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Voices of experience : the mental health consumer and psychiatric survivor movements and their implications for ethical clinical practice

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Sophia Zucker
Voices of Experience: The Mental
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Practice

ABSTRACT

This theoretical thesis explores the origins of the modern concept of "mental illness" and traces the development of the mental health consumer and psychiatric survivor movements, modern social justice movements that work to change and/or dismantle the system of oppression that has long denied those labeled mentally ill the right to make basic decisions about their own lives. Working from a critical theoretical frame influenced by historical discourse analysis and post-structuralist theory, the thesis first examines the multiple constructions of madness and mental distress in the Western world since the Middle Ages, suggesting that the current biomedical model of mental illness is similarly constructed by modern social, political, and economic forces. Attention is then turned to the mental health consumer and psychiatric survivor movements, and the discourse utilized by each movement to challenge the dominant biomedical discourse. Finally, implications for social workers and other progressive/dissident mental health professionals are explored. Ultimately, this thesis suggests that ethical clinical practice is possible when clinicians listen to the voices of those they serve and continue to question how knowledge and power are (re)produced in the mental health system.
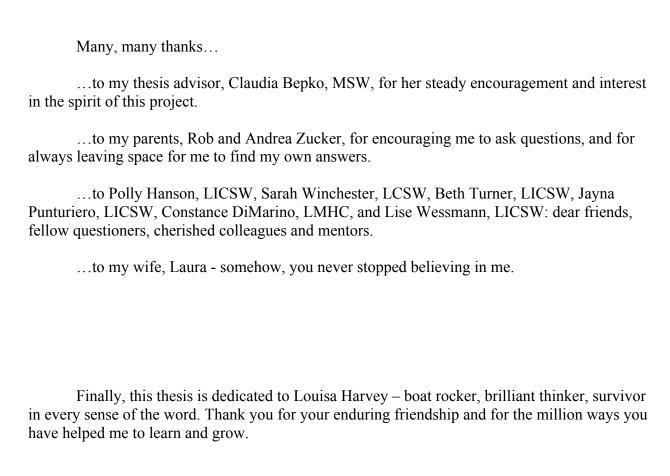
VOICES OF EXPERIENCE: THE MENTAL HEALTH CONSUMER AND PSYCHIATRIC SURVIVOR MOVEMENTS AND THEIR IMPLICATIONS FOR ETHICAL CLINICAL PRACTICE

A project based upon an independent investigation, submitted in partial fulfillment of the requirements for the degree of Master of Social Work.

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2014

ACKNOWLEDGEMENTS

Many, many thanks…

…to my thesis advisor, Claudia Bepko, MSW, for her steady encouragement and interest in the spirit of this project.

…to my parents, Rob and Andrea Zucker, for encouraging me to ask questions, and for always leaving space for me to find my own answers.

…to Polly Hanson, LICSW, Sarah Winchester, LCSW, Beth Turner, LICSW, Jayna Punturiero, LICSW, Constance DiMarino, LMHC, and Lise Wessmann, LICSW: dear friends, fellow questioners, cherished colleagues and mentors.

…to my wife, Laura - somehow, you never stopped believing in me.

Finally, this thesis is dedicated to Louisa Harvey – boat rocker, brilliant thinker, survivor in every sense of the word. Thank you for your enduring friendship and for the million ways you have helped me to learn and grow.

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CHAPTER I

Introduction

The field of social work has, from its inception, been concerned with the task of ameliorating suffering. The earliest social workers concerned themselves with what were seen at the time as social issues, particularly poverty and women's rights (Healy, 2008). As the field – for better or for worse – has become professionalized and aligned with psychology, many social workers have begun to focus more on what is referred to as mental health and mental illness, historically the purview of the fields of psychiatry and psychology (Tomes, 2008).

However, clinical social work remains qualitatively different from psychology. Our field has its roots in social justice and remains focused on a person-in-environment understanding of individual struggles, setting it apart from other clinical fields (Stewart, 2013). An examination of the social work code of ethics (National Association of Social Workers, 2009) reveals a set of values based on this social justice history, charging social workers with the task of responding to human pain in a way that respects human dignity and individuals' right to self-determination.

A genuine commitment to these values necessitates a thoughtful examination of what is meant by concepts such as self-determination. In a recent review of social work literature on the topic, Scalfano (2013) points out that definitions of self-determination are numerous and diverse; there is significant contention as to the range and limitations of an individual's right to make decisions about their own life. Given this, and given the history of social workers and other helping professionals participating in and perpetuating a range of social injustices in the name of help (Park, 2008a), it is imperative that we continue to interrogate the methods, models, and

theories of treatment that guide our work. It is not enough to merely assess their efficacy in

treating certain ailments or addressing particular problems. We must also pursue meaningful

discourse regarding the underlying purpose of any action taken in the name of help or treatment,

honestly questioning whether those actions truly adhere to the values of human dignity and

choice.

Who makes decisions about what kind of help is available to which people? To whom are

we responsible when attempting to provide that help – to the individual? To the agency or

government or funding body? When does help stop being helpful and become a mechanism of

social control over the behaviors of those who have been deemed different or deviant? In order to

answer these questions, we must understand how we have come to conceptualize and address

various problems and experiences in a historical context.

Mental Illness and Mental Distress

Perhaps no topic lends itself to the kind of critical exploration suggested above as readily

as our understanding and treatment of people who have heard voices, experienced extreme mood

states, or had other experiences that are currently understood as evidence of mental illness

(Clegg, 2012). Current approaches to treatment are vastly different from those accepted in the

past, and all are rooted inextricably in their historical, political, and social contexts (Smith,

2012); a truly rigorous analysis must take into account social forces well beyond medical or

other treatment-oriented professions. Of particular interest to social work, with its dual focus on

clinical care and social justice, are the questions delineated above: who makes decisions? Why is

this the case? Who is truly served?

The term "mental illness" is itself a product of a particular historical moment and a

particular framework of understanding. It has not always been the case that mental distress has

been viewed as an illness analogous to a medical condition and, therefore, treatable by biological means such as medication (Gomory, Cohen, & Kirk, 2013). A wide range of fields including theology, psychology, forensics, and biology have long been concerned with the thoughts, emotions, and behaviors that are currently seen as evidence of a mental or brain-based illness (Pfeifer, 2006; Smith, 2012), seeking to understand their meaning and cause as well as their treatment. Indeed, "treatment" as such has not always been the social response to mental distress (Grob, 1991). Depending on the moment in history, the cultural context, and the various identities of those involved, what is now seen as mental illness has been understood in widely differing ways. These frameworks of understanding – be they religious, moral, social, medical, etc. – have engendered corresponding responses well beyond the biomedical framework favored today (Grob, 1991; Smith, 2012).

Linking these seemingly disparate approaches is a common thread: an essentially top-down framework in which decision-making and interpretive power is held by an outside force, be that a religious authority or a medical doctor (Emerick, 1996; Everett, 1994). Particularly in the last century, however, social movements have arisen that argue for a different approach to the phenomenon of mental distress, and this thesis is concerned first and foremost with them. Across differences in ideology, these approaches have at their center the knowledge, experience, and motivation of those who have experienced these extreme states in their own lives (Adame & Knudson, 2007; Everett, 1994). Rooted in liberation and civil rights activism, these movements call into question long-accepted assertions about the meaning – or even the existence – of mental illness as a discrete and identifiable entity. They argue persuasively against any notion that those labeled mentally ill are less equipped to understand and make decisions about their own lives (Chamberlin, 1998; Masterson & Owen, 2006).

Structural Overview of the Thesis

As summarized above, this thesis will focus on the culturally bound and ever-changing meaning of mental illness in Western society. Given the stated commitment of clinical social work to approaching individuals and groups in a way that is both conceptually and practically respectful of their right to make choices about their lives, the purpose of this work is to pay attention to the voices of those people who have themselves been labeled mentally ill. Two related but undeniably different social movements will be explored, each of which has emerged as a response to existing systems of treatment, and each of which influences and interacts with systems of service provision for those labeled mentally ill.

Within the theoretical thesis format, mental distress/mental illness and its treatment is framed as the phenomenon, which will be examined through the theories – the values and ideas – of each of the two social movements. The first of these is the mental health consumer movement, which is closely linked to disability rights activism and the independent living movement (Jacobson & Greeley, 2001). In the past half-century, "recovery models" based on the tenets of the consumer movement have become the primary framework for service provision to people with "psychiatric disabilities" in the United States and Canada, and are relatively common in the United Kingdom (Campbell, 1991; Everett, 1994). The second perspective that will be explored in this thesis is that of the psychiatric survivor movement. Also concerned with individual rights and self-determination, this movement questions the existence of mental illness as a distinct entity (Plumb, 1993). Instead, the psychiatric survivor movement understands the phenomenon as a distress response to unbearable social and environmental stressors (Adame & Knudson, 2007).

Following this introduction, the next chapter of this work (Ch. II) will lay out the critical theoretical framework through which I will explore the phenomenon of mental distress and its social construction. This framework will draw on post-structuralist philosophy and associated methods of inquiry that allow for a critical examination of social, economic, and political forces that shape the manifestation of human behavior as well as the language that we use to discuss and describe it. Chapter II will also lay out my own position as a researcher and the potential perspectives and biases that my experience may bring to this thesis.

Chapter III will undertake a fuller exploration of the history of extreme states of mental distress, as well as the current state of understanding and treatment. As has already been established, there has by no means been a consistent framework for defining the concept of mental illness, let alone a consensus regarding its meaning or etiology (Clegg, 2012; Gomory et al, 2013). This work will attempt to trace the arc of this ever-changing phenomenon as it has existed in its various social and historical contexts. It will also seek to establish the current state of affairs, taking a position that questions claims of enduring or universally accepted explanations.

Chapter IV will focus on the mental health consumer movement. This chapter will take an in-depth view of the movement, including its roots in ex-mental patient consciousness raising and advocacy (Chamberlin, 1978), and in the disability rights and independent living movements (Jacobson & Greeley, 2001). Concepts such as "psychiatric disability", and "consumer", which are commonly used in systems of service provision today, will be placed in their social and historical contexts, emerging from the activism and research of those involved in this movement.

In Chapter V, the focus will turn to the psychiatric survivor movement. The ways in which this movement is intertwined with the work of consumer and disability rights advocacy

(Everett, 1994) will be explored, as well as the points of divergence that mark the differences between those who understand themselves to have a psychiatric disability and those who seek to undermine or call into question the existence of mental illness or psychiatric disability as an identifiable and discrete entity (Adame & Knudson, 2007).

Chapter VI will discuss and synthesize the preceding chapters. The ideas and activism of the consumer and psychiatric survivor movements will be explored again through individual stories of madness, and various ways of approaching extreme mental distress will be examined in light of the movements as well as in the context of current treatment standards. The perspectives of radical and crossover clinicians – those who sit at the intersection of consumer, survivor, and provider (Bassman, 1997) – will be integrated as well. Finally, questions will be raised in light of this analysis, and implications for those engaged in clinical and social justice work around issues of mental health and mental illness, self-determination, and policy-making will be explored.

In sum, this thesis will seek to deepen understanding of the influence of civil rights and liberation movements on dominant approaches to mental health and mental illness through the lenses of the mental health consumer and psychiatric survivor movements. It will offer a snapshot of where the movements stand today, their relationship to the dominant paradigm regarding mental distress, and suggest areas of further exploration for those concerned with reforming – or perhaps dismantling – current systems of mental health care.

CHAPTER II

A Critical Theoretical Frame

While this thesis is not specifically a work of philosophy, I found myself in need of a philosophical frame as I approached the task of outlining and understanding the phenomenon of madness as a way to provide context for the social movements I wish to study. In my struggle to define and contain the concept of madness, I found myself again and again facing the impossibility of tracking this moving target as a static *thing*. As discussed in the previous chapter, this work takes a questioning position, reluctant to accept a particular notion of truth and ever-aware of the shaping forces of history. In order to remain true to this approach, I needed a framework that could allow me to focus not simply on the phenomenon itself, but on the myriad forces – knowledge, power - that have shaped it.

This thesis takes as its primary subjects social movements that are actively seeking to effect change in the name of justice and freedom. As such, I sought an approach to the historical part of the work that would take a critical stance – not simply reporting facts, but questioning their validity and constantly seeking to contextualize knowledge and understanding. In my search for a guiding framework, I found my way to post-structuralism (Sarup, 1989), and from there to critical theory (Wodak, 2009) Finally, I arrived at critical discourse analysis, and specifically historical discourse analysis (HDA) – an approach to social science research that seeks "not to find truths about past events or to identify the origins or causes of past events, but to expose history as a genre—contingent, ambiguous, and interpretive" (Park, 2008b, p. 394).

HDA is not a step-by-step method of analysis, but a framework in which to wrestle with ideas and events in their historical context. Its post-structuralist, and specifically Foucauldian, roots encourage a critical and interpretive approach to the process of analysis as well as to the subject. As such, rather than attempting to apply some kind of "pure" HDA to the phenomenon of madness, my hope is to explore the topic with the critical, interpretive, and social-change-minded lens demanded by this type of analysis.

In this chapter, I will give a brief overview of historical discourse analysis and its philosophical and ideological roots. Having done this, I will outline how this analysis will inform the thesis. Next, I will turn to the issue of language, particularly important in an analysis that is based on examining discourse. Finally, I will discuss the strengths and limitations of this study, focusing in particular on my own identities, motivations, and discursive position as a social worker, a researcher, and a human being.

Post-Structuralism

As mentioned above, historical and critical discourse analyses are research frameworks based in a post-structuralist – specifically a Foucauldian - approach (Park, 2006; Wodak, 2009)**.** Post-structuralism is a philosophical theory that arose in the wake of the subject-based theories such as existentialism that had prevailed in Western thought through the mid-twentieth century (Oksala, 2008). For the purposes of this thesis, post-structuralism's most salient tenet is its challenge to the notion that meaning is static or exists independently of perception. Post-structuralism argues that meaning is embedded in instability: it is created and enforced by social forces and the narratives (called "master-narratives") that emerge from these forces (Oksala, 2008). History, then, is not an independently existing account of past events, but a story that is told about belief systems and how power has circulated in various times and places (Sarup, 1989).

Foucault's particular take on post-structuralist thought lends itself especially well to this thesis because it is specifically a critical theory – that is, a radical philosophy seeking social change. Foucault did not offer a concrete explanation for the world as it is or as it has been, but repeatedly asked questions that are inherently without definitive answers, and charged his readers to do the same. Philosophy and history, in this framework, are tools that are to be put to the task of "relentlessly question[ing] dogmatic beliefs and intolerable practices in contemporary society. We should read him for no lesser reason than to change the world" (Oksala, 2008, p.5).

Discourse Analysis

Discourse analysis is one approach to implementing Foucault's imperative. It attempts to examine history through the lens of discourse, which in this case refers to the linguistic, political, and social forces that shape meaning and action (de Pinho, Kantorski, & Bañon Hernández, 2009). Park (2006) discusses at length the challenges inherent in applying a critical analysis to historical matters, "resisting the pull of conventional linear history" (p. 173). She also grapples with the necessarily incomplete nature of any attempt at such an analysis, acknowledging that a full analysis would have to include "nothing less than the total recounting of the shapes and tenor of the political, social, cultural, and moral reckonings" (p. 173) that together comprise a given discourse. Not only is such a task unrealistic, but it is not loyal to the deconstructive nature of the analysis itself.

In the spirit of this central conflict, this thesis will be inspired and informed by the thrust of critical and historical discourse analyses without attempting to exactly recreate the methodology exemplified by Park (2006; 2008c), for instance, or de Pinho et al (2009). It will grapple with the discourses that have shaped the changing meanings of madness, maintaining an

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awareness of these meanings as reflective of social forces and the mechanisms in place to enforce social norms.

Language

Critical discourse analysis and its historical relative, historical discourse analysis (Park, 2006; Park, 2008c) take language – the specific use of individual words, phrases, or larger chunks of text – as their primary units of analysis. That is, in order to understand history as a genre, they look to the ways that language shapes and reinforces – and, in turn, is shaped by and reinforced by – historical constructs and ideas. As discussed earlier, this thesis is not a pure historical discourse analysis, but rather is influenced by the social consciousness and interpretive stance of the approach. That being said, it would be deeply remiss to ignore the reality that, in writing this piece, the language I choose to discuss historical phenomena is not separate from the phenomena themselves. There are countless words and phrases that I could use to write about madness, and those words are embedded in social and historical contexts that participate in the construction of the phenomenon. If we accept this premise, language choice becomes in itself an act of social change.

The language used to describe and interpret what is now often referred to as "mental illness" has varied widely over the course of history and in accordance with the systems of knowledge and power in place in a given historical moment (Gomory et al, 2013)**. I**n writing about these moments, I can use the words of the time period to a certain extent, but not without a critical stance, understanding that the language does not exist separately from the social forces that created it. Certainly, when writing about the social movements that are at the heart of this thesis, I will use the language embraced by each movement: each movement has, after all,

chosen the words it will use to refer to itself and its members with the understanding that language changes how we think and react to the world around us (Adame & Knudson, 2007)**.**

If the language I use to discuss movements and systems of understanding will be the language used within those movements and systems, I am left still with the task of choosing the words I will use in the thesis as a whole. This is not an easy task, and I have struggled to come to a decision that feels both practical and mindful of the constructive – and therefore potentially helpful or harmful – nature of words and word usage. Ultimately I have chosen to use the words "madness" and "mental distress", more or less interchangeably, as the default names for the phenomenon at hand. The reason for this choice is that these words are essentially non-clinical; in today's medicalized environment, the language of disease and disorder has infused both professional and lay discourses (Gomory et al., 2013), and to default to the term "mental illness" would be to privilege this discourse over that of dissenting voices. While this is not a perfect choice, it has been made consciously; while I cannot – as none of us can – step completely outside the prevailing discourses of the moment in which I write, my choice of language has at least been made with this understanding in mind.

Definition of Terms

For the purposes of this thesis, "madness" and "mental distress" will be used more or less interchangeably to refer to the kinds of psychological, emotional, and possibly spiritual experiences that are today generally referred to as "mental illness", and particularly "severe and persistent mental illness". I will not attempt to narrow these categories down diagnostically, given that diagnostic categories are context dependent and employ language based solidly in the discourse of the biomedical model (Clegg, 2012). The term "mental distress" will be used

judiciously, because it contains within it an interpretive evaluation of individual experience – an assumption that the experience is, in fact, distressing or unpleasant.

Strengths and Limitations

What does it mean to engage with a topic as diffuse and wide-reaching as madness in the context of the limited scope of a master's thesis project? One thing that it inevitably means is that this project is incomplete. No one document can fully explore and illuminate the historical discourse surrounding the concept of madness, nor can such a document do full justice to the complex and discourse-changing influence of the social movements that will be examined. I take on this project with the full understanding that it is merely a drop in the proverbial bucket. At the same time, it is in the spirit of social change that I have chosen to write about this topic, and social change cannot begin without critical engagement, even in the most general way. As such, I look at this thesis as a beginning point for myself as a scholar, a clinician, and an activist, and it is my hope that as I wrestle with the ideas in this thesis I can offer to others a space for their own questioning.

On a more practical note, I want to acknowledge that I have chosen to look separately at the mental health consumer and psychiatric survivor movements, despite the fact that there is disagreement both from within and outside of the movements as to whether or not they are indeed separate from one another at all (Adame & Knudson, 2007; Everett, 1994).My choice to separate them and examine each on its own is based in my interest in discourse and my understanding that the consumer movement and the psychiatric survivor movement are seeking to change the prevailing discourse in different, though related, ways. There are many points of connection, and the movements have frequently both worked together towards common causes and been lumped together in error (Everett, 1994). In choosing to give each movement its own

chapter I hope to make space to listen to the unique voices and intentions of each as well as illuminate points of overlap and common goals.

Finally, I want to turn my attention to my own role as writer and researcher. In keeping with the spirit of critical discourse analysis and its post-structuralist approach, I have no intention of attempting to erase my own presence from this thesis. My choice of topic and most of all my approach to this topic is deeply informed by my personal and professional lived experience. I am an emerging clinician and therefore a "provider" of services, to use the language of the mental health field. My thoughts and my research about madness are therefore informed by my education, my clinical experience, and my experience as someone who is privileged within the system of power that encompasses the provision of mental health services.

At the same time, I am a person who has lived experience of mental distress that has, at times, been profound and life-altering. I have been personally influenced – primarily in ways that I consider positive – by providers of services, particularly psychotherapy. I must also acknowledge that I have held significant privilege as a "consumer" or "patient", in that my other identities (particularly my whiteness, my education, and my middle class background) have protected me from the kind of abject oppression experienced by many who interact with the systems currently in place to help or control people labeled mentally ill. My distress has also largely manifested in ways that are more socially sanctioned than in the case of people who hear voices or have more unusual experiences of reality, and so I have been primarily approached as a person in pain and needing help rather than a social deviant or someone who is ill. I cannot call myself a psychiatric survivor, for instance, but nor can I artificially distance myself from those who have been oppressed in more overt ways by the system that has helped me. As I write this

thesis, it is my intention to actively and openly acknowledge my own experiences and identities

as they relate to the topic at hand, and to understand them as a part of this research.

CHAPTER III

The Social Construction of Madness

History tells us that human beings have always been concerned with issues of difference

and deviance in individual and group behavior (Gomory et al, 2013). What changes, as has

already been discussed in this work, is the framework – the system of knowledge and

understanding through which we interpret and respond to these varying experiences and

behaviors (Park, 2006). A critical historical lens makes it possible to explore the social,

economic, and political forces that have shaped these responses and understandings in earlier

moments, but it is more difficult to see the same forces at play in the present. And yet, because

these forces are not impartial, because they shape how human beings are treated, social justice

demands that we turn the same critical lens on the present as we do on the past.

In the previous chapter, I outlined the critical theoretical and methodological approach

that informs this thesis. In this chapter, I will use that approach to examine the past and present

of the phenomenon of madness in the Western world, as well as the discourses that have shaped

and interacted with the phenomenon. Particular attention will be paid to the allocation of power

and knowledge and the ways in which that allocation has constructed the concept and

manifestation of madness and mental distress.

It is not the goal of this chapter to catalogue or describe every twist and turn in the story

of this phenomenon; not only would this be impossible, but it would be antithetical to the goals

of critical theory (Park, 2006). Rather, the goal is to capture a sample, a representation of the

changing discourses surrounding the phenomenon of madness, in order to better understand the discourse of today and to set the stage for the emergence of the civil rights movements that are the true subjects of this thesis. In order to do this, I have chosen several historical moments that were significant turning points in the construction of madness in the Western world, and will undertake a brief analysis of the discourses at play in each of those moments. I will then turn a similar critical lens on the current dominant discourse, the biomedical model of psychiatry (Deacon, 2013).

The Middle Ages: Madness as a Mind/Body Affliction

The majority of literature on the phenomenon of madness during the middle ages in Europe and the Middle East suggests that the division between mind and body so commonly accepted in modern philosophy had not yet taken hold (Harper, 1997). Madness, then, was expressed as an external (spectacular) manifestation of a simultaneously internal and external experience, thought to be of the body as well as of the spirit, and often associated with religious possession or affliction. The mad were identifiable by their behavior, and treatment was largely physical in nature, an attempt to balance the body in order to balance the spirit (Eghigian, 2009).

In its manifestation, medieval madness served what Harper (1997) calls "a didactic function" (p. 387): madness, like all illness, was frequently perceived to be a divine punishment for sin, and its visibility served as "dire warnings of the physical consequences of spiritual turpitude" (p. 387-388). The symptoms were easily identifiable and classified into discreet categories (maniacs screamed and rent their clothes; melancholics could be identified by their darkened skin from excess black bile, etc.). Treatment for the inner (spiritual) condition was performed on the outer, bodily form. Prayer was also thought to be an appropriate remedy for

some kinds of madness that were understood to be spiritual afflictions or demonic possession (Nguyen-Finn, 2012).

Power and knowledge during this time period were held by the church and systems of feudal government (Nguyen-Finn, 2012). The discourse of sin and spiritual affliction acted as an interpretive lens for the behaviors that were understood as madness. The visible and clearly unpleasant physical symptoms of the afflicted served as cautionary tales, warning those around them of the perils of deviant behavior and reinforcing the power of religious and feudal obedience.

The Industrial Revolution: Warehousing the Mad

The industrial revolution marked a significant change in the size and density of communities, centralizing populations in cities rather than spread out in small agricultural settlements. Population also increased overall, as access to healthcare and adequate diet increased. This time also marked a shift in the allocation of responsibility for the care of those individuals deemed to be mad or unable to care for themselves due to disability or poverty (Grob, 1991).

With these social and economic changes came the advent of the workhouse (Grob, 1991): not a place of treatment but a warehouse for people who – due to any number of internal and external factors – were not able to meet their own material needs within the industrial system. In return for barely life-sustaining food and shelter, workhouse residents labored at menial jobs for long hours under abhorrent conditions.

What is striking about this development is the lack of distinction made between the mad, the impoverished, the criminal, and the disabled at this time (Sarup, 1989). Rather than being punished or saved, as might have been the case in the Middle Ages, in the industrial age

"between [the destitute person] and society an implicit system of obligation was established: he had the right to be fed, but he must accept the physical and moral constraint of confinement" (Foucault, 1967, p. 48). The discipline of confinement and of work served to control and to keep separate those whose behavior or attributes – be they endemic or externally caused – did not conform to the norms of the newly industrialized society.

The 19th Century: Asylums and Moral Treatment

By the early 19th century, the failure of generalized confinement and workhouses to address issues of deviance as well as unemployment had been largely accepted by those in power (Sarup, 1989). At the same time, a growing focus on humanitarian reform drew attention to what was seen as the particular needs and characteristics of the mad as opposed to other deviants, marking a shift from the mass warehousing of the destitute and deviant more common to the 17th and 18th centuries. The notion that the mad needed treatment and that mass confinement might in fact be making them *worse* caused a great deal of public concern and unrest (Symonds, 1995).

From this unrest came policy changes such as the Lunacy Act of 1845 in England, which made provisions for the custody and treatment of the mad separate from the confinement of the criminal and unemployed (Symonds, 1995). Reformers such as Tuke in England and Pinel in France have been credited with the beginning of the asylum movement; the word *asylum* suggesting refuge for the mad from the dangers of the workhouse. Some have argued, however, that asylums may have served more to protect the public – including the poor and the criminal previously housed with the mad – from the "frightening bestiality of the madman" (Sarup, 1989, p. 68).

Asylums, particularly those modeled after Tuke in England, advocated what was called a "moral treatment" for madness (Luchins, 1988). Reformers in the United States as well as in

England and continental Europe advocated treatment for the mad that was based on utopian ideals popular among the educated classes at the time. Asylums were places where, with proper care and guidance, afflicted individuals "could perfect themselves, to be rid of sin and to be transformed, saved… the insane could be transformed so that they could return to society as healthy and productive people" (Luchins, 1988, p. 472-473). Treatment included both religious and occupational activities (prayer, agricultural work) and took place in a carefully coordinated environment in which even the architecture of the asylum was seen to be an aspect of treatment (Shilkret, 2008). Patients were restored to health not simply when they ceased to display deviant behaviors, but when they demonstrated reformed thoughts: when they agreed with the necessity of their treatment and showed the ability to resist immoral urges (Luchins, 1989).

Embedded in this ideology is yet another iteration of the belief that the mad must be somehow controlled or reformed. The "kindness" of the moral treatment approach might alternately be seen as paternalistic control, wielding power over not only the behaviors but, ultimately, the thoughts and desires of its patients. While asylums freed the bodies of the mad from the physical violence of the workhouse, Foucault (as cited in Sarup, 1989) described this transition as one of internalization: where once there was external confinement, moral treatment imposed mental and spiritual imprisonment that had a similar managing effect on those deemed most deviant.

The Early 20th Century: Mental Hygiene and the Medicalization of the Mind

In the first decades of the 20th century, two separate movements – one social and one medical – emerged that once again changed the face of mental health treatment and the understanding of madness. Arising in response to the failing, overburdened asylums that had previously been the primary location for treatment of madness, somatic psychiatry and the

mental hygiene movement began the slow push towards community-based care that we see today (Pols, 2001). These movements also set the stage for the rise of the biomedical model (Cohen, 1993), which will be discussed in greater depth later in this chapter.

Somatic psychiatry. Well into the beginning of the 20th century, the field of psychiatry was divided in its understanding of the etiology of the conditions it sought to treat. Those who ascribed to a somatic – that is, physiological – explanation were particularly committed to furthering research into the medical causes of what was now beginning to be referred to as mental illness. Using the rationale that, since mental illness did not appear to be declining in prevalence despite radical social changes, the somatic psychiatrists insisted that the conditions must be a result of biological disease processes, and that effective medical treatment would no doubt be discovered at any moment (Pols, 2001). Psychoanalytic theory, then still primarily the purview of psychiatry, was also on the rise at the time, and supported the view that mental illness was essentially a form of disease (Cohen, 1993). Somatic and psychoanalytic psychiatry gained power in the field over the first several decades of the century, in part in an effort to bolster the failing reputation of psychiatry as a less-than-credible arm of medicine (Hess & Majerus, 2011).

The mental hygiene movement. In parallel to the rise of psychiatry as a somatic field, a social movement emerged that became known as the mental hygiene movement. Where somatic psychiatry claimed that mental illness was a biological process, the mental hygienists believed that mental distress and the associated behaviors were primarily a result of social ills and should be addressed accordingly (Toms, 2010).

Mental hygiene originally arose in response to maltreatment of patients in asylums and mental hospitals (Pols, 2001). The moral treatment of the 19th century, while ideologically

distinct from the generalized confinement of previous eras, in practice often resulted in the same kind of warehousing and abuse that were common in earlier times (Symonds, 1995). Mental hygienists, led by one-time mental patient Clifford Beers, sought to address these abuses, but were ultimately persuaded to focus on prevention and early intervention of mental problems. They located these problems within the individual inasmuch as they were individual responses to social problems such as poverty, lack of education, etc. Interventions in mental hygiene were focused on structural preventive measures and involved professionals from a range of fields (social work, psychology, education) as well as lay activists (Pols, 2001).

The mind as a medical object. Despite their obviously divergent premises, mental hygiene and somatic psychiatry's simultaneous growth produced a combined discourse that paved the way for the rise of the biomedical model in the later 20th century (Cohen, 1993). The important ideas were that external circumstances could exert their power to make identifiable changes in the mind of the individual (per the mental hygienists); and that the mind was an identifiable object to which medical treatment could be applied in a controlled way (per somatic psychiatry and psychoanalytic theory). Together, these ideas created an objectified and medicalized notion of the mind (Cohen, 1993), fueling what would become a lucrative industry for psychiatric medications and building fertile ground for a biomedical discourse of mental health and mental illness.

The Biomedical Model

In the late twentieth and into the twenty-first century, the dominant discourse on madness is that of the medical model – specifically what is known as the biomedical model or disease model of mental illness (Deacon, 2013; Engel, 1992; Oken, 2000). The thrust of this discourse is

fairly easily summarized as "the notion that mental disorders are brain diseases" (Deacon, 2013, p. 847).

The biomedical model of mental illness is rooted in the larger biomedical model of disease, which works from an assumption that there is a normal state of health, from which illness indicates a deviation of some kind. Furthermore, these deviations are physiological and most appropriately corrected by physiological means (in the case of madness, largely through medications) (Double, 2002). Embedded within this framework is an assumption that deviations are consistent, identifiable, and measurable.

Historical roots of the biomedical model. It might be surprising to the modern mind to realize that this idea is neither universally accepted nor has it always been the prevailing understanding of the phenomenon of madness. In fact, the biomedical model is a relatively modern invention and has been fueled in large part by entirely non-psychological (and often non-medical) forces, particularly political and economic ones (Clegg, 2012; Deacon, 2013). These forces have shaped the current discourse sufficiently that we are often unaware of their power, which is essentially how discourse works (Park, 2006; Wodak, 2009).

An analysis focused on systems of power and knowledge asks what groups or ideas are given power in a particular discourse (Park, 2006; Park, 2008c). In the case of the biomedical model, the language of health and illness places knowledge and power in the hands of doctors, of scientists, and in the economic interests of the companies that produce psychiatric drugs (Arney, 2010; Cohen, 1993). Furthermore, power is still held (as it has almost always been) by those who make decisions *for* and *about* those who are affected. Illness is a special area of knowledge, and in this model the power to make someone well is in the hands of those who hold that knowledge.

The beliefs and associated allocations of power inherent in this discourse are self-perpetuating, as are all mechanisms of power (Oksala, 2008). After all, it is in the interest of powerful entities to hold onto their power. In this case, the belief that mental illness is a disease contains within it an underlying belief that it is a problem to be solved: no one wants to be sick. That belief repeatedly hands power to those who have (or are believed to have) the knowledge and ability to "cure" mental illness, and those players (the medical field, the scientific research field, the companies that produce psychiatric drugs) have an interest in pursuing questions whose answers will lead back to the biomedical framework.

Achievements associated with the biomedical model. It would be irresponsible, even in this obviously skeptical overview of the biomedical model, to ignore what good has come from it. There is no shortage of literature, both scientific and anecdotal, that attests to the relief that some people have found in medication as a form of symptom relief (National Institute of Mental Health, 2012). Whether or not one questions the demands that society places on individuals to conform or to live up to particular standards, it is undoubtedly the case that some have found that medications allow them to more easily or effectively meet those expectations. Additionally, many credit medication with drastic reduction in experiences that have felt utterly unbearable (National Institute of Mental Health, 2012).

One of the most oft-referenced effects or intentions of a move towards a biomedical model of mental illness is a reduction of stigma historically associated with madness. A physiological explanation for unusual behavior, according to this line of reasoning, removes blame from individuals: when one's behavior is understood to be due to a "chemical imbalance", for instance, it follows that one is not strange or bad, but is simply ill (Deacon, 2013).

Some criticisms of the biomedical model. Popular discourse continues to perpetuate the belief that medicine has begun – and presumably will continue – to understand more and more about mental illness as such, systematically chipping away at the prevalence and negative impacts on individuals and society. Comparisons between mental illness and diabetes (both being seen as chronic medical problems to be managed by medical means) and the notion of chemical imbalance as an explanation for anxiety or sadness are some examples of the way in which the biomedical model has become part and parcel of how we think about mental distress (Arney, 2010; Double, 2003). Critics of the biomedical model argue that, despite the promises made by the medical field, aggressive focus on the physiological etiology of mental distress has not appreciably decreased the prevalence of mental illness, improved the quality of life of those who are served by the mental health system, or addressed the level of stigma faced by those who have been diagnosed with major mental illness (Cohen, 1993; Deacon, 2013; Engel, 1992).

Today, after over a century of the hegemony of biomedical discourse, neither statistical nor anecdotal data indicates a general improvement in the lives of people who have been labeled mentally ill (Deacon, 2013; Engel, 1992). The United States, where the biomedical model holds particular power, has the highest rates of prevalence and chronicity across diagnoses, as well as alarming increases in disability benefits being sought for mental health related concerns (Deacon, 2013). Far from a testament to the effectiveness of the biomedical model, these numbers speak volumes about how far we are from adequately attending to the needs of people in distress.

In their analysis of language in historical writing on madness, Gomory et al (2013) suggest that the biomedical model and the language used to perpetuate it may serve as a smokescreen of sorts, concealing how little the medical field actually knows about the nature and etiology of mental distress: "…it remains an open question whether the psychiatric profession is

treating medical diseases entailing impersonal pathophysiological processes, or instead

responding to the moral and behavioral anguish of individuals failing in the

game of life" (p. 124).

Conclusions

In this chapter, I have attempted to trace the phenomenon of madness in the Western

world by looking at the discourses that have shaped it over the past several centuries. It is

important to note that it is not only the understanding of madness that has changed throughout

history, but also that the actual manifestations of distress have varied greatly depending on the

context. Within a post-structuralist framework, we can understand these changes in manifestation

to be responses to the changing allocations of knowledge and power that have shaped cultural

discourses about madness over time. Rather than regurgitating accumulated knowledge, I have

attempted to consider the social and political forces at play throughout history.

The nature of discourse is that it is not always easy to "hear" it and to understand its

power to shape our world. In focusing on the complexities of the current prevailing discourse, it

is my intention to call into question what we think we know about what is referred to today as

mental illness – to make visible the often-invisible discourse in order to engage with it critically.

Today, just as in the past, the stories told by powerful voices shape not only what we believe, but

the actual shape and nature of the phenomena around us. Viewed over time, one theme that

emerges across the varied discourses is that of striving to change or control those who express

deviant or unusual behavior. Whether the mad have been seen to be possessed, to be morally

deficient, or to be ill, the systems of power have been activated to confine, reform, or medicate.

To wrestle with the notion that the seemingly benign (offering medicine to the sick) might in fact

be simply a reiteration of social control is the kind of analysis that is at the heart of this thesis. To

return again to the utility of this kind of critical engagement, we must acknowledge again that power is not neutral and discourse is seldom benign. Naming and exploring the discourses around madness shakes us out of complacency and makes space for questioning the status quo.

This process of questioning also sets the stage for the next two chapters, which will take a more in-depth look at the psychiatric survivor movement and the consumer movement. Their individual and interrelated histories will be explored, with particular attention paid to their challenges to the dominant discourse. As civil rights efforts, these movements are essentially Foucauldian in nature: they trouble the complacency with which we listen to the "master-narratives," the stories that have been told and retold about why things are the way they are, and demand a redistribution of power and knowledge. While they are practical rather than theoretical movements, the critical theory approach to research lends itself beautifully to documenting and analyzing their role in the changing nature and understanding of the phenomenon of madness.

CHAPTER IV

The Mental Health Consumer Movement

The previous chapter's focus on current and historical understandings and frameworks of treatment for mental distress emphasized the history of top-down approaches to individual and community struggles with madness. In the next two chapters, I will focus on social movements that have challenged this expert or professionalized view, suggesting that lived experience is an equally valid – indeed, *more* valid – source of expertise than professional training and education. Each of these movements has grown out of a perspective that directly challenges the dominant discourse, offering new language and a new understanding of madness and mental distress.

In the present chapter, we will turn our attention to the mental health consumer movement, also known as the mental health recovery movement. In recent years, the recovery model of mental health care has become the standard, at least in name, by which publically funded mental health service provision in the United States is measured and designed (Gordon, Ellis, Siegert, & Walkey, 2013). This model's roots in disability self-advocacy are not always acknowledged – or possibly even known – by providers and service agencies. This chapter will strive to illuminate the discourse of the disability rights movement as it relates to the mental health consumer movement and its perspective on madness and mental distress. This framework will then provide a backdrop against which to examine the present-day implementation of a recovery model of care (Gordon et al, 2013; Slade et al, 2014) and to evaluate its effectiveness in

adhering to the values and intentions of those who fought to see it established and validated

within the mental health care system (Bluebird, n.d.; Chamberlin, 1990).

The Disability Rights Movement

The term "consumer" is one that is familiar to most people in a market context – that is, a

consumer of goods or services. Its use in the case of the "mental health consumer" is evidence of

the mental health consumer movement's connection to the disability rights movement: the civil

rights movement that fought for passage of the Americans with Disabilities Act of 1990

(Myerson, 1992). The ADA, although it continues to be re-assessed and revised, was the

culmination of decades of advocacy by activists fighting for an end to discrimination, abuse, and

exclusion of people with disabilities from their communities, with wide-ranging effects in social,

educational, employment, and economic realms (Perlin, 2000). Where these exclusions had been

seen as natural results of a person's affliction or condition, the disability rights movement

worked to place them in context as civil rights abuses that must be remedied. Disability was

relocated outside of the individual body or mind and into the structure of a society that does not

provide accommodations for different abilities (Shakespeare, 2006).

The term "consumer" is one offshoot of the protections provided by the ADA, indicating

choice and agency by people with disabilities over their environments and with regard to services.

The term is one that is firmly rooted in capitalism, with its emphasis on individual choice and

individual rights. To be a consumer, rather than a patient or invalid, connotes full citizenship in a

capitalist system of selecting and purchasing goods and services. The disability rights movement

has continued to advocate for consumers' rights to independent living, to accommodations that

allow equal access to housing, work, and education. In her brief history of the disability rights

movement, Arlene Myerson (1992) succinctly states the movement's underlying assumption

"that people with disabilities want to work and are capable of working, want to be members of their communities and are capable of being members of their communities and that exclusion and segregation cannot be tolerated" (para. 30).

The mental health consumer movement has a history distinct from that of the disability rights movement (to be explored more fully later in this chapter), but much of its discourse draws heavily on the discourse of disability outlined above. The concepts of psychiatric disability and psychiatric rehabilitation (Gilfedder, 2010; Goldberg & Killeen, 2005; Weingarten, 2005) link the consumer and larger disability rights movements, and have facilitated ongoing efforts to more fully include protections and accommodations for psychiatric disability into policies protecting people with disabilities (Mechanic, 1998).

The Origins of the Consumer Movement

In 1978, a book was published that would become the cornerstone text of the consumer movement. Written by Judi Chamberlin, who would become the "mother of the movement," *On Our Own* "expose[d Chamberlin's] own abuse at the hands of psychiatry and [gave] a detailed account of burgeoning consumer run alternatives" (Lewis, 2006, p. 339). Chamberlin, who would go on to write many more articles about consumer-driven approaches to mental distress, was herself someone who had been labeled as mentally ill as a young woman, and spent many years living with the personal and political implications of this label. Along with a growing group of activists, Chamberlin began to question and then to fight back against the powerful forces and assumptions that perpetuated abuses against people in the name of psychiatric treatment (Chamberlin, 1978).

Chamberlin wrote *On Our Own* at a time when there was little recourse for people who had been labeled mentally ill or "crazy." She wrote eloquently about her own experience of

learned helplessness: how previously functional and even happy people became "mental patients" via their time in mental health institutions. They were told they were crazy and sick, and so they became crazy and sick, less and less able to make choices for themselves (Chamberlin, 1978; Lewis, 2006). Chamberlin documented others' stories as well, with repeating motifs of understandable distress (such as Chamberlin's own despair after a miscarriage) being interpreted by professionals as mental disease. Rather than care and compassion, they were subjected to involuntary hospitalizations and were treated against their will with shock therapy, insulin therapy, and experimental drugging. Because they were seen as unable to make decisions for themselves, mental patients had no way of fighting back: dissent was seen simply as further evidence of mental illness (Chamberlin, 1978).

Chamberlin, and others involved the early days of ex-patient organizing such as Patricia Deegan (1990) and Leonard Roy Frank (1982), wanted something different. The social and political climate of the 1970's, with its energy and focus on civil rights activism, contributed to an environment in which they could begin to imagine fighting for change (Bluebird, n.d.). As has been the case for many, if not all, anti-oppression and civil rights movements, the consumer movement began with consciousness-raising (Chamberlin, 1978; Chamberlin, 1990) – people helping themselves and one another begin to imagine that it was possible to take issue with the status quo; that perhaps things might not always be as they had been for so long.

As these initial consciousness-raising efforts began, there was a focus on sharing stories. Members told the stories of their lives, of what had happened to them in hospitals and in other treatment settings, and the ways in which those "treatments" had shaped their sense of themselves and what they saw as their possibilities. While individual experiences varied, "it became clear that distinct patterns of oppression existed and that our problems and difficulties

were not solely internal and personal, as we had been told they were" (Chamberlin, 1990, para. 13).

As groups grew in numbers and membership, their goals expanded from consciousness-raising to include a range of activist and support projects: lobbying on behalf of hospitalized patients, working to make broad policy changes on local and national levels, and organizing consumer-run alternatives to a mental health system that the movement agreed was broken at best (Chamberlin, 1990; Lewis, 2006). The movement crystallized around a growing understanding that the egregious treatment of people in hospitals and other psychiatric treatment settings were human rights abuses, and that systemic change was the only appropriate solution. That "crazy people" themselves were the most appropriate and knowledgeable advocates for systemic change was a notion that would shape the consumer movement; its impact and implications continue to reverberate today.

Initially the movement was a bit more radical than its current manifestation. Words like *inmate* and *survivor* were used, indicating a clear sense of the mental health system as a tyrannical ruler. Scholars looking back have identified two general camps that emerged as the movement developed (Adame & Knudson, 2007; Chamberlin, 1990; Lewis, 2006). One major camp took the original radical stance and extended it. This group argues that mental illnesses may be a creation of powerful forces in society, or natural variations of human experiences of distress, but it rejects the idea that this distress can or should be "cured" by professional intervention and argues vociferously against the mental health system as a whole (Lewis, 2006). This camp, known variously as the psychiatric survivor or antipsychiatry movement, will be explored further in chapter 5.

What has become today's consumer movement has emphasized a partnership model, focusing on consumer empowerment and peer services in collaboration with professionals (Adame & Knudson, 2007). Mental health treatment is presented as an individual process, one in which personal hopes and goals shape what treatment is appropriate and how it is accessed. This camp's roots have remained more deeply entwined with the disability rights movement (Lewis, 2006), and it is this camp – the consumer movement – that has had the most measurable impact on systems of mental health treatment, particularly in the English-speaking world (Gordon et al, 2013).

Recovery

Disability discourse is very different from the discourses of illness (the biomedical model) or of moral/social failing. Connecting the concept of madness/mental distress to the concept of disability has allowed for a great deal of social action on behalf of the civil rights of people formerly labeled as "crazy" and warehoused without a voice (Lewis, 2006). This language – of disability and particularly of rehabilitation – has also given rise to one of the cornerstone concepts of the consumer movement, which is the idea of *recovery*.

Like nearly all concepts related to human experience, recovery is difficult to operationalize and is understood at its root to be a highly individual experience. The literature of the consumer movement presents various definitions of recovery, and there is also a significant body of work on recovery that is written by mental health professionals (Gordon et al, 2013; Slade et al, 2014). One article (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011) notes that professionals tend to define recovery via measurable outcomes (ability to hold down a job, compliance with treatment, symptom reduction, etc.), while consumer-driven definitions focus on recovery-as-process, emphasizing themes such as hope, meaning, and purpose as well as

empowerment. While each of these perspectives may be potentially useful, the consumer-driven concept of recovery as an individual and evolving process falls more in line with the empowerment focus of the movement itself (Chamberlin, 1990). Within this framework, recovery is removed from the more traditional/top-down perspective of social control, and places the right to determine the benchmarks of healing squarely in the hands of the individual consumer.

The Impact of the Consumer Movement on Mental Health Treatment

In the United States, the United Kingdom, Canada, and Australia (Gordon et al, 2013; Leamy et al, 2011), the recovery model of mental health treatment, which is based – at least to an extent – in many of the principles of the consumer movement, has become a widely accepted approach to mental health treatment, and is used by many publically funded programs for individuals who have been diagnosed with "severe and persistent" mental illness (Gordon et al, 2013). While the implementation of these programs remains problematic in many ways, it is a testament to the work of the consumer and disability rights movements that the language of independence and self-determination has been adopted by mainstream providers of mental health treatment.

Increasingly, programs that receive government funding are employing peer support workers – paid staff hired on the basis of their own lived experience of madness, trauma, or mental health treatment (Bluebird, n.d; Chamberlin, 1990). Some consumer-run drop-in centers, which are resource centers for people who self-identify as consumers, are receiving Department of Mental Health funding for some of their programs (Bluebird, n.d.), perhaps indicating an increasing understanding among mental health professionals and policy-makers of the value of non-professionalized approaches to ameliorating mental distress. Drop-in centers and similar

consumer-run resource centers are generally available to all people, whether or not they are

engaged in mainstream treatment; this openness serves to de-hierarchize a part of the mental

health system, recognizing that an individual's choice to engage or not engage with the dominant

framework around mental distress should not determine their access to support.

Consumer voices are increasingly being heard across all levels of policy-making and

treatment implementation, and the language of recovery and consumer advocacy has become

commonplace in many – if not most – publically funded mental health care settings (Gordon et al,

2013). This is a direct result of decades of advocacy and against-all-odds dedication by

consumer groups and individuals, and has had measurable positive impact, both on the

experience of individuals and on the overall efficacy of treatment (Leamy et al, 2011). As is the

case in any fight for civil rights, however, when policy begins to reflect the protections

demanded by activists, some will say that the fight has been won. This argument reflects

ignorance of the structural forces that support oppression even in the context of protective

policies (Hinson & Bradley, 2006). In the next section, some of the structural and power

imbalances that perpetuate oppression even in recovery-based models of care will be examined.

Problems in the Implementation of Recovery Models of Care

In the 1970's, long before the recovery model had been introduced into mental health

care systems, Judi Chamberlin and her colleagues had already identified many ways in which

partnership models could reify oppressive systems of power (Chamberlin, 1978). Chamberlin

notes that partnership models, despite their supposedly flattened hierarchies, maintain a

delineation between professional and client, well and ill, capable and dependent. Designed

largely by professionals, these models of care place the power to determine success and failure in

the hands of those who also have the power to control access to resources and to identify consumers as "good" or "bad" recoverers (Chamberlin, 1978; Slade et al, 2014).

Nearly half a century later, after years of work on the part of consumers to make their voices heard in the mental health system, Slade et al (2014) published an overview of "uses and abuses" of the recovery model by professionals in mental health care. These modern-day concerns bear a striking resemblance to those voiced by Chamberlin and others in the early days of the movement. In addition to the familiar concerns about false partnership and misrepresentation of shared power, Slade et al (2014) identify a new set of abuses related to the recovery model's growing familiarity as a treatment modality. These are focused on the misrepresentation of recovery as "the latest model" (p. 12), a perspective that can be picked up and discarded at will, and therefore might not warrant institutional investment of resources or attention.

Slade et al (2014) also illuminate a major concern posed by the professionalization of recovery: that adoption of recovery models by the mental health system can – and does – result in hijacking or co-opting of recovery principals. Numerous articles (Slade et al, 2014; Leamy et al, 2011; Gordon et al, 2013) have been published, either by consumers or with consumer input, expressing concerns that partnership models of care often have goals and benchmarks designed by professionals. These goals are often measured in terms of symptom reduction or benchmarks of normative functioning such as employment or ability to live independently (Leamy et al, 2011; Gordon et al, 2013). While some individual consumers might identify these as personal recovery goals, consumer activists point out that outcome-based measures of recovery with outcomes determined by professionals are both simplistic and potentially oppressive, reiterating the very power dynamics that the recovery-based models strive to challenge and to deconstruct (Slade et

al, 2014). A truly person-centered and recovery-focused model, they insist, does not strive to make people "normal" but to support people in building or re-building lives that are meaningful based on their own abilities, needs, hopes, and goals (Weinberg, 2013).

Another major question is whether any system can be said to be truly recovery-based when there is still the possibility of involuntary treatment. While consumer activists have partnered with providers with some significant success, the debate around compulsory medication and commitment remains with little resolution in sight (Agnetti, 2009). Many consumer advocates argue that, where the potential to force treatment remains, any suggestion of shared power or equality is a sham (Chamberlin, 1978; Frank, 1982). Consumer groups have continued to advocate against forced treatment and for the rights of individuals to choose whether they identify as patients or not (Chamberlin, Rogers, & Sneed, 1989). In particular, they argue against forced treatment to prevent possible harmful behavior, citing that even the American Psychiatric Association admits that professionals have "no special knowledge or skills with which to predict dangerous behavior" (Agnetti, 2009, p. 39). Under such circumstances, it remains uncertain whether recovery models of care can possibly reflect the goals of the consumer movement or if they are simply hegemonic efforts at social control dressed up in the clothing of empowerment.

Conclusions

It is clear that the mental health consumer movement's tireless activism over the last half-century has been effective in changing the face of mental health treatment, particularly in the English-speaking West. This chapter has traced the development of the movement, with particular attention paid to its connection to the disability rights movement. Disability discourse has profoundly affected the trajectory of mental health consumer involvement in policy-making

and treatment design and implementation. It has provided a framework through which "mental illness" can be understood as a psychiatric disability rather than a sickness, and consumers as individuals deserving of protection and respect under the law (Lewis, 2006). The work of the consumer movement as well as the larger disability rights movement has vastly improved the quality of life and quality of care of many people who might once have been subjected to lifelong involuntary treatment and egregious abuse (Chamberlin, 1990).

The mainstreaming of consumer ideas, however, has some implications that are less than rosy as well. Valid concerns are raised regarding tokenism (Trivedi, 2010) and co-opting of consumer ideals by professionals and government entities (Slade et al, 2014). While the driving ideology of the mental health consumer movement can be summed up in the now-familiar slogan "nothing about us without us" (Sadler, Fulford, & Hoff, 2009, p. 607), some question whether it is possible for the kind of empowerment and self-determination demanded by this battle cry can ever be achieved in the context of the existing mental health care system (Adame & Knudson, 2007).

In the following chapter, attention will be turned to the voices of some of those who voice these concerns. The psychiatric survivor movement, distinguished from the consumer movement in part due to its skepticism regarding cooperation with the mental health system, takes a more radical anti-establishment position in the fight against psychiatric oppression and proposes quite a different solution: the dismantling of the system altogether.

CHAPTER V

The Psychiatric Survivor Movement

The previous chapter traced the development of today's mental health consumer movement, from its earliest days of radical anti-establishment organizing to its current partnership approach. The dovetailing of ex-patients and the larger disability rights efforts gave rise to the discourse of psychiatric disability, and the work of activists like Judi Chamberlin created inroads and connections between the two separate – but intimately connected – movements. These growing connections have allowed for tremendous progress to be made in the name of inclusion and empowerment for people who use mental health services, and policies are beginning to change to reflect respect for the expertise of consumers alongside professionals.

As has been discussed in earlier chapters, the distinction between various "factions" of what has come to be called the consumer/survivor movement can be difficult to pinpoint (Adame & Knudson, 2007; Everett, 1994). Some scholars and activists feel that commonalities outweigh differences and ought to be foregrounded (Lewis, 2006) while others argue that the movements are ideologically distinct and reflect measurably different word-views and agendas (Everett, 1994). The question is further complicated by the historical reality that, even if they are ideologically distinct, the two camps are rooted in a shared history and have many shared heroes and leaders (Morrison, 2003).

For the purposes of this thesis, I have separated the two movements in order to examine their different – though connected – discourses. While each movement challenges the dominant

biomedical discourse, they do so in distinct ways with distinct epistemological differences that lead to differing conclusions about the meaning of madness. While the consumer movement's alliance with the language of disability evidences its commitment to empowerment and self-determination, the survivor movement's challenge is even more existential. It lifts the burden of madness from the individual and places it squarely on society, framing deep psychic distress as a reasonable reaction to an unreasonable world (Lewis, 2006).

The History of the Movement

The psychiatric survivor movement shares a great deal of history with the consumer movement. Indeed, the account of early days of grassroots organizing and consciousness-raising given in the preceding chapter is a part of the history of both movements, and the important figures (Judi Chamberlin, Leonard Roy Frank, Pat Deegan) are heroes and leaders in the eyes of consumers and survivors alike (Bluebird, n.d.; Chamberlin, 1978; Morrison, 2003). Chamberlin's early works, for example, took a much more anti-establishment perspective, primarily before most inroads were made with the larger disability rights movement. In the 1970's, when *On Our Own* was published and became the organizing text for those who had experienced abuse in the name of psychiatric treatment, the discourse of the movement had a more radical, or even militant, ring to it. Words like "inmate" were used to describe people held in psychiatric hospitals, and the language of radical action was reflected in the names that survivor groups chose for themselves, such as the Mental Patients Liberation Front (Chamberlin, 1978).

The progression of the ex-patients' movements into what has become known as the consumer movement was documented in the previous chapter. The current chapter, however, focuses on the parallel progression of the more radical voices that remained more directly anti-establishment and maintained their more radical stance. While the "legitimization" of consumer

activists by state and federal involvement and funding beginning in the 1980's and 1990's can be seen as an important coup, a more radical survivor perspective might view this involvement as the beginning of the slow co-opting of the movement by those in power (Morrison, 2003).

While the public face of the movement turned its attention to partnership and negotiation with the mental health system, anti-establishment voices that argued against the system altogether were not silenced entirely (Morrison, 2003). In response to the advent of the "Decade of the Brain" (Sabshin & Weissman, 1996) in the 1990's, the survivor movement re-energized, bringing forth the original arguments and challenges to systems of power that fueled the actions of the 1970's ex-patient groups (Morrison, 2003). With the burgeoning resource of the internet as a platform for organizing, survivor groups with a more radical human rights focus such as Mindfreedom, MadNation, and Support Coalition International continued to organize against the hegemony of medicalized psychiatry and the erasure of human experience by biomedical explanations for suffering (Joseph, 2013; Morrison, 2003).

In the 1990's and into the 2000's, leaders such as David Oaks (Morrison, 2003) and Justin Dart (Lewis, 2006) have emerged as prominent voices in the survivor movement. Inroads have been made with international human rights work, solidifying the movement's position that the concerns of the survivor movement are, in fact, human rights concerns (Morrison, 2003). They call not only for a re-assessment of the way we treat people who experience madness or extreme states, but for a total overhaul of a system that they see as one that imprisons, tortures, and dehumanizes people for reasons that are – at best - poorly backed up by science and – at worst – lies designed to bring profit to drug companies and other major corporations (Mosher, 1999). As has been the case in many liberatory human rights movements, there has been a push to reclaim a proud identity from one that has been shamed and oppressed; Mad Pride (Lewis,

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2006) events now take place the world over, with activists taking to the streets to protest oppression by the psychiatric system and to take ownership of madness as a valuable – even cherished – identity with an important place in the world.

Questioning Power, Questioning Truth

In order to more fully understand the perspective of the psychiatric survivor movement, this next section will take a more detailed look at the language and ideas that form its "dissident discourse." Lewis (2006) presents a highly accessible breakdown of the movement's dual epistemological (meaning-making) and political (policy-changing) mission, what he refers to as a struggle with "both truth and values" (p. 340). This framework is useful not only in understanding the movement as it currently exists, but in clarifying why and how the psychiatric survivor movement has adjusted its language and goals to the political climate, and the ways that the social/political environment has shaped the movement. One way of thinking about it is that while psychiatric survivor activism has at times centralized and joined forces with consumers, the epistemological aspect has remained much more radical, offering a wide range of explanations for extreme experiences that are directly opposed to both the biomedical model and, to an extent, to the disability model. Lewis suggests a three-part model that further explains the mission of the psychiatric survivor movement: to undermine "stereotyped representations of individualism, medicalization, and normality" (p. 340).

Individualism. Lewis (2006) describes individualism as the perspective that madness is "a personal tragedy" (p. 340). This conceptualization is rooted in capitalist notions of individual responsibility – a mad person might be personally "afflicted," but that affliction is located in the individual, and the proposed solution is similarly focused. Medical and

psychological interventions that seek to change a person's biochemistry or cognitive processes, for instance, are evidence of a cultural affiliation with individualism.

The discourse of the survivor movement stands in direct opposition to the language of individualism. One very common thread in the literature of the movement is the idea that madness is frequently a result of cultural or interpersonal trauma (Adame, 2006). Personal narratives of madness often frame extreme experiences as understandable responses to traumas that shatter a person's sense of self and the world. Madness is interpreted in its cultural context as a reaction to societal ills such as greed, isolationism, and materialism (Greenfield, 2013).

Within this anti-individualism frame, the appropriate response to madness also shifts. If madness is a distress signal, a sign that something in a person's culture or environment is not right, the solution must be similarly located in the environment. Compassion, support, and meaning-making with others who share similar values and experiences are seen as the necessary conditions for healing. On a larger scale, madness is seen as a societal problem, and questions are raised about how to change the conditions of society that elicit such intense expressions of pain and distress (Lewis, 2006).

Medicalization. Medicalization refers, simply put, to the reign of the biomedical model as discussed earlier in this thesis. It is the prevailing explanatory discourse in Western societies, providing a framework for understanding problems that upholds individualism (Lewis, 2006). In a Foucauldian sense, it also (re)produces the power of the biomedical field by reinforcing the idea that only those with specialized (medical) knowledge have the power to address problems of human suffering.

The psychiatric survivor movement is particularly invested in contesting medicalization because it is in the name of medical care that so many of the movement's

members have experienced abuse (Adame, 2006; Bluebird, n.d.; Chamberlin, 1990). Many

survivor organizations, particularly Mindfreedom International (Lewis, 2006) run ongoing

information campaigns designed to bring nuance and skepticism into the conversation about

medical explanations for madness. They demand that practitioners be honest regarding how little

is truly known about the etiology and "cure" of mental illness, interrupting the hegemony of the

medical field. Many survivor organizations are also invested in exposing what they believe to be

the extraordinarily high risk of many psychiatric drugs, questioning the assertion that the medical

field knows enough about how these drugs work to assert that the potential benefits outweigh the

documented risks (Bola & Mosher, 2002).

      Normality. The final piece of Lewis' (2006) three-part model refers to the power of the

normal/abnormal binary. Perhaps more than anything, this concept shores up medicalization,

enforcing the ideas that some individuals (in this case, individual minds) are normal and others

are not, and therefore must be fixed. In challenging this dichotomy (between valued and

devalued, right and wrong, well and ill) the psychiatric survivor movement challenges some of

the most powerful underpinnings of modern society. Many argue that their experiences of

extreme states and even of intense mental distress are not indicators of abnormal brains (Adame,

2006). These states can be experienced as valued abilities, as deep insight and capacity for

critical engagement, or as a process of spiritual awakening. Removing the imperative to assess

for normality, they argue, leaves space to understand "mental illness" for what it has to offer to

the individual and to society (Lewis, 2006).

      Individualism, medicalization, and normality work together to perpetuate a system that

pathologizes certain kinds of bodies and minds. Each theme works with the others to create a

framework in which it has come to seem natural or even obvious that mental distress should be

interpreted as a problem within an individual, attributable to biological causes, and in need of correction. The psychiatric survivor movement seeks to destabilize that framework by undermining each theme and therefore interrupting the feedback loop that perpetuates the current discourse.

It is no wonder that the psychiatric survivor movement experiences such tremendous ridicule, pushback, and vitriol. After all, its mission is not simply to change how mental health services are delivered. Even the consumer movement's powerful change efforts and their demand to have consumer voices heard and respected in the mental health system at least maintains some acceptance that there ought to *be* a mental health system (Adame & Knudson, 2007). In contrast, those who consider themselves psychiatric survivors are attacking the system at a much deeper level, questioning the nature of reality and revealing assumptions that have been accepted as truths.

Voices of Dissident Professionals

The psychiatric survivor movement is frequently (and mistakenly) associated with the academic and professional perspective known as anti-psychiatry (Oaks, 2006). I hesitated to include a section on anti-psychiatry in this chapter, wanting to avoid re-enacting the silencing of survivors' voices and privileging of the voices of professionals. At the same time, the contributions of dissident professionals – largely psychiatrists – such as Thomas Szaz, R.D. Laing, and Loren Mosher have been important in the development of the voice and language of the psychiatric survivor movement (Lewis, 2006). Their "expert" support has been "a very important means to challenge and undermine the authority of the existing structures of the mental health system and encourage others to speak out against the dominant narratives of diagnosis and treatment" (Morrison, 2003, p. 94).

Because the focus of this work is on survivor voices, I will offer just a brief summary of the contributions of Szasz, Laing, and Mosher. They are by no means the only "expert" voices that have been important to the movement, but they are particularly well-known and frequently cited as allies in survivor literature. R.D. Laing is best known for what has become known as anti-psychiatry. A doctor who worked primarily with people diagnosed with schizophrenia, Laing was interested in the meaning of experiences such as hallucinations and delusions. He took the position that psychosis, rather than being an expression of individual defect, was a meaningful and essentially sane response to an insane world (Lewis, 2006).

Thomas Szasz is known by many in the psychiatric field as a radical for his position that mental illness is, in essence, a myth (Lewis, 2006). His arguments follow an essentially Foucauldian structure, noting the systems of power that create and reinforce the myth of mental illness and the punishment/corrective action that is taken in the form of involuntary treatment of all kinds (Szasz, 1992). Szasz is not generally beloved by his psychiatric peers, but his arguments against involuntary commitment and other forms of forced psychiatric treatment have served to both inspire and scaffold the work of the psychiatric survivor movement (Lewis, 2006, Morrison, 2003).

Loren Mosher, also a psychiatrist who worked primarily with those diagnosed with psychosis, was the creator of an alternate model of treating and understanding schizophrenia and other extreme states (Morrison, 2003). His Soteria Model (Bola & Mosher, 2003) was essentially a therapeutic community approach that treated psychosis as a "developmental crisis" and used emotional and spiritual support and safety much more often (and, reportedly, to better effect) than psychoactive drugs. Mosher was also well known for his resignation from the American Psychiatric Society in 1998, citing his disillusionment with the APA's alliance with drug

companies and unilateral adherence to the biomedical model (Mosher, 1999; Oaks, 2004). Mosher was beloved as a friend and ally to the psychiatric survivor movement, and was on the board of Mindfreedom International, a major survivor organization (Oaks, 2004).

Conclusion

The present chapter has looked at the psychiatric survivor movement and its dual efforts to make substantive practical change as well as to challenge the prevailing understanding of madness and its meaning. Not surprisingly, the pushback against the survivor movement has been both more aggressive and more dismissive than the arguments against the consumer movement (Morrison, 2003). This may be in large part because psychiatric survivors seem to pose a much greater threat to powerful parties: they are not satisfied by partnership or allegiances with mental health system, but continually question and criticize and shed light upon the nature of the system itself.

Survivors have an especially daunting task because in speaking out against psychiatric oppression they always run the risk of their voices being silenced or ignored. The very experiences that bring them to the movement – surviving the abuses of psychiatry – can be used to dismiss their legitimacy or ability to think and argue. Because the abuses against which they fight are perpetrated in the name of benevolence (protecting "mentally ill" people from themselves and/or protecting society from their behavior) and are supported by scientific inquiry, survivors must strike a careful balance between righteous outrage and counter-arguments couched in language that the scientific community can understand and is willing to hear (Lewis, 2006).

Partnerships with allied "experts" add perceived legitimacy to the movement's arguments, but the risk is also run of these professional voices co-opting or overshadowing survivor voices,

effectively re-enacting the very system of power and control against which they fight. Layered over this dilemma is an ideological and political dilemma: if the battle is against the mental health system, is it useful or wise to partner with the system at all, even with dissident members?

The following chapter will take up where this and the previous chapter have left off, and will engage with some of the questions that the movements themselves struggle with in forming alliances and articulating arguments. In particular, I will focus on the intersection of professional and consumer/survivor experiences. How can mental health professionals ally with these grassroots civil rights movements without reiterating oppressive systems of power? What are the challenges and potential risk of such alliances? I will also spend some time exploring the experiences of those whose identities straddle the boundaries between professional and current or former "client" of mental health services, whose experiences have led them to choose to be a part of the field in spite of – or because of – this aspect of their identity.

CHAPTER VI

Discussion

When I set out to write this thesis, I had a certain idea about what I would find or what I would want to say. I also had a certain perception about the mental health consumer and psychiatric survivor movements, their differences and connections. As I read and understood more, my understanding of these delineations changed, leading to more – not less – complexity and more questions about the structure and purpose of the thesis itself. One concern that has been mentioned at times throughout the thesis is the question of interconnectedness between the movements. I have struggled with the "dangerous usefulness" (Brooks, 2012) of separating the consumer and survivor movements. What risks might I be taking or subtleties might I be overlooking by writing and researching as though the movements were truly separate? Conversely, what might be lost by following the trend and referring to the consumer/survivor movement as a single entity?

Because this work takes its lead in part from discourse analysis, and particularly given the attention paid in Chapter 3 to the social discourses surrounding and shaping the manifestation and understanding of madness, I paid particular attention to the language and discourse of the movements. Ultimately, my decision to look separately at the consumer and survivor movement was influenced by discourses that seem to be different in important ways, despite a shared history and a number of shared ideals.

The differing discourses of the consumer and survivor movements point to, among other things, different understandings of what madness is, what it means, and what constitutes appropriate social action. One useful comparison might be to think of the difference between second-wave feminism, with its focus on leveling the playing field, equality in the workplace, and policy to protect women's rights (Braithewaite, 2002) with third-wave feminism. Third-wave theory, which integrates critical race theory, queer theory, and other post-structuralist perspectives, seeks to go beyond male/female equality by questioning the reality of the gender binary and other essentialist categories (Hardin & Whiteside, 2012). In this comparison, the consumer movement might be analogous to second-wave feminism; its discourse challenges systems of power that prevent consumers from acting on their own behalf and making decisions for themselves. The consumer movement has worked within the mental health system and in partnership with providers to make consumers' voices heard and to create and enforce policies that protect consumers' rights (Chamberlin, 1990). The survivor movement, in contrast, calls into question the very reality of sanity and madness, just as third-wave or post-structuralist feminism questions the relevance and existence of gender binaries outside of their social and political contexts.

Of course, the same criticism that applies to the "wave" model of feminism applies to the above analogy: that framing a movement in terms of waves implies chronological progression and ignores parallel or concurrent developments, or the ways in which differing goals and ideologies intersect and influence one another. The histories of the consumer and survivor movements as recounted in the preceding chapters are clearly not only interconnected, but are interdependent. Could consumer rights advocacy have taken place without the fire and radicalism of the early ex-patients' organizations? Without the cumulative weight of the

consumer movement's partnership efforts, would survivors' more radical epistemological

argument have garnered as much attention as it has from researchers and critical thinkers in the

fields of sociology and psychology? I would argue that the answer to both of these questions is a

resounding no.

Perhaps the best way to understand or frame the consumer and survivor movements, then,

is as a pair of offshoot movements stemming from a common source. In order to adequately

understand either one, it is important to understand the other. Furthermore, in order to fully

understand the two together, it is vital to understand the social and political forces that were at

play in the early days of ex-patient organizing, and how those forces have continued to shape the

movements as they develop. Holding a dual awareness of the separateness and connectedness

allows for a dialectical approach, making space for the range of identities, agendas, and realities

that are contained between and among the two movements. With this dialectic in mind, I will

now turn to some reflections on the implications of consumer and survivor frameworks for the

tasks and identities of mental health professionals, particularly social workers.

Consumer/Survivors and Professional Social Work

More and more frequently, social work literature is concerned with the potential ethical

conflicts posed by the field's commitment to social justice and its identification – intentional or

otherwise – with systems of power that have historically been oppressive or abusive (Park,

2008a). The field's stated commitment to self-determination, as discussed in the introduction to

this work, clashes with the reality that social workers are often tasked with enforcing social

norms and controlling access to resources (Joseph, 2013). In the following sections, I will look at

the ways in which social workers and other clinicians might interact with the ideas and actions of

the consumer and survivor movements.

Social workers as activists. As social workers, where should our allegiance lie? Joseph (2013) reviews the history of abuse and coercion in the name of mental health treatment and concludes that "the professed values of the social work profession are actually more compatible with psychiatric-survivor movements than with allegiances to the biomedical model of psychiatry" (p. 267). Joseph's article carefully examines the professed values of the social work profession, compares them to the history of the medicalization of human distress, and finds the match a poor one. He suggests that social workers can and should ally with psychiatric survivor movements by listening to and advocating for the changes that they demand. At the same time, social workers' position of privilege (professional status) must not co-opt the voices of survivors themselves. Professional advocacy can only be truly effective in the context of listening first for what the experts – survivors themselves – have to say and allowing their knowledge to shape social action.

Although Joseph (2013) makes a strong distinction between consumer and survivor perspectives, I would add that this framework for professional allyship/activism applies as well to working alongside consumer activists. While the consumer movement has become far more familiar to and accepted by the mental health system than the survivor movement, the threat of the co-opting consumer voices by providers remains. Dissident and progressive clinicians can work against the subtle silencing of consumer voices by remaining vigilant to this possibility. Certainly an increased awareness of the fluidity and socially constructed nature of a biomedical understanding – or any socially enforced understanding – of madness asks that professionals slow down and question our assumptions about who possesses knowledge about the needs and experiences of people in distress. From this place of questioning, perhaps true allyship with both consumers and survivors is more possible.

Burstow (2004) suggests a range of actions that "progressive psychotherapists" (p. 141) might take to support and join consumer and survivor groups in their efforts. These include co-writing articles with survivor experts, helping clients access survivor or consumer supports, publicly endorsing/supporting statements made by movement groups, and mounting joint campaigns around education or policy-making. Burstow (2004) and Joseph (2013) both emphasize that these actions are conditional on professionals respecting the expertise of consumers and survivors over and above professional experience and training.

Social workers as therapists. With the growing emphasis on biomedical models of diagnosis and treatment and evidence-based/manualized therapies, clinical social workers and other therapists are encouraged – and frequently required - to rely more on therapies with standardized steps and quantifiable outcomes such as cognitive behavioral therapy (CBT) (Adame, 2006). Many in the consumer and survivor communities take issue with these types of therapies, stating that they offer "temporary life-style solutions to people's problems in living rather than addressing the larger cultural and political contexts from which these problems have emerged" (Adame, 2006, p. 68). Further survivor critiques of manualized approaches to treatment include their location of problems in individuals, their adherence to biological explanations for suffering, and their focus on symptom reduction (assimilation) over personal fulfillment and human connection (Adame, 2006). Essentially, these are critiques of the hegemony of individualism, medicalization, and normality (Lewis, 2006) that propels oppressive systems of control in the name of care.

In her moving account of the "spirit breaking" that occurs in forced treatment for mental distress, Deegan (1990), herself a psychiatric survivor, suggests that empowering and respectful therapy occurs when "both parties are available to "be moved by" the thoughts, perceptions, and

feelings of the other" (p. 309). She refers to the development of relational and intersubjective therapy models as alternatives that allow for creative, individualized, and mutual healing relationships between therapists and the people they serve. Narrative and other postmodern approaches to therapy that emphasize strength and meaning while locating problems in the individual and cultural stories in which they are embedded are also viable alternatives to behavioral and biological approaches (Combs & Freedman, 2012).

Therapy is often available on what is essentially a tiered or stratified basis, with insight-based and relationship-focused approaches available primarily to those who have more privileged identities, financial resources, and "sanity." Those who have been identified as less sane/more "mentally ill," and/or who have oppressed identities (particularly in terms of race and class) are more likely to be offered manualized or biologically based treatments that prioritize normalizing behavior over seeking insight, finding connection, or making meaning **(**Zrenchik & McDowell, 2012). A commitment to practicing relational or narrative therapy – and striving to practice in such a way that makes these therapies available to all - might then be considered a form of therapist activism.

Crossover clinicians: Managing multiple identities. I identified myself early in this thesis as an individual with a personal interest in the topic at hand. As a social worker and as a person who has navigated my own experiences of mental/emotional distress, I am particularly interested in the intersection of consumer or survivor and professional identities. In my exploration of the literature of the consumer and survivor movements, I was surprised to see how little has been written about the experiences of those who straddle both worlds. It is common to see distinctions made between consumers/survivors and professionals that do not leave room for the possibility that some individuals might identify as both. What literature exists on this topic

tends to focus on the experience of stigma faced by those mental health professionals who choose to "come out" to their colleagues about their survivor or consumer identities (Adame, 2011). Given this, it is understandable that many crossover clinicians might choose not to reveal their dual identities at all in their professional lives. It is also important to note that some movement groups, particularly survivor groups, may not welcome the participation of professionals and may understandably view those with dual identities as traitors to the cause (Burstow, 2004).

Despite the challenges to owning and managing dual identities, there have been survivor-therapists who have been leaders in both the consumer and survivor movements. Ronald Bassman (1997), Dan Fisher (1994), Bonnie Burstow (2004), and Patricia Deegan (1990) are mental health professionals who have been open about their experiences as consumers and/or survivors and who have utilized their dual identities to enhance both their clinical work and their activism. Adame (2011), in her qualitative study on the experiences of survivor-therapists, notes that most of her interviewees entered the field out of a desire to help others avoid the abuses they experienced themselves.

Adame's (2011) findings point to several broad themes that have implications for overall development of the clinical field and the consumer/survivor movements as well as for collaboration and for "lessening the dichotomies between 'us and them'" (p. 335). One is that survivor-therapists, who have had clinical training as well as personal experience of treatment, seem to favor the relational, experiential, and insight-based approaches to therapy discussed earlier over behavioral or biologically-based treatments. As mental health care continues to move towards more quantifiable and manualizable treatments, those clinicians who work with more humanistic approaches may find allies in the consumer and survivor movements, forging

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important collaborations and mobilizing for change. Adame's (2011) participants are clear that they see a role for therapists and other mental health professionals even as they continue to criticize the prevailing discourse and systems of power that promote oppressive treatment in the mental health system. They urge both professionals and the consumer and survivor movements to strive for more nuanced evaluations, suggesting that those survivor activists who have denounced any kind of professional mental health care might feel differently about voluntary, humanistic therapy than they do about forced hospitalization and drugging. Finally, the survivor-therapists who participated in this study are clear that progressive/radical therapists and the survivor movement need one another's support and collaboration, and that continued courage, humility, and risk-taking on both sides is necessary in order to forge meaningful and useful connections across difference.

Areas For Further Exploration

In my attempt to give an adequate overview of the complex topics contained in this thesis, I have not spent much time focusing on the intersection of psychiatric oppression with other kinds of oppression. This intersection could – and perhaps should – be the topic of its own major work. The history of psychiatry and related mental health professions is one rife with examples of systematic oppression in the form of diagnosing and pathologizing race, gender, ability, sexuality, and class (Joseph, 2013). One particularly egregious example is that of the 1800's diagnosis of *drapetomania* - the "mental disease" that caused slaves to run away without provocation (Joseph, 2013). Homosexuality's history of diagnosis and treatment is more well-known, and points again to the ways in which time, place, and political/social environment shape the manifestation and meaning of all kinds of identities and behaviors.

There have been concerns raised that the prominent voices in the consumer and survivor movements are overwhelmingly white and middle-class (Trivedi, 2010). While the movements have a long history of shared ideals and shared activism with the feminist movement (Deegan, 1990), there has perhaps been less public attention paid to the realities of consumers and survivors who also identify as people of color or who come from poverty. How might the experience of the mental health system differ for people who experience oppression on multiple levels? Bringing critical (race) theory, with its focus on institutional oppressions (Brown, 2010), to bear on the discourse of the consumer and survivor movements as well as on the dominant psychiatric discourse might be one way to further explore these important ideas and experiences and to work towards dismantling oppressive systems of all kinds as they relate to madness and mental distress.

Final Reflections

Feminist and other post-structuralist research approaches acknowledge – even celebrate – the subjectivity of the researcher and the interconnectedness of researcher identity with the process of inquiry (Burman, 2009). In that spirit, my own experience, identity, and curiosity has fueled this project and has shaped the questions I have asked and the answers, however complex, that have emerged. It also seems important to acknowledge that, while I have attempted to be aware of my own biases and the limitations of my experience, it is certain that there are things I have missed, misunderstood, or misinterpreted unknowingly, and that another researcher might have asked similar questions and arrived at different answers.

To review, the questions that guided my inquiry have focused on meaning (where did the concept of mental illness come from? How valid is it? Who has benefitted - and who has been harmed - by a biomedical explanation of distress? How have the consumer and survivor

movements challenged the hegemony of this explanation?) as well as practice (what do these challenges to the dominant discourse mean for social workers and other clinicians? Is there a way to move towards ethical practice while supporting the ideas and values of the movements? What place is there for clinicians who also identify as consumers or survivors?). Many of these questions do not have concrete answers, but generate an ongoing process of examining assumptions, listening to dissenting voices, and re-evaluating existing systems of knowledge.

It is my hope that the process of inquiry that guided me in exploring these issues – psychiatric oppression, social construction, and especially the powerful alternative frameworks proposed by those who have experienced madness and oppression first-hand – has produced a piece of beginning scholarship that can be of use to others. In order to avoid the pitfalls of the "helping professions" – condescension, colonization, erasure of identity and experience – it is essential to ask questions about how we know what we (think we) know, and who has the power to construct and disseminate that knowledge. The process of calling into question what is "known" about competency, about distress, and about what constitutes a life worth living beyond the trifecta of individualism, medicalization, and normality, is a humbling one. It is, however, necessary to the practice of ethical social work, and even more so to the process of bringing a "liberatory consciousness" (Love, 2010) to clinical practice.

I have tended to feel torn between my commitment to clinical social work and my skepticism about biomedical explanations for human distress, struggling to find a balance that takes into account both my genuine belief in the potential healing power of therapy and my commitment to dismantling oppressive institutions. Adame (2011) notes in her study of survivor therapists that for clinicians who hold "unconventional and critical views on the mental health care system, it is all too easy (and detrimental) to fall into a cynical and pessimistic mindset

about the profession" (p. 336). Delving into the history and epistemology of these grassroots movements may be one antidote to that pessimistic mindset; the possibility of collaboration between these movements and progressive/dissident professionals suggests all kinds of potential new directions for both the movements and the mental health professions.

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