapter presented the findings of this research by organizing data from various sources into six themes (Findings 1-6). The purpose of this chapter is to engage in a deeper analysis and interpretation of these findings. The Findings chapter separated data to find patterns and linkages among the two groups while this chapter is meant to construct a more integrated and holistic picture. The Findings chapter categorized the data and each person’s own words to develop a narrative that is the foundation of the research. This chapter analyzes, interprets and synthesizes the information. This discussion is grounded in the literature on mental health and the results of these findings builds on the literature in order to add to the understanding of how state administrators and consumer-advocates perceive mental illness as they endeavor to work together to enact policy and practice. This chapter concludes by examining my assumptions outlined in the Hypothetical Concept Model in Chapter 1 and a summary that incorporates the effect of bias in interpreting the findings.
The overriding conclusion that has emerged from the four research questions and six findings is that state administrators and consumer-advocates exist within two separate symbolic universes that have moral, political and economic implications. Both state administrators and consumer-advocates achieve their identity and each group knows itself by anchoring their identity within their symbolic universe. As Berger and Luckman (1967) state, “The symbolic universe orders history and locates all collective events in a cohesive unity that includes past, present and future” (p. 67). Foucault (1961) in his critique of modern society claims that defining mental illness is less about scientific validity than it is about moral judgments often couched in terms of positivism and humanism that ultimately lead the “mentally ill” to “moral imprisonment.” State administrators as the dominant group continue to see their role as one of maintaining social, moral and institutional order as they define mental illness primarily through an illness framework. Consumer-advocates remain on margins of the mental health system. Their symbolic moral universe is rooted in a history of powerlessness and control by the State in which they have been categorized by illness, morally defined, subjugated and treated. Their role now vacillates between cautious opposition and adherence to State control. Their adherence is rooted in their fear of losing funding and relevancy because they are seen as too radical.

For state administrators, their role and legitimacy is precarious as they try to contain and assimilate a varied and fractured consumer movement that threatens their legitimacy and the established social order of their symbolic universe. State administrators have been able to hang on to the normative values and the knowledge
regarding mental illness by both excluding and coopting consumer-advocates and by modifying their own position to make room for the more moderate ideas of consumer-advocates. This research demonstrates that consumer advocacy presents a challenge and perhaps a threat to the authority of state administrators and the mental health system’s status quo.

The symbolic universe of state administrators had long been self-sustaining and maintaining in a society that legitimized and prized their role as guardians and keepers of social order. However, the symbolic universe of the state administrators, like all symbolic universes, is inherently vulnerable to deviant versions. For state administrators the emergence of consumer-advocates from the historically separate and chaotic world inhabited by the “mad” can be seen as a direct threat to their legitimacy and institutional authority.

Consumer-advocates have emerged and made historic advances to overcome the role of patient in order to have a say and stake in a system whose symbols have long defined and oppressed them. For consumer-advocates their symbolic universe is rooted in a history of coercion, abuse and victimization by the state and professional system. Consumer-advocates, in this research, continue to see mental health through a social framework in which issues of stigma, marginalization and disempowerment by the state continues to loom large.

This study shows an emerging relationship between state administrators and consumer-advocates but a relationship that lacks communication and trust as their discourse attempts to span the gap between the two symbolic universes. The focus of
consumer-advocates on the importance of their role in battling pervasive stigma and the need for people with lived experience to be central in the mental health system can be seen as an effort to overcome an historical pattern of coercion and abuse of mental health patients by the state. The focus of state administrators to remain relevant in an unstable mental health system in which consumer-advocates challenge the status quo can be seen as their effort to retain legitimacy as well as their historic control over the mental health system.

Consumer-advocates emerged in the 1960s and 1970s to challenge the policies and treatment services in the field of mental health at both the federal and state level. These activists originally called themselves ex-inmates or ex-patients (McLean, 2002). This study shows that they continue to struggle with a minority status in this system and are, in effect, operating as outsiders to the state’s dominant vision of itself. This research also shows that state administrators are willing to modify their symbolic universe but neither they nor society as a whole shows little inclination to radically alter the status quo by giving significant power to consumer-advocates.

There are few relationships in history as separate and unequal as that between the state and the mental health patient; perhaps the relationship between slave and slave owner, jailer and jailed come close to the divergent experiences and historically separate symbolic universes of state administrators and consumer-advocates. The separate symbolic universes of state administrators and consumer-advocates are social products emerging from a deep, intimate yet ultimately imbalanced and sharply drawn history. This history makes it difficult for these two groups to work together to create shared
values, a shared vision or shared accountability when implementing mental health policy and practice. Mathew, a consumer-advocate, actually gets close to the reified role of state administrators and finds some legitimacy in it:

I think that as a state, as a bureaucracy in general, you kind of have to stay in this middle ground because you have a lot of different entities and interests that you’re having to interface with, so you can’t really go too far afield, I mean because you have to have a coherent center that you can stand. You can’t be a different voice. There’s a certain shifting and there’s a certain kind of finessing of different things but there has to be some center to hold so there’s a level of consistency so…(Mathew).

The findings show two groups fixed in their roles trying to talk across separate symbolic universes with a small degree of success while maintaining varied and on the whole negative perceptions of each other’s role. The findings illustrate a mental health system that is continually on the brink of a crisis and one that is unable to support its own staff’s sense of agency. The research describes a mental health system in which state administrators say it is important to involve consumer-advocates while either coopting or marginalizing them when developing policy and practice. The research demonstrates how incredibly important inclusion is to consumer-advocates and how the history and presence of stigma is prevalent to their worldview and demand for inclusion. The research details how these two groups see the overwhelming need to develop stronger communication and trust and, indeed, establish a common paradigm that will accommodate both their world views. The research shows an emerging – albeit fractured
relationship that may provide an opportunity for each group to find common ground and to reinvigorate each group’s sense of humanity. As Hardt and Negri (2005) suggest, qualitative research and in particular listening to people in their own voice can help us move beyond the static, self-satisfied and dependent democracy to a place of questioning and constructive resistance.

The name of Analytic Category 1 is “On the Margins”. This category speaks to Findings 1, 2, 3 and 4.

**Analytic Category 1: On the Margins**

The first research question sought to determine how state administrators and consumer-advocates perceive their role and the role of each other. From this question the two groups begin to explain and legitimize their roles and priorities placing their biographies in two separate symbolic universes. The literature places role theory within the social construction paradigm and suggests that behavior is based largely on a person’s role or roles. According to role theory each social role comes with a set of duties, expectations, norms and rights which a person comes to conform and align (Blumer, 1969; Mead, 1934). Sandy typifies the role expectations of a state administrator:

> My goal for the organization… is to improve our internal communications, organizational functioning first and foremost and then our interface with and collaboration with both sister agencies, stakeholders, consumers, and those that provide services under our auspices (Sandy).

Amy typifies the role expectation of a consumer-advocate and someone with lived experience:
There are people around the state, other consumers, who tell me how glad they are that I’m in there speaking for them, speaking for people who may not be able to, and also being a symbol of the fact that recovery’s possible (Amy).

As Wieck (1979a) says, a person’s commitment to a role can increase when they experience enjoyment in their role, feel a loyalty to others in the same role, receive rewards for role enactment or avoid punishment through role enactment. In addition, according to Thoits (1983), a person’s role can help provide them with existential meaning and behavioral guidance. State administrators seem to be stuck in an organizational system and culture that seems ill prepared to support them in their role and one in which they are unlikely to feel much fulfillment or sense of control. For example, Mary, the Quality Improvement Manager, stated, “Well, if you want to know the honest truth, I don’t think a lot of other people think my job is very important but it’s essential”.

In addition, Phil, a former commissioner stated:

I have strong opinions but I was swimming upstream and it felt like somebody else needs to be in this role that has the actual mental health background. I was at risk of failure because I just couldn’t go to the next step (Phil).

Consumer-advocates expressed frustration in trying to fulfill their role and described ways in which they felt marginalized by state administrators including cooption or an implicit and at times explicit pressure not to speak out too strongly. Amy, a consumer-advocate, described this concern when speaking about a former commissioner:

He is not a friend of the consumer voice and has already made a decision to cut back on the number of meetings with the transformation council which was
supposed to be all about the community voice because he hears it from other places. He doesn’t think he needs to hear it again (Amy).

In the context of social construction theory, institutions can be seen as a collection of roles in which people like actors enter and exit throughout time, accepting their role and the role of the institution (Berger & Luckman, 1966; Nelson & Winter, 1982). Let us first consider the role of state administrators through the lens of social construction theory. Phil, appointed as commissioner, was new to the mental health system. He strongly favored increasing the role of consumer-advocates but he talked about the static institution he found complete with predetermined expectations. It is not surprising that he was only to last a little under a year in his position:

Probably because I hadn’t spent 25-30 years in the mental health system and it was all fresh and new to me… but there was a certain amount of lip service on that end. Patting them (consumer-advocates) on the head and saying yea, that’s all very well and good but we know over here what’s really needed (Phil).

Leaders may fall into roles and forget that they are the creators of institutions and come to see these institutions as outside of themselves and no longer within their control (Berger & Luckman, 1966; Nelson & Winter, 1982). Each state administrator talked about an institution that was to varying degrees outside of their ability to change or move forward. Two former commissioners talked about a system that was not only outside their ability to change as leaders but one in which they felt victimized by the system. Phil said, “I was the commissioner of mental health for a year but it felt like five. It was extremely intense. The house was on fire every single day no matter what you did. I didn’t have the
expertise to keep going.” Matt, another commissioner, said, “It took me about six months to detox from having been in that job… When I came into the job as commissioner I read books on kidnapping and survival to prepare for not being kidnapped and not being a victim. From my perspective the mental health system from top to bottom was victimized.”

Sixteen years have passed since the *Surgeon General Report on Mental Health* (1999) and the *President’s New Freedom Commission on Mental Health* (1999) concluded that the time had come for increasing the opportunities for consumer choice in the delivery of services. Yet to date, state administrators have been unable to create a system that integrates consumer-advocates into the decision-making structure in a meaningful way. How much of this is due to a mental health system on the verge of crisis; how much is due to a system that inherently fosters the status quo; and, how much of this is due to a lack of trust regarding consumer-advocates? There is literature that suggests that leaders in different organizations will, at times, support an unjust social agenda because they have been hired and trained into their role and, within that role, are expected to conform to the prevailing agenda of their organization (Chomsky, 2000; Rapp, 2001a).

We also see in this research that state administrators are more likely to take a medical or illness orientation toward mental health even while there is ample literature that suggests that if we were to look at mental illness as a social condition we can then account for the negative effect of stigma, prejudice and discrimination toward people labeled as mentally ill (Bassman, 2005; Corrigan & Calabrese, 2005; Corrigan & Watson,
It appears from this research that state administrators may not have this social orientation and may question the ability of people labeled as mentally ill. Consider the state administrator Mary’s concern that may confuse passion with stridency: “I think they’re more effective when they are less strident, frankly.” Sandy also considers their stridency and even the legitimacy of their role, “And certainly in terms of being collaborative with the advocates, that has been truly difficult because some of the same folks who are advocates are also those that bring lawsuits and there may be some conflict there of interest essentially.”

Thornicroft (2006) talks about how difficult it is for consumer-advocates, as current and former service users, to influence and affect mental health services and policy after having worn the label of mentally ill. The state administrators use phrases and terms like “stridency” that seem to undermine consumer-advocates as leaders. In the social construction and the symbolic interpretative framework, words have the power to reveal or conceal and can be used to promote or demote a definition or approach (Jenkins, 1992). Mark’s concern regarding consumer-advocates is potentially telling.

There is an oddity to me about mental health advocates in that they almost all find themselves at some point or another telling some of the most personal moments of their life, recounting them on public record, which always I find slightly disturbing that it’s almost as if in order to get anybody to listen, they have to stand naked in front of everybody.
This concern is probably not in line with how people with lived experience see the importance of telling their story in order to de-stigmatize mental illness and bring legitimacy to their need to be included in developing a mental health system. Here state administrators may be missing an essential component to wellness that through their work they should be most of aware of and that is the ability to transform “illness” identity through a narrative approach that helps people to develop a meaningful story (Lysaker et al., 2010).

Nate is a bit more open to the inclusion of consumer-advocates but delineates a clear boundary and limit for peer involvement while questioning their decision-making ability:

Peers have to be a part of what happens around the treatment and care and support of the people with mental illness but it isn’t a good idea for peers to be involved in all aspects of care such as running and directing facilities because there are things that happen for people in which peer services may not help (Nate).

Nate’s comment aligns with the literature that suggests that once people are labeled as mentally ill their decision-making ability is called into question (Corrigan & Calabrese, 2005; Corrigan & Watson, 2006; Holmes & River, 1998; Link et al., 1999; Lsaker et al., 2010; Martin et al., 2000; Thornicroft, 2006). Nate’s caution over sharing too much power is consistent with what researchers have uncovered in studying social stratification theory in which a hierarchy of credibility exists between social roles with those in superior roles seen as representing official morality while those in subordinate roles are seen as violating that morality (Becker, 1967). Research has noted that mental
health providers and administrators are often skeptical of peer lead mental health services and are reluctant to coordinate with or refer people to those services (Chamberlin, 1990; Constantino & Nelson, 1995; Emerick, 1995; Gartner & Riessman, 1993; Halperin, 1987; Hardiman, 2005; Salzer et al, 1999; Stromwall, 2002). Researchers studying a class-based system suggest that historically superordinate groups like state administrators get to define the issues, set the agenda and determine services while subordinate groups like consumer-advocates may be challenged to get their voice heard. Therefore subordinate positions correlate with less power, lower morality and even deviance. Status conflicts between those in superordinate and subordinate positions do arise and become caught up in competing symbols, perceptions and worldviews (Ben-Yehuda, 1990; Goffman, 1963; Schur, 1980).

This idea of being on the margins also appeared during the document review. State administrators may also be concerned with their legitimacy and relevancy as evidenced by the discussion documented during the October 6th, 2015 meeting between consumer-advocates and state administrators. In this conversation consumer-advocates were talking about the ineffectiveness and danger of medication as well as the traditional treatment system. A state administrator wondered out loud to the group about the relevancy of his role when he said, “This conversation, quite frankly, is a little upsetting. I like to think we do good work and help people but the conversation here makes me think we are irrelevant.” This exchange exemplifies the threat of the consumer movement to the status quo and symbolic universe of state administrators. Thornton (2008) explains the consumer movement, emerged in last quarter of the 20th century, to undermine any
definition of mental illness and pose the conceptual question by asking if mental illness is more myth than reality. In contrast, state administrators find their legitimacy, authority and financial security in defining mental illness as summed up by Sandy who stated, “I get my definition of mental illness from the DSM.” We are reminded of the power of definition by Szasz (1973) who writes, “The struggle for definition is veritably the struggle for life itself…the one who seizes the word imposes reality on the other: The one who is defined is subjugated…”

The dominant definition does not need to be true; it needs only the force of power, legitimacy and repletion to be successful. One tool that reinforces the definition and structure for state administrators is the Department of Mental Health. The Department of Mental Health has become the instrument for how society views normal and abnormal mental capacity and therefore who has access to treatment. It also determines how mental health providers and pharmaceutical companies are reimbursed. Pharmaceutical organizations aggressively market drugs to state legislatures and state mental health administrators creating a strong economic connection between pharmaceutical companies, mental illness and state administrators. Since funding for the mental health system depends of diagnoses and reimbursement for an illness, anything questioning the foundation of that system for state administrators might be suspect. Wes, a consumer-advocate, questions the system and need for defining and classifying mental health:

My biggest point to drive home is that we do people a tremendous disservice by stigmatizing and formalizing mental health issues. I think that people are so worried about having a diagnosis, rightfully worried, about having a diagnosis,
having it follow them, having it impact their relationships and their work a…so I think that if we had a situation where you didn’t need a diagnosis to receive care, we’d have a lot better mental health for everybody. It’s the hardest thing I think (Wes).

On the other hand, mainstream consumer organizations like the National Alliance for the Mentally Ill which, in this state is quite aligned with state government, will often point to the high prevalence rates of mental illness to express their need for more funding (Horowitz & Wakefield, 2006).

Consumer-advocates think their role is critical for the mental health system because of their lived experience which gives them empathy and a unique ability to understand and combat stigma. In addition, according to role theory, roles can also be useful in helping marginalized people develop a sense of self based on social interaction and role fulfillment (Faris 1934; Mead, 1934).

According to this research consumer-advocates feel marginalized by state administrators with little access, power or sufficient funding. Some are concerned about retaliation if they speak up. The funding they do have according to four out five of the participants is used to coopt their advocacy efforts. Amy, a consumer-advocate, talked about her perception and fear that the state is coopting the advocacy movement: “After Irene, when (the new commissioner) came in and took over, he bought out the consumer voice. He totally bought it out and the way he did it, he bought it for a million dollars.” In the literature on peer services some have argued that the hiring of consumers has often
been based on “tokenism” rather than a sincere desire to integrate consumers in to professional teams as equals (Roose & DeBie, 2003).

Amy spoke about coercion in discussing the firing of an executive director from one of the state’s leading consumer-advocate organizations:

The rumor is, the word was very much with the support, endorsement, whatever, of the Department of Mental Health and the new leadership (of this organization). I think they (the Department) were ready to point to other problems to push her out, and there was an element of “she is a burr under the saddle”. Maybe not even a conscious one (Amy).

Amy continued by speaking about the pressure she felt as the editor of the consumer advocacy newspaper, “I’ll tell you when, working on this article for the September issue ...there wasn’t any doubt in my mind what I was risking, that I might get word from the board president saying , you can’t write that article”.

Wes, like Amy, talked about being compromised or coopted by state funding. He talked about the organizational change that occurred as formal funding came from the state and about the struggle within the organization between its early more radical history and its emergence as a state funded mainstream organization:

We started as a survivor movement, so essentially it was a grassroots, almost liberation type thing where people who’d been through forced treatments, electric shock therapy, five point restraint, forced medication …over time we got recognition, grants. As we got grants, there was pressure to do certain things associated with the grants (Wes).
Mathew talked about dangers of state funding for advocacy because of the expectations that come with it:

Yea, I know, I think that is a real issue. How do you get around though is another question. I’m not really sure because people do need eat. There’s a real danger in it becoming a job. I think when you look at some of the hardcore original advocates; they were doing it because this is life and death for people, for themselves. You really lose something when people start getting paid (Matt).

The literature review cited research that has shown the difficulty of collaboration between the two traditional treatment system and consumer-advocates. According to Mueser (2002), the core nature of the relationship between professionals and consumer-advocates remains a one-way exchange of help and is remarkably similar to a provider-recipient relationship. For example, Dan talks about the one-way exchange feeling undervalued by state administrators, “We’ve never really had adequate funding and personally I think we do a lot of work…I think they need to sit down with us at the table and be real about what’s for funding out there for peers and be a little more fair with the money that is available.”

For consumer-advocates, not being included may have stronger more negative implications because of their history of victimization by society and control by the state. Faris (1934) researched the effects of social isolation for people on the margins of society. Social isolation hypothesis contends that a mental illness can occur when people are cut off from intimate social relations over extended period of times.
In summary, although there is progress on including consumer-advocates into the mental health system, there remains a significant gap to full inclusion based on the varied perceptions regarding mental health among these two groups. Thus, consumer-advocates remain “on the margins.” These varied perceptions are the result of the two separate symbolic universes of state administrators and consumer-advocates. These symbolic universes have led to a relationship that is both separate and unequal with state administrators holding not only the power and legitimacy in the mental health system but the very definition of what it means to be mentally ill.

**Analytic Category 2: An Emerging and Shared Relationship**

This category speaks to findings 5 and 6 which are *Bridging the Gap* and *Finding Common Ground*. Consumer-advocates have emerged to enter into the dialogue regarding mental health issues and are involved in discussion regarding mental health policy and practice. The federal government has recognized the need to put consumers at the center of the services system. State administrators in this research are vocal about the need to involve consumer-advocates even if they have not followed through with the practice. Consumer-advocates feel they have a vital role to play and, in general, feel from an historical perspective they have come far, however even as they continue to feel disenfranchised by state administrators as evidenced by this research.

What is important from the social construction framework is the notion that a symbolic universe and the legitimations that are part and parcel of that universe are part of the human imagination or perhaps lack of imagination and has no objective existence or independent status outside of the individual creation. In this research we see state
administrators and consumer-advocates position themselves vis-a-vis a potentially shared universe. What may be emerging in this dialectical relationship between state administrators and consumer-advocates is what Berger and Luckman (1967) refer to as a shared core universe. For Berger and Luckman, modern, pluralistic societies are bound to have different partial universes co-existing in a “state of mutual accommodation.” For Berger and Luckman, this discussion took place in reference to existing ideologies. However, is not this phenomenon a possibility among two groups with an historic power differential which one is trying to right and the other is trying to slow through varying degrees of cooperation and cooption? In this paradigm state administrators could continue to pretend that their centuries old monopoly of the mental health system and their unconditional power over consumer-advocates as patients remains or they could, as this study suggests, begin to legitimize the devolution of their absolute control.

In this way, what Berger and Luckman (1967) refer to as the pluralism of modern society that, by its very nature, acts as an accelerator for social change may in fact be a subversive moment as consumer-advocates are both skeptical and more creative vis-a-vis the status quo and the taken for granted reality of state administrators. This subversion may be a necessity and lifeline for consumer-advocates due to their historic marginalization in which they have no legitimacy, agency or expertise when overtly challenging the present reality as defined by state administrators. In this context, suggestions made by state administrators are inherently in tune with the historic and current institution that they by and large established and suggestions made by consumer-advocates are at least in their immediacy counter to this institution and reality. This foray
into a shared core universe may lead to the ambiguity both among consumer-advocates and state administrators express as they consider their own efficacy as well as their relationship with one another in light of their historic roles.

Amy summed up this ambiguity by saying that even though people still do not understand the role of consumer-advocates she feels like there is progress.

I feel like people just still don’t get it. I have to step back and remind myself, no we’re really making progress and I know from external feedback that people feel that I am effective in helping making that progress (Amy).

Lynn is the only consumer-advocate who talked positively about the role of the state:

The state really wants to connect all the mental health orgs so that we are all trying to capitalize on the core competencies that we bring to the table. And they want to work with the advocacy organizations to provide that lived experience with education and support and advocacy (Lynn).

The perception among state administrators, in general, is that they are doing everything possible to include consumer-advocates. Nate thinks there is progress but points to the increase in funding which has brought consumer-advocates into the system. This funding he suggested has allowed a culture or forum in which people do not need to be “forceful.”

I think now because we’re working so closely together and, but also because we’re funding, it’s a different kind of advocacy so I think it’s changed the tenor of a lot of the advocacy that you hear and some of it I think is because we are funding these programs but also I think it’s because just the dynamic and the
culture has changed. The people are coming to advocate already have a seat at the table and so they don’t need to come from that forceful perspective (Nate).

The progress seems limited by Nate’s own admission. The department had a consumer-advocate position for a brief period of time but the position was not continued:

We got the federal mental health transformation grant to create new peer services in the state, we actually had a position here at DMH, a peer position, I acted as a coordinator of the position…when the person who was in that position, she decided to leave the position, we chose not to refill it just because we didn’t have funding for it (Nate).

Research shows that many state mental health authorities encourage the hiring of consumers to work as paid providers in mental health treatment programs. However, some have argued that the hiring of consumers has often been based on “tokenism” rather than a sincere desire to integrate consumers into professional teams as equals. This could also be due to operational issues such as poorly defined roles, policies and procedures, and workflow (Roose & DeBie, 2003).

We should remind ourselves, however, that socially just leaders are committed to transforming oppressive and exploitive social relations through dissent and resistance if necessary (McLaren, 2000; Rich, 2001). Phil is the only administrator expressing a desire to transform the system in favor of consumer-advocates even though Amy did not see it this way nor did others comment on this. Either way, as learned, Phil was thwarted in his attempts:
I brought those peers front and center in that planning process and we actually appropriated more money than had ever been appropriated for the peer groups to strengthen them because I came to the conclusion that peers were absolutely central to solving the problems that we face in the state in mental health, so we did some very I think innovative and cool things and I was very sorry after I left to see some of that go backwards (Phil).

Just as we see some progress in bringing the two groups together, we see some convergence on how state administrators and consumer-advocates think and talk about the causes of mental health issues. Mary summed up the position taken by state administrators who say there are diverse causes of mental illness but tend to see it more through an illness framework.

It is a combination of genes, chemical imbalances in the brain and the environment. The way people live, the way they grow up, the way their parents live, what they learn as they grow up, the way their parents treat them, the way their friends treat them, any number of things (Mary).

Liz summed up the perspective of consumer-advocates when she said:

I kind of look at mental wellness and that there are different degrees of a person’s wellness and your capacity to be able to function. It consists of many different things. I look at it as physical, spiritual kind of all-encompassing because if that is out of balance then your mental health gets out of balance. I kind of look at it as an overall well-being of the person themselves (Liz).
Mathew reinforced the point that consumer-advocates are more likely, in general, to look at mental health through a social rather than illness framework; however he also suggested that Liz’s own organization like the state takes a more medical orientation.

They use a mental illness framework in all their material and most of the people who we work with won’t work with them for that reason…They really embrace the framework of like this is a disease and you have to acknowledge that and there’s no shame in acknowledging that and getting the help. They’re serving and that there’s some tension there (Mathew).

In summary, there has been historic process in the emergence of consumer-advocates from passive patients or recipients of mental health services to having a say in those services. They are beginning to bridge the gap and carve out a place within the mental health system. This research shows that in spite of that progress, they do perceive themselves to be on the margins of the mental health system.

**Revisiting Assumptions**

It is useful to revisit the two basic assumptions underlying this study that were stated in Chapter 1. My first assumption was that state administrators and consumer-advocates would have different perceptions of mental health. This assumption is based on personal observation during meetings with state administrators and consumer-advocates as well as research that shows that consumer-advocates are more likely to take a social perspective of mental health. A second assumption is that the strategies among state administrators and consumer-advocates for assisting people with mental health issues are likely to diverge. This assumption is based on the literature cited in this study that shows
that the consumer-advocate movement has emerged in response to a long history of state
control and a perceived need for more consumer driven services. The question I
considered at the outset of this research is if in light of their past relationship, could state
administrators and consumer-advocates effectively work together to develop mental
health policy and practice? How does each group understand, think and feel about their
current role and relationship in light of their tangled, imbalanced but intimate history?

My first assumption was not entirely true. I did not find, as I supposed, a rigid
medical orientation on behalf of state administrators or a rigid social orientation on behalf
of consumer-advocates. Although state administrators were more likely to focus on the
medical model and consumer-advocates were more likely to focus on the social model,
both groups merged more than I assumed toward a holistic biopsychosocial approach.
Also, while both groups diverged on the strategies with state administrators much more
likely to be in favor of forced treatment, there was surprising unanimity albeit with
reluctance among consumer-advocates that forced treatment may be at times necessary.
This information becomes an important development in terms of these two groups
emerging relationship. However, even though these two assumptions were not fully
realized, using the social construction framework, I did assume that these two groups
would find it hard to connect based on their histories. Indeed, what I found was that these
two groups exist within two separate symbolic universes that are anchored in their own
historic roles with competing sets of values, norms and concerns. In sum, I found an
emerging relationship in which both state administrators and consumer-advocates were
engaging with each other and one in which formal relationships were formed and
memorialized through grants and contracts. This emerging relationship is still at a rudimentary level which is unfortunately undermined by two varied symbolic perceptions of the world held by each group.

I continue to be aware and concerned of my bias in this research. Having witnessed a strange and seemingly brutal mental health system growing up, I continue to wonder about my lens when viewing the current relationship between state administrators and consumer-advocates. It was my experience long ago that is in line with the literature that shows that the state often resorts to coercion and violence to enforce the separation of the sane from the mad, including the use of electro-shock and other methods such as forced treatment that are still legal today (Whitaker, 2002). That is why qualitative research and in particular listening to people in their own voice was important as I attempt to divorce my biases from the experiences of consumer-advocates and state administrators.
CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

The purpose of this phenomenological research study is to compare how five state administrators and five consumer-advocates perceive mental illness and how these perceptions impact policy and practice. The conclusions from this study follow the research questions and the findings and address five areas: (1) acknowledging a dysfunctional mental health system; (2) recognizing that consumer-advocates remain on the margins of the mental health system; (3) the stigmatizing surrounding mental health; (4) converging notions on the causes of mental health and; (5) realizing the need to improve the relationship between state administrators and consumer-advocates. Following is a discussion of the major findings and the conclusions drawn from the research. This discussion is followed by recommendations and final reflections on this study.

Working Within a Dysfunctional Mental Health System

The first major finding of this research is that state administrators and consumer-advocates are working within a dysfunctional mental health system. This is particularly true for state administrators who described a mental health system that compromised their role and effectiveness. They talked about the personal toll it takes to work in such a system. Both state administrators and consumer-advocates talked about the high turnover rate among state administrators and the corresponding problem that arises of stability and continuity within the mental health system.

A conclusion to be drawn from this finding is that the mental health system in this state needs significant attention and possibly restructuring. This dysfunctional system
may be one additional factor in the reluctance and inability of state administrators to fully include consumer-advocates into mental health policy and planning. As we have seen state administrators and consumer-advocates are functioning within two separate symbolic universes which in and of itself makes it hard for the inclusion and integration of consumer-advocates. A further conclusion that may be drawn is that when there is a mental health system in disarray, this may serve as another reason for state administrators to be wary of including consumer-advocates. The opportunity is that consumer-advocates can play a role in restructuring and rebalancing the mental health system so that it is no longer reactive but proactive and that it has a culture that is open, inclusive and able to respond to change.

**Recognition That Consumer-Advocates Remain on the Margins of the Mental Health System**

The second major finding was that consumer-advocates said their role and effectiveness was impeded or marginalized by state administrators and that state administrators expressed reservations about fully including consumer-advocates in the mental health system. In spite of state administrator’s perceptions that they may be doing all they can to include consumer-advocates in the mental health system, it is clear that there is a separate and unequal relationship between state administrators and consumer-advocates. State administrators as the dominant group continue to see their role as one of maintaining social, moral and institutional order as they define mental illness primarily through an illness framework. Consumer-advocates remain on margins of the mental health system. These two groups are living in separate symbolic universes and the
relationship today is still rooted in a provider/patient relationship rather than a relationship of equals. The symbolic universe of each is based on a history of social interaction in which the role of each becomes socially objectified. For state administrators their symbolic totality reinforces institutional order, legitimacy and moral authority. This subjective symbolic reality is simply taken for granted by state administrators and, though not studied here, perhaps by the public and to a degree consumer-advocates themselves. For consumer-advocates their symbolic reality is based on a history of coercion and moral confinement, on the values of freedom and self-determination. A conclusion that can be drawn is that both groups will need to develop new pathways for communication and new structures that will foster stronger collaboration.

**Recognizing a Fragmented Consumer Advocacy System**

In this finding we see the emergence of a variety of consumer advocacy organizations. This finding highlights a divide among a newer and more professional, direct-peer service and the more traditional grass roots direct-peer service as well as an overall division between peer direct-services and public advocacy. It may be important going forward that consumer-advocates consider ways to merge their collective voices.

**Stigma as a Driving Force**

It is clear from the findings that consumer-advocates are driven in their work by the stigma that still exists in the public and mental health system. It is also clear that state administrators my hold some of these stigmatizing attitudes as they express reluctance to fully include consumer-advocates in the mental health system. Not unlike finding 2,
stigma can be addressed by finding new ways to include consumer-advocates into the mental health system and by developing forums for them to relate others and tell their stories.

**Building on Areas of Agreement**

In this fourth finding there is agreement on the biopsychosocial nature of mental health conditions among state administrators and consumer-advocates. Although state administrators were much more likely to take an illness approach to mental health, it shows an emerging consensus on the fundamental nature of mental health and to a degree strategies to treat it. One can conclude that this consensus has its best hope in a holistic approach to mental health that includes social, health and spiritual interventions as well as biological. This holistic approach may help bring mental health out from under the heavy burden of diagnoses into the mainstream of general healthcare and as a result de-stigmatize mental health.

**Acknowledging the Need to Talk and Build a Stronger Relationship**

There was agreement among state administrators and consumer-advocates that the relationship between them needs to improve. Both groups know that they exist in a new world of mental health care in which they will be to some degree monitored, evaluated and even funded based on their ability to work together. There are perceptions among consumer-advocates that they have been coopted and even coerced by state administrators or that their participation is mere tokenism. On the other hand state administrators seem to distrust the ability of consumer-advocates to fully participate in the mental health system and, in particular, to make decisions. One conclusion is that
there is a foundation to build upon as we see a nascent convergence in ways both groups think about mental health and the acknowledgement, if not the willingness, to build stronger relationships.

**Recommendations**

The following recommendations are based on the findings, analysis and conclusions of this research.

**Recommendations for the mental health system.**

1. **Commit to a voluntary mental health system**

   As consumer-advocates and state administrators come together in formal and informal ways to discuss policy and treatment, the hope is that both will enter into a dialogue of mutual respect that can foster shared goals, values and accountability for customers seeking help rather than establish two parallel and divergent systems of care. For the dialogue to have purpose, the two groups will need to continue to find common ground on the most controversial aspects of service and treatment that seem to point to fundamental issues and emotions surrounding choice, freedom and social justice, including involuntary commitment, forced treatment and the elimination of coercion. The social justice compass seems to point toward public policy that favors a totally voluntary mental health system although the methods are not quite worked out. This direction is memorialized in basic principles of law and justice, including civil rights legislation such as the Americans with Disabilities Act (ADA). There are many hurdles including a reluctance within the disability rights world to defend with equal passion the rights and humanity of people with mental health conditions. Like most Americans the disability
rights movement may be quick to accept the historical and demonizing stereotypes that people with a mental illness are dangerous and incompetent (Hillman, 1975).

2. Merge the mental health department into the health department

It is evident from this research that a range of people including state administrators and consumer-advocates challenge the neurobiological approach to mental health, recognizing other factors such as the historical, cultural and philosophical dimensions of mental health. Now that health care has embraced the social determinants of health and has broadened its perspective on physical health and illness, it might be time to consider placing the mental health system into the general health care system. This realignment may help with issues of stigma and it may also maximize limited resources and streamline services so people have a coordinated and single entry point for their healthcare.

3. Create a state financial reimbursement system based on a health need rather than diagnosis

The state should pursue a federal waiver that creates general healthcare funds for people with a mental health issue moving away from reimbursement based on diagnosis. The state will reimburse services provided by practitioners based on a healthcare needed rather than a specific diagnosis. Unfortunately funding tends to drive our services and our definitions. The mentally ill has become a category, formalized by the DSM and made real through the vocabulary and metaphors our language offers us (Bateson, 1972; Lakoff & Johnson, 1999; Linville et al., 1986). By creating a global fund that does not rely on a mental health diagnosis, stigma will be reduced and more people will access healthcare.
4. Create a new mental health community

It is generally acknowledged that consumer groups should cultivate a sense of belonging and purpose to those who might feel isolated due to their mental health status (Green & Franco, 2011; Townley et al., 2011). In social capital theory there is the concept of bridging capital which is an opportunity to have normalized relationships outside of the context of the mental health system. Bridging is living among and interacting with neighbors who do not necessarily have a mental illness (Townley et al.). Also, it is acknowledged in this research that there needs to be stronger communication between state administrators and consumer-advocates. The goal here is to create a new community of state administrators, practitioners and consumer-advocates who can break down the dominant narrative regarding “mental illness” and develop a counter-narrative to repair the damage that continues to be done to people with lived experience. This may best take place outside the current mental health system in a more informal setting both in person and online. This community will be a shared environment where each person has a sense of belonging and shared commitment to one another.

**Recommendations for State Administrators**

1. Create an Office of Consumer Advocacy

Hire three full time people with lived experience to operate an office of consumer affairs within the mental health or health care system. This office will be responsible for addressing concerns and complaints and will assist with policy development and practice implementation. This office will answer to the commissioner.
2. State employment - Hire people with lived experience

Create strategies to ensure the number of people with lived experience employed by the
department at all levels reflect the ratio of people with lived experience in the general
population of the state.

Recommendations for Consumer-Advocates

1. Create a consumer advocacy network

This network would not be allowed to receive federal or state dollars. It will be funded by
membership dues and philanthropic organizations. It should recommit itself to
challenging and encouraging a system that is fully democratic and fully equal.

Recommendations for Further Research

It is recommended that a larger group of state administrators and consumer-
advocates be involved in testing their perceptions of mental health.

In light of this the following should be considered:

1. Based on the limitations of this current study and to correct for the researcher’s
bias, research of a large sample of consumer-advocates and state administrators
should be conducted to assess whether the same or similar findings are uncovered.

2. The research should go beyond interviews, meeting observations and document
review to include a written survey to address particular perceptions in a tabular
format.

3. Further research should include a larger sample and array of consumer-advocates
to include the categories of consumer groups discovered in this research. These
would include informal peer organizations providing individualized services,
professional peer organizations providing individualized services, and advocacy organizations looking at the larger issues of policy and practice.

Researcher’s Reflections

Coming to the close of this study it is important to reflect on the journey that both consumer-advocates and state administrators have taken over their long and intimate history together. There are state administrators committed to their work and to doing the absolute best they can do for people with lived experience. However, we know by looking through the lens of critical theory that their social interaction is claimed by universal truths and dominant definitions that are hard for people in power to ignore. It is state administrators’ job, when possible, to deconstruct these meta-narratives and prevailing myths regarding mental health and people with lived experience. This study touches on core cultural assumptions regarding rationality, sanity and normalcy that contribute to a creation of opposites of us and them. There is progress and there is opportunity to do as Martin Buber, theologian and philosopher says we must do and that is to move our relationships that are based on the “I-It” to ones based on the “I-Thou. In an “I-Thou” relationship we see our existence and our humanity in the other as if it were ourselves.

This study was a collaborative effort as it was done by the generosity, interest and curiosity of both state administrators and consumer-advocates. As Friere (1970) states, all relationships are inherently reciprocal. We are deeply affected by the oppression we are under and by the oppression we impose. It is deeply gratifying to see these two groups begin the dialogue on mental health that may eventually free them both.
REFERENCES


Vermont Eugenics: A Documentary History


Hurricane Irene was a large and destructive tropical cyclone, which affected much of the Caribbean and East Coast of the United States during late August 2011. Irene is ranked as the seventh-costliest hurricane in United States history.

The Center for Medicaid and Medicare is part of the federal government that monitors and licenses mental health facilities such as state hospitals. Hurricane Irene was a large and destructive tropical cyclone, which affected much of the Caribbean and East Coast of the United States during late August 2011. Irene is ranked as the seventh-costliest hurricane in United States history.
DATA COLLECTION PROTOCOL

Sources of Material

The semi-structured interviews will explore perceptions of mental illness of state administrators and consumer advocates in their own words. Semi-structured interviews do not adhere to a set of fixed questions but allows the researcher to respond to new ideas as they are brought up in the interview. Meeting observations will allow me to gather quotes, understand the roles to these two groups and gather insight into their conduct and behavior. Participant observation will happen at public meeting convened by the Department of Mental Health as well as meeting initiated by consumer advocates. Documents will include meeting minutes, newspaper articles, mission statements, policies and procedures and reports. Documents or artifacts provide the ability to focus on how human beings make sense of their world and helps us put participant interviews into context (Bruner, 1991). Together semi-structured interviews, observations and document review is meant to provide for a triangulation of the data.

Introduction to Key Informant Interviews

I will introduce myself to prospective participants as a UVM doctoral candidate in the Education and Leadership Program. If I do not know the person professionally I will share with potential participants that I live in Vermont with my wife and three children and that I am currently working as an administrator for anti-poverty programs in Vermont. I will provide this overview of my study to potential participants:

“Thank you for meeting with me and for your consideration to participate in this study. My goal in this study is to understand the perceptions of mental health or illness from the perspective of consumer advocates and state administrators. I am interview five consumer-advocates and five state administrators. All of the participants in this study are adults like you who have sought out a leadership position in consumer advocacy or state administration.”

I will then present my research questions & design to prospective participants and I will email this information to them in advance of the key informant interviews. Once these contacts have expressed an interest in participating, I will email them the consent form to be reviewed and collected at the in-person interviews. I will then review the consent form with each participant briefly before beginning the interview.

Interview Approach

- I will Begin with easy to answer questions and move towards ones that are more difficult or controversial.
- I will ask big, expansive questions
- Arrange to interview your respondent in a quiet, semi-private place
- Use prompts
- Make sure that you have set up a second shorter interview to help you clarify or ask any questions you missed after you have transcribed the interview.
- I will end with my script
Interview Themes and Questions

This study analyzes perceptions of mental illness among state administrators and consumer advocates by focusing on three main themes:

1. Roles of State Administrators and Consumer Advocates
2. State administrator and consumer advocate beliefs regarding the existence and causes of mental illness/mental health*
3. State administrator and consumer advocate perceptions of mental illness as a problem
4. State administrator and consumer advocate strategies for how to treat mental illness

Interview Questions

Theme 1: Roles of State Administrators and Consumer Advocates

1. Tell me about your background? (Probe: Why did you become a consumer advocate / state administrator)?
2. Tell me about your role as a state administrator / consumer advocate your role? (Probe: What are your Goals? How effective do you feel you are in reaching your goals?)

What do you think is the role of consumer advocates / state administrators? (Probe: How effective do you feel they are in their role?).

Theme 2: Beliefs regarding the existence and causes of mental illness

3. How do you define mental illness? Where do you think your definition comes from?
4. What do you think are the causes of mental illness?

Theme 3: Perceptions of mental illness as a problem

5. Would you talk about your view of mental illness in VT, the nation? (Probe: Is it a problem? Growing? Decreasing? What kind of problem(s)?
6. How do you think consumer advocates view mental illness? / How do you think state administrators view mental illness?

Theme 4: Strategies for treating mental illness?

7. What do you think are the best strategies for treating mental illness?
8. Tell me about a time when you felt effective in helping people with a mental illness.

* Mental health and mental illness are used interchangeably.
# INTERVIEW PARTICIPANT LIST

*Interviewee ID will be label in the following way

Participant initials.YYDDMM.role initial.interview #. Interviewer ID
Ex: KY.05/19/14.SA.#4.PD

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Data Storage Protocol

1. Record interviews
2. Each evening—download interviews securely into computer as back up
3. Label each interview utilizing the following system:
   a. Participant initials.YYDDMM.role initial.interview#. Interviewer ID
      Ex: KY.05/19/14.SA.#4.PD
4. Transcribe interviews and save to a secure network.
5. Upon completion of the study, the data will be permanently deleted. The anonymity of the participants will be protected at all times and participants will sign a consent form prior to the interview process.