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Unveiling Recovery: A Discourse Analysis of Mental Illness Recovery Narratives

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UNVEILING RECOVERY: A DISCOURSE ANALYSIS OF MENTAL ILLNESS

RECOVERY NARRATIVES

by

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ABSTRACT

UNVEILING RECOVERY: A DISCOURSE ANALYSIS OF MENTAL ILLNESS
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by

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The discussion of mental illness recovery, both academically and socially, has

been framed mainly as a morally necessary medical pursuit and has left shadowed the

deeper social and cultural implications of recovery ideologies and practices. Previous

research has embraced the growing demand for recovery-based practices in mental

health organizations, especially those led by persons labeled mentally ill (or "peers");

however, they have yet to more deeply uncover and understand the subjective

meanings of recovery. More specifically, how cultural and social interactions of daily life,

while both experiencing and being labeled mentally ill, direct the course and meaning of

an individual's recovery journey. Utilizing publically presented online narratives and

discourse analysis methodology, the study reveals hidden implications of mental illness

recovery culture and thematic social meanings of the recovery process. This exploration

reveals the dynamic, symbiotic relationship between persons with mental illness, culture,

and the social responsibility of recovery.

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1. INTRODUCTION

Literature written by psychiatric survivors, as well as their online narratives, reveal the visceral trauma psychiatric and social treatment brought to their lives and the struggle to attain vocal power to generate personal and social reform (Buck 2011[2007]; Campbell 2006; Cohen 2005; Estroff 2004; Oaks 2011). What began as an inquiry into understanding how persons with mental illness discuss, reinforce, and subvert normative ideas about illness, stigma, and political rights in advocacy-based online forums naturally evolved and adapted to consider the other end of the spectrum: recovery. With the large body of work already dedicated to mental illness stigma[1], my path led me to analyze the implications of the culture of mental illness recovery and the contradictions within its practices. The following research project seeks to more deeply understand the notion of mental illness recovery and the methods by which it is attained. Within the growing body of research on recovery, the discussion leans toward the exaltation of clinical achievement; and, in so doing, it erases the deeper cultural dimensions of experience and the practical individual and social work required to reach this state of social being. Even with the notion of recovery moving throughout the medical and cultural West, those labeled mentally ill attest to the lack of compassion not only in their

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[1] Goffman 1963; Link, et al 1991; Weiss, et al 2001; Corrigan and Watson 2002; Corrigan and Matthews 2003; Corrigan, Markowitz, and Watson 2004; Estroff, Penn, and Toporek 2004; Coker 2005; Rüsch, et al 2005; Weiss, et al 2006; Yang, et al 2007; Jenkins and Carpenter-Song 2008; Link, et al 2008; Phelan, et al 2008; Abdullah and Brown 2011; Link and Phelan 2014; Corrigan 2015

treatment by professionals, but also in the public's treatment of them as family, friends, and neighbors, as well as in the media's depiction of madness as violent and unrelenting.

Through their experiences of oppression and, especially, organizing to create change, persons with mental illness adopted different subjectivities to identify themselves within the newly charged political climate. It was the 1970's and the beginning of the "mental patients' liberation movement" (Chamberlin 1990; see also McLean 2000); groups were organized into various sects of philosophy and radicalism. Though not all people chose to identify as such, the three groups were composed of consumers, survivors, and ex-patients (or ex-inmates), or "c/s/x" (Estroff 2004). Consumers were persons who actively engaged with psychiatric treatment, and wanted to continue to improve the relationship between those labeled mentally ill and health care providers. Survivors had been traumatized by psychiatry and society, yet through their pain found a way to heal and discovered a new power within. Their survivorship was worn like a badge and a testament to their resiliency in the face of adversity. Ex-patients were the most radical of the sects, having experienced the greatest injustices and confinement by the hands of medical professionals, law enforcement, and their communities. They wanted total separation from and abolition of psychiatric practice. Over time these groups evolved and, today, most widely identify, if at all, as a consumer or survivor (for a greater discussion of social movements in psychiatry see Chamberlin

1990; Crossley 2006; McLean 2000, 2010). I favor "survivor" throughout this thesis as it was the most common usage among my sample population; however, it should be noted these subject identities were not expressed regularly or consistently by narrative authors.

While we have accounts of peer-run groups and organizations who have demonstrated their ability (and the difficulty therein) to provide support and advocacy for people with whom they can identify (Lewis, et al 2012; Austin, et al 2014; Myers 2015), there is little empirical research focused directly on persons with mental illness and the meanings behind their philosophies and methods for recovery. It is pertinent we develop a culturally-informed idea about mental illness recovery from a first-person point of view, as well as understanding behind the value and meaning of the practices utilized in their attempts to attain this coveted status. The demand to have their experiences shared and listened to is still great, which is why this research focuses on the recovery narratives of persons with mental illness. Using digital space and personal narrative, persons with mental illness are making space for long-ignored voices as a tool to reframe their social perception. If you could recover from mental illness, and if people were highlighted for their capabilities rather than their perceived detriment and social danger, then persons with mental illness would be regarded as dignified. If they were dignified in the eyes of the people in and outside of their communities, they would be treated in ethical and just ways.

<u>Background</u>

Goffman's (1963) influential book about stigma provided social researchers with a new way to discuss social deviances and the effects personal identity renders in cultural and community relationships. As the foundation for much stigma-related research (see footnote 1), it also helps to provide a theoretical structure from which to build an understanding of how people and communities overcome these inherent biases in philosophy and performance (Goffman 1959). Focusing on the social stigma of mental illness labels and behaviors also necessitates a focus on other coexisting concerns like freedom and capabilities. Through accounts of historical and present experiences of persons labeled mentally ill, it is still widely believed said persons are "psychologically and socially inferior" (Szasz 1970:xv), which has led to the widespread creation of organizing efforts to reform social, political, and medical views and practices. Sen (1985; 1999; 2003; 2005), in his discussions and research on development practices, offered the theory of "capabilities" to move passed the focus on individual economics and assets to illustrate the vast differences in opportunities for persons with identities and characteristics which fall outside of the social and cultural pinnacle. For persons with mental illness, who are most often considered to have few capabilities, such as social prowess, intellectual advancement, and romantic companionship, it turns the discussion to show them in a new light. If they can be accepted and considered for who they are

and what they have experienced, and if the influences of social life and cultural practice

can be juxtaposed to that life narrative, then perhaps researchers and developers can

begin to understand how those subtle structures of everyday life have incredible

emotional, social, and political impact on those labeled as different. The research on

recovery is growing rapidly as many seek to understand the nature of recovery

(Jacobson and Curtis 2000; Jacobson 2001; Jacobson 2007), its practices in institutional

and community settings (Austin, et al 2014; Lewis, et al 2012; Myers 2015), and its

limitations (Hopper 2007). While spoken of in medical terms and achievements, recovery

from mental illness and the treatment received as a person labeled mentally ill is

inherently social and cultural. Therefore, the ways in which recovery is described and felt

by persons with mental illness is of considerable importance.

Digital space has offered the opportunity for many people with mental illness to

make sense of their experiences, of themselves, and of the social climate in which they

find themselves immersed (Ginsberg 2012). It is a way to organize and promote change

within cultural constructions of what it means to be mentally ill, and challenge the

stereotypes of illness behavior. In the United States, where democratic participation by

the public is one of the most important aspects of personal freedom and of democracy

itself, these sentiments have naturally embodied technological platforms developed to

create and sustain social improvement initiatives. Two important components—

participation and 'voice'—represent the cornerstones of democratic development.

"Voice" is the ability to "represent oneself and the right to express an opinion" and participation is the act of using one's voice to add one's story to the greater discussion (Tacchi 2012:225). 'Voice' and participation, then, can be great methods to increase cultural capacity and the aspirations of marginalized populations. By allowing the marginalized and socially excluded to more greatly participate in political and development processes, they would be able to be in control of their social empowerment (Appadurai 2004:66). This presentation of stigma as the inhibitor to help, and the power of "sharing your story," was salient throughout many of the narratives found within both data sites. By sharing their experiences, both negative and positive, authors not only exercised their "basic right of the mentally ill speak their minds," but foster a performative platform for testimony and witnessing to trauma, injustice, and social healing (Cresswell 2005:1669). This research desires to understand these aspects of narrative performance surrounding mental illness recovery.

The Study

The current project has studied the online narratives written by persons with mental illness to investigate the following questions: (1) What are the cultural implications of recovery from mental illness, or how has culture shaped our ideas of mental illness recovery, and (2) What are the contradictions within the practice of recovery? I ask these questions so more will be known about how these philosophies

and strategies reinforce or subvert normative ideals of mental illness and health. The main data was collected from narratives and testimonies of individual participants on two mental health advocacy website discussion forums. Additional data came from the organizations website content, as well as previous research; both conceptual and descriptive works conducted in the field. I drew heavily from large bodies of literature on stigma, recovery, performance, and morality, as well as digital ethnographic methods.

The rise of National Alliance on Mental Illness (NAMI) helped to reinforce alliances between families and clinicians. Where other groups organized to avoid working with health professionals, families affected by mental illness saw the need for closer relationships with psychiatry, not only for their loved ones, but also for themselves. Beginning in 1979, they formed a coalition that created support and advocacy programs for families and individuals who experience mental illness and have grown exponentially through federal, and pharmaceutical, partnerships. By reinforcing the biomedical model of psychiatry and highlighting mental illness as an organic brain disease, families could receive the support they had long been denied. Once penalized for being the cause of their loved ones, especially children's, mental illness, they could now be sufferers themselves and could express their need for support. Today, NAMI continues to work mostly with families and individuals affected by mental illness that are seeking treatment. They are still supporters of the Western biomedical model, and conduct and sponsor research to find better ways of treating mental illness. Their

mission relies on education, advocacy, listening and understanding, and leadership within the community. They have grown to become the nation's largest grassroots mental health organization to include hundreds of local affiliates and organizations, run mostly by volunteers, to provide support and education to those in need. Their current work is focused on stigma by encouraging people to "see the person, not the illness."[2]

In 1986, the group that would organize to create Support Coalition International—the future MindFreedom International (MFI)—started the *Dendron* newsletter on Human Rights and Psychiatry, published by Clearinghouse and funded with a start-up grant from Levinson Foundation. In May of 1990, Support Coalition International was co-created by psychiatric survivor and activist David W. Oaks during a counter-conference and peaceful protest of the Annual Meeting of the American Psychiatric Association (APA) in New York City. In 2005, led by Oaks, the organization evolved once again into MindFreedom International (MFI) and furthered its mission of providing justice and reform within Western psychiatry. Today, MFI is an international human rights coalition, and a registered non-profit, IRS 501(c)(3) organization of over 100 grassroots groups across the world dedicated to providing a wide range of information about mental illness, treatment options, social inclusion, and recovery. Due to the lack of scientific results to support such claims many remain unconvinced of the biological, typically Western, model of psychiatry, which claims mental illnesses are

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[2] http://www.nami.org/About-NAMI

organic brain diseases. Their goals are succinct, but sizeable: "win human rights

campaigns in mental health"; "challenge abuse by the psychiatric drug industry";

"support the self-determination of psychiatric survivors and mental health consumers";

and "promote safe, humane and effective options in mental health."[3] In other words,

they advocate for the respectful and dignified treatment of persons with mental illness

both medically and socially. This includes the freedom to choose how to treat mental

illness, as well as the opportunity to make autonomous and informed decisions by being

given *all* methods of treatment and recovery including those that fall outside of Western

medical practice, which relies largely on pharmaceuticals.

My preliminary hypotheses developed while considering the social history of the

sites. NAMI and MFI are sufficiently different in ideology and styles of organization

because of their socio-political history. In theory, the people who participate on the site

will be aligned to the organization's ideologies: NAMI will be composed of mainly

consumers who consider mental illness in biological or genetic terms. There may be a

few survivors in the group, but I do not expect there to be any who advocate for the

abolition of psychiatry. I anticipate participants on NAMI to feel more secure in their

treatment and their relationship to psychiatry, although there may be some discourse

about providing options for treatment beyond pharmaceuticals exclusively. I expect

there to be a considerable presence of family members, or other persons in close social

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[3] http://www.mindfreedom.org/who-we-are

connection to the person with mental illness, discussing their own experiences, as well as the experiences of those they love suffering from mental illness. Naturally, narratives will be written in both first- and second-person. MFI, on the other hand, will be composed of mostly psychiatric survivors, with a few more radical persons and a few consumers, but the majority will consider mental illness a social construction rather than a biological fact. Justice will be the greater overarching narrative theme, rather than best methods for mental illness treatment. Within both sites, I expect some labeling of themselves along the survivor-consumer spectrum, however, these terms can be slippery. Some find the term "survivor" to be too radical, while others resent being called a "consumer" when they have faced forced treatments and do not feel like they participated as an informed consumer in an open market (Campbell, 2006).

The research will be conducted through discourse analysis of individual, publicly presented material found within each of the websites discussion forums. Other data from the websites will also be subject to content analysis to compare and define how individuals and the organizations construct their views on mental illness, health, and recovery. Considering the online environment may be one of the few spaces some individuals feel comfortable expressing themselves, discourse analysis is invaluable and provides "immediate practical application[s]" (Silverman 1993:122). Because my project is fundamentally concerned with language, the way people convey their experiences and meaning to others, discourse and content analysis are appropriate methods.

Anthropologists and sociologists may find this work helpful as they continue to study

mental illness, health, and recovery, as well as reform and development in these areas.

Those involved in mental health justice and advocacy may also find this research of the

various thematic philosophies that provide purpose and passion for recovery and reform

illuminating.

2. LITERATURE REVIEW

To understand the significance of narratives written about the experiences of

mental illness recovery and practice, attention must be paid to moral constructions and

their influences on social behavior and opportunity. Stigma, theorized most notably by

Goffman (1963), has been the focal point of progressive social, medical, and psychiatric

research. His contributions have provided greater awareness of individuals' experiences

of perceived stigma and coping mechanisms, but they also provide a critical foundation

for understanding the opposite side of the spectrum: recovery. In conjunction with

Goffman (1959; 1963), the capability approach, as conceptualized and advanced by

Amartya Sen (1985; 1999; 2003; 2005), has offered a distinctive lens for analyzing

differences. It is a person-centered approach to consider structural barriers and morally

salient cultural practices. Together, they provide a framework from which to build an

understanding of recovery as a cultural and social practice.

Goffman's Foundation: Performance and Stigma

To help us better understand the human social experience, Goffman (1959) provided the metaphor of theatre, the performance of a narrative in front of an audience; the dialectic, of course, being about the performances, or interactions, between people in the social world. Performance, then, may be considered as "all the activity of a given participant on a given occasion which serves to influence in any way any of the other participants" (Goffman 1959:15). The metaphor of the theatre captures this action through the movement and dialogue of the actors on stage, and the reactions and emotions made or felt by the audience. Through performance, the actor "expresses" themselves and "impresses" another, however, the expression comes twofold: the way it is "give[n]" and the signs it "gives off" (Goffman 1959:2). In other words, a person expresses information believing it is being delivered in a certain way, which is then interpreted by the receiver with the possibility of the information being misinterpreted or disbelieved. To continue with the metaphor of theatre, the stage actor may say one thing, but then do another, resulting in an impression of mistrust by way of their expressions. To help navigate, each of the actors makes "inferences" (Goffman 1959:3), facts that cannot be proven by any quantitative method, yet are made based on the knowledge we have arriving into the situation, attained during the interaction, or by the needs to be met. For example, the audience may recall an earlier display in the narrative that lends weight to either their trust or mistrust in the actor, altering their

impressions. These performances, naturally, do not occur in a void, and are lent supports through "fronts" (Goffman 1959:22), such as the material setting. Another front, the "personal," includes signs of "appearance" and "manner" (Goffman 1959:24). These are the signs that are expressed most or all the time, such as age, gender, appearance, speech patterns, etc....This is not to suggest these will not come to contradict each other, but we will discuss that later.

The moral character of the conversation declares if a person carries the preferred social characteristics or performs, whether implicitly or explicitly, in the appropriate way, they incur the moral right to be respected and taken as truth (Goffman 1959:13). The expectation to perform accordingly, that is, expressing the proper signs clearly enough to lead to the desired moral and social impression, could lead the actor to conceal information from their audience. It is appropriate to assume the audience is receiving the polished and practiced version of the actor's narrative, having safely erased unorthodox activity contributing to the production and mistakes corrected through practice (Goffman 1959). Conversely, they may inflate the importance of that particular performance, or the relationship of the audience to the actor, to make one feel like the performance is speaking to them in a special or unique way to accomplish the goals they set out to attain. These "masks" (Goffman 1959:57, quoting Santayana) worn in social interaction to acquire a desired outcome are the paramount display of social discipline, of lines and actions rehearsed and understood to function in particular ways

to attain certain goals. However, we also must consider the ways the information

expressed may not conform to preferred social standards, the instances where a mask or

front is not performed appropriately, or is performed incompletely. This result is stigma.

By Goffman's (1963) definition, stigma refers to a "deeply discrediting" (3)

characteristic that informs how people—with and without the same characteristic—will

relate to them. Stigmatizing characteristics can be further divided into two categories:

the discrediting and the "discreditable" (Goffman 1963:41). The discrediting is a visible

and recognizable attribute, while the discreditable attribute is more invisible and,

therefore, not yet revealed to others. The relational component within the definition,

along with the two kinds of characteristics, points to an inextricable link between stigma

and social identity. Whereby a person's "actual social identity" (Goffman 1963:2) is

composed of attributes and characteristics that can be proved, a person's "virtual social

identity" (Goffman 1963:2) is constructed through subjective judgments—true or

untrue—predicated on a perceived stigma. Finally, the ego, or "felt" (Goffman 1963:105)

identity of a person is their own subjective sense of their life and character. Underneath

the relationships between the stigmatized and the "normals" (Goffman 1963:5), or

people without stigma, are fundamental moral beliefs orchestrating complex identity

norms and deviations to create social order.

Visible identity characteristics act as signs and symbols, which help to inform

others about a person. These signs or symbols may relate to prestige, their stigma, or be

a "disidentifier" (Goffman 1963:44), a sign that is misinterpreted as a discrediting

attribute. Stigmatized individuals, when interacting with others, might feel an

uncertainty about how they will be treated, and act with more awareness or

consciousness of themselves and their situation. Therefore, people in possession of a

discrediting or discreditable attribute manage its visibility through mechanisms such as

"passing" (Goffman 1963:73) or "covering" (Goffman 1963:102). A discreditable person

can *pass* by covering up, intentionally or by coincidence, their discreditable attribute,

thus rendering themselves normal in front of people who have no information about the

person's discreditable stigma. Passing can be viewed not only as a method for

protecting information, but also as part of the socialization of what is normal and what

is not accepted. *Covering* differs from passing in that the stigma is noticeable, or unable

to be concealed, but the person goes through efforts to make their stigma from being

too noticeable, or the focus of the interaction.

The experiences embodied by the stigmatized person create what Goffman calls

a "moral career" (Goffman 1963:32) of adjustments and socialization. He identifies four

themes that I have summarized as: childhood socialization, kinship, adult-onset, and

cross cultural or cross-context. The childhood socialization theme stems from a stigma

one is born with, such as a congenital disease, or occurring very early in life so that they

learn about their stigma while also learning how the world perceives it. For instance,

stigma related to gender or ethnic identity. Kinship involves the family's, and to some

extent the community's or neighborhood's, ability to protect and nurture the young so they grow knowing they are normal and capable human beings. Once the child enters public school or interacts more closely with public institutions, and is removed from the protection of similar and supportive faces and traditions, their ideas about their identity will be confronted, and they may be placed in institutions considered of their "own" (Goffman 1963:33). For example, a blind child may be removed from public school and enrolled in a school for those who are blind, or a child with educational disabilities could be placed in the school's special education program. The third theme, adult-onset, involves people who become or realize their stigma later in life, someone who has already developed ideas about normalcy before becoming deficient in their own eyes. A person with mental illness who has grown up in a supportive family environment and never made to feel as if their illness was a disability or indicator of their self-worth may be confronted with prejudice and discrimination in their work place, or may have trouble finding work. The cross-cultural theme involves people who have been socialized in a different context, and are required to adapt to life in a new context, such as immigrants or adults progressing through sexual reassignment and gender transitions. This moral career, whatever the theme, is about navigating different spaces that hold different values, some of which are supportive of the stigmatized and others which are not. It is important to note the complexity and importance of the space's scale and context. Some spaces that seem intrinsically supportive, such as the school for the blind or a

special education class, may actually be more stigmatizing and distancing because the stigma is the focal point of the institution. Here, the blind child and the developmentally challenged child are not able to prove to the world they are capable, or kind, or like the other children because they are being separated and contained in specific spaces with others who share the same condition.[4]

This social dichotomy of self and other necessitates the formulation of an in-group and an out-group (Goffman 1963:113-115). In-group is the group of people who share the same stigma, and are labeled and identified through their discredited characteristic as peers or a homogenous community. The community is only as homogenous as the stigmatized attribute, thus, whatever their other identity markers, they will most likely find most of their teachings about their stigma and its management from their peers. Those who understand the discredited or discreditable, but do not carry the same characteristics, are what Goffman calls "sympathetic others" or the "wise" (1963:20, 28). These people, who have developed relationships with the stigmatized group or belong to the family of the stigmatized person, may become wise and privy to the real life experiences the discredited face and develop an understanding how they are full human beings no less capable than any other. These people may find the stigma of their friends or loved ones is passed onto them because of their *in* with the group.

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[4] It is important to note in the present day spatialized segregation does not exist in the same way as it did when Goffman wrote this work. What once had been clearer distinctions of total institutions are now more integrated. For example, organized orphanages are no longer active; those institutions have evolved into foster care systems and private adoption agencies.

Some individuals, who find an affinity focusing on their stigmatized attribute and the treatment they receive, may seek out or develop structured organizations that are active either socially or politically. They might find this work particularly engaging and spend more and more time advocating for their stigmatized peers and operationalizing methods to reduce the prevalence of stigma against them. As a "professional" (Goffman 1963:27), they might find themselves maintaining the organization's publication, working with other groups and, in turn, producing their own bias of the importance of their own group. In-group organizations may introduce an aggressive idea for moving forward, and these can come with some problems. Removing stigma, as a goal, may thrust the individual into a politicized life they did not engage in before, ultimately making them more individualized and infamous. Goffman states the further they try to "separate [themselves] structurally, the more like the normals...they may become culturally" (1963:114). Therefore, if the goal is the opposite, not inclusion, but distinction that demands respect, they might find themselves adopting and reinforcing the larger normative cultural structure. For example, radical anti-psychiatry activists in the early 1970's—ex-patients and ex-inmates—who sought emancipation from psychiatry and other harmful societal structures, found it difficult to forge alliances with other groups. Their distrust of potential survivor/consumer allies and the government reinforced a separatist ideology, an "us and them" dichotomy, which was exactly what they were trying to reform. While their strategy provided them with the spotlight for recognition, it

also served to highlight the anarchist elements of their radical agenda, which led to an inter-organizational ideological divide, and the eventual absorption of ex-patients into the survivor/consumer movement (McLean 2000).

The out-group, on the other hand, is this normalized wider society around them and their group. It considers people not so much in political ideas, but in psychiatric ones (Goffman 1963:115), or the rhetoric of appropriate and inappropriate behavior and conduct. Not only are the discredited expected to act in accordance with their stigma, but they are also to act as the teacher for normals who do not understand their experience as anything but morally controversial. The discredited is to be pleasant, happy, abiding by (medical) labels, and always willing to give a bit of information about themselves or their stigma to others, if it has not already been announced or made noticeable by the individual. If each party completes this social duty—the discredited as educator and the discreditor as inquisitive student, it will create a "phantom acceptance" leading to "phantom normalcy" (Goffman 1963:122). Here, the discredited individual is accepted in the moment for what and who they are, though nothing but their stigma may be known about them. However, it is deemed sufficient, because the social rules in place were upheld.

There are outstanding identity norms in all matters of social life, not merely the stigmatized, and everybody has, in some way and at some point, realized they do not measure up to the ideal and perform different methods to pass or cover. In other words,

identity norms create deviations and conformities. Since this is the case, all persons are a

"normal deviant" (Goffman 1963:131), in that everyone performs stigma management

during their lifetime. Therefore, the stigmatized and the normal are not two distinct and

separate groups of people who happen to interact in public; rather they are a social

process constituted of two roles that every person plays during some phases of their

life. We are constructed into complex power and performance relationships where those

whose attributes or behaviors are conceptualized as atypical, inappropriate, or immoral

face ostracization from participation in, and the creation of, specific social lives. To

understand the richer meaning of these performances and how they relate to mental

illness and recovery, we must further explore the capability as a developmental process.

Sen's Development: The Capability Approach

The "capability approach," pioneered in the 1980's by economist and philosopher

Amartya Sen (1985; 1999; 2003; 2005), is a theoretical framework to consider and

maintain two assertions: the freedom to pursue and achieve well-being is morally

significant, and the path of this freedom lies in a person's capabilities, or their ability to

do and be, to create a valued life of their own making (Sen 1999; 2003; 2005). The

capability approach has been used to analyze various areas of development, including

by anthropologists and sociologists working within community-based mental health

services. It has been especially salient in the discussions surrounding mental health reform and the implementation of "recovery" in community-based practices.

Within the capabilities approach, the "constituent elements of life" are considered as a set of "functionings"—"doings and beings"—by which an individual can be evaluated for "quality of life and the capability to function" (Sen 2003:43-44). These functionings can be of any criteria, from the "elementary" to the complex, such as "escaping morbidity and mortality, being adequately nourished" and being able-bodied to "achieving self-respect, taking part in the life of the community and appearing in public without shame..." (Sen 2003:44). Groups of these functionings form an assessment of a person's overall well-being. In other words, an individual's quality of life can be analyzed by way of specific criteria decided by *X*. Their ability to pursue and achieve those criteria presents affinities and limitations in each, what Sen calls capabilities. Theoretically, it is a useful tool; however, it becomes even more slippery when placed in practice (for a broader, yet succinct discussion see, Selgelid 2016). Sen did not develop the theory to determine and "freeze" a list of capabilities by which all cultures and practices are evaluated (Sen 2005:158). Institutionally, a list of capabilities may be helpful in determining priorities and values, however, the theory is meant to be used reflexively, continuously informing and reforming discussions regarding, and practices of, development.

Rhetorically, a capability can also be considered as an opportunity such as the

opportunity to receive higher education or the opportunity to access nutritious food

and clean water. Thinking about capabilities as opportunities distinguishes "whether a

person is actually able to do things [they] would value doing, and whether [they]

possess the means or instruments or permissions to pursue what [they] would like to

do" (Sen 2005:153). Ability, of course, may depend on other intersecting circumstances,

such as physical or mental capabilities, outside resources, environment, and perceived

stigmas, as illustrated below. The capability model distances the theory from a person's

"means," such as their income and assets, and highlights how two people can have

widely different opportunities even when they have the same means. A capability lens

offers a deeper analysis of the everyday life where we can seek and understand the

precarious relationship between "commodities and capabilities," our economic wealth

and our ability to live as we would like (Sen 1999:619); it is being able to live long and

healthy, achieve the 'good life'—whatever those desires may be, individually unique, yet

collectively valued.

Sen (2005) uses the example of a disabled person and an able-bodied person,

both with the same income and assets yet they experience dissimilar opportunities or

capabilities to achieve the same goals (153-154). To further elaborate, let us consider

the two people above in a hypothetical situation. Both are seeking new homes and have

their eyes set on apartments downtown. Economically, they possess similar income and

assets and both can afford the higher housing and lifestyle costs of living in the area.

Physically, however, there are differences in capability. The able-bodied person does not

need to consider mobility in their housing plan because they are capable of moving

through the world unencumbered. The manager of the housing complex will most likely

be of a similar able-bodied status, and our house-hunter can anticipate being

considered as an intelligent, accomplished person. The person with physical disability,

however, must carefully consider how accessible their new home will be, as well as the

accessibility of the surrounding neighborhood. If the home or the neighborhood has not

been constructed in consideration of physical limitations, it may prohibit our friend from

living in that area. It is also possible they will have their other capabilities judged based

on their physical condition. Or they may experience prejudice and be turned away. This

example illustrates how the capabilities approach provides an opportunity to view social

life not through commodities or means, but through the subjective practice of everyday

life. Therefore, while they make look the same in terms of means, our two friends are

widely different in terms of capabilities, or opportunities.

      Capability is not only the opportunity to have various and successful functionings,

but also the freedom to make use of those opportunities or not. Having access to many

options and being able to choose which ones work best is an essential component of

the capability approach. Freedom, here, is about the extent by which a person is able to

choose, not what they actually choose (Sen 2005:154-155). In other words, it is being

able to assess all the options and choose which combination they desire. Let us consider

this using our two house-hunters mentioned above. After seeing the downtown

complex, they have both decided to compare other options resulting in a total of four

housing listings, two inside the city limits and two in surrounding suburbs. Our able-

bodied friend, who likes to ride their bike and uses public transportation, is not as

interested in the housing options farther outside of the city. After considering all their

options, they end up renting from the downtown complex. Our other friend has

seriously assessed the accommodations of each housing option and found the listings in

the city are not as physically-accessible and the suburbs more greatly meet their

physical needs. However, they, too, rely on public transportation and living in the

suburbs would result in an extra 30 minutes of one-way travel time. Although they

would like to live in the city where it is easier to travel to work and other activities, they

choose to live in a suburb where prioritized capabilities are met. As a result, our friend's

opportunity to pursue other meaningful and valued activities will be affected. In this

example, one person has access to all the options and can make a free choice, while

another has only half the options and must make a limited choice between functionings.

Even though one person ended up choosing the original option, through the capability

approaches lens, one person had less freedom and autonomy than the other because

they lacked access to some of the existing opportunities.

Capabilities, or functionings or opportunities, are inherently tied to all other

aspects of social life both on the individual and the societal level. A person's ability to

pursue different opportunities successfully can be assessed to distinguish quality of life

and available freedom. The capabilities approach is useful when analyzing experiences

beyond economic control and available assets, such as ethnicity or gender or mental

illness, to see deeper into what people value and how they navigate the structural

challenges of attaining their goals. When we use it to focus our understanding of

recovery from mental illness we gain a deeper insight into its implications, but also

unearth still missing pieces.

Recovery: Capabilities and Mental Health

The possibility of recovery from mental illness has been, and continues to be, an

advocated reality since the civil rights era. Individuals with direct experience and their

allies, as well as medical professionals, have worked tirelessly to promote dignified

recognition and equity for persons with mental illness, as well as their caregivers and

loved ones (for a greater discussion of social movements in psychiatry see Chamberlin

1990; Crossley 2006; McLean 2000, 2010). Though "recovery" has been included in

common rhetoric for some time, its definition and practice remains ubiquitous and fluid.

Starting in the '90s and blossoming after the millennium, new ideas of recovery

emerged through the development and practice of community-based consumer- and

peer-run mental health services. The medical definition of recovery as treatment

compliance and hospitalization assessment was being met with the idea of "capabilities,"

a self-directed practice focused on valuing what people can and are able to do in the

present rather than valuing resources they possess (Hopper 2007; Lewis, et al 2012;

Austin, et al 2014; Sen 1985; 1999, 2003, 2005). In this way, recovery is not only a

medical practice and personal emotional journey, but also a social and moral process of

dignity and recognition.

Recovery from mental illness has been described by social scientists as a

subjective process of active participation, a nuanced state of becoming where agency

and self-determination remain paramount for the necessary generation of the dignity

and hope needed to thrive in social life (Jacobson and Curtis 2000, Jacobson 2001,

Jacobson 2007, Austin, et al 2014, Myers 2015). Active participation in recovery, as

opposed to passive participation, is having the ability to make decisions for oneself and

to lead one's own life. The ultimate goal being to lead a life rich with value and

meaning, being able to participate in everyday life in socially valued ways. In institutional

settings recovery practices follow a developmental trajectory. They focus on establishing

hope and renewing senses of possibility, regaining competencies in skills and behaviors,

reconnecting with and finding a place in society, and mending or resolving past wrong

doings (Hopper 2007; Lewis, et al 2012; Austin, et al 2014). Individually, these practices

take different forms as they learn what works best for them and navigate their access to

different opportunities. Recovery is often considered a lifelong action of affirming and

reaffirming status as a stable, contributing member to the larger community. In other

words, recovery is about developing better practices and maintaining them to lead a

meaningful life.

Social research on recovery, largely taken place in consumer-run or peer-

supported organizations to analyze the practice and embodiment of recovery through

peer-support, found peer-support to naturally adopt an intimate agent-centered

approach (Austin, et al 2014; Lewis, et al 2012; Myers 2015). By using their own

experience to frame their expertise and embodying recovery practices, peers could help

others find their own path to recovery (Austin, et al 2014:881-883). The experience of

mental illness symptoms and system navigation is an important tool for understanding

how best to support another person having those experiences. Peer-to-peer is a

naturally level playing field where agents can see themselves in the other, empathize

with their present position and offer experience-proven support and aid. For example,

peers at an organization in New York City revealed how their recovery practices help set

the goals for others under their mentorship (Austin, et al 2014). Establishing and

maintaining a status quo helped peers see the possibility in their own futures and the

value they still possessed. Recognizing themselves in another was important for

understanding their own capabilities. Another study at "Open Arms" demonstrated how

"reciprocal support—where one is just as responsible for providing support as for

receiving it" fostered better recovery practices (Lewis, et al 2012:64). Being relied upon by others and recognized as a person someone could count on provided the opportunity for valued social recognition and fostered feelings of community and family. In a more recent study Myers (2015) described the intrinsic value of "moral agency," or being considered a person of value and deserving of "intimacy," or meaningful social relationships, the "oft-overlooked driver of recovery" (13). In each of these cases, peer support helped foster hope and meaningful relationships within their in-group, and perhaps an understanding of possibilities available to them "on the outside" (that is, outside of the mental health system); however, the practice of recovery is only possible if people have *access to* those real opportunities on the outside.

In her ethnography conducted within Horizons and their "Peer Empowerment Program," Myers (2015) revealed tensions between staff and peers as they tried to negotiate between their different definitions and practices of, and obligations to, recovery. Peers and consumers wanted to make their own decisions about their care and their life moving forward. They wanted to have control of their finances and spend their time in ways meaningful to them. Staff at Horizons wanted those same things for consumers and peers; however, they believed it could be attained if they actively participated in treatment and skills building to help develop responsibility, accountability, and work ethic. Whereas peers considered "empowerment" the necessary catalyst for engaging autonomous capabilities, staff considered it a "slippery" word

(Myers 2015:87). For staff, empowerment may provide the opportunity to make a self-guided decision, but it did not mean consumers had the skills or capabilities to make the "right" choice (Myers 2015:91). To be considered "recovered" in this organization, a person had to go through the steps of becoming rational, autonomous, and hardworking; this journey would prove their worth and value as an intimate member of society, but it was revealed at Horizons that many people failed in this journey to thrive on the outside and continued to survive within the mental health and justice systems (Myers 2015:155). While they had access to intimate relationships within their in-group, consumers at Horizons were unable to effectively access opportunities and relationships within the out-group where true "recovery" happened.

When we apply the capabilities approach to this case, and others, gaps are revealed in current understandings of recovery. Through the lens of the capability approach "equality, not healing" becomes the main operative (Hopper 2007). Having the ability to access opportunities for health care, skill building, intimate and supportive relationships, and gainful employment is predicated on more than participating in the mental health system, peer-run or otherwise. Structures of race, gender and class have been missing from many accounts, as well as aspects of poverty and other material deprivation. The paths to attaining resources and finding stable employment are often spoken of as entirely feasible, however, we can see from Myers (2015) and others accounts this is not the case (Hopper 2007; Lewis, et al 2012). The innovations needed in

mental health care are poorly attended to, as are the tools used in successful reform

(Hopper 2007). While this research project is unable to address all the above disparities,

I strive to include these critical aspects of structure and context.

*   *   *

The definition and use of recovery by scholars has been purposefully left open for

interpretation. As Sen (2005) warned against the solidifying of criteria by which to

measure qualities of life and available opportunities, so have social scientists left open

the possibility of various meanings. I use this to my advantage when analyzing the

discourse of persons participating within the sites observed (more detail to come in the

next chapter, methods). Therefore, the first question becomes an inquiry into the

cultural implications of recovery from mental illness. In other words, how has culture

shaped our ideas of recovery from mental illness? I expect to find evidence of recovery

as a necessity, as something a person should be pursuing if they experience mental

illness. Just as a person with cancer is expected to fight it and attempt to overcome, so

too is the expectation of the person with mental illness. I also expect to find evidence of

recovery as a deeply individual process. The moral contradictions inherent in those who

possess stigmatized qualities (Goffman 1963) would necessitate their need to prove

their worth to society and accomplish recovery from mental illness on their own. This

would innately leave some incapable of attaining recovery, particularly for those who

experience severe (and often less understood) cases of mental illness such as severe

schizophrenia and bipolar disorder. For those who occupy multiple oppressed groups,

such as having a severe mental illness and being Black or LGBTQ+ or poor, attaining

recovery on one's own will be even more structurally difficult to achieve. Though I

expect recovery to be a goal for many people participating in the sites, I also expect to

see accounts of people who deny the need for recovery. I believe some will be outraged

by the societal expectations of recovery, and these persons will advocate for the

acceptance of the individual as they are. It is these individuals who call into question the

need for recovery and in so doing illuminate the controversy within.

Recovery is not merely clinical, but cultural and social. The repercussions of

having mental illness are widely known, which is why recovery is so fervently sought. The

heroism of overcoming a crushing obstacle, like mental illness, tends to seem inherently

positive. Trials and tribulations along the way are all glorified in the wake of victory. Yet

for those with mental illness, trials and tribulations may be all they have as they attempt

to prove they deserve recognition, respect, and opportunity. Therefore, I analyze

recovery deeper still to ask a more pertinent question: What are the contradictions in

the practice of recovery? Is it truly about wellness and health, or about performing in

appropriate ways? By looking intently at practice as a moral process we may begin to

understand the social experience of recovery and the cultural implications therein.

3. METHODS

As an exploratory project into the discussion and views of mental illness recovery

as told by persons deemed mentally ill, I chose to utilize sites and data found online

within advocacy based forums—National Alliance on Mental Illness (NAMI) and

MindFreedom International (MFI)—to investigate the implications within the culture of

mental illness recovery and the contradictions within its practice. The Internet, as a

communication tool, was typically discussed in a utopian/dystopian fashion, but it is not

devoid of valuable meaning (Baudrillard 1994), and provided for me a whole other arena

to study and consider for my fieldwork. Digital media has been instrumentally important

to the process of knowledge production and community building within disability

communities (Ginsberg 2012), and those who have been categorized as such. Digital

ethnography gained momentum after 2000, and has included attention to the use of

social media as a tool for community and political engagement (Hookway 2008; Mitra

2010; Horst and Miller 2012). This online landscape, I believed, would provide a place for

persons with mental illness to gather and express themselves in a supportive and safe

environment. I utilized discourse analysis and grounded theorizing (Hammersley and

Atkinson 2007:159) for my methodological approach to determine the themes and

metaphors used by persons with mental illness to describe their philosophy and practice

of recovery.

I considered these places immersive and believed they would generate a wide

range of experiences and philosophies about mental illness recovery. I assumed,

because the narratives were posted online, the participants of the sites would have internet access and the ability to type and communicate their experience in this type of platform. I also assumed people would be influenced by the sites ideologies and operations, or they would gravitate to a place that held similar viewpoints or expressions like their own. Therefore, the narratives and stories I would find within the sites would naturally adopt similar genres or themes. It was also possible the narratives would not conform to the ideologies of the organization in a significant way, and instead shed light on a different kind of social subversion in cyberspace. I did not expect the groups within the sites to be homogenous or for every member to consider their experiences—and what should be done about them—in the same way (Horst and Miller 2012:1-2), and suspected people participating on these sites might also be engaged in counter active ways to the dominant social and political contexts of the greater United States. I anticipated for participants on NAMI to feel more secure in their treatment and their relationship to psychiatry, although I also expected to find some discourse about alternative recovery options beyond pharmaceuticals exclusively. On MFI, I predicted more outrage and concern with psychiatry and treatment with demands for greater self-determination, and autonomous decision making. The most prominent demand I expected to see in this site, however, was the recognition of their dignity as rational human beings.

There are, however, some important differences between a physical site and a digital site, such as lack of physical, in-the-moment evidence and the inability to measure honesty. Because the author was in full control of the narrative, which was told ex post facto, there would be certain information to which I would not have access. Goffman (1959) told us to be aware of the "stage" (244). Because online narratives must be taken at face value, and are open for viewing by anyone, the author may be staging their life-episodes to frame themselves in a desirable way (Hammersley and Atkinson 2007:124; Wikan 2000:229). That is, they may not tell the whole truth, and it would be next to impossible to tell. Hookway (2008) argued against this idea. He claimed the anonymity of online forums, such as the use of nicknames or pseudonyms, let the author wear an "online mask" which would allow them to speak more openly and candidly about themselves (Hookway 2008:96). He even went a step further to ask: "Does it really matter?" (Hookway 2008:97). For the sake of this study, I granted the authority of experience to the authors of the narratives and did not believe in the presence of intentional deceit. From a feminist standpoint, I observed their narratives as personal and cultural truths expressed by those who had often been told by those with greater power their experiences were exaggerated, misinterpreted, or personally unfathomable due to their mental illness status (Estroff 2004; Hammersley and Atkinson 2007). I came to these narratives believing the author knew their experiences better than I did, and I took them at their word. I assumed their narratives were their truths, and did

not spend time questioning their validity. Therefore, the question of honesty was irrelevant.

Data Collection

The exploration for my online sites involved searching for key words like "psychiatric survivor" and "mental illness advocacy" using 'Google,' a well-known and reliable search engine. I chose this language purposefully to explore beyond the medicalized meaning of mental illness recovery and into the complex cultural and social nuances of its use. The history of psychiatric survivorship and advocating organizations will not be covered in this research (again, for a greater discussion of social movements in psychiatry see Chamberlin 1990; Crossley 2006; McLean 2000, 2010), but their organized experiences with mental illness and the mental health care system not only helped to shape the emergence and evolution of recovery within the system and the community, but also the opposition to that growing ideology and practice. The variances in conceptions of mental illness, treatment, care, and recovery, I believed, would provide rich material for understanding its intricate cultural and social inflections.

Quite a few websites were uncovered; however, many of the sites were either no longer active or had very little activity in the six months prior, or they required me to create a username and password to partake in the community. Following guidelines within the ethics discussion hosted by the Association of Internet Researchers (2012), I

purposefully shied away from the sites requiring this type of user sign up, which

suggested to me greater privacy and user monitoring, and looked still for public

webpages and community exchanges. MFI was one of the first pages to come up

harboring an open site when searching 'psychiatric survivor,' and while I had known of

NAMI before this project, I was pleased to see their chat area was open to the public as

well. Again, I chose these sites because they were widespread throughout the country

and had been operating successfully for quite some time. Their web pages were up to

date, but most importantly, people were utilizing the sites as a place to express and

discuss their experiences with mental illness, stigma, and recovery.

Data was collected from each of the sites during the fall and winter of 2015. I

collected 210 narratives: 107 from MFI and 103 from NAMI. I read more material than I

gathered for inclusion and analysis while looking for cases which related closely to my

initial questions. I acted as an unobtrusive observer exploring the landscape and

conversation to get a feel for the context and practices of participation, as well as to

root myself within the sites. I collected what was already present, and did not make any

attempts to deceive the users of the site by, for example, posting my own narrative of

mental illness experiences, 'liking,' or 'sharing' their posts through my own personal

online media. I chose this "lurking" method of intense observation— "reading...without

taking part" (Day and Keys 2008:6)—to be respectful of a sensitive population sharing

their experiences online. To ensure nobody would be identifiable from the analysis,

names and pseudonyms were removed along with any other information that may lead to personal identification, such as physical location and post title.

Site Formatting

Site One: NAMI

The formatting of each of the sites was quite different, both stylistically and contextually. NAMI's page had a more modern style and feel with soft edges and eye catching interplay with links and resource pages on the site. It opened with upcoming news at the forefront, and more news as you scrolled down the page. Site links resided along the top, with opportunities to 'Learn More,' 'Find Support,' 'Get Involved,' or 'Donate.' Under a link titled 'Get Involved' was another link to 'Share Your Story,' which led to their two web-based campaigns. "Ok 2 Talk" and "You Are Not Alone"—NAMI's two forums—were dialogical, directed toward youth, and both focused on talking about mental illness and health experiences. Getting young people talking was an important advocacy tool NAMI highlighted "because of the stigma attached to mental illness, it's often hard for those suffering and their families and friends to talk about what they're going through." Openness about one's feelings and experiences was deemed the first step to finding the courage needed to reach out and seek help during early onset of illness. Further, if "cultural knowledge is accumulated only as it becomes relevant to one's life" (Wikan 2000:223), then this platform was also about providing specific cultural

knowledge to people who were just coming to understand what it meant personally,

socially, and culturally to have mental illness. To frame the moral character of persons

with mental illness, NAMI upheld that mental illness was "essentially biological in

nature...not behavioral,"[5] condemned stigmatizing remarks and behavior towards

persons with mental illness, and encouraged people to be open about their mental

illness and stigmatizing experiences. If mental illness was not a "failure of character and

will,"[6] and if people were speaking openly about their mental illness, then mental illness

conditions and treatments would no longer be hidden, shrouded in mystery, and feared,

but out in the open able to be viewed as a regular and common experience.

These campaigns were bridged to another social media site, Tumblr (tumblr.com),

which focused on microblogging: the sharing of multimedia, hashtags and other content

in short-form blogs. This website, which has been targeted for use by youth or college

aged persons, provided greater access and, perhaps, a less intimidating (i.e. familiar)

space in which young people could share their narratives, images, and personal feelings.

The layout of the campaigns on the NAMI website adopted a similar feel as Tumblr with

each rectangular post being arranged Tetris-style on the page. Larger posts were

condensed with a prompt to 'read more.' Each post, even shorter ones, could be opened

individually to read on a bigger screen, and to see associated hashtags, likes, and shares.

In this way, talking about one's own experiences, as well as interacting with the

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[5] NAMI Policy Platform, revised 12th edition. 2016:3.
[6] NAMI Policy Platform, revised 12th edition. 2016:3.

experiences of others', was deemed an important tool to uplift the community and

normalize mental illness and treatment as a regular medical experience. Within most of

the narratives, however, people had not yet been able to access mental health care

services or elicit help from friends or family. They were struggling, hidden, and fearful of

the ramifications of coming out.

Site Two: MFI

MFI's site had a straightforward feel to it with stark lines in geometric patterning,

a remnant of early start up pages and those managed on smaller budgets. Their main

page included site links lining left featuring their campaigns, alternatives information,

advocacy handbooks and webinars, and FAQs. Links with their mission statements,

media, and ways to get involved shone in deep bold along the top of the page.

Cascading underneath were recent news stories, places to donate, and brief member

features through "We are MFI." Under 'MFI Campaigns,' the MFI forum—I Got Better—

was the first of many listed, but it was the only one offering the opportunity for

community members to share and partake in each other's experiences.[7] The campaign

focused on narratives of recovery, hope, and resilience to change the dominant social

narratives of mental illness being a hopeless, chronic affliction. MFI believed that sharing

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[7] The campaign offered the opportunity to share stories and videos; however, at the time of my data collection there were only a few videos, which led my focus to lie in the narratives. They have since added many more totaling over two dozen.

one's story was an act of advocacy and testimony that would not only help encourage

others with mental illness to stay hopeful and on the path to a thriving life, but it would

also help change societal perspectives towards persons with mental illness. The focus on

recovery was important because many people with mental illness receive the message

they are not going to recover, but be dependent on psychiatric medication for the rest

of their lives.

The narratives were individually listed links featuring a title and moniker, and had

to be opened to be read. In this transitory way, it was almost like you were opening a

door, or turning a page, like you were being invited in. The tone of these narratives

stood in stark contrast to NAMI. It was a declamatory platform rooted deeply in moral

and political ideologies of recovery and resilience, not only from mental illness, but from

the treatment they received within the health care system. Testimonies to the possibility

of recovery, of creating a life of their own making, was powerful in creating the

opportunity to bear witness. In the telling of their stories, the authors were prompting

readers to *do* something to change the world around them; and in the reading of the

narratives trauma and healing were empathetically witnessed (Mattingly and Garro

2000). This kind of advocacy became crucial in the attempt to normalize or subvert the

experience of mental illness, defend those in the system who were under maltreatment,

and provide education and representation for those seeking healing and community. As

veterans of themselves and of the system, it was here, in the presentation of their

survival stories, they imparted cultural knowledge about mental illness and recovery for those entering, leaving, or still a part of the mental health system or volatile social environments.

Data Analysis

A "grounded theory" (Hammersley and Atkinson 2007:159) approach was used to allow dominant discourse patterns to emerge naturally. The language in the narrative were first analyzed around descriptions of stigma, recovery, and care with an interest in the telling of their social interactions. I focused on how they discussed their experiences with mental illness and treatment, both personally and socially. I then explored strategies or methods used to talk about and perform recovery. Finally, I investigated how these might reinforce or subvert normative ideals about mental illness and health. Through this analytic trajectory, the focus on the implications and cultural practice of recovery evolved.

To achieve ethnographic familiarity with the data, they were read repeatedly. A printed set was created for the beginning stages of the process; the ability to physically write notes on the paper as it was read was a process which helped to ground me in the narratives, themselves. This printed set was used for open coding strategies, which sought identity markers, temporal orientation in real time and narrative space, and their social experiences of illness, as well as broad patterns for investigation. The data were

also stored and further coded utilizing the CAQDAS (computer aided qualitative data analysis software) (Hammersley & Atkinson 2007:154), "NVivo." The data were thematically clumped into various groups like "peer support," "religious faith," "self-determination," and "self-help." Then, each group was analyzed and coded for similarities, contradictions, and further overlapping themes. The printed and digital copies were reflexively used to compare notes and deepen the analysis. This process was repeated until prominent discursive patterns were revealed. From there, a theoretical account of the patterns was developed.

Two major patterns and foci were identified. One in the first-person thematic discourses of recovery itself as a clinical experience, a soul level transformation, a form of justice, and as a social phenomenon. The other lied in the subtle ways which the narratives worked to reinforce the normative cultural ideals of mental illness by portraying the bootstrap method of recovery. However, in so doing, they also subvert mental illness as a personal, debilitating disease and demand acknowledgement of the true disease: social conception.

Limitations

There are, however, some important boundaries of my research and methodology, which must be considered to understand the scope of this project. First, this project was not intended to be an ending to a long line of academic endeavors, but

rather a beginning to a different line of inquiry. As such, it naturally adapted an exploratory approach, which, for cultural anthropology, threatens to leave the analysis more shallow than deep and enriching. Second, the use of website narrative data rather than in-person interviewing necessarily lost information pertaining to identity and experience, as well as inferences like body language (Wikan 2000). Understandably, digital convenience costs in face-to-face engagement. I will not be able to explain stylistic or performative differences between the online communication and the actions of the individual outside of their participation in the site. My use of discourse analysis methodology helps to reiterate the fluidity and flux of narrative, the continuous process and variation that accrue over time. I do not seek to make definitive claims through these narratives about mental illness experiences, but to further elucidate conceptual models so the research moving forward is done with intentional and thoughtful inclusion of the first-person perspective. Finally, while this study takes place in forums found within socially active groups, the present research will not be considering the efficacy of anti-stigma campaigns or saliency of social movements, however these are necessary and worthy endeavors for future consideration. Given the outcome of this project, more could be done to understand the social experiences of mental illness and recovery interplay between offline and online, as well as digital inclusiveness in social movements. Further, because the sites utilized operated on a national level the cultural context remained broad, and should not be used to generalize specific community

experiences; however, it may be a useful comparison or foundation from which to build upon.

4. DATA PRESENTATION

The diverse array of age groups found within the two sites I investigated led me to analyze the experiences and developments within different generational groups. A review of the narratives presented on the sites led to the appearance of distinct themes, which I analyzed on a spectrum of stigma to recovery: from uncertainty, fear, and shame of having (or the potential of being diagnosed with) a mental illness to an acceptance, knowledge, and self-awareness that allowed some individuals to regain their autonomy, practice recovery, and thrive. National Alliance on Mental Illness (NAMI) forum users were confessional and tended to focus on their social relationships, especially on the potential fragility and devolvement of that support system if or when their mental illness was brought to the surface. Conversely, MindFreedom International (MFI) forum users were more declarative as they looked back on past experiences with mental illness and the health care system. They tended to focus on their own personal, autonomous development, especially within their struggle to break out of harmful family and psychiatric holds. Using case studies, I outline and illustrate experiences of stigma as a foundation for understanding the culture and process of recovery. Though the cases are categorized and separated, the narratives in both forums carry common discourses of

resilience and strength, made more remarkable when it is perhaps easier to be ill, as one

person on MFI remarked: "It is sometimes easier to just give in, accept that label, and let

yourself be mentally ill. Then no one expects much of you, and you can't disappoint

anyone. You might even be eligible for SSI—free money." The real question then

becomes, at what cost?

The cost of the future is grappled in each post and case study I provide, but it is

always toward the future that people are oriented. It is this practice of moving between

one end of the spectrum, stigmatized and ostracized, toward the other, conscious and

recovering that is most interesting. They are not intending to return to the person they

were, but are concerned with becoming more than they, and others, believe themselves

to be. It is this desire for a future — a prosperous and lively future — that drives people

to question their current state and to take the risks required for true self-discovery and

evolution. I speculate, then, that recovery is much more than the clinical management of

illness symptoms or a societal expectation. Recovery is a complex and layered practice

of cultural and moral performances. It is a lifelong exercise in self-presentation and

adversity politics where it becomes important to understand the systems in which they

live—the systems that uphold sexism, ableism, homophobia, and poverty.

An Uncertain Future

First Person Narratives

"...the stigma makes it harder to try and accept yourself for who you are..." –Anonymous, NAMI

In the first-person narratives throughout the NAMI sites, people struggle to understand what their emotions mean and why they feel the way they do. At the same time, they are distraught over what others might think of them. Their speculative discourse includes possible diagnoses and uncertainty in revealing how they are truly feeling with those closest to them, typically parents and friends. Most narratives express a deep shame in even the possibility of having a mental illness, which leads them to remain silent about their emotional suffering. The fear in revealing their anguish lies in the idea that there will be a stigmatizing response from their loved ones, such as the idea their loved ones will think mental illness is somehow a choice or a lack of moral character, whereby they will be treated differently or abandoned by their family. They confess their desperate desire to reach out for help and to divulge how they are feeling, but the fear of losing their social connections and supports holds them back and leads them deeper into hidden emotional despair. This fear is similar across most facets of social life, including within places of education and employment. Should their illness interfere with their employment, it is believed that it would lead to losing respect and opportunities at work or losing their job altogether. To understand these perspectives more clearly, I will elaborate using two cases from the NAMI sites, the authors of which I will call Anya and Beata.

<u>Anya: The Lone Warrior</u>

Anya wrote on the NAMI *Ok 2 Talk* page that she began experiencing depression

before attending high school, a "battle," as she calls it that led her to believe she would

not survive beyond her 16th birthday. It is a battle that continues now as she studies at a

University. For her, depression feels like "my mind is attacking me and there is a dark

cloud over my head to the point where I cannot even think and half the time I'm on the

verge of tears." Anya feels like she is turned against herself, sabotaging every moment

without reason or clarity. Even though it is *her* experience, she still finds it difficult to

articulate, having been unable to truly discuss with another person what she feels. When

she has made attempts to do so, the reactions from family and friends were

discouraging.

> "I want them to accept me, so I don't have to always keep my emotions
> hidden or be extra cautious about saying how I feel in front of them,
> because they'll wind it down to me being "crazy" and or "extra sensitive". I
> want my friends to understand. I don't let many people know of my
> struggles because of the stigma behind it, so only a handful of my friends
> know, and they still know very little. I've been able to open [up] a lot to my
> best friend, but even then I'm still cautious, because I feel like my disease
> may drive her away."

By revealing less about her experiences with depression, Anya feels like she is less

burdensome to her support system and less burdensome to her own mind. Because she

already struggles with her symptoms in addition to keeping them hidden, she sounds

exasperated with the idea of opening up only to have her concerns dismissed as "extra

sensitive." It would be too much to also bear the questions or looks or reprimands from

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those she cares most about. What she uses as a tool for personal survival also feeds her

illness. Her isolation and bottling up of her emotions leads only to her own torment,

eventually releasing in even more harmful ways, such as self-harm and anorexia/bulimia.

More than anything else Anya wanted her mental illness to be recognized as a

medical condition, a disease, so she may begin to become well with the support of

those around her, which is why it is so much more hurtful to her when people see her

depression as a choice.

> "The worst part of depression is being alone in your disease. No matter
> how hard you try, your friends and family just don't get it. Even the ones
> who try their best to listen can never really understand the dark whole
> your mind is trapped in. All I want is for them to understand. I want them
> to understand that THIS IS NOT A CHOICE. I want my family to understand
> that I am not defective, or crazy, or whatever they may think. I have a
> disease, no different than my mother having cancer."

Much of Anya's anger in her post comes from other's responses to her behavior or

dialogue insinuating that her depression is a choice. According to her mother, Anya, if

she wanted to, could simply stop being depressed, could stop acting out in harmful

ways, could communicate and interact with others peacefully, and could fulfill her

responsibilities as a young adult like everybody else. However, this is far from how Anya

experiences her depression. For her, depression is like a brain disease — a mental

cancer. When a person has cancer, or other debilitating disease, the family comes

together to support them in their recovery. They rally to keep up morale and strength,

to give their loved one something to fight for. Unlike depression and other severe

mental illnesses, cancer typically has an end. With treatment, the cancer should die away, leaving the person well again. However, when we consider a person with severe depression, as in Anya's case, it is typically thought they may never be fully well again in the sense that treatment is no longer required. Certainly, treating and surviving cancer is not so neatly packaged. Even if a person does become well, they may have to make significant lifestyle changes to help prevent further disease from occurring. Anya wonders how her depression is any different from a disease like that?

Beata: The Silent Mother

Beata told the readers of NAMI's *Not Alone* forum that she has experienced depression for as long as she can remember—from girlhood to adulthood—and it has come and gone in varying intensities and effect. She has grown to become a fiercely dedicated working wife and mother of two young children while continuing to juggle depression's "three personalities," a trio of debilitating symptoms comprising her illness that she describes as "The Baster, The Filter, and The Weights." The Baster fills her mind with "darkness, despair and hopelessness;" The Filter "removes all color from the world" rendering it only in shades of grey; and The Weights hang off her limbs and ears making it "hard to move, hard to breath, hard to put one foot in front of the other." Beata describes her depression in the sense of physical symptoms that limit her ability to focus, see, and move in her world. It renders her unable to participate fully in an

otherwise incredibly successful life, a life being lost to her need to cover her symptoms

and true experiences.

At the time of her entry, the weights had grown too heavy and Beata felt as if she

had nowhere to turn:

> "People in my life don't understand depression. They look at me and I can tell
> they don't get it. The only exception is my mother; but she's hopefully forgotten
> those times, and I don't want to send her back there. So maybe if I explain how
> depression feels, they'll start to understand."

Beata describes her life as being truly blessed. She describes a happy childhood and

young adulthood free of trauma. The family she is building is full of love, and she and

her husband are each successful. They are even trying for another baby. It is the life

everyone dreams of having, Beata says, "except depression-free." It is a life requiring

much of Beata, and though she wants nothing more than to be there for every moment

and need, much of her time is consumed with covering her symptoms and passing as if

she is fully present in her life. In her excerpt, Beata asked the reader, "How can you tell

when a person is depressed?" and replies with a defiant testament to her ability to pass

as the contrary: "You can't. We're some of the strongest, bravest, most resilient people

you'll ever meet. We could take out Vegas with our poker faces. But it's all an act." Her

reasons for the act echo similarly to Anya's, a lack of understanding from people who do

not have depression and a fear over losing those they try to let in. Additionally, Beata

feels tremendous gratitude for her life and its success, which only makes her feel worse

for having depression and allowing it to get in the way of enjoying and being present

for herself and her family.

The act she displays, however, is exhausting. It is hard to cover and perform when

you have been doing it for years, when symptoms are at their peak, and when other

people are relying on you. Where Beata perceives her family to be more understanding

than most, she assumes her employer will not, and the consequences for the inability to

perform at work may mean a debilitating loss of financial security, as well as

professional dignity. She elaborates:

> "The hardest part is the pretending. Putting on a brave face. But "fake it to
> you make it" so does *not* work. Especially at the office. If I had a full-body
> cast, I could say, "I'll be a couple hours late today – running slow." Or, "I
> need some damn time off!" But if I say, "I can't stop crying, and getting in
> the car to drive to work feels like the hardest thing I've ever had to do, and
> I really, truly, don't know if I can get out of my pajamas today," they'll think
> I'm emotional basket case, and a slacker. Even those who try to
> understand would view me differently."

Whereas Anya considered her depression like a physical disease, Beata sees her

depression as a moral impairment she should be able to keep under control to

manage the responsibilities of her life. Though it was not something she chose,

depression is not something to be put out in the open for other people to

manage, support, or treat. Beata is to take charge of her life, prove she is not a

"basket case" or a "slacker," and uphold her end of her social, familial, and

institutional contracts. The fear of losing those she loves and is loyal to drives her

forward. If she can keep up her appearances, then no one should know about her

silent sorrow of feeling like she is a thousand miles away from the moments in

her life. If she can maintain the façade, then no one should know about how bad

her depression has become.

Third Person Narratives

"Its so confusing for those who love you. Sometimes I wonder if it's more
challenging for us than for the person who is living inside a mental illness."
–Anonymous, NAMI

NAMI also featured the narratives written by caregivers or closely

connected relationships to persons with severe mental illness. Romantic partners,

parents, and friends are also fraught with uncertainty and frustration for caring

for an ill person, but also in how they, too, are supported through such a process.

Many expressed a lack of understanding about mental illness and how to help

loved ones; it being so difficult to truly know another person's experience and the

motivations behind their actions. Is this them acting right now, or the illness?

They also discuss being alone in their caregiving responsibility; for example, a

mentally ill family member remains the responsibility of the family rather than the

community coming together to support their neighbors in their caregiving needs.

In these narratives, they seem to be telling us how much easier it is to forget that

those caring for someone who is ill also need support. They may not have mental

illness, yet their experiences are stressful and, sometimes, traumatic. They, too,

are calling for recognition. They, too, are asking to be accepted.

The first case study below features a parent, whom I will call Carl, unsure

how to help his child. In the second, Diana recounts her husband's daily struggle

to maintain both his caregiving and institutional responsibilities. Through their

narratives, we will be able to understand the struggle of the caregivers, as well as

gain further insight into the lack of moral support for people struggling with

severe mental illness.

Carl: The Exasperated Father

Carl is a hardworking man who strives to do right by his family and provide

opportunities for his son's success — a real traditional bootstraps[8] kind of man. His son,

however, has always been "different." Carl describes him as being a physically

uncoordinated child compared to other kids his age, which led to him being bullied by

his peers. At one point, the bullying escalated into a horrific sexual assault, after which

Carl's son completely shut down and Carl almost lost all hope as he watched his son

blankly and carelessly drift through his youth. Carl, however, thought he could provide

the opportunities his son needed as an adult. As his son reached adulthood, Carl

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[8] I use this metaphoric phrase—"bootstraps" or "pull oneself up by their bootstraps"—to reference a self-sustaining process, or a person who prefers to use their own resources and skills rather than seek outside help or assistance.

expected him to work for himself and more greatly contribute to the family household

in which he was living. However, in similar patterns as before, Carl watched his son

languish and be taken advantage of. When his son became severely delusional, Carl's

frustration and helplessness rose as they devolved into ceaseless shouting matches.

Unable to communicate with each other, Carl did what he thought was best:

"It got so bad, that I had to put him out. He lived in a shelter for a while,
but even the shelter would not tolerate his unruly behavior. I got divorced,
and he got disability and moved in with his mother. At least I knew he was
safe..."

Carl's greatest frustration lies in his son's own inability to care for himself or perform his

social obligations like other people. Even when Carl found jobs for his son and handed

him everything he believed his son needed to succeed, he could not understand why his

son was unable to perform the work. Carl does not understand his son's delusions or

where they come from, rather, they are an excuse for his son to not have to fulfill his

responsibilities. In his bootstrap way, Carl expected his son to pick himself up and march

on. However, the strife between them continued to escalate, which led to the

dismantling of Carl's marriage to his son's mother. Though Carl, in some way, knows his

son is mentally ill he is unequipped to support him in healing his past traumas or

empower him to take charge of his life.

Towards the end of his entry, Carl discusses reconciling with his son's mother.

Once again, they are all living together under the same roof and experiencing the same

problems. His son's delusions are constant, and he is "making life unbearable." Carl,

once again, feels frustrated and helpless:

> "We have no peace in the home, he won't pick up after himself, shouts
> profanity at me if I try to get him to clean up his messes or do anything
> constructive. I have two choices–I either continue this way, enabling him to
> do nothing constructive, and to avoid getting the help he needs, and allow
> him to make us miserable, or put him out so he can live under a bridge
> somewhere."

It is evident here that Carl does not believe he is able to help his son any longer. He

cannot provide for his son the stability he needs to take care of and provide for himself.

The care he needs seems to exist somewhere else, in a shelter perhaps. Carl does not

seem to have any knowledge of therapy options or doctors, and never once mentions a

possible or confirmed diagnosis for his son. Turning to his religious faith provided no

answers either:

> "I hope that [there's] another alternative, although I haven't found it yet.
> So far, my prayers have gone unanswered, and there is no human help
> either. I have given him a deadline to find another place to live. It will hurt
> like hell to have him removed from the premises, but I don't see another
> alternative. This is hell. And it never ends."

It is apparent Carl is not attached to community mental health services or resources if he

believes his only option is to remove his son from his home, or has negative feelings

toward hospitalization as an option for care, however, neither of these is mentioned in

the post. What is incredibly clear is how heartbroken Carl is in implementing such an

ultimatum. He is worried about his and his wife's wellbeing, as well as his son's, but is

certain he cannot provide the help his son needs. Once again, Carl is trying to get his

son to take up his responsibilities in the only way he knows how: by digging in your

heels and getting to it. He does not understand how his son's past trauma and illness

affects his ability to complete those tasks and obligations, and believes if he removes all

comforts provided for him that his son would understand what he is supposed to do.

Carl hopes, in some way knowing it is not simply going to 'click' for his son, that

someone will find him and be able to provide for him the care and support he needs.

Diana: The Woeful Spouse

Diana's husband, whom I will call Eric, is the main supporter and caretaker of

Diana and their family, and works in the software entertainment industry. His position as

team leader requires him to "maintain morale and lead by example," while spending

long hours working tirelessly towards strict deadlines on various projects. Diana

revealed in her NAMI narrative her experiences of severe Bipolar Disorder, separation

anxiety, and chronic suicidal urges, symptoms and needs that compete dangerously with

Eric's demanding work schedule. Not only is overtime expected of him, but the positions

typically do not come with health insurance and, if the project slows or wraps up, layoffs

loom on the horizon causing stress and strife within their family. In her narrative, Diana

questions the weight of her burden on her spouse and main support system and

wonders if she is holding him back on a fuller life as Eric's demanding work conditions

conflict with his caretaking responsibilities.

Diana laments how her illness has "affected his [Eric's] work performance

drastically" and they have experienced "mental illness of a spouse" to be an increasingly

problematic reason for Eric needing time off:

> "...as soon as my husband...requests time off [to take care of his wife with
> mental illness]...his performance/attendance thereafter is immediately
> scrutinized. Instead of receiving support as if his spouse has an illness, he's
> seen as a liability. This was not the case with another employee there
> who's wife had been diagnosed with cancer (is doing well now [thumbs up
> emoji]). The entire company rallied around him, raised $$ for her
> treatment, gave him deserved and fair leniency as far as attendance. It was
> clear that this disease was taken seriously, no one's character/work ethic
> was in question." (brackets added by E. Albert)

In the excerpt above, Diana questions their institutional support by wondering why a co-

worker's spouse's illness is more accepted and appreciated than her own. Is not her

distress—and that of her husband—legitimate? Are they not as hurt and as tired as the

other family? Is the threat of harm and death not just as possible with Diana as it was for

the other person? Are they really asking too much? With the precarious nature of Eric's

industry, adding greater caregiving responsibilities creates an even more tumultuous

balancing act. It seems as if he is dropping responsibilities on all sides: at work for

requesting time off when 50+ hours weeks are expected and at home where his wife

and children need him physically and emotionally. Eric's family also relies on his income

to support them. Any hint at a loss of his job causes tremendous stress on everyone.

Because it is her illness that requires such large emotional support, Diana feels

responsible for Eric's failing at work even though she also feels it is unfair treatment on

them both. Since Eric's job already does not offer health insurance to help support

himself and his family, Diana feels the institution could, at least, try to be more

understanding of Eric's caretaking responsibilities. Meanwhile, Eric is in the middle trying

to make it all work.

The stress of juggling these responsibilities has brought Eric and Diana to a

difficult place: Eric wants Diana to start ECT[9] (electroconvulsive therapy) treatments to

help manage her severe Bipolar Disorder. In her telling of this, Diana responds bitterly

and lashes out not only at the institution, but also towards Eric. Not only will they have

to purchase health insurance, they will also have to meet demanding deductibles. Will

Eric's job rally to support her treatment now? Will ECT really change anything, or will it

only make everything more demanding? Diana is not hopeful:

> "…my husband will only receive judgement and scrutiny for missing time
> at work, after my ECT treatments, because I'll be basically useless. How can
> I be when I have four kids? I feel I'm planning to fry my brain, greatly
> affecting my functioning, memory, availability to others (expecting a
> grandchild end of this November)…just for his job. Just so he can keep
> working in the industry. He just wants to fix me so he can keep working.
> He keeps telling me it wouldn't matter where he worked, I would still be
> bipolar, and have all of these issues."

Diana portrays Eric as believing the ECT will help manage her illness, but Diana believes

she will be of even less help than she is currently. The after effects of ECT will leave

Diana further debilitated and languid; she will not be able to take care of their children

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[9] ECT, electroconvulsive therapy, is a treatment administered under general anesthesia whereby small
electrical currents are passed through the brain resulting in a momentary seizure believed to reverse the
symptoms of some mental illnesses. (www.mayoclinic.org, accessed August 18, 2016)

and Eric will need more time off work to help her at home on and after treatment days. Eric's suggestion for the treatment presents itself to Diana almost as a betrayal; Eric only wants to fix Diana so she will be less burdensome and he can get on with his life. Diana already feels like she is trying hard to be supportive and in control of herself, and worries that ECT will prohibit her from maintaining any semblance of responsibility for herself or her home. Yet, she is considering the treatment for the sake of her husband, a person she feels most burdensome towards and a person she wants to see the happiest.

It is clear both Diana and Eric are frustrated, feeling like there are very few options available to them. Where they once found strength, there are only feelings of burden and strain. Eric struggles to juggle demanding work responsibilities and his passion along with his caregiving responsibilities at home. Diana is struggling to be more independent to alleviate some of the burden on Eric, going as far as seriously considering a potentially debilitating treatment she would not have chosen for herself. Among it all, Diana considers the institution's responsibility to support their employees. Why was Eric's coworker supported when his wife had cancer, but Eric himself is not supported when his wife needs care? How are they going to support themselves and their family with the added burden of expensive health insurance and ongoing medical treatments? Will the institution care about their suffering at all? Or will they simply find another person to take Eric's place? In her narrative, Diana's greatest fear comes to the surface: she knows she cannot live without Eric, but can Eric live without her?

<p style="text-align:center">*   *   *</p>

In each of the four case studies presented above, whether it was written by a person with mental illness or a caregiver and loved one to a person with mental illness, they are in even greater anguish about the possible pain they are causing to their loved ones. People with mental illness are agonizing as they hide their true feelings and needs from their family, worried they will be too much of a burden or too difficult to understand to receive help. They are worried their families will disown them and worry over what would happen to them if they lost their support. In Carl's case, we can see how a caregiver, in this case a parent, can become overwhelmed by the effects of the illness. Lines are quickly drawn without understanding where mental illness comes from, why it occurs, and how to help someone through psychosis. These walls, built on both sides, create a tragic sense of loss. People with mental illness feel like they are losing themselves to their illness, but also to their families as they move through life wearing a mask to hide their true selves. Caregivers feel as though they have lost loved ones to the illness, the psychosis being too severe and thick to see how the person they love could ever come back from it. Everyone, it seems, feels ashamed for not being able to meet the expectations and needs required by or believed to be required by those closest to them.

<u>Finding Courage: Power Within Fear</u>

"I can trace now how systematically, I was taught to believe that I was defective and sick...I no longer subscribe to that lie." –Anonymous, MFI

In some cases, there comes a point where enough is enough. Enough hiding, enough fear, and enough feeling like they are on the brink of losing themselves. Though fearful and confused, the human spirit and desire to thrive could not be quelled. Even though the following two cases from the MFI site reveal very different reactions to the mental health system, each person required tremendous strength to go to a place where they recognized, cared, and fought for themselves. Emma found the strength within herself to open up and allow the mental health system to work for her. Frankie found the power within them to take back control of their life and rise above the dominating labels and ideas of society. Finding support in different places, each of them took the first step to move forward in a meaningful way. Turning their fear into fuel, they became the catalyst needed to spark a self-revolution.

Emma: The Architect

Emma recently came to MFI to share her own story of transformation and recovery. Having been diagnosed with Borderline Personality Disorder, she experienced severe psychosis and was chronically suicidal, performing self-harm for many years. Though she had tried to manage her illness as best as possible, it was not enough. Emma lost her job and, over the next few years, drifted in and out of the hospital. She describes her experience and capabilities at that time as being incredibly limited:

"In the Summer of 2011, I was a court ordered patient at a state psychiatric hospital. I couldn't walk outside without a staff member accompanying me. I couldn't choose my own meals. I couldn't wash my own clothing without supervision."

The lack of trust afforded to her and the restraints placed upon her while in the hospital were devastating. Would this always be her life, she wondered—constant supervision and the fear of her own hands? Would she ever be able to command her own destiny?

During her stay in the hospital Emma learned about Dialectical Behavior Therapy (DBT), the treatment that would ultimately lead her to her recovery practice. She spent the rest of her time in the hospital reading and learning about DBT and, finally, when she was "discharged [she] joined a DBT group and...totally threw [her]self into learning and practicing the skills." Though she worried about the effort required of the program and her own ability to overcome the illness that had consumed her life, she was determined to create a life she was proud to live. The support of her peer group and therapy team helped Emma stay focused on her commitment to not performing self-harm and her goal of getting better. As she progressed through the program, she began to feel less "helpless and hopeless" and more in control of her emotional responses. For the first time in a long time, Emma felt capable. Capable of not only managing her illness, but also capable of thriving.

DBT provided Emma with the skills she needed to practice her recovery every day. She describes "recovery" as:

> "...living an abundant life...I have the skills I need to accomplish anything at all. I'm the architect and builder, and I am creating a life worth living. I am enjoying my blessings, I am solving my problems, and I am mourning my losses. I am thankful to be alive, every day."

What once had seemed insurmountable for Emma was now a light breeze. Though she had worried about the energy and effort it would take to overcome her illness and stick with the DBT program, the support of her peers and her own determination to change pulled her through to the end. Now, she looks forward to the future and she cannot wait to give back. What she describes as "complete and total recovery," Emma uses her skills effortlessly to "handle the highs and lows of life." As the architect of her life, Emma is building herself a promising future while currently attending graduate school, an opportunity she secured with a full scholarship. What once was merely a fleeting dream in someone else's life has become an incredible reality for Emma, and it is only the beginning.

Frankie: The Driver

Frankie told MFI they had been diagnosed early with bipolar disorder, and had spent considerable time consumed in the mental health rhetoric of care and recovery. For years Frankie was "convinced [they] had a biological brain disease," and would never move passed the suffering they experienced and attain the "normal life" everyone sought. Years of medicinal cocktails had done nothing but make Frankie a shell, interfering with the now narrow semblances of their normal life:

"[The medications] make me feel numb, dysphoric, apathetic, and slow, make it hard to think, feel, concentrate and make decisions. [They cause] weight gain so I feel bad about my body...[I] also feel like I'm being sucked down into a coma when taking drugs - worse when first put on them. I've had to lower the dosages in order to be functional at work, and am still in that process."

Frankie could not understand why they were not feeling better. If they had this disease, then these treatments should be providing relief; instead, they only increased their symptoms and every new medicine added a new contender to the mix. Months of weaning off one medicine or dosage clashed with starting another, making Frankie feel either hollow and empty or panicked, raged, and violent. While Frankie felt like they were stuck on the "med-go-round," their doctors remained optimistic, always encouraging and subtly enforcing new regimens with the promise of a different result. Finally, feeling completely hopeless, Frankie made a drastic realization.

In a moment of clarity, Frankie realized they were in control of their own self. They had always been in control. Despite everything they had been told about their "disease" and the insurmountable suffering they would experience for the rest of their life, Frankie realized that only they were responsible for the way they felt; everything that had happened to them was because of they had been refusing to take ownership of their actions and emotions.

"I recognized that a certain amount of suffering would have to be tolerated while building a better life, and that the "treatment" was what happened because I *didn't* take ownership of my life. I grew to regard

drugging not as "treatment" but as punishment for disobeying social norms, freedom from the hospital as parole for good behavior... I grew to have a non-medical view of my behavior, that also admitted the truth...I had problems and was "acting out"."

Frankie understood that no one was exempt from sadness or anger or frustration. This ownership of oneself and the responsibility required for driving one's own life was bound to come with some pain, and it was the way one handled that pain that made the real difference.

Additionally, Frankie had now come to consider mental health care just the opposite: the inability to cope with one's daily strife led to medical punishment and incarceration, a debt to be paid. Caught in a catch-22, Frankie could either come to understand affliction as a part of their life and carry on in a socially obedient fashion; or, they would be punished for their actions and be medically subdued into a shell of their former self. In the unveiling of a sadistic side to "recovery" and "care," Frankie found the fire to separate from the "med-go-round" and move towards a new philosophy and practice.

"I think we live in a profoundly spiritually sick society [where] "recovery" [is] a shallow term to refer to someone who is now capable of complying with social norms without spilling their suffering out into the world, a person who can go to work, have friendships, have a family, e.g. "go along to get along". It says nothing about the oppression and repression that poison so many lives, or as Thoreau would say, that means "the mass of men lead lives of quiet desperation.""[10]

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[10] The quote is a well-known one of Thoreau's found within *Walden and Civil Disobedience* (1854). The full quote reads as follows: "The mass of men lead lives of quiet desperation. What is called resignation is confirmed desperation. From the desperate city you go into the desperate country, and have to console yourself with the bravery of minks and muskrats. A stereotyped but unconscious despair is concealed

In a dystopian depiction, Frankie's eyes widened to a world where many people suffer

desperately, for and by various sources, and yet they are silent, unable to react for fear

of the consequences. Indentured to the majority's vision of normal reality, people work

tirelessly to appear "normal." Frankie now knew that if they were going to survive this

life, they were going to need to reclaim their mind and their body—their self. Through

the practice of "increasing self-reliance, self-awareness, and responsibility," Frankie

could do what was required to get themselves out of the mental health system they now

considered heinous and fulfill greater social obligations. Revolution, after all, could only

happen if you were free.

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The previous cases of Emma and Frankie highlight the stark differences between

individuals coming out and seeking help from the mental health system. Emma found a

community of caring professionals, as well as a community of kindred-spirited peers.

Frankie, instead, felt as if they were being subdued and belittled, punished for not being

able to perform like everybody else. Both, in turn, had to find the courage within

themselves to create the strength needed to survive their precarious paths to one of

inner peace and fulfillment. The purpose each of them found in their journeys,

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even under what are called the games and amusements of mankind. There is no play in them, for this
comes after work. But it is a characteristic of wisdom not to do desperate things."

respectively, will be carried forward into the future shaping their dynamic practices and meanings for wellness.

Thriving Recovery

"We have to look far beyond terms like "mental health", "emotional health", or "recovery" to really get at what is happening in our culture and world." –Frankie, MFI

When people talked about recovery on the MFI website, it was described as a lifelong process encompassing many different methods and resources unique to everyone, but all used to attain a life of purpose and fulfillment. Site users described recovery in different ways, such as "work," "a process," and a practice for "becoming an expert of your mind and body." I will favor the use of 'practice' when describing recovery, not only for consistency, but also because of the words' implications regarding the daily routine in discovering and/or maintaining the methods and resources that positively engage subjective recovery. It is through this practice of recovery that people find what methods work best for them. Recovery was also described by many as having a life of power and purpose by being able to care for their families and communities, as well as being able to contribute to the larger society. Empowerment, education, and advocacy were critical to becoming autonomous and self-determined, the fundamental foundation of a practice of recovery. For everyone, ultimately, recovery meant becoming stronger and more resilient. Rather than being a process of returning to who they were before the illness, or a process of staying the same, recovery was a future-oriented

practice of evolving and adapting into someone different, someone greater than the person they once were.

For people in MFI, the first and greatest contention in the practice of recovery was the involvement of psychiatric medication and treatment. Some people described recovery as being completely free of psychiatric medication and other treatments, such as therapy. For these people, recovery meant the complete recession of illness symptoms allowing them to be a place of total self-reliance. For others, the use of psychiatric medication and therapy was the best way to manage their illness symptoms, but only if their psychiatric doctor listened and catered to the person's desires for their treatment and care. The reasons for these preferences differed, but many people, especially those with more severe mental illnesses such as schizophrenia, described experiencing a total lack of hope by psychiatric professionals for any semblance of recovery. Instead, they were often considered with little ability to convey the truth, where any objection to diagnosis or treatment meant the patient was receding further into their psychosis. Having mangled their trust in these professionals, they sought out alternative and non-psychiatric measures of recovery, not only from mental anguish, but also from psychiatric abuse. Still, others found their greatest supporters in their therapists and doctors. Once again, mental illness and the road to recovery become different practices for everyone. The following cases will demonstrate two starkly different experiences within the mental health system.

Gina: The Challenger

When Gina had her daughter, she experienced a change in her social roles as well as debilitating post-partum depression (PPD). In her MFI narrative, Gina explained the terror and difficulty of keeping her symptoms, which were escalating into suicidal psychosis, hidden from social workers and aides attending her case. She described feeling like she had to "perform 'normally' for the worker not to punish [her]," as well as her fear that "[she] wouldn't act normal enough." Though she was overwhelmed with her new role as a mother, while also juggling work and school, she did not want to lose her daughter or be deemed unfit to care for herself and her new child. Somewhere deep down she knew this was beyond herself and her own experience.

Wanting to get the help she needed, Gina sought out a supportive social worker, someone she could trust to come out with her true feelings and needs. The person she confided in ended up being so much more than Gina hoped. The social worker explained to Gina that her PPD was a combination of her body alerting her, as well as the societal pressures of her new roles.

> "She taught me how to listen to my body. She explained historical legacies of women being raised as 'natural caregivers' and [the] societal belief that this was not work that deserves support (financial, societal, day cares etc.), was like a generational trauma. Putting my biology within the framework of an oppressive social environment was amazing! It's like it wasn't my fault, my failing, [or] my weakness."

By thinking about her body and her experience as a "generational trauma," Gina could

contextualize her feelings into something larger than herself. Rather than thinking of

herself as unfit or broken, Gina could find herself within other women who had

experienced the same thing. She was a new mother caring for her child on her own

without receiving any additional support or understanding, working to support them

both, and in school to provide her and her daughter greater opportunities in the future.

As a woman and mother, Gina was expected to fulfill her multiple social roles without

complaint or noticeable struggle. When she did struggle and social workers became

involved, Gina fell further into the belief that she was failing as a woman and mother

because she was having difficulty. Once she knew her struggles were relevant, and with

the validation she needed, Gina regained the hope that "[her] PPD was a 'normal'

reaction to difficult life circumstances."

     While in school for social work, Gina learned more about societal constructs and

about herself; however, as she began to understand she also became weary of the

individualized language of "recovery" and "getting better."

> "I worry that getting better means better able to manage unfair life
> situations. I would rather make life more fair than learn how to survive
> oppression. Recovery and getting over it and surviving are unjust terms in
> my mind because they still focus on the individual without recognizing the
> society within which our biology is contextualized."

Leaning on her own experiences, Gina saw "recovery" and "getting better" as a cover for

compliance with expected behavior, which did not always work in favor of the individual.

Instead, this expected behavior could be demoralizing, dismissive, and oppressive. Gina

felt like she could not take a day off work without people thinking she was a "slacker," or

that she could not express frustration or anger without a family member commenting

on her need to increase her medication to quell her "hormonal" outbursts. From her

own experiences, she could see how she was expected to behave in a grateful and

gracious manner, to take responsibility for the things she had brought on herself and

get on with her life, even when she knew it was larger than herself, even when she knew

it was societal invalidation of and for her womanhood, motherhood, and mental illness.

Though she received some validation from her social work professors who

reassured her that her experience "of the mental health system and traumatic history"

were important to her work and her ability to empathize with and help others, Gina

needed more. She needed to be the challenger for herself and for others, just as her

social worker had been for her. Gina concluded her MFI narrative by saying she became

the activist she needed, promising to channel her recovery, social work, and activist

energy into healing an ill society.

Helen: The Enduring Believer

Helen's story weaves a tale of wrongful diagnosis and psychiatric abuse and

trauma. In 1965 when she was just 17 years old, nearing the end of high school, college

out-of-state looming on the horizon, Helen's heart was broken by her high school love.

In addition to her heartache, Helen's parents were on the verge of divorce; emotions

were running high. One day, in late spring 1965, Helen's mother shuffled her into the car

and brought her to a psychiatrist. She was labeled too quickly, Helen believed, with

depression and was scheduled for treatment via ECT (electroconvulsive therapy). Over

the summer of that year, Helen endured 16 rounds of treatment, as well as daily

medication. During one such ECT treatment Helen felt herself wake up, unable to call

out or blink. Excruciating pain ripped through Helen's brain, as if someone "bashed [her]

head with a hammer." Still, the treatments carried on and soon it was time to leave for

college.

College on the other side of the country proved to be challenging. Helen was

incredibly lonely, had begun having horrible nightmares, and was terrified of going to

sleep. Making a lot of calls home expressing her loneliness and homesickness only

seemed to make her mother weary and annoyed. Finally, on one night when Helen

called her mother crying, she was told to "pack her bags and come home." Her parents

picked her up at the airport in their two-door Volkswagen. At first, Helen did not think

anything of it, but soon she noticed the tension filling the car. "Where are we going?"

she kept asking, but neither of her parents would answer. Suddenly, Helen knew her

parents were not going to be bringing her home and she slumped into a state of shock.

> "I was in the hospital 5 weeks (during Jan/Feb 1966). I kept telling the
> nurses and the shock doctors that I was not crazy, that I had called my
> parents and they had told me to come home. The doctors did not believe
> me about contacting my parents and their telling me to come home...I

also begged them to stop shocking me. But of course this kind of protest only makes the situation worse. If you deny their diagnosis, that means you are crazy, so I finally stopped complaining as much as I could stop."

No one was on her side. Her parents brought her back to a place of pain and the doctors' only thought every protest was a sign of her worsening condition. Years later, when Helen could confront what had happened to her, she found within her old hospital records a diagnosis change. Noted in her file, dated for the time during her second hospitalization, was the diagnosis of "schizophrenia" and comments of her resistance towards her diagnosis and her treatment. She knew, and recounted how, the only way to get out of the hospital was to follow their rules and do what the doctors wanted. The sooner she complied, the sooner she would be released. However, release from the hospital came with few privileges. Helen's mother was still in control of making her medical decisions, so the next three years came with shocks and medication.

When she turned 21, Helen could take matters into her own hands. She finished college and found work out of state, far away from her parents and the trauma she experienced. She found another psychiatrist who was willing to talk and, more importantly, to listen. They helped reaffirm what she had always known to be true: she was never mentally ill and she did not need any kind of treatment. Over the next two years, the doctor helped Helen come off all her medications and by 1975 she was medication free. Finally, her future opened and she intended to live it to the fullest.

In the present day, now many years later, she recounts how her recovery was not one of surviving disease or illness, but of surviving psychiatric and familial trauma and abuse. After breaking away from harmful psychiatry, Helen returned to school, earned her Ph.D and taught as a university professor for over 10 years. She met a man she has had the privilege of loving for almost 40 years. And she continues to believe her diagnoses were wrong and she had never been mentally ill.

> "I got better because I was never mentally ill and I knew it and held on to that knowledge, in spite of the doctor and my parents who wanted me to believe I was…I did not get better from mental illness; I got better and recovered from psychiatric abuse. I was never mentally ill."

* * *

Many people who posted on the NAMI site were young people, often still in high school or early university years. Many were grappling with past trauma and the weight of newfound responsibilities as they were expected now to move on from childhood fantasies and create an adulthood reality. Anguish riddled their narratives, as well as the fear of disappointing and letting down those they loved the most. The hardest part in transitioning was having little power and knowledge to make their situation better and realizing they were not going to be able to do it on their own. If they were going to survive, and for many it was about survival, they were going to have to learn to rely on the support of others. Easier said than done when the messages concerning mental illness are commonly negative, painting pictures of dangerously unstable people with

little to offer and no ability to change. So, they covered their symptoms, they passed as well and as best as they could, while slowly sinking deeper into their own private despair. In some cases, when the desire to survive overcame their desire to stay hidden, they called out for support and revealed their emotions and insecurities, about the wrong that had been committed against them. In some cases, they were not only ready to grow, but ready to bloom.

For those participating in the MFI forum, recovery meant many things, but it was always oriented toward a future of promise and light. Whether it was called a process, a practice, or work, it meant having purpose and power to contribute positively to their families and communities. It also meant paying it forward to others who were in their own process of discovery and evolution. Sometimes recovery practices included therapy and medication, and other times it meant being completely free of any psychiatric influences. Regardless of which path a person chose to walk; autonomy and self-determination were paramount. Mental illnesses often made people feel like they were not in control of themselves or their lives; sometimes, participating in psychiatry made them feel dependent, too. Having the ability to control of their lives, their treatment, and their practice was the key to coming back stronger and more resilient than before. Recovery was never a practice of returning to who they were, but a transformation into the person they were always meant to be.

For others participating in the MFI forum, recovery and mental illness were merely constructs used for the oppression and suppression of certain types of people. These systems were tools that sought to distract from greater societal ailments such as poverty, racism, and sexism. Though the individual themselves may be sick, the real sickness could be found in the complex power structures of social life that guided expectations and behaviors. Mental health care, then, was the mechanism used to enforce such societal goals, whereby traitors of the social code became lost in hospital corridors, drugged and shocked into submission and complacency. Care was born not of nurturance, but of punishment; the release from which only occurred when one had been cured of their various failings. Rather than seeing the individual as the one who was sick, it was society that was insane, unable to recognize or face its own mental anguish in its true form. The foundations and contradictions of recovery will be further analyzed in the next chapter.

5. ANALYSIS

My hypotheses about the practice of recovery followed closely with Goffman's metaphor of theatre (1959), whereby we perform according to the expectations of the social spheres we occupy. Therefore, recovery practices could also be considered as lessons in learning how to perform as "normal" (Goffman 1963:131). The United States has a rich history of rugged bravado, expansion, and transformation. From early

settlements to westward expansion and global contribution, the character of the West is

involved, available, and hard-working. These sentiments have solidified themselves

within the cultural values of personhood and the social expectations for performance,

but not without scrutiny. Persons with mental illness have been advocating for greater

opportunities and visibility for many years, and this pursuit has led to the current state

of mental illness and recovery conceptions. Within the majority, however, mental illness

is still considered a deviancy from what is expected because it infringes on a person's

ability to perform appropriately and attain social statuses such as a successful career

and community, growing family, and financial independence. Stigmatizing stereotypes

about violence and incompetence increase the fear of having mental illness and lead to

devastating self-doubt upon diagnosis. Attempts may be made to pass as normal or to

cover up the aspects of the attribute that tell their stigmatizing condition, however,

these measures are still considered inferior to the actual attainment of the appropriate

action. The cultural correction for mental illness, therefore, is recovery—stabilization and

accountability—which must be practiced and perfected to establish oneself as a

contributing member of society. In a way, it is practicing how to perform in the world as

a "normal deviant," where it is acceptable to have mental illness if it does not interfere

with the attainment of valued functions and moral expectations (Goffman 1963:131).

Yet, to be a normal deviant implies there is great contradiction hidden

underneath; therefore, it is first important to uncover the cultural implications of

recovery and its practice. In other words, how has culture framed our ideas about recovery from mental illness? By analyzing the discursive use of recovery and its underlying meaning it is revealed that what has been characterized as a highly individual process with little social responsibility required takes place through social interaction, opportunities presented therein, and the freedom to make use of them or not (Sen 1999; 2003; 2005). Therefore, I look deeper to question the contradictions inherent to the practice of recovery, how they are upheld and subverted by the site organizations and persons with mental illness. As many came to recognize recovery as a symbiotic social practice of community responsibility, they also came to view society as profoundly sick and focused much too closely on illness, oppression, and death rather than on love and life. This further bolstered their sense of purpose and sought justice in providing recognition and support for others still in the system. If we look deeper into the relationships and interactions presented in the narratives and the practices of recovery commended by the authors, we can further delineate the nuances within these contradictions of the larger culture of mental illness recovery.

How Structure Shaped the Narrative

Before entering conversation about the content and cultural meaning within the narratives, attention must first be paid to the architectural nature of the sites themselves. The organization of space, language use, and available prompts frame

potential expressions and can greatly affect the narrative course and construction of

selfhood. On NAMI, authors were prompted to share their stories for themselves, but

also to be a beacon for someone else, to let them know another person was out there in

a similar situation. Narratives were free form and could be as long or as short as authors

desired. Photos or other art, like memes, could be included as part of their post, though

it was much more common to see either a photo share or a narrative rather than a

combination. Hashtags, a common quality feature of tumlr.com, which was the

connected youth-popular platform to the NAMI forums, were present at the end of all

narratives to highlight the keywords or phrases illustrating their context.

 Organizational moderation of the narratives was present in that all were reviewed

before final posting. Guidelines were straightforward: no offensive or inappropriate

language, no personal contact information or marketing, and posts exceeding 800

words may be shortened or not posted at all. Coinciding with the free form architecture,

the space aligned their goals of speaking openly and sharing one's story in a supportive

environment as a means of diminishing the stigma surrounding mental illness. Readers

could like or share the post on other social media platforms, but they were not able to

comment. On one hand, this negated all possibility of hurtful conversation from and

among participants; however, on the other hand, it also highlights the author as a

singular, individual entity experiencing mental illness and stigma.

On MFI, authors were prompted to share their story of mental illness and recovery. This began as a survey conducted in 2012 (for survey questions, see Appendix), which led to the creation of the MFI I Got Better forum. Of the 390 original participants of the survey, about 20% of submissions were carried over to create the first stories on the platform, although it was unclear how these were selected. Participants who came after the initial survey wrote in a free form narrative style, or they had the option of submitting short videos. While the original surveys were noticeably moderated with the use of in-text brackets; for example, "A PA [Physician's Assistant] in a clinic I go to…" (MFI Anonymous) and "[At one point] I actually lost my support and my job…" (MFI Anonymous), the free form narratives neither exhibited the same kind of attention, nor was their process for selection made apparent.

The page to share your story prompted new authors to start with something about harder times and then to continue by sharing something about better times and how they are living a life of hope and recovery. Contributions of this form were highlighted as beacons of resiliency for those looking for personal inspiration and community. A limit of 1000 words, usage of paragraphs for readability, and a compelling title were also suggested. Once posted, readers could print the testimonies, but there were no other options to share the narratives across social media platforms or email. In comparable fashion as NAMI, and probably for similar reasons, there were also no options to comment on the narratives or engage in a dialogue. Because of the initial

survey examples presented on the site, as well as the prompting before submitting one's

own narrative, the flow and progression of the stories were specifically molded to

highlight the triumph and possibility of recovery for the severely mentally ill.

This architecture accentuates the hidden implications discussed in this analysis,

especially sources of "authority" (Malaby 2009). Through the architecture of the

narrative, the person with mental illness becomes the fighter of a heroic battle against

the illness within themselves and the sickness of societal perception. They are the

authority of their own experiences and how it is shared, a power noted in their

narratives to often be lacking in their lives. Yet, the authority of the forums spaces lie

solely in the NAMI and MFI programmers. The contributors and consumers of these

sites are not able to change the code in any way, to direct the dialogue or narrative

focus through continued conversation, or elicit more information from neither users nor

the organization itself. The opportunity for more deeply connected user generated

content comes with certain possible ramifications (Dibbel 1998; Malaby 2009) and it is

possible that greater focus on maintaining authority and respectful space between users

would simply be too much for the organizations to handle. Further, exuding this type of

authoritarian complex could lead to fall out between the organization and user's

themselves; especially if argumentative sides are perceived to be taken or users feel they

are being directed toward a certain type of practice for how to "best" handle their

situation, little of which can be known in the current construct of the forum.

The lack of opportunity for social interaction in these spaces and the individual

focus demanded from each post directs the conception of the mental illness experience

as an individual—therefore, not a social or cultural—responsibility. Therefore, even

though the organizations have missions of creating community, bringing people

together to shatter misconceptions of persons with mental illness and their treatment,

the one-way structure of the sites alienates the individual experience as singular. With

the "impressions" and "expressions" (Goffman 1959:2) already staged and embedded in

organizational authority the forthcoming performance of the narrative authors naturally

presented as forward-focused rugged individualists attaining recovery through strength

of character.

Recovery Exists in the Future

Both sites, though clearly divided in focus and audience, carried the same

temporal orientation for recovery. Recovery exists in the future; it is the promise of what

could be and what is possible. However, it also participates in perpetuating an idea of

what *should* be. This future orientation is significant in two ways, one practical and the

other ideological. Practically, orienting persons toward a future of possibilities is

preventive. Self-harm and suicide are major medical concerns for many people with

severe mental illness, more so when anguish is unknown and they are isolated from

support and care resources. A devastating way some people realize the hurt and needs

of a friend or loved one are through self-harm, and failed or successful suicide attempts.

A major part of mental health goals within the NAMI organization, for example, are early

intervention and establishing visions of the future so young people know they have

reasons to hold on. Hence, discussion groups like "You're Not Alone" and "Ok2Talk."

Recovery would not be as powerful if it did not have a happy ending, an opportunity

worth fighting for. The idea of grass being greener on the other side of mental illness

suffering generates a pastoral image of a future in recovery to not only inspire hope, but

also the ambition to work for it. With recovery, you can not only reach the other side,

but sow the land and reap the benefits.

The future of recovery also generated an ideology, or a philosophy, which utilized

metaphors to describe and inspire the recovery journey. Website and narrative authors

not only described a medical journey of searching for and attaining wellness, but also

the social and political implications of being identified as mentally ill. It was common

rhetoric for narrative authors to characterize themselves as a "fighter" who would not

give up, and to proclaim they would someday win the "battle" and overcome their

mental illness. This warrior bravado was not only for the sake of personal wellness, but

was maintained to reestablish and reaffirm respect and dignity within social

relationships. The NAMI forum participants, who were not yet in self-described stages of

recovery, were still adamant about their future in recovery. Anya's narrative (The Lone

Warrior, Ch. 4) is one example. She felt alone and knew she would need to rely on

herself if she were to ever "beat" her depression. It was a solo battle against a thousand

enemies and if she were to succeed she would need to harden her resiliency and believe

in her ability to recover. She maintained, "…even though I haven't quite had it beat yet, I

know that I won't always be sick and I will beat this thing." This mantra, as well as similar

sentiments like MFI's forum title "It Gets Better," help to bolster a belief in the future,

and not just any future, but a specific future without mental illness anguish and,

therefore, without the social and cultural repercussions of being identified as such.

Within the MFI narratives, where participants were of an older generation and

had greater experience with mental illness and the health care system, recovery was an

awareness they had achieved and were maintaining in the present. Most echoed similar

rhetoric as those in the NAMI forum as they recounted their past experiences, whereby a

belief in themselves and their ability to overcome the trauma of illness and subsequent

care was necessary to survive the battle to recovery and the continuing adversities they

would face to maintain it. Whether the hardship came from within or from outside

forces, they had to fight to find the right support system, to restore or maintain

autonomy, and to prove to the world—with or without mental illness symptoms—they

were worthy of dignity, respect, and recognition. Recovery, itself, was not the end of this

battle. It was a new mantra to live by, a new lifestyle for every day. Whether it involved

participating in the mental health care industry or the complete removal of its presence

from one's life, recovery was a practice for the rest of one's life. There would be hard

days, but if they stayed on a path of recovery, were diligent and determined to overcome mental illness and stay out of the health care system, they would. This determined positivity and dedicated vocation in recovery, along with this future orientation, create a kind of manifest destiny paramount to mental illness recovery culture.

Contradictions Between Treatment and Recovery

Treatment for mental illness and mental illness recovery may sound synonymous, and indeed have been used interchangeably. However, it is important to note contradictions in the use of terms resulting from the point of view and the perspective by which one experiences mental illness. Characterized by who is telling the narrative and how they perceive the events, there exists three positions: first, second, and third. Following Estroff's (2004) description, the person who has been labeled mentally ill, such as our MFI authors, are considered to occupy the first-person position. It is their direct experiences, which they have shared, that we are interested in understanding more clearly. Further, they are the persons with the first-hand experience of mental illness. Second-person position belongs to close social ties, family or friends, to the one labeled mentally ill. These individuals may be involved in the care or support of their loved one, whether presently or in the past, or as hopeful involvement for the future. The third-person position is occupied by medical personnel who have been trained in a specific

moral understanding and practice of health care (Estroff 2004:283-284). With unequal

numbers follows an imbalance in power; the authority of medical morality overcomes

the authority of illness experience effectively aligning the second and third positions.

Many persons with mental illness are left feeling alone and powerless, if not also rather

untrusting. It is the evolution of the relationships between the first-person and the

second- and third-persons which shapes the meaning between treatment for mental

illness and recovery not only from mental illness, but from the mental health care

system and oppressive societal expectations.

First-Person Perspective

Most MFI authors, because of their own social experiences with mental illness

and recovery, distinctly discussed treatment and recovery occupying two separate

atmospheres. Treatment was an element of mental health care where medical

professionals and disease ideologies ruled. Some described the beginnings of the

medical side of their journey as hopeful; when you are sick, you see the doctor and they

will let you know what treatment you need and be your guide back to health. Their

anecdotes revealed trust in the wake of stigma and fear, and a willingness to take the

socially necessitated risk to gain back control of their lives. But as many continued to

frequent the hospital—progressing from voluntary visits to involuntary commitment and

mandatory treatment—the tone of their experiences changed. Doctors became colder

and unsympathetic, and most experienced similar trends among others in their social lives as they failed to progress, medically and socially, as expected. As they became more greatly embedded in the mental health care system, they began to undergo a transformation they did not expect. After being given a diagnosis, all behavior became subject to question. As their discussions of ambitions and pursuits were tempered by family, friends, and medical personnel with counters to the contrary, as credibility and respect were lost in the eyes of those around them, their mental illness label became their identity. The desire for college education, an intimate relationship, a successful career, children, autonomy and independence were no longer the focus of their present and future. Instead, symptom management and medical regulation were the foremost concerns of the "good" patient. Any other focus was framed as contributing to their mental condition or as proof of their desire to be mentally ill. Over time, with the degradation and loss of the meaningful aspects of their lives and their new focus on their illness, many lost hope in ever being anything other than a "mental patient" or "crazy person." Lally (1989) described this process as "engulfment," a psychological and social transformation of one's identity. By his description, engulfment occurs in three stages and begins when a person realizes they are somehow a part of a stigmatized group (i.e., mentally ill). In this stage, they are still hopeful and distance remains between their self-identity, or the way they and others see them, and their illness. As symptoms worsen and hospital exposure increases, they begin to question themselves and

internalize their illness identity, as do the others around them. In the final stage of engulfment, they—the person with mental illness and their social group—have fully internalized their mental illness as their primary identity characteristic (Lally 1989:259-263). They are no longer Ingrid: woman, daughter, aspiring scientist, lover of the ocean and gelato. They are Ingrid: paranoid schizophrenic who cannot seem to pull it together at home or follow her doctor's orders.

Second- & Third-Person Perspective

Many family and friends of persons with mental illness, as well as medical professionals, tend to view mental illness in a similar fashion: a life-long condition that can be managed with different treatment options, most commonly, pharmaceutical medications. However, they must be willing to be treated and maintain their treatment plan. If they were receiving treatment for their illness, then they were on the road to recovery. Failure to seek or maintain treatment was likened to a relapse, falling back into old, bad habits. As we saw in Carl's narrative (The Exasperated Father, Ch4), he expected his son to be active in treatment so he could go on to be a self-sufficient man. It was when his son refused treatment and his behavior led him to be removed from the group home in which he was living that Carl began to wonder if there was any hope left his son. Doctors and medical staff can also experience a similar loss of hope when they continually treat the same patient for the same reasons. Over time patients may be

labeled "resistant and uncompliant" (Castille, Muenzemaier, and Link 2011:246), as doctors also struggle with the restrictions placed on their ability to provide necessary care (Luhrmann 2000). As family, friends, and medical professionals go through their own kind of engulfment process their trust in their ability to help someone lessens more and more. Recall Diana's narrative (The Woeful Spouse, Ch4), where she discussed a hectic family schedule. Her husband, Eric, worked long, and often uncertain, hours while she managed the home, children, and severe bi-polar. Though struggling with stress, Diana dutifully abided by her medication schedule and believed a more dependable and consistent work environment for her husband would allow him to be at home more regularly, if not more often, which would provide the extra stability needed for herself and their family. Her husband, Eric, suggested instead she try a different kind of treatment, electroconvulsive therapy (ECT), since medication did not seem to have been as effective for some time. In her excerpt, Diana expressed her sense of betrayal at her spouse's thought of pursuing ECT, a treatment which resonated for her as a type of punishment for not being able to manage life and illness better on her own, for daring to suggest her partner participate more actively in the responsibilities of their home life. What seemed like a logical treatment plan to Eric was to Diana an insinuation of her personal failures, first, as a person with mental illness and, second, for not being able to perform her social roles as expected because of that illness.

Because these positions are frequently unbalanced among each other, finding it difficult to understand one another's position and experience, small differences in meaning continue to have incredible impact. Estroff (2004) described this as a "don't get it, can't get it" standstill (286). From the perspective of the first-person, medical professionals, family, and friends who have not experienced mental illness (in Estroff's case, schizophrenia) do not truly understand it and cannot because they do not have any experience living with it. They do not hold the authority of experience to dictate what should happen, what should be. Yet, the person deemed mentally ill is discussed in symptom categories and negligent behavior. It is like they are being erased as a person and replaced with this illness. Ironically, family, friends, and medical professionals echo similar sentiments as the first-person. The individual does not understand what is happening to them and what they do because they have schizophrenia, they do not want to acknowledge they are acutely ill and require scientifically sound treatments to stabilize their condition and manage symptoms. Further, they are unable to understand they are ill because schizophrenia prohibits this kind of self-awareness (Estroff 1989:191). For example, a person in a state of psychosis was coerced by their spouse to a hospital emergency room. Confused and combative, they were given a limited choice of oral or hypodermic pharmaceutical medication to stabilize their immediate condition. They were admitted for the mandatory three day stay before they were released with a month's supply of medication (MFI, Anonymous). The hospital, as an institution, can only

offer short-term treatment like evaluation and medication due to many coexisting

factors like insurance regulations and high demand for care. Patients receive the

immediate care they need, but without additional social support and opportunities

many end up coming back, which is what happened with the author in the above

example. They procured a nickname, "frequent flyer," or those who often visit the

hospital with the same or worsening needs (Luhrmann 2000:97). Therefore, taking

medicine and/or actively participating in one's treatment and recovery impresses to

others a sense of rationality, which increases the subject's moral goodness and makes

them more deserving of help, dignity, and support (Myers 2015:57-86). The moral

ideology embedded in this kind of treatment practice considers the "good" patient as

one who answer's the doctor's questions, abides their instructions and takes their

medication on schedule. The inability to comply, which results in frequent visits back to

the hospital, degrades the patients moral standing in the eyes of the doctor, as well as

their loved ones. Thus, a frequent flyer or a "bad" patient, someone who is unwilling to

take responsibility for themselves and their illness needs. As if it were an individual

choice, the bad patient becomes someone who wants to be mentally ill. If a person with

mental illness must choose recovery to be considered valid and worthy of dignity, which

leads to opportunities for a successful life, then within the recovery framework of

Western society mental illness is fundamentally conceptualized as a choice. If the

individual does not choose to modify their individual attitude, to prescribe to and

maintain socially desired methods of recovery, then they are choosing mental illness, as well as the social and cultural stigmatization stemming from their inability to conform to Western hegemony.

To more clearly illustrate these perspectives and the contradictions in the meaning between treatment and recovery, let us reconsider from chapter 4 Frankie's narrative. Frankie's narrative illuminates a critical, though subtle, discrepancy in mental illness recovery culture: treatment coerced, forced, or made out to be the only option by second- and third-person characters is perceived by persons with mental illness as an assault on themselves and their capabilities; yet, when treatment options, even when similar or identical to those suggested by the second- and third-person, were pursued by the first-person they stood as testament to their own autonomy and self-guided efforts to make themselves well. This is a critical, though subtle, discrepancy. It is not about the destination or the result, but rather the experiences during the journey; and it is these experiences that create the division between treatment for mental illness and the recovery described by many persons participating on the sites involved in my research. To briefly recap, Frankie had been diagnosed with bipolar disorder and had been on pharmaceutical medication for many years. Having experienced many ill side effects from the medicines, Frankie was always prescribed some new "cocktail," yet the same dismal results continued. Their doctors were always encouraging, however, and adamantly maintained they would one day be successful in finding the right medication

combination to stabilize Frankie's condition. They were always coming out with new kinds of drugs, Frankie quoted the doctors, you need to be patient and perhaps accept your current quality of life as the best it is going to be. Frankie, however, was tired of the "med-go-round." As their doctors continued to reaffirm medication and mediocre quality of life as the best it could get, Frankie finally lost all trust in the mental health care system. If this was the best they could do, then either the doctors were incompetent or treatment was a sham. After conforming to societal expectations for treatment without result, Frankie decided it was time to try an autonomous and self-guided approach. It was time for them to reclaim their identity, to cast away the expectation of behaving as "normal" in a "profoundly spiritually sick society." By taking charge of their life, Frankie rejected treatment and the system's notion of recovery as an empty promise used to control the desperate masses. By going it alone with "self-reliance, self-awareness, and responsibility" Frankie could reclaim their life.

If You Only Work Hard...

The idiom of "bootstrapping"—'to lift oneself up by their bootstraps'—has been used in literature since the late 19th century to describe the process of lifting oneself up the social and economic ladder through the sheer will of individual effort, hard work,

and personal responsibility.[11] In the United States, it is an American Dream element

often referenced by persons who were raised in low or middle class families and

through their own personal determination "made it," that is, found great personal

success and rose to the top of the social and economic ladder. Though most commonly

seen utilized within economic spheres, bootstrapping pervades American culture and

ideas about individual behavior. Rugged portrayals of people creating a life of their own

making, building a well-developed family, and supporting one's children so they attain

more than their forefathers are commonplace in bootstrapping descriptions and the

goals of a meaningful life.

Recovery organizes itself around these bootstrapping cultural ideas. Per American

bootstrapping culture, a person should always strive to be better or to provide more

than what they are or have been. Hence, a person with mental illness should be actively

working to overcome it. While people may use mental health services in their recovery,

the responsibility for attaining recovery and sticking to a treatment plan is placed on the

individual. Only the individual can overcome, no one else can do that for them. But

overcoming illness is not enough, it is simply the first step to the actual goal of

bootstrapping culture, which is attaining the American Dream. Therefore, a person with

mental illness should always be working to overcome their illness so they can attain the

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[11] Though found referenced within many literary works, early foundations include author Horatio Alger, Jr. (1832-1899) and "The Workingman's Advocate" (Chicago, IL Newspaper 1864-1877).

essential components of a successful American life: employment, intimacy, and personal

success. The presence of these aspects in a person's life help to define who in American

culture is morally recognized and who is immorally burdensome. A person who

overcame their mental illness and went on to attain the highly-prized cultural goals may

be morally recognized by society as a contributing member and be valued for their

participation. Conversely, a person who did not participate in recovery or who was

unable to due to lack of resources, severity of illness, etc…may be rendered invisible and

mistreated, a price to pay for their immoral behavior and burden on family and society.

MFI narratives, which focused on recovery, described the exhausting work to find the

right providers who would be willing to work with them on their terms. The years, often

decades, spent trying and weaning different medications, living in and out of the

hospital, trying for better relationships with family, and/or battling fear and stigma were

always paired with a reminder of their resolute optimism to continue fighting for

recovery. They had to remind the audience and themselves they were working hard,

continuously, to achieve recovery because the alternative has the potential to be

significantly devastating.

The stereotype of the bootstrapping ideology as individual heroes with

boundless optimism has considerable implications regarding public perception of

persons with mental illness, treatment, and recovery. Believing everyone functions and

experiences the world similarly and with matching energy leads people to question the

severity of a person's mental illness. Though it is natural and human to feel discouraged or exhausted or defeated sometimes, persons with mental illness are not allowed the luxury of expressing any vulnerability. Almost every author contributing to the NAMI and MFI forums discussed being questioned about the sincerity of their illness experience and having feelings and concerns invalidated as "extra sensitive" or an overreaction to what everybody experiences in their everyday lives. In other words, most people discussed what little room was afforded for mental illness experiences in their public and private social lives. It was a part of them they had to keep discrete and hidden so it would not disrupt everything around them. This culture of rationalizing a person's concerns about their mental health as an overreaction to everyday circumstances leads to seeing this behavior as a lack of moral character or in possession of other personal failings. If they were more determined or had more ambition, or if they worked harder, they would be able to overcome the seemingly small bumps of everyday life and participate like everybody else.

More significant, however, is the expectation of working for recovery. Persons with mental illness are expected to desire and seek out recovery. They are responsible for identifying their mental illness, finding care and treatment, working for recovery, and maintaining recovery for the rest of their lives. They must show the world they are trying and fighting to be better so they can fulfill social and cultural expectations. If they are not working for recovery every day, they are not doing enough; yet, this work is still

expected to be independently driven. The placement of total responsibility for recovery on the individual reaffirms the bootstrap ideology: individuals are responsible for pulling themselves up into recovery and should they fail the blame must lie somewhere within them rather than in social and cultural perspectives and structures (or lack thereof). It reaffirms mental illness as a personal failing rather than a difference in ability, a legitimate medical issue, or a complex personal and social experience. It is easier to use this victim-blaming rhetoric to say if they only worked harder for recovery, and if they took more responsibility for their care and their wellbeing, and if they tried to not be mentally ill, then they would become better and be able to contribute like everybody else. This, however, leaves no room to criticize societal structures or cultural ideologies surrounding mental illness and recovery, or the care (again, or lack thereof) for the genuine people it affects.

This pervasive ideology about mental illness and recovery generates a glaring conflict of interest when considering the presentation of dialogue and narratives within each of my data sites. On the one hand, these sites proclaim themselves as advocates for persons with mental illness and opponents of stigma. The work they do is meant to raise awareness, provide advocacy and education, and create greater acceptance for persons with mental illness within the larger community. For greater outreach and community inclusion, both provide web space platforms where people can talk about their experiences with mental illness stigma, family and community, and the mental

health care system. It seems there are no boundaries on what people can share as far as

memories of family abuse, self-harm and suicide attempts, messages of hope and

inspiration, and the lack or generous showing of compassion or assistance from certain

authorities (school officials, police, doctors, social workers, law makers) to those in crisis.

This openness provides a sense of safety and freedom to be themselves and speak

honestly about their experiences with mental illness, especially the social interactions

which then frame their perspectives and methodology for pursuing wellness and

fulfillment.

     While the dominant narrative theme of overcoming mental illness and systemic

oppression to achieve the American Dream inspires hope, it also solidifies who can

triumph and who will not. Identity factors like gender, race, class, sexual orientation, and

health status continue to be misrepresented or skewed within discussions and stories

about the success of recovery (Hopper 2007). Though some MFI individuals did not offer

identity information, the narratives which offered photos of the author, a name, or

descriptions of their identity were predominantly perceived as white, heterosexual, cis

woman-identified, and from middle class families. Further, many illness diagnoses fell

into categories of bipolar disorder, major depression, and anxiety. While many of them

discussed repeated hospitalizations, living in poverty, losing custody of children, or

working hard to regain the respect of their family members, their stories also tended to

include the attainment of the meaningful aspirations of American life: the rekindling of

familial relationships, graduating from university, having successful jobs and community

ties, romance and family, and buying their own home. Many of them discussed having

the support of a spouse or other close relationship who helped them along the way; few

had to face the journey of achieving and maintaining recovery on their own. Even if it

took them many years to find the right provider or care, many MFI authors still

described themselves as able to cross the crucial barrier of "in recovery" to "recovered."

Standing in stark contrast to narratives presented on the MFI forum, for example, Myers

(2015) discussed the difficulty for clients to transition from the in-group of Horizons to

the out-group of society where recovered goals took place (characterized in her

research as employment and intimate relationships), she also revealed many of the

people who participated in the Horizons program where non-white, poor or homeless,

and had severe mental illness diagnoses, like schizophrenia. Though considered "in

recovery," many of the clients were never able to leave the Horizons program to live a

truly recovered life. Unintentionally, the overwhelming dominance of the narrative

authors identity effectively erases co-occurring stigmatized identity experiences of

persons with less structural power. Therefore, on the other hand, by portraying a certain

kind of person as recoverable—which assumes a certain kind of person is not—these

sites also reinforce mental illness as a personal failing and, therefore, can contribute to

accompanying stigma.

<u>The Practice of Recovery</u>

"Through making new sense of the world, human beings recover." –Anonymous, MFI

As the literature stated and the narratives performed, the meanings of "recovery" are vast and nuanced. Methods differed across organizations, yet there were philosophical similarities through many cases and bodies of work (to briefly summarize from chapter 2: active participation, renewing hope, skill building, and societal inclusion) (Hopper 2007; Lewis, et al 2012; Austin, et al 2014). Nonetheless, an outline of recovery's dominant discourses among the first-person perspective is missing from our accounts. Recovery began, for many participating on MFI's site, with an internal conversion. It was a practice of reframing their identity from the "crazy person" or "mental patient" into someone of their own construction, a meaningful and moral character. This inherently led to a practice of acceptance within, but also outside themselves. As they constructed new meaning in their lives, their world responded and provided dignity, credibility, and further opportunity. The practice of recovery was more than symptom management or a change in individual attitude because it involved more than the individual labeled mentally ill. Recovery was a symbiotic social practice of recognition and dignity, which uncovered the final contradiction inherent in the bootstrapping ideology: no one, mentally ill or stable, accomplishes anything on their own.

Because recovery is not merely a clinical experience, but a social one, the nature of first-person social experiences with mental illness naturally made more meaningful or

prevalent certain recovery themes. As Sen (2005:158) advised, it is not my goal to devise

a stiffly structured definition for recovery or to further highlight its subjectivity, however,

there is benefit in understanding the first-person meaning of recovery in their journey.

For example, it is through their subtle thematic discussion of recovery that we can begin

to appreciate the wider social involvement necessary to its development and success.

Within my data, I have identified four discursive themes: clinical recovery, recovery as

self-identity, recovery as social identity, and recovery as justice. Akin to Goffman's

(1963:32) discussion of "moral careers" of the stigmatized person, these themes

highlight the embodied experiences of mental illness recovery. Again, these categories

are stiffly structured for the sake of their explanation; people do not experience life as a

"kind" (Mattingly 2012:169) or category, therefore, it was commonplace to encounter

some or all these aspects of recovery's themes within their narratives.

Clinical Recovery

Recovery occurring in a clinical setting was discussed least of all among MFI

participants, due much in part to the foundation and philosophy of the MFI organization

itself (for this discussion, see chapter 3); however, there were some cases where clinical

experiences led to a state of recovery. This theme was characterized by wellness

occurring while staying in the hospital, either short- or long-term. I hypothesized this

theme to occur mostly in isolated incidents of acute psychosis rather than to persons

with ongoing and severe psychological illnesses. I would have thought their experiences

with the mental health system and authorities, with having autonomy and bodily

integrity taken away, would have prohibited any ability to generate trust and healing in

the hospital environment. Interestingly, however, this was not always the case. In one

such narrative, an author, whom I will call Jessa, recounts how, while in the hospital after

"30 years of suffering with severe depression," she began to feel a sense of community,

dignity, and trust (MFI, Anonymous). Having experienced coercion by authorities and

hospital staff, Jessa was surprised by the experience which led her to recovery.

> "...I was not alone anymore when eating, I did silly crafts with peers, I talked with
> others on the ward, I cried to some of the nurses I trusted, and they told me I was
> very bright. Some of the staff treated me with respect and as a human being, and
> I journaled the entire time I was there."

Jessa talked about her supportive psychiatrist she met in the hospital who introduced

her to books and other people who would help her to "connect with how to change

[her] destiny" (MFI, Anonymous). When she left the hospital, Jessa felt, for the first time

in a long time, a sense of freedom.

> "Slowly but surely I began recovering: I decided to write my own memoir about
> my journey, I began exercising, I let go of people who were not healthy for me, I
> focused on surrounding myself with the animals that I worked with that always
> seem to feed my soul, my medicine was changed, I found part-time work, I began
> taking better care of myself by dressing up and doing my makeup and hair, and
> people started to notice the change."

Through her support groups, she met people who would listen. Jessa was enabled to

express herself genuinely and feel hope in her future. Working together as allies rather

than adversaries changed the whole experience of mental illness and recovery for Jessa.

As people saw her differently—her actions now reflecting moral choices—they began to

treat her differently. Rather than as a faulty brain and body, Jessa could be a person with

dignity. To be treated with dignity and respect, regardless of mental illness (or other

coexisting identity factors), conveyed a sense of care for their personhood. Because she

began to uphold the social values in behavior, perception, and expectation (Jacobson

2007: 294), Jessa could maintain her ability to command herself, to have others listen,

and requests or needs considered and met.

Though it is said dignity cannot be destroyed, given its nature as a fundamental

component of humanness and personhood (Jacobson 2007), most persons participating

on the MFI forum, as portrayed in the data presentation (chapter 4) and noted above,

did not express having dignified or positive social and clinical experiences. Many

expressed being patronized or infantilized by family, friends, and medical personnel

when displaying symptoms of mental illness or requiring an irregular need because of it.

They were subjects to coercion and manipulation by family, friends, and medical

personnel, which left them feeling betrayed and victimized. After repeated experiences

of hopelessness and shame, many fell into that state of engulfment (Lally 1989) and

became what they perceived everyone believed them to be, first and foremost: mentally

ill. For many authors, they had been under the influence of this identity for quite some

time, many for years, until they decided it was time to try something new. The medications and therapies they had tried were not helping them to be the person they wanted to be, and there seemed to be gradually fewer human supports also. Many narrative authors articulated they were unable to find their way to recovery and wellness because they did not believe they could. To move forward into recovery, many did what I described as a traditional bootstrap ideology: they steeled their spirits and pushed themselves into the unknown.

Recovery as Self-Identity

To find recovery, authors described how they had to change the way they felt and viewed themselves and mental illness. It was no longer about being made to feel content in their position, but asking "what they should be capable of" and how they might go about achieving such capabilities (Hopper 2007:875). The characteristics of this theme included a fortifying of self to create inner change, and reclaiming autonomy. They had to distance themselves from the toxic messages they were receiving from family, friends, and the mental health care system to create and establish new meaning about themselves and their lives. If the people who had been surrounding them did not understand what they were going through, why they needed to question the system and their social and medical treatment, then they would find people who did. Some note an initial spark, an interaction, which led them to question what they had been told about

themselves and their illness (Cohen 2005). One example, whom I will refer to as Kerry, it

was described how a music teacher introduced him to piano and the power of music as

a channel for inner peace. Playing the piano for that first time gave him a sense of calm

and allowed him to release all this energy he had inside, which had caused him great

emotional distress. It was in that moment Kerry realized there were natural, non-

medicated ways to not only control symptoms, but to heal and reclaim his identity.

Others had to search for different faces, to find their peers, or other people who had

been labeled mentally ill and who had similar life experiences (Austin, et al 2014; Lewis,

et al 2012; Myers 2015). Like Lynn, who found herself being shuffled and stonewalled

between autism and mental health groups, all which labeled her "too high functioning"

for their help (MFI, Anonymous). It was not until she found a student advocacy group at

her university that she was able to feel confident in, and accepted for, her personhood.

Establishing these relationships were crucial to attaining the inner conversion of self

because it meant being surrounded by people who accepted and respected them for

who they were as a whole person. It was having people who would not pathologize their

actions, especially behaviors they considered to be part of their normal everyday

functioning.

These inner conversions were only successful because they had inter-personal

validation. Someone to reaffirm their action as valid and acceptable, someone who

responded with respect, care, and support for them and their journey. Most importantly,

to be validated with dignity meant maintaining one's ability to determine for themselves how their recovery would progress. It was the difference between being offered a helping hand with equal partnership or a leash from which one person would lead and another would be led. This shows why it was so devastating to Diana (The Woeful Spouse, Ch4) when her husband requested she try a different course of treatment for her bipolar disorder. It made her request for a steadier home life and greater participation from her partner unacceptable, and it belittled her authority of experience as a woman, wife, and mother with severe mental illness as a poor or undesirable reaction to current treatment. Rather than feeling validated in her concerns, or even courageous for expressing a stigmatized need for greater support, Diana found herself wondering if she were even worthy of an intimate relationship. Conversely, as we saw in Gina's narrative (The Challenger, Ch4), having an ally who helped her understand the history of womanhood and mothership was crucial to Gina's ability to reframe her self-identity from someone who was "failing" and "weak" to someone who was caught in a complex cultural web. The social worker who validated and dignified Gina's experiences with trauma and mental illness rather than treating her like a broken person affirmed to Gina she had the power to heal, grow, and be a beacon for others who had similar experiences.

As structured recovery and support methods tried to implement the idea that

"being a patient is only part of becoming realized as a person" (Austin, et al 2014: 884),

some questioned why they had to become a patient to be seen in full personhood.

Were they not a person before ever being a patient? Why exactly was subsequent

dignity and respect hinged on first being seen as mentally ill? On one side, taking steps

to seek treatment and pursue recovery shows to the second- and third-perspective

persons that the first-person is rational and wants to become better. As a socially

accepted method for wellness, the pursuance of patient status shows the kind of

rationality required for consideration as a moral, dignified person (Myers 2015). On the

other side, this is also a way to inspire hope to persons who are otherwise feeling like

they are in a hopeless situation. To conceptualize patient status as part of the process to

greater healing minimizes the distressing effects of coercion to get them to, and while in

the hospital. It also instigates that place of hopelessness as the foundation from which

they can rebuild themselves and their lives. However, this tool for reframing identity can

still come with its share of stigmatizing side effects. If mental illness erased their

personhood, which then necessitated the need for patient-status to reclaim inherent

social privileges such as being treated with dignity and respect, then it served as further

proof that individual recovery was essentially a tool of social control.

Recovery as Justice

Recovery, to some, was not something to strive for or wield as a saving grace to

suffering. Rather, shaming people for having mental illness, imposing treatment and

recovery methods with demands for lifelong preservation were tools of an oppressive

society unwilling to embrace difference. Recovery was a by-product from the fear of the

unknown and the unwillingness to make time and space for people characterized

outside of the social pinnacle. The theme of recovery as justice is characterized as

healing from psychiatric violence and social control. While these narratives may sound

thematically similar to those portrayed in the section above, there existed in these a

certain kind of anger. Anger toward the labels so easily given and so difficult to remove.

Anger toward the treatment of their person by family and medical personnel and at

being subjected to treatments (and a long list of side effects) they did not want or need.

The narratives which I identified with this theme featured authors who sought revenge

in their recovery (if they called it that), who developed a righteous fervor in their

separation from the mental health system (Corrigan and Watson 2002). Both Frankie

and Helen found a justified sense of recovery as they realized they could accept they

had been given a label, but were free to minimize or reject it within their reality. Recall

Frankie (The Driver, Ch4), who had taken medications for years and felt like the only

thing they received were more mental and physical illness side effects. Their "turning

point" came when they realized they could be miserable on the meds or be potentially

miserable without them. In a bootstrap-style transformation, Frankie realized if they did

not take responsibility for themselves and their life, they were going to continue to be reprimanded. They came to see pharmaceutical treatment as a punishment for their unacceptable behavior. The hospital had become a prison where you could get parole for good, sociable conduct. As they "pulled themselves up," the medical view Frankie had of themselves and their illness faded. They renounced mental illness and the notion of recovery; "recovery," Frankie said, "buys into the notion of a "disease" or at least a "disorder," which was the language used to keep certain people down (MFI, Anonymous). It was not until Frankie took matters into their own hands that they found alternative options which helped to align and balance their life and wellbeing.

Helen (The Enduring Believer, Ch4) was even more adamant in her need for justice after the treatment she had received while in and out of the hospital. Always maintaining she was "never mentally ill," Helen compromised her sense of self to get out of the mental health system. After repeatedly denying their diagnosis of her and her need for pharmaceutical and ECT treatments, Helen learned the only way she was going to get out of the hospital was if she were compliant. If she admitted she had mental problems and needed to be in the hospital, then the doctors and nurses would treat her with more kindness. Though performing as the "good patient" helped to ward off additional ECT treatment sessions, they were persistent and traumatic. Helen remained resolute in her truth; she was not mentally ill: "I knew it and held on to that knowledge, despite the doctor and my parents who wanted me to believe I was" (MFI, Anonymous).

Justice came for Helen years later, when she finally found a psychiatrist out of state who was willing to let her set the pace and determine the course of her recovery, which included weaning off all remaining pharmaceutical medications and validating her as a survivor of wrongful psychiatric practice. Though Helen had close friends and a loving partner who advocated for her over the years and helped her recover from psychiatric abuse, it was the confirmation and defense of her lifelong sanity by medical professionals that provided closure and freedom. Being defended and deemed recovered by those who had vilified her was justice in its purest form.

The ability to determine their life course was crucial to the authors on MFI, as it is for many in the cultural West; however, for people like Frankie and Helen it was even more important because it had been taken away. The experience of having others dictate what they should be doing with their lives, how they should adjust their expectations to match that outcome, that feeling of hopelessness made regaining and maintaining their own autonomy even more essential. Knowing and feeling like they were in charge of their bodies was empowering. Because of this, their action and narratives adopt the bootstrap premise: one against the world, fighting to make it, and the final triumph in their success. Though their narratives involved these elements, it also highlights how this mindset allowed them to validate their identities and participate in ways of their choosing. With this freedom and the capability to self-determine they

could focus on what they were able to do and be, and nurture that self into a person of their own making (Sen 2003; 2005). Notably, having people around them who respected their experience and were willing to support them in the ways they consented, not only provided validation, but greater access to opportunities to practice recovery. By having a community of people who were willing to nurture their growth—to practice with and for them—they could feel like a dignified member of social life.

Social Recovery

Experiences in the mental health system and recovery led many to question and examine societal structures and their place within them. As narrative authors reframed their ideas about themselves, they also began to question the ways in which recovery ideologies are upheld. The theme of social recovery emerged when authors highlighted the larger societal structure and how those around them contributed to illness and wellness. It recognized the greater responsibility required by the surrounding culture to generate not only individual wellness, but community and societal healing. By considering how factors of gender, race, class, and mental illness interact underneath greater social and cultural ideologies they could begin to shift some of the internalized blame and responsibility from themselves to society and its structure. They did not need to recover from mental illness. It did not make them less of a person and it was nothing of which to be ashamed. Rather, they criticized the larger society and culture to provide

greater opportunities to be valued. Mental illness did not occur in an emotional bubble, or an individual vacuum; therefore, for actual recovery to occur, it would be necessary to critically assess how direct and perceived experiences of trauma, racism, sexism, homophobia, and poverty contribute to stress, mental illness development, and subsequent loss of dignity and trust from others. By demanding others practice with and for them, they could further subvert the detrimental bootstrap ideology of recovery and install in its place a civic call to action.

Many people who participated on the MFI website were activists themselves who sought to change the narratives about persons with mental illness. Through their criticism of their own societal and medical experience with mental illness, they not only wanted to provide personal advocacy, but opportunities to seek recovery and heal through widely different channels. Most profoundly was Gina (The Challenger, Ch4) as she questioned the integrity of recovery in her resentment toward its commonplace notions and appearing "normal" as necessary to be valid. The language of recovery, she said, was about learning how to "survive oppression" and "unfair life situations" rather than making life fair for people who do not possess equal power and privilege. She wished,

> "...that as a woman, that people saw my anger not as hormonal only, but as a symptom of society's disease of invalidating me as a woman and dismissing me because I'm "crazy." My recovery is not about me as an individual, but about recovering within a society that is hell bent on segregating me!"

Why was she was responsible for "getting over" social injustices predicated on her

ancestry and womanhood when society was also responsible for dismantling violent

structures to create acceptance and opportunity for all people? By keeping the focus on

the individual illness, it allowed the cultural illness of discrimination and oppression to

continue quietly in the background. Gina channeled all the anger she had been directing

against herself and focused it into her activism, which directed ways for cis- and trans-

women to feel strong, safe, and empowered.

Lynn, from the example above, found through her student group the ways she,

too, could provide psychiatric survivor advocacy. Finding a community which would

accept her "regardless of whether or not I am on medications, seeing a "professional,"

crying "too much," flapping my hands, etc." was incredibly difficult, and made Lynn

realize "recovery isn't just personal, or the responsibility of the individual" (MFI,

Anonymous). Instead, recovery was a part of the larger cultural system which sought to

force people into certain ideologies of mental behavior and rhetoric. By placing the

blame of mental illness on the individual, it not only set them up to fail in recovery, but

worked to exonerate the very structures which participated in its inception. The work to

change the narrative of recovery from an individual goal to a social responsibility meant:

> "...you are surrounded by those who love you, whether human or other species,
> and these beings respect the various parts of you and your various ways of
> being...Recovery doesn't mean you're "better"/"not ill"/not mad; to me, it means
> that you can still be your glorious mad self, but have the support to handle
> challenging stuff...Each time we treat each other with respect and work out of an

anti-oppression perspective, we are helping each other and helping society" (MFI, Anonymous).

Recovery, as a "social project" (Hopper 2007), is not primarily about healing. Because of the construction of power and performance relationships in the United States, those whose behaviors or actions are conceptualized as atypical, inappropriate, or immoral face ostracization from participation in, and the creation of, specific social lives. Mental illness has the power to socially obstruct a person from living a meaningful and personally fulfilling life. Through this process, dignity, which is inherent to recognition of personhood, is lost. Participation in socially sanctioned treatment options has the power to return this dignity. However, as the authors recounted their experiences with treatment, health care, and community interactions, it became obvious this did not always lead to the social welcoming they were expecting. Something more would have to be done to reestablish themselves as dignified, capable, and deserving of respect. Recovery, as we have seen from this perspective, is about opportunity and participation; it is political. The greatest freedom Sen (1999) identified was the "freedom of avoidable ill-health and from escapable mortality," (620) and it has been demonstrated how a "minimally decent life" (Selgelid 2016) may have been considered healthy by some standards, but clearly was not enough for the participants of MFI. Instead of merely seeking wellness, recovery seeks to revolutionize the larger medical and social culture surrounding mental illness to provide greater access to intrinsically

important freedoms (Sen 2003:48). This includes access to various alternatives to provide a wide range of choice to pursue recovery and social inclusion in the ways that best fit their individual needs and goals. For some people, like Lynn, recovery needed to include a community space where she could appear without shame. Or Gina, who also needed the opportunity to advocate for herself and others, to participate in the reframing of not only her own identity, but the cultural perceptions of persons with mental illness, their presumed quality of life, and their presumed capabilities. For others, like Helen, recovery was about validating her sense of personhood and what she always knew to be true. Though recovery was about attaining wellness and control over mental illness symptoms, it was also a practice of unearthing, criticizing, and subverting the invisible standards used to measure a life of quality and moral goodness.

<p style="text-align:center">*　*　*</p>

To make these potential capabilities a reality, the people surrounding them had to provide the right support and motivation. These narratives not only serve as a sense of hope for others who feel like there is no place for them to turn, but also illuminate the complex construction of mental illness recovery. Though considered an individual practice, with harrowing implications to boot, they reveal the incredibly social nature of healing from trauma, stigma, and structured care. They demonstrated how healing included a reframing of their identity, which is contingent on interpersonal validation. Recovery occurred because they had a community of people who were willing to listen,

who allowed them to maintain control over their bodies, and were willing to practice

with and for them in the ways best suited to their needs. Even though recovery from

mental illness is shrouded in manifest destiny and bootstrap rhetoric lingering from the

West's culturally embedded history, it reveals therein the contradictions which seek to

be its undoing. Using discursive themes found within the narratives themselves

illuminated the importance of perceived capabilities during the recovery journey. Having

the opportunity to define recovery for themselves and pursue it in the ways meaningful

to them is what allowed the individuals participating on the MFI to express success.

The implications of this research reveal the individualistic cultural nature of the

recovery discourse, which is highly problematic considering the social nature of actual

recovery practices. What has been framed as an individual responsibility, which thereby

leads one to lose credibility and moral standing in the community, lends itself to uphold

the most dangerous cultural conception of mental illness: that it is somehow a choice.

The narratives, which hold the authority of experience, reveal these contradictions. First,

that "treatment" and "recovery" are not synonymous and are developed and defined

through social interactions over time. Second, that though the platforms for sharing

narratives seek to highlight the potential for recovery among persons with mental

illness, they also sustain detrimental cultural assumptions of who can pursue and

achieve recovery. Finally, they express the societal responsibility for creating space and

greater opportunity for people who do not perfectly match the cultural status quo; and,

in so doing, subvert the Western's culture of bootstrapping to success as a phony caricature of actual everyday life.

6. Conclusion

Though the sites belonged to organizations which both work on behalf of persons with mental illness, they bared considerable differences in their focus, goals, audience, and forum architecture. NAMI featured a younger audience, predicated by their focus on early intervention and providing safe spaces for youth and allies to talk about their experiences and emotions. Through the free form expression of the platform, many people participating in these forums had not yet been given a diagnosis of mental illness, or experienced hospitalization or ostracization from their communities; however, their narratives depicted the isolation they felt within themselves as they began learning how to navigate a world which punished people for being mentally ill. Through their discourse, they revealed the fear of the possibility of being labeled and diagnosed with mental illness. Most frightening were the potential reactions from family and friends should they be deemed mentally ill. Many were convinced this diagnosis would prompt their closest social ties to leave them alone to face what lay ahead. Allies, or persons who knew people with mental illness and wanted to advocate for them, who had witnessed a lack of compassion by school officials or other authorities, were also concerned about how a diagnosis of mental illness affected their peers' chances of

success in school and beyond. Quite harrowing, these narratives were fraught with the confusion and trepidation of those who had yet to experience what may come of a life with a mental illness label.

On MFI, where expressive individualism was built into the platform, the narratives read quite differently. The authors on this forum were typically older and had experienced being given a diagnosis, many were hospitalized more than once, and declared their outrage toward societal and clinical treatment. In their narratives, they shared their struggles with mental illness, with the health care system, and with societal and cultural oppression. They also shared their triumphs, and focused on how they could reach a state of recovery when they reclaimed their power and found a community of people who were willing to allow them to have control of their lives and medical decisions. As they learned how to practice recovery and wellness in a way that worked for them, they discovered a whole new way to live. Some identified as consumers, who utilized pharmaceutical medication or ongoing therapy as part of their recovery practice. Others, some of whom identified as survivors, proclaimed their recovery a success when they could release themselves from all aspects of the health care system. Still others wanted nothing to do with the notion of recovery because there was nothing from which to recover. For them, having mental illness should not necessitate and demand its expulsion, but should be embraced as a mere fraction of their personhood, a small part of themselves like their passion for art or their love of

jazz. As veterans of the system and of cultural repercussion, they declared a need for a

greater focus on societal structure which allowed those deemed outside of social

pinnacles to be subject to hate, oppression, and loss of opportunities.

The theory utilized to bolster the background and analysis of this research were

important for multiple reasons. First, in their proliferation within the discipline of

anthropology and their salience through time and cultural change. The reflexive nature

of Goffman (1959; 1963) and Sen (1985; 1999; 2003; 2005) have allowed for continued

use through generations of scholarship and cultural flux. The thoughtful and intuitive

nature of their philosophy are what has allowed scholars and practitioners of cultural

critique to deeply analyze societal practices and underlying motivations for structural

development.

Second, in how both theorists focus and position fit the present subjectivity of

the persons participating in each of the sites. NAMI, for example, exemplifies Goffman's

(1963) discussion of stigma and the practices utilized by persons to pass and cover for

normal. Though many were not quite considered full adults by societal standards, their

"moral careers" (Goffman 1963:32) developed in adult onset. These participants had

grown to see and know the world in a certain way, a way which prohibited the

acceptance of mental illness as a regular and honorable part of some people's lives.

Their fear of being diagnosed and worry over the potential societal discipline attest to

this. The stigma of mental illness was so strong, it greatly affected their performance in everyday life and their developing subjectivity as an adult in America.

On MFI, where most authors had moved beyond the fear of stigma—had, indeed, lived it to its fullest—and were now focusing on recovery and activism for themselves and those still in the system, Sen's contributions became of the utmost importance. As veterans of mental illness and societal misperceptions, they had become more aware of the ways structure implicitly and explicitly worked against those labeled as different. Once they could regain their autonomy and choose their own path, they were free to change their capability measurements from clinical perspectives to a personal one (Sen 2003; 2005). They changed their focus of achieving American dream hood in the usual bootstrap fashion expected by the greater society to concentrating on their own capabilities and the practices which fit them best. They had transformed from trying to be what society expected into what they desired for themselves, and in so doing they were able to impress to others their possibilities and have them taken as truth (Goffman 1959). As those around them came to trust the presentation of self before them they became involved in their recovery practice, which provided greater opportunity for community engagement and personal success so they could become the person they always knew they could be.

The narrative illustrations by the authors on NAMI and MFI reveal the utmost truth: we are all "normal deviants" (Goffman 1959:131). The outstanding identity norms

of social life deems that everyone, regardless of mental illness or not, does not measure up to the ideal. The stigmatized and the normal are not two distinct and separate groups of people who happen to interact in everyday life; rather they are a social process constituted of two roles every person plays during some time of their life. The complex power and performance relationships in which we are constructed constitute the attributes or behaviors conceptualized as atypical, inappropriate, or immoral, as well as those to the opposite effect. To allow people to be themselves and appreciate them for who they able to be and what they can do, no matter how prolific or incidental, is the key to attaining greater societal and cultural fulfillment.

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APPENDIX:

MFI "I Got Better" Forum Optional Question Prompts

How long has it been since the last time you took any psychiatric medication?

Are you currently receiving any of the following services within the mental health system?

Are you currently taking any prescribed psychiatric medications?

About how long has it been since the last time you took any psychiatric medication?

Have you ever taken a prescribed psychiatric medication?

Have you experienced any serious physical health problems as a result of your psychiatric medications?

In total for your whole lifetime, about how long have you taken psychiatric medications?

To the best of your knowledge, have you ever been given a psychiatric diagnosis?

Can you give examples showing you have gotten better from a mental or emotional problem, such as how you are doing well or accomplishing goals you have chosen?

During your mental health care, have you often felt hopeful about your chance of getting better?

If you have ever received a hopeful message that your recovery from a mental health or emotional problem was likely, what was the source of that message?

During your mental health care, have you often felt hopeless about your chance of getting better?

If you have ever received a hopeless message that your recovery from a mental health or emotional problem was unlikely, what was the source of that message?

Has a mental health provider ever told you that you could not reach a personal goal because of your psychiatric diagnosis?

Has a mental health provider ever told you that you could reach a personal goal because of your psychiatric diagnosis?

How recovered do you consider yourself from any mental health or emotional problems? Please use your own definition of recovered. Indicate your level of recovery using a 10-point scale with 1 being "not recovered at all" and 10 being "fully recovered."

If you could send a brief message to someone receiving mental health care today who is feeling hopeless about getting better, what would you say?

If you overcame hopelessness that you could get better from a mental health or emotional problem, was there a turning point for you? Please describe:

In what ways have you found psychiatric medication harmful, if any?

Have you found psychiatric medication harmful?

In what ways have you found psychiatric medication helpful, if any?

Tell us what recovery means to you. How would you define recovery from mental health or emotional problems in your own words?

Generally speaking, which of the following categories of what some people call alternative mental health practices, if any, have been the most helpful in your path to recovery?

What are some ways you maintain your recovery from a mental health or emotional problem?

What were some of the main causes of your mental health or emotional problem?