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Family Response to a Diagnosis of Serious Mental Illness in Teens and Young Adults:

A Multi-Voiced Narrative Analysis

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Sociology
College of Arts and Sciences
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Dedication

To my children, Douglas J. Engelman Jr., and Melissa J. Horn

To all individuals and their families who are living with a mental illness diagnosis

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Abstract

Narratives are stories, stories persuade, persuasion is necessary to develop social problem consciousness, and social problem consciousness is a necessary element of mobilization toward social change. Thus, narratives are intrinsic to social change, both in the form of policy and legislation, and as evidenced by transformations in culture and consciousness. In this dissertation I analyze narratives about mental illness in families because they reflect what we think of as common, everyday understandings about these experiences. Through these analyses, I hope to learn how individuals and families understand the diagnosis of mental illness through stories they tell about how they cope with and manage this new a frightening experience. I examine these experiences as they operate on three different levels; individual, family, and organizational, employing multiple qualitative research methods including autoethnography, narrative analysis of the online presence of an organization, and thematic analysis of personal interviews.

In the first empirical chapter, an autoethnography, is my personal story, written in the first person, giving the reader an account of my experience with my son's schizophrenia. I bring the reader into the story, sit them down next to my son, and have them experience the tension of the moment when he revealed his hallucinations to me. My objective is that readers feel my fear, they feel the panic I felt, and are taken through the multitude of emotions I experienced in that moment of epiphany, and subsequent hours, days, weeks, and years of confusion, fear, frustration, and grief.

In the second empirical chapter I analyzed text mediated narratives found in the website of what may be the single most influential non-governmental organization (NGO) active in the

field of mental illness education, the National Alliance on Mental Illness (NAMI). Two overarching narratives emerged in the data I analyzed – opposing understandings of what serious mental illness is, and how it should be treated. One narrative supports a "medicalized" understanding of what these diagnoses mean, and what should be done. Another suggests that, while mental illness is medical problem that can be effectively addressed through professional intervention, "society" exacerbates the condition through the many hurdles it imposes on those who have been so diagnosed. Understanding the stories about mental illness told by such organizations is important because these narratives have the power to shape both public understandings of what mental illness means, and the stories individual people tell about their own experiences.

The third and final empirical chapter reports thematic analysis of interviews of parents of individuals with a diagnosis of serious mental illness. Few families are prepared for that moment when they first learn their son, daughter, sibling, or parent is living with a mental illness. In those initial hours, days, weeks, and months, families are suddenly faced with painful, stressful, and fear laden realities that were never anticipated. These families are forced to restructure their entire world around the fact that they are now living with a family member who is no longer accepted in society. Despite variations in family structure and experience, three common themes emerged from these narratives: 1) the immediate, sometimes desperate, search for relief from symptoms and an extended battle over treatment, 2) the desire to accept this new reality, and to support and advocate for their child, and 3) eventually finding and maintaining family equilibrium. After first demonstrating how parents' stories reflect these themes across the spectrum of respondents, I evaluated how these themes may or may not connect to NAMI's organizational narrative and dominant cultural understandings about mental illness.

Chapter One:

Introduction

Narratives are stories, stories persuade, persuasion is necessary to develop social problem consciousness, and social problem consciousness is a necessary element of mobilization toward social change (Loseke 2019). Thus, narratives are intrinsic to social change, both in the form of policy and legislation, and as evidenced by transformations in culture and consciousness (Poletta 1997). I choose to analyze narratives about mental illness in families because they reflect what we think of as common, everyday understandings about these experiences. As Donileen Loseke (2019:17) argues "Everything about narrative is social. Stories are social in their *contents* because, in order for a story to be evaluated as believable, it must more-or-less reflect audiences' understandings of the typical meanings of objects, events, and people."

The "narrative turn" in the social sciences began with the idea of moving away from natural science models toward constructionist models, which meant a shift from examining questions of cause to questions of meaning, and from "conceptualizing people as made by society to conceptualizing society as made by people" (Loseke 2019:15). Socially circulating stories can lead people in marginalized identity categories to be evaluated by strangers as deficient in face-to-face interactions (Loseke 2019). For example, the "normal" character can be used as a way to evaluate *acceptability*, which in turn, can become a justification for some form of *social hierarchy*: As a measure of acceptability, the "normal" character found in socially circulating stories signifies those who obey rules, and who do not disrupt, as *superior* to those who do not obey rules and are disruptive. Listeners to stories are expected to assume that these

stories featuring individual characters are adequate representations of social *archetypes*, be they positive or negative. In some instances, we are even asked to take a single person's story as an exemplar of a *typical* story (Loseke 2019).

In this dissertation, I employ multiple qualitative research methods including autoethnography, narrative analysis of the online presence of an organization, and a thematic analysis of personal interviews. Chapter Two, an autoethnography, is my personal story, written in the first person, giving the reader an account of my experience with my son's schizophrenia. Autoethnographic accounts help the author *show*, rather than *tell* the reader about their experience (Frank 1995). In my story, I bring the reader into the story, sit them down next to my son, and have them experience the tension of the moment when he revealed his hallucinations to me. When social scientists employ traditional jargon-laden writing, the reader may be either challenged, or perhaps even humiliated. Instead, "evocative" autoethnographies help us connect with our readers. Since we occupy the same world as our readers, they should not have to "struggle endlessly to understand and relate to us" (Bochner and Ellis 2016:79). By taking this autoethngraphic approach, my hope is that readers feel my fear, that they feel the panic I felt, and are taken through the multitude of emotions I experienced in that moment of epiphany, and subsequent hours, days, weeks, and years of confusion, fear, frustration, and grief.

In Chapter Three I analyze text mediated narratives found in the website of what may be the single most influential non-governmental organization (NGO) active in the field of mental illness education, the National Alliance on Mental Illness (NAMI). Recognizing how various forms of narrative: cultural, institutional, organizational, and personal operate at different levels in society, and by considering the reflexive interplay among them is critical to understanding "how narrative identity works, and the work narrative identities do" (Loseke 2007:663).

Put another way, we can't truly understand personal narratives without first understanding the widely circulating narratives of powerful organizations by which they may have been shaped. By analyzing this organization's narratives, we may gain a fuller understanding of how it connects with individuals and families who access the website, often the first move when in crisis. I evaluate these questions: What are NAMI's stories about mental illness? Who are the villains, victims, and heroes, and what moral can we find in each of these stories? How does NAMI understand the issues faced by people living with a mental illness? What does NAMI want the website visitor to "do"? How does NAMI advocate for these individuals and their families, and what are the implications of their advocacy for lasting social change?

Chapter Four reports thematic analysis of interviews of parents of individuals with a diagnosis of serious mental illness (SMI). Few families are prepared for that moment when they first learn their son, daughter, sibling, or parent is living with a mental illness. In those initial hours, days, weeks, and months, families are suddenly faced with painful, stressful, and fear laden realities that were never anticipated (Walton-Moss, Gerson, and Rose 2005). These families are forced to restructure their entire world around the fact that they are now living with a family member who is no longer accepted in society (Rose 1983). The anticipated cultural narrative of an "ordinary life" (Green, Darling, and Wilbers 2016) is replaced by visions of a future filled with fear of social stigma, fear that their family member will not "get well," and fear that the family won't be able to cope with this new reality.

As Linda Rose (1983:509) argues, a family's effective adaptation to such an event is "associated with making clear what appears incomprehensible, managing that which feels out of control, and finding relevance in confusion." How and where do families of those diagnosed with

mental illness find the ability to make this situation manageable, bearable, and ultimately

hopeful? What internal processes, and external resources contribute to an end result that is both

fulfilling for the family and the individual, and creates an environment within which both can

live and relate positively to one another? Are the narratives about mental illness promoted by

NAMI reflected or contradicted in these individual stories? It is the pursuit of the answers to

these questions that motivates the research in this chapter.

In Chapter Five, the discussion section, I review the major findings from each chapter,

and consider how they address the research questions that were proposed in each project. Here, I

also entertain a discussion on the merits of the method employed in this dissertation. I then

consider how these chapter findings, taken together, will help me achieve my overall research

objectives. Finally, I consider possibilities for future research that will build on the foundations

laid in this dissertation.

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Chapter Two:

Endings and Beginnings: An Autoethnography of a Father's Journey Through His Son's Madness, Loss, and a Quest for Meaning[1]

My son, Douglas J. Engelman Jr. died early in the morning of December 19, 1998. The sudden, tragic ending of his life also signaled the ending of mine – at least, the life that I had known. I had been, for the previous eight years, a member of an exclusive group as a parent of a child who at the age of 20 had been diagnosed with drug-induced schizophrenia. The day he died, I joined an even more exclusive group as a grieving parent. At the time, I had no notion or understanding of labeling theory, but I knew that I was different, set apart. People that knew me as a bereaved parent would not see me as the person I was before, but as someone who was less than whole. As a sociologist, I now have a better understanding of how such defining labels work. And I understand how they can influence one's life course.

In this autoethnographic project, I recount the terrible dread I felt when I first learned about my child's mental illness. I would come to know multiple dimensions of deep and profound loss. How can I cope with this? Can I help my child? What do I do? Personally transformative experiences like mine tend to create writers because, as "wounded storytellers," (Frank 1995) we feel compelled to share our stories with others. The stories that follow describe moments in my relationship with Doug Jr. that forever changed my life.

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Fear of the Unknown, Stigma, Caregiving, and a Sense of Loss

      My Son Has Schizophrenia, Now What?

      When a loved one is diagnosed with a serious mental illness like schizophrenia, bipolar disorder, or depression, it takes a heavy toll on caring family members (Walton-Moss, Gerson, and Rose 2005). The anticipated cultural narrative of an "ordinary life" is being challenged by this unexpected turn (Green, Darling, and Wilbers 2016). We may be forced to become caregivers, advocates, case managers, and life coaches, all while grappling with a lack of understanding of the disease itself. As I did, many families question their ability to make these adjustments, and to deal with their own reaction to the illness (Maurin and Boyd 1990; Magliano et al. 2000; Walton-Moss, Gerson, and Rose 2005).

      When an individual is struggling with the symptoms of a serious mental illness they may be unable to critically evaluate their own experience, and are often demoralized (Rose 1983). They most often lack insight into the existence of the illness, and may even reject the idea of a cure. In either case they may resist the diagnosis, and thus the need to seek treatment (Karp and Tanarugsachock 2000). The result can be an environment rife with conflict, tension, and stress. When my son was diagnosed with schizophrenia, he responded in this way - lacking insight, and uncertain of the meaning of this diagnosis.

      In the midst of the chaos that is mental illness, the burden often falls to caring family members to research and organize all of the resources available in order to navigate this new experience, as well as the resolve to access help for ourselves. The sudden acquisition of a label of mental illness in the family is similar to the diagnosis of other disabilities in early childhood (Green, Darling, and Wilbers 2016). In line with the findings in previous family research, our family's ability to come to terms with these circumstances, and to establish a satisfying

relationship with Doug greatly increased the burden and stress we experienced (Scazufca and Kuipers 1996).

Families typically conceptualized a positive future in four subcategories; 1) reaffirming hope for the future, 2) redefining relationships, 3) maintaining stability while striving for growth, and 4) reaching conclusions. While a complete examination of the processes that families experience following a diagnosis of mental illness is beyond the scope of this paper, I draw on three themes within the body of literature on mental illness in the family: fear of stigma; caregiving responsibilities; and loss of the child that was (Walton-Moss et al. 2005)

Stigma is Our Great Fear.

Mental illness is one of the most stigmatized conditions in our society (Link and Phelan 2001; Corrigan and Watson 2005; Pescosolido et al. 2008; Corrigan et al. 2009). Because of the enduring social climates of secrecy, fear, and the tendency for others to perceive persons afflicted as weak, dangerous, and unpredictable, mental illnesses represent unique and uncomfortable experiences for the family (Phelan, Link, Steuve, & Pescosolido 2000). Beyond the impact on the family, many consider stigma to be a significant barrier to recovery from the mental illness itself.

Currently, research on stigma is conceptualized along two dimensions; public stigma and self-stigma. The stigmatized individual is perceived by society as being part of a social group that is considered undesirable, to be feared, and/or mistrusted (Corrigan and Watson 2005; Corrigan et al. 2009; Markowitz and Engelman 2017). Those with mental illness are from such a group. When a person's behaviors are labeled a "mental illness" this triggers negative stereotypes (such as fear and dangerousness), leading to changes in ones identity (Corrigan and

Markowitz 2004). This type of stigma is frequently characterized by a desire for social distance on the part of the public.

Researchers have found that both having a mental illness and the act of seeking counseling are stigmatized (Vogel, Bitman, and Hammer 2013), leading the individual to adopt what is often referred to as self-stigma. Self-stigma, leading to a fear of rejection by others, prohibits many persons from pursuing life opportunities for themselves (Link 1987). Stigma, both public, and that which is internalized, can be seen as inhibiting recovery and a favorable life outcome for the person with mental illness.

In addition to navigating this unfamiliar new terrain, our family feared stigma by association, the so-called "courtesy stigma" (Goffman 1963). Family members who live with the ill relative experience more stigma than those who do not, simply because their acquaintances are more likely to know about their relative's illness and because their normal everyday interactions may heighten the acquaintance's probability of contact with the patient (Phelan, Bromet, and Link 1998). Although Doug did not live in our home following his diagnosis, we were still very careful not to reveal his mental illness to friends and neighbors. In the beginning, we were so fearful of being caught up in the negativity that is born of stigma, as other research has shown, we found it extremely challenging to maintain a positive, fulfilling relationship with him (Rose 1996).

Suddenly, We Are Caregivers.

With a shrinking base of public mental health facilities, and with private mental health services increasingly out of reach financially for individuals struggling with mental illness, it tends to fall to caring families to assume the caregiver role. Burden associated with caregiving of those with a mental illness has been well documented (Maurin & Boyd 1990; Jones, Roth, &

Jones 1995; Bibou-Nakou, Dikaiou, & Bairactaris 1997; Greenberg, Kim, & Greenley 1997; Perlick et al. 1999; Magliano et al. 2000). Difficult behavior associated with these impairments can tax cognitive and emotional resources of caregivers, who often report anxiety about what might happen if they are not around to provide care, even for temporary breaks. Overall, caregivers report feelings of isolation, financial difficulties, relationship problems, and physical complaints related to their caregiving roles (Bainbridge and Broady 2017).

Research on caregiving has shown that informal family caregiving also carries economic, social, and psychological costs. Families that are capable of mobilizing significant financial and emotional resources are able to cushion or avoid the consequences of the stress process, while those that lack the necessary resources are at risk of experiencing greater stress (Pearlin 2002). In our case caregiving for my son often involved a significant investment of time and energy that could otherwise have benefited others in the family in terms of material goods, money, social relationships, and so on. The costs are high.

Given all of these emotional, physical, and financial demands, it may be surprising to some to find, however, that caring for family members with disabilities and other health conditions can be a rewarding experience in many ways. Providing such care for a loved one has been reported to strengthen the bond between family members, and can even provide the caregiver with a sense of purpose and well being (Bainbridge and Broady 2017; Green, Darling, and Wilbers 2016). My family's experience bares this research out.

Our Sense of Loss is Profound and Enduring.

A diagnosis of serious mental illness typically follows an event, or a series of events in which the individual is acting in ways that his/her family has previously not experienced. The individual is different. Like most families we were unprepared for this change. Parents of a child

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diagnosed with mental illness may experience a profound sense of loss, not unlike that which is experienced by parents whose child has died. Feelings of loss and accompanying grief are complicated by the fact that child is still with the family, and an ongoing relationship needs to be established (Atkinson 1994).

For the person with mental illness, the disease alters the manner in which the world is perceived and processed. For the parents, the disease alters the child they once knew (Chafetz and Barnes 1989). Common factors that make it difficult for parents to assimilate the totality of the loss, thereby complicating and prolonging the task of grieving are; the occurrence is unanticipated, there is no lost object for parents to mourn, there is a lack of finality to their loss, and experience of the loss changes over time (Bruce, Schultz, and Smyrnios 1996; Davis and Schultz 1998; Godress, Ozgul, Owen, and Foley-Evans 2005). Often, our experience of loss and grief is not recognized or validated by society. Our grief may not be addressed by mental health professionals, or is often misperceived as evidence of pathology (MacGregor 1994).

For us, learning about Doug's diagnosis marked a beginning; the need to learn about the disease, and the need to accept its existence, and the need to embrace an understanding that he would likely never be the person we once new. A great deal of research shows that the ability of families to reach this point of understanding and acceptance offers the potential for positive relationships to develop (MacGregor 1994; Godress, Ozgul, Owen, and Foley-Evans 2005; Richardson, Cobham, McDermott, and Murry 2013).

Autoethnography as Method

Autoethnography has its roots in ethnographic fieldwork, initially discussed in the literature as a way for the fieldworker to draw data from their own experiences and subjective insights (Emerson 2001). Autoethnography is now seen as a research method that offers the

researcher the opportunity for "systematic introspection," critical for exploring and documenting neglected subjective aspects of lived experience (Ellis 1991). The autoethnographer seeks to make personal experiences meaningful to a wider and more diverse audience than can be reached through more traditional research methods, thereby making personal and social change possible for more people (Ellis et al. 2011).

Personal narrative is an accepted approach to autoethnographic writing in which the author treats himself or herself as the phenomenon under study, and writes an evocative story about his or her lived experience (Ellis et al. 2011). Personal narratives allow readers to see through the author's lens, to help them understand not only the author's experience, but also to relate those experiences about which they've read to cultural narratives that have meaning for the reader (Loseke 2019). An autoethnographic narrative affords the researcher the opportunity to produce "meaningful, accessible, and evocative research grounded in personal experience," sensitizing the reader to experiences "shrouded in silence, and forms of representation that deepen our capacity to empathize with people who are different from us" (Ellis et al. 2011:274).

As a research method, the goals of an autoethnography are similar to those of other more conventional methods, but they are conceived in different ways. For example, I had no "field notes" to rely on for this project. It would be another twenty years before I would even know the term. This personal narrative autoethnography relies completely on memory. Reconstructing these experiences required that I gain a new understanding of what memory is, and how we can use our recollections of "what happened" in telling and showing. Mark Freeman (1998) argues that arriving at the "truth" involves looking at the past, present, and future, not as a simply linear continuum, but as a dynamic process in which meanings of our lives are always subject to past events, and future anticipation.

I could only write this story by weaving together memory - actual events that I could be certain of – within an emotional context that relies not simply on how it felt then, but how it feels now, knowing what has transpired since. For example, in this story I memorialize my son in several ways that I would not have had I written this story while still in the throes of his mental illness. I describe him as an attractive, heroic, almost mythical figure, because that is what he has become to me after reflecting on his life and death over the past 20 years. I only learned of his amazing "recovery" from the depths of schizophrenic psychosis after his death. Information gleaned from his medical records, and a recent face-to-face meeting with his therapist, have filled in many gaps in my understanding of the trajectory his life was on at the time of his death. This information has to influence how I think about him, and what I write about him.

The process of constructing a narrative in this way brings a richness and wholeness to my written account that only this intersection of life and literature can offer (Freeman 1998). However, for some this raises the question of an "authentic" representation of reality. This narrative form may well be the answer to this question of authenticity. "Narrative may be a solution to a problem of general human concern, namely, the problem of translating knowing into telling" (White 1980:5). Instead of relying solely on memories as a series of isolated events, we can infuse them with feeling and emotion, and allow the reader, through his own cultural understanding, to convert those events and emotions into something meaningful.

The Call of Calls

December 1998

I'm awakened out of a deep sleep by the ringing phone on my nightstand. It's the middle of the night. *Who could be calling at this hour?* I groggily wonder as I notice the large red numbers on my digital clock. 2:22.

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"Hello?" I answer.

"Dad." Pause. "Dougy's dead," my daughter, Melissa's voice cracking.

"What?" I ask. Confused by a combination of shock, and my deep sleep torpor.

"He and his friend Bobby were driving out the Parkway East to Bobby's house around midnight. The car turned over, we don't know how or why. It was icy and snowing, I guess. Dougy was thrown out. He had massive head injuries. He died," her voice steadies.

"Are you sure?" I asked, understanding what Melissa is telling me, but hoping somehow they've made a mistake.

"My mom is with him at the hospital. Alleghany General, if you want to talk to her. He was pronounced dead there. They're letting her sit with his body for as long as she needs to."

His body? I think to myself. Suddenly, anguish erupted from inside of me with a force that put me on my knees, sobbing uncontrollably. Somehow, I managed to get a few more details, as Wendy, my wife, comforted me, enveloping me in her arms, and sobbing along with me. I told Melissa I loved her, and promised to call her back in the morning. It took a while for this reality to hit me. What a surreal moment it is when one first hears of the death of their child. What was, only moments before, a person they love, a person who occupies a supremely important place in their life, is now just a body. I imagine it, cold, broken, and lifeless on a stainless steel table in the darkness of the hospital morgue.

The Story Begins

April 1990

"I'll be down in a sec." Doug tells me.

"OK. Take your time. No hurry." I reply, as I click my car phone back into its cradle. I am almost dreading seeing him. I don't know what to expect. As I wait for Doug to come down

to the car, I recall the phone conversation with officer Thomas last night, still skeptical of what he had told me.

"I think he may be schizophrenic." He had said, getting right to point.

I couldn't truly comprehend what this statement meant. *Schizophrenic! How? Why? How would he know? He's just a cop in a local small town department. He doesn't have the training to even make that call. He said so himself!*

I recall the events of the last few days that led to my phone call with officer Thomas. Doug is in town for a visit. Wendy and I were already alarmed because he had dropped out of school in his second semester. He'd done pretty well his first term, but he says he just can't handle the stress right now. He promised he'd be going back when he's ready. He's been with us for a week or so. It's been obvious to us that he's changed, different. He is usually upbeat, warm, full of joy, always a big smile, always playful with Jake, our two years old. What we've seen this time is different. He's been dark, sullen, and silent. He's not taking care of himself either. Not showering, and his clothes are a mess. He seems distracted, and preoccupied most of the time. He's staying up late and sleeping most of the day. I've been feeling the tension. Wendy is pregnant with our second child. Her patience is shortened by the pregnancy, and by Doug's really disturbing behavior.

There have been a few moments when he seemed himself. We both love to play catch in the back yard. I had played some minor league baseball, and helped coach him in little league. Playing catch in the back yard was something we've done from the time he was able to walk. The past week we'd gone out a few times, and I'm pretty sure he enjoyed it, to a point. We're usually out there for twenty or thirty minutes at a time. The few times we've gone out this visit, he's lasted just a few minutes and needed to stop. Something is distracting him…occupying his

thoughts. Wendy thinks maybe it could be drugs. He smokes pot regularly, but it can't be that. It's some kind of malaise I've never seen before in him. What's going on with him? Melissa has seen it too, but says she doesn't know what it is either. I asked her to invite Doug to her place for a few days earlier in the week. Maybe she can talk to him and get some idea. It was there, at her apartment in La Grange Park, that this story really began.

The Psychotic Break

Yesterday morning, around 11:00, the phone rang, it was Melissa.

"I don't know what's up with Doug," she cried, exasperated and upset. "He was out on the back porch yelling to no one. I was really scared." She continued.

"Yelling about what?" I asked.

"He kept repeating…why do they have to die?" She replied, her voice recalling a sense of panic.

"What?" I asked, unnerved by the mental image. *This just doesn't sound like Doug,* I think to myself. I rarely hear him raise his voice. *What the hell is going on with him, anyway?* I wonder, feeling both frustrated and fearful. Not waiting for her reply, "How long did this go on?" I asked.

"I don't know, maybe ten minutes." She replied.

"Did you get him calmed down?" I asked.

"I told him I was calling the police," she said.

"Did you?" I asked.

"I *had* to. I was scared…he was talking about someone freekin dying." She replied defensively.

"Did they come? The cops?" I asked.

" Yes," she replied. "When I told Doug I called the cops, I think it kind of shocked him into coming in and calming down. By the time the officer came to the door, Doug was in the living room. Quiet. After the officer talked to him outside for a while, he came in and talked to me. He told me that I should try and get Doug to Loyola hospital. It's not far, and they have a really good mental health unit. He told me that Doug should go there and be looked at. I don't think he meant committed. I don't know. He didn't really say anything about what he thought was going on. Just that Doug was confused and wasn't thinking straight. I got his name and number if you want to call him."

"Ok. Thanks." I replied, after getting the number. "I'll call him and try to figure out what's going on. If Doug wonders why we talked, tell him I'm coming by tomorrow around 10:00 to pick him up for breakfast. Ok? And, thanks for calling the police. I know that must have been hard. Love you." I said as I hang up.

"Bye dad." Melissa replied. "I love you too,"

I called the number right away.

"Officer Thomas is not on duty right now," I was told by the desk clerk.

"Can you tell me when he is due back on?" I asked.

"4:00 to 12:00 tonight. Do you want to leave a message?" The clerk inquired.

"Please." I implored. I gave the clerk my name and number, and told him a little about the situation. "Please ask officer Thomas to call me when he has a minute, would you?" The clerk assured me he would. I put the phone down, remembering what Melissa had told me. *The officer thinks he's mentally ill? Talking to himself...about someone dying!* I'm overcome with fear and confusion. I have to see him!

Epiphany

At that moment I think about my uncle Harry, my dad's brother, who we used to go visit at the Elgin Asylum. My dad would usually take my brother, Rich, or me with him. I always wanted to carry the carton of Winston cigarettes - my dad's usual offering to his big brother. Uncle Harry had been diagnosed with schizophrenia when he was in his 20's, and spent the rest of his life in that place. I was only a little kid, but I could see he was only a shell of a person. I remember his nicotine stained fingers, and the emptiness in his eyes as we sat on a bench in the garden. He was mostly unresponsive to my dad's typical inquiries.

"How are you doing Harry?" My dad would ask, hopefully. "How are they treating you?" Harry shrugs in response. Moments pass in uncomfortable silence.

"Jesse and Bobby (Harry's children) say hi." Offers my dad, resigned to the fact that Harry isn't talking this day. Harry responds with a nod and an empty smile.

With this image of my uncle in my mind, I ask myself, *is that going to be Doug's life? Is that what this means? Doug is like that?*

Later that night, officer Thomas returned my call. It was about 8:30. After identifying myself, and telling him how concerned I am about Doug, he told me what he was thinking.

"From what your daughter said, and how your son talked to me about what was going on, I'd say we might have caught him in a psychotic break. He may be schizophrenic. I'm not trained in psych work, but I've seen this. And it's almost always young people." He takes great care to explain what he saw and heard from Doug, and then gives me the same advice he has given Melissa earlier. "You should really try to get him checked out, sir. I can't stress that enough." He counseled emphatically.

"Oh, uh ha, I understand. Thank you officer." I replied, not truly comprehending it all. *Psychotic break?* I repeat to myself as I put the phone down. *He's like…psycho?*

<center>*Revelations*</center>

All of this flashed through my mind in an instant. Still lost in thought, I am startled as the car door suddenly flies open. Doug crams his large frame into my little 3000GT, his demeanor dispelling what he *had* to be feeling. Just twenty-four hours earlier he had a run-in with police, and was told that he should check into the psych ward. He seems almost blasé. "Where're we going for breakfast?" He asks, casually. *Maybe he wasn't surprised by what officer Thomas told him*.

He's just over 6'3", slim, with dark brown hair, athletic, but not overly muscular. Most people say he looks like me. I always beam with pride when I hear that. We share many things; the "Engelman" chin, passed down through the generations, dark complexion, thick, wavy brown hair down to his shoulders, a certain physicality that people are attracted to. He showered and has clean clothes on today. He looks great. He doesn't look…well, like he's crazy. I look him in the eyes, and I *do* see something. Is it fear? Or is it confusion, maybe shame? In that instant, I begin to understand, but I had no idea what to do or say. I hadn't answered his question about breakfast. I must have been looking alarmed and confused.

"What's up?" he asks. "Well…I'm wondering the same thing," I reply, cautiously. "What were you doing that made Melissa call the police?"

"I, ah, can't really remember" he replies.

"She told me you were yelling about someone dying. What's that about?" I ask. He sat for a moment that seemed an eternity, a confused look on his face.

"Um, I don't know. I'm not really sure." He finally responded, nervously. I sensed he was about to tell me, but wasn't really sure I wanted to know. It was a threshold I was really hesitant to cross.

"Come on, man. Something's up!" I persisted. "Wendy and I have both noticed you've been acting different since you've been here. What the hell is going on?" I ask. "Can't you tell me?" I'm worried, and I think it shows. I'm not angry. I'm just scared. In his face I see confusion, fear, and anxiety. I don't know whether to start the car and drive, or sit there. I turn toward him, angling my body so I could look him straight in the eyes. "Tell me." I demand.

"I don't know." He replied. "It's confusing."

But he begins to tell me about two people that were "with him." A guy named Dave, and a girl named Wendy. *Wendy? Why Wendy?* I wonder. I must have looked confused, even disbelieving.

"She is here," he claims.

"Who?" I ask.

"That girl, Wendy." He says, clearly frustrated.

"Where?" I ask.

"Here, in the car." He insists, his voice getting louder, almost pleading with me to believe him. He turns slightly to the back seat, as if to confirm her presence. "She's in the back. Can't you see her?" he asks, hopefully. Instinctively, my fingers gripping the steering wheel tightly, I look in the rear view mirror, knowing there's no one there, but hoping there is. Every inch of my body feels the rush. It's fear. My heart is pounding. I can't catch my breath. It's only a few seconds, but it feels like minutes. Not wanting to show my fear, I try to relax. I need for him to feel that this is all ok, and that I believe what he is telling me.

"I can't see her." I say. "But I believe you." *Oh, my God! The officer was right. He's freekin hallucinating!* As my shock slowly recedes, I suddenly feel the impulse to drive…to move…to do something! I put the five-speed stick shift into first. "Let's get some breakfast." I say, not waiting for approval. The movement of the car seems to help him process what is happening to him, and how to explain it to me. He seems relieved that I believe him. But he has to make sure.

"There was someone in the car," he insists. "She comes to see me all the time." *Was? He just saw her there, in the back seat. Now she isn't?* I don't argue the point.

"OK." I say. "I want to hear all about her."

The next hour is a blur. I just keep on driving as he talks. We crisscross the Burlington Northern RR tracks a half dozen times. We drive through neighboring LaGrange, then into Western Springs, over Interstate 294 to Hinsdale, past Grauve Mill, over to Oak Brook Mall, and back to LaGrange.

Outside the sun shines brilliantly. The April sky is a pristine, cloudless blue. With my car seemingly on autopilot, Doug keeps talking. In the close, dark, confines of my M3000, Doug shares a chaotic, mystifying world with me. Like someone trying to describe his dreams, he struggles to bring me into this world of his…a reality that he sees, hears, and feels. Here I sit, alongside my son, whom I love and want to protect, hearing him describe impossible, frightening things that are difficult to imagine, let alone believe. I know him, yet I don't. He's not the little boy I raised. He's a stranger to me. But, he's my son. *God, I am so frightened for him.*

Dave and the girl he calls Wendy are frequent visitors. Wendy, more than Dave. Once, she came into his room, got into his bed, made love to him, and left. It was as real to him as if it had actually happened. He describes her beautiful body in detail. She wanted him, and it made

him feel good. *He's describing the young girl who lives across the street from him. I'm sure he has told me about her before. But, now, he thinks she's coming to make love to him.* When that part of the story is over, another comes to him.

"Dave's in my room all the time," Doug explains. Dave taunts him about his sexuality. "He thinks I'm *gay*." He says, mimicking Dave's disdain. "I *hate* that motherfucker!" He screams. This rush of anger is jolting. This is real to him. Suddenly, he doubles over in pain. *What the hell is happening?*

"What's the matter?" I ask, stunned.

"They're can put their hands inside me." He says in anguish, looking at me helplessly. Grabbing his midsection, he doubles over in agony. "They did this to me before. Stop them Dad, please make them stop," he cries. I see the same look in his tear-filled eyes that I had seen when he was little and hurting. *I imagine my little boy again.* The moment ends almost as suddenly as it began. Finally he sits back in his seat, exhausted, and closes his eyes.

<center>*Back To "Normal"*</center>

Many minutes pass in silence. Suddenly I spot a McDonald's. "Hey, how about stopping for something to eat?" I suggest.

"That sounds great, Dad. I'm really freekin' hungry." He replies.

I look at the clock on the dash. "Damn, it's after 11:00. No more breakfast!" I say, trying to normalize things.

"That's cool. I'll get my usual," he replies, with a sudden grin that sends a wave of relief over me. *He seems OK.* As we step out of the car my feeling of exhaustion recedes. *Maybe it's going to be OK. Maybe this is just temporary. I think to myself, hopefully.* We go inside and order. He gets the Big Mac meal with a large Coke, me a coffee. I'm not really hungry any more.

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I'm just relieved to be doing something with Doug that I have done a hundred times before. As we wait for the order, we both fall silent, each appreciating the normalness of the moment.

"Go grab that booth in the corner." I suggest. "I'll get this. Do you want anything else?" I ask?

"Nah, I'm good. Thanks." He replies as he ambles over to a table.

I wait for the order, pay for the meals, and organize things on the tray, all the while still letting what I just experiences settle in. As I slide into the booth, putting his tray on the table, my mind drifts. *Is he thinking about what he told me? I wasn't sure if he was even aware of what he had just told. Is he hallucinating right now? Or is he just relieved that he isn't?* He eats voraciously, while I let my mind relive flashes of the last 15 years.

My Promise

We'd been through a lot together: a divorce when he was five that included contentious legal battles with his mother, Bobbie, over visitation, child support, alimony, you name it. Selfishly, without really considering the impact on Doug and his sister, I had brought several women in and out of his life over the next five years. Eventually, I settled into a more stable pattern of working hard during the week, and spending the weekends together, trying to make our lives as "normal" as possible. The inconsistency in my social life, and in our living situation, and the stress caused by the combative relationship with his mother had really been tough on Doug.

Bobbie seemed to relish putting Doug and Melissa between us, once refusing to let me see them unless I upped my child support beyond the court ordered amount. Years before, our therapist had prophetically confided in me that Bobbie could not then, and probably never would, experience a positive relationship with a man - something stemming from her traumatic

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relationship with her father. She seemed to relish arguing with me whenever I would see her. She seemed so angry all the time. I know Doug couldn't stand being in that situation – loving both his parents – yet often being the subject of the anger between them. He had always been really sensitive, not really able to deal with conflict and anger. Yet, through all the crap, he seemed to be a happy, joyful kid.

I remember Doug at 5 years old. As I pulled out of the driveway in my 15-year-old VW Beetle, with everything I owned in the back seat, I saw his tears through mine. "Don't go," he pleaded. *I had no choice, did I?* Bobbie made me want to leave, claiming, "I don't love you. I don't think I ever did. I don't want to be married to you." I had stayed for a year. Eventually, though, she pushed me out. I left him for the first time.

I remember Doug at 10 years old. We had figured out how to get by. He and Melissa visited on weekends. I involved them in my life. It was working. But, it was 1982, the economy had tanked in Pittsburgh, and I had met Wendy, the love of my life. She had her reasons for leaving Pittsburgh. We both needed better jobs. *I had to go, didn't I?* We decided to move to Chicago. As Wendy and I pulled out of the driveway after saying our goodbyes, a fully loaded UHaul in tow, his eyes revealed his confusion and pain as I left him a second time.

Now I sit in the McDonalds, watching him, promising myself that I'm not going to leave him a third time. *He is sick. And he is alone with this sickness. He needs me. What do I do now? I don't know anything about what he's dealing with. Is schizophrenia something that can be cured? Is there any way I can help him?* We sit in silence, understanding that things will never be the same. Despite my fears, my confusion, and my uncertainty about what our future will be, I silently promise that I will never leave him again.

The Story Ends

December 1998

Eight years had passed. As I sat with Doug in that McDonalds, what seems like a lifetime ago, how could I have imagined what the future would bring? I knew almost nothing about mental illness. I feared him, I feared for him, and I feared our future. I knew my life was about to change, but how? Little did I know that over the next eight years, I would become, at times, his caregiver, his mentor, his life coach, and his closest friend.

After his psychotic break, Doug had stayed with us another week or so before he went back to Pittsburgh. There, he had several incidences, some with neighbors, some with the police, that ultimately placed him in a psych ward for a 30-day evaluation. Following his formal diagnosis of schizophrenia, his mom sent Doug back to me in Illinois. I didn't know it at the time, but she was in the throes of depression. She just couldn't deal with all that it would take to help him. Bobbie pleaded with me to take care of our son.

After many long talks with Wendy, and despite all of our fears and uncertainty, we understood that we needed to help Doug in any way we could. Bobbie drove Doug to a halfway point between Pittsburgh and Chicago, somewhere on the Indiana Turnpike. I will never forget seeing him in the passenger seat as I approached her car. The change in his appearance from the last time I had seen him just a few months before was shocking. He was loaded with anti-psychotic drugs, barely conscious, his body bloated. As we transferred him and all of his belongings into my car, he remained completely silent. The four-hour ride home was uneventful. I tried to engage him in conversation, desperately wanting to understand what was happening to him. It was pointless. He had no memory of what had happened, nor did he seem to understand

what his future was to be. I did feel a sense of satisfaction that I was going to be able to help my son, tempered by a raging fear of the unknown.

The next few months were a difficult, painful, stressful time for our family as we tried to figure things out. I got him into a program with Cook County - psychiatric care, medical care, and housing. The program consisted of a 30-day hospital stay at the Loyola Mental Health Unit in Maywood, roughly 15 miles from our home in Aurora. Following that stay, Doug spent 6 months in a group home near the hospital. After he entered the group home, I was able to bring him home on weekends. We lived in a comfortable, three-bedroom home in a quite neighborhood. Doug usually slept in the finished basement when he came for a visit. Jake was 3 years old, Kelsey was an infant. To be honest, we were sometimes afraid of him being around the kids. Imagine, loving your son, wanting him to be happy, wanting him to be part of the family, yet all the time afraid of what he might do.

I felt both frustrated, and guilty for having these fears about my son. In many ways I blamed myself. After all, my uncle was schizophrenic, and my dad an alcoholic. His mother and I had put him through years of stressful experiences. Reading as much as I could about his illness, I learned that stress combined with a family/genetic predisposition created an environment in which a psychotic break could occur. Yet, despite the guilt, the relationship strains, the financial and time burdens, things did get better. I adjusted to our new reality. Slowly Doug began to show signs of improvement. He had setbacks for sure, but eventually he found work, moved into an apartment with another patient, and occasionally seemed just a little bit like his old self.

He stayed in the Chicago area just two years, moving from one housing situation to another, attending group therapy sessions, and taking life skills classes, all the while his doctors

experimenting with this drug or that one. In late 1992, he decided to move back to Pittsburgh, and live with his mom. By then, his symptoms were being managed fairly well, and he was able to work part time. Pittsburgh was his home, and he needed to go back.

For the next four years, I had to adjust to the idea that I would not be a big a part of his life. We did talk by phone regularly, and he came to visit a few times a year. Over those years, we didn't really see much change in him. He continued hearing voices. His meds caused the side affect Tardive Dyskinesia,[2] leaving him with facial tics. He hated it. He didn't have much of a social life. I recall feeling pretty hopeless, thinking that this was as good as it would get.

Then things changed. In 1996 he started to see a new therapist, and a psychiatrist who put him on a relatively new anti-psychotic injection. It was like magic! At the same time, he asked me to start helping him manage his life. I managed his money, his housing, and his transportation, just about everything it took to keep him functioning as he continued therapy. I don't know why he suddenly asked for my help, but it made me so happy to be involved, and helping. Perhaps it was maturity. He just seemed ready to take on an adult life, and willing to acknowledge that he needed help. Over the next few years, we grew closer than we'd ever been. After so many years of pain, frustration, and setbacks, he really did make it back to being the happy, caring, son I new.

On December 16, 1998, at about 8:00 a.m., as I sat having my morning coffee, the phone rang. It was Doug.

"Hey, what's up?" he asks. "Not much, just getting ready for work. What's up with you?" I ask, nervously. *I'm always a little nervous when I get a call from Doug unexpectedly. Does he*

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[2] A neurological disorder characterized by involuntary movements of the face and jaw.

need money? Did he have a problem at work? Is everything ok? This time, it was a surprise…a good one.

"I just called to say how great I'm doing. How happy I am." He replied, brimming with pride and confidence. I know I paused before replying.

"Awesome man!" I say. "I'm so glad to hear this!" *Here it is. Finally!* The call I've been hoping to get for so many years, but was never really sure it would come. Doug has shown signs lately. I had helped him move into a new apartment in July. He had some friends help, and then we all enjoyed a few beers at the tavern around the corner from his new place down on Pittsburgh's South Side. It was great to meet his friends. He had just started working full time for his old company, installing carpet. It's what he had done for summer work during high school. He had his own tools, and was starting to make decent money.

I saw him in October at my brother's wedding. He looked great, interacted with everyone in the family, and had a great time. Everyone commented on how well he seemed to be doing. When I dropped him at the train station to head home from that trip, we hugged. I remember how good it felt. It was just normal. A few weeks later he had called me to tell me about his new "friend," Abby. He had sent me a picture of them at a Halloween party. I don't think I'd ever seen him smile that big. He was in love, but wasn't sure if he should tell her about "it." I suggested he wait a little while. He agreed.

"So, what's happening?" I ask, quickly scanning these recent events in my mind. *Is something going on with his job, Abby, his new apartment?*

"Not much." he replies. "I'm waiting for my boss to pick me up for work." He goes on. "I had a few minutes so I just thought I'd call and say hey. Oh, I did like you suggested and

made an appointment at the Pitt admissions office. The lady I called can't meet until after New Years, though."

"That is so great, Doug. I'm proud of you, man!" I say, with a mixture of satisfaction and relief.

"Yeah, I'm pretty excited to see if I can get back in school. Work is good, too." He replies, obviously pleased with my reaction. I hear a car honk in the background. "That's my boss. Gotta go." He says. "I'll call you on Christmas. You'll be home, right?" He asks.

"Yup. Talk to you then." I reply. I clutch the flip phone tightly in my fist to emphasize the strength this conversation has given me.

That was the last time I heard his voice. Just three days later, on December 19, at about 2:00 a.m., I received the phone call that would alter my life again, this time forever. Out of a deep sleep, I answered the ringing phone on my nightstand.

"Hello?" It was Melissa. "Dad." Pause. "Dougy's dead."

The Telling Begins

Turning to Autoethnography

I have a foothold in two worlds. I am a grieving parent. First I grieved the loss of my son, as I knew him, to a diagnosis of schizophrenia. Then I grieved his death, and still do. I am also a burgeoning scholar whose self-imposed mission is to share my story, with the hope of positively impacting families of others who have had similar experiences. Any analysis of this work must attend to both perspectives. In this analysis I address two questions. Why write this story? Why choose autoethnography as the method?

When Doug died I began a journey that brought me to this moment. Soon after his death I understood that I had to "do" something. I could not change what had happened, nor could I let

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my world collapse inward. I was forced to reevaluate everything I thought I knew about myself. A complete discussion of that experience would take us well beyond the intended scope of this project. What is germane to this project, however, is the profound sense of guilt I felt. As I recall in this story, I had abandoned Doug at least twice in his adolescence. I had contributed to placing him in an extremely stressful environment as a child. Finally, I had the "mental illness gene." My uncle's life spent in an asylum, and my father's alcoholism attested to that. What could I do with that baggage? I was certain that I could not carry it around for the rest of my life. In my role of grieving parent, one who was laden with guilt, I spent a half dozen years in a kind of limbo between despair and hope.

Eventually, hope won out. In 2007 Wendy suggested I read a new book that had just hit the bestseller list – *Crazy,* by Peter Earley (2007). Pete had penned this poignant, yet hopeful, story of his son Mike, and their experience with Mike's diagnosis of schizophrenia. *Crazy* was an inspiration to me. If I could write a book like that about my journey with Doug, I thought, perhaps it would inspire another parent who is experiencing what I had. Somehow that could lessen the pain. Somehow it would give Doug's life greater meaning and purpose. That moment stands out as one of the most significant in my life. It led to a series of decisions, twists of fate, and a healthy dose of good luck that brought me to this career as a scholar. The first question I posed here, the why, is answered primarily from the perspective of me as grieving father. As Arthur Frank (1995) posits, the "wounded storyteller" employs a quest form of storytelling that enables the teller to meet suffering head on, accept it, to use it. I am a wounded storyteller who chose to write this story as a form of self-preservation.

Of course I knew nothing of autoethnography until I entered the academic world. It was in the second year of my masters program I first read about the work of Caroline Ellis and Arthur

Bockner, in developing this relatively new form of research. It struck me as the perfect vehicle for my story. I could write a personal narrative that was compelling, while placing myself in the project, and report my experience in a way that could further the research in this area. Some autoethnographic work is rooted in concepts that are analytical or theoretical, as a way to explain social phenomena, while others, like *Endings and Beginnings*, take a more evocative approach in an attempt to make emotional connections with the reader (Ellingson and Ellis 2008). I chose this method because I believe that in making that emotional connection to the reader who is immersed in this struggle with mental illness, and by sharing my lived experience, I bring to that individual a sense that he/she is not alone. All of those who have experienced that "moment of epiphany," when we first learn about our child's illness, can benefit from an understanding that we are part of such a community.

Recalling these events surrounding my introduction to Doug's illness, I felt the fear of the unknown. I knew that mental illness was stigmatized, and I feared that stigma. I, like many others, hid my son's illness from friends and neighbors. I know the frustrations that caregiving can bring. And above all, I know the feeling of loss that accompanies a diagnosis of serious mental illness in a family member. In this autoethnography, I am able to use the power of a positive, active voice to let others know they are not alone in their fears, frustration, and feelings of loss. As I matriculated through my academic career, knowing that my ultimate goal was to write this story for you, the reader, as well as for myself, I gradually came to understand that autoethnography held the promise of fulfillment.

Future Directions

We can't do anything about the future but plan to be part of it. Unlike most student-scholars who are about to earn their degree and launch their careers, I have to think about

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longevity. I could not discuss the future of my work without a recognition that my career is likely to be significantly shorter than most of my peers. This is not an expression of negativity, nor is it unduly pessimistic. I have to deal with these realities, and plan accordingly.

Mental illness is a big problem, and it's getting bigger. Diagnoses of various forms and degrees of mental illness are increasing annually, especially within younger demographics. More U.S. adolescents and young adults in the late 2010's compared to the mid 2000's experienced serious psychological distress, major depression or suicidal thoughts, and more attempted suicide (Twenge 2017). The threat of stigma is a significant barrier to both family support, and help seeking. Scholars are working hard, and making great contributions in these areas of social response to mental illness and other disabilities. What can I realistically hope to contribute? I think about this question constantly. A way to ensure a focused, effective effort is to narrow the scope of my work. I have chosen to target families, because that is where my experience has been. This project is just one of a series of projects focused on families of individuals diagnosed with a mental illness and other disabilities.

This story begins with the "epiphany," that moment when Doug first revealed his mental state to me. That is far from the entire story. Ultimately, I am committed to revealing many of the moments of pain, frustration, anger, and love that occurred over the following eight years until Doug's death. During that period, I learned some of what it takes to not just survive the experience, but to grow and prosper in it. Over time, Doug and I learned how to manage our lives together through love, anger, negotiation, and lots of compromise. It is my hope that in sharing this story in its entirety, other parents and siblings living with a mental illness in their family can find the satisfaction and fulfillment that my family and I did as we took this journey with Doug.

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As I have developed this project over the past three years, I have regularly shared this

work with my students. The feedback has been helpful in crafting this work, and has also

provided me with encouragement along the way. As I worked to polish this final draft for

publication, I shared it with my Introduction to Sociology class. Below is an excerpt of an email

I received from a student after having read this story.

> As a reader, I could feel the emotion in your writing as you described how it felt to learn your son was suffering from a mental illness. What I liked best was how you focused on how you coped with this news, being a positive force in your son's life. The narrative dialogue in the story makes the reader feel as though they were in the situation with you, making it more relatable. You talk about the stigma surrounding mental illnesses and how that stigma can be pushed onto the family as well, and how the family often has to pick up some of the pieces to care for their child. As someone who has struggled with depression over the past few years, I often feel as though I'm burdening my family by putting any problems I may be having on them. Because of this, I tend to try to keep to myself, not disclosing the extent of any issues I may be having. After reading your story, however, I can understand now how having that trust and support in the family can make such a big impact. If there's one thing I took away from your story it's that you had such a positive impact on your son and his mental illness once the line of communication had been opened. Families need to have these open and honest conversations about mental illness just as they would with physical illness. In doing so, the stigma slowly starts to diminish. I know you say you don't see yourself as the leader of any social change regarding mental illness, but your story is capable of affecting many.

I don't know how I could articulate my hopes and aspirations for this work any better than this

young student did. It is a humbling experience to have been given a chance to impact just one

life in this way.

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Chapter Three:

Organizational Narratives of Mental Illness: Analysis of Publicly Available Texts Produced

by the National Alliance on Mental Illness (NAMI)

My objective in this chapter is to explore ways in which a powerful organization depicts

the consequences of and appropriate reactions to serious mental illness in publicly available

narratives[3]. I first discuss the ways that narratives help us understand conflicting notions of our

social world. I then do an evaluation of the *National Alliance on Mental Illness (NAMI)* website.

NAMI arguably is the largest and best-known NGO providing education, support, and advocacy

for individuals and families of those who have been diagnosed with a serious mental illness in

the United States. Understanding the story NAMI tells about what mental illness is and how it

should be handled is, therefore, important because these stories can shape understandings of

individual lives. I focus on those content areas of the site that contain messaging that I believe

produced the most powerful and impactful narratives about mental illness.

The Work that Narratives Do

What is called the "narrative turn" in the social sciences began with the idea of moving

away from natural science models of social life and social research toward constructionist

models, which meant a shift from examining questions of cause to questions of meaning, and

from "conceptualizing people as made by society to conceptualizing society as made by people"

(Loseke 2019:15). I choose to analyze narratives about mental illness because they reflect what

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[3] In examining the NAMI website, where possible I focused on stories about individuals who had received
diagnoses of serious mental illness such as schizophrenia, bipolar disorders, and depression. With the array of
diagnoses now reaching over four hundred in the DSM-5, it would be impractical to address more than the most
serious.

we can think of as common, everyday understandings about these experiences.

As Donileen Loseke (2019) argues;

> Everything about narrative is social. Stories are social in their *contents* because, in order for a story to be evaluated as believable, it must more-or-less reflect audiences' understandings of the typical meanings of objects, events, and people: Stories about "being possessed by the devil" are evaluated by most Americans in the current era as probably not true; stories of "mental illness" would not have been understandable to citizens of colonial America.

Cultural Codes within Narratives.

Cultural codes are what Loseke (2019:24) has called "systems of meaning" because they become resources that enable the listener to "construct as well as evaluate story plots and morals." Stories of mental illness, for example, often feature the cultural code "normal" which defines expectations about what behaviors, attitudes, orientations, and so on are expected of social members. When we hear that an individual's behavior is not "normal," what does it signify to others? Not normal could be construed as "colorful," "eccentric," "weird," "dangerous," "sociopathic," and so on. It is the story within which these symbolic codes are imbedded that gives the listener clues to understand story meanings and moral lessons.

Stories support particular kinds of behaviors and moral evaluations so the stories that organizations such as NAMI tell can be powerfully important. For example, a "mentally ill" narrative character is evaluated as "normal" when stories depict them as obeying rules, and of not disrupting. Within commonly circulating cultural codes, such a "normal" character is *superior* to those who do not obey rules and are disruptive.

Stories persuade, persuasion is necessary to develop social problem consciousness, and social problem consciousness is a necessary element of mobilization toward social change (Loseke 2019). Thus, stories are intrinsic to social change, both in the form of policy and legislation, and as evidenced by transformations in culture and consciousness (Poletta 1997).

Focusing on the success of LGBTQ social movement activism over the past few decades, for example, scholars have shown how formula stories of concepts such as "identity construction," "adaptive processes," "coming out," and so on have helped to normalize these experiences, thus leading to a broader understanding and acceptance of the LGBTQ identity (Joos & Broad 2007). This is but one example of many social movements, characterized as "identity movements," whose goals are to change the understandings of the contents and evaluations of particular identity categories. Such *subjective* changes in ways of thinking and feeling can yield *material* changes in lives (Loseke 2019). The power of narratives, in the form of formula stories, can unleash significant social forces leading to fundamental social change.

The Forms of Narrative.

Loseke (2007) discusses four kinds of narratives that circulate in social life. First, there are *cultural narratives,* often found in the mass media that construct the identities of "types" of people, such as "the mentally ill," or "the disabled." Stories told using these common character types, and common tropes about these characters, are often disparaging, and can help shape public responses to these individuals. Next there are *institutional narratives,* which also construct stories around types of people, but do so with the explicit goal of supporting or opposing legal and public policy decisions. *Organizational* narratives—such as those told by NAMI—are similar to institutional narratives, and are used to justify social service provisions to the types of clients served by organizations. In examining the reflexive relationships between organizational and institutional narratives, Loseke (2007:671) argues "organizational narratives work to develop images of their 'typical' client because these images justify organizational procedures and services by offering stock answers to important practical questions: Who is our client? What are our client's problems? What does our client need?" Institutional narratives, on the other hand, are fundamental to the process of policymaking by helping policymakers sort through cultural

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narratives of "types" of individuals toward which policies are targeted. Finally, there are *personal narratives*, defined as stories that social actors tell to make sense of their own selves and experiences and to locate themselves in the social world (Loseke 2007; Kusow and Eno 2015).

The Family as Audience for Organizational Narratives of Mental Illness

Families are very often on the front lines in fighting and advocating for the family member who has been diagnosed with a serious mental illness. With a shrinking number of public mental health facilities, and with private mental health services often out of financial reach, it is frequently left to families to provide the safety net for family members diagnosed with a serious mental illness (Walton-Moss, Gerson, and Rose 2005). Families in which a member is diagnosed with serious mental illness report a variety of new experiences, fears, and challenges. Because of this, they will need to connect their experiences to culturally circulating stories about mental illness that will help them understand what they are facing.

The acquisition of a label of mental illness in the family is similar to the diagnosis of other disabilities in early childhood. This can take a heavy toll on the family, as the anticipated experience of an "ordinary life" is altered by such a diagnosis (Green, Darling, and Wilbers 2016). Family members may suddenly feel they need to become caregivers, advocates, case managers, and life coaches, all while grappling with a lack of understanding of the variety of professional and public understandings the diagnosis itself.

The family member experiencing symptoms associated with a serious mental illness diagnosis may disagree with professionals and family members about the diagnosis itself and/or the need to seek treatment (Karp and Tanarugsachock 2000). Individuals with a diagnosis of a serious mental illness may reject medicalization – the biological and genetic explanations of their experience - imposed by medical professionals (Beresford 2000). They may not see themselves

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as emotionally or mentally distressed, but instead celebrate their difference and their particular perceptions.

In addition, when a family member's behaviors are labeled a "mental illness," negative reactions such as fear that they may be dangerous and unstable can be triggered (Corrigan, Markowitz, and Watson 2004). The diagnosis of a mental illness also can be characterized by public social distance when they are perceived as belonging to a social group evaluated as undesirable, feared, and mistrusted (Corrigan and Watson 2005; Corrigan et al. 2009; Markowitz and Engelman 2017). The family may also experience stigma by association, the so-called "courtesy stigma" (Goffman 1963). Family members who live with the person diagnosed with a mental illness may experience more stigma than those who do not, simply because their acquaintances are more likely to know about their relative's illness and because their normal everyday interactions may heighten the acquaintance's probability of contact with that individual (Phelan, Bromet, and Link 1998). When family members are caught up in the same negative social framework that the individual is experiencing, the prospects for maintaining positive, fulfilling relationships are greatly diminished (Rose 1996).

It is clear that family members of persons diagnosed with serious mental illness experience a variety of problems that send family members on a search for information and support. Often this search culminates in access to websites such as NAMI's. The stories told by these organizations, therefore, are important because they have the potential to shape the feelings and behaviors of family members in relation to the mental illness diagnosis and the family member who bears it.

NAMI: A Powerful Voice in the Narrative of Mental Illness

NAMI, initially a grass roots organization literally formed by a group of parents around a kitchen table in 1979, has developed a national network of state, local, and volunteer

organizations that work toward the reduction of stigma toward mental illness through education programs, information dissemination, public awareness events and activities, and lobbying efforts. NAMI identifies its mission as being "dedicated to building better lives for the millions of Americans affected by mental illness" (NAMI 2019).

The organization talks about using a four-pronged approach to "building better lives" for individuals with mental illness and their families: 1) *Education.* Offered in thousands of communities across the United States through NAMI State Organizations and NAMI Affiliates, NAMI works to ensure that hundreds of thousands of families, individuals, and educators get support and information at state and local levels. 2) *Advocacy.* NAMI works to help shape national public policy, and provides volunteer leaders with the tools, resources and skills that impact people with mental illness and their families. 3) *Helping People in Crisis.* NAMI's toll-free help line offers instant, personal response to hundreds of thousands of requests each year, providing free information and support. 4) *Leadership.* Public awareness events and activities, including Mental Illness Awareness Week and NAMIWalks, work to fight stigma by encouraging public understanding and acceptance. The public relations arm of NAMI works with reporters to encourage citizens to understand how important mental health is. Headquartered in Arlington, VA, the organization has approximately 1,000 state and local affiliates and is represented in all 50 U.S. states, Washington, D.C., and Puerto Rico. NAMI is funded primarily through pharmaceutical company donations and individual donors, as well as private and public sponsorships and grants (NAMI 2019).

Families involved in NAMI come from widely disparate locales and social strata, yet find themselves involved in a common struggle - coping with and managing a diagnosis of serious mental illness. In such circumstances, "the more social relations involve people who are strangers to one another, the more these relations are – and must be – informed by pre-existing

images" (Loseke 2012). These images, often referred to as cultural narratives, are capable of informing disparate individuals and families about hitherto "unknown worlds," and thus become, according to Loseke, "crucial components of social life in complex social orders" (p. 252). When families are first introduced to the idea that a family member is "mentally ill," they enter the kind of "unknown world" to which Loseke refers. For many individuals and their families having received a diagnosis of mental illness, the NAMI website may be their first entre into that world. Due to its prominence, NAMI has the potential to shape the understandings and actions of family members. Understanding the story this particular organization tells is, therefore, important to understanding the social experience of mental illness in the family.

Methods

All organizations create and maintain a repertoire of stories. Anyone who spends time looking at an organizations' website, for example, will encounter such stories, and a sense of how these stories connect to broader cultural narratives (Barley and Kunda 1992). NAMI is no exception. Their website is an accessible and visible purveyor of the stories NAMI produces. The Internet has enabled the deployment of online spaces for organizations devoted to supporting marginalized groups to promote themselves, and for their participants to aggregate and tell stories that had previously been silenced (Maloney 2013; Egner 2019a, b). Online spaces also provide geographically separated participants with opportunities to share their lived experiences. This is particularly useful for people with disabilities who may be prevented from interacting with other people with similar shared experiences due to geographic distance or inaccessible environments (Egner 2019a).

The NAMI website is inviting, with relatively intuitive upper level navigation, simple but effective graphics, and a welcoming color scheme. Below the "surface," the NAMI site is both comprehensive and complex. Unlike nearly any other organizational data source, websites are

non-linear in structure and function. They are replete with links and redundant sections that can be tricky to navigate, and that require the researcher to "map" in order to fully understand the structure and organization of content. The NAMI site contains a "Site Map" section that provides visitors with all of the content in one easy-to-analyze document. I have included the initial page of this document with a link to all 40-some pages in Appendix B, and will be making reference to it throughout this analysis.

The NAMI website site map shows 10 major sections, and approximately 450 subsections, three levels deep. Some of these sections (such as "About NAMI," "NAMI Leaders," "Join NAMI," and "Convention") are dedicated to organizational matters, thus are not designed to appeal to the individual or family in crisis. While material in these sections certainly is part of the overall story NAMI tells, my interest here is specifically in aspects of the NAMI story that might shape understandings of mental illness among individuals and members of their families in crisis who access the site for that reason. I rely primarily on two sections that are targeted at those individuals or family members: The "Learn More" section contains information about NAMI's understanding of what mental illness is, how it can be recognized, its prevalence, and recommended treatments. What is NAMI's message to them? The "Find Support" section contains information about the NAMI Helpline, NAMI Programs, and Living with a Mental Health Condition. The NAMI site also contains a repository of individual stories that are sanctioned by the organization (NAMI/Personal Stories). I use these stories to illustrate the broader themes reflected in the organizational narrative. The target audiences for the sections I have analyzed are people in crisis.

I employed Loseke's (2012) formula story research methods in this analysis. This process involves four steps; First, I read all sections for *story content*, considering such questions as: who authored the story, is the story being claimed as fact, who are the intended readers, and what is

the author's ultimate objective in telling the story? Next, I performed repeated *close readings* of selected sections through which plots, characters, and morals begin to emerge. Because we all bring different understandings to our interpretation of these stories, they mean different things to different readers. Some may evaluate a story as believable and important, others may evaluate the same story is unbelievable or unimportant (Loseke, 2012). Thus, it could be argued that my interpretation may not be the same as my reader's interpretations. This is the nature of formula story analysis.

The third step is to categorize and clearly identify *descriptions of characters*. Each story has its distinct characters; some are heroes, some are villains, and others victims. Characters may be individuals, organizations, institutions, or society as a whole. The final step is to *unpack symbolic codes*. This is where we are able to connect statements, opinions, concepts, and ideologies to values that are represented in the stories. These stories evoked many more questions than they did answers. As readers we are forced to make some hard choices about what we believe to be true and important, who is in the right and who is in the wrong, and what comments these stories make on our society.

My goal here is not to evaluate the accuracy or moral worth of the NAMI story about mental illness. I am not asking if they are saying the "right" things about what mental illness is, or how it should be treated. As stated above, organizational stories are narratives, and narratives can influence those who are exposed to them. The narrative may be thought of as positive, it may be thought of as negative, it may be assumed to be true, or it may be resisted. Rather than perceiving the NAMI narrative as positive or negative on its face, I am looking at how a potentially influential organization depicts mental illness in publicly available spaces. In the sections that follow, I examine what stories are told by NAMI.

Findings

Two overarching narratives emerged in the data I analyzed – opposing understandings of what serious mental illness is, and how it should be treated. One narrative supports a "medicalized" understanding of what these diagnoses mean, and what should be done. Another suggests that, while mental illness is medical problem that can be effectively addressed through professional intervention, "society" exacerbates the condition through the many hurdles it imposes on those who have been so diagnosed.

The Mental Illness is a Medical Problem Story

The plot. In this story, NAMI conceptualizes mental illness as a medical problem that must be diagnosed by a mental health professional such as a physician, psychologist, or psychiatrist, and that treatment should consist of psychotropic drugs and/or therapy as determined by mental health professionals. Although NAMI warns that the difference between "expected behaviors," and what might be "signs" of mental illness can be difficult to distinguish, they nonetheless advise that it is best to seek help from a mental health professional:

> There's no easy test that can let someone know if there is mental illness or if actions and thoughts might be typical behaviors of a person or the result of a physical illness. (Learn More/Knowing the Warning Signs).

Readers are cautioned to "get help" by being told that they should not be afraid to reach out to their "health insurance, primary care doctor, or state/county mental health authority" for resources (Learn More/Where to Get Help). While NAMI instructs "there is no medical test that can accurately diagnose mental illness," they urge readers to talk to a "qualified mental health professional (who) will use the *Diagnostic and Statistical Manual of Mental Disorders* to assess symptoms and make a diagnosis," which is deemed the necessary first step in "developing a treatment plan that could include medication, therapy, and other lifestyle changes" (Learn More/Receiving a Diagnosis). In short, the plot of this story is about individuals experiencing

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feelings and behaviors that are unusual should immediately consider the possibility that they are experiencing a mental illness, and should seek proper medical care as a first step toward feeling "normal" again.

The characters. The hero character is the most important character in NAMI's story. The heroes are the medical community - mental health workers and clinicians, physicians, psychiatrists and psychologists. Pharmaceutical companies, through the drugs that are recommended, are also heroes, as is NAMI itself.

Mental health professionals as heroes. Most of the content in the "Learn More" section of the website is devoted to explaining what mental illness is, how prevalent it has become, and information about "treatment." I put this term in quotes to emphasize that the idea that, in this context, this term has significant symbolic power. By employing the term repetitively, NAMI encourages readers to connect a *mental health problem* with the idea that it is a *medical problem*. As with cancer, for example, the treatment could be surgery, or it could be chemotherapy, but it most certainly must be directed and performed by a licensed medical professional. In this section of the NAMI site, treatment is discussed in the same way. I found dozens of instances where it is used in the texts within the Learn More/Mental Health Treatment section such as; "treatment choices," "treatment plans," "treatment teams," "treatment options," and so on. This term is inextricably associated with the notion of medical care in the Western lexicon.

Another culturally symbolic term in this context is the word "symptom." When referring to an individual's behavior as a "symptom" of mental illness, we generally interpret this to mean that mental illness is a medical problem. While this word is synonymous with many others that could be employed such as; "characteristic," "pattern," "sign," or "trait," when the term "symptom" is used to describe behavior, the reader immediately understands it to be a medical phenomenon that requires medical treatment.

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NAMI makes reference upon reference to all manner of medical personnel that should be used to provide diagnoses and treatment. These medical professionals therefore are heroes in this story. The site devotes an entire subsection (Learn More/Mental Health Professionals) listing and identifying the various types of medical personnel that the visitor might seek, or come in contact with, during their mental health treatment journey:

- Ph.D - Doctor of Philosophy in Psychology
- Psy.D - Doctor of Psychology
- M.S. or M.A – Psychology
- M.S. or M.A – Counseling Psychology
- M.S. or M.A – Marriage of Family Therapy
- LPC - Licensed Professional Counselor
- LMFT - Licensed Marriage and Family Therapist
- LCADAC - Licensed Clinical Alcohol and Drug Abuse Counselor
- LICSW - Licensed Independent Social Workers
- LCSW - Licensed Clinical Social Worker
- ACSW - Academy of Certified Social Worker
- NCLEX, National Council Licensure Examination
- PMHNP-BC, Board Certification in Psychiatric Nursing

Virtually every mental health professional on this list is identified with letters before their titles or roles. In our highly credentialed Western culture, such signifiers encourage an understanding of the importance carried by credentials indicating advanced education.

NAMI as a hero by promoting a medical story of mental illness. NAMI promotes the medical narrative in many ways. It suggests what types of assistance various categories of professionals can be expected to offer: *Psychologists* are trained to evaluate a person's mental health using clinical interviews, psychological evaluations and testing. *Physicians and Psychiatrists* make assessments through a medical history and interview, diagnose the condition, and prescribe drug therapies. *Therapists* assess emotional needs and help the patient understand and cope with thoughts, feelings and behaviors. According to NAMI "Working with one of these

mental health professionals can lead not only to symptom reduction, but to better ways of thinking, feeling and living" (Learn More/Types of Mental Health Professionals).

NAMI constructs themselves as heroes in the fight against these dreaded afflictions by emphasizing and supporting the idea that mental health professionals can and do have a positive impact on the lives of those who may have a mental illness. According to Loseke (2009:514) "heroes are people whose behavior exceeds that of the ordinary, so it follows that heroic deeds should be relatively uncommon and should distinguish only a few people." By constructing mental health professionals, and the medical community at large as heroes, and by advocating for medical interventions, NAMI reifies the narrative that mental illness is purely a medical problem, with medical solutions, to be managed by medical professionals.

Pharmaceutical companies as heroes. Our common understanding of who heroes are, and what heroes do was summed up by Loseke (2009) above. This understanding can be stretched a bit: Understanding mental illness as a medical problem addressed by the *mental health community* encompasses a vast network of individuals, companies, and institutions of which it is comprised. Pharmaceutical companies in the U.S. are a significant segment of that network and make major financial contributions to NAMI.

Above I discussed the idea that the term "treatment" in the context of mental health/mental illness triggers an understanding that mental health is a medical concern. NAMI devotes an entire section (Mental Health Treatment and Services) to that understanding. Prominent within that section is a subsection titled *Getting Treatment During a Crisis.* Here, NAMI introduces the idea of "crisis response," which in turn creates a narrative suggesting that whatever behavior it was that motivated the visitor to enter the NAMI site must be urgently managed by a "mental health crisis response service." The developing narrative puts the visitor in the position of need, with NAMI identifying the appropriate response services.

Subtly, paragraph 2 of this subsection contains the term, "psychiatric crisis," which encourages making connections between the behavior sending the visitor to the site, the idea that it is a crisis of mental health, and that some medical intervention is needed. Just below the "crisis" section just described, the visitor finds the subsection *Mental Health Medications*. The first subsection within this area, *Types of Medications*, opens with this sentence:

> Some people are afraid that taking a medication will change their personality, but most find that medication allows them to take charge of their lives.

Here, NAMI is offering the visitor hope in the form of psychotropic medications. The two most often prescribed categories of drugs used to combat serious mental illness - antipsychotics and antidepressants - are given major coverage, nearly all of it positive.

- Antipsychotics *reduce or eliminate symptoms of psychosis* (delusions and hallucinations) by affecting the brain chemical called dopamine.

- All *antipsychotics play a vital role in treating schizophrenia and schizoaffective* disorder.

- Some antipsychotics can also be used to *treat acute mania, bipolar disorder and treatment-resistant depression.*

- Antidepressant medications *improve symptoms of depression* by affecting the brain chemicals associated with emotion, such as serotonin, norepinephrine and dopamine.

- Some antidepressants may be useful for *post-traumatic stress disorder (PTSD), generalized anxiety disorder and obsessive-compulsive disorder (OCD)* but may require higher doses.

While these two drug types are made highly visible in this section, many other less commonly known categories are also discussed in great detail, including anti-anxiety medications, mood stabilizers, and what are known as "off-label and generic medications" (Learn More/Treatment/Types of Medications).

In this section, fifty-eight individual medications are identified and described. I use one of those fifty-eight, CLOZAPINE[4], to show the tremendous detail with which NAMI constructs the meaning these drugs, and their use in managing "symptoms" of mental illness. First is the generic name, *Clozapine*, followed by three brand name variants and the doses available:

- Clozaril® - Tablet: 25 mg, 50 mg, 100 mg, 200 mg

- FazaClo® - Orally disintegrating tablet: 12.5 mg, 25 mg, 100 mg, 150 mg, 200 mg

- Versacloz® - Oral suspension: 50 mg/mL Generic name: clozapine (KLOE za peen)

What follows is over 2,100 words of text devoted to explaining the use, benefits, practice, and possible side affects of the use if this one drug.

Here is a list of the paragraph subheadings in this section:

> *What Is Clozapine And What Does It Treat?*
> *What Is The Most Important Information I Should Know About Clozapine?*
> *Are There Specific Concerns About Clozapine And Pregnancy?*
> *What Should I Discuss With My Healthcare Provider Before Taking Clozapine?*
> *How Should I Take Clozapine?*
> *What Happens If I Miss A Dose Of Clozapine?*
> *What Should I Avoid While Taking Clozapine?*
> *What Happens If I Overdose With Clozapine?*
> *What Are Possible Side Effects Of Clozapine?*
>> - *Common side effects*
>> - *Rare/serious side effects*
> *Are There Any Risks For Taking Clozapine For Long Periods Of Time?*
> *What Other Medications May Interact With Clozapine?*
> *How Long Does It Take For Clozapine To Work?*

A random examination of 10 of these fifty-eight subsections, each devoted to an individual drug, revealed an average word count per drug section of 1,613 words. Extrapolated, we can project approximately 93,500 words of text being devoted to the pharmaceuticals that are one of the very

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[4] The URL for the CLOZAPINE page: https://www.nami.org/Learn-More/Treatment/Mental-Health-Medications/Types-of-Medication/Clozapine- (Clozaril-and-FazaClo)

first forms of "treatment" suggested by NAMI. In this story pharmacological interventions become the first, and most important step in treating diagnosed conditions. At the bottom of each of the 58 pages, under "Provided by," are the logo and name of the College of Psychiatric and Neurological Pharmacists, "in partnership with the National Alliance on Mental Illness." Arguably, NAMI is acting as a "marketing partner" for Big Pharma[5] by portraying medications as heroic tools in the fight against the villain that is mental illness.

The Moral. NAMI conceptualizes the onset of mental illness in relatively simple terms. Mental illnesses are medical problems, to be diagnosed, treated, and managed by medical professionals, in conjunction with drugs produced by the pharmaceutical industry. Much of the information NAMI imparts to site visitors supports this idea, providing the visitor a clear trajectory to what they characterize as a "better life."

The NAMI story proposes that when an individual first experiences thoughts and behavior they believe may be caused by a mental illness, the first thing they should do is to disclose this to people who are close to them, and seek medical treatment. Ultimately, the road to a better life begins with finding a trusted "partner" in the form of a psychiatrist, medical doctor, therapist, or counselor. "If you have a mental health condition that may benefit from medication, you should consult a mental health specialist, such as a psychiatrist, rather than relying on a primary care doctor" (Learn More/Treatment). As one individual whose personal story is included on the NAMI site put its:

> NAMI gives individuals and families the opportunity to get support and education as well as a platform for advocating for themselves and others. Even though I was working on my issues, it was primarily done behind closed doors. NAMI blew that concept wide open (Personal Stories/Managing My Mental Health).

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[5] The term often used to refer to the pharmaceutical industry, lobbying groups, NGO's, and politicians who collectively benefit from participation in the $3.5 trillion prescription drug industry.

Summary. In this story, receiving a diagnosis signals the beginning of the recovery process. Because mental illness is a biological, genetic phenomenon, it is *always* treatable, and reliance on medical professionals is *always* recommended. Post diagnosis, there are many dimensions to a holistic, long-term recovery that may also need to be addressed. Among the challenges are: ongoing care getting, housing, ongoing psychiatric care, therapy, and counseling, pharmacological plans and regimens, and community based programs such as wellness training, support groups, and vocational training, In this NAMI story, the organization and its supporters are there to provide education, support, advocacy, and encouragement to both the individual and their family who do the right thing by seeking and following medical treatment and professional guidance.

The Social Response to Mental Illness as a Social Problem Story

The plot. In this second story, NAMI warns individuals and families that once a diagnosis of mental illness is made, the social lives of the individual, and often their family, may never be the same. Society may reject them. Their life chances may be diminished, and their futures become cloudy. Unlike "medical" problems such as cancer, heart disease, and diabetes, diagnoses of a mental illness brings the prospect of encountering social hurdles and barriers that can be lifelong, often seeming insurmountable. Because of the likelihood that the individual and their family will encounter these social barriers, NAMI advises them to be careful *when* they tell, *what* they tell, and to *whom* they tell about what they are going through. Not everyone, cautions NAMI, has the capacity to show empathy, understanding, and support.

The characters. There are heroes, villains, and victims in this story. The heroes, NAMI and is cadre of donors and volunteers, challenge villainous narratives that victimize people with a diagnosis of mental illness though social stigma.

Society as villains, victimizing individuals diagnosed with a mental illness and their

families. NAMI depicts individuals with a diagnosis of mental illness, and their families, as

being victimized by both the general public and possibly their own social network, in the form of

social rejection and stigma. Because of this, NAMI suggests their social network and personal

relationships must be dealt with in a careful, thoughtful way, in order to avoid potential discord.

These individuals are very likely to face different forms of social injustice, and that they often

made to feel that the situation is their fault.

NAMI cautions that the general public stigmatizes and blames the individual, despite the

fact that "As with other serious illnesses, mental illness is not your fault, or that of people around

you" (Find Support/Living with A Mental Illness). NAMI advises the consumer to be prepared to

experience social isolation, personal relationship problems, and work/professional difficulties.

Here the visitor is cautioned to be very thoughtful about disclosing their situation:

> You have to weigh the advantages and disadvantages. Consider the potential negative
> impact on things like stigma from coworkers against your need for special
> accommodations, which are considered part of your civil rights (Find Support/Living
> With a Mental Illness Condition/Succeeding at Work).

They must be careful to whom and when they disclose their illness:

> Because of the fears and misconceptions that surround mental health, even well meaning
> people may not know how to react to your disclosure (Living With a Mental Illness
> Condition/Disclosing to Others)

Work and romantic relationship issues are addressed, all leading the reader to an understanding

that they must be careful about when and how they should reveal their illness, but also insisting

that ultimately, despite the inherent risks, honesty and openness are of paramount importance.

> A good relationship provides valuable social support during difficult times, whereas a
> bad relationship can worsen your symptoms, particularly in cases of depression. (Living
> With a Mental Illness/Relationships).

In general, the person living with a mental illness is warned that they are likely to experience high levels of stress related to their illness, and of it's negative ramifications.

> Stress can strain your body and make it impossible to function, contributing to worsening symptoms of your mental illness. For example, in schizophrenia, it can encourage hallucinations and delusions, while in a bipolar disorder episode it can trigger episodes of both mania and depression. Finding effective ways to deal is crucial to living well (Living With a Mental Illness Condition/Managing Stress).

The implication here is that the individual should be prepared with strategies and processes to help avoid, or at least reduce stress because it will effect their potential for recovery and their prospects for "living well."

Disclosing ones mental illness to anyone is seen as a risky venture. The person living with a mental illness is cautioned to consider both the pros and cons before deciding to reveal their diagnosis. One is told that he/she will need emotional support, and that not everyone is equipped or prepared to give it. There are considerations about the impact on employment, social life, and family life. Strategies, timing and selection are all critical to successfully maintaining your former life and relationships.

Once someone has been informed, the individual will understandably be concerned about his/her response. One sign that the recipient of this information can handle it, advises NAMI, it is if they "Treat you the same during or after the disclosure. Friends stay friends. Colleagues stay polite and interested. If you continue to get the same 'vibes' from people, you can be pretty sure that your disclosure has not changed the relationship for worse" (Find Support/Living with a Mental Illness/Disclosing). Knowing that certain people are aware of an important part of your life and that they accept you and support you can be incredibly helpful and liberating. In this story, this level of acceptance and support is rare, and should not be anticipated. Though the warnings NAMI offers, and the advice it provides, NAMI implies that the reader will need these

resources and information in order to live well as a person with mental illness, one that in many ways will be shunned and set apart from the rest of society.

NAMI as a hero in the fight against mental illness. NAMI portrays itself as a caring and understanding organization with the capacity to provide support and advocacy for those living with a mental illness. By making a financial contribution to NAMI, site visitors are promised that they too can take on a heroic role in this story by sending the message that "no individual or family is alone on their mental health journey" (Get Involved/Donate). The *Donate* link informs readers that, by donating to NAMI, they will be helping make a "better tomorrow" when "all people affected by mental illness can experience hope, recovery, and wellness in a world free of stigma" (Get Involved/Donate).

The main *Get Involved* page suggests to the visitor that getting involved *will* make a difference in the lives of Americans living with a mental illness by combating the main villain in this story, which is stigma.

> Together with our grass roots volunteers we work every day to provide help and hope to millions of Americans. The first step is helping us stop stigma against mental health. With your help, we can stop stigma from being a barrier against those seeking help and speaking out (Get Involved)

Following this, visitors are prompted to click on a box titled "Take the Stigma Free Pledge" which links to a page that begins with the question, "Do you have Stigma," then prompts readers to "Take the Quiz" (Get Involved/Take the stigma free Pledge). By taking the quiz, visitors are invited to uncover ways in which they have played an unwitting role as stigmatizing villains. By taking the pledge, they are reassured that they can be converted from villains to sympathetic heroes who can join the fight, and ultimately help those unable to advocate for themselves.

The Moral. In this story, NAMI depicts the plight facing people living with a mental illness in relatively simple terms. It sees an individual and their family facing an emotionally

draining task ahead - dealing with the vast array of challenges they will potentially face in navigating through society with a mental illness; social stigma, difficulties in their personal relationships, problems at work, hurdles and roadblocks in their interactions with insurance companies, and in accessing health related services.

Summary. In this story, while arguing that medical intervention for mental health problems is always the initial first step, NAMI warns that it will be the social and institutional hurdles faced by the individual and their family that most often dictate the difficult life trajectory one can expect to experience post diagnosis. "Mentally ill" is a label that is often stigmatizing, is often lifelong, and in many ways may exacerbate an already difficult experience. In this story it is society that places the highest hurdles, and creates the greatest burden on those who have been diagnosed with a mental illness. NAMI and its volunteers and donors provide a ray of hope through heroic advocacy and empathetic understanding in an otherwise villainous world.

Discussion

In this project, I sought to understand how NAMI, through the narratives it produces, might shape the experiences of individuals diagnosed with mental illness and their families. My findings suggest that both of the stories NAMI tells about mental illness might shape the experience of individuals and families in both positive and negative ways.

The story NAMI tells about mental illness as a medical problem might be helpful in reducing blame and self-blame. In this story, rather than dangerous villains, people with mental illness diagnoses are given the role of blameless victims of biology and disease who can be helped by heroic medical intervention. Numerous studies have shown that self-blaming can have an extremely negative affect on both the individual and their family. Many of these same studies have also shown that by characterizing a diagnosis of mental illness as having a biological or genetic origin, self-blame is reduced (Whaley 1997; Link et al. 1999; Pescosolido et al. 1999,

2010; Phelan et al. 2000; Martin et al. 2000; Corrigan and Watson 2007; Corrigan et al. 2009; Wirth and Bodenhausen 2009; Boyd et al. 2010). NAMI consistently reinforces the notion that mental illness is not the "fault" of the individual, and by association, the family. NAMI argues that the failure of the public to understand this "fact" can exacerbate already challenging circumstances.

> As with other serious illnesses, mental illness is not your fault or that of the people around you, but widespread misunderstandings about mental illness remain. These misperceptions add to the challenges of living with a mental health condition (Find-Support/Living with a Mental Health Condition).

According to NAMI, people regularly overcome the challenges of mental illness that can inhibit the experience of a happy, productive life. Through developing and following a treatment plan, it is argued, one can dramatically reduce many symptoms. People with mental health conditions can and do pursue higher education, succeed in their careers, make friends and have relationships. NAMI argues: "Mental illness can slow us down, but we don't need to let it stop us" (Find-Support/Living with a Mental Health Condition).

This message may buoy the spirit of the site visitor in crisis, whether they are an individual or a family member. It's not their fault. They are the victim of a cruel, unexpected, and often terrifying disease. This is one message that NAMI is conveying by taking the position that mental illness is not a personal weakness, but a manifestation of some genetic or biological trait gone haywire – not unlike cancer, heart disease, or diabetes.

Being caste as a victim of a medical tragedy, however, is not universally appreciated by individuals with mental illness. The Mad movement, initially a response to Big Pharma and profiteers in the psychiatric system that make a living labeling and medicating, is beginning to argue more publicly that their own "interpretations of madness" should be honored, and that the medical narrative is biologically reductionist. Mad Studies proponents, sometimes referring to

themselves as "psychiatric system survivors," advocate for alternative forms of helping people experiencing mental anguish that are based on humanitarian, holistic perspectives in which people are not reduced to symptoms, but are understood within the social and economic context of the society in which they live (Menzies et al. 2013).

The story NAMI tells about the problematic social response to mental illness is in some ways consistent with the Mad Studies perspective in that it shifts blame from individuals and families to stigmatizing others and unhelpful social contexts. This NAMI story, however, also castes individuals and their families in the role of passive victims. NAMI paints a very dire picture of how the individual will be perceived by society, possibly adding to self-stigma that has been shown to be so damaging to both the individual and their family.

The stigma toward individuals with a diagnosis of mental illness has been exhaustively researched, and is well understood by scholars (Link 1987; Link et al. 1999; Pescosolido et al. 1999; Swindle et al. 2000; Martin et al. 2000; Phelan et al. 2000; Schnittker et al. 2000; Gonzalez et al. 2005; Anglin et al. 2006; Kuppin and Carpiano 2006; Corrigan and Watson 2007; Corrigan et al. 2009; Wirth and Bodenhausen 2009; Boyd et al. 2010). Since Goffman's (1963) groundbreaking work, the term stigma and its association with disabilities of all kinds has been entrenched in the Western cultural lexicon, and is generally understood by the public to be associated with those who have a diagnosis of mental illness.

Scholars have argued that the way in which the general public perceives people with mental health problems is significantly dependent upon the nature of their diagnosis. Individuals with a diagnosis of schizophrenia, for example, are often thought of as dangerous and unpredictable (Crisp et al. 2000). Individuals dealing with alcohol and drug addictions are not only seen as dangerous (Markowitz and Engelman 2017), but the public also blames them for their addiction (Crisp et al. 2005). There seems to be a general consensus that anyone with

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mental illness is unreliable, especially in close, familial, relationships. Many believe having a mental illness reduces intelligence, and an individuals' ability to make rational decisions (Angermeyer, Matschinger, and Corrigan 2004).

NAMI, in its messaging to visitors, does little to quell fears of stigma should one consider revealing their diagnosis. Indeed, the site is replete with warnings and recommendations relating to when, how, and to whom one should share their diagnosis with family, friends, and employers. I argue that, while attempting to do a service to the reader by preparing them for what they might expect as a social response to their diagnosis, NAMI may actually be inadvertently triggering the process of "self-stigma" within the individual. In Bruce Link's (1987) *Stages of Self-Stigma Model,* devaluation and discrimination by society is the first stage. Self-stigma has often been equated with perceived stigma, a person's recognition that the public holds prejudice and will discriminate against them because of their mental illness label (Link 1987). Self-stigma can be extremely damaging to the individuals' prospects for recovery (Corrigan et al. 2009) and their potential to achieve the "better life" NAMI is projecting for those who follow their recommendations.

This chapter has focused on narratives of mental illness that are publicly broadcast by an organization with very broad reach and with ties to powerful professional and corporate interests. Understanding the stories about mental illness told by such organizations is important because these narratives have the power to shape both public understandings of what mental illness means, and the stories individual people tell about their own experiences. Personal narratives do not necessarily have to conform to those of powerful organizations, but whether people choose to tell stories that conform, resist, or contradict them, the believability and moral weight of the stories individuals tell will be judged by others within the context of widely circulating stories like those told by NAMI. In the next chapter, I turn my attention to individual stories told by

family members who have had contact with NAMI because a member of the family was diagnosed with serious mental illness.

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Chapter Four:

"Our Child is Mentally Ill"

Managing a New Reality Though Confusion, Anxiety, and Uncertainty

Melinda: ...We thought we had a thriving son all through high school. His sister had gone to the university the year before Gary graduated, so he decided that he wanted to go there as well... And, literally three weeks after we dropped them off, we get a call from his new roommate's father...Gary was exhibiting some of the same signs and symptoms [of a family member] who had been diagnosed with bipolar disorder years earlier; staying up all night for many days, blasting music, talking to people that aren't there. We were pretty ignorant. You know you hear the words bipolar disorder, manic depression. You freak out, right? We're so clueless. We really had no idea!...

How do families like Melinda's in which a member has been diagnosed with mental illness make this situation manageable, bearable, and ultimately hopeful? What, if any, barriers do they encounter and what resources do they use as they try to create an environment within which the family can live and relate positively to one another? It is the pursuit of answers to these questions that motivates this dissertation project. In this chapter, I explore the kinds of stories Melinda and other individuals who have had contact with the National Alliance on Mental Illness (NAMI) due to a mental illness diagnosis in the family tell about navigating this experience in in-depth interviews with an insider to the experience. I first review literature on some hurdles families of people diagnosed with mental illness have reported in previous research. I then analyze transcripts of in-depth interviews with fourteen parents, twelve of whom were recruited through a chapter of NAMI. I explore themes that emerged in these interviews, and then evaluate the

degree to which these themes conform to, resist, or contradict NAMI's widely circulating understanding of what mental illness is and how it should be handled.

Few people are prepared for that moment when they first learn their son, daughter, sibling, or parent is living with a mental illness. In those initial hours, days, weeks, and months, families are suddenly faced with painful, stressful, and fear laden realities that were never anticipated (Walton-Moss, Gerson, and Rose 2005). These families are forced to restructure their entire world around the fact that they are now living with a family member who is no longer accepted in society (Rose 1983). Like families of children with other kinds of disabilities, they may find that the anticipated cultural narrative of an "ordinary life" is replaced by visions of a future filled with complex and extended caregiving responsibilities, fear of social stigma, fear that their family member will not "get well," and fear that the family will not be able to cope with this new reality (Green, Darling, and Wilbers 2016).

With elusive access to public mental health facilities, and with private mental health services increasingly out of reach financially for individuals with a mental illness diagnosis, it is often left to families to provide a safety net and to organize all of the resources available in order to help the individual, as well as the family, access services (Karp and Tanarugsachock 2000). As noted in chapter two, previous literature on mental illness in the family suggests that among the hurdles families may face as they come to terms with a mental illness diagnosis are those associated with caregiving in a fragmented and hard to access mental health system (Bainbridge and Broady 2017; Bibou-Nakou, Dikaiou, and Bairactaris 1997; Greenberg, Kim, & Greenley 1997; Jones, Roth, & Jones 1995; Magliano et al. 2000; Maurin & Boyd 1990; Perlick et al. 1999), and the stigmatization of mental illness by others in the community (Corrigan and Lundin 2001; Corrigan and Watson 2005; Link 1987; Link et al 1989; Link and Phelan 2001; Pescosolido et al. 2007, 2008). A family's effective adaptation to such an event is "associated

with making clear what appears incomprehensible, managing that which feels out of control, and finding relevance in confusion" (Rose 1983:509). To gain clarity and control, parents of children diagnosed with a variety of disabilities often embark on extensive and extended searches for information and services in a process Rosalyn Benjamin Darling has called parental entrepreneurship (Green, Darling, and Wilbers 2016). In the case of mental illness, such an entrepreneurial process is likely to lead to NAMI which may be the single most influential non-governmental organization (NGO) in the field of mental health in the U.S. and has a wide reach through public information campaigns and education and support programs. Research also suggests that in response to perceived stigma, individuals and families may seek to avoid encounters with the public and seek out interactions with members of the category Goffman (1963) calls the "wise," that is others who also have experience with a mental illness diagnoses (Link et al 1989, Green 2001). The search for individuals who are wise to the experience of mental illness in the family may well lead to NAMI's support networks, and educational programs like Family-to-Family (FTF).

As we saw in the previous chapter, NAMI tells two very particular types of stories about what mental illness is and how it should be handled. One important story line is that mental illness is a medical condition that victimizes individuals and families and that can be successfully treated through heroic medical and professional intervention. This NAMI storyline resembles what Arthur Frank (1995) has called a restitution illness narrative in which something goes wrong, correct actions are taken, and normal life is restored. NAMI asserts that when unusual feelings and behaviors are noticed in oneself or a family member, the correct course of action is to seek and follow medical and professional advice and treatment, including medications. A second story line is that even though individuals and families are not to blame for the medical tragedy of mental illness, people with mental illness and their families will be victims of stigma

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and inadequate social support. This storyline incorporates aspects of what Frank (1995) calls a quest narrative of illness in which story tellers depict illness as a transformative experience that can lead to personal and collective enlightenment. NAMI seeks to combat stigma and improve the lives of people with mental illness by telling stories in which people and families live well with mental illness after diagnosis and treatment.

People with mental illness and their families are encouraged to join with NAMI to change the hearts and minds of the public through education. As NAMI tells the story that those diagnosed with a mental illness are not to blame for their condition, a story no doubt meant to improve the spirits of those individuals and their families, at the same time the organization depicts social rejection and stigma as a major hurdle that will inevitably be faced. In this way, NAMI is also telling a chaos story (Frank 1995) in which there will be a continuous struggle with conflicts within their social network, at their place of employment, and even in romantic relationships. Through the efforts of NAMI and other powerful organizations, these two kinds of stories have become deeply embedded in western cultural understandings of what it means to be diagnosed with mental illness.

Recruitment

Following approval from the University of South Florida's Institutional Review Board, (Appendix C) I began to recruit participants through a local NAMI chapter located in a suburb of a major city in the Midwestern United States. Started in 1979, NAMI has developed a national network of local chapters, volunteers, and other like-minded organizations that promote medical treatment of behaviors associated with a mental health diagnosis, and seek to reduce the stigma of mental illness through education programs, information dissemination, public awareness events, and lobbying efforts.

The NAMI chapter through which I recruited participants for the interviews described in this chapter has garnered a reputation as one of the most effective NAMI chapters in the county, offering several family education programs for clients and their families such as FTF, an educational program that NAMI developed in the 1980's. The NAMI narrative of mental illness might, therefore, be expected to have shaped the stories interviewees told me about their experiences, either directly or indirectly through NAMI's widely broadcast public information and education campaigns.

Researcher Positionality

I also have a personal connection to NAMI and the stories it tells about mental illness. I first encountered NAMI as a volunteer shortly after the death of my son, who had been diagnosed with schizophrenia at the age of twenty-one. Access to families who are coping with a family member who is mentally ill can be difficult. Because families tend to internalize a kind of self-stigma, they may be reluctant to freely discuss these extremely personal issues with strangers. I know first-hand the feeling of dread should the secret of my child's mental illness become public. I initially refused to acknowledge to anyone the severity of my son's schizophrenia. Eventually, however, as I became more involved with NAMI, I was able to share my story with others. I was able to gain access to my research participants through my personal experience as a parent of two children diagnosed with mental illness, and my connection with NAMI.

While an undergraduate, I began doing research on the effects of mental illness on the family. At the urging of one of the trainers associated with the local NAMI chapter near the college I was attending, I enrolled in a twelve-week FTF class. There I met several sets of parents, and first began to understand that many families who are faced with the sudden reality that their child's life, and therefore the life of the family, is about to change in a profound way,

feel desperately in need of information, resources, and support. It was this realization that motivated me to engage in this research. In 2010, I conducted interviews with five couples from that FTF class, leading to a paper upon which this research builds. Over the intervening years, I have developed a relationship with one of the national "trainers of trainers" in the FTF program who provided information on my study to approximately forty families of individuals diagnosed with serious mental illness (SMI) that have gone through the FTF program. Twelve members of ten different families contacted me and agreed to participate in this project. Two members of one additional family found out about my study through my natural contacts and asked to participate.

Participants

All of the family members I interviewed were parents (eleven mothers and three fathers) of people diagnosed with SMI. In three families, more than one child had been diagnosed with mental illness. All respondents were non-Hispanic white, and came from suburban middle-class families. The respondents' children had been diagnosed at least fourteen years prior to the interview, with the longest time span since diagnosis being twenty-seven years. Diagnoses include bi-polar I, depression, mood disorders, obsessive-compulsive disorder (OCD), pervasive traumatic stress disorder (PTSD), schizophrenia, and social anxiety disorder, sometimes in combination with eating and substance use disorders. At the time of the interviews, seven of the mothers, and two of the fathers were serving as trainers for FTF for a local chapter. Even the couple in the family not recruited through NAMI had some contact with the organization. At the time of their son's diagnosis, over 20 years ago, the couple attended a support group meeting, but did not find it helpful. They have had no further involvement with NAMI.

Methods

Because all of the respondents were located in the Midwest, I allowed them to schedule interviews at times that were most convenient for them, rather than attempting to arrange face-to-

face meetings during limited time frames during which I could travel to them. During the interviews, participants were asked to recall, in as much detail as possible, the behaviors initially triggering concern, the diagnoses that ensued, and the impact the diagnosis and subsequent treatment had on the immediate family, extended family, neighbors, and friends. Although I had a set of written questions and prompts to guide the interview (Appendix D), I let the interview "go where it should go" in order to allow participants to tell their own stories in their own way. As I began each interview, I gave the respondent a brief introduction to the project, and my background as a parent of two children who have been diagnosed with a serious mental illness. The respondents generally said that knowing my personal history made it easier for them to share their family stories with me. The interviews lasted between 45 minutes to 2 hours, and resulted in nearly 150 pages of typed transcripts in which all names were changed to protect confidentiality.

As a first step in my analysis, I employed Eviatar Zeruvabel's (1996) *lumping and splitting* concept of grouping ideas. *Lumping* entails creating "islands of meaning, clusters of things (acts, events, objects, traits) that are regarded as more similar to one another than to anything outside the cluster" (1996: 422). Whereas *lumping* involves overlooking differences within mental clusters, *splitting* entails "widening the perceived gaps between them, thereby enforcing their mental separateness" (1996: 424).

Once key thematic ideas were identified and highlighted through verbatim quotations, I compared them to the parents' "whole cloth" narratives (Green 2015) to ensure that themes and quotations were consistent the stories these parents wanted to tell, and that I do not allow my own biases to influence my understanding of what these parents wanted me to hear.

Findings

The stories I analyzed for this chapter are unique. Diagnoses differed. Age at diagnosis ranged from toddlers as young as three and a half to individuals in their mid-twenties. The size

and make-up of the families varied widely. Some parents reported being happily married and extremely close, while others reported distant relationships with spouses, or being divorced. Despite variations in family structure and experience, three common themes emerged from these narratives: 1) the immediate, sometimes desperate search for relief from symptoms and an extended battle over treatment, 2) the desire to accept this new reality, and to support and advocate for their child, and 3) eventually finding and maintaining family equilibrium. After first demonstrating how parents' stories reflect these themes across the spectrum of respondents, I will then discuss how these themes may or may not connect to NAMI's organizational narrative and dominant cultural understandings about mental illness.

The Search for Symptom Relief and the Battle over Treatment

All of the families in this study experienced a period of chaos and uncertainty as their children began to exhibit behaviors that were eventually labeled as symptoms of mental illness. Descriptions of these behaviors ranged from just "odd," to "not normal," to outright "dangerous." Mary, whose son Randy was eventually diagnosed with depression says, for example, that she knew something wasn't right, but didn't know what to do about it. She says the situation left her "…trying to get a handle on something I knew was different, and no positive impact, your hands are tied, an awful situation." Similarly, Eric discusses his son Paul, who began "acting out" at a very young age, even before he began elementary school. Like many participants, Eric at first resisted the medical label of mental illness as an explanation for his son's behavior. He says, "…but as time went on, you could tell it was not just being naughty - there was something going on. I think the one thing that, I guess, your first reaction is denial and you don't want your kid to have a problem." Eventually Paul was diagnosed with bi-polar disorder as a young adult.

In some families, things took a dramatic turn that left parents searching desperately for a

medical solution. Rebecca recalls how she and her husband Dan literally drove cross-country, from the Midwest to Northern California to find their son Will, who had gone missing for a week from the university he was attending. Eventually he was located hundreds of miles from the school.

> *Rebecca:* Okay. I remember it like it was yesterday. It happened in the fall, and we received a call from my son, (Will's brother) and actually he had disappeared for about a week, and we couldn't find him. We later found out that he had gone to a pot farm in California or somewhere on the coast there, and he was asked to leave there. It was the first time he was in mania, although I didn't know it at the time.

Rebecca and her husband picked him up and drove him back home, stopping several times on the way in hopes of getting medical treatment:

> *Rebecca:* All of the sudden Dan saw a hospital, so he drives to the ER, and Will's like, "What are you doing dad?" We didn't really have a plan. We didn't really say anything, and he goes, "Great. You guys need the hospital," so he goes marching in there, sees a security guard, and he's like, "I'm glad you're here. You need to arrest my parents." Then he bolted, but they had cameras and were watching. They had safety officers at the time, and they were able to locate him in the parking lot, and they did bring him in. That was the first hospitalization.

> Like many mothers of children with disabilities (Green, Darling and Wilbers 2017),

several parents who participated in this study reported feeling blamed by others for their children's behaviors. Mary discusses how her family members interpreted her son Randy's behavior, which she describes as being "not normal" from a very early age.

> *Mary:* They would see the "normal" periods, and then the "not normal" periods, so they ascribed it to (Randy) being spoiled. Their explanation was that we, mainly me because I was a stay-at-home mom, were not good disciplinarians. That was their assessment of the situation. At the time, my dad said, "What the kid needs is a good spanking."

Mary experienced mother-blame when what she needed were answers, not accusations and criticism. Under such circumstances, a diagnosis and treatment may be sought to provide relief from blame, but even after a diagnosis, parents may continue to feel blamed by others. For example, Eric, whose twin sons were both diagnosed with bipolar 1, talks about how his

extended family simply did not accept the idea of a "mental illness," instead attributing his sons'

behavior to "bad parenting."

> *Eric:* We never really hid the fact that these boys had bipolar. My sister and brother in law, they had an entirely different outlook. He just had bad behavior. There was no… they didn't see it as a disease or illness, it was bad parenting, things like that.

We can hear the frustration and exasperation in his voice as he describes the family's lack of

understanding, even after a diagnosis had been made.

Parents also described going to great lengths to find the right professionals to provide a

medical diagnosis and treatment for their children. Mary, for example, says:

> Then, we got a referral for a child psychologist, and we only went with those that were highly, highly recommended. We interviewed 3 or 4 before we ever chose one, we never went with the first available within our (insurance) plans. The internet wasn't really big back then, but we scoured psychology magazines, the best of the best, and tried to get one in the this area, which we assumed were some of the best in the country to choose from.

Finding a service provider, even one thought to be the "best of the best" doesn't necessarily lead

to effective treatment or a clear cut path to "normalcy." Mary goes on to say, for example,

> We met a child psychologist when he was maybe 4 years old. We saw this guy for 6 months, and he had no clue. He didn't know what it was. He thought maybe it was Tourette's syndrome. He said he's never seen this before. We were keeping journals of behavior, but it was just a constant for me to keep a journal. We tried behavior modification but nothing seemed to really click. He didn't know. You get to the point, 4 or 5 years old, we were all overwhelmed physically. We had another baby, and Randy was really not right with the baby. We felt like we were living in high alert all the time, trying to protect the baby from the 4-year old.

After many years of parental "high alert," Randy was eventually diagnosed with depression as a

young adult.

Eric describes a very scary situation in which his son was prescribed medication that was

inappropriate for his eventual diagnosis of bipolar I.

> We took him to this psychiatrist and he saw her for a while and he was having these outbursts where he was out of control, basically, and she prescribed him Paxil. Anyway, we gave him this Paxil. Giving an antidepressant or whatever to somebody that has bi-polar is an absolute no-no and he just went off the rails. I mean, you couldn't do a thing

with him other than just hold him tight so that he wouldn't hurt himself, wouldn't hurt somebody else in the house. That right there, to me, was concrete evidence saying he really has an issue. And then, you kind of get in to the feeling of being sorry - sorry for him, but you're kind of sorry for yourself - it's tough.

The chaotic period of searching for effective treatment can be extended. Responding to my question about the amount of time between when they first noticed Randy's "not normal" behavior and his diagnosis, Mary says:

Let me think, probably about 2 years because it was somewhere between treating him and there was all kind of other stuff in there, you know how it is, all kinds of trips to neurologists, blood work, and all that kind of stuff. I would say about 2 years, he was about 3½ when we first took him, and he was in kindergarten when he started on medicine…

Even when parents find service providers who are confident in their diagnosis and recommendations for treatment, the treatments they prescribe may not be acceptable to the child. Alissa whose son Ron was first diagnosed with social anxiety disorder, then later bi-polar I, spent years attempting to get her son into treatment. It wasn't until he was in high school, and was really feeling his social anxiety, that Alissa was able to convince him to undergo an assessment. He was still years away from agreeing to treatment:

Alissa: Ronny did go through with the assessment, and he was diagnosed with anxiety and OS (other symptoms) not specified. They wanted him to work with a psychologist there. It turned out to be not a good fit. Ronny did go to counseling maybe once or twice, and they did start him on a medicine. So the doctor said I want you to come back in 30 days and tell me how it went. So, Ronny went back after 30 days of taking this antidepressant, and Ronny said it didn't work. The doctor explained that sometimes you have to experiment, and he could try another one. But, Ronny did not want to try another one. So at that point, you know, you can't force him to swallow meds, so it just dropped after that. He wasn't willing to go any further. So by the time Ronny graduated from high school we didn't know what was going to happen. You know, here's this kid in the basement all the time.

Sometimes there are good reasons for people diagnosed with mental illness to resist medications. Side effects can be very problematic. Heather, for example, describes her son Bo's experience with a series of pharmacological drugs.

Heather: He was on Lithium and Abilify. At first, they gave him Risperdal, too. Really, it took away all his creative abilities. He was like a shell of himself. He had an issue with swallowing, so they gave him another drug to combat that issue. He didn't get the tics, but it was something about swallowing. And that was side effect of the Risperdal, at least that's what they said. But the Risperdal, then, they took away because of the swallowing. It was when he was out from under our roof again when he went off his meds, and when he did it, he did it cold turkey. He hated them.

Like so many other parents, we can hear the frustration in Heather's voice as she describes seeing her son struggling with medication side effects.

Medication compliance varied widely in the stories parents told, both across time and between children. Jeanne, who is the mother of twin boys both of whom have been diagnosed with bipolar I, describes the very different experiences she has had with her two sons:

Jeanne: I have four children and my middle children are identical twin boys. Both suffer from Bipolar I. My son, Jon, was diagnosed when he had his first and really only episode to this point when he was 15. He was hospitalized for probably about a month and we pulled him out of public school and put him in a therapeutic day school. Jon has always been completely medication adherent, which is shocking but true, he just turned 26 and he's pretty high functioning. He has two jobs, he has a girlfriend, he has an active and good life. His identical twin brother's name is Joe. When Joe was 21, he had his first of several psychotic episodes. He's been hospitalized maybe three or four times and the medication adherence with Joe has been different. He hasn't always been adherent. Joe suffers from more depression than we've ever seen with his brother and we've seen him go through one bought of very serious depression.

While all of the stories told by study participants involve initial anxiety and confusion about how to get help for a child whose behaviors are interpreted as "not normal" and the "try, fail, try another drug" cycle is common among these stories, some participants also told success stories in which children became medically compliant over time. Lauren and her husband Dave, for example, said that their son James is doing well some 27 years after being diagnosed and treated through the VA. Lauren recalls the early days of James' treatment for symptoms that first occurred while he was in the army:

Lauren: We were very fortunate because this doctor was involved with the county health department, the major local medical center, and a really good VA hospital. Luckily, James' first symptoms began when he was in the army, so he got into the VA hospital.

There was a little trial and error with medications, so this doctor finally said the only way to do this was to put him in the hospital for a period of time to see what medication works. He had tried so many different ones that did not work. James stayed at the VA hospital (4 months) while most hospitals today will only keep you 10 days and you're out. You can't change medications for just 10 days to find the right one. It was the VA hospital that saved his life. To this day I thank goodness he was a veteran, otherwise I don't know what would have happened.

When I asked Lauren why she thought James had been so reliably compliant with his meds all these years, she said:

Well, you know I think when James was told this medication you are going to take the rest of your life, or you're gonna die...and the fact that he did try to take his life twice when he went off meds early on...I think he thought that it was very very true. So now he goes and gets his medications every week, we never have to remind him.

It may be that the structured system of support and authority provided within the VA hospital was effective in convincing James to accept the medical diagnosis and recommended treatment. Mary also feels that her son Randy has benefited from social support, though from a much less structured source. Mary feels that Randy's success in living well with his diagnosis is due in part to his ability to monitor his own moods and to a supportive group of friends.

Mary: From 16 to 26, he is toying on and off with medication, and we don't know if it's bipolar, or just cycles of depression. But he knows himself very well now. He can feel when one's coming, and he knows what to do. He has a very good group of friends that know him well, and they know exactly what medication he takes or doesn't take. If something's up with him, he knows they'll be there for him in the middle of the night or any time of day if he needs something.

Heather shares the story of how, after literally years of denial, her son Bo was eventually lead to understand and even embrace his diagnosis during an emergency room encounter with particularly sensitive medical staff. After much maneuvering, Heather and her husband got Bo to the emergency room. Here is how she describes Bo's positive reaction to the encounter:

Heather: I stood in the background and the nurse looked at me, and I just mouthed the word "manic" to her, and she just let him talk, and they took him straight in. My husband and I sat out on in the waiting room until they came and got us. It was a full hour and a half. When they came out they said, "Bo would like to see you." He had been crying and said to me, "Mom, someone just explained my entire life to me. Someone just explained

exactly how my brain thinks." We were lucky. But I think it was because we didn't pound in the idea that we were going to have his brain checked out, you know what I mean? And so when they went about it in a backdoor way and described feelings and things, how he saw and viewed things, he just started bawling. He was just like, "Mom, I thought I was the only person in the world that thought like this." It was mind blowing.

Heather attributes Bo's revelation to "luck," but clearly it was also the result of years of love, patience, and hope.

In summary, this first theme encompasses stories about attempting to find a way out of chaos through medical diagnosis and treatment. Parents describe many barriers to success in these stories including blame (particularly mother-blame), difficulty finding competent medical services, problematic treatment side effects, and resistance to treatment from children diagnosed with mental illness. These are the villains in their stories. The chaos of the "searching for treatment" period is described as lengthy and exhausting by most participants. The heroes of their stories in this theme are the friends and family members who provided understanding and support and professionals who were able to connect with their children in ways that led to medically compliant behavior. Eventually, families moved beyond the searching stage and began to live within a new reality that includes a mental illness diagnosis for their child. The next theme describes the ways in which families talk about navigating this new reality.

The Need to Support and Advocate for Their Child

When a child who was previously perceived to be "normal" begins to exhibit unexpected behavior, parents may have a difficult time accepting the idea that their children are now different from what they expected them to be. Most often, the new reality does not hit home until some diagnosis is made, medications are tried, and some form of therapy is attempted. During the initial chaos of searching for treatment, parents may persist in the belief that their child can be "restored to normal." Over time, a new realty settles in, and parents are forced to make some decisions and figure out how to tell new stories about family life that are acceptable to

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themselves and others. Will they love and support this child, whom they are now coming to understand is not the person they thought they knew? How far are they willing to go in protecting, advocating, and supporting this person? Almost without exception, parents in this project fully embraced this challenge, despite not truly understanding the nature of the new relationship they were about to enter into with their child.

Alissa talks about navigating life with her adult son Ron, who had been diagnosed with social anxiety disorder at a young age. As a young adult, after manifesting more disturbing symptoms in high school and his first attempt at college, Ron was subsequently diagnosed with bi-polar I, and was put under the care of a therapist:

> *Alissa:* But long story short, while Ronny was home he was still isolating in the basement. Smoking pot, of which we said you definitely cannot do this in our house. So, there was definite tension. He's be up all night, sleep all day, and I'd be the one making the appointment with a counselor in the area. There was clearly, you know, he had no desire to go. It was all, you know, me doing it. And what I learned during the process of doing this was, well the counselor said to me, this is going to take about two years. And all I could think was two more years with this kid in my basement, basically doing nothing. Gaming, staying up all night, not going out or anything.

Despite Alissa's own anxiety about how this situation would play out, she and her husband persisted in supporting their son. Eventually, that support was rewarded when Ronny returned to college, earned his degree, and is now working full time in the field he has chosen:

> *Alissa:* At that time Joe (Alissa's husband) and I were even thinking about writing up contracts, like in order to live here you are going to have to get a job, and so on. I have a really strong faith so I prayed. A lot a lot of praying. I will say, at about the two year mark, Ronny made this announcement that he was going to go back to college. We wanted to make it clear that we financially were not going to help him do that. And, so he went back to online (classes). Through that time he finished. He graduated.

Alissa credits Ronny's success in part to the social support and encouragement he received from his girlfriend. She says:

> I think that his girlfriend had a lot to do with that because she was just kind of like take baby steps, you know, so it wasn't this big push, and he had someone who loved him, you know that kind of a thing. And I will tell you, the day after he graduated he go a job

as a computer science analyst. He just got married a year ago, and they just moved into their house, and that's kind of how Ronny's story ended.

Dave also describes the importance he attributed to the promise of social support in a crucial moment as he tries to convince his son James to accept a voluntary commitment to the VA mental health unit that would ultimately last over four months. This conversation took place while James was in the throes of a series of psychotic breaks. A lengthy commitment was thought to be his only chance after weeks of experimenting with a variety of anti-psychotic drugs:

> *Dave:* Well one of the things that we did, which was smart, but quite by accident. I told him, I say's listen, someone in the family will be there every day to visit you. (Here, I can tell that Dave is getting overwhelmed emotionally. He slows down his speech, he takes several deep breaths, and his voice begins to crack). And of course that happened. And the nurses would tell him how lucky he was to have a family that cared enough to come visit him (voice still cracking) every day. Someone was there every single day for 4 months while he was in that hospital. Might have been a brother. Might have been a sister, or my wife, or myself, but someone was there. As I said before, I was traveling for work a lot, so I couldn't guarantee that I would be there, but that someone would. Eventually they finally found the medication that would satisfy the situation. And he's been on the same medication ever since.

Dave felt that he needed to convince his son that this plan was the best course, and that a daily visit from a family member for over four months would be the ultimate show of support. Similarly, Jeanne talks about the importance of family support in the lives of her twin sons with diagnoses of bipolar 1:

> *Jeanne:* Everyone's always been very supportive. When both boys had their episodes my daughter and my youngest son both witnessed it, so they know how undeniable it is and they've always been super supportive, so has my husband. Well, of course there was emotion, but I used my intellect, my resources, my energy, and I made it a big part of my life. My husband and I are big advocates for the boys and I think that's a big reason why they're doing as well as they are.

Most parents with other children talked about the tremendous support for these children have displayed for their siblings. There are, however, exceptions both within and between families.

Maggie describes her frustration at how some of her other children have reacted to her son Josh's behavior:

> *Maggie:* We also talked to his brothers about it. A little less supportive. We have to remind them that Josh has a mental illness. Something that's happening inside him. They're like, "he's just smoking pot. Quit the shit, go back to school and be normal." Well, that's not going to happen (laughs). And Josh's reaction is, I am normal, I just have issues. So the one that has issues is speaking intelligently, and the other two are a pain in my butt in trying to keep the family together.

For some families, a big part of the acceptance and support they show for the member with the mental illness diagnosis is evidenced by stories about willingness to deal with anticipated stigma. The idea that mental illness is one of the most stigmatized conditions in our society is well known far beyond the halls of academia. Our respondents may or may not know anything about Goffman, Link, or Corrigan, but they do understand their loved one may be shunned by other family, friends, or neighbors, and that they may also be subjected to the stigma associated with being "bad" parents. Recognizing the potential for stigmatizing reactions from family, friends, and neighbors became a significant challenge for some parents. For others, reactions from siblings, extended family, and friends to their child's diagnosis came in the form of acceptance, support, and encouragement.

Mia describes how Paul, her son, refused to let anyone know what was going on with him. He anticipated, through his own self-stigma, that others would look at him as different and less valued because of his mental illness:

> *Mia:* In the mentally ill world, having anybody with any sort of aggressive behavior, is just gonna get someone kicked out of all facilities. So, he was constantly being kicked out of the facilities, which caused additional stress. Him not being in recovery, him not feeling well about himself self-esteem wise, and creating conflicts between relationships. Simultaneously, Paul's symptoms were starting to get worse. With his bipolar diagnosis, his moods were worsening. Because of his own self-stigma, he was not one to go seek out any additional support, or help, or therapy, he didn't want us speaking about it to anybody. It had been a household secret of what we had been managing on a regular basis.

Alissa explained how her son Ronny was "different" from his brothers, and how that difference

manifested in being treated negatively by kids that he had grown up with. In Alissa's opinion,

this became a significant roadblock due to his fear of stigma:

> *Alissa:* My other two sons are athletic, and Ronny is not. So, there was a difference there.
> So, Ron being more introverted, very bright, mechanically oriented, the other two not.
> My middle son wrote a paper about bipolar disorder because he knew about my mom. He
> knew her before she died, and they loved her to pieces. I don't know why Ronny
> wouldn't have been more receptive. You know, he used to complain about stomachaches
> in the morning and I asked him about that much later. And he said the reason he didn't go
> was because, well he did know the kids, they we were in the same school district their
> entire lives, but he just didn't want to be different. (If not for the fear) he would probably
> be in a better place now.

Alissa is clearly distressed with the knowledge that Ronny might have lived a better life, and

would be in a better place were it not for his fear of being stigmatized.

These examples demonstrate that it is not uncommon for individuals and families to be

wary of the stigma commonly associated with a diagnosis of mental illness. Not all families have

the experience however. Lauren and Dave, for example found that their son James' diagnosis had

a positive effect on the family. The youngest of six children, James immediately received strong

support from his parents and siblings alike as they undertook a daily four-month vigil at his

bedside while he was hospitalized. Dave says that, in the intervening years, James has become,

in a way, the "favorite son." When asked about James' long-term outlook, thinking about what

happens to him after they are gone, the fact that the family has rallied around James gives Lauren

great comfort:

> *Lauren:* Well, we have an attorney that deals with special needs trusts. What we found
> out was that we would have to appoint someone who would be willing to take care of
> James, more or less, after we are gone. At the time we looked into this we had two sons
> who were bachelors, and they both said that they would make sure James was taken care
> of. Since then one of them got married, and I asked him, what if your new bride didn't
> want to have anything to do with James? He said well then I wouldn't have married her.
> (laughs). The other son said that he would take care of the paperwork that is involved,
> and another one can take care of the social part, so they said they would take care of him
> as long as they are alive. We are blessed because he has so many siblings. I think in the

long run it's brought our family closer together. I think, you know, of the ones who have stepped up to the plate and promised to take care of James when we are gone. (describes where all kids live) and whenever anyone calls the first thing they say is how's James doing? If anything, it's brought our family closer together, rather than caused a separation.

These stories suggest that some parents can, and do, adopt a patient, supportive, and protective attitude toward their child, despite the realization that their child is not the person they knew.

Finding Family Equilibrium

In this project thus far we have focused primarily on the relationship between the parents and the child that is now living with a mental illness. More broadly, the dynamics of the family are potentially impacted by this sudden, unexpected change in a family member. Like any other disability, when one family member's needs require a greater focus, usually demanding attention in terms of time, and often money, other members may be required to adjust to an entirely new set of relationships. How did the parents in this study facilitate these adjustments in their family? Were they able to maintain some sort of equilibrium, or do these events serve to change the ways the family functions, for better or worse? Of course, in some instances the family may already be dysfunctional, perhaps even contributing to the development of the illness.

Winona describes an unusual situation, in which she has two adopted daughters, both of whom have been diagnosed with a mental illness. Mandy, the older daughter obtained a dual diagnosis of substance abuse and persistent traumatic stress disorder (PTSD) after serving tours of duty in both Afghanistan and Kuwait. Patty has been diagnosed with an eating disorder, and obsessive-compulsive disorder (OCD), and Winona also refers to her as a "hoarder." Winona describes a "terrible jealousy" between the two that has been a factor in the family for many years. Both are now adults. Patty lives with Winona and her husband, Mandy has been on her own for many years. Notwithstanding all of the discord, Winona claims to have "a close relationship to both of them." This example is illustrative of the idea that families, even within

the dynamics of existing conflicts, can somehow reach a point of equilibrium that enables

individual relationships to remain intact. In this exchange Winona talks about how she and her

husband have arrived at a place she seems comfortable with:

> *Winona:* Patty is seeing a counselor. She has seen the same counselor she did when was hospitalized, who has been a godsend. And we have a wonderful relationship with her. We don't know what they talk about, but when we see a problem, we call her and leave a message on her phone and things are better within a couple of days. And she gets meds. My husband manages that. She takes Trileptal that does wonders for her. It helps her with her impulse behavior. We tried to reduce it because she's going to be promoted to assistant manager of Goodwill, which we're just thrilled about. The doctor thought it would help her to concentrate if she reduced that, but then she started getting angry and doing the same kind of antisocial things. The Trileptal just does wonders for her.

> *Interviewer:* So, it sounds like your husband is pretty involved in this as well. Would you say you share the load equally? Is he also a trainer at NAMI?

> *Winona:* Yes, we have class together, and we've gone to all the NAMI support groups together.

> *Interviewer:* So basically you're fifty-fifty on all of this? That's not always the case, as I'm sure you know.

> *Winona:* We weren't always fifty-fifty either, but we all get wiser.

Winona does not say it in so many words, but the implication from this story is that the mental

illnesses these children developed motivated Winona and her husband to band together in

seeking help. They eventually found comfort in working with each other teaching classes for

NAMI, and they have developed separate but equally satisfying relationships with each daughter.

In another example of a family finding equilibrium through discord, James talks about

how his son Will is attempting to rebuild a relationship with his younger brother, Dan, who has

not fully accepted the idea that Will is "sick." First, James describes the relationship, and how he

and his wife are trying to deal with it:

> *James:* Okay, really his brother has been slow. Of course, he's a young adult in college himself at the time, and even though he's seen the worst of him, his denial is much stronger, or has been, to the point where he thinks that it's our fault because we give in too much, we should be hard knocks and that's it. That's a hard thing to do, to decide if you're gonna do the enabling or empowering, which part you're gonna do. We were constantly stirring that, trying to make the right decision. That's what people come to our

support group or Family to Family for. We always try to let them know that their decisions are the best ones being made because everybody has a lot of guilt over that. He's (Will's brother) been slow to come around with it, he doesn't actively, first-hand help out, but we're not shy of communicating with him what's going on. I think, over time, he's come to understand that it is a serious thing, and it's real. But it's taken him a long time to come to terms with it, and not be in denial on it, but I think he's better now.

James and his wife Rebecca are sensitive to what Dan is feeling. They understand that they can contribute to helping Dan accept Will's situation. At the same time, James and Rebecca have accepted their role and, like Winona and her husband, are making the best of this by working for NAMI as trainers in the FTF program. As James talks about Will's future, it is clear that he has concerns, but he also seems satisfied that Will is doing what he can do, and that they've done the best they can to help put Will in the best possible position to succeed in life.

> *James:* So the thing that I think is very fortunate with (Will) that he responds very well to medicine. I meet people that struggle, never find the right thing. I'm not saying he's found exactly the right thing yet. I think that's the magic pill, perse, and no pun intended, but they need to work with the doctor closely to get that dialed in, and he's not quite to that point, but I think the medicine that he's on right now is the best he's ever been on. He's on latuda and lithium, and we're getting through the fall without him in total mania. He's very level, and level-headed thinking, and he's gonna be starting a part-time job tomorrow, which is great. He's on this disability now, and when they did the disability, we got the ruling and everything from the judge, and they read that, and it's a real thing. So I think his life is completely different than it was, then what we'd thought it would be 8 years ago, 7 years ago, and I think he thinks the same thing, too.

Despite this recognition that recovery, if it comes, is not a right away thing, James seems to feel confident that with continued medication Will has a future to look forward to.

Liz and her husband Eric have two sons diagnosed with a serious mental illness at extremely young ages. John, now 29, was first diagnosed with bi-polar disorder at about 8. His younger brother Bobby was also diagnosed with bi-polar at about 6. Liz describes John's behavior in much darker terms than Bobby's. After many, many very stressful years living at home, actually experiencing verbal and physical abuse from John, Liz finally demanded that Eric force John to leave their home. Bobby, who was far more docile and accepting of his diagnosis,

is still living with Liz and Eric. Their journey, while emotionally and financially difficult, has

brought Liz, Eric and Bobby closer together. John is with a partner and living an independent

life. He refuses to accept his diagnosis. Liz remains wary of John and his partner, but welcomes

them to her home on holidays and other family occasions. Responding to my question about her

assessment of Bobby, Liz reveals a very satisfying relationship with her younger son:

> *Liz:* Oh, yeah. He says mom, if John would just admit the he has bipolar disorder, and if he would just take the medication, he would be ok. He really is insightful. He's just such a different person. I think he could really go places. If you could get the support, or someone could mentor him. I don't know. Where are they going to be in 20 years, we just don't know.

> *Interviewer:* Right. I'm getting the feeling that...you know you and Eric are just so wrapped up in this. It's such an overwhelming part of our family experience, it's got to be really hard to detach in any way and have your own life. Is that a fair statement?

> *Liz:* Yes. But, it's so much better. Again, John does not live at home. We're not "responsible" for him. It's up to him to figure it out. We're here to help him, but...and if he were to fall apart we wouldn't say it's your problem. Maybe it's partly because I'm no longer being abused by him. When he was home, it was a very abusive situation. It was such a high level of stress and anxiety it was ridiculous. Over the past few years, with the help of Bobby's therapist, I went back, I teach pre-school, I'm teaching piano. I am kind of doing my own thing. It's been very healthy. I've not been as available. You know, in the past he would get very angry when I wasn't available to him at all times. So, at one point I just decided, I've gotta live my life. It was very freeing. I'm better at…well he's going to be mad, so let him be mad. I don't have to try and change it. In the past, I owned a lot, and now I don't.

> *Interviewer:* That's great. That sounds healthy. Now the last few questions. Do you attribute these changes to your own growth, or is more about just not having the same level of responsibility for John?

> *Liz:* You mean like not being sucked into the drama (chuckles)? I think so. Because when he was living here, and not working, and ruining his room, and, well even if it was behind a closed door I was constantly angry. Because we were letting him get away with doing nothing, and we were working our butts off. Of course when they're little we support them in all ways, emotionally, monetarily. But, at some point it's like ok, you're an adult now. We can't support you without you being a part of it. So yeah, it's probably some of both.

> *Interviewer:* You've been there. What advice do you have for people in that situation?

> *Liz:* OK. So, I tell people, the biggest thing is that they (the parents) need to be on the same page. That is what we were missing for a very long time.

Liz's life is much better now that John is no longer under their roof. While this is not a utopian world they occupy, the family has reached a kind of equilibrium. In her own words, it took a very long time to get there, but it is satisfying nonetheless.

Like so many other stories, Heather's experience with Bo has been a roller coaster ride. Over the past 10 years Bo had gone on and off his meds numerous times. On the meds he has been functioning well, attending college, and living alone in the city. Off the meds he is unable to manage his life, and tends to wind up back at home. Recently, Bo seems to have stumbled on a situation that offers Heather real hope:

> It is frustrating and that's exactly how he is, he gets to the point where he's feeling really good and it's like why do I need this anymore and go off. But this last episode that he had, he ended up in three weeks of outpatient therapy and he got a brand new psychiatrist then, and this psychiatrist gave him something out of the box, or I should say, off label. So, the second day, his dad and I were out, and we got a text from him that said, "Oh my gosh, Mom, it's like somebody just gave me eyeglasses for my brain." Those were his exact words.

After such a revelation, Heather and her family have reason to think that Bo is on the right track:

> I'm guardedly optimistic. I'm not 100% there yet because, this will be the first fall in the past five that we have not had incident. It's always September/October. He has landed back at home seasonally, September/October, and his initial break was October. He wasn't hospitalized every year, but every time there was an episode, it was in the fall. So I say guardedly optimistic because when he left in January for this job we made a pact that if he was still taking his meds (she describes how they confirm this) by June, which was six months almost to the date of his birthday when he turned 31. That instead of him coming to visit us, we would come to Cali so he could show us the ropes of where he works, where he lives, what his daily life is like, and that's exactly what happened.

After experiencing such a dramatic transformation, Heather laughs as she lightheartedly recalls thinking, "where's my kid and what did you do with him." Of course things may go off the rails again, but for now the family, and their individual relationships are intact, despite many, many years of turmoil.

Melinda, who we were introduced to at the very beginning of this project, has also experienced many, many, years of frustration, tension, anxiety, and strained relationships. She

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and her family, however, have maintained a strong, resilient, and persistent position of support, and advocacy for their son Gary. You will recall he was initially diagnosed at the age of 18 during his freshman year of college. Now, 18 years later, he finally seems to have reached the point at which he is open to accepting his diagnosis, and to the idea that he can enjoy a happy, productive life by staying on his meds. We hear the resolve in Melinda's voice as she describes the tenacity with which she and her husband worked to maintain family relationships as they supported Gary. Here she is responding to a question about how Gary's sister was dealing with Gary.

> Oh, over the years it was very hard on her because he was so self-centered. So, all the attempts to keep a good relationship and be supportive have been on our part. I mean you could never count on him, in any family situation. You know it was one sided. Like, you could count on us, but we really couldn't count on you. And, you know, that's painful. You're like, what the hell. But, like he's got the illness, you can't give up. You know, we've all got more enlightened perspectives now. We always knew he had to be accountable. We always new it had to be a two-way street. But, we always had to be supportive. So, you know, you just keep doing it. And you keep thinking this will be the silver bullet, this will make the difference. And, here I am saying, well, maybe this time will make the difference.

After a frightening incident where Gary set his apartment on fire and was arrested, he was sent downstate for a court ordered rehabilitation. We hear a mixture of sadness for Gary's lot in life, and optimism about the possibility of a real breakthrough in Heather's voice:

> We still don't know the reason. I mean it was definitely on purpose, but I don't know why. I took it as a sign that maybe… I'm ending my life…getting rid of my belongings. I don't know. (Heather then describes Gary's journey through the criminal justice system over many months. I (sigh) didn't think we'd ever see our real son again. (At the new facility) he had two really invested, experienced, engaged social workers working with him. The stay there is minimum 3 to 6 months. And also we were concerned because they don't mandate meds, but he agreed to take them! I'm sure they got his buy in by saying, you know, you'll be here forever. So, he started to respond to the medication. They've got him reading, they've got him exercising, and he's due to come back to the local hospital tomorrow! With an after-care program like one I've never seen. So, here we go again. We've got hope. And I've had conversations, and my husband's had conversations with Gary that we've never had in his life with him. Well, for the first time he is taking accountability for what has happened, and what will happen in his life. That he is in charge of it, and we are supportive in a perimeter role as family members, only if he's

taking the right steps for good health. (Her voice shakes a bit here). I think he finally understands the magnitude of what he has done, and how it affects his family negatively. The people he's been working with have, you know, broken through. Maybe God's plan was that it had to get this scary. I don't know. You know (excitedly) I said to the women working with him, "we might have maturity on our side finally."

This heart-wrenching story is exemplary of the stories of resiliency, patience, and hope that their child will someday come back to them that were told by the participants in this study. In these stories, parents may or may not have the child that they once knew, but they persist nonetheless in creating some sort of family equilibrium, while supporting their child through the frustrating, frightening, and chaotic experience that is mental illness.

Discussion

I began this project inspired by an idea articulated in Linda Roses' (1983) observation about a diagnosis of mental illness: "A family's effective adaptation to such an event is associated with making clear what appears incomprehensible, managing that which feels out of control, and finding relevance in confusion." What does adaptation actually look like for families suddenly dealing with a diagnosis of mental illness? What are the themes common to families in this study? Through these interviews I've seen how families can effectively adapt to their new circumstance through seeking treatment for their child, supporting and advocating for them, and doing whatever they could to foster a sense of optimism and promise within the family.

A diagnosis of mental illness can be traumatic and life changing for both the individual and their family. The research in this area is abundant, and well documented. What is not as common in the literature is research on how families have dealt with these circumstances on a day in and day out basis. How do families come to terms with this stressful situation? How do families find the ability to manage circumstances that are totally unfamiliar? And, how do they find relevance, in other words, value and meaning, in relationships that have become distant, strained, and sometimes frightening? My participants told stories that left me in awe of the

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strength that these families possess, and in their ability to rally around a wounded member - not always, but most of the time.

There are certainly limitations to this study. The participants in this research are all white, middle class American citizens and parents of the individual who was diagnosed with mental illness. Therefore, results of this research are not generalizable to the broader population of family members experiencing diagnoses of mental illness. Would the experiences recalled by same sex parents, parents in families of color, or parents of families in poverty without similar resources and access to care be different? What about the very wealthy? Would the recollections of siblings, grandparents, or other family members be different from those of parents?

Furthermore, all but one participant is, or has been, an active member or employee of NAMI and therefore may have been to some degree indoctrinated into the NAMI narrative of medicalization. Findings of this study, combined with those of the previous chapter, indicate a powerful relationship between the narratives NAMI produces and the stories these parents tell about their experiences with mental illness in the family. Perhaps a similarly constructed project with a more diverse group of families not affiliated with NAMI would generate very different results. There is clearly a need for a great deal of further study among populations representing different gender identities, sexualities, races, ethnicities, social strata, and exposure to NAMI to see how widely the cultural narrative of mental illness that is promoted by NAMI has spread.

My positionality within this population and my lived experience may have been both help and hindrance throughout this process. As noted above, my history as a NAMI volunteer and ally helped facilitate access to these families. My personal story may have helped my participants open up to me. On the other hand, it was difficult for me to remain totally detached and objective while conducting the interviews. Did I get the real story, the "truth," because of my familiarity with their stories, or would a more detached, dispassionate researcher have been able to dig

deeper? We can't know the answer to these questions. This project hasn't been about discovering the "truth" about the experience of mental illness in the family. Rather, it explores the kinds of illness stories parents tell about the experience within a very particular context, an interview with a fellow parent known to have shared both the experience having a child diagnosed with serious mental illness and known to have participated in NAMI as a volunteer.

In Arthur Frank's *The Wounded Storyteller* (1995) he refers to serious illness as a "loss of 'destination and map' that had previously guided the ill person's life," requiring them to construct a new relationship with life and the world. So it is with serious mental illness. While Frank focuses on stories told by people who are ill, both my own experience and the stories told by my interviewees suggest that parents of people diagnosed with mental illness also experience a "loss of destination and map" and engage in a re-storying of family life. The three narrative forms Frank describes: The restitution narrative, the chaos narrative, and the quest narrative, are all found in stories about mental illness in the family, and were also helpful to me in reconstructing my own.

The plot of the restitution narrative is: "Yesterday I was healthy, today I am sick, but tomorrow I will be healthy again." The heroic character in this narrative is the remedy (the drug, or the physician, the self-help group) that enables the storyteller to return to health. The chaos story is the direct opposite of the restitution narrative. In it, the storyteller can't get better and suffering is all there is. In quest narratives, suffering is met head on, accepted, and used for personal and collective transformation (Frank 1995). The restitution and chaos narratives were found to emerge in both the NAMI narrative analysis (chapter three) and the family interview thematic analysis found in this chapter. I address the quest narrative in the Postscript found in chapter five.

The NAMI narrative that mental illness is a medical condition that can be diagnosed, treated, and to some degree managed, if not cured inspires stories of restitution. The stories included in Theme 1 of this chapter suggest that the first impulse of most of these families was to get medical help to manage symptoms and reduce chaos. For many, accessing information from NAMI provided a palatable path forward. By employing medical terms such as "treatment," "symptoms," and "diagnosis," among others, the medical narrative of mental illness creates for the family a recognizable framework within which they can come to terms with their children's behaviors and experiences. There are concrete steps to take. Symptoms need to be diagnosed by a medical professional. Treatment protocols need to be determined and followed. Other forms of therapy may well be forthcoming. This readily recognized medicalized framework not only helped families navigate through the chaotic early days of the experience, but it also offered hope that a restitution narrative in which the child and family return to "normal" might eventually be told.

The medical narrative of mental illness that NAMI tells was overwhelmingly accepted among the parents who participated in my study. In nearly all of my interviews, participants talked about how the information they received from NAMI, often through its website, was crucial to their understanding of what they were dealing with, and what they should do about it. Their understanding of the NAMI story was that medical intervention would stop their child from acting "crazy," giving them time to do the research needed to identify long-term strategies and resources. The parental desire to care for and "fix" their children was powerful, and NAMI provided them with a way to readily understand what was happening in acceptable terms. The problem, of course, is that this narrative, like all organizational narratives, is too simple to represent real life experiences.

In the stories told by my participants, it became clear over time that "restitution of normality" wasn't possible and that chaos would be an intermittent aspect of their lives at best. They told stories about learning to navigate a messy social and emotional environment. They also told stories about advocacy and support for a child that had become, most often, very different from the person they once knew and loved. Accompanying the desire to advocate and support, were other complex emotions such as anger, sadness, resentment, and fear. Stories in Theme 3 indicate that families came to understand that there was a much longer game that needed to be played that did not conform neatly to the sick today, well tomorrow expectations of a medical restitution narrative. Social support played a key role in stories in which parents worked tirelessly to try and pull their families together though repeated chaotic crises. Parents told stories about steadfastly dedicating time, emotions, and financial resources in an attempt to find a path for their children that would ultimately lead to his or her being able to live a "better" if not a "normal" life. NAMI consistently reinforces the idea that a "better life" is attainable, but not without dedication and perseverance, both of which were evident in the stories parents told.

NAMI's second narrative, that mental illness is highly stigmatized by others, is also clearly reflected in the stories told by these participants. NAMI's story about stigma invites quest narratives in which families join forces with the organization to fight stigma by transforming public opinion through outreach and education. Joining such a quest can feel empowering and most of the parents included in this study had answered this call by participating in NAMI initiatives like the Family-To-Family program. Fending off the fear of social rejection, both for their child and the family by association, was a primary focus in a number of stories included in Themes 2 and 3. Parents were often reluctant to reveal their circumstances to extended family, neighbors, school officials, members of their religious congregation, and their broader social networks.

While the information NAMI provides about the stigma families are likely to face may be helpful in preparing parents for what is ahead, it might it also exacerbate the fear of social rejection. It seems possible that a consistent drumbeat of warnings about stigma and negative social response might leave the family in a precarious position in which they may turn the NAMI narrative of anticipated social rejection into a chaos narrative, an internal time bomb, waiting to detonate. The conflicting storyline that individuals and families are not to blame for mental illness, but will be blamed by the public anyway may be confusing, frightening, and ultimately discouraging for the individual and their families. Could NAMI, by warning readers of the stigma that they are likely to face, be inadvertently discourage families from the pursuit of resources and support in order to keep the family secret? A thorough evaluation of the toll this kind of "family secret" can take could be an important avenue for further research.

In addition, NAMI's medical and stigma narratives are deeply intertwined. The defense against stigma that NAMI proposes is to educate the public that mental illness is a medical tragedy for which individuals and families should not be blamed, as long as they work tirelessly to seek and follow recommended medical treatments, which often include hospitalization and medication. Many individuals with mental illness, as well as Mad Studies scholars and activist are strongly opposed to the medical narrative of mental illness promoted by NAMI and other organizations allied with the psychiatric profession and pharmaceutical industries. They critique the biological determinism of psychiatry and are deeply suspicious of the role played by pharmaceutical companies with financial interests in promoting medication as the preferred line of treatment for mental illness (Menzies et al. 2013).

Instead, they advocate for finding alternative ways to help people who experience mental anguish that are based on humanitarian, holistic perspectives in which people are not reduced to symptoms, but are understood within the social and economic context of the society in which

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they live (Menzies et al. 2013). Another future area of research would be to evaluate the degree

to which less deterministic counter narratives of mental illness like those proposed by Mad

Studies proponents will work their way into the public understandings of what mental illness is

and how it should be managed in the future.

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Chapter Five:

Discussion, Implications, and Limitations

I have a foothold in two worlds. I am the father of two children diagnosed with a serious mental illness. I am also a scholar whose mission it is to further my understanding of the ways that individuals, families, institutions, and society at large respond to people who are living with a diagnosis of mental illness. In both my professional and personal roles I have come to know many individuals and families faced with the difficult task of managing life with a mental illness. I hope to be able to offer unique and valuable insights because of the dual roles I occupy. I have but a single objective: to help to improve the social and institutional response to individuals with a diagnosis of mental illness, and thereby to help improve their lived experience. In this dissertation I take the first steps toward this objective through analyses that operate on three levels: the individual, the family, and within an organization.

This dissertation project has implications for future research, pedagogy, and practice. I employ an emancipatory research approach because my own experience, along with my research have shown that both the individual with a diagnosis of mental illness, and their families, are most often destined to be moved to the margins of society. Emancipatory research, a term born out of critical feminist studies, and later disability studies, seeks to give voice to marginalized populations within academic discourse. As I have shown in this project stigma is, and has historically been a significant micro-level social barrier to those associated with a mental illness diagnosis. I have also argued that beyond stigma, those individuals and their families are certain to face macro-level structural and institutional barriers to a more positive life course; difficulty

finding housing, barriers to furthering their education, difficulty finding jobs, lack of adequate

health care, and so on. Through this emancipatory approach I hope to give voice to those

individuals and their families.

Emancipatory research has its detractors, to be sure. One prevailing argument is that

individuals with impairments may not wish to express themselves in a way that positions them as

"victims of forces beyond their control" (Green 2016). Rather, they may want to express

themselves in a way that highlights their success in the face of such barriers. I chose to believe,

however, that bringing the voices of the marginalized to the attention of both the academic

community, and society at large can enhance the possibility of achieving positive social change.

I began to address this emancipatory goal of bringing the marginalized voices of parents

of people diagnosed with mental illness into the academic discourse on mental illness by making

myself vulnerable through sharing my personal experiences as a father. In Chapter Two, I share

my story of the moment my son disclosed his mental illness diagnosis to me. Autoethnographic

accounts help the author show, rather than simply tell the reader about their experience. In my

story, I bring the reader into the story, sit them down next to my son, and have them experience

the tension of that pivotal moment. Some autoethnographic work is rooted in concepts that are

analytical or theoretical, as a way to explain social phenomena, while others, like *Endings and*

Beginnings…, take a more evocative approach in an attempt to make emotional connections with

the reader (Ellingson and Ellis 2008).

I chose this method because I hope that in making an emotional connection to readers

who are immersed in this struggle with mental illness, and by sharing my lived experience, I

might bring a sense that they are not alone. I believe that those who experience that "moment of

epiphany," when we first learn about our child's illness, can benefit from an understanding that

we are part of a community. Recalling these events surrounding my introduction to Doug's

illness, I felt the fear of the unknown. I knew that mental illness was stigmatized, and I feared that stigma. I, like many others, hid my son's illness from friends and neighbors. I know the frustrations that caregiving can bring. And above all, I know the feeling of loss that accompanies a diagnosis of serious mental illness in a family member.

This chapter holds interesting implications for future research, my own and others, pedagogical practices, and the ways those practicing in the fields of mental health/mental illness might think about their work. Under the umbrella term of standpoint theory, sociologists have long discussed the ways that researcher positionality, be it culturally based, gender based, or race/ethnicity based, may significantly enrich scientific inquiry (Smith 1997, Hekman 1997, Wylie 2003, 2013, Harding 2004, Rolin 2009). A complete analysis of this broad topic is beyond the scope of this paper, but thinking about this work, within the constructs of such a theoretical framework, can give us some insight into what the implications of this work may be.

As a social scientist, objectivity is thought to be an essential epistemological element in research. Standpoint theory challenges the notion that neutrality, a component of objectivity, leads to uncovering of "truth." Neutrality may be helpful in learning of facts, or causal relationships, but some have argued that a keen interest in a subject born of personal experience and involvement allows for greater exploration through insights that encourage expanding the range of hypotheses on a given research topic. In particular, some *standpoints* (as opposed to *locations*) have the especially salient advantage that they put the critically conscious knower in a position to grasp the effects of power relations on their own understanding and that of others (Wylie 2003). Understanding power relationships is an intrinsic element in impactful social science research.

In terms of pedagogical implications, it is not difficult to appreciate how deep personal experiences in a given topic, mental illness and the associated social stigma in this case, might

improve the instructor's ability to reach students. By lying bare his/her personal or familial relationship with mental illness, the instructor gains both empathy and respect for their willingness to be personally exposed in this way. Resistance that might normally exist may be overcome. Trust may be more easily established. Communication is likely to be enhanced. Students are more likely to be open and willing to share their own experiences. All are extremely valued properties of effective teaching.

I do not propose here that this project *will* have a profound impact on all mental health practitioners, social workers, and therapists. As I noted previously however, discussing my past with families of individuals with a mental illness diagnosis has led to a more open, trusting and authentic dialogue about what mental illness is, what impacts it has on individuals and families, and what measures can be taken to begin to cope with these very sad, frustrating, and often chaotic circumstances. If this work can be disseminated to that broad constituency, perhaps it will find an open and willing audience, and help encourage greater and more fruitful dialogue around this important topic. If individuals and their families can be moved to a more open dialogue, that can only enhance the effectiveness of those who are working to help them.

There is more of my son's story to be told. I attempted to sketch in what transpired between us, within our family, and his steps toward recovery over those eight years between his diagnosis and his death. There is so much more to tell. Ultimately, I hope to share the full story with both the scholarly community, and the general public. I believe that by fully sharing my experiences with my son, and his experiences with medical and social organizations, our story can help others who may be going through these same experiences, either individually or as a family.

In Chapter Three, I sought to understand how NAMI, through the narratives it produces, might shape the experiences of individuals diagnosed with mental illness and their families. Two

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overarching narratives emerged in the data I analyzed – intertwined understandings of what serious mental illness is, and how it should be treated. One NAMI narrative supports a "medicalized" understanding of what these diagnoses mean, and what should be done. Another suggests that, while mental illness is medical problem that can be effectively addressed through professional intervention, "society" exacerbates the condition through the many hurdles it imposes on those who have been so diagnosed.

These two stories that NAMI tells are no doubt meant to give the website visitor, whether they be the individual who has received a diagnosis, or a family member, hope for a positive outcome – the "better life" that NAMI holds out as possible. The medical narrative offers a recognizable framework within which the visitor can understand what is to be done, and holds the promise of recovery. The stigma story, on the other hand, may well cause the reader to adopt a sense of self-stigma, which can be damaging to their life chances.

This portion of the research project revealed what I believe to be a significant gap in the research with regard to what I would call the "social model of mental illness." Much research has been done, and many opinions have been voiced, on the topic of stigma toward those with diagnoses of mental illness. NAMI deploys this narrative in its widely circulated educational and public awareness campaigns. Stigma is certainly one barrier faced by individuals diagnosed with mental illness, but there are others. Disability scholars have articulated a social model narrative of disability that shifts the plot from how individual bodies are disadvantaged by impairments to the hurdles faced by individuals with various impairments as they attempt to participate fully in social life. While this narrative has inspired activism, empowered people with disabilities, and inspired policy change that has removed some barriers for people with disabilities, a number of disability scholars have noted that the social model narrative has not been sufficiently inclusive.

Mental illness in particular has been noted as an area in which social model-based

research and activism has been lacking (Shakespeare 2013). I hope to build on this dissertation project with future research on structural arrangements that keep individuals with mental illness and their families from participating fully in educational opportunities, meaningful employment, and the social and cultural life of their communities. Yes, stigma, as represented by personal fears, misunderstanding, and revulsion is a significant problem. However, as a social scientist I hope to do more. Looking to disability studies as a model, I hope in the future to evaluate not only social stigma that exists on a personal level, but also the structural and institutional barriers faced by individuals and their families.

Both the medical model and the social stigma as a social problem narratives serve a needed purpose for the visitor who may be in the midst of a mental health crisis. But, could NAMI do more? While not an observation shared by all participants, several suggested that NAMI could do more to advocate for expanded federal support for certain groups. Currently, according to some, NAMI seems reluctant to argue for more community-based funding, particularly in underserved communities of color. Nowhere on the NAMI site do we find programs and outreach specifically designed to reach people of color. NAMI's emphasis seems geared to promoting and enhancing the position of pharmaceutical companies and the use, some might argue overuse, of prescription medications, eschewing other forms of therapy that can be accessed at the community level. Research has shown that families of color are more reluctant to access drug therapies than whites (Ward, Wiltshire, Detry, and Brown. 2013). NAMI could do more to attend to this disparity.

In Chapter Four I turned my attention to individual stories told by family members who have had contact with NAMI because a member of the family was diagnosed with serious mental illness. The stories I analyzed for this chapter are unique. Diagnoses differed. Age at diagnosis varied greatly. The size and make-up of the families were very different. Despite these

differences, three common themes emerged from these narratives: 1) families were motivated to begin an immediate, sometimes desperate search for relief from symptoms and an extended battle over treatment, 2) parents chose to accept this new reality, face it head on, and support and advocate for their child, and 3) most families sought, and eventually found a point of family equilibrium.

While this project was successful in helping me understand how some families navigated the uncharted waters of a diagnosis of mental illness, there is much more to be done in order to fully understand family response to mental illness more broadly. As noted in the chapter, demographically the families in this project represent a relatively narrow slice of our population. They are also alike in that they had contact with the NAMI narratives of mental illness. Whether it be social strata, educational levels, access to resources, geographic considerations, or religious affiliations, much more research needs to be done in order to map individual and family stories about response to a diagnosis of mental illness across our population.

How Narratives of Mental Illness Intersect, and Their Real World Effects

In this project I sought to understand what stories are told about mental illness at three different levels; personal, family, and organizational, and I asked questions about what the stories mean, how they may or may not have an effect on each other, their reflexive relationship, how they relate to the prevailing cultural narratives of mental illness, and what implications they may have for the prospects of social change. What is profoundly important in this work, and other work that will follow, is Loseke's assertion that "ignoring or minimizing the importance of cultural, institutional, and organizational narrative identity yields an erroneous image of social actors as free agents who can construct any story of their selves that they wish" (2007:677). Related to these macro-level discourses, these organizations, programs and groups attempt to influence the personal narratives of individuals associated with them (2007:678). Understanding

these fundamental ideas about narratives led me to the realization that these questions of interconnectedness between different levels of narratives relating to mental illness needed to be identified, and empirically examined.

In a sense, each of the narratives I analyzed can be said to both influence, and be influenced by the others. The personal level narrative, the story I wrote about my experience with my son's mental illness, reflected my understanding of mental illness as I had experienced it in my family, and what I "knew" about the stigma associated with these conditions. The narratives about mental illness produced by the families similarly were informed by culturally circulating stories and symbolic codes that held dire warnings about impending social stigma and rejection, and, at the same time, hope for relief through medical intervention and therapies. Some of this was "known" by these families through their social own milieu, the media, and in many cases, the organizational narrative generated by NAMI. NAMI's organizational narrative in turn, reflects much of the commonly accepted "medicalized" version of what mental illness is, how is can be managed, and to whom the individual or family should turn to for help.

I found a reciprocal relationship in which each level of narrative informs, and is informed by, the others. As an individual having personally experienced this reflexive cycle, I understand the comfort one may derive from developing perceptions about this experience that have been produced by powerful organizations and are widely accepted. As a social science researcher, I hope to work toward illuminating culturally circulating narratives about mental illness that are not productive and fail to address individual, institutional, and structural barriers that prevent people diagnosed with mental illness and their families from living full and meaningful lives within their communities.

Postscript: Behind My Quest for Meaning

Many who read this dissertation may ask, why embark on this "Quest for meaning" while in a doctoral program? The answer to that question has a story arc of its own that I recall for you here. When Doug was diagnosed with schizophrenia, I became a member of an exclusive group, a parent faced with the prospect of a life having been changed forever, and fear and panic that comes with that realization. The day he died I joined an even more exclusive group as a parent grieving for his child. At the time, I had no notion or understanding of labeling theory, but I knew that I was different, set apart, and that people that new me as a bereaved parent would not see me as the person I was before. I could never have imagined just how much different life would be. As a sociologist, I now have a better understanding of how such defining labels work. And I understand how they can influence one's life course.

At first, I was simply lost. In the months before Doug died I had been in the midst of putting together the biggest business deal of my career. Just a few weeks earlier I had signed a letter of intent to sell my online business for (literally) a million dollars. I had worked for years to develop this business and find a buyer. With Doug's death, I simply lost interest in this enterprise, and pretty much anything else. I could not attend a business meeting. I couldn't participate in a conference call. I couldn't do anything that required contact with the outside world. I could barely get myself to leave the house.

Only the most important people in my life could reach me emotionally. Wendy, my wife, was there for me – in every way. She had lost her stepson, whom she loved dearly. Yet, she surrounded me with her love, understanding and support – and I took it in. I needed all of that so desperately. Our children, 10-year old Jake, and 7-year old Kelsey, honored Doug's memory in ways they could. Jake, by wearing Doug's favorite Steelers cap and Kelsey, by placing Doug's last Christmas gift to her in a place of honor in her room. The only person outside of family I had

any interest in talking to was our Pastor, Dick Johnson. Ultimately, Pastor Johnson became my guide on the new path that I would walk. Dick offered me the most important piece of advice I will ever receive. "Don't be a victim," he told me again, and again over those first few months. "Doug died that night. Not you" He counseled. "What happened - happened to Doug," Dick continued to hammer home to me.

Eventually, I did embrace the notion that I was not the victim. Even though it was so tempting to feel sorry for myself, and to want others to feel the same for me, I saw how damaging self-pity could be. Dick had encouraged me to attend a weekly meeting of grieving parents called Compassionate Friends. At first, I found comfort there. Everyone understood. Everyone sympathized. Soon though, I realized the group was enabling parents to hold on to their grief in a way that seemed very unhealthy. I resisted the idea that I might be coming to these meetings for three, four, or even five years like some did. Thinking about Dick Johnson's advice, and wanting relief from the grip of grief, I had to find a new course.

Just as I had done when I learned of Doug's mental illness, I began to read. I read about loss and grief, and about recovery. Eventually, I read the book that would reset my life course for good, *Crazy: A Father's Search Through Americas Mental Health Madness,* by Pete Earley (2007). Pete's son Mike had been diagnosed with schizophrenia, like Doug. Pete had many of the same experiences I had had with Doug. His journey offered me a kind of roadmap. It wasn't long before I knew that my way out of the emotional wilderness of grief would be to write about my life as Doug's father, caregiver, life coach, and best friend. How better to celebrate his life, and to give it meaning, than to share it with the world? But how?

I wasn't a writer. I'll be honest here and admit I tried. More than once I began to write our story. But, I simply couldn't. I started and stopped dozens of times. Four years went by, then six, then eight, then ten. I was getting nowhere with my feeble attempts to tell our story. I needed

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training. My business interests had dwindled to the point that I couldn't sustain our former lifestyle. Frankly, I had no interest in expensive homes, cars, or vacations. Our kids were now gone off to college. It was time to downsize, and reconstitute my life. Time to return to school and learn how to become a writer. Thankfully, Wendy was on board.

I had in hand an associate degree in business that I had earned in my twenty's. Having met with admissions at a small liberal arts college in the area, I found I needed some additional credits. In December of 2008, nearing the ten-year anniversary of Doug's death, I enrolled in a course at the local community college. I took one course in the spring of 2009, another in summer, and then enrolled at North Central College full-time in the fall of that year. I began my life as a full-time student as a sophomore, majoring in English. I was on my way to becoming a writer. Or so I thought.

As in most liberal arts colleges, I was required to take an Introduction to Sociology course. So much for becoming a writer. I was smitten, of course, by the works of Marx, Durkheim, and Weber – the "Holy Trinity of Sociology," as professor Geraty called them. But mostly, it was Goffman who me pulled into this work. *Stigma: Notes on the Management of a Spoiled Identity* would become my bible. It wasn't long before I found myself sitting in Dr. Geraty's office in the Soc house on campus. "I think you should consider transferring to Sociology as your major. I know you have this story about you and your son that you want to write, but there is so much more you could do as a sociologist to help other students. Mental illness is a huge problem on college campuses. And, most schools just haven't grasped the scale of the problem. You can do a lot." She told me encouragingly. I didn't take much persuading. I took up sociology as my major the next term. By the end of my junior year we were talking about grad school. "Me? Get a master's degree?" I would ask incredulously. Eventually, I came to embrace what I now know was my calling all along.

In the second year of my MA at Northern Illinois University (NIU), I was fortunate enough to meet Dr. Maggie Kusenback from the University of South Florida (USF). Escorting her around campus as the grad colloquium rep, I had morning coffee with her at a Starbucks. She was intrigued by my story, and suggested that I consider applying to their relatively new PhD in sociology program. "We have the perfect mentor for you. Dr. Sara Green is an internationally known disability scholar." She claimed proudly. "You need to email her." She urged. "I think you could be a great fit." And so I did.

My Turn to Autoethnography

Epistemologically, and methodologically, USF and NIU were very different. My training at NIU had been heavily quantitative. As Sara Green and I began to talk about the possibility of me applying at USF, she told me about Donileen Loseke's work on narrative identity and about the autoethnographic work of Caroline Ellis and Art Bochner. Having had classroom training in the most basic of quantitative methods, I approached the idea of total immersion into autoethnography, and the work of Ellis and Bochner, with uneasiness. I knew little about qualitative methods and nothing about autoethnography.

As I read more and more of their work, and began to understand their specialty, I came to realize that I had found the perfect academic home for me. Under the direction of Green, Ellis, and Bochner, I reasoned, I would be able to write about my experience with Doug, not as distant researcher, but as both actor *and* researcher. And so I did. It was under the direction and mentoring of Art Bochner in his narrative class, that I first began to write this story about my journey with my son through his mental illness, recovery, and then his tragic, unexpected death. As an assignment in that class, I was once again exposed to an author with whom I could identify, and a story from which I could draw for inspiration. Michael Berube had written *Life As We Know It,* the story of his family's experience with his son, Jamie, who had been born with

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Downs Syndrome. As I hungrily consumed his work, I was given another road map, of sorts, as to how I might tell the story of my son, and perhaps enlighten or inspire others.

Along the way, I became aware that I also needed to look carefully at cultural and organizational narratives about mental illness that may have shaped my understanding of my own experiences and those of others. I read Donileen Loseke's work about the social power of narratives and the ways in which stories told at different social levels are intertwined (Loseke 2007, 2019). Armed with what I learned from these authors and mentors, I began to construct the story that became this dissertation.

As Frank (1995) argues, personally transformative experiences like mine tend to create storytellers because we feel compelled to share them in this form. Those of us who need to tell our own unique stories compose them by adapting and combining narrative types that cultures make available. Frank (1995) suggests three narrative "types"; restitution narratives, chaos narratives, and quest narratives that are available to those of us who need to tell our stories. He writes about the narrative forms that describe a tellers experience with a physical illness. Similarly, these processes help depict my own journey of loss, and recovery. Each of these narrative types, argues Frank, reflects strong cultural and personal preferences. Yet, each, in its own way, impacts "listening" to the narrative. Listening is difficult because these stories of loss, and trauma, "mix and weave different narrative threads" (p.76). By proposing a typology of narrative types, Frank suggests that these threads are more easily sorted out. I have chosen the quest narrative as my storytelling vehicle.

The quest narrative affords the ill (wounded) person a voice as teller of his/her own story. It is only in quest stories the teller *has* a story to tell. Borrowing from Campbell (1972), Frank describes the three stages of the quest narrative. The first stage is *departure.* It begins with a call that announces the sudden change the individual is about to undergo. Mine occurred when my

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daughter Melissa told me about Doug's psychotic break, followed the very next day by that moment he revealed his mental illness to me in that car ride. Like others authoring quest narratives, I knew a change was coming, and that it would involve great suffering. Initially, like many others, I was in disbelief, a form of denial, but eventually gave in to the reality and crossed the "first threshold" (Campbell 1972:189).

The second stage is *initiation.* Tellers of quest stories use this idea of initiation as a metaphor for belonging. As I sat in that McDonald's restaurant with my son, reflecting on what I had learned about his mental illness, I knew that life would never be the same. Almost immediately, I sought information through others' storytelling. As this research began to reveal experiences that other families had gone through, I felt akin to that group that was previously unknown to me. I began to imagine a quest narrative telling my readers how I, now the *storyteller,* had been transformed through the experience. I knew I have been given some sort of insight that must be passed on to others, thereby giving my life a sense of meaning, and a purpose.

The third stage is the *return.* The teller returns to his life as one that is no longer debilitated by the experience, but who bears the "mark of the brotherhood of pain," as I did. In the early years after my son's death, I sought some pursuit, some path that would allow me to make sense of the tragedies that I had experienced; first, my son's devastating diagnosis of schizophrenia, then the long years of uncertainty – would he ever be well again? Finally, just as I came to believe in his future, I experienced his sudden, tragic death. How could I make sense of this? As Campbell argues, the marked person lives in a world they have travelled beyond, becoming "the master of two worlds" (p. 118).

Encouraged by others who had travelled the same journey I was on, I knew that I could only find peace, and a future that mattered, by telling my story to others. Membership in such a

brotherhood gives the teller a credential that is necessary if they are to effectively impart their knowledge to others. Frank (1992) employs an inspirational metaphor for those who write such stories – the Phoenix, reinventing itself from the ashes of the fire. I humbly submit that I am not the Phoenix, rising from ashes, but I do feel a sense of having been reborn[6]. Having had that experience of rebirth, coupled with my training as a sociologist, has led me to take up this work as a means of learning, sharing, and somehow helping.

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[6] I refer here to the Kuhnian notion of paradigm change, not the Christian concept of spiritual rebirth.

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Appendix A

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Appendix B

NAMI Site Map (Page One)

Site Map: http://nami.org/sitemap[7]

HOME PAGE

- Find Your Local NAMI List (/Find-Your-Local-NAMI-List)
- Home (/Home) Logout (/Logout)
- Learn More (/Learn-More)
  - Know the Warning Signs (/Learn-More/Know-the-Warning-Signs) Mental Health Conditions (/Learn-More/Mental-Health-Conditions)
    - Related Conditions (/Learn-More/Mental-Health-Conditions/Related-Conditions)
    - Risk of Suicide (/Learn-More/Mental-Health-Conditions/Related-Conditions/Risk-of-Suicide) Anosognosia (/Learn-More/Mental-Health-Conditions/Related- Conditions/Anosognosia)
    - I Am Not Sick I Don't Need Help! (/getattachment/Learn- More/Mental-Health-Conditions/Related-Conditions/Anosognosia/I_am_not_sick_excerpt.pdf?lang=en-US)
    - Sleep Disorders (/Learn-More/Mental-Health-Conditions/Related-
    - Conditions/Sleep-Disorders) Mental Health By the Numbers (/mhstats)
- Treatment (/Learn-More/Treatment)
  - Types of Mental Health Professionals (/Learn-More/Treatment/Types-of-Mental-Health-Professionals)
  - Psychotherapy (/Learn-More/Treatment/Psychotherapy)
  - Getting Treatment During a Crisis (/Learn-More/Treatment/Getting-Treatment-During-a-Crisis)
  - Treatment Settings (/Learn-More/Treatment/Treatment-Settings) Mental Health Medications (/Learn-More/Treatment/Mental-Health-Medications)

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[7] This URL will take you to the entire site map on the NAMI website consisting of over 450 pages.

Appendix C

University of South Florida

Institutional Review Board Approval

2/28/2018

Doug Engelman
Sociology
4202 E Fowler Ave.
Tampa, FL 33620

RE: **Expedited Approval for Initial Review**
IRB#: Pro00030955
Title: NAMI Family Study: Understanding Family/Patient Dynamics & the Effects of Stigma.

Study Approval Period: 2/26/2018 to 2/26/2019

Dear Mr. Engelman:

On 2/26/2018, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within, including those outlined below.

Approved Item(s):
Protocol Document(s):
Application for IRB - Interview Protocol

Consent/Assent Document(s)*:
IRB Verbal Consent Form**

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent documents are valid until the consent document is amended and approved. ****Consent form with waiver is not stamped.**

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

<center>**Appendix D**</center>

<center>**Interview Guide**</center>

Introductory Questions.

1. I'd like to begin by getting to know you a little better. Can you tell me a little about yourself and your family?

2. How did you become involved with NAMI?

Part A – Disease, diagnosis, and treatment background:

3. I know this is difficult, but it would be helpful if you could think back to when you first began to notice that _____'s behavior was beginning to change, and tell me about that experience.

Probes (only to be used if this information isn't embedded in the story thus far told)

What did he/she do that drew first your attention?

Describe the circumstances under which you first became aware that this behavior might be a disorder.

How did this awareness make you feel?

Did anyone else in your family notice changes? What did they say or do?

If _____ was in school at the time, was there any indication that teachers or other students noticed the change?

4. Can you tell me about the day you found out about his/her first <u>formal diagnosis</u> of mental illness?

Probes (only to be used if this information isn't embedded in the story thus far told)

Where were you when you found out?

How did you react?

How did you feel?

What is your son/daughter's current diagnosis?

Were there other diagnoses before this one?

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How long has he/she been diagnosed?

Describe the specific circumstances under which he/she was diagnosed.

Were you directly involved with the diagnosis?

5. Can you tell me about your experiences with his/her treatment for the diagnosed disorder?

Probes (only to be used if this information isn't embedded in the story thus far told)

Were you involved in the treatment in anyway? Describe

Has he/she remained in a consistent treatment regimen since diagnosis?

If not, how often has he/she strayed from his treatment regimen?

What was your reaction to this failure to comply with treatment?

6. What recourses have been most useful to you and your family?

7. What problems have you encountered, if any, in trying to access medical, social, educational and other support services and resources for your son/daughter or your family?

Part B – Family/social structure, dynamics, & reaction:

8. How has your life changed since the diagnosis?

9. What impact has the diagnosis had on your family?

10. How have family members and friends reacted to the diagnosis?

Probes (only to be used if this information isn't embedded in the story thus far told)

Briefly describe your family: individual members, their relationship with your son/daughter, and their general attitude about an SMI diagnosis.

Briefly describe the extended family. Are they aware of his/her illness?

If so, generally describe their reactions to his/her illness.

If not, why did you choose not to disclose the illness?

If you are aware of the reactions of his/her social network to the illness and diagnosis, please describe what you know about this. How have these relationships changed since the diagnosis?

11. What's it like to be at family gatherings with _____?

Probes (only to be used if this information isn't embedded in the story thus far told)

Do you believe that your immediate family sees any changes in behavior? If so, describe their reaction.

Do you believe that your extended family sees any changes in behavior? If so,

Can you give me some examples?

12. What's it like to be out in public with _____?

Probes (only to be used if this information isn't embedded in the story thus far told)

Do you believe that people you don't know notice anything unusual about _____'s behavior? If so, describe their reactions. (If the preceding descriptions are of negative response)

As a parent, describe how it feels to see others react negatively to your son/daughter whose behavior is not his/her fault.

What do you think others think about family members of someone with a mental illness diagnosis?

13. What actions of family and friends have been most problematic for you?

14. What actions of family and friends have been most helpful?

Part C – Suggestions for Change

15. If you could make changes in the way people with SMI diagnoses are treated, what would they be?

What changes would you like to see in the way mental illness diagnoses are made?

What changes would you like to see in the way mental illness diagnoses are communicated to individuals and their families?

What changes would you like to see in the delivery of mental health treatments?

What changes would you like to see in the way people with mental illness are treated by the public?

What changes would you like to see in the services and accommodations provided to students with disabilities in schools and colleges?

What changes would you like to see in the way people with SMI are portrayed in the media?

Part E - Perceptions of NAMI's Family-to-Family education program:

16. Has the program been helpful for you and others in your family?

17. How do you feel about the way that this program is structured and delivered?

18. Has this experience changed the way in which you communicate with (name of family member)?

19. What changes would you like to see?

Wrap Up Questions.

20. What are the biggest challenges of being a family member of someone with a SMI diagnoses?

21. What positive changes, if any, have you seen in your family as a result of the experience having a family member with SMI?

22. What do you think could be done to make it easier for people with SMI diagnoses to be more fully included in the life of the community?

23. What advice would you give family members of someone newly diagnosed with SMI?