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Laura Drabelle Valentine
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NAVIGATING MENTAL HEALTH CARE ACCESS IN LOUISVILLE:
AN ETHNOGRAPHY OF LOCAL RESOURCES AND CARE ASSEMBLAGES

By

Laura Drabelle Valentine
B.A., University of Louisville, 2014

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A Thesis Approved on

July 30, 2018

by the following Thesis Committee

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Dr. Angela Storey (Thesis Director)

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Dr. Christopher Tillquist

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Dr. Sarah Raskin

DEDICATION

I dedicate this thesis to its participants, who shared their knowledge with me and trusted me to do their experiences justice. I hope I have achieved that.

"The worst is done, and it has been mended. And all will be well, and all will be well, and all will be very well." —Julian of Norwich, a closing statement at DBSA meetings (Depression Bipolar Support Alliance 2018)

ABSTRACT

NAVIGATING MENTAL HEALTH CARE ACCESS IN LOUISVILLE:
AN ETHNOGRAPHY OF LOCAL RESOURCES AND CARE ASSEMBLAGES

Laura Drabelle Valentine

July 30, 2018

This thesis examines barriers to care access present in Louisville, Kentucky's community mental health care infrastructure, and how individuals who seek mental health care experience and navigate those barriers. This thesis expands research about the impacts of health care reform following the Affordable Care Act and adds to literature about the political economy of health-seeking behaviors. Drawing on assemblage theory and ethnographic research with both care-providers and care-recipients of Community Mental Health Care Organizations, I argue that both groups attempt to alleviate barriers to care access and facilitate mental health recovery through the development of formal and informal strategies. Examining the ways that these individuals find creative and agentive solutions to the challenges of structural and institutional precariousness and chronic mental illness can be useful findings for developing effective mental health interventions.

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NOTE FOR THE READER

1. *Pseudonyms:* All study participants have been given a pseudonym, unless they are identified as using their real name.

2. *Terminology:* Throughout this text, I use interchangeable terms for individuals working or receiving care from community mental health care systems, to reflect the multiple subjectivities they inhabit. For individuals living with mental illness, I use the terms *care-seekers, care-receivers, patients, mental health consumers, clients, members [of an organization];* for service-providers, I use the terms *care-providers, employees, staff.*

3. Throughout the text, I redacted the names of community mental health care organizations and hospitals unless contextually relevant, to respect the privacy of individuals who participated in my study, especially when care-providers described anonymous examples of their clients' experiences.

4. I minimally edited quotes for clarity; I often removed details like verbal tics or tangents while keeping the quotes intact.

CHAPTER I:

INTRODUCTION

The short bike ride from my apartment to Paul's wound through cluttered traffic. The air was thick with gasoline fumes and music drifting from open car windows. When I arrived, I waited on the front porch, drenched in sweat and breathing lungfuls of hot air. It was the height of summer and a blindingly bright day but when Paul finally answered the door, he led me into a dark, cool apartment. I had arrived anticipating a mess, and took in the sight in the gloom of drawn curtains and stale air. Paul had already begun to clean; things were collected into roughly organized piles. Ash and cigarette butts overflowed the ashtray. Empty cigarette boxes were cluttered together on the living room coffee table, beside soldierly lines of old Styrofoam cups. Bits of dirt clung into the carpet. A stack of dirty dishes climbed from within the kitchen sink. Overall, the apartment was in a telling sort of disarray. This mess had built up around him over the past months, after he had given up on cleaning entirely. Even as he greeted me with a hug and a joke, Paul seemed uncharacteristically drained. He showed me into the bedroom where there were several baskets of clean laundry. We sat on the floor and got to work folding. We casually chatted about things, jumping from topic to topic, evading entirely the fact the Paul had recently been discharged from psychiatric inpatient. Now that he was back at home, he had a lot to attend to. Paul lives with Major Depressive Disorder as a result, he says, from "fairly mid-level to low-level but constant abuse from both peers and adults" throughout his childhood.

During our interview, he said that it had been about 28 years since his *first* hospitalization. So, at the time that I showed up to his house to help him clean, it was not the first time his symptoms had become severe enough to warrant checking himself into the hospital. He had put out a call on social media after being discharged, asking for help piecing his life together after this most recent depressive episode. Like many people who experience mental illness, acts of self-neglect were signals of Paul's declining mental state (Patel et al 2014; Lauder 2002). Years later, when I met Paul to interview him for this thesis, he was also cleaning. He wanted to organize his new apartment where he lived with his new wife, to force a routine which would help him keep an eye on his mental health. Keeping note of behaviors rejecting routine, such as neglecting personal hygiene or not cleaning, could act as early signs embedded in everyday life that could help Paul prevent a re-hospitalization or a self-endangering crisis. For Paul, the bottom rung of symptoms includes suicidality, and checking himself into the hospital is done, voluntarily, as self-preservation. Paul said:

> "I've always given this analogy, for long term mental health. The first time you come into it, you're on the cliff and you've made the really great decision like, oh, shit! I'm on this cliff! And maybe you've fallen off, maybe you wake up with charcoal in your mouth because you tried to OD— happened to me once. So, shit, what happened to me there? Oh, okay! I didn't go over the cliff, I caught myself here."

Here he indicated another spot on the floor, a little behind where he stood. "And then the idea is to eventually catch yourself like—" he took several steps farther back, and continued:

> "back here, and to keep setting these benchmarks further back. You keep trying to up your moment of crisis. You're still going to have a crisis of mental health, but ultimately the goal is to catch the crisis before you lose the job, before you lose the relationship, before, you know. A lot of times, people are like—"

He paused and walked forward, off the cliff, where he was standing before, saying:

> "oh, shit! Now I'm in crisis. I torched that! So the question is, how to create those benchmarks—how to create those flags. And that's both an internal thing and, very scarily for mental health people, it's an external thing."

Managing one's own mental health, in this view, requires creating strategies in one's own life to maintain mental wellness and stability while grappling with complexities and uncertainties found in individual, institutional, environmental, and emergent challenges of such (Hines-Martin et al 2003). The relationships between and among and between internal and external influences—forces originating within an individual and their own reckoning with their mental illness, and forces originating outside of the individual—direct the types of health-seeking decisions individuals can make and have consequences for mental health outcomes. Paul is able to manage his mental illness with access to counseling and medication, access which is contingent on having insurance. But through nearly three decades of interacting with mental health care systems, Paul's insurance status has been inconsistent. Becoming symptomatic means a lot of things for Paul. Self-neglect can run deep, from avoiding basic tasks like cleanliness to failing to pay utilities, credit card bills, rent, or file taxes. Losing employment, coming close to eviction, symptoms feeding conflict in interpersonal or romantic relationships were all potential outcomes of his languishing mental health. So stability, recovery, and mental wellness were questions of the internal and the external: how could Paul adopt daily strategies to monitor his mental health, while also ensuring that he had consistent access to technologies of care, including insurance, that allowed him to remain stable? Paul was one of the Kentuckians who benefited from the implementation of the Patient Protection and Affordable Care Act (ACA) and Medicaid expansion in Kentucky. He relied on Kynect, a health-care marketplace model, to find insurance and manage his own care. When Kentucky Governor

Matt Bevin was appointed and dissolved Kynect in 2016, Paul had to adapt to the change. Now insured under Medicaid, Paul said that generally he found the services he received helpful. But, he said could always expect a mental health crisis to arise and explained that avoiding destabilization was contingent on more than insurance. Across interviews I did with patients and providers of Community Mental Health Care Organizations (CMHCOs), tensions between both internal and external forces were germane to my central research question about barriers and facilitators to care access.

Research Context

This research focuses on Louisville, during changes over the last several years in community mental health care. New initiatives and system integration efforts were launched even during the few months of my data collection in 2017 and 2018. Louisville can be a useful context for researching how barriers to accessing and maintaining care are structured in the context of large-scale health-care system changes translated through CMHCOs, auxiliary institutions, and the strategies of individuals as care-providers and care-seekers and can perhaps shed light on similar infrastructures nationally. The Community Health Needs Assessment 2014 (CHNA) released by the Louisville Metro Department of Public Health and Wellness indicate that residents have concerns about the state of mental health care access and overall health disparities in the city (Community Health Needs Assessment 2014; Healthy Louisville 2020). In the CHNA, survey respondents expressed concerns about mental health specifically, in describing most needed areas of health service improvement, with noted barriers to care including cost of treatment and the stigma of seeking care for mental illness (Community Health Needs Assessment 2014). Concerns about mental health were mirrored by concerns about health

disparities in the city overall—which mirrors stark geographic segregation by race and socioeconomic status (Community Health Needs Assessment 2014; Healthy Louisville 2020). Learning of this, I became curious how people who were experiencing low access to mental health care were managing their mental health. What resources did individuals draw on and how were they used? In structuring this research, I hypothesized that individuals would draw on care assemblages comprising informal, meso-level, and formal health care resources, ranging from public, semi-structured support groups to community health resources, to occasional or sustained contact with medical professionals and doctors. I wanted to understand how individuals moved among and between these entities in this landscape, and what structured their decisions. I wondered if there would be patterns as to how health-seeking decisions were limited by individuals' social, economic, geographic, and political contexts. As well as how individuals were utilizing mental health care resources in Louisville, I wanted to know what types of barriers to accessing or sustaining care directed, limited, or influenced the resources they used to receive mental health care.

From October 2017-April 2018, I undertook a qualitative research project to interview care-providers working in CMHCOs as well as care-seekers who were patients of CMHCOs to analyze what barriers to care individuals face when seeking mental health care in Louisville, how they navigate complex care systems, and what resources they draw on. My research examined three inter-related questions:

> *1. What barriers to care do patients/individuals experience when seeking services*
> *from CMHCOs and other community resources necessary to meet their needs?*
> *2. How do those barriers interact?*
> *3. When people experience low access to mental health treatment, what do they do?*

Examining barriers to care is a crucial foundation of knowledge in order to understand how individual health-seeking behaviors are produced. As a result of the ACA, around 382,000

Kentuckians gained insurance coverage since 2014 (Robert Woods Johnson Foundation 2016, cited in Garrett and Gangopadhyaya 2016). In expansion states, Medicaid expansion was associated with a reduction in cost-related barriers to recovery for health care consumers, which extended to long-term outcomes such as being able to afford medication on a regular basis (Sommers et al 2016). Of health outcomes, mental health appears to be the most significantly impacted by Medicaid expansion (Winkelman et all 2017). Recent research undertaken in Louisville examining mental health care access among West Louisville residents before and after the implementation of the ACA indicates that Medicaid expansion did have an overall positive impact on mental health care access and utilization; however, other barriers persisted for individuals in seeking or maintaining care (Buchino 2016). My data, in concordance with broader bodies of research on mental health care access, suggest multiple mechanisms by which barriers to care may operate and may point to larger systemic issues with community mental health care delivery which extend beyond mere access to care, where barriers to care themselves are formulated across larger social inequalities (Buchino 2016). Barriers to accessing care are concurrent with barriers for overall stability and self-management of mental health and recovery. For example, one mental health consumer, Kate[1], said:

> "I got charged for my last visit [at the hospital] and it's on my credit report
> even though I was involuntarily institutionalized, so that's great when I try
> to get a job because the first thing on the top of my credit report."

Experiences of this nature were a trend throughout my data, where care access as entry into services was not the only barrier to managing mental health that individuals faced in seeking care. When I discuss "care access" in this thesis, what I describe is access to

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[1] Real name

strategies to manage mental health in the long term. There are markedly beneficial outcomes to the elimination of financial barriers to care access and the provision of specific assistance programs intended to mitigate the effects of social determinants of health. However, increased economic access to health services alone should not be mistaken for an individual's wholesale increased ability to utilize or maintain those services, where barriers to care are multi-level and recursive. This thesis argues that both care-providers and care-seekers rely on care assemblages, either independently or as co-produced efforts, to facilitate ongoing access to mental health care treatment or maintain mental wellness. This occurs in the context of precariousness generated by recursive barriers to care which include macro-level social, political, and economic forces in equal power to micro-level social relationships between individuals, in communities or within institutions.

Uncertainty was a frequent theme in interviews, where large-scale institutional entanglements between CMHCOs and auxiliary resources (such as the Louisville Metro Police Department, EMS, or the Coalition for the Homeless shelter system, for example) produced projects which could be at risk for funding loss, were subject to operational changes because of shifting legislation about health care, which raised questions about responsibility and executing the logics of intertwined organizations, or which challenged individuals to create cohesion between different aspects of the care landscape which were not easy to maintain. This, as well as the anticipation of changes in health care policy and environmental barriers to care reflecting social inequalities, creates environments in which care providers and care seekers frequently must adapt to changing or precarious circumstances, carving out pathways to stability and recovery through multi-directional barriers to care. Care-providers and care-seekers described how the ongoing experience of

barriers to care could create tenuous care access, in which it was possible to be buffeted in and out of services.

My data suggests that interactions between barriers to care at different levels create confounding factors for maintaining mental wellness and making progress in treatment for some individuals (Hines-Martin et al 2003). Mental illness is a long-term experience which changes throughout an individuals' life course; some patients may experience a mismatch of time, where the pace of working through the recovery process is at odds with the actual pace in which one experiences symptomatic episodes, barriers to care, and other stressors. Drawing directly from the categorization used in Hines-Martin's analysis of barriers to care among African-American residents of Louisville in 2003, I identified barriers at the level of individuals, institutions, and environments, while my data also suggested that larger structural influences such as political changes impacted care seeking decisions individuals could make. Most of my data revealed a picture of Louisville as housing a progressive CMHC landscape, which often includes efforts at systems integration with non-CMHC services, such as the criminal justice system, transportation systems, housing assistance programs, food assistance programs, and other social services programs. There is ample need for research into these relationships in more detail, beyond what this thesis is capable of. The experience of this system is contentious; interviewees often expressed contradictory messages in which this landscape was possible of having great utility for recovery and facilitating positive mental health outcomes as well as disruptions and defeats. The data in this thesis may contribute to ongoing efforts to confront an alleviate barriers to care access at these multiple levels.

Many interviewees described barriers care-seekers face to staying in care, avoiding

cyclical destabilization or decompensation congruent with other stressors, or experiencing a series of accumulated burdens or a process of marginalization because of acute episodes and their consequences. Within and without care systems, individuals—both care providers and patients—work to create stability. Individual strategies for maintaining wellness might range from the informal—for example, one patient interviewee told me they bought their psychiatric medication as needed from a drug dealer when they couldn't afford the cost of the prescription out of pocket—to the formal, in which care providers create treatment plans intended to fit a messy human experience into a Medicaid-billable form. Facilitating recovery in the context of the CMHC system, my data suggests, lies in the space where patients and providers work to span individual, institutional, environmental, and structural barriers which are experienced by both groups.

<u>Literature Review</u>

Louisville's community mental health care infrastructure and related resource landscape reflects the paradigm shifts of mental health care reform eras, beginning with post-World War II de-instutitionalization and subsequent social movements through the following decades (Patel et al 2014; Stein et al 2014). De-institutionalization gained momentum in the mid- to late-1950s, in accordance with post-war shifts in ideology away from institutional care and towards the integration of mentally ill individuals into the community, spurred by human rights ideologies, concerns about the sustainability of institutional models of care, and the development of novel, effective psychiatric drugs (Patel et al 2014: 8; Stein et al 2014). The 1963 Community Mental Health Act was intended to galvanize de-institutionalization through the mandated release of previously institutionalized patients into the community for care (Myers 2015; Patel et al 2014).

However, the majority of those patients were released into a community bereft of supportive resources; a shortage of funding and health care professionals upheld too few community-based care organizations, and many of the individuals who were released form institutions entered jails, prisons, or became homeless (Myers 2015; Patel et al 2014; Stein et al 2014). Current 21St century community-based care infrastructure focuses on systems integration as a direct intervention to the remaining gaps in ideal continuity of care models (Patel et al 2014; Durbin 2006). There are still many care-recipients in CMHC systems now who remember these shifts in mental health care delivery (Myers 2015; Stein et al 2014). In fact, the course of mental health care reform was increasingly shaped by these patients themselves, also enacting roles of activist-citizens, entering the experience of mental illness into political and social arenas through advocacy movements focusing on the person-hood of people living with mental and the importance of their participation in modes of treatment delivery (Stein et al 2014; Estroff 2004). The current mental health care reform era is referred to as the "Recovery Era," in which mental health treatment is geared towards "[a] process of change through which individuals improve their health and wellness, live a self- directed life, and strive to reach their full potential" (SAMSHA 2012). As many CMHCO staff I interviewed described to me, this cohered with efforts towards integration of services where the goals associated with an individual's mental health recovery might involve access resources for any of the four major pillars of recovery: health, home, purpose, and community (SAMSHA 2012).

In Louisville, three dedicated CMHCOs—Centerstone, Wellspring, and Bridgehaven—coordinate with emergency psychiatric services such as University of Louisville Emergency Psychiatric Services, Central State Hospital, Our Lady of Peace, and

The Brook, and with auxiliary services such as the Louisville Metro Police Department, Louisville Metro Department of Corrections, and the Coalition for the Homeless system of homeless shelters. Also held in the network of care resources are formal and informal social services, such as food assistance through organizations like Dare to Care or small-scale food pantries, SNAP, low-income physical health providers, housing assistance programs such as Housing First, and many others. The interventions available across these resources are intended to hold individuals stable in the community as well as create a stopgap for individuals who experience quick institutional cycles or cycles of decompensation. Community mental health care organizations drawing on the recovery philosophy, and which are integrated with larger resource landscapes which might be brought into a client's care, make a project of integrating mental health consumers into a community of their choice where they are expected to self-manage their illness. Typically, this was expressed to me as avoiding hospitalizations, arrests, or decompensation and debilitating symptoms, stability in employment and maintaining housing, and receiving care through routine but minimal contact with service providers and relying on non-paid informal support systems. This might be done through assembling institutional resources around an individual, via cooperative and integrated projects. However, systems integration faces numerous challenges. Barriers to systems integration include the compartmentalization of mental and physical health services as well as a lack of dedicated multidisciplinary teams specifically addressing mental health care interventions in quickly changing health-care landscapes globally (Ellis 2016).

Several CMHC providers I interviewed for this project expressed that the ACA had influenced the ability of CMHCOs to collaborate Prior to the ACA, all CMHCOs in

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Louisville were affiliated through a central hub, Centerstone, through which small CMHCOs billed insurance. After the implementation of the ACA, site de-affiliation prompted a renegotiation of each CMHCO's relationships to one another, as smaller CMHCOs gained the ability to expand services and care-providers navigated new intra-organizational relationships for patients who received care between them. Further, Medicaid expansion allowed for an influx of new patients eligible to receive mental and behavioral health services. CMHCO employees described adapting to larger numbers of intakes, limited program capacities, and projects to accommodate larger numbers of new patients (this is more fully discussed in Chapter Two). In addition to these changes, care-providers described to me the precarity associated with mental health programming. Partnerships between CMHCOs and auxiliary organizations could be tenuous or temporary, novel intervention models might be briefly funded with uncertain futures, or longer-standing programs might lose funding and disappear altogether. In this uncertain environment, mental health care relies on the efforts of individuals to bridge institutional relationships and assist patients in creating pathways to move through, especially when a change causes divergence. Patients themselves may rely on care assemblages between multiple CMHCOS, emergency or informal mental health resources, or other social services. In Chapter Three of this thesis, I will further address institutional relationships, individual-institutional relationships, and system entanglements as components of creating interventions and strategies for navigating barriers to care.

To answer questions about barriers to care access, and to examine how individuals make health-seeking decisions in the context of them, I draw on assemblage theory. Chenhall and Senior expertly recount one metaphor Deleuze and Guattari provide

of how assemblages are formed as processes of "de-territorialization" and "re-territorialization," wherein an object/person/component within a synergistic, processual, shifting, and multi-level relationship with other objects, people, and components may take on certain characteristics in that structure. However, when the object/person is removed from that context, they take on characteristics of a new structure (Chenhall and Senior 2017: 183). I argue that "care" is an assemblage, a project and a process that is shaped by relationships between individuals and the micro-politics between them, CMHCOs and auxiliary resources, the concrete environment, paradigms of mental illness and health, as well as larger sociocultural, economic, and political structures. Barriers to care access are a core feature of this assemblage, as is the concept and concrete experience of access, both of which can and do change over time. Health status, care access, and strategizing enter an assemblage through an individual, who themselves exist as a component of larger assemblages of social processes. In the narratives I collected from both CMHCO staff and mental health consumers, change over time and shifts in care access or their health status were important themes. When individuals are territorialized within "formal" care systems—enmeshed in insurance, health clinics, doctor's offices, medication management, etc.—they perform a specific set of actions appropriate to that type of care access. When they are de-territorialized from care systems due to a loss or lack of access, the strategies and behaviors they enact to maintain their mental health adapt to such a change.

However, these are not static. The concept of assemblages emphasizes ripples and lines of constant change (Deleuze and Guattari 1987). Assemblages are temporal arrangements of things, which work together in a space (of time, of place, etc.) (Müller 2016). Deleuze and Guattari's discussion of assemblages is contested with regards to its

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practical application to the social sciences (Little 2012). Further, several scholars have applied this approach to health research at different scales. Edquist argues for the emergence of a global "mental health assemblage," contributing to the changing frequency of eating disorders in non-Western nations and developing countries (2008). This assemblage, she asserts, is formed of transnational diagnostic codes for mental health and health projects implemented in developing nations directed by medical and political authorities formulated of international actors (2008). Regional assemblages are produced by the melding of lay or local knowledge and behaviors with global diagnostic categories, redefining and pathologizing cultural behaviors (Edquist 2008). Dombroski, McKinnon, and Healy recognize the process of birth as an assemblage, in which women, medical professionals, and non-human elements of the birthing process interact with ideologies and paradigms about birth in a "relational economy" (Dombroski et al 2016).

Further, Pollack's ethnographic work examining assemblages of diabetes care among Native American residents in Chicago describes how over time, concepts of indigenous identity, family, and community have been shaped by the context of diabetes within that population (2017). The practice of diabetes care has been integrated with cultural practices of family and community, and yet has shifted traditional practices around food, meals, and eating. Pollack argues that social relationships within Native communities in Chicago have been influenced by the epidemic of diabetes in that population (2017). Pollack herself draws on Guell's ethnographic work about diabetes management among Turkish immigrants in Germany who are excluded from formal health care systems, who manage diabetes through the enmeshment of disease and culture (Guell 2011). Despite their socially marginalized positions, these individuals work within their contexts to create

workable solutions to manage their health, with strategies shaped by sociocultural meanings of illness and care and these individuals' relationships with broader social structures.

As such, I wish to ground assemblage theory through the practice of everyday life and concepts of bricolage, strategy, and tactics which are responses within and informed by individuals' involvement with these assemblages—an argument I draw from Guell's interpretation of de Certeau (Guell 2011; de Certeau 1984). Müller explains that assemblages are both temporal and "productive"; assemblages "produce new organizational paradigms, new behaviors, new expressions, new actors and new realities" (Müller 2016: 29). Assemblage theory embraces changing contexts of care, relevant to my research focus on transforming and recursive barriers to care and creates space to understand how care is managed in these contexts. Care assemblages, then, produce sets of adaptive behaviors and strategies for managing mental health in changing contexts. As such, I have also drawn on other social theories about health which emphasize relational dynamics in society.

Recent scholarship about barriers/facilitators to care access have drawn on multi-level analysis to identify how barriers to care come from different directions to intersect at the level of the individual. Identifying ways in which barriers interact often becomes a sociological or anthropological inquiry, looking at structural processes and their outcomes (Phelan et al et al 1995; Singer 2017). Mendenhall argues that barriers to care access cannot be interpreted as singularities (2012). Simply aggregating lists of barriers doesn't yield meaningful results, and possible ways that multiple barriers can become articulated in an individual's life are countless. However, the specificity of these articulations can also

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reveal common threads of power structures present in society and how the impact of extant social inequalities is perpetuated. Assemblage theory livens a social determinants approach, emphasizing relationships between an individual and the complex networks they inhabit. Researching barriers to care with a multi-level approach supports the directions medical anthropology is moving in, "that illuminates how larger structural factors figure into both microlevel social processes and the individual's emotional and physical health" (Mendenhall 2012: 15).

Of course, care access is a crucial component of achieving good health and social context plays a significant role during the course of a disease. A lack of access to treatment and prolonged experience of an illness can lead to long-lasting negative outcomes. Illness exists as part of a feedback loop of social inequalities, vulnerabilities, and dynamics of care access (Manderson 2016; Mendenhall 2012; Kline 2012). Influences at the level of the individual, the family, and the community, as well as the availability and operations of care-providing institutions, bureaucracies, governments, and spanning infrastructure like health care reform, are all significant for understanding the incidence and course of disease. At a broader level, structuring the relative impact of these influences on the course of a disease are class, race, gender, culture, and geography.

In sociological literature, health and care access are interpreted as signals of social inclusion, exclusion, and the overall structure of social inequality (Farmer 1999; Hays 2009; Mendenhall 2012, Guell 2011, Guell 2012). Phelan et al. argue for multi-directional influences on disease incidence. First, they argue that the individual experience must be contextualized in a broader social analysis which realizes "risk for risks"; second, they argue that status conditions (socioeconomic, racial/ethnic, sex, gender, housing insecurity,

food insecurity) determine access to modes of alleviating disease and its risk (Phelan et al 1995: 80). On the second point, they also include the influence of life events such as deaths, births, changes in employment, or available social supports, which may compound social vulnerabilities (Phelan et al 1995: 81). This layering of vulnerability is also described by Manderson as a process of "recursive cascades," in which disease enters into feedback loops with social conditions, subsequent life events, and can create a process of destabilization (Manderson 2016). The framing of disease incidence and its outcomes in a synergistic social framework has been implemented across the literature. These analytical frameworks allow discussion of the complicated, layered processes by which diseases interact with social, political, and economic forces at the site of the individual body (or mind). Such analyses, which forgo framings which identify individual lifestyle choices as the only way that disease vulnerabilities are created, and instead contextualize illness—including health-related decision-making—in a socioeconomic and political economy context, up to and including behaviors that can lead to further vulnerabilities, like substance use or interpersonal violence (Phelan et al 1995; Mendenhall 2012; Nichter 1981). These are contexts—and approaches—which are inseparable from analyzing the social experience of mental illness, especially where symptoms of the disease can lead to harmful secondary health problems (Patel et al et al 2014).

Recent scholarship about care access argues that individuals who experience little to no access to medical care will often draw on assemblages of informal resources to maintain a state of health (Chenhall and Senior 2017; Pollack 2017). The onset of an illness can register as a crisis, a life changing event, or merely as another drop in a bucket of trials (Farmer 1999). For chronic illnesses, the personal interpretation of what the illness means

in relation to other life goals can lead to an individual's decision to not seek care at all. Drew's research about the attitudes of women living in Eastern Kentucky who choose not to seek treatment for cancer displays how "fatalistic" decisions are the result of individual values as well as structural constraints to care (Drew 2011). In Fletcher's ethnography of health behaviors in Central Appalachia, she found that individuals worked to maintain insurance—and therefore care access—through modalities that ultimately could have long-term negative outcomes (Fletcher 2017). Her research participants expressed "job lock," in which they were unwilling to change jobs for fear of risking their health benefits; in another example, a couple contemplated divorce to ensure that the wife, who had a chronic illness, would become eligible for Medicaid (Fletcher 2017). Territorialized within care systems, these individuals still engaged in a political economy of choices. Further, in Carney's ethnography about undocumented migrant women who are blocked from formal care systems, she describes how these women carve preventative care out of available resources. For example, she describes how one mother drew on developed social supports and mutualism in which she volunteered at food pantries to provide her family with fresh, nutrient dense food. This action was intentionally undertaken as a preventative health measure, to reduce the risk for nutrition-related illness while the woman and her family were excluded from health care systems. These examples situate the health-related attitudes and decisions of the individual in interactions between other sets of environmental, institutional, and structural barriers to care. These accounts of agentive adaptiveness reflect how individuals draw on varied assemblages of activities constituting health-seeking or caring activities. In my research, mental health consumers and care-providers described similar undertakings.

A Brief Overview of Mental Illness

Mental illness follows the same epidemiological patterns as physical illness in accordance with socioeconomic status and race (Safran 2009). Safran quotes the Substance Abuse and Mental Health Services Administration definition of this disparity as "the power imbalances that impact practices influencing access, quality, and outcomes of behavioral health care, or significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rate in a specific group of people defined along racial and ethnic lines, as compared with the general population" (Safran 2009: 1). While mental illness does occur in any echelon of a population, the burden of disease rests disproportionately on individuals with a low socioeconomic status, people of color, and in rural-urban divides where individuals with low geographic access to care in resource-sapped areas have worse health outcomes (Cummings 2013). Stress has a strong influence on mental health and mental illness, and the stress associated with social marginalization has marked overall health outcomes (Mendenhall 2012).

Individuals living with mental illness are at risk for developing concurrent physical health issues through many channels, including diseases transmitted through behaviors surrounding substance abuse, or conditions such as diabetes, cardiovascular disease, or related to behaviors such as self-harm or a lack of hygiene, to name examples (McCabe and Leas 2008; National Coalition for the Homeless 2009; Mendenhall 2012; Chaddha et al 2016). The burden of disease for mental illness results in significant mortality and morbidity; individuals living with a mental illness tend to die 25-30 years sooner than their counterparts without mental illness (McCabe and Leas 2008). In his co-morbidity

framework, Nichter urges the recognition of "socially contagious" idioms of distress, in behaviors like smoking and substance use, which may create vulnerabilities in social contexts where such behaviors are normalized to cope with stress (Nichter 2016). Mendenhall extends Nichter's co-morbidity framework by centralizing a syndemics approach to negative feedback loops of marginalization and disease clustering. Mendenhall argues that the disease itself is not an "endpoint," but part of a lifelong, lived experience with confluent stressors contextualizing the disease, its etiology, and what measures individuals are able to take in response (Mendenhall 2012). Syndemic theory agrees with other literature about the "life course" of mental illness in which a person's experience with it will continually change—the presentation of symptoms, a person's access to treatment, the success of different treatments, consequences of active episodes, will all fluctuate to create varying levels of health throughout an individual's life (Patel et al 2014). The lifelong experiential nature of mental illness and its embeddedness in "the everyday" are central to interpreting the role of social inequality and political economy responses to mental illness and its outcomes (Guell 2011; Fletcher 2017).

This research did not focus on a specific set of mental illness diagnoses. Narratives and experiences collected in interviews vary greatly, with the impact of illness ranging from occasional disruptions of work, education, or difficulties with interpersonal relationships and self-harming coping strategies, suicidal ideation and attempts, to acute psychosis and arrests. "Mental illness" describes a broad spectrum of disease expressed in a muddled area between genetics, environment, life exposures, society, and culture (Patel et al 2014). The illness experience is embedded in complicated paradoxes of selfhood, agency, and social role; paradigms for making sense of the illness experience are many

(Nichter 1981; Myers and Ziv 2016). To interpret mental illness as a significant public health concern is contingent on recognizing that it is, in fact, a disease of which symptoms and behaviors can produce tangible consequences (Patel et al 2014). Qualitative research can embolden why issues of mental illness are important, timely, and ubiquitous while attending to qualities of the illness such as change over time and the role the illness might play at different points in an individual's life course. Diagnoses can even change. One care-provider I interviewed explained that a frustration for individuals seeking help for the first time was that their diagnosis was based on which symptoms were presenting when the patient sought care, which could lead to multiple changes in diagnosis at each contact:

> "[T]he first time a person shows up for treatment, they have no idea what they're showing up for and the presentation often times is different than what it's going to be in five years. So, you have somebody who has bipolar who shows up because they're depressed. You call it depression. You treat depression. They develop a mania […] [S]o then they come back and they— you diagnose them with bipolar disorder. And then a little bit later they start showing signs of psychosis, so they come back to the hospital and you call it something totally different."

Diagnosis is an important part of receiving social services including disability, appropriate treatment, and may be personally meaningful for an individual. So, while I didn't specifically ask care-receiving interviewees about their diagnosis, I did ask about the process of receiving one and how it affected their treatment or care access. Therefore, it is important to outline mental illness classifications and how mental illness can become a negative feedback loop. Patel, Minas, Cohen, and Prince outline common mental illnesses as being classed into Common Mental Disorders (including depression), Anxiety Disorders, Somatoform Disorders, Bipolar Affective Disorder, Schizophrenia, Substance Use Disorder, Dementia, Developmental Disorders and Behavioral Disorders (Patel et al 2014). Anxiety disorders comprise symptoms of feeling fear, apprehension, or unease

which disrupt daily functioning, beyond the scope of normal fear responses (Patel et al 2014). Somatoform disorders are primary the experience of physical symptoms and sensations for which patient seek medical treatment, with no ailments present. Bipolar Affective Disorder and Schizophrenia are well-known for their debilitating symptoms. Bipolar Affective Disorder presents as cycles of mania and depression. When manic, individuals are prone to risk-taking behaviors and grandiose mindsets, with a surplus of energy; they may engage in promiscuous sexual activity, overspending or engaging in other reckless behavior, or go without sleep (to name some manifestations). This manic phase is followed by a depressive phase. Schizophrenia is rare but can become debilitating, although the clinical manifestations are diverse. Schizophrenia manifest as the experience of auditory and visual hallucinations or delusions about reality.

Depression receives significant attention in research about chronic diseases in general, due to it being "one of the most burdensome disorders in the world" (Patel et al 2014: 34). Depression, further, can offer insight into how the manifestation of symptoms in response to stress can become severely debilitating. The typical symptoms of depression include fatigue, persistent low mood, and disturbances in daily activities including sleeping, eating or maintaining activities of daily living. Individuals might engage in self-neglect and self-harming behaviors (Patel et al 2012; Lauder 2002). More severe symptoms can be auditory and visual hallucinations or psychosis (Patel et al 2014). In this way, depression can be a useful exemplar for how mental illness symptoms can become debilitating, if a person goes without treatment in the long-term, sometimes bolstered by stress. When I interviewed the mental health coordinator at the Kentucky Refugee Ministry, she explained:

"I see a lot of women from the Middle East struggle hard. And I think, culturally, they were homemakers to start, most of them. And then they come here and their husbands are working, their kids are all going to school and learning English really fast, and they never dealt with the beheadings and the bombing and the constant warfare they had witnessed […]. And so a lot of them get super depressed and even getting a little psychotic with their depression, hearing voices and seeing things that aren't there. And they're the ones that end up at [CMHCO], if I can get them there, if I can talk them into it. But that takes years."

As well as highlighting the need for culturally relevant services in mental health care and difficulties with language services, this case demonstrates how a loss of social supports, social isolation, trauma, and long-term untreated mental illness can escalate to more severe symptoms. Estimates of disease burden rely on Disability-Adjusted Life Years (DALY) to evaluate how many years of life are lost as the result of a disease (WHO 2018). The DALY for mental illness has been estimated to be 13.0% globally (Vigo et al 2016). In the United States, mental illness carries an economic impact around 193.2 billion dollars annually (National Alliance for Mental Illness 2018). While all mental illnesses can have severe, debilitating effects, psychosis or delusional states were described as particularly disruptive to a person's life. Alina, nurse practitioner told me about a bipolar patient:

"I had this client—without sharing too much of her private details—who was perfectly fine. Twenty-five-year-old mother, working, everything was going fine for her, and had this, like, really intense manic episode where she was just luridly psychotic. Ended up doing all of these illegal things, basically, got sent to jail, lost her kids, the whole thing. Her whole life just dissolved in this very, very, very short amount of time. Getting really psychotic, for like, a month, like manic and psychotic and going off the chain, is bad for your life! … [S]he doesn't have her kids now, it's very sad. She's working towards getting it back, but it's an uphill battle."

This swift, devastating type of episode was also described to me by two interviewees who had experienced psychosis. The consequences of behaviors during a psychotic episode can be long-lasting, sometimes permanent. Mental illness is associated with a process of

destabilization which occurs because of active symptoms leading to the loss of natural supports (family, friends, community) and resultant isolation, difficulty maintaining activities of daily living (ADLs) including basic hygiene, and difficulty maintaining employment and housing (National Coalition for the Homeless 2009; Ellis 2016). Typically, this process of destabilization is highlighted in the over-representation of mentally ill individuals among the homeless (National Coalition for the Homeless 2009). Nordt, Muller, Rossler and Lauber defined this process as "social under-achievement," in which the early onset of a mental illness can create educational difficulties which give rise to difficulties entering the labor market, or "social decline," in which active episodes of mental illness and hospitalizations can negatively impact competitive employment (Nordt et al 2007). Nordt's findings fit into research about the long-term, life course outcomes that mental illness can have on an individual. Recursivity and vicious cycles are recognizable in the course of a lifelong experience with mental illness. When a person experiences the onset of a mental illness, they may face multiple, interactional structural, environmental, individual, and institutional barriers to seeking care. However, the symptoms of a mental illness can also lead to emergent barriers which lead to destabilization and "social decline," such as being arrested and developing a criminal history, which can lead to difficulties finding employment and concurrent difficulty maintaining housing. Further, some mental illness presentations are debilitating to the point that maintaining everyday activities becomes impossible and navigating complex care systems which span CMHCOs and require time, effort, and attention to the detail of paperwork and waiting to be filed through bureaucratic systems, can seem insurmountable. Difficulty navigating care systems alone was mentioned in interviews as a major reason that individuals struggle to maintain care,

contextualized by other external barriers. In this way, mental illness becomes recursive and cyclical, interplaying with extant and emergent barriers to care. As such, explanatory frameworks about mental illness outcomes such as social decline, drift, or causation (which I attend to later) must be contextualized in the social origin and influence on disease.

Methodology

Recent scholarship about barriers to accessing care and the shaping of care-seeking behaviors has drawn strongly on qualitative and ethnographic methods (Nichter 1991; Guell 2011, Guell 2012; Kline 2012; Mendenhall 2012; Carney 2015). For six months, beginning in October 2017 and lasting through April 2018, I collected qualitative data, relying on ethnographic methods including semi-structured interviews, surveys, and participant observation. Qualitative data was important to this research question specifically because narrative experiences effectively reveal barrier interactions, changes over time in care-seeking and the care landscape, and the sets of behaviors that arise in the context of these care assemblages. Research about health-decision making becomes more revealing when research is focused not just on *what* services people use, but on *how* people use them; a space effectively filled by ethnographic questioning (Thompson and Nichter 2011). Though my study was small, I did achieve thematic data saturation and was able to corroborate much of this data with scholarly literature. I collected 18 interviews in total between two categories of subjects, identified either as care-providers or care-recipients.

Care-Providers

The care-provider category accounts for 14 interviews and includes a range of professions

related to mental health. This sample contains one nurse practitioner, one clinician, two advocacy group members working on issues of behavioral and mental health including substance use, two social workers, three program directors and five peer supports. Within these categories, individuals often held multiple titles within organizations. For example, a licensed clinical social worker might be working as a program director, and a peer support specialist might also carry out clerical duties.

Overlapping expertise was most significant among peer supports. "Peers" are individuals with the lived experience of mental illness who are employed in community mental health organizations in a care-giving role. The peer model has proliferated since the 1970s, bolstered by advocacy and activist movements organized by individuals experiencing mental illness themselves (Peers for Progress 2018; Stein et al 2014). Peers, in my data, occupied varied roles which bridged the formal and the informal. In some cases, peers were trained to carry out therapeutic models and lead group therapy. In other cases, as one peer put it, they acted as a "professional friend." Throughout my data, peer supports described their roles ith providing care with a referent to their own ongoing experiences receiving it. As such, peers offer an important and interesting bridge between the words of formal care models and the everyday practice of mental health management.

Overall, care-providing interviews spans three CMHCOs, two nonprofits, and two advocacy groups: Centerstone, Bridgehaven, Wellspring, NAMI, Kentucky Refugee Ministry, People Advocating Recover (PAR/APAC) and Citizens of Louisville Organized and United Together (CLOUT). I recruited study participants through three modes of contact: e-mailing or calling general contact information for an organization with an explanation of my research and a request of who I might speak to; directly contacting the

CEO or President of an organization to request interviews; or directly seeking an interviewee as the result of an outside referral or as the result of targeted sampling. Once in contact with an interviewee, I relied on snowball sampling based on interviewees recommendations of which of their coworkers would be willing to also meet with me. Occasionally snowball sampling would bridge organizations in instances where interviewees suggested I meet with a person at another organization who they believed to be a good fit for my project. Snowball sampling was well-suited for this project because of the sensitivity of the subject matter—this was especially the case in the second half of the project, when I interviewed adults living with mental illness (Maxwell 2013). Through snowball sampling with care-providers, I could access a "range of information" through individuals with varying positionality within institutions and relative to mental health care delivery, an important component of this sampling method (Maxwell 2013).

Using this referral system provided by snowball sampling also allowed me to meet with a variety of individuals in different positions, which provided well-rounded perspectives of barriers to care. A peer support specialist might observe different things than a psychiatric nurse practitioner or an administrator. Once situated in organizations, I worked with interviewees to determine boundaries of my research. For example, at one small CMHCO, Bridgehaven, I used a general contact form online to inquire about recruiting study participants. I was then connected with the organization's peer supervisor, from whom I was directed to get approval to interview any peer support specialists employed there. Data collection with care-providers formed the bulk of my research. For this group of interviewees to be eligible to participate in the study, any interviewee had to be 18 years old or older and be employed or volunteer with community mental health care

organization, or mental health-related support group or advocacy group.

Care-Seekers

I also collected surveys and performed semi-structured interviews with four care-recipients/patients of CMHCO resources. I consulted with University of Louisville professors who had done qualitative research with mentally ill adults to determine how to best approach research with this group in an ethical way which reduced the most risk for study participants, while allowing them to freely discuss sensitive topics. Based on these conversations, I implemented several layers of filtration in my recruitment process to ensure that individuals participating in my study were eligible and able to provide consent and assent at the time of the interview. In the first step, I asked all potential interviewees to take a survey which asked explicit questions about their eligibility as well as general questions about their experiences with community mental health care in Louisville. To be eligible for the study, care-seekers had to be 18 years old or older, have been diagnosed with a mental illness or received a dual diagnosis, currently be in treatment, and be sober at the time of the interview. At the time of the interview, I used a consent assessment to ensure adapted from Jeste et al's "A New Brief Instrument for Assessing Decisional Capacity for Clinical Research" (Jeste 2007). I excluded individuals who had a cognitive impairment, required a Legally Authorized Representative to assist them during the interview, did not pass the consent assessment, or who otherwise did not fit the demographic requirements of the eligibility criteria.

I crafted data collection instruments to offer interviewees the lowest risk participation I could. Surveying is regarded as an extremely low risk data collection method

for individuals with psychiatric disorders (Yanos et al 2009). Interviewing, similarly, only carries minimal risk, and negative emotional experiences can be avoided by giving interviewees multiple opportunities to decline to answer or to leave the interview entirely (Yanos et al 2009). Further, I allowed interviewees to access audio files and digital transcriptions of their own interviews if they wanted to do so, and showed interviewees written passages from this thesis using their responses to give them the opportunity to clarify meanings and ensure they felt they were being fairly represented. At the end of interviews, I offered all interviewees in this category with a folder of contact information for psychiatric resources or other potential needs, which interviewees could take or refuse.

In my initial research proposal to the University of Louisville's IRB, I proposed two methods of recruitment for this interviewee category. In the first, I intended to approach the largest regional CMHCO (Centerstone) with a plan to recruit patients for my study through flier distribution and referrals from therapists, who could help to identify individuals meeting the study eligibility criteria and who were interested in participating. However, while Centerstone considered my study, they ultimately determined that they would be unable to provide me with the resources I needed to carry it out.

As a result, I relied on the second proposed recruitment method, which was informal and allowed me to approach individuals I encountered during my research, asking if they would be interested in participating. To clarify, I did not approach individuals within clinical settings or field sites but drew on organic connections beginning with my own social network (targeted sampling) to begin snowball sampling. This method allowed me to build rapport with potential study participants through shared social connections. Mental illness is a sensitive subject, and I wanted to ensure that a mutual friend could be a link

between myself and new interviewees. Snowball sampling allowed me to rely on study participants to broker meetings with potential new participants. However, this method is time consuming. Relying on interviewees to help me further my data collection could lead to dead ends, when they were not able to suggest another person. Further, my own inexperience as a social researcher, lack of exposure with vulnerable populations in a research capacity, and lack of institutional oversight (as in research on mental health which takes place in a bounded clinical setting), caused me to be selective.

Data Analysis

A grounded theory approach directed data analysis for this project. While reviewing the data, I used the program QDA Miner to generate generative, descriptive codes about the experiences of receiving and providing mental health care. I coded care-provider and care-receiver data separately. Then, I re-coded the same data sets (barriers to providing care, barriers to receiving care), following the three core research questions to identify specific themes. For example, I searched for explicit and implicit identification and discussion of barriers to care ("what barriers to care do patients/individuals face…?"); then, I parsed out examples in which interviewees described barriers becoming concurrent with one another or with mental illness itself ("how do those barriers interact?"); finally, I identified and coded descriptions of the ways in which individuals created strategies to maintain care while experiencing barriers to care ("when people experience low access to mental health treatment, what do they do?").

In comparing data from both sets of care-providers, I spent some time with data from the five peer support specialists I interviewed. Because of their experience as both

care-providers and care-seekers, I split their data between analytical categories. When they described experiences of providing care, I coded the data accordingly. When they described their past experiences seeking-care, I analyzed it according to generative codes for care-seekers, while making notes to myself of the ways their narratives were still occasionally discursively parsed as an experience of providing care. For example, when a peer support would retell a personal experience, mobilized as a therapeutic message for care-seekers or a way to explain developing therapeutic connections with car-seekers, was not the same as instances when a peer support would share their own experience to talk about care-seeking in general or the burden of mental illness.

After coding each interview according to both generative and selective modes, I began to make notes of saturation. I extrapolated data attached to the codes and re-ordered them categorically (the skeleton of Chapter Two) and kept notes of the frequency within the data set in which certain themes were mentioned. Interestingly, both groups of participants would describe certain barriers as constituting both a barrier to providing and receiving care. There were many parallels between what prevented care-providers from delivering care to their clients, and what care-seekers described as barriers tor receiving quality care even as they observed care-providers attempting to help. This is both challenging and a useful point of analysis for making recommendations for improving health care delivery. On one hand, it reflects the nature of long-term community mental health care as co-constructed between care-providers and care-seekers. Recognition of mutual challenges to care reflects system literacy among both categories of study participants. On the other hand, these challenges still limit accessibility of care and set the foundation for discussion about how care-providers and care-receivers must critically

engage with care landscapes to facilitate long-term recovery, where it otherwise may not be able to be facilitated by care-providing entities themselves.

Participant Observation

To further frame the ethnographic nature of this research, I performed participant observation in semi-private spaces such as Depression Bipolar Support Alliance support groups, Addiction Policy Action Committee (APAC) meetings, and Citizens of Louisville Organized and United Together (CLOUT) planning meetings. These sites are expanded on in more detail in the "Research Sites" section. In these spaces, I hoped to absorb more about both the lived experience of mental illness, in the case of DBSA, or large-scale political changes in mental health and addiction policy, as with APAC and CLOUT. In these spaces, I was permitted to take notes about my general experience, without identifying participants, and the information I gathered in these meetings aided in spring-boarding further literature review for my thesis and informed supplemental questions I might ask interviewees. I chose these sites based on either their influential involvement in community mental health, as was the case for the two advocacy groups, or because care-providers or care-seekers mentioned them. Two peer supports I interviewed mentioned that they had used DBSA for ongoing therapeutic support; one of the two became a group facilitator for an LGBTQ-specific DBSA support group. Overall, participant observation contextualized, but did not direct, the course of research.

Limitations

The care-seeking group of interviewees decidedly shows the time and resource limitations

of this thesis project. This data is limited by both the sample size as well as the politically and demographically limited range of respondents, who were all white and politically left. Further, all four interviewees explained that they had benefited from formal treatments, including psychiatric counseling or regular medication, and had established knowledge about their mental illness that drew on biomedical explanations. As such, it's important to note that my emphasis on speaking with current utilizers of local CMHCOs potentially leaves out individuals who do not desire those types of treatments or work to maintain their mental health care through alternate means. It is also not necessarily the case that someone receiving care from these organizations must ascribe to biomedical paradigms about mental health or believe in the effectiveness of a specific treatment to be receiving it. Therefore, this data does not include individuals who understand the experience of mental illness in different sociocultural ways or who are ambivalent about receiving treatment, which could change how interviewees identified and discussed barriers to care. This is addressed in more detail in Chapter Two.

Other limitations arose in the practical execution of this project. Originally, I planned to distribute the survey in public spaces with the goal of gathering enough data to perform quantitative analysis. My prospective distribution sites included homeless drop-in centers, community centers, and libraries, all of which had computer labs, or in the waiting rooms of clinical sites. However, I received total non-response from each site. Instead, I administered the survey to interviewees prior to interviews, to screen for eligibility, create specific questions for each interview, and get specific responses to inquiries. Survey data was thus only used as a framing and screening device for interviews.

Research Sites

Louisville is a mid-sized city and the largest urban center in Kentucky. Located on the Ohio River, the Northern border of Kentucky, Louisville balances Midwestern and Southern cultural influences. However, Louisville remains racially and socioeconomically segregated (WFPL 2018). There are stark income differences between Louisville's West, South, and East neighborhoods. In 2018, the Louisville Department of Public Health and Wellness released a map displaying self-reported poor mental health in the city (Health Equity Report 2017). The data, which was taken from the Behavioral Risk Factor Surveillance System (BRFSS), indicated that residents in census tracts in West and South Louisville generally reported a higher number of poor mental health days per month than did residents in East Louisville. It's difficult to set parameters for assessing mental health at this scale as poor mental health and mental wellness are not necessarily indicative of a presence or lack of mental illnesses and psychiatric disorders. The stress associated with low socioeconomic status and race/ethnic identity, as well as environmental factors like unsafe housing or poor nutrition or other struggles of living in poverty may certainly play a role in self-reporting about mental health status (Mills 2015). However, this data is indicative of larger social determinants of health, where such stresses may influence mental illness incidence, treatment access, and outcomes.

Louisville's CMHCOs are clustered in downtown Louisville (North Central Louisville). For care-providers' interviews, I specifically selected clinical sites which provided community mental health services, excluding private practice mental health providers as well as general hospitals from my research. Louisville has three primary CMHCOs which provide a range of clinical services: Centerstone, Wellspring, and

Bridgehaven. Until 2016, the primary CMHCO for the region was Seven Counties, which was partially state funded. In 2016, Seven Counties as a local entity saw "34,000 people annually in its 31 locations across Bullitt, Henry, Jefferson, Oldham, Shelby, Spencer and Trimble counties" (WFPL 2016). In October of 2016, Seven Counties became absorbed into a larger national community mental health organization, Centerstone. One rationale behind this change was to expand the organization's capacity in a more cost-efficient manner (Courier-Journal 2016). The shift was broadly expressed to news media not as a buyout or a merger, but as an integration which would preserve Seven Counties' regular operations, client base, and service providers, while drawing on the increased capacity of Centerstone, to provide expanded services to a growing number of clients (WFPL 2016). The influx of newly insured patients with access to coverage for and behavioral health services because of the ACA posed a challenge for CMHCOs in Louisville. Centerstone remains the largest CMHCO in the state and the region and is the largest nonprofit in Louisville. Leadership of Seven Counties passed form founder Howard Bracco to current CEO Tony Zipple in 2011, and by 2014 was the largest regional nonprofit, generating a 96.12-million-dollar local income (Louisville Business First 2016).

Kentucky is divided into 14 regional community mental health landscapes (KARP 2018). Prior to the ACA, Jefferson County, in which Louisville is located, was included in the "Seven Counties" CMHCO region. The eponymous organization acted as a central hub for insurance billing and the provision of specific services. After the implementation of the ACA, CMHC sites became unaffiliated, with smaller programs able to expand the range of their own service provision. For example, after becoming unaffiliated with Centerstone, a much smaller program, Bridgehaven, hired their own medical prescriber and was able to

offer prescriptions and medication management to clients who had formerly sought that service outside of the program. To the Jefferson County/Louisville service region, Centerstone remains an important player in community mental health care and provides four main types of services: Child and Family, Addiction/Substance Use, and Adult Services. Adult services, which were the focus of this research, encompasses from crisis/emergency services to regular counseling services, assistance with housing, employment, and the criminal justice system, and more direct-contact services such as ACT (Assertive Community Treatment) teams, an ASET Team, a Mental Health Outreach team which engages with the homeless, TAYLRD (a drop-in center for homeless youth who need psychiatric services), targeted case management, peer support, a day program, a mobile crisis unit, a Living Room model drop in center, vocational services, and services focusing on holistic needs such as an on-site wellness center (Centerstone 2018). With their barrage of services, Centerstone continues to serve the same seven county region with 25 physical locations. Locally in Louisville, Centerstone shares clients with Bridgehaven and Wellspring.

Bridgehaven is a day program for adults living with mental illness, dual diagnosis, or intellectual disabilities (Bridgehaven 2018). With only one location, in downtown Louisville, the client base of Bridgehaven is small but the program acts in part as a diversion program, helping clients prevent re-hospitalization or arrest, if they are individuals who frequently loop institutional circuits. In interviews with employees of Bridgehaven, they all identified social isolation and a lack of daily activity as a major barrier to maintaining mental wellness or achieving recovery. One interviewee described Bridgehaven as a "safe place to practice things [clients have] learned from their therapists

as far as social boundaries, social cues, social interaction. Also, we help find members jobs because ultimately this is not the final place for [them]." Bridgehaven primarily consists of group therapy run by peer counselors, and provides art therapy, medication prescribing and medication management, and counseling.

Wellspring was designed, according to one interviewee, as a transitional housing program accommodating individuals who were still institutionalized in the 1980s. Wellspring facilitates Housing First and "scattered site housing" for its clients who are in the SMI/SPMI population. Wellspring also offers case management, peer support, and supports two Crisis Stabilization Units (CSUs) able to house 18 people at maximum capacity. CSUs constitute a, lower level of care than inpatient hospitalization but offer services which are a step above other non-outpatient care settings. In interviews with employees from Wellspring, the CSUs and Wellspring proper have differences in the types of services they can provide and the possibility of referrals between them.

Across interviews, Centerstone, Bridgehaven, and Wellspring were described to be coordinated organizations between which patients could access assemblages of formal care—two examples from interviews included a patient who attended Bridgehaven's day program while receiving medication prescribing and management at Centerstone, and a peer support counselor from Bridgehaven would accompany them to Centerstone to pick up medication. In another instance, a member of Bridgehaven was approved for an assisted housing program at Wellspring (despite being on a wait list). Working from information gained in interviews from these three field sites about other resources or organizations interviewees reported coordinating with, I selected other field sites. One site was the Kentucky Refugee Ministry, a refugee resettlement agency which provides health

coordination services and has a dedicated Mental Health Coordinator to assist refugees in finding care and providing basic case management. I included two informal support groups, NAMI (National Alliance on Mental Illness) Louisville and DBSA (Depression Bipolar Support Alliance). NAMI Louisville is the local chapter of the National Alliance on Mental Illness, a nonprofit which engages in education and awareness campaigns about mental illness. They organize support groups for individuals living with mental illness and support groups for families or caregivers of individuals living with mental illness. I intended to do participant observation with NAMI but was turned down, and instead only interviewed the acting president of the local chapter. DBSA, on the other hand, allowed me to perform participant observation at their weekly meetings. This is an informal support group with sites across Louisville and Southern Indiana, which are facilitated and attended by individuals struggling with mental illness. They follow a structured mode of communication and sharing. When I inquired about participant observation, the facilitator I spoke with instructed me to only speak generally of my experience at DBSA without identifying any other member. I attended these meetings sparsely after I received approval from the University of Louisville's IRB to do so. I also attended monthly CLOUT planning meetings, in which I took on a participatory role in meeting discussions. I took opportunities to join CLOUT in closed meetings, including with LMPD officials and Metro Council members. However, I did not record notes at either of these meetings as I was not able to ask for consent from all parties present. As such, these meetings acted as framing devices for further inquiry in the literature, but I did not enter discussions into my data. Similarly, I attended APAC (Addiction Policy and Action Committee) meetings, a local addiction recovery advocacy group. These meetings were useful for me to formulate further

lines of questions for interviewees, but again, because I did not ask the room for consent, the content of these meetings was not entered into my data. Participant observation allowed me to explore some avenues of social attitudes surrounding mental health care infrastructure in Louisville, but ultimately only contributed to explorations of the literature.

Chapter Overview

In Chapter Two of this thesis, I categorically outline the barriers to accessing or maintaining care described by both care-providers and care-seekers across the above research contexts, to answer my two initial research questions: *What barriers to care do patients/individuals experience when seeking services from CMHCOs and other community resources necessary to meet their needs?* And, *How do those barriers interact?* In this analysis, I have categorized barriers according to a scheme used by Hines-Martin, Malone, Kim and Brown, which breaks barriers to care into Individual, Institutional, and Environmental categories (2003). The interactions between these categories lead to what I refer to as emergent barriers: circumstances which result from active symptoms of mental illness and act as stressors, exacerbating negative symptoms, or as destabilizing forces which create a loss of status or lost opportunity for individuals who are mentally ill. I make suggests for patterns of how individuals become stuck in care systems, articulated as access cycles and stagnation.

In Chapter Three of this thesis, I return to assemblage theory to answer my third guiding research question: *When people experience low access to mental health treatment, what do they do?* This chapter focuses on how individual care-providers and mental health consumers construct assemblages of strategies and tactics to either facilitate care access

(for both parties) or maintain stability (for individuals living with mental illness). I articulate the agency-structure tensions which are present in these activities, identifying them in the context of neoliberal ideologies of health and health care.

In Chapter Four, I conclude this thesis with a proposal that questions about "care access," when carried out with qualitative, ethnographic methods, raise further questions about "care maintenance" in the context of assemblages.

CHAPTER II:

BARRIERS TO CARE

Modern CMHC is based around the concept of "recovery" and stability—not necessarily to cure. The recovery concept pervaded discussions with care-providers and contextualized much of the data I collected. SAMSHA defines recovery as "a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential." (SAMSHA 2012)[2]. Recovery, in this definition, is the summation of "Health," "Home," "Purpose," and "Community," concepts used as guiding principles for mental health management. Overall "health" is described as:

> "Overcoming or managing one's disease(s) or symptoms—for example, abstaining from use of alcohol, illicit drugs, and non-prescribed medications if one has an addiction problem— and for everyone in recovery, making informed, healthy choices that support physical and emotional wellbeing" (SAMSHA 2012: 3).

Though this iteration of the "meaning" of recovery has been contested in the literature and its efficacy in practice questioned across the literature, ideas about "recovery" and stability nonetheless pervaded my data from both care-providers and care-seekers. This chapter examines barriers to accessing, maintaining, and providing care across Louisville's CMHC

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2   As per the contentious nature of recovery philosophy in application, SAMSHA's "working definition" of recovery was initiated around 2010 (SAMSHA 2012).

infrastructure, exploring how these barriers become disruptive forces, effecting individuals' stability.

Literature about barriers and facilitators to care often utilizes a sorting method to analyze data, though scholars differ in their methods. I categorized my data according to a method used by Hines-Martin, Malone, Kim, and Brown-Piper, which grouped barriers to care into three categories: Individual, Institutional, and Environmental (2003). However, how I classified and sorted individual barriers into these categories differed from that study in some ways. The mental health consumers who I interviewed were insured and utilizing services from a single CMHCO at the time of this study, while elaborating on other, persistent barriers. Care-providers described the barriers facing clients who were able to receive care by merit of being insured. Therefore, care "access" is most accurately understood as an ongoing project; "access" described a process, not an event.

Throughout interviews, individuals described how struggles towards care access encompassed: physically getting into services, navigating and adhering to health care treatment, and making decisions about one's own care. Further, "access" in an integrated CMHC system extends beyond receiving treatment for symptoms and includes securing other resources an individual might need to become stable—to be "recovered." Barriers to care access or provision also became articulated as barriers to recovery and stability; ongoing processes which might be threatened, disrupted, or waylaid.

First, I provide an overview of the data, then present a categorical, ethnographic analysis of the barriers to care that interviewees described. I conclude the chapter by exploring several ways that barriers to care become interactional, which reflect larger, systemic trends in mental health care delivery in the United States. This chapter argues that

barriers to care access can contribute to situations in which mental health care patients become stuck in the system. Access cycles, becoming "stuck in stability," and accumulating social burdens are three outcomes I explore in the conclusion of this chapter.

Access cycles were a significant finding of my research, concerning how some patients of CMHCO systems repeatedly move through the same care resources, because they encounter persistent or disruptive barriers to care access. This finding connects into a larger body of scholarship about so-called "vicious cycles" in mental health (WHO 2007). The combined experience of barriers to care access and active symptoms can create emergent circumstances that complicate recovery ongoing. For example, being arrested and charged can impact finding housing or employment. An active substance abuse diagnoses concurrent with mental illness can create difficulties finding integrated care, as can physical illnesses that result from self-neglect, a lack of self-care, or persistent lack of access to preventative measures (Kaufmann et al 2012; Nichter 2016). The mechanisms by which these individual outcomes (cycling, accumulated burdens) occur are not singular, as the following examination of barriers to care individually reveals. These outcomes are the result of systemically rooted, multi-directional forces in which barriers to care become recursive. Many barriers to care from both patient and provider perspectives which were present in my data are also corroborated in other research studies about barriers to care, suggesting larger, systemic problems with health-care delivery—topics which I examine further in the conclusion of this chapter and the subsequent chapter. Care-providers and patients find themselves, as individuals, holding together care assemblages between the informal, the meso-level, and the formal.

I begin this chapter by examining the various barriers to care by category,

addressing individual barriers, institutional barriers, environmental barriers, and insurance.

Individual Barriers

Individual barriers encompass influences on health-seeking decisions which relate to a person's own knowledge, perceptions, and opinions about mental illness and mental health care. Individual barriers often related to the relationship between patients and care providers and the relationship between patients and their broader social context, as it informs personal decision-making about mental health. At its simplest, and the way that this barrier has been articulated across scholarly literature, is as a set of "attitudinal" barriers to accessing care such as instances in which a care-seeker does not know where to go for help, how to use services, doesn't believe that their illness is severe enough to warrant medical intervention, or wants to attempt to handle the issue on their own, outside of a formal setting[3] (Hines-Martin et al 2003; Andrade 2013). In my data, care-providers described how negotiating a client's "ambivalence" about receiving treatment was an important part of creating a treatment plan that would be effective and acceptable for the client. Deborah, a care-provider who supervises a case management team, said:

> "There's always choice. What's good on paper and sounds like a great plan, and the consumer says yep, yep, yep, I wanna do it! And then they're ghosts, we can't find them. They fall off the grid and so, man, that sucks. Sometimes we're checking a rest stop or to see if they got locked up. We're at the hospitals and if we know that they're frequent loopers, I might call some of my contacts and say, so-and-so back there, have you seen them? And if they're cool, we'll go and engage and if not, we'll wait 'til they turn up—

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[3] Deciding to manage a mental illness without the use of formal psychiatric care is not itself negative, as narratives in Chapter Three expand on. In the context of the cited studies, "attitudinal barriers" simply described things preventing individuals from using psychiatric resources (Andrade 2013). Something being described as a "barrier to care access" does not necessarily assume that care is required or should be desired. As this thesis argues, a "barriers to care" analysis simply displays how individuals' choice, opportunities, and agency are limited in the context of barriers to care becoming recursive and interactional.

they tend to turn up."

Describing ambivalence as a process of making choices about whether to engage in care raises questions about the roles of self-identity, agency, empowerment and dis-empowerment, and the social context in which health-related decisions are made. Interviewees who lived with mental illness often narratively described a process of realization of naming and understanding the nature of their experiences. Oftentimes, they said that the onset of symptoms was many years before they first accessed treatment. During that time, several interviewees said that they experienced recurring problems, struggling to control their symptoms and not knowing they might need medical intervention.

Societal, community, and familial cultures a person inhabits does play a role in shaping care-seeking behaviors, awareness or knowledge about mental illness, and perceptions or opinions about appropriate responses (Kraus and Stein 2012; Myers 2015). Several interviewees described how seeking care was shaped by tensions with their families or social contexts and required reconnoitering their own self-identified role in their family or community or the roles of their family or communities in their lives.

Navigating one's social environment in the context of care-seeking for mental health was described, ultimately, as an internal struggle that involved external negotiations. As such, the pressures of social networks, communities, families, friends, stigma, attitudes, or even support concerning the topic of mental illness are interpreted as individual barriers to care. The three most common individual barriers to care described by interviewees were: (1) learning how to navigate health care systems/learning how to use treatment resources, (2) experiencing active symptoms, as a care-seeker, and (3) a lack of natural supports in a

care-seekers life. In the subsequent sub-sections I will examine each of these common individual barriers in turn.

Navigating Systems

Both care providers and care-seekers described challenges in the logistical aspects of carrying out activities related to their care, such as where and how to access services, learning how to utilize treatment technologies such as medication or counseling services, adapting to the internal cultures of care-providing institutions and maneuvering through inter-institutional systems. Where Louisville community mental health care is hinged on integrated resources, "treatment" including establishing entry into assistance programs or social services could span multiple geographic areas, institutions, and care-providing individuals. Entering care, especially for chronic illnesses, asks for a patient to learn how to carry out these activities, including enacting complex subjectivities of patient hood and care logics (Guell 2011). Care-providers described often assisting clients with activities surrounding care, for example: filling out forms and applications to establish or apply for benefits, or explaining where and how to refill prescriptions, mapping out bus lines to different locations and practicing the routes. The complexity of navigating care systems— both within them and between them—was often noted. However, Louisville's spanning care landscape could also be beneficial. Harry, a peer support specialist, came to Louisville from rural Kentucky, where, he said:

> "One of the reasons it took me as long as it did to recover and to get well is because I didn't know how to use services. I also lived in a rural town where there weren't the same kinds of service available. I have said many times that had I had a place like [CMHO]] that was more forward thinking and had a person-centered approach, I would have recovered a lot more quickly

instead of two steps forward, five steps back sort of thing for ten years."

In this landscape, care access is fundamentally a question of use and of learning how to effectively utilize treatment[4].

Care-providers often impressed on me the "work" of treatment, in which they attempted to educate patients on how to use services, which involved developing insight, expertise, and ultimately take control over their own care. Providers typically expressed that patients had to be "willing" and dedicated to active engagement with their own treatment, which included learning and making choice about the technologies and devices of that treatment plan. Whether or not a patient of CMHCO was "willing" to learn how to properly utilize different types of treatment, such as therapy, was explicitly described by care-providers as a barrier to their recovery. Parallel to this was the expectation that patients would develop self-advocacy to direct and choose the types of treatment they did and did not want to receive. This is a component of the recovery philosophy of care, which (in theory) emphasizes that treatment is to be patient-lead—a shift from paternalistic models of care in the past, when people living with mental illness had little control or input about their own treatment (Myers 2010).Care-providers described themselves as advocates helping their clients learn be agents of their own care, able to be system literate.

However, care-providers often explained that the first step to this as breaking down wariness, distrust, and bad past experiences which colored care-seekers perceptions of institutions as a whole or providers as individuals. Indeed, later in this chapter, I outline

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[4] For a more detailed exploration of how to "use" treatment, including how care-seekers come to understand the subjectivities and biosocialities of "patient-hood" in care settings and how this space is negotiated, see Chapter Three. In the section about care-seekers' strategies in response to barriers to care—especially in institutions themselves—questions of power, agency, and "logics" of care become more pertinent in discussions of navigating care systems.

the powerful influence of individuals' experiences with rigid power hierarchies favoring providers, which constitute a serious barrier to care access.

Nonetheless, a "working relationship" balancing the expertise of both providers and individuals seeking care is expected in the recovery model of care (Kraus and Stein 2012). A peer support counselor, Colleen, told me:

> "[W]hen they're new to service, because therapy has changed so much, they're a little more eased into it, you know? A lot of our therapists have learned to try to erase that hierarchy. But, it's still some nervousness. A lot of people that are on probation or with CPS, they really struggle with honesty. Because they think that we're the police. So, just to try to make people see that that's not our role, we can't help them if they're not honest, and were not here to call their parole officer or to do any of those things, we're here to help them get better."

Trusting relationships where care-seekers felt in control of clinician interactions, respected, or that the therapist was a good fit, was described as facilitating effective care. For care-providers, peer specialists often bridged the gap between care-seekers and unfamiliar clinical spaces or processes. Peer specialists played an important role in encouraging care-seekers to stay in services or try new treatments. When patients feel low efficacy for the services they receive and don't trust care-providers, they are more likely to drop out of care (Andrade 2013). As such, becoming system literate entailed breaking down individual reservations about mental health care, building trust between providers and care-seekers, and then together constructing intentional plans and activities around navigating spanning services.

Active Symptoms

"During a crisis, I'm pretty much fucked," Afina told me, during our interview. She only

experienced a brief window of time during prodromal psychosis when she was cognizant of an impending manic episode. This was a crucial time for her to seek services. Once a manic episode began, Afina explained, she was powerless to control them or realize that she was experiencing one until after the episode ended. Feelings of intense powerlessness are one way of many that individuals living with a mental illness may describe their active episodes (Andersen and Larsen 2012). Experiencing active symptoms poses a significant barrier to seeking care: symptoms may present as a lack of motivation, self-efficacy or a fatigue, self-neglect; anxiety about service contact and imperceptible but impactful lowered functioning; or may be as severe as delusions, hallucinations, psychosis, or suicidality. Varying between different mental illness diagnoses, active episodes can last for days, weeks, months, or years. Active symptoms were often described as an initial barrier to care access in both emergency and non-emergency situations.

"[F]or people who struggle with making appointments, that's a barrier," said Colleen, a peer support specialist. She continued:

"Sometimes people just can't make appointments. If you're mentally ill and depressed, and you have a thought disorder and voices are going through your mind and you have a one o' clock appointment, like...?"

This sentiment was mirrored by a nurse practitioner:

"Obviously, being psychotic makes it really hard to make appointments. Or like, I have people with severe anxiety who are like, oh my God, I've been nervous about this appointment for the last week. I didn't know if I was going to make it."

Beyond struggling to make or keep appointments, individuals who are experiencing active symptoms may get arrested, commit acts of self-harm, or damage interpersonal relationships (Patel et al 2014). Their employment and housing may end up in jeopardy or

lost altogether (Patel et al 2014).

Afina, who has been arrested while symptomatic, felt that the misinterpretation of her actions and behaviors delayed their being triaged to appropriate care. For Afina, arrests have been both facilitators and barriers to accessing care, depending on if she was then transferred to appropriate services. For example, on one occasion, she encountered police while acutely symptomatic and received an MIW[5]; on another instance, she was arrested while actively symptomatic, and did face criminal charges. Another care-seeker, Kate, said that the first time they were arrested during a psychotic episode, they were placed in a detox cell. The officer did not recognize their symptoms as psychosis and was therefore unable to discover that Kate, in fact, had an active MIW because their name was taken down incorrectly at the time of the arrest.

These examples constitute "emergent barriers," situations in which untreated or active episodes of a mental illness create accumulated burdens for an individual. Afina told me that she had been fired from a job in the past because of her criminal history, and had difficulty finding employment. Care-seekers and providers who lived with mental illness told me that they had struggled to maintain employment, housing, sobriety, personal relationships, or schooling because of persistent, active mental illness. Three of the four care-seeking interviewees indicated in their surveys that active symptoms had prevented them from seeking or accessing care in the past. The long-term outcomes of these episodes could sometimes jeopardize future care. Lauren, a CSU clinician, told me that she felt one of her organization's strengths was not releasing clients from their care whose episodes of mental illness lead to potentially long-lasting or destructive effects. She said:

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[5] Mental Inquest Warrant; in Kentucky, MIWs allow for adults to be legally involuntarily committed.

> "I've seen our clients get so ill to the point that they set their own apartments on fire or flood their apartments or, I had a client run away to California and was gone for three months, but we don't give up on them."

Vriska, a peer counselor, told me a story about how one of the first things she did after being hired was to assist with a client whose symptoms had led to nearly being evicted:

> "[T]his one guy was going to get kicked out of his apartment because he had been very symptomatic and hadn't cleaned or thrown anything away in like a year. So it was pretty gross. Me, another peer and a clinician and eventually our maintenance guy went over there and cleaned the shit out of everything and the maintenance guy fixed his sink, so he could pass his inspection. He had recovered a lot but by that point, it was just too overwhelming."

In other instances, however, active mental illness episodes could eject mental health consumers from services entirely. Siobhan, a program director, told me:

> "One of the hardest reasons is when they're homeless and their behavior has blown them out of being able to use any of the shelters; they've been banned from the shelters. So when we try to offer that resource, they're like well, I can't use that anymore because they won't let me back in."

The ways that mental illness interfaces with other social processes resulted in difficulties for maintaining stability for care-seekers.[6] Active symptoms manifested most often as creating recursive and compounding difficulties for care-seekers, where symptoms clashed with other social processes.

Social Networks, Support Systems, and Stigma,

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[6] The experience of symptoms itself can be complicated and meaning-laden. Individuals can hold contradictory views about their own experiences. As such, discussing the potentially destructive nature of acute episodes is not to present mental illness as a wholesale negative experience, but to describe the ways these episodes interact with the social context of this study. Vriska, a peer counselor, told me that she was surprised peer counseling was a job and that "being depressed is a marketable skill" because she had been told by a care-provider in the past that mental illness is often at odds with notions of "ideal" citizenship and social participation. The context in which an illness occurs should be considered when discussing the severity of its outcomes and far-reaching effects.

Integration in "communities of choice" in which individuals living with mental illness participate and contribute is a pillar of recovery philosophy (SAMSHA 2012). In practice, care providers described observing differential outcomes for patients who did and did not have supportive social networks or reliable natural supports in their life, constituting friends, family, neighbors, or other community members who were proximal to the everyday lives of patients and could act as informal resources for them. Both groups of interviewees described that living in a toxic social environment was a stressor that worsened or triggered challenging symptoms.

Family had a significant influence on care access and treatment outcomes. Negotiating family ties could become a central component of treatment. This might include, for example, when a patient found it necessary to break contact with family, when the family may have broken contact with the patient, or when families took on an active role in helping the patient navigate treatment. Alina, a psychiatric nurse practitioner, said she had observed that patients with active, supportive family involvement often had a link to consistent service they otherwise might not:

> "[T]he people who have a family member, for instance, who is their advocate, are doing really well. People, you know, whose parents have resources and say, you know, keep on them and take care of them and bring them to their appointments, and tell me if something's going off. I've had a parent come, I've had a mom come before to her son's appointment and tell me, I can't find him. He really needs to come in and see you, I think he's using, I don't know if he's taking his medicine, he really, really needs to come in, and I was like, you know what? Bring him in next Wednesday— we do injections on Wednesdays […]. Find him by next Wednesday. And she found him, like, outside the bowling alley or something. So, she brought him in the next week. But like, having an advocate who goes to their appointment when they can't find their kid and is like, I can't find my kid! He is like having a problem, we need to do this, like...he needs to get his injection and he needs to be seen."

Family members acting as caretakers fulfill the role otherwise provided by CMHCO employees, case managers, clinicians, and peer supports. However, individuals living with mental illness may have tenuous or damaged relationships with friends, family, and community members (Patel et al 2014: 262). One peer support told me about observing clients whose families took advantage of their access to social services and benefits. Several care-seekers described that unhealthy or abusive filial relationships played a role in causing the development of their mental illness; otherwise, family relationships were potentially emotionally charged. This barrier also works concurrently with larger sociocultural stigma about mental illness, which informs familial relationships between a mentally ill person and their relations. Harry, a peer support specialist, said:

> "In one instance, somebody might have a family member who knows about mental illness but isn't supportive. […] But then you may have people who are dealing with mental illness but can't even tell the people around them because they don't want to hear. My parents would hear it, they just didn't want to help, but many people's parents don't want to hear it at all because of the stigma attached. And so, in that sense, not having community support or family support is a very real barrier because of the stigma."

The intersection of stigma and community created challenges for Russel, another peer support specialist, when he began seeking care for this own mental illness. In 2008, Russel experienced a mental health crisis after being fired from a job.

"[...] I had had suicidal thoughts before; I had contemplated suicide before, but this time it was a lot more serious, a lot more severe," he said. Struggling with his mental health waylaid plans to finish school, to initiate a career, and to buy a home; all goals he said he wanted to accomplish by a certain age. He went on: "[I] had these rigid little thoughts: I want all these things! And depression and anxiety came, and it was like, there was a four-year period where I didn't work."

In the meanwhile, Russel relied on crisis hot-lines and informal support groups, finally moving towards formal therapy. In the present, Russel asserted that these life experiences were still valuable. Though the trajectory of his life had been disrupted and Russel felt paralyzed in inaction, he expressed that he otherwise would likely never know about issues surrounding mental health care. His recovery, stability, and employment as a peer manager were a redirection in his life, a reconstitution of older goals that he was beginning to accomplish despite the disruption. This was a motivational sentiment that he imparted to his clients. Russel described that he grappled with self-doubt related to the perceptions about mental illness that he had grown up with, rife with negative stereotypes or a denial that the disease even existed, or could occur in his own life and sociocultural context:

> "...[M]y biggest hurdle was with stigma. Where I grew up, I grew up in West Louisville, and I had head of mental illness, but didn't have a great understanding of it. It was not talked about. And it's kind of true, in the African-American community, mental illness is kind of this dirty little secret that nobody really talks about. So, when I was feeling this severe depression, I didn't feel like I could talk to anyone about it. I didn't feel like I could talk to my parents about it. I couldn't go to my pastor or my church members about it. It was just like, where do I go to get help?"

Interviewees described how internal and external stigma about mental illness could inform other areas of care access. Practical barriers to accessing care, such as a general lack of knowledge, combine with individuals' struggles to interpret and make sense of their own daily experience. For example, Russel described feeling uncertainty at the outset of seeking care:

> "I went online and saw two support groups. One met downtown and one met in the Highlands, and I was like, I'm gonna go to this one in the Highlands[7].

7   The Highlands is a primarily white, middle to upper-middle class neighborhood in Louisville; it is a

> I went and there weren't a lot of African-American people there, and so that kind of made me feel uneasy. Maybe it's true that black people don't...and I've heard people say, black people don't get depressed! Maybe it's kind of true. Maybe this really is all in my head and I'm in this denial stage, but the longer I stayed, the more I saw that this effects everybody."

Over time, Russel began to reform his own self-identity surrounding his experience of mental illness. Interviewees described how the process of seeking care occasionally warranted breaking family ties, renegotiating difficult family or community dynamics, or shifting previous knowledge paradigms about mental health and mental illness. Russel explained: "[I]f I knew what I know now, I know I should have reached out more. I could have reached out." I asked him if, in hindsight, he could identify other people in his immediate social network who exhibited signs or having struggled with a secret mental illness.

> "My church I've been a member of my whole life […] we had a Deacon […]. He played Center every year, huge UofL fan, smiley guy, just really loving. Would do anything for anyone. And for years, that's how he was and about...I think it was two years ago...there was no warning. Committed suicide. He was at home with his wife; she said he got up off the sofa, went out to the garage. She heard two shots and that was it. And I remember when I was going through my really depressive episodes, I was trying to hide it. I would be in church and would just be in tears, because I'm sitting here thinking about trying to kill myself while everyone else is praising the Lord. And you just never saw any kind of sign, like he never talked about feeling down or anything like that. And suicide is so preventable. It leaves so many questions, it was just like, did he know that he wasn't the only one who ever felt this way? Did he know that it's going to pass? Did he know that he could reach out to somebody and talk about this before he did what he did? I just remember, it really rattled me […] because it never got talked about in our church. Like, there was a black cloth put where he sat, we had his funeral, but nobody talked about how he actually died. Come to find out, the family didn't want it talked about [...], I feel like if we talked about it, he would still be here. If we brought up that, you know what? We deal with depression. It has nothing to do with our faith. It has nothing to do with being black. Maybe

popular shopping and business district with several public amenities such as bus lines, parks, and libraries. Despite its mixed income status where it nears downtown Louisville, as a residential area, it is regarded as fairly affluent.

he would still be here if he knew, if we just talked about it and said, hey, it's okay to feel this. People feel this. You don't have to kill yourself. There's people you can talk to."

Stigma and the public perception of mental illness have a noted impact on health-care outcomes (Parcesepe and Cabasa 2012). While stigma is expressed across categorical barriers to care at multiple systemic levels, at the individual level its presence can be a powerful inhibitor to seeking care. Perceptions about individuals with mental illness range from assumptions that they are dangerous (either to themselves or others), to pervasive internalized shame about having a mental illness, or others' feelings of punitiveness towards behaviors associated with a mental illness (Parcesepe and Cabasa 2012).

Questions of stigma and how it shaped care-seekers' interactions with their social environments persisted throughout my research. The day after the February 14, 2018, Parkland School shooting in Florida, I attended a DBSA meeting where the conversation shifted towards uneasiness, disappointment, and cynicism about the news of the shooting. Attendees discussed the anticipated flood of high-profile discourse about mental illness, much of which they perceived to be hurtful misinformation that reinforced negative stereotypes. Already in the group on several occasions, attendees had spoken of tensions with family members or employees to whom they had disclosed their illness. They told stories about being faced with doubt, blame, exclusion, or frustrating coddling from others about their personalities, behaviors, and past actions with regards to their mental illness. I spoke up, at one point, and asked the group if they felt that their personalities and behaviors had become pathologized, either by themselves or others even when they weren't related to a mental illness diagnosis at all: it seemed that a person's entire self could be reduced to symptoms of their mental illness. The group agreed, and one woman spoke on this stigma

(paraphrased): "That really keeps people from getting help."

Care-Providers' Individual Barriers to Care:

CMHCO employees described to range of individual challenges, including burnout, cynicism, futility, or frustration (either with individual patients or with the system overall), limitations on time or available resources to meet the needs of clients, and difficulty finding healthy boundaries or emotional distance from their work. Peer counselors, especially, described the importance of maintaining boundaries, as their jobs straddle the formal and informal. For this group of care-providers, avoiding becoming re-traumatized or having their own symptoms triggered by direct contact work was described as important. Although "recovery" as a set of care practices or technologies is contested, the approach is intended to emphasize co-constructed goals and interpersonal relationships between care providers and care seekers (Klaus and Stein 2013). Brodwin's ethnographic research among ACT (Assertive Community Treatment)[8] Teams discussed the specifics of provider-patient relationships as one of transmitting ideological messages about care, but Brodwin also observes how futility is an outcome experienced by care-providers who contend with human clients—difficult, sometimes unpredictable, hard to fit into treatment plans (Brodwin 2011). Indeed, futility and social or emotional distance from a patient was noted in one interview by a case manager, who said:

"We're working with a consumer now that because he loops so quickly, and

8 ACT (Assertive Community Treatment) is a model which utilizes coordinated teams of care providers from different backgrounds to engage clients in services. Clients are individuals who typically reside in the community but benefit from this intense, sustained contact with providers (Brodwin 2011; NAMI 2018). In my own data, care-providers described ACT and other higher level interventions as reserved for severe cases, which were, in part, predicated by clients' documented difficulties in treatment (see also: discussions in this chapter about insurance). a

so often, we can never get his SSI established. He has a state guardian, who, because he has a—a rather colorful past, the state guardian doesn't even believe that he can change and you find a lot of that."

The interpersonal relationships between care-providers and clients, as established previously, is significant. I elaborate more on how negative experiences receiving care play out later in this chapter when I describe barrier interactions.

Institutional Barriers

Institutional barriers constitute any instance where care access is influenced from factors within a CMHCO or care organization itself, or from interactions between care organizations or other institutions. This category is expansive, with barriers occurring at the level of individual relationships between care-seekers and institutionally-based providers, or interactions between either care seekers or providers and institutional mechanisms. Receiving poor customer service from a single point of entry system was regarded by some interviewees as impactful as being ejected from care outright because of a program closure. Experiencing ongoing difficulty with care systems could result in patient burnout, including feelings of frustration or exhaustion. Because care-seeker experiences are more fully described in the latter sections of this Chapter and throughout Chapter Three, this sub-section focuses only on care-providers' perspectives.

Most often, institutional barriers were described as preventing patients from easily working through care systems, losing access to services during their treatment, or were organizational limitations which prevented care-providers from delivering needed services to clients. Institutional barriers also reflect the struggles of care providers to deliver care under the duress of these barriers. In the Recovey Era of mental health care, Kraus and

Stein argue that the practical implementation of recovery ideals across CMHCOs has been difficult because of persistent underfunding, limitations of managed care, large caseloads and burnout (Kraus and Stein 2012). However, they did find that employees at institutions implementing recovery-oriented approaches reported less burnout tan those that did not (Kraus and Stein 2012). Conversely, Myer's assessment of one CMHCO's novel approach to recovery philosophy which included a wholly peer-run program, upended staff, who struggled to renegotiate their role with clients under programming promoting a newer, more hands-off approach to care delivery (Myers 2015). In my own work, it did occur that care-providers described the need to be adaptive to care landscapes that could change quickly.

Recursivity of Barriers in Service Delivery

Care providers explained that institutional barriers became recursive: a systemic shortage of psychiatric staff and the high turnover rate of CMHCO employees could lead to other barriers to providing care, such as overwork and employee burnout, which could manifest as high staff turnover and, consequently, long waits for treatment for care seekers. Community mental health sees an exceptionally high rate of burnout (Green et al 2014), which can also impact efforts at inter-organizational coordination. One clinician explained that part of her job involves educating staff at other CMHCOs about the range of services they could provide, to be a resource for patient referrals. She told me:

> "I think one of the biggest challenges I run into is just, retention of the workers that make referrals, because there's such a high turnover at so many of these agencies that I may go out and talk with a group, and then if I came back three months later, there might be a whole lot of new faces."

At this level of direct service, the co-constructed model of provider and patient relationships is made especially clear, where patients were frustrated or worn down by how care-providers' stress effected their own care. Turnover among therapists could result in patients being repeatedly shuffled to new care providers. Kate, a care-seeker, said they had cycled through multiple therapists during the past two years as a patient of one CMHCO, which was:

> "worse than pointless, because it's extremely abandoning and it's not helpful. I would start to get to know someone and feel comfortable, and give them everything from the catalog that they could try to help, and then they're gone because they can't make any money because they're overloaded, because they have hundreds and hundreds of case files and different people and they're not getting adequately compensated for the work they're asked to do which is an impossible amount of work."

High turnover and understaffing could also prevent clients from receiving care. Alina, a nurse practitioner, said her CMHCO went a month without a medical scheduler:

> "I had a bunch of holes in my schedule because they had the people at the front desk trying to schedule appointments and like, they also had to do their regular job, so—yeah, I sat around a lot! Yeah, and, you know, we didn't have someone for medical records for a while so nothing was getting scanned in to medical records, like, if the primary care office was faxing stuff or whatever. All of that—that's support staff turnover is a problem—therapists—therapists have really, really high, very high burnout rate. There's a lot of cynicism."

One clinician explained that long waits to get treatment became a confounding factor for individuals who were stepping down from treatment, who required follow up care at a lower level of intensity:

> "[One hospital]'s outpatient psych department, which is probably the only other large mental health care provider that takes Medicaid, is on routinely a six to eight month wait."

Typically, several weeks to months for outpatient care was described as a typical wait time

for treatment. Related to this, occasionally, care providers expressed frustration with patients being turned away while seeking care at hospital settings. One employee said:

> "I've seen a lot of clients during my tenure […], you know, those people who cycle in and out constantly because they—quickly—[I] have heard providers say, 'we just don't that that person anymore, they're too volatile or they're here all the time.'"

The ways in which these direct-contact barriers to care operated reflected a major finding of my study, which involved the parallels between barriers to providing and barriers to receiving care. Keeping with Manderson and Warren's recursive cascade concept, recovery is located in the space between care providers and patients, where the "interweaving and compounding" of challenges of institutional and individual limitations to accessing or receiving care bar care-seekers from treatment (Manderson and Warren 2018). An observation of my fieldwork is that oftentimes, care-seekers don't have a course to accessing resources and strategies for ongoing self-management of chronic illness *except* through institutional contact and movement through care systems, including auxiliary organizations. For example: one clinician who saw many homeless clients said she recommended to them they make contact with local care systems, even if they did not prefer to stay in shelters. Being documented in that system—especially being documented *often*—would make somebody more eligible to receive particular services. Pathways to accessing resources, then, are contingent on participation in and movement through these vast systems. Recursivity of institutional challenges occurs in the space of one institution or across institutions, creating barriers to providing care which are writ in the everyday lives of care-seekers.

Institutional Capacity, Growth, and Change

For care-providers, adapting to change was routine. With health-care and funding often the focus of policymaking, care-providers were familiar with how quickly care landscapes could shift. At the time of my data collection, Governor Matt Bevin proposed a Medicaid work waiver—the first to be proposed in the United States, and a topic of concerned conversation with interviewees and at field sites. Even at this occurred, CMHCOs were still adapting to the influx of newly insured patients, who became eligible for services after Medicaid expansion. However, several care-providers also commenting on shrinking pools of federal and state funding. The source, sustainability, and availability of funding was a foundational facilitator or inhibitor of carrying out mental health care interventions and sustaining initiatives beyond what was insurance-reimbursable. Marcus, social worker and program director at one CMHCO, said that mental health was often given short shrift compared to other issues:

> "[T]he light gets shined on one area or another and it doesn't usually get shined on the mental health part, until there's a mass shooting somewhere and they're looking for something to blame it on."

Zachary, co-chair of Citizens of Louisville Organized and United Together (CLOUT), which was working on several pieces of mental health-related advocacy, said: "One thing […] that I find encouraging and maybe a little discouraging at the same time, is that there's a lot of good stuff going on, just not enough of it and the thing that seems to be holding it back is just money." This perception—that despite a robust number of programs, they were severely limited by funding—was throughout care providers' interviews. Interviewees from some organizations occasionally mentioned that they were unable to provide certain services to clients, despite seeing a need, simply because they could not capacitate such

services. For example, a clinician from Wellspring's CSU said that she felt certain clients' care could have more efficacy if the organization could provide its own case management, a service they did not have.

At Bridgehaven, a lack of physical space to house their growing program was a pressing issue, limiting how many new patients the small organization could take on. At the time of my data collection, Bridgehaven was deliberating over plans to expand into other buildings or into a neighboring vacant lot. An interviewee from Bridgehaven commented that, among challenges the institution faced, increasing the physical space available was "[A] big one that we're on, it's just taking a while. It's too fucking crowded!"

Further, changing service populations challenged CMHCOs to adopt culturally competent care. Jean Henry[9], president of NAMI's Louisville chapter, explained that she felt the national organization was "behind the times" on recruiting new volunteers or attracting younger people: an aging population of volunteers created a worrying prospect. She told me that the Louisville chapter itself was too small to have secured funding for more expansive, specific, and needed programs focused on certain populations like veterans, targeted programming for college students, or culturally relevant care for people of color. Jenny, a mental health coordinator at a local refugee resettlement agency, said that she felt there were ways in which the mental health care system was exclusionary by failing to provide language accommodations for her clients.

This extended into other concerns voiced by care-providers about CMHCO's ability to provide culturally competent care; care-providers who worked with immigrant or refugee client populations voiced concerns about navigating ethnic or cultural differences.

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[9] Real name

Concerns about culturally competent care also arose surrounding typical client-provider relationships. One employee told me: "A lot of people find it really hard to relate to their therapists, cause like, you don't know what it's like to be poor! And we don't have any black providers at [CMHCO]." In another setting, a clinician told me that in the past the organization had struggled to adapt to the usage of LGBTQ-oriented language. As a result, at least one patient had voluntarily left treatment early because staff had not used their appropriate gender identity to address them.

Coordination, Communication at the Institutional Level

Concurrent to intra-organizational programming changes, interviewees described how the care landscape and relationships between institutions were also changing in response to the ACA and other healthcare legislation. Seven Counties merging with Centerstone in 2016 was one such adaptive change, to expand service delivery and organizational capacity (Courier-Journal 2016). However, across organizations, employees described how the mechanisms of the ACA in Kentucky—specifically, site de-affiliation from centralized, regional providers and the creation of the BHSO category for licensed mental health care providers—resulted in some tensions while renegotiating organizational relationships. One CMHCO employee divulged their perception about these changes:

> "[O]ne of the other things that frustrates me is working together. […] For years we operated in these little silos and the idea was, we'd expand Medicaid and people would have choice, we'd all work together and kind of level the playing field. And everyone is circling their wagons and trying to protect their own little—it hasn't made the silo situation better. We had a couple of secretaries switch over as part of the process and so it's made it all a little more difficult but—I talked about with referrals mainly to [our organization], hospitals being more willing to hang on to people than to let them go, and that's kind of the impact it's had. While it should help

everybody, people are kind of trying to get as much as they can for themselves."

Multiple care-providers said that they believed de-affiliation of CMHCO sites in the region was a positive influence, encouraging organizations to become competitive and provider better care. However, coordination was a necessary part of providing treatment and the norm across both care provision and care-recipiency, even stretching beyond mental health-related services. I asked Marcus, a program director, about this coordination:

> "We're focusing on what the individual wants, so that could include church, it could include food stamps, it could include food pantries depending on what their need is. We coordinate services with payees, we coordinate services with social security, with food stamps. Just depends on what the individual needs."

Marcus's explanation exemplifies how care-providers and care-seekers co-construct care assemblages between institutions and across care landscapes. Across interviews with care-providers, finding opportunities across complex resource landscapes to meet the needs of clients was common, requiring coordination between CMHCOS and external care institutions.

However, perceptions about disorganization, a lack of coordination, or a lack of communication between CMHCOs were occasionally voiced by care-providers. Zachary (of CLOUT) said: "[T]here's a lot of good stuff going in Louisville but often the left hand doesn't know what the right hand is doing." CLOUT, as a multi-denominational religious group focused on social justice issues, used their significant member base to help secure funding for a Living Room program which now exists at Centerstone, as a collaborative partnership between Centerstone and the Louisville Metro Police Department. CLOUT played a mediating role in coordinating efforts to initiate that program as well as begin

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conversations about others. Zachary added:

> "I think that different organizations would develop various ways of dealing with mental health or addiction issues but they just wouldn't include everybody. I mean, everybody has their own [...] piece of the problem. But there wasn't anybody trying to coordinate it all."

Coordinating care or establishing a care continuum for mental health consumers occurred as an individualized effort, performed between patients and care-providers. Care-providers described a vast amount of coordination between CMHCOs and external resources; however, such care assemblages are contingent on an individual being able to navigate the internal cultures and regulations of multiple institutions. Between CMHCOs, this coordination was routine. Between CMHCOs and external, non-mental health care providing resources, this could be more difficult. Several interviewees alluded to the difficulty of bridging care between CMHCOs and recovery houses or rehabilitation programs. The schedules on which homeless shelters operated could be unmanagable for homeless mental health consumers who held second or third shift jobs, or from which they had been banned entirely because of past acute episodes. Residential rehabilitation or recovery houses for substance use might not allow a patient to bring psychiatric medication into the program.

Further, the logistics of managing one's everyday life among and between multiple institutions could prove difficult. Care assemblages, in which patients utilized multiple CMHCOs for care, could provide important networks of varied services to meet multiple needs, but navigating these webs of care often clashed with patient's knowledge or ability to keep track of these assemblages. For mental health consumers with a dual diagnosis (concurrent mental illness and Substance Abuse Disorder), seeking emergency care can be

a challenge; most CMHC emergency facilities in Louisville are not equipped for medical

emergencies like overdoses or withdrawals. Marcus said of his own CMHCO:

> "So, we get a referral at the CSU for somebody who is an alcoholic, who
> drinks and uses daily. The doctor at the CSU is less likely to want to work
> with that person because of their fear for withdrawals. We're not a medical
> facility. That limits us and I don't like that. With alcohol, with
> Benzodiazepines and now she's doing that with opioids. I appreciate her
> reluctance and her limitation but I don't like that that limits us and so I want
> us to develop new ways so that we can hang on to those, so we can begin to
> treat those people."

Conversely, he said of referring patients out of the organization:

> "If we want to send somebody to [a rehabilitation facility], they won't take
> them if they're on an anti-psychotic medication. I think [that provider] is
> what a lot of people think of around here when they think of services,
> because they're so big and they see so many people. But it doesn't work for
> our clients." [10]

Care-Providers as Gatekeepers

Despite recovery-model emphasis on the expertise of patients and the supportive, more

pliant role of care-providers in assisting care-seekers achieve recovery goals, several

interviewees described care-providers acting as gatekeepers. This occurred in two major

ways. First, in instances where interviewees told me stories of working with therapists or

care providers whose care was perceived as unhelpful, ill advised, or harmful. This arose

in scenarios where individuals were turned away while seeking care or whose care

providers refused to continue seeing them, instances were care providers' advice was

ethically questionable, or when care-providers and their clients occupied vastly different

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10 Contextually, Marcus was saying that typical Substance Abuse programs did not work for Dual
     Diagnosis patients who were clientèle of his CMHCO, cause of the differences in program
     requirements versus Marcus's clients specific needs (who needed to take medication, and could not
     participate in programs which banned or limited it) and also because, as Marcus expressed, he felt that
     he had seen many SMI/SPMI clients struggle with routine Substance Abuse programs such as AA.

cultural or ideological backgrounds and could not find common ground. The other way that this theme emerged was in care-providers lamenting about their own struggles to grasp the full complexity of health care infrastructure to offer their clients the best care. Where "access" to resources for mental health in the current model of care delivery is rooted in navigating community mental health institutions and participating in formal services, the dynamic between care-providers and care-seekers carries a strong influence.

Environmental Barriers

In this category, care-providers cited such barriers to care as a lack of transportation, homelessness or housing insecurity, and living everyday lives with basic needs unmet such as hygiene, food, safety, or other structural inequalities that prevented care access or maintenance. Among care-providers, environmental barriers to care constituted serious inhibitions to providing care, and the most significant limitations for care-seekers abilities to make progress in care. One interviewee told me:

> "[W]ith some of these folks with a mental illness that we're talking about, they're disadvantaged enough from a socioeconomic perspective that going to see a therapist once every other seek may help a bit, but it's going to solve the pressures of their life which is complicated their mental health situation. So, there's a lot of doors shut for these folks."

Intergenerational poverty complicates mental health care when individuals' families are unable to act as caretakers for them as they are "too poor to house and look after them" (Patel et al 2014: 143). Patel et al present an overall argument for the synergistic relationships between demographic, biological, environment events, economic, and social influences which contribute to the incidence, severity, and the treatment of a mental disorder (Patel et al 2014: 119). Lauren, a clinician at a CSU said:

> "Obviously, for individuals who come in in psychiatric crisis, medication and therapy are helpful but for a lot of people there are those external stressors that are still there when they leave, and they don't know how to deal with them; homelessness or lack of income or not being able to find appropriate services for their kids."

While the psychosocial distress of poverty should not itself be mistaken for a mental illness, the presence of mental illness can interplay with these stressors (Mills 2015). Lauren also described the necessity to parse the symptoms of mental illness out of stress evoked from general social marginalization, poverty, or environmental stress. She addressed how, when assessing patients, she had to be careful not to pathologize patients' lived experiences by mistaking the outcomes of environmental stressors such as irregular sleep patterns or skipping meals, for the active symptoms of a psychiatric disorder. As Lauren explained, poor eating habits and irregular or disrupted sleep are potentially symptoms of poverty or stress as well as mental illness. Likewise, a lack of basic tenants of stability (poverty or socioeconomic status, lack of transportation, lack of housing or housing insecurity) were described by care-providers to be major contributors to care access cycles in which the stress of environmental barriers to care prevented mental health care consumers from maintaining treatment or from making progress in treatment.

Transportation

A lack of transportation prevented patients from keeping appointments, being able to get prescriptions filled or picked up in a timely manner. Lauren noted that while at the CSU, patients were able to experience short-term improvements because of on-site care; once discharged, the logistics of up appointments without easy access to transportation could prevent patients from adhering to that treatment. When I met care-seeker Afina for our

interview, our meeting places were limited to a range of several streets in downtown Louisville which were accessible by bus, as she did not have other transportation. In the past, she had been deterred from attending an informal support group in which she was considering becoming trained to be a facilitator because, "I sought out the [meeting] that was closest to me, and it would take three buses and a half a mile to walk." Only two buses are required to reach the CMHCO where Afina receives regular treatment.

Access to transportation expands into the everyday logistics of getting to and from services. When I interviewed Russel, a peer counselor, in Winter, he noted that attendance was much lower than usual that day because of the cold[11]. Louisville does have a public transit bus system, the TARC[12], which nonetheless itself was described as potentially difficult to navigate for care-seekers. Harry, a peer support counselor, said:

> "[E]ven if somebody has a TARC bus pass, if they're symptomatic—the symptom particularly of hearing voices—they're not going to remember the bus. They don't want to ride the bus, it makes them worse. So, Medicaid is looking at it, saying, you've got a TARC pass and the person is saying, yeah, I also have very severe symptoms right now that prevent me from using that and so it's another uphill battle you have to fight with them to say, hey, medical necessity again. Medical necessity, they need more transportation."

Convoluted service limitations and restrictions on transportation created difficulty for patients and the care providers tasked with alleviating that barrier. Russel, a peer counselor, said:

> "Well, we help members get signed up with Federated Transportation. Federated has a lot of really weird rules, like, if you live with somebody who has a car, you cannot receive services. Or if you have a car in your name—and it might not even be running—you cannot receive services. There's a lot of member who are just, for no reason of their own, not being

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11 It was 27 degrees when I left the interview around noon. The CMHCO, which I had visited a month earlier to interview another employee, had been crowded and lively. That morning, the building was mostly empty.
12 Transit Authority of River City

able to receive a service they could really benefit from.

Multiple care-providers expressed frustration with the limitations placed on transportation assistance. R, a care-seeker, said:

> "I don't drive. I live in the bum-fuck of nowhere so there's no other transportation. It's hard to get a Medicab because you have to—I have cars at my house, so my parents have to get a letter from their employer saying I don't have access to the car that's just sitting in our driveway because I don't drive."

For R, their lack of transportation further complicated making and setting appointment times, which often fell outside of typical business hours because of the availability of a parent to give them a ride.

Housing Insecurity/Homelessness

Within the literature, mental illness has been shown to be recursive with homelessness through multiple processes. First, mentally ill and homeless individuals may face diagnostic discrimination (in which mentally ill individuals are less likely to be hired for jobs because of the double-burden of stigma surrounding both mental illness and homelessness) (Benbow et al 2011). Further, homeless individuals often encourager structural and logistical barriers to accessing care, from which they experience difficulty escaping (Lewis et al 2003; Paudyal 2017). Homelessness or housing security took on many forms as a barrier to care, described by care-providers as ranging from an acute and stressful circumstance, to one where patients struggled to maintain housing because of active symptoms. Harry, a peer counselor described homelessness as a stressful impediment to making progress in treatment. As he explained:

> "We service several people who are without permanent housing. [...] If

somebody is without a home, it makes it infinitely more difficult for them to participate meaningfully in services, or meaningfully in their treatment, and so you will see people who are without housing and you'll see their recovery stall. They'll be in here, from day to day, but are they doing any better? By my standards—and I'm not a clinician, take it or leave it—no. No, they seem more stressed out than they did yesterday, until finally they can get into permanent housing, then they can stop worrying about their Maslow's needs and can begin working through actual issues."

For homeless mental health consumers, barriers to care can become especially severe. In their research in the UK, Paudyal, MacLure, Buchanan, Wilson, MacLeod and Stewart recorded barriers to care among the homeless as being compounded by the distractions of daily survival as well as navigating the practical logistics of accessing care, such as sleeping outside of medical offices or stowing away medicines in hiding places in one's clothing to avoid them being stolen (Paudyal et al 2017). In my own data, a CMHCO employee said that one of her organization's clients, with whom she had worked, occasionally stayed in an alley on her street. Lauren said that the climate itself could influence the number of admissions they received:

"[W]e do see an increase...which, rightfully so, we consider it a crisis, but we see an increase in users who are experiencing homelessness during the winter. So, when it was zero degrees outside, I would say about half of our clients were experiencing homelessness, but that's a crisis. I mean—it's a housing crisis, but if you're already symptomatic or you're struggling with depression, your voices are going to get louder. Your depression's going to get worse if you're trying to stay warm and not die. So, we do see that, I think that's some of it, but there seems to be a larger trend that the summer months are a whole lot lighter, and I'm sure there are lots of other factors."

For housing insecure clients, difficulty attaining low income or assisted housing could be difficult. Housing assistance programs, while effective, had long waits. Living in unsafe and unsanitary housing was a concern for patients and providers: two CMHCOs divulged to me that they had gotten—and treated—bed bugs in their buildings. While I received a

tour of the site, the employee I spoke to mentioned, off-handedly, that many of the CMHCO's clients lived in low-income housing; many of these housing sites around Louisville are burdened by bed bug infestations (WFPL 2018). The experience of unhygienic living spaces or living situations which felt socially unsafe such as residing with a family member with which a patient had a poor relationship, were identified as potential severe stressors.

Unmet Needs

Food insecurity, safety, and hygiene were all aspects of environmental barriers which care-providers described as being influential for treatment progress and outcomes; they are often related to access to stable housing and reliable transportation but exceed them as well. These three factors further contribute to the development of concurrent physical health problems among individuals who are mentally ill, and marginalized populations in general. Access to nutritional diets has social and physiological associations with better mental health care outcomes, both in circumstances where individuals can provide for their families (not doing so exacerbates social stress) and in circumstances where individuals are malnourished. The latter was mostly a concern for care-providers in my data, all of whom parsed food insecurity as an issue of being unable to actively engage with the treatment process. Colleen, a peer counselor, told me:

> Colleen: I had a person the other day, like, losing weight—starving, did not have food. Let's go get food stamps and a food box while we're there! Like, literally crying because they just got approved for food stamps.
>
> LV: Is that something that people will be open about? Not having food?
>
> Colleen: Yeah, they will—very much so. Probably all the time, they'll tell

> me pretty much anything they don't have. Sometimes I have to pry it, because that is one thing—like you said, making sure those other needs are met. Because if you're hungry, what is your therapist going to do with you?

Food insecurity, in this example, is a very concrete barrier to care. Food insecurity and malnutrition are also posited to be associated with social stressors regarding one's role within the household or the risk of the development of physical illnesses (Seifert et al 2004). Further, malnutrition (vitamin deficiency) is associated is also associated with mental ill health or poor cognitive functioning (Seifert et al 2004). Care-providers often spoke about basic needs going unmet according to Maslow's Hierarchy models of functioning. Siobhan, a program director, said:

> "[T]hese folks that are coming to us have all these basic needs that do interfere with treatment because they're so busy with the survival needs, and we have nowhere to house them right now. There are plans that people are talking about, it's a matter of getting funding which is the other problem."

These unmet needs are the result of the internationality of multiple vulnerabilities and barriers to care access, which may or may not become recursive with the symptoms of mental illness; unmet basic needs like food insecurity create physiological stress, while homelessness and inability to maintain hygienic practices can lead to vulnerabilities towards the development of infectious diseases[13].

Insurance

As the focus of large-scale health care reform, insurance plays a foundational role in health

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13 During the time of this data collection, a Hepatitis A outbreak occurred among the homeless and IV drug-using populations in Louisville; when I spoke casually of this to friends and interviewees, they did describe efforts within their agencies to vaccinate patients who were homeless or who resided in recovery boarding houses.

care delivery models. While Medicaid expansion led to the increase of individuals able to receive mental and behavioral health care in Kentucky, care-providers often found themselves struggling to negotiate their clients' needs with insurance limitations or pre-authorizations. Zachary, a member of CLOUT who was a retired social worker and spent most of his career in mental health, said:

> "I think a lot of insurance have a very rigid model of: you come in, you get your therapy, and you go. And a lot of folks we're talking about need more than that. If you're a nice, middle class white person with a complicated bereavement, [CMHCO] will be all over that. But if you're somebody who's really struggling with a lot of different issues, and a drug addiction on top of that—because most of the disadvantaged people we encounter have multiple problems."

In addition to the variety of institutional, individual, and environmental barriers, issues with insurance acted as a very significant obstacle to providing care, even as it was a primary facilitator of care access. Indeed, insurance as a barrier to care or as creating complexities surrounding treatment planning or care delivery featured in every provider interview. Post-ACA, the payer source for CMHCOs is almost entirely through insurance reimbursement as well as some grants. As such, experiencing a lapse in insurance, losing insurance, or not having insurance but being unable to pay for care out of pocket creates a wholesale lack of access for care-seekers. When I inquired to care-providers what their clients did to cope when they experienced gaps in services or a loss of insurance and access to care, they typically stated that they didn't know—if that happened, the door would be closed for those clients until they could have their insurance reinstated. Interviewees from all three CMHCOs said that on a case-by-case basis, they could waive or defer payments, provide sliding-scale services, or judiciously draw from grant money which could cover the cost of payment for clients. Siobhan said:

"We can only do what we can get paid for a lot of times. Like for the crisis team, I can't tell you how many services we eat a week for free because the person doesn't have funding yet and we're working with them on getting funding but in the meantime, we've providing hundreds of dollars of free services which […] effects the company […]."

The type of insurance that a client had might place limitations on the amount or the type of treatment they could receive. Navigating the complexities of a patient's insurance to provide the most effective care was described to be a barrier to providing care. For some patients, lapses in insurance can pose significant problems for maintaining contact with services. This was especially pertinent in cases where clients tended to loop quickly through institutions, or often ended up in jail. Deborah, a case manager, told me:

"[F]or a lot of consumers who are transitioning out of jail or transitioning out of prison, depending on how long they've been in prison, it's a guarantee benefits have been suspended, whether private insurance or regular insurance, because when you're in a state facility, they fund—you know, there's a different payer source for that. So, getting their insurance benefits established or reinstated is a gigantic barrier."

Similarly, other social benefits such as SSDI are supposed to lapse after 30 days in jail or prison. Losing insurance and having trouble reinstating it could be a causative factor for losing access to mental health care altogether. Further, the necessity of working through insurance pre-authorizations as a process was a frustration for care-providers who expressed that they possessed the expertise to know that their patient would benefit from a certain treatment but were unable to get pre-authorization for the treatment until their patient had "failed" multiple times. Alina, a nurse practitioner, explained to me:

"[W]e are wasting a lot of time trying to get prior authorizations for medications, and you think—we have somebody on the clock getting paid to get it through, and the insurance has somebody on the clock trying to not get it approved—for things like Melatonin! Yeah. It's a huge pain the butt. They won't cover Melatonin because it's over the counter, but I have people that can't afford over the counter meds, that's why they're on Medicaid or

Medicare, or whatever. And I know that this would help them with fewer side effects than something else I could give them. The guanfacine is like a non-stimulant ADHD med, but needs a prior authorization that almost always gets rejected. If they have not failed on at least two psycho-stimulants, they won't approve guanfacine. So, if I have someone who's say, a person with an addiction history with ADHD, I have to try them on two stimulants first before I can give them the non-stimulant."

"Failure," she explained, was at the crux of insurance pre-authorizations. Throughout this interview, she repeatedly commented on how evidence was required to bring out more intensive interventions for patients. However, providing this evidence to insurance companies left patients at risk for decompensating:

"I'm not prescribing the really expensive new medicines, like, there's a couple new anti-psychotics, and least one new antidepressant that I would use if I did not know how much they cost. But I don't prescribe them, because we are managing scarce resources and I know that those Medicaid dollars come from somewhere and there are other medicines that work nearly as well, maybe with a few more side effects. So, I'm not sitting here like, my patients need the most expensive stuff. But they need the one that works. If I know somebody is going to be in the hospital if I can't give them a long-lasting injection, why do they have to be hospitalized first? They do!"

Of long-lasting injectable and other medications that she described as more useful in the long run for indigent and transient clients as well as for young adults experiencing symptoms for the first time, she added:

"[These medicines] should be, basically, first line for young people experiencing psychosis these days but they're not because insurance doesn't want to cover them until after they've failed and been hospitalized a bunch on their oral anti-psychotics that they don't take."

While insurance was a primary facilitator to care access—as having or not having insurance could determine if a patient was able to get in the door of CMHCOs at all—the complexities of resolving the ever-changing and complex needs of patients with the more rigid structures of insurance proved to be an ongoing difficulty for care-providers.

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Emergent Barriers and Barrier Interactions

Overall, my research suggests several persistent, systemic issues with mental health care access and service delivery, which are locally expressed but may be indicative of broader trends in mental health care landscapes. Overarching themes of precariousness and uncertainty about the future pervaded the lived experience of barriers for both care-providers and care-seekers. In this section, I describe how the above categories of barriers to care become recursive and interactional, producing this precarity as well as a range of emergent challenges for both care provision and care seeking in Louisville. Throughout a life course or in the daily lived experience of mental illness, any interaction of barriers to care access may occur. Therefore, it's more useful to identify larger processes structuring care access and delivery (Mendenhall 2012). I did not collect enough data to begin to realize specific clusters of barriers or among any specific populations, but the interactions I propose are occurring point to larger questions formulating in research about community mental health.

First, I explore institutional-individual barrier interactions which often manifested as care-seekers having bad experiences via service contact. Then, I examine how environmental-institutional barriers interact to produce precarity and urgent waiting in changing resource landscapes. Finally, pulling in individual-environmental barrier interactions, I argue that several major trends emerged from the data which warrant further research about the lived experience of barriers to care and which are made more burdensome by structural inequality. Emergent challenges reflect the recursivity of barriers: these are instances where mentally ill individuals' symptoms became enmeshed in

the occurrences of their everyday life, including the pressures of barriers to care access, could result in such outcomes as a loss of employment, loss of housing, broken interpersonal relationships/ a loss of natural supports, the development of concurrent physical illnesses, substance abuse, or criminal justice system involvement. I propose that the individual experience of these interactions can be understood by Luhrmann's concept of "social defeat" and that barriers to care produce particular patterns of social disempowerment against which care-seekers work to create agentive solutions: vicious cycles or instances where individuals become "stuck" in their expected course of recovery.

The Negative Experiences of Being Ill

Though selfhood and the illness experience are complicated matters explored throughout sociological literature, in my own data mental health issues were—because of my own line of questioning—described by means of their outcomes. Negativity related to the experience of mental illness existed across categorical barriers and frequently occurred in narrative descriptions of the ways in which individuals' mental illness became recursive with those barriers. In this section, I will explore how these negative experiences relate to a larger structuring of the outcomes of barriers to care.

For mental health care consumers, bad experiences with service contact were common; how these experiences acted as a deterrent to seeking or accessing care was often discussed by both care providers and patients. Poor past experiences with mental health care services ranged widely, from feelings of frustration with staff or institutions, demoralization with outcomes or progress, feeling unsafe in treatment settings, to feeling traumatized, dehumanized, or dis-empowered by care providers or throughout the process

of receiving treatment.

These experiences—even when institutions rectified practices—acted as ongoing deterrents to care. For example, two interviewees explained that when arrested while actively symptomatic they did not receive psychiatric evaluations, medication, treatment, or transfer to a hospital. Recently the Louisville Metro Police Department has implemented more assertive mental health care, with increased CIT training. Despite this effort, distrust and suspicion of police remained for these two interviewees; Zachary, whose work with CLOUT included data collection with members of CLOUT's inter-faith member base and spanned over twenty religious congregations across Louisville, said that the relationship between police and Louisville citizens living with mental illness was a major community concern.

Across these interviews, the most severe experiences occurred in restrictive care settings: psychiatric inpatient, hospitals, or in jail. The experience of inpatient settings included perceptions of disorganization or chaos, and one interviewee explained that they had struggled in the past with patient-provider hierarchies in which they felt unheard, dismissed, or disrespected. This could escalate to more overt instances of being overpowered: one interviewee, Kate, spoke of multiple instances between psychiatric hospitals and jails of being involuntarily overmedicated, forcibly contained or restrained, and being forcefully coerced into receiving certain types of treatment or medication. They said that they recalled one occasion when a doctor in a psychiatric hospital became angry with them, and mobilized their anger in a punitive way:

> "I had a very mean doctor […] the last couple of times that I went [to the hospital] who I intensely dislike and who, when she left for the weekend, I

had to see another doctor. I was like, please give me a PRN or something. My anxiety is severe! And he gave me another kind of antipsychotic but only like, point five milligrams of it. And it helped! He was a great doctor. *My* doctor came back, saw that he had changed my medication, became angry with me, and told me that she thought I was not bipolar, rather, I was—what is it?—borderline. She, like, arbitrarily decided to tell me, when she was angry with me because she didn't like how another doctor had decided to treat me, that I was borderline. She's a fucking bitch."

In this anecdote, consequences of the power dynamics between mental health consumers as individuals who are occasional subjects of institutions is clear; macro-level hierarchies are passed down in micro-political interactions in care settings.

Individuals who live with chronic illnesses undergo shifts in their own understanding of their illness in relation to themselves and their lives over time (Myers and Ziv 2016; Estroff 2004) The conclusions of Stein's ethnographic study of "mental health system historians"—individuals who have experienced mental health care systems through reform decades—indicated the pervasiveness of negative experiences while in restrictive hospital settings (Stein et al 2014: 44). Stein writes, "Regardless of the mental health reform era in which they were hospitalized, participants recounted hospitalization experiences that made them feel unnecessarily helpless, demoralized, and traumatized" (Stein et al 2014: 44). The cause of this, Stein posits, quoting Storm and Davidson (2010), is that inpatient hospital settings tend to rely on "[t]reatment philosophies, structural hierarchies, policies, and practices," which do not consider the desires of the patient (Stein et al 2014: 44).

Most of the negative experiences care-receivers described to me either pertained to what they felt were inefficient, unwieldly or confusing care systems or to their specific relationship with care-providers and care delivery models. This level of analysis challenges

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explanatory models of mental health outcomes that do not consider these nuanced social relationships. Explanatory frameworks like social drift and social causation, for example, identify mental illness as the product of poverty or poverty as the product of mental illness (Patel et al 2014; Mills 2018). However, these frameworks do not always account, I argue, for agency or the politics of decision-making which surround health-related decision making. Mental health care consumers' movement between care organizations, in and out of acute or restrictive settings, experiencing changes in care access, health status, employment, experiencing shifts in barriers to care, and many other factors guides my own interpretation of mental illness outcomes as a complicated interplay of factors limiting and facilitating individual agency, empowerment, or disempowerment in different contexts.

This analysis recalls Myers and Ziv's usage of "social defeat" which occurs through ongoing contact with clinical psychiatric settings. They draw upon autobiographical narratives of African-American adults living with mental illness that included instances in which their own interpretations of their experiences were discouraged, in favor of those provided by care providers. Myers and Ziv extrapolated this concept from Luhrmann, who uses it to describe how individuals living with schizophrenia inhabit a web of intersecting vulnerabilities in their social context, in which they experience "repeated instances of physical or social insults in which one party is made to feel less powerful" (Myers and Ziv 2016: 397). Myers and Ziv extend this to repeated negative experiences with institutional contact (Myers and Ziv 2016). Such a range of experiences applies to the perceptions and opinions of care-seekers and care-providers who reference the deterrent of a bad experience receiving care. I argue that the experience of social defeat also describes the outcomes of multiple, intersecting barriers to care—even while CMHCOs work to model interventions

which are empowering for their clients. Questions of power, empowerment, agency, and defeat are important to consider when examining the differential outcomes of barriers to care, where mental health consumers live with everyday uncertainty compounded by the many, unpredictable ways in which care access can be interrupted.

A Changing Resource Landscape: Precarity and Waiting in Mental Health

Precarity and uncertainty pervaded my discussions about health care landscapes, with interviewees concerned widely about how care delivery might change in the face of further funding shifts and health care reform. The narratives that care-providers offered about their own histories in CMHCO were punctuated with frequent shifts in programs, gains and losses of program funding, and instances where CMHCOs frequently had to restructure care delivery to prevent patients from falling out of services because of these changes. For mental health consumers, at the intersection of multiple vulnerabilities and social programs, fluctuations in the resource landscape could be deeply disruptive. This demonstrates how, at a very large scale, care assemblages can also be tenuous, and how the ways in which disadvantaged individuals who rely on access to and eligibility for specific programming (such as Medicaid, Medicare, assisted housing, etc.) to achieve stability are often subject to the combined pressures of precariousness over time.

In the 1980s, Wellspring operated a supportive housing called Ardery House, which was specifically geared towards individuals living with a mental illness—the only housing program of its type in the region. The program offered skill-building as well as a range of formal therapeutic services, while residents lived onsite; residents were SMI/SPMI sufferers who also experienced homeless. A peer counselor at Bridgehaven told me that

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many of their members were on the waiting list for Ardery House. When the program

closed last year, the loss "caused some serious problems. Like, crisis serious problems with

some of those people," the peer counselor told me. The peer counselor continued:

> "[T]he guy I'm thinking of in particular, he was living somewhere else but
> he was on the wait-list to get into Ardery House. But the place he was living
> was an incredibly toxic situation and he was getting more and more
> paranoid. Long story short, I ended up taking an MIW out on him because
> he told me he was planning on killing someone; he had told his primary
> something else, I told her what he said to me, we went straight to the
> courthouse. So, I'm not saying that if Ardery House had been around, he
> wouldn't have done that, but if he hadn't been living where he was, if there
> had been some hope on the horizon...but, there wasn't at that point."

As the above anecdote to care indicates, a barrier can be a stressful event and is always

constituted as something which disrupts, disturbs, or stalls an individual while they seek

mental illness recovery. In the above example, an individual held between two CMHCOs

still faced the layered pressures of individual barriers (an unhealthy social environment),

environmental barriers (housing insecurity), and institutional barriers (shifts in

programming). The experience of waiting and the precariousness of stability are larger,

emergent themes of barriers to care which manifest across care-seekers experiences in

tangible ways.

Shifts in the local resource landscape extend beyond CMHCOs and include

environmental barriers to care. The closing of a Kroger grocery store on South 2nd Street

was described as a confounding issue for CMHCO patients who lived in assisted housing

in the vicinity. The grocery was accessible by foot for the neighborhood, in which are

located both Bridgehaven's campus and Wellspring's main office as well as one CSU and

multiple housing program sites for clients. I asked the peer counselor about food insecurity

and other basic needs for the organization's clients, and she told me: "We're a food desert

now, do you know that? Because the 2nd Street Kroger is gone, it's just a shell. Where the hell are people supposed to get groceries?" Such an event highlights the ways in which precariousness in the lives of already marginalized people articulates with the experience of a mental illness and seeking treatment.

Vicious Cycles, Stagnation, and Accumulating Burdens

Vicious cycles associated with mental illness are well known and well researched (WHO 2007). The recursivity of mental illness and poverty "increases the risk of mental illness among people who live in poverty and increases the likelihood that those living with mental illness will drift into poverty" (Lund et al 2011: 1502). Lund extrapolates two theories of how mental illness cycles work: social causation and social drift. These are related to the concept of social defeat, in that they describe—at their core—mechanisms by which individuals living with mental illness become marginalized. Social causation posits that the incidence of mental illness is higher among already-marginalized individuals; social drift posits that individuals who experience a mental illness will experience, through accumulated burdens incurred because of the illness, a down-shift in social status. I extend discourse about these theories by discussing two mechanisms suggested in my data which described how barriers to care become interactional: access cycles or becoming "stuck" in stability or within the mental health care system.

Access cycling describes the process by which mental health consumers experience repeated processes of progress and regression, stability and instability, treatment access and lack of access. The manifestation of access cycles as moving through an "institutional circuit" of jails, hospitals, shelters, or homelessness is well-known (Myers 2015). My data

suggests that cycling can occur for mental health consumers at other paces of time, across

multiple levels of functioning or stability, and in response to experiencing concurrent

barriers to care. For example, a clinician at Wellspring's CSU told me about a female

patient who was on a fixed income; until her mother's recent death, the woman and her

mother had lived together, where the woman acted as her mother's caretaker. Struggling

with her own mental health, the woman's mother was a hoarder and the house was infested

with bedbugs. The mother died, and the woman continued to live in the house along with

the infestation and all her mother's belongings. The clinician said:

> "She had been admitted to a hospital, stepped down to us, was with us for about a week. That's where I think a case management aspect to the CSU would have been helpful, because from a clinician standpoint we were like, we can't do much of anything, but having someone that can help her identify an exterminator that helps clean and will do payments [would help]. And we tried! So she left, she discharged, and then called again the next day in crisis again because she was overwhelmed: because we had treated the symptoms, we had treated the depression and the suicidal thoughts and all of that. She had gotten sleep because she can't sleep at home, she has bed bugs! But then we release her back to the same stressor."

In another example, Paul described to me the access cycles he experienced with treatment,

insurance, and recovery:

> "[M]y mental health isn't super thriving. I can operate on a certain level. It's not the level I can make the most money at, my attention is real spotty. The other day I lost an hour, don't know where it went. [...], so there's that whole function. In my experience, it's been: I'm at zero functioning level, I have no money, I've lost a job, I've got another hit on my credit report that I just really don't care about anymore, uhm, and I qualified for all these free services. This is getting ready to happen to me again, by the way, within this calendar year—by the end of this calendar year. Back taxes and all that kind of stuff. So, at some point, they're going to check my financials and they are a lot better than when I started because I am getting treatment and I'm able to maintain more ADLs, so, they're going to insist I pay for my own. [...] So, I was kicked out of the system because there's now some 10-99s out there saying that I'm making some money, but I can't afford it

on my own, and so I start just slowly backing out of the system, eventually losing my job, getting evicted, more dings on my credit rating, yada, yada, so then I'm back in the place where I check in. It's a big cycle."

Examining these cycles against the goals of recovery philosophy leads to further lines of questioning about how different barriers to care may carry different weight and where effective mental health interventions lie. Mills warns researchers to carefully examine the claims of social drift and social causation as they relate to poverty-mental illness cycles to avoid reifying over-diagnosis of poor individuals through misidentifying stress as a mental illness (Mills 2015: 214) Keeping with her criticism, I focus on the "multidimensional" aspects of such stressors as poverty, in how barriers to care are mobile and shifting. Theories about the mechanisms behind the social patterning of mental illness (social defeat, social causation, and social drift) highlight outcomes from processes of recursivity and accumulated burdens, where barriers to care become interactional and create multidimensional stressors for individuals living with mental illness.

Evans and Repper describe recursivity in the process of social exclusion, by which stigma and stereotypes of mentally ill individuals prevent their success in the labor force, perpetuating stigma of mentally ill individuals being unfit for work (these are accumulating burdens). Through this stigma mentally ill individuals are prevented from achieving what, in the current era of mental health reform, is the foundation of social participation and the ideal of "recovery"—that is, achieving "a positive community presence and a valued status within society" (Evans and Repper 2000: 15). Recovery philosophy calls for stability in the context of an individual's life, with treatment—while contentious—being focused on individual's self-actualization. Criticisms of recovery-philosophy examine its inconsistent

application across CMHCOs in the United States and as a treatment model remains in flux (Myers 2010; Stein 2011). Recovery-philosophy may become becomes tied into neoliberal citizenship politics, asserting sets of behaviors and goals mirroring ideal social participation as individualized, responsibilized, and entrepreneurial actors (Nelson 2005; Myers 2015). As such, a situation like Paul's, in theory, should include a continued upward trajectory as he gains pieces of stability—not a back-cycle into active symptoms or a self-destructive crisis of mental health. Like Paul's experience of being unable to escape these access cycles, care-seeker Kate described how they experienced the mental health care system as inescapable. Kate described how, in the past, they had been ejected from are systems for recurrently missing appointments:

> Kate: And then it was just like, how do I...how do I get care? If you're poor, you have no path to it and you really have to aggressively pursue care in order to get it. And if you're psychotic or you're experiencing psychosis or you're hearing voices or you're in an altered state of being which is how we're supposed to talk about it..."

> LV: You're not going to be able to aggressively seek care.

> Kate: You can't, you can't, you don't have your shit together barely enough to even do anything so all the hoops you need to jump through in order to access care, especially like, I have a friend who's on public assistance, she's; a crazy person, she's poor, she's on a fixed income, she gets SSI. She has no vehicle. And everything that she needs is far away, it's like, when you are going to see somebody who is basically a useless therapist and in order to do that it's going to take you two hours to get there, two hours to get home, and then in between you've got somebody who doesn't respect you and doesn't listen to you, what's the fucking point? Just tell me what the point is.

> LV: No point?

> Kate: You're jumping through hoops to keep maintaining this public assistance, but honestly like, this mental illness is holding me back because if I actually were able to procure some kind of employment that would pay me even forty-thousand dollars a year, twenty-thousand dollars a year

would go to care. I would be in exactly the same position I'm in now, working a job that I can't handle because I'm insane and I honestly can't work forty hours a week—I can't fucking do it. I can't. I'm an artist and I'm a crazy person, I cobble together my living from various sources but if I were to somehow start earning money, I would be even more fucked than I am now, so it's built into the system that I can't succeed, because I can't receive any care then.

During an interview with a program director at one CMHCO, I asked about access cycling in relation to the expected linear trajectory of recovery, using Paul's (anonymous) anecdote. They replied:

"It's exactly that. We don't have the parameters in place. That's our assumption, that once they're fully functioning that they'll be able to get insurance through their employers but insurance is horrifying. It's very expensive. And that does happen. It's hard because we can't afford to have people live on disability their whole life, but they wind up on disability their whole life for that exact reason […]."

Re-integration into the community and independence from social services is encapsulated in recovery ideals (SAMSHA 2012; Novella 2010). A peer support specialist said to me, of forming new natural supports: "they need community supports, they need good support groups […] just to be able to identify those non-paid supports so that they don't have to rely on service providers all the time; they can rely on churches or the community or organizations and people out there, and to be a safety net." The ideals of recovery can also be empowering; individuals living with a mental illness can survive and thrive in the process of their treatment and, indeed, achieve recovery (Myers 2016). However, the complexity of individual experiences identified within my research warrants further investigation into the ways that recovery, as a process, is interrupted by encountering barriers to care. Further, it is critical to acknowledge the ways in which disjointedness among multi-level systems to treat, evaluate, and support individuals can result in instances

where individuals become stuck in these systems, unable to move forward because of consistent barriers to care creating disruption, and often living with the daily precariousness of their circumstances. The peer support specialist, Russel, told me:

> Russel: I know a lot of people that deal with mental illness also and right now they're stuck in stability because they're on their meds, they have a place to live, and they're on disability and that's it. And they don't...they're not seeing yet that there's more to that. [O]ne time, I wanted to go on disability and my therapist actually talked me out of it because she said she felt it would handicap me, and I can see what she meant by it, because I knew people who were on it and they wanted to do things, but they were afraid to because—well, if I make this leap, I'm going to lose my disability. And fortunately, those people actually flew when they were off of it, so—
>
> LV: [paraphrased] Something I've been thinking about, it seems like once you do have some type of benefit, that it will keep you stuck.
>
> Russel: In my own recovery, a big thing I had to learn was to start taking more risks, branching out of my comfort zone and I think for a lot of individuals who are on disability, they feel like they cannot take risks because if their risk fails, they can lose all that they have. A lot of them depend on disability, so it's not like they—if I earn a couple of dollars too much, I could lose my disability and then lose everything.

In Russel's description, he addresses an important idea: for some, risk-taking is simply riskier. This specific interpretation of stagnation associated with disability recalls Myer's argument about the governing technology of care paradigms such as the recovery model. In her ethnographic work at the CMHCO Horizons, Myers describes how mental health care consumers become the subjects of CMHC systems; they experience a "re-institutionalization" because they are entangled within the many subjectivities of ideal patient-hood, in which their efforts at developing moral agency are ironically constrained within an organization—or within care landscapes—that espouses to promote such a process (Myers 2015). However, participation in these services is contingent on an individual—here, as a consumer of care services—learning how to navigate the internal

cultures and logics of multiple institutions; inclusion is contingent on consumers agreeing to certain modes of treatment, to regulations, to rules of how to properly engage with these entangled systems. Russel is describing that individual's full potential is constrained by the fear of risk of losing eligibility for these services which they rely on to avoid precarity.

However, being "stuck" is not only iterated as "stuck in stability," in which individuals stagnate against an encouraged, forward-moving recovery process. Care-providers often described that their work's purpose was to help their patients develop the resources necessary to break out of vicious cycles—whether of behaviors, of institutional circuits, of gaps in insurance. Then narratives of care-seekers included frequent discussion about how individuals actively responded to either their own poor mental health or barriers to care. My data suggests that individuals both as care-providers and care-seekers are very much actively making decisions about how to navigate barriers to care. However mobile these individuals are in terms of moving through a care landscape, experiencing vicious cycles, progressing and backsliding in treatment, responding to recurrent crises of mental health or life events in a non-linear experiential process, these mobilities still exist on a plane of structural marginalization which is worth asking questions about, in the vein of Mill's reinterpretation of the health-poverty nexus and Luhrmann's concept of social defeat which asks us to look at how social interactions and relationships of different types produce disempowerment. Care-providers, as elaborated earlier in this chapter, noted that they observed marked differences in the ability of people to effectively take advantage of care if they experienced fewer challenges overall.

Barriers to care become recursive and accumulative, iterated within complex social systems which inflict social defeat through everyday interactions between these systems

and mental health consumers. Descriptions of how barriers became interactional did indicate "social defeat," in which care seekers are buffeted by accumulated barriers to care, emergent consequences of active symptoms, stigma, and extant social marginalization. Environmental barriers featured across care-providers' interviews disproportionately to other barriers, other than navigating systems or bad experiences; it is still worthwhile to examine how these stressors act as a persistent barrier to care, where the stress of poverty or structural inequality very much becomes a stressor that can worsen symptoms or prevent illness from being treated.

In her work, Luhrmann emphasizes that schizophrenia is a "chronic, long-term experience" (Luhrmann 2007: 143). She also argues not only for the social origin of high mental illness incident among socially marginalized populations, but a social cause for the severity of the illness. In conceptualizing the mechanization of disempowerment, marginalization, and stress, the ways in which mental illness can create accumulated burdens in the lives of those who live with it is important. My point is not to reiterate old ideas about psychiatric disorders which frame them as incurable and those who live with them to be tragic. Luhrmann writes that the paradigm about such diseases as schizophrenia used to claim that they were permanent states of being, and that a person could never recover; further, that a person who was diagnosed with a mental illness could expect to live a life of social, never able to win the struggle with their disorder. My data, as well as the data that others have collected, does indicate that chronic illness is circular—an oroborous of social origins and social effects. In this, disease incidence is higher in marginalized populations and the burden of disease is heavier for these individuals, which can create circumstances where individuals who are ill are stuck at the center of multiple stressors,

each recursive with each other, or even that actions taken during acute episodes of illness can carry long lasting or permanent social exclusion, destabilization, or social decline , from the perspective that individuals' agency becomes limited while experiencing barriers to care (Manderson 2016). Their agency may become even more limited when encountering layered stigmas of criminal records, gaps in employment, homelessness, or public episodes. Further, interpretation must address that types of barriers to care access that a CMHCO patient may experience are directly related to the echelon of society they occupy, their class, their gender, their race and ethnicity, and their national background.

As Luhrmann succinctly argues: "This is not, it should be said, the care that our health system in some sense 'intends' to deliver" (Luhrmann 2007: 147). The efforts of individual staff members of CMHCOs and ways CMHCOs design their programs and policies overall are a fine balance between what is defined as best practiced, evidence-based practices, the structural constraints of funding or legislation, and the needs of mental health consumers. CMHCO infrastructure in Louisville was widely regarded by both providers and patients as helpful, and my data also carries countless examples of care providers who go above and beyond on behalf of their clients, which I explore in Chapter Three. Care-seeking interviewees, even when describing their current struggles, were all individuals making plans for their own recovery and were participating in treatment through CMHCOs in a cooperative effort towards preventing future crises. However, ongoing research, including self-reflective research produced by institutions, and more recent work turning a critical eye on the current mental health care era must question the capability of care landscapes to capacitate the populations they serve. The social and economic mobility of mental health patients—either in down shifts or cycles—do not line

up with the assumption of recovery philosophies of care which call for patients to become independent and able to live in stability in their communities. Rather, my data warrants further investigation of how barriers to care become interactional to produce circumstances in which individuals may become chronic users of CMHCO systems or other social services.

CHAPTER III:

AGENCY AND CARE ASSEMBLAGES

In Chapter Two, I outlined important aspects of barriers to care and how they become interactional. The patterns which emerged were ones in which the everyday lives of individuals living with mental illness were made precarious by the recursive nature of social and structural environments in which they experienced their illness (environmental barriers), compounded by Individual and Institutional barriers. I argued that barriers to accessing, maintaining and providing care create situations in which the trajectory of developing stability was disrupted. In some cases, individuals accumulated social burdens which perpetuated their marginalization; in other cases, individuals were caught in vicious cycles. I move into Chapter Three by carrying forward the lived experience of precariousness, time, waiting, barriers to both receiving and providing care, and how individuals respond to them.

I begin by describing the strategies of mental health consumers' care assemblages. I identify how strategies are formed in response to changing contexts of care access/barriers, knowledge or understanding of their own experience, personal motivations and values. In examining how care-seekers develop strategies and make choices about utilizing available resources for mental health, I raise questions about the practice and definition of "recovery," stability mental health in conflict with the recovery philosophy

and expected trajectories of progress in treatment. Then, I examine how care-providers develop strategies to meet the needs of their clients. I argue that individual care-providers are called on to reconcile multiple institutional logics, and cohere elements of a broad care landscape, making these elements work together where otherwise they would not. I interpret these actions, also, as the production of care assemblages.

Assemblages, Recovery and the Experience of Precarity

As I have stated before, CMHC in the United States shaped by the "recovery philosophy" mental health era, implemented during the Second Bush Era, in 2003 (Myers 2010). Although I did not explicitly inquire about the nature of recovery philosophy in interviews, care providers often articulated its values in delivering treatment and the expectations they had for their clients. However, the recovery model itself remains contentious. Scholars point out that its implementation is inconsistent from place to place, and the specific ways that the goals of recovery are to be carried out are not unified (Myers 2010; Kraus and Stein 2012, Stein et al 2014).

Warner explains that recovery model of mental health care is an artifact of the 1960s and 1970s consumer-lead mental health reform movement, which called for "empowerment, collaboration, and a recognition of human rights," in mental health treatment as paths towards patient-lead recovery (2009: 1). However, Warner also notes that there are conflicts between patient-lead and clinical perspectives on effective pathways to recovery, what recovery entails, and if it is possible with or without certain kinds of treatment (2009). Indeed, differences in perspectives on recovery—how to measure it, what it means, and how to achieve it—between mental health consumers and providers have

been explored in the literature (Warner 2009). This becomes an important and perhaps troubling area of analysis, given feelings of coercion and control acting as barriers to care in institutional settings, as I described in Chapter Two. Further, the concept of recovery has been mobilized in public health literature as a description of functional stability representative of ideal citizenship and social participation (Myers 2010; Henwood 2011). Scholars have interpreted this emphasis on recovery as being a modality of neoliberal governance in public health, which is then translated through mental health care organizations (Myers 2010; Henwood et al 2011).

In this context, the trajectory of recovery assumes that as a patient works through their treatment, they achieve moral agency and behave according to models of ideal social participation, they will be able to disconnect themselves from assistance programs, disability, or Medicaid (Novella 2010; Myers 2010). This is one way that notions of neoliberal citizenship are proposed to be transmitted through care systems, in line with larger public health trends of self-care and self-management of disease enmeshed with ideals of individual responsibilitization (Novella 2010; Henwood et al 2011; Fletcher 2018).

In practice, the question of "recovery" is a question of empowerment, disempowerment, and how individual agency is structured in the context of care systems and barriers to care access, conflicts of knowledge, expertise, and experience, tensions between experiential, lay, and biomedical definitions of recovery. In this contentious landscape are care assemblages and the types of strategies individuals develop to maintain mental health.

The role of the individual in structuring care between disparate resources was

common throughout my data, between both care-seekers and care-providers. Lauren, a clinician, explained that care-providers at her organization undertook formal and informal measures to meet their client's needs: care-providers would ensure that their clients got connected with resources for, as she specified, transportation (whether with a bus pass or offering their own transportation) and food assistance services. At all three CMHCOs—Centerstone, Wellspring, and Bridgehaven, care-providers described instances where their colleagues undertook detailed, personal tasks to help their clients. One clinician picked up a patient in her own car on the way to work; another employee watched a patient's child while the patient was in a therapy appointment, going so far as to buy the child lunch. These are intimate, individual caring acts carried out by care-providers to facilitate recovery for their clients. Though informal and mundane, they point to a larger effort to facilitate care by removing or alleviating barriers. To do this, care-providers stitched together strategies—including informal assistance—to assist clients in negotiating the complex logics of the institutions they worked for. Therein was a careful, but creative, balancing act. However, Lauren succinctly pointed out:

> "I mean, that doesn't help the systemic problem that people have with transportation and food, but at least individually, case by case, we're making sure that those clients don't have those barriers."

Throughout her interview, Lauren recalled the political economy and social context within which patients made health-seeking decisions. Where mental health recovery and stability tied into broader social stability, the types of choices that many individuals make are constrained, as Lauren said, by these barriers to care.

Novella argues that the linear-directional ideal of recovery—as a "passage" through the mental health care system—and the ability of individuals to receive mental health care

while maintaining their functional lives may not accurately reflect the reality of individuals who are chronically ill (Novella 2010). Recovery, conceptually, does not meet the challenge of chronicity, where chronicity meets other forms of social disempowerment (environmental barriers to care) and where the mental illness itself is debilitating (for example, for individuals who become chronically homeless) (Novella 2010). The system simply works much better, Novella argues, for individuals who can remain functionally stable while interacting with it (Novella 2010). As such, the question of who is able to "recover" in this complex are landscapes, fraught with multiple levels of barriers to care, pervades.

> I met with Harry, a peer counselor, who described his own process of recovery:

> "I had a lot of treatment, I had a lot of interventions, I had a good therapist, I tried! You know? And when something didn't work, I tried harder, and that's what I preach that to them. I say, you know what guys, I know what it's like to work at something and have it not work and say, you know what? Screw it. I'm not going to try anymore. I did that. And then I went in the hospital again and without a job and no friends and hadn't did anything meaningful for years and years and years. And then I realized that, yeah, I had bad treatment at a certain point. I had medicines that put me in the hospital—first generation anti psychotics are awful," he chuckled, "If you've ever...they are beyond awful. Haldol and Risperdal both put me in the hospital. I've been on over twenty [medicines]. So, I understand wanting to blame the system. I did for a number of years."

Harry had arrived at our meeting directly from a speaking event he had done, as a peer, on behalf of his employer. As I quickly learned through our several-hour meeting, Harry's soft-spoken countenance and sharp intelligence loan themselves to what seems like an endless stream of work. Before and during the interview, we were continually interrupt by other staff calling on him with updates, questions, and requests about daily tasks. Harry said, rightly, "I stay busy as Hell." He drained a large thermos of coffee as we talked,

explaining that he had been sleeping badly all week and had taken on overtime hours. Multiple times, he repeated the sentiment that he was beginning to feel spent and that in the past assuming so much stress would have triggered troubling symptoms. But, in recovery, he said that he had since learned to recognize and wisely stretch his own limits, planning and making time for self-care. He said that he had almost asked to reschedule our interview, but he knew that he could muster his remaining psychological and emotional energy to do it, because in his recovery he had dedicated himself to developing insight and self-learning based on his own illness experience. This undertaking was the result of shifting from an external to an internal locus of control. He explained that, at the speaking engagement, he encountered the trainer who had administered his peer certification:

> "[S]he said—when I first went through the training—she said, you were so angry. She said, when you told your story about the medical establishment it was very much a finger pointing. This doctor screwed me over, this doctor screwed me over, this insurance company screwed me over, and she said, you hit on all those same points today. She said, I was listening very closely to see how you related and emphasized the same information and she said, you hit the same points but you did it in a totally different way, there was more of an emphasis on self-responsibility and not finger pointing. And while I had shitty—bad doctors, bad treatment, I still had a responsibility to say, okay, you still want things in life. How are you going to get them? You can't sit back and blame everybody else for the hole that you're in. They may have had some part but they're not going to pull you out and there's a lot of maturity in saying, yeah, the situation I'm dealing with is not my fault but it is my responsibility to pull myself out of it and it's the hardest thing to—when you ask somebody and say, how did you do it? Somebody who's in the middle of two steps forward, three steps back--sometimes it's hard to say, you just gotta keep trying when they say I'm tapped out of trying. Sometimes I have to be a cheerleader and say, just one more day. Just one more day. Just keep trying one more day."

However, Harry also explained that he found his own process of recovery mystifying in some ways; he was unable to identify what differences lay between individuals who had achieved recovery and those who struggled, time after time, to do so—living out

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experiences of taking two steps forward, then three steps back. Even across the scholarly literature on this topic, this process of recovery is mired in complexities. There is much to be said for the importance of the length of time a person may spend in circumstances which perpetrate trauma or prevent an individual from moving away from the daily stress of environmental or individual barriers to care. An approach to interpreting barriers to care as interactional and perpetuating the precariousness of already precarious lives is one key to the question of why recovery is achievable for some, and why others struggle to reach or maintain it. I argue that to answer this question, it's imperative to observe modes of empowerment, disempowerment, and limitations and facilitators of agency within care assemblages, which generate the types of strategies individuals can develop to manage their own mental health.

In assemblage theory, questions of social power are cut in more nuanced ways. For example, Chenhall and Senior explain how employment and education are expected to be correlates of health outcomes: a lack of employment and education are associated with worse outcomes, while employment and higher levels of education are associated with better outcomes (2017). However, in their research in Ngukurr, an Aboriginal village, they observed more complex structures of social capital, social status, and social relationships at play. Women who achieved higher levels of education outside of the village gained opportunities to find employment; however, women who chose to pursue vocations often did so by sacrificing opportunities for marriage, child birth, and raising families. In capitalistic, neoliberal Western contexts, higher levels of education, employment, and financial earning are expected to confer social protection, capital, and positive health outcomes. However, in Ngukurr, women who were well-educated and employed

experienced a loss of social capital and status which they otherwise would gain by participating in traditional gender roles: marriage, child rearing, and family life (Chenhall and Senior 2017; 192). As such, Chenhall and Senior argue for a more nuanced examination of how health outcomes and choices related to health intersect with processes of empowerment and disempowerment.

I argue that among care-seekers, strategies for maintaining mental health and stability are negotiations between the experience of social defeat and disempowerment and the development of agency within the confines of intersectional barriers to care. This is not to say that recovery is a force of will; again, the realities and persistent, severe stress of marginalization and structural inequalities still constitutes very real circumstances where individuals are stuck, yet unstable, within care systems. A social context framework using assemblage theory still very much embraces the precariousness of marginalization. However, care assemblages form in response to uncertainty and precariousness, and perhaps more closely examining the strategies that individuals draw on to maintain their mental health can offer important insight into what must be addressed socially to allow individuals struggling to find stability and opportunity. So, the discussion turns back towards stability—and precariousness.

Precarity as a working concept has developed across social theory to describe the state of uncertainty and anxiety created by neoliberalism and expressed especially through the everyday lives of the "proletariat," enmeshed in social hierarchies in which they are at the whim of labor, capital, and "wage relation" (Neilsen 2015: 188). Neilsen's argument extends to a global scope, including in it an analysis of transforming neoliberal projects from the 1980s on, encompassing large-scale environmental changes, technological and

industrial shifts, and their influence on the everyday precarity that individuals face in our world. He describes it as a sort of pervasive mental unwellness and anxiety in the current era, "intensified by the reality of deepening social and material precarity" (Neilsen 2015).

I argue that this trend of precarity is also the foundational characteristic of how mental health care consumers live when interacting with their own social/environmental contexts, and within the entangled institutions dedicated to delivering their care across multiple arenas of life. Working from this definition presents a workable view of how barriers to care access create precarity for individuals who are living with mental illness, its incidence and severity social in origin. Precarity exists at every point of institutional contact for both care providers and care seekers, all of whom are instructed to act out different but complementary types of "work" towards the concept of recovery, itself (in practice) a mutable category of desires, directions, and contestations. Myers, in her work, makes several notes about how it would be foolish to discount recovery as a philosophy calling on respect, dignity, and agency in mental health, as an untenable concept; in fact, like all concepts, it is merely contentious (Myers 2015). And, indeed, individuals embodied and enacted their agency to safeguard against precarity. Care-seeker and care-provider responses to precarity took on intentional, creative, experimental, and experiential forms where individuals living with mental illness drew on formal and informal strategies to seek stability. In this way, they create care assemblages based on their position within or without care-systems. When care access shifts continually over time, the strategies developed to respond and maintain stability also change—these constitute new, reformed assemblages, adapted to new situations. These responses are diverse and individual while reflecting commonalities of experience. In them, one can observe differences between "choice" as an

objectively rational decision, and "choice" made under the limitations of active symptoms or social disempowerment and a lack of resources (Henwood et al 2011: 2027). Care assemblages, then allow us to examine different types of power structures and social relationships (Chenhall and Senior 2017).

Agency, Person-hood, and Patient-hood: Care-Seekers' Strategies

This section examines the illness experience itself throughout a mental health consumer's life, and how individuals develop strategic methods to maintain mental wellness through periods of fraught care access. Care-seekers described multiple tactics to safeguard themselves from the deleterious effects of a mental health crisis. In their efforts, care-seekers demonstrated creative strategies to manage their own mental health across levels of system engagement, from directly working within mental health care systems strategically to access desired care, or through informal or illicit means of maintaining wellness outside of formal care. Care-seekers relied on experimentation, drawing on experiential knowledge of their own symptoms and behaviors as well as their learned knowledge of mental health care systems and formal interventions, forming assemblages of tactics to maintain a sense of wellness or agency.

Individuals living with mental illness are dynamic social actors, not passive or docile recipients of care, even while acutely symptomatic. In care-seeker Afina's recollection of her manic episodes, she describes a reasoning process in which she engaged critically with her mania, responding to her delusions by making reasoned choices in the context of that reality. Person-hood does not disappear under the pressure of an active episode. Most recently, Afina was arrested during a manic episode while she was with her

daughter in a semi-private building in the middle of the night. She explained to me that throughout the episode her actions were informed by past incidents with police, when her daughter had been taken from her, which she wanted to avoid:

> "It was like, I was afraid to talk to her because my illness was convincing me that I had lost her from the previous major episode, two years back, and that my guilt basically brought her ghost to me and I still hadn't gotten past that. So, I thought it was like a test. So, if I acknowledged her to [the police], that then they would still have to be in my life and do whatever, so I was afraid. [...] So, the entire video and everything, other than that, when [the police] were about to take me out, I didn't want to risk anything happening to her despite the fact that my episode had like conflicting realities."

Both Afina and another care-seeker, Kate explained that they desired treatment which recognized that active symptoms did not remove their person-hood, while it still did alter their agency (Kate specifically mentioned that being asked to sign consent forms while experiencing psychosis was a baffling practice, because people in that state, "can't fucking read!"). Interviewees who were mentally ill expressed a desire to be treated with a respect for their agency even while symptomatic; this is reflected in ethnographic work about autobiographical power and patient control of narratives as a major component of recovery from mental illness (Myers and Ziv 2016). Among all four care-seekers, control and interpretation of their own narrative and illness experience were highly valued; Afina contended the account of her arrest which was put forth in the charges against her and in the news coverage about her. Kate similarly claimed autobiographical power while speaking out about their negative experiences while institutionalized or in jail, or in their treatment by doctors, nurses, and police officers. Throughout this chapter are examples of ways care-seekers enacted agency in the face of precarity has been translated into self-advocacy. Autobiographical power, which I also parse in terms of self-learning and

questions of self-identity, is exhibited in each instance, perhaps providing insight into the extent of "choice" in health-seeking behaviors even as they are limited by social determinants of health or other barriers to care.

Afina's situation is a clear example of the far-reaching damages that mental illness can affect in an individual's life or throughout their social network. However, her own insight into her psychosis exemplifies that an individual's person-hood is not subsumed by a mental illness. The concept of autobiographical power is important for understanding the ways in which care-seekers grapple with their own agency in disempowering situations including experiencing barriers to care and develop strategies to manage their mental health. Similarly, care-seekers described the importance of becoming reflexive and self-aware about how one's illness worked, what warning signs to look for, and what intervention techniques worked best. If that intervention included entering formal care, these strategies included developing system literacy.

When interviewees could remember the contents and events of an episode of acute mental illness, the experiences offered important insight into paths to chart towards prevention in the future. The nature of mental health recovery as non-linear was a commonality between both sets of interviewees, while interviewees who divulged that they lived with a mental illness described an experiential process of self-learning, where repeated mental health crises and interactions with care systems lead to the development of "tactics," or strategies, concepts I derive from Guell, who adapts them from de Certeau, to describe the ways in which mentally ill individuals experiencing low access to care create assemblages of techniques in their daily lives to maintain functional stability (Guell 2010). This process does mirror the practices in place in community health, wherein

progress is accepted to be rife with mistakes, setbacks, challenges, even bad luck, towards developing "moral agency" (Myers 2015).

In Guell's ethnographic work, diabetic Turkish immigrants living in Germany are functionally excluded from formal care systems. Guell explains that within formal care systems, individuals living with diabetes receive treatment focused on self-care through "non-clinical" behavioral changes: self-monitoring and self-control of diet and lifestyle changes to manage illness (2010: 519). Conversely, Turkish immigrants receive medication "with little ambition to educate patients toward "expert" self-care and lifestyle intervention," which reflects their wholesale exclusion from care systems (Guell 2010). Instead, Guell argues that disease in this population is regarded as unmanageable by care-providers themselves, and who then must "give" care in lieu of promoting more agentive self-management (2010). However, self-care is necessitated and enacted by Turkish immigrants, even as they are excluded from these care systems. Guell argues that "self-care is driven by the diabetic body, tangibly felt in failing kidneys, blurred vision, or numb feet," rather than through the expectations of health and body politic writ in behaviors regarded as ethical or moral self-care (2010: 520). These immediate needs became the basis for seeking "creative" solutions to make everyday life "habitable" (2010: 520). Similarly, care-seekers whom I interviewed explained drawing on assemblages of self-care and formal care when they experienced low or no access to treatment, not out of a motivation to properly participate in ethical or moral subjectivities, but to avoid the tangible and often consequential or unpleasant experience of mental illness.

Unlike the participants of Guell's ethnography, however, individuals living with mental illness in this research context are not permanently excluded. More commonly,

mental health consumers in Louisville described punctuated contact, in which access might ebb and flow in accordance with multiple forces (see Chapter Two). Therefore, it would be inaccurate to interpret the illness experienced as completely divorced from the internal cultures of CMHCOs or broader social interpretations of mental illness, such as family and community, or cultures of stigma. It is the case that care-seekers draw on knowledge from sources both informal (personal experience, social experience) and formal (institutions, biomedical paradigms, and evidence-based psychiatric techniques) to create strategies for navigating care systems or maintaining mental health when care access becomes difficult. Like the participants of Guell's work, they relied on creative tools, assembled from system contact and personal experiences with their own mental illness.

In each interview, I asked care-seekers what they did to maintain their mental health during gaps in treatment or when they lost access. I also explicitly inquired about the techniques individuals used to self-manage their mental illness and where they learned them. What they described were often assemblages of care strategies, drawing upon the concept in the same manner which Chenhall and Senior parse assemblages, as contextual relationships between "peoples, objects, and larger structures formulated by governments and other organizations" (Chenhall and Senior 2018). The everyday strategies of mentally ill individuals to maintain stability and functioning range from illicit, informal means in everyday life to strategic maneuvering within care systems, to learning about different types of formal care strategies and choosing preferences. For example, care-seeker R described to me in detail that they had tried various forms of talk therapy such as CBT, DBT, and psychoanalysis, and included reading the work of theorists involved with the creation of those therapies to best understand and choose the most effective types.

Conversely, Paul, specifically, told me that he rationed medication and, in the past, had

used illicit substances, while he knew of acquaintances who would access psychiatric drugs

illicitly when they lost access to care:

> "[F]or the people that get kicked out, because they've missed one day and then getting back, that seems like the hugest thing and then shame and you have to explain—whoa! And so, they just stay out of the system, and they still self-medicate. Most of the ones, I think, just tend to find…if they have anxiety, you know, start some weed—they're going to medicate. They're going to find something that makes them feel not mentally ill. That's why you have mental health and addiction being so concurrent is, you know, self-medication. So, when you can't find a pharmacy—I mean, we live in a pharmacy, there's drugs everywhere—you'll use alcohol or what we call legal drugs, there is a black market for—I know ADD people try to score Ritalin, I know people try to score antidepressants, I know people who try to score anti-anxiety medicine. Honestly, I'm having a really bad day cleaning this room—maybe a little whatever will get me in the groove, but it would make me shake and I was like, no, that's okay. So, I stopped that. Then, the people who know they're going to be kicked out of the system for whatever reason, you start—like—"

He grabbed two pill bottles off the dresser and shook them at me.

> "I take this medicine every day, I need it. This [other] medicine, to keep me from the raging side effects of it. Now, [the first] medicine is supposed to expire; but I still have [the other medicine], because I take less of it than I need. But then you start getting to the point that you're kicked off of services, you start hoarding old medicine. And—some people know, as you get closer, what to do. You find a routine, find an outlet, find a friend, you know? But a lot of times it's just like—tick, tick, tick, tick, tick, tick, tick tick: here we go! And it's like, how long is that trip up the roller coaster going to last?"

On the "roller coaster," as it were, everyday life became balanced with mental illness—

how far could one be stretched before breaking? How much stress was it possible to

assume? How long could decompensation be held off? Work was an especially tricky

space to navigate. Paul has held employment of vastly different types, from well-paid

advertising to low-income positions to make ends meet. He told me that contracting and

freelance work are often good fits for people with symptoms like his, where stints of poor

mental health and subsequent avoidance of or inability to work are better disguised in self-

set deadlines and flexible schedules:

> "I'm lucky that I'm a very physically fit mentally ill person. I don't use a lot
> of sick days. I don't get sick a lot. So, I have learned a really nice food
> poisoning is good; I've learned a nice array of illnesses I can use to call into
> work for a sick day that doesn't track. I don't use my sick days generally,
> until I get really depressed."

Competitive employment is a frequent subject of mental health research, especially in

analysis of the laboring person as embodying citizenship and recovery ideals. The ability

to engage in competitive employment is a cultural signifier of social success and potentially

offers some practical means to independence from social services (Nordt et al 2007). Being

gainfully employed is associated with higher self-efficacy for individuals living with

mental illness and is a component of how recovery has conceptually been interpreted

through public health initiatives (Nordt et al 2007). However, chronic illness can impact a

person's ability to maintain employment (Nordt et al 2007). Especially for Paul, who often

described that working at higher income levels which made him ineligible for Medicaid

oftentimes kept him from accessing care because of the out of pocket cost of copays or

mental health treatment, managing his mental health relied on carefully using sick days.

Recalling Paul's experience with access cycles from the previous chapter, repeated courses

through these access cycle, while representative of the recursive nature of barrier to care,

did result in patients becoming actively engaged with developing strategies to avoid these

destructive cycles in the future. "The roller coaster" became a thing to be avoided; barriers

to care became things to be navigated and alleviated as they arose. This took places across

levels—experimentation, strategizing and developing tactics occurred at individual,

institutional, end environmental levels. These suggestions from my limited data with care-seekers nonetheless resemble conclusions across broader ethnographic work about care-access. These narratives describe the methods utilized by care-seekers I interviewed to construct individualized care assemblages; just like experiencing barriers to care access which may interact in any number of ways, intersecting at the individual, so do their strategies to alleviate those barriers and maintain their mental health become highly individualized. As such, these narratives are not suggesting that these are modes of coping typical to call CMHCO clients but may be representative of some creative and agentive strategies that are framed by wider neoliberal medical institutions.

Navigating Systems and Self: Experiential Self-Learning and Its Role in Recovery

Checking into the hospital has never been a good experience for Paul. During his interview, he often spoke of how going to the hospital for emergency psychiatric services for the first time was a frightening and troubling experience:

> "[I]magine […] this is your first time in a crisis, you don't have a lot of family supports, you've been on that slow burn...you've faded away from friends, you've kind of drained your bank account, now you've been unemployed for maybe two or three weeks, you're getting ready to get evicted, you know that's gonna happen, and you really want to kill yourself. You just feel it pound in your head. So, you do a quick Google search: [CMHCO] comes up, and all you know is to maybe go there and you walk into that room. Even before the locked door[14], drop in hours are this and this, and you gotta sign this and do that, you know. There isn't a thing where it's like, sit down, here's a cup of coffee, what the hell's going on? There is jail and the emergency rooms. That is what emergency psychiatric medicine is in the United States. That's it! And we wonder why people don't like to go to the emergency room, because if you go to [the hospital] emergency room, you got some people that don't have access to the health care system, so they're just there for the flu and the cold, and they're just little shits. You

14   The CMHCO where Paul received care had installed an electronic door.

got other guys that, good God, just got shot in the face fifteen times.[15] And you've got a full blown, you got your normal gallery of crazies. There was one woman named Butter Woman, she had one eye and she always had a stick of butter on her, like, she would cover herself with butter and put butter in any hole, uh, yeah, and so...what does someone who's in crisis for the first time try to—you know! There is, still, for people who haven't been in it, there is that internal stigma. And so now that you've sucked it up and I'm going to go get help and I'm in that room now and I don't have the tools to go, disease is a spectrum, no—it's like, fuck! Am I this crazy? And the first time you end up in a seventy-two-hour hold waiting room, you will have that moment, like, oh, shit!"

He explained that through the course of repeated hospitalizations, however, he began to shift his self-view:

> Paul: you have to take a moment, you have to take a deep breath and go: I'm in this same room. I'm in this same line. I'm accessing services from the same place that this [more visibly symptomatic] guy is, and allow that humility to come in. Because the thing is, high functioning psychotics, generally we have a pretty strong narcissistic edge about us so it's pretty easy to believe that my psychosis is different and wonderful and the ones that afflicted Keats and Yates and Wilde and not—
>
> LV: The same crazy effects the crazies?
>
> Paul: Exactly, exactly. It's a reminder. Like, no, we're in the same room for a reason; I just have maybe a couple better tools and a better vocabulary than he does, but yeah. I'm in this room and I need to remind myself I'm in this room right now—I'm no better, nor worse, than anyone.

This represents a process of experiential self-learning which pervaded the narratives of care-seekers as well as care-providers who experienced mental illness, in which the repeated processes of active symptoms and their consequence prompted the development of new strategies to maintain stability. Multiple hospitalizations, arrests, or repeated negative outcomes of active episodes lead to both a processual re-framing of oneself in

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15 Knowing well Paul's ability to capture the dramatic, I did ask him later about the patient he called Butter Woman, wondering if it was something of a tall tale. "That one stuck with me," was his response.

relation to one's illness as well as the development of experimentation and strategizing around how to manage mental health in daily life. Navigating one's illness identity and therefore developing self-awareness, and therefore taking active measures to prevent such fallout, was described as an important component of learning what types of strategies would work. All four care-seekers described stitching together formal and informal methods of care. Paul's combined strategies of hoarding medication or managing his symptoms with illicit substance (and subsequently stopping when such methods didn't work) as well as formal strategies learned in counseling and personalized techniques like establishing sets of routines or benchmarks to monitor his own mental health, each acted as effective coping mechanisms at different points in Paul's life. These assemblages of knowledges, techniques, and tactics were drawn from different experiential points in his life as a care-seeker, which he could then utilize as his circumstances changed. As I described in the introduction, self-neglect was one of the most significant red flags for Paul to monitor his own mental health. Becoming aware of the onset of these minor behavioral or cognitive changes (or wholesale prodromal symptoms, for care-seekers who experienced psychosis) was described across interviews as a major influence in preventing a crisis, and a fundamental tactic. However, this only occurred through several episodes. Paul said, of self-learning, self-awareness, and "dealing" with mental illness as a serious problem:

> "People who are cocky don't deal with it. They go on and they blast and they run a hundred miles an hour, not realizing that they are more than likely revisiting some of their old, bad habits and then they crash again. And depending on the age they are, they're going to neither break it on some breakup or some bitch or something like that. Or, they start to get wise and realize this is a life-long disease they have to medicate and monitor and be

vigilant about, depending on how many times it takes[16]—generally two or three."

Afina expressed a similar sentiment:

> "[...][T]here was the 2014 major episode and I think that was my wakeup call to come to the realization that, here I am, I can no longer rely solely on regular coping mechanisms—methods, rather—I have to take medicine on a regular basis. So, I got one of those gigantic pill organizers and it became like, a religious thing with me. I had to constantly take my medication and I took therapy seriously and I took group seriously and things like that, and the only episode that occurred up until last year was one time before [my daughter] came home [after separation], and that was due to a medicine change."

Understanding that assemblages shift over time, changes in self-identity and the characteristics of one's own experiences are important to the process of adapting tactics and strategies to manage one's mental illness. Temporality and changing meanings of things in response to new knowledge or circumstances is a core component of assemblages (Chenhall and Senior 2017). Through repeated episodes of acute symptoms, Paul and Afina each had a realization—that they had to manage their mental health through different means—that enacted a change in strategizing. For Paul, accepting the severity of his own mental illness enacted a shift in care assemblages, where he began to include in it the viability of voluntarily checking himself into the hospital, a care resource that he initially found frightening and objectionable. For Afina, a significant experience with an acute episode lead her to orient her management of her mental illness to include new strategies, and a new assemblage of self-care. These examples also demonstrate how care assemblages are constructed in response to precariousness, where mental illness itself can generate such precariousness in an individual's life and an individual's changing mental health status itself

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16   "How many times it takes," as in how many mental health crises or how many negative consequences thereof a person experiences.

is part of a complex assemblage.

Self-Advocacy, Power, and Strategy in Care Settings

"The longer you're in mental health treatment, it teaches you not to be honest," Paul said.

"You know certain words are buzzwords that will get you...you know. If you're smart, you

know, I don't have suicidal thoughts, I have suicidal ideation.[17]" Navigating institutions

according to behaviors of compliant patient-hood became his primary method to reach

what forms of treatment he knew, from experience, to be most effective for him.

Hospitalizations were functional as well, and often indicated to Paul himself family, and

friends of the actual severity of his mental state. Hospitalization allowed Paul "to lock

myself away from knives for a while. [...] [I]t's a good indicator to yourself that you've got

to do something and it's a good way to get—if you've cycled out of the system, it's a good

way to cycle back into the system because, generally, when you leave an inpatient program

after 72 or 96 hours, you've been referred to a caseworker."

However, the hospital itself could be an uncomfortable and unsafe environment,

with intermittent and abbreviated care delivered by staff, about whom Paul was extremely

skeptical. The hospital was a necessary evil to be suffered to survive in the short term, and

then to access more effective care. To move through a hospitalization with this goal in

mind, Paul had become system literate. He described that he had learned to selectively

divulge information, using (or not using) key words or phrases he knew would result in

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17 This comment refers specifically to avoiding hospitalization. Expressing suicidal thoughts or intentions
     to a therapist activates certain measures to hospitalize a person for their own safety. Paul using
     "suicidal ideation" instead is to avoid this occurrence; he is describing lying to his therapists due to a
     fear of being hospitalized if he admits to feeling suicidal.

certain outcomes:

> "[As well as SMI/SPMI clients, you have people like] me, that are high functioning, fairly good manipulators, can read situations, and at that point when you're in a situation like that, when we're trying to get your ticket and access to like, a lot of the times when you check in, you've lost access to prescriptions and stuff like that, so I'm trying to get a script and a doctor and then I'm gonna short circuit or...I wouldn't say sabotage, but really not do a lot of work I need to do because it's my job to get release as soon as possible for my own feeling of safety."

Becoming system literate is an important component of maintaining mental health care access; this is furthered evidenced in Chapter Two, in which one of the most frequently mentioned barriers to accessing or maintaining care involved mental health consumers learning how to navigate care systems and landscapes. The way in which Paul had become system literate were based in his experiences with difficulty accessing or maintaining care in the past. Paul had been ejected from care for not having filled out paperwork correctly, for being non-compliant with treatment by missing appointments or not rescheduling appropriately, for example[18]. However, Paul expressed that he had learned to retain his position within care systems—including simply keeping appointments—by translating the internal cultures of CMHCOs into an awareness of his own "patient" role, aware of how different subjectivities or postures might influence his care. For example, the CMHCO where Paul gets care has a policy for rescheduling appointments: it must be done 24 hours before the appointment. Once, Paul didn't reschedule his appointment and simply didn't go. Later in the day, he realized that he needed to replace the battery in his car. When he went into the office, Paul had the receipt for the car battery ready and explained that he had

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18 Both Paul and Kate, receiving care at the same CMHCO, said that this CMHCO in particular had taken measures to make penalties for no-calling/no-showing less severe in the recent past, including implementing phone reminders.

missed the appointment when he realized his car battery was dead. He was not penalized

for this, he says, because he didn't often miss appointments and that his white lie still was

accepted an understandable reason to miss an appointment. However, Paul explicitly said

that he felt he possessed privilege over patients who presented in less coherent ways, had

more severe symptoms, or who might be seen as more consistently unreliable.

"I had enough mental faculties that I could play the system," Paul said, "But, people

that are going through crisis and just one day getting out of bed is too much and they realize

that—and getting on a bus with all those people and all that shit?" Paul says he feels these

individuals may not be able to manipulate the situation as he did. Staying in care systems

through navigation of the system's rules and policies became a focus of strategizing.

Another care-seeker, Kate, enacted agentive patient-hood by becoming a fierce self-

advocate. When I asked Kate what strategies they used to maintain their mental health,

they told me:

> "It's more about the ways I've learned to assert myself within the context of
> having all my power taken away—*all* my power taken away from me.
> Learning what my rights are, and then ruthlessly insisting that my rights be
> respected, like the time that I was in the hospital during the presidential
> election, when George Bush was in office and he was against Kerry, and I
> was like, I have a right to vote in this—I have a right to vote! And they were
> like, 'we can't really take care of it,' and I'm just like, 'what do you mean?
> I'm going to call the fucking *Courier-Journal*, because I have a right to
> vote.' And eventually—but it took—and then my mother—the hospital
> didn't help me do this, my mother was able to go get the ballot and do all
> the legwork and drive halfway the fuck across town and then again and then
> again and then again, to get me the paper work that I needed in order to be
> able to vote absentee because the hospital took away my right to vote."

Because of such experiences, Kate paid close attention to the power dynamic at work

between patients and providers in clinical settings. In inpatient group therapy sessions,

Kate would read the expressions of volunteers and group facilitators and listen to how they

spoke to other patients. Like Paul, being hospitalized, for Kate, was often a necessary intervention while acutely symptomatic. In these closed quarters, however, instances of coercion, control, or mistreatment resonate. Kate expressed that they had experienced good treatment in the care of attentive, respectful doctors, but that overall, they perceived the hospital as an environment where paternalistic power hierarchies were still the norm.

"[T]hey make you think that being in the hospital is the worst thing that can happen to you, and there are still abuse issues, but it's nothing like it used to be," they told me. Still, they added later: "you can't legislate nurses to believe that people who are insane are people that deserve respect. There are plenty of caregivers who give zero shits about any of the people who are around them." Where a negative experience in a care setting—and Kate described several—is regarded as a barrier to care, direct self-advocacy acts as a strategy to counter it. Many of Kate's experiences with care involved repeated instances of figurative and literal power struggles between their own illness experience and the logics of institutional mental health care. Kate described micro-political care relationships in which they were mis-gendered by long-term care-providers, in which they received unhelpful suggestions that did not meet their reality (Kate told me that a care-provider once suggested to them and they enter rehab, when Kate told them they had quit smoking marijuana and was feeling a little depressed as a result), to more direct struggles such as being put into physical restraints. They expressed that they often experienced conflict in institutional care settings because their personality was naturally at odds with behaviors expected of them. In one hospital, Kate said:

> Kate: […] [T]he doctor was like, you're taking Depakote and I was like, no, I'm not taking Depakote! I take Seroquel. And she was like, you're taking Depakote. And I was like, okay, I refuse all medication. This was

after I'd already been institutionalized six or seven times, so I knew what my rights were. Which, you get a psychotic person to sign a consent form, guess what?! They don't know what's on the consent form cause they can't fucking read.

LV: Yeah [...] I don't like the term high functioning but I don't know another way [to describe self-advocacy as Kate is describing]. So, you are obviously intelligent and have been through the system enough times to advocate for yourself...?

Kate: Which took years to figure out.

LV: And a lot of people don't know how to do that.

Kate: And they never do, and then they get over medicated to the point where it's abusive. I've seen people I was institutionalized with at Seven Counties, just sitting there, fifty or eighty pounds heavier than they were in the hospital just like— [imitates a brain-dead, babbling sound]. And it's like, this is abuse! What you're doing to these people is abuse. Like, clearly abusive. This is not normal, when this person is like, not there anymore.

In Kate's attitudes about hospitalization, care, and receiving treatment is evidence of an assemblage. In the context of a clinical inpatient setting, Kate's specific use of treatment and self-advocacy responded to the *use of control, coercion, or disempowerment* they experienced. If care-providers enacted paternalistic models of top-down care, or if they respected Kate and mutually worked with their desires, shifted Kate's willingness to participate in prescribed care. Tools and technologies like medication, different forms of therapy, and forms of control such as isolation rooms, chemical and physical restraints, were all mobile components in this assemblage. Hospitals and medication are not inherently negative in Kate's view despite bad past experiences with subjugation and mistreatment. Their interaction with these resources, however, changes as those entities are re purposed either as a modality of power (when Kate can make their own decisions about how those tools are used) or as a modality of control (when these tools are forced on them).

This is reflective of Dombroski, McKinnon, and Healy's discourse about how the "right choice" for individuals about their health may not be congruent with governing "logics of choice" in health systems at large, where decision-making occurs via care/knowledge assemblages constructed by care-seeking individuals through the changing circumstances of care (Dombroski et al 2016). Kate's self-identity and self-advocacy were developed over time, through repeated experiences with hospitalizations, including negative ones, while their overall set of strategies for coping with their mental health included self-management strategies in their everyday life as well as specific sets of strategies in different types of care-settings to maintain what they found was the most effective treatment.

Holding off a Crisis

Before she left for the Greyhound Station, Afina remembered to grab a butcher knife and a box cutter. It was a long walk late downtown from her Portland home, and it was late at night. "I wasn't about to risk someone hurting me," she explained. "Despite the fact that I was out of my frigging mind, I didn't want to take any chances." The details of that evening are fuzzy, other than getting arrested. Afina was in a manic episode and experiencing psychosis. When she got to the Greyhound Station, police came across her—and the knives. Of the arrest she said: "[B]ecause of the fact that I'm poor and I have nobody to bail me out or anything, I basically had to take the charge and plea guilty to possession. It's bullshit." When I prompted her further, she added: "That's pretty much—every single time I've been arrested, it's been due to me having my episodes."

The onset of Afina's symptoms was in 2004, other than minor incidents in her

childhood, which she says was marked by neglect, psychological and sexual abuse. She began treatment at Centerstone around 2010 or 2011 but says she "didn't get serious" until 2014, in which she experienced an especially serious episode, in which she was met with an MIW and which resulted in her daughter being removed from her care. Through multiple manic episodes and multiple arrests, Afina began to recognize a small window of time in which she exhibited prodromal symptoms. Prior to being arrested at the Greyhound Station, Afina attempted to check herself into two different psychiatric hospitals:

> "There was one place that I was having an episode, and I was kind of like, spiraling, and it hadn't yet gotten so bad, but I had gone to [a large hospital] and told them that I couldn't sleep and I had the issue with my bipolar or whatever, and they told me to take some Melatonin. And [another large hospital] told me the same thing, despite the fact that I had a notebook that I insisted they saw. Like, there was pages of me just, like, nonsensical bullshit. That's a clear sign that I'm having an episode and yet they totally didn't admit me or anything."

She says that the day of her arrest, she called 911, asking to be hospitalized at a specific hospital. The dispatcher informed her that as well as emergency service personnel, police would be dispatched to assist with transporting her. Not wanting to experience another encounter with police, Afina had hung up on the call. Later that evening, she left for the station. However, Afina's push to enter services was a component of holding off a crisis and involved self-monitoring of symptoms. On this topic, Paul said:

> "I think everyone gets their own coping mechanisms. I think the one, universal one that I kind of hear across is that—routine and benchmarks. […] [H]aving a routine is good because the first thing a routine does is let you know when you're not doing it."

The development of self-monitoring through techniques like awareness of behaviors or symptoms typically followed reflective processes after several mental illness crises. Afina told me about multiple instances of, in hindsight, recognizing the brief time she had before

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her symptoms became unmanageable. During these times, she interacted with case managers and therapists, with 911 operators, who did not recognize her behaviors for what they were. Of one past incident, she says:

> Afina: I had met with one of my case workers who had been assigned to me, specifically with the purpose of preventing another episode from getting bad again. I spoke to her—and this was around the time that I was recording myself on my phone calls, and I have a few recordings of me telling her I wasn't sleeping, that I wanted to stop getting into social work at UofL, I wanted to start singing and I mean like...I've always wanted to sing, but to completely dismiss my career opportunity or whatever, and just like, acting totally manic, you would think that somebody would set off the alarms! Say something! Do something! And I'd actually seen several […] special therapists through the Michelle P Waiver and my CPS worker that Friday, and nobody ever said anything. It's fucked up. It's fucked up.
>
> LV: You'd think someone would notice!
>
> Afina: I was trying to—my episode had not yet gotten really, really bad and so I was running it across her to see whether...I was like, am I crazy? I'm not crazy. I even said something like that to her, and so I was reaching out, it just wasn't... a lot of people have the false expectation that when you have a psychotic episode, that you're able to go to somebody, but there are always so many...there's only so much time before an episode really gets bad, that you can do anything and if you're talking to the wrong people, thinking that they're the right people, and being told by others that they're the right people to talk to, then you're fucked.

Self-monitoring strategies rely on an acute self-awareness gained through repeated experience with one's illness. Guell explains that self-monitoring is a tactic individuals use to interpret and assuage the risk imbued from their illness (Guell 2012). Self-monitoring, often parsed as the development of insight, self-awareness, or reflexivity in mental health recovery discourse in my interviews, nonetheless occasionally takes on tangible forms in observing one's environment (such as Paul's insistence on using the cleanliness of his own home as a way to monitor for signs of increasing self-neglect and depression) or the artifacts of one's daily life (for example, Afina's notebook). Though mundane—even

minute—these are described as behaviors which allow individuals to seek treatment at appropriate times, before their illness becomes too severe. Afina described going one step further, to avoid being turned away from care in the future:

> "I just had to ask my therapist last week, if I was to go to Centerstone and ask her to pull out an MIW, would she? Because that would be the only time that somebody would admit me [to emergency inpatient psychiatric services] […]."

This was the practical solution to Afina's recurrent difficulties accessing care in the early stages of mania, before the episode became more acute. She knew from experience that past a certain point in the onset of a manic episode, she would no longer be fully in control of her own decision making. Kate, similarly, spoke on the importance of self-awareness and self-monitoring:

> "It's hard and I feel like especially when it's in a crisis situation, it's hard for me to recognize exactly what is going on. [...] Seeking help in that situation, it's like, I have to be forcibly institutionalized, like cops come to my house and take me away, that's what happens to me, so...you know. And I'm better about this now. I think, what has helped me the most is learning to monitor what's happening with me and there's some very key indicators. So, the first: I must take my medication at night or I'll have trouble sleeping. I must get more than four hours of sleep and if I don't, it's a warning sign. I have to remember to eat food. Very, very, very basic things, but I'm understanding that when those very basic things get out of whack, there is a serious crisis potentially on the horizon and it's time—and I will do this without seeking care—I will double up my medication, triple up my medication if I have to. 'Cause [Seroquel's] not really a dangerous medication [...] and I know that I only take fifteen milligrams at night so I know I'm okay to take up to three hundred milligrams without it being dangerous and I'm not going to overdose myself. I'm not on other medications. That's what I do! I'm like, this is wrong, I'm not doing well. I know what I need. And I've never had a doctor trust me. My nurse practitioner is constantly trying to up my dosage and I'm just like, can you stop with this? Because I don't need to be a vegetable. I need to sleep and that's all I need, thank you."

In these examples, self-knowledge gained through experience with mental health crises and care systems produced sets of knowledge informing care strategies to prevent future crises

from occurring. Afina, who frequently expressed to me that her manic episodes, if untreated, became unmanageable and heavily consequential, enabled an effective intervention through formal channels. Using the concept of territorialization, as Chenhall and Senior use it, Afina's strategy to avoid crisis is an assemblage territorialized within formal community mental health care systems. Conversely, Kate's care assemblage adopts self-management of medical technologies such as medication as a mode to orient their care away from reliance on the direction of care-providers. This is an assemblage of the formal (medication) and the informal (self-monitoring of daily habits and overall wellbeing).

Experience of Providing Care:

Ultimately, both care-providers and care-seekers exhibited strategic sets of behaviors which are shaped by a political economy of choice in particular contexts. Care-providers, like their clients, engaged in creative strategizing to remove or alleviate barriers to care that can be conceptualized as care assemblages. Treatment as "co-produced" between mental health consumers and providers is a key feature of recovery models; within the space of co-production is a necessary reconciliation of expectations, perceptions, and even power dynamics (Kraus and Stein 2012; Myers 2015). Dombroski, McKinnon, and Healy explain that "care" is necessarily an assemblage where the worlds of care-provider and recipient collide in the context of communications and negotiations that shift moment to moment (Dombroski et al 2016). Though the focus of their research is childbirth, not chronic illness, the notion of "care" as itself an assemblage formed between two parties seeking agreement about care while interacting with larger structures and non-human objects in the care setting, is significant.

Care-providers described co-production of treatment in terms of connecting a client's "willingness" and ability, including structural or environmental limitations on making health-related choices, to the care-provider's own willingness and ability to access other resources. Care-providers' efforts reflected the complexities of reconciling entangled institutional goals. Coordinating services within a spanning continuum of care is an important aspect to delivering community mental health (Durbin 2006; Ellis 2016). Novella describes these modern care systems as "transinstutitional," extending beyond delivering mental health care alone to include "auxiliary" organizations such as prisons, nursing or boarding homes, and I would argue food or housing assistance (Novella 2010). Care-providers act as individual mediators of these transinstutitional landscapes, assisting care-seekers in creating effective care-assemblages (O'Daniel 2018). Oftentimes, care-providers described to me in explicit terms how their clients' care bridged institutions. Deborah, a case manager, provided me with an example of how effective coordination between specific individuals between institutions could become an effective intervention:

> "So, there's a consumer who loops [hospital] all the time. […] I don't think he's a US citizen, but his Visa is not expired but is soon to be. Something happened that he was supposed to check in, so they like, suspended him in the system so he couldn't work. But he's homeless, way, way SMI and symptomatic, so much so that he's been barred from a lot of the shelters. So, he loops—getting locked up in jail, they send him to [hospital] for MIW, he goes to [another hospital], says he's going to come out [and connect with our services]: 'yeah, yeah, yeah, I'll do it'. He gets out: 'I'm gonna engage [with your services], yeah, yeah, I'm gonna be at [a specific shelter],' we go there and he's gone. Can't find him. And then we'll catch him again and he's in jail or at a [a hospital]. Well, last time he was in [one hospital], he agreed to go to [a specific program for homeless men]. [I was receiving his mail, including mail from the immigration office], they put his address down so I knew where he was and he had given permission to his […] clinician, call me! So, they said, we've got him, he's gonna be here just this short amount of time, we're trying to set him up with a job. I was like, I'm so glad you called me, I've got some mail and I'll bring it over to you guys, let me know

what's up, keep me posted so when he's ready to transition out of your program and it's time to come back [to us], we can step in and do the engagement. He's still in their program right now. His clinician and I talk probably every few weeks or so—she just updates me on his status, so we've got our hand on the post to be able to know, okay, when he's ready we can help him transition out."

In this example, multiple barriers to care are assuaged through system integration and coordination between CMHCOs and auxiliary organizations. Deborah explained that holding together resources on behalf of this specific client was a stopgap to keep him connected with resources to interrupt his frequent institutional circuits through emergency services, homelessness, or jail, as he explored his own ambivalence to treatment and decided when and if he wished to further engage with mental health services. As care-providers, Deborah and her colleagues from other institutions attempted to integrate their client into care systems, transmitting knowledge about what steps would be necessary to recover or find stability, which can be contentious in complex, changing care landscapes or when individuals face multiple barriers to care. Their role as care-providers was to facilitate movement through care systems on behalf of their client, who was unable to do so alone. Another care-provider told me:

"I don't know how much we can expect our clients to keep up with the system. We can't even keep up with the system. So, I think that one of the ways we try to help remove some barriers is by being that buffer for our clients and kind of help them navigate the system, advocating for them, making sure that those thing that are obvious are removed from their way."

Several care-providing interviewees mentioned their role as advocates, supporting their clients and assisting them in shouldering a journey through complicated and sometimes burdensome care landscapes. The system literacy and occasionally gate-keeping power that care-providers possess position them as important links between care-seekers and other

resources. To do this, care-providers engage in assemblages constituted by their clients' social contexts, the barriers to care facing their client, the care-providers own resources at hand, and the links that care-providers can make across potentially coordinated or integrated care systems.

Institutions and the Role of the Individual:

As well as the concept of institutionalization, I draw on the concept of entanglements to characterize initiatives in Louisville's CMHC landscape. In explanations of these spanning projects, in which multiple institutions—both CMHCO and auxiliary—would coordinate, care-providers (or auxiliary staff) were asked to make difficult, discerning decisions about how institutional entanglements informed how they could cohere assemblages or instances in which they acted as a barrier to care. This came through most clearly through discussions I had with care-providers about police involvement with CMHCO initiatives. Police forces often act as auxiliary organizations to CMHCOs (McKenna et al 2015). During my field work, and as I mentioned before, Centerstone opened a Living Room program which is only utilized by police. The effort itself was result of coordination between multiple local entities, not-for-profit, volunteer, and public entities included.

Multiple interviewees said that LMPD officers were put in the position of being "social workers" when they encountered mentally ill individuals in public; further, interviewees from two different CMHCOs discussed the frustrations that police had with either patients or staff (occasionally, a police officer who dropped off a client to a CMHCO may need to return to pick them up again, if their behavior is too aggressive). When I asked an employee at a drop-in center how police officers decided to bring mentally ill

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individuals to the drop-in center or to jail, the employee told me that it was ultimately up to the individual police officer's discretion. The hard line, they told me, was that they were not equipped to manage belligerent or aggressive behavior[19].

In practice, discretion is a sticky area. Since 2003, the LMPD has had a Crisis Intervention Team. Since 2015, the LMPD has worked according to President Obama's 21st Century Policing Task Force which calls for CIT training for all police recruits to appropriately deal with individuals they encounter who are mentally ill (Insider Louisville 2017). Care-providers generally spoke in positive terms of these changes, including efforts at increasing coordination between CMHCOs and the police force. One care-provider expressed gratitude for a few neighborhood police who were familiar with their CMHCOs clients and, if in need, would bring them to CMHCO if there seemed to be a problem. On the other hand, mentally ill individuals are often overrepresented in jail and prison populations (NPR 2018). In Louisville specifically, residents had concerns about the relationship between mentally ill individuals and police, particularly after incidents in which mentally ill individuals had been shot or killed by police; such was the motivation, as Zachary, of CLOUT, told me, for the organization's activism surrounding police reform with regards to mental illness interventions. Though my project did not focus on police/CMHCO relationships and I have no data to represent how this issue is experienced by police officers themselves, such partnerships characterize care landscapes of the current mental health era and therefore require further research as to the practice, efficacy, and

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19 While the topic did not arise in every interview, several care-providing interviewees from different CMHCOs discussed that it did occasionally occur that they called police. Normally, this had to do with threats against oneself or others, as in a declaration to want to commit suicide or harm another patient or staff member.

outcomes of these relationships. The practice of discretion, as an individually-located judgment made through reconciling multiple external logics, can be made complicated by such changes in the care landscape for individuals expected to take on a care-providing role.[20]

However, reconciling differing logics between institutions or entities also occurred within CMHCOs, typically at the site of treatment planning and negotiating insurance. Louisville's CMHCOs are supported largely by insurance reimbursements, grant funding, and perhaps some state or federal allocations. Treatment planning itself was one sphere of strategizing for care providers to attempt to extend care as far as possible for clients, where care-providers managed the middle ground between insurance limitations and the needs of their clients. One clinician explained to me negotiating patient needs with the limitations of a Managed Care Organization:

> "[W]e got all of our clients on an MCO and started to provide targeted case management or TCM and peer supports and CCSS which is some kind of community support services, but the problem with that was they don't want to provide it long-term. They're like, teach them the skills that they need and then back off and so we don't lie on our documentation, I'm not saying that, but you have to be careful when you're writing the plans, because you have to get authorized for three months at a time, you have to make sure not to put all of their goals on the first plan because otherwise the insurance company will come back and say, they don't need that goal anymore. So, you just pick a goal like learn to identify meds, that's our goal and in three months it will be—learn to take morning meds and so you stretch out services because nobody wants to fund ongoing services forever. But I think with some of our population, if they have that, which is a lot cheaper than inpatient care every other month, they would do so much better, but I think funding sources look at the here and now and not the, we could save hundreds of millions of dollars over the lifetime of this person but right now we don't want to spend this money."

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20 Throughout my interviews, when relationships between CMHCOs and the police were discussed, it was often in the capacity of identifying the potential benefit of such a cohesive partnership while wondering at how to reconcile such complex entanglements.

Tensions between the expectations of a treatment plan and a patients' engagement with other services provided by CMHCOs was also a difficult issue to resolve for care providers. One employee told me a story about writing treatment notes:

> "[Another employee] was asking, for this particular [patient], and the issue was grandiosity, uhm—when they go to the [gym] with us, how is the [gym] directly linked to them working on their grandiosity? [...] [S]he could just say, hey, look, this is a bad objective, he's in a group that isn't fitting the objectives on his treatment plan, but I can fudge these notes, I can go about my day. Or she can stop and say, hey, wait, what is in his treatment plan? What is my job as a peer to help him implement the treatment plan at the [gym]? Are they even compatible? So, what do I need to do? So, we identified, we're going to contact this therapist, see if we can modify his treatment plan, we're going to talk to that person specifically about how they feel about that treatment plan, we're going to re-talk to that person about our job as a peer and what we're going to do in providing soft confrontation. So, with his grandiosity, we notice contradictions in his statements and then we point those out, it's the only way we're going to confront him, we're not going to call him a liar. It's strictly when he contradicts himself, so we implemented those things […]."

In their analysis of macro-micro relationships in health-care, Bodolica, Spraggon, and Tofan argue macro-level health care governance fails to account for micro-political negotiations and relationships such as "patient preferences and other devices for monitoring the encounters between care-givers and receivers" (Bodolica et al 2015: 791). Care-providers are often tasked with fitting the messy human experience into the structures of insurance plans, contingent on treatment plans, also contingent on the services provided by and internal logics of CMHCOs, which themselves are governed by macro-level legislation about health care.

Care-Providers as Care-Assemblers:

Care-providers often described working across symbolic, emotional, and physical spheres to assemble care around their clients. They did so by working within the confines of their

client's social context, working the abilities, desires, and resources a client had into potential pathways to achieving greater stability. This recalls a phenomenon described above, where the actual health-seeking behaviors of mental health consumers do not always fall in line with neoliberal pushes towards responsibilitization or market rationality.

Siobhan, a program director, told me about a past client:

"I worked with a gentleman who spent almost a year out in the forest. Finally got tired of it, came in, he was on SSI, got—I think—six hundred dollars a month, but was a dad so some of his chunk went to his kids. Wound up, I think with about four or five hundred left, so we tried again on the housing. He doesn't want to do a boarding house, that's not safe to him, which is one of the options he could do, but really wanted an apartment. All of the studio apartments require three months security. Three months! […] [S]o there's no way for them to even get through the front door, even though they have the money for that month."

Here, Siobhan worked with her client to adapt his own perceptions of need and his own goals to seek a workable housing solution. Care-providers were often at the intersection of negotiating the everyday needs of their clients—sometimes urgent, such as homelessness, food insecurity, or a lack of transportation—within the limitations, allowances, and resources available within and without their own institutions. O'Daniel notes that although care-providers create important linkages for their clients within care landscapes and offer individualized support for clients, their efforts to hold together such assemblages of care with their clients may still fail in the face of larger structural pressures such as environmental barriers or the influences of insurance (2018). Chapter Two of this thesis provides ample examples of instances in which barriers to care resulted in ongoing difficulty for mental health consumers to achieve recovery.

However, care-providers still attempted to alleviate these barriers for their clients through the provision of individual labor, as possible within the resource-limits of

institutions. This might include advocating for a specific patient to receive financial assistance through waived treatment costs or treatment financed out of institutional grants, or it might take a more direct form. Peer counselor Colleen told me that when building trust with new clients, she tried to accommodate care that was the most accessible and comfortable for her clients, including meeting them in public places or meeting them at their homes or on their front porches, if it was more comfortable for the client. Though, as she described to me, her job was really to work with clients on the everyday experience of symptoms (for example, Colleen might accompany someone to the grocery store if they experienced inhibiting anxiety about that activity), she also acted as a liaison between the client and other care-providing parties if she came upon other stressors in her client's lives. She expressed that if she noticed a client was food insecure, she might assist them in applying for food stamps or getting food from food pantries. She said:

> "So, like, even today, I was at someone's house and I noticed that all they had was flip-flops. I mean, it's Winter, it's thirty degrees, and you're wearing flip flops. Do you have shoes? 'Oh, I don't know where they are! I don't know. I promise I have them.' Okay, let's go get you some shoes. [...] Just ensuring, that, when you have someone who has memory loss or a thought disorder, just keeping track of when they're going to get their food stamps and is their insurance going to be good? So, sometimes their letters come to me. [...] So, making sure that they have the things that they need."

The measures Colleen took to fulfill her duties for her client are typical of other care-provider's interviews, in which individuals described involvement with the minutiae of their client's lives (for example, receiving the individual's mail). Regarding another significant barrier to care, transportation, Colleen said:

> "[Transportation] can be a barrier for our population, we do have options like getting them hooked up with Federated and Tarc 3 and all those awesome things, but those things take time. So, offering: I can come to you

if you like[21]."

Nelson argues that care-providing staff form the link between non-English speaking health care clients in New Mexico and health care systems, which increasingly rely on technology to facilitate access and which therefore exclude individuals who either don't have access (lack of communication or transportation) or face a language barrier (Nelson 2005). She writes,

> "Although the design of the system itself would normally result in the loss of such clientele or would incur added costs if forced to address these difficulties, the efficiency model prompting the use of this technology appears to function effectively only because of the extra efforts of staff. In other words, they are adapting to the system by making it perform in ways that it would not without their help."

This is translated across my data not as literal technology, but systems intended to work to allow the "passage" of individuals through the trajectory of recovery (Novella 2010). The technologies in place to allow for an individual's trajectory through treatment and social services towards recovery do not necessarily operate at all under assumptions of efficiency and logics of choice (Dombrowski et al 2016). Recalling the importance of a mental health care consumer's ability to navigate care systems as well as self-advocate or receive advocacy, care-providers acted as important advocates internal to CMHCOs. Care-providers acted as links between resources, and even between barriers to care. The types of duties that care providers offer to their clients include the minutiae of such activities as filling out paperwork, educating clients about how to pay bills, apply for services, keep track of medication, make budgets, practice healthy coping mechanisms or socialization, a

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21 This anecdote was in response to Colleen explaining that her job as a peer counselor involved working with clients on particular symptoms. She provided the example that she might drive a client to the grocery store if they experienced anxiety about food or related activities.

veritable rigmarole of activities. Peer counselors told me stories, for example, of riding bus routes with their clients to help accustom them to the activity. Recalling Lauren's anecdote about providing care for a woman living with bed bugs, Lauren and her fellow staff attempted to compile resources for the woman: an activity that typically would fall to a case manager, which Lauren's organization does not currently provide. Colleen told me:

> "So, like, even today, I was at someone's house and I noticed that all they had was flip-flops. I mean, it's Winter, it's thirty degrees, and you're wearing flip flops. Do you have shoes? 'Oh, I don't know where they are! I don't know. I promise I have them.' Okay, let's go get you some shoes. […] Just ensuring, that, when you have someone who has memory loss or a thought disorder, just keeping track of when they're going to get their food stamps and is their insurance going to be good? So, sometimes their letters come to me. […] So, making sure that they have the things that they need."

Throughout this synthesis, I have provided examples of ways care-providers assist care-seekers in holding together care assemblages by acting as imperative linkages between care-seekers and other resources, on both macro and micro scales. Comments referring to meeting needs on an individual basis, taking care of problems as they arose, providing varied and adaptive services to match clients' needs, indicate how care-providers respond to the precarious and changing contexts experienced by their clients. Again, drawing from Nelson's synthesis of health care systems in New Mexico, care-providers assist mental health consumers in facilitating care within systems which otherwise may not cohere, and to navigate barriers to care access or maintenance which otherwise might make such actions impossible for care-seekers.

Like Fletcher argues, the political-economic and agentive interpretation of health-seeking behaviors, the types of things that people do to maintain their health care access or their health status overall, reflect larger power structures in society. For example, in this

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chapter I discussed how autobiographical power and narrative control were utilized by care-seekers to claim authority over the experience of their mental illness. Myers and Ziv describe how mental health patients are often dis-empowered within medical establishments by being denied autobiographical power; they collected data from individuals who experienced psychosis about how patients' self-explanations and narratives were discouraged by care-providers who impressed medicalized explanations on them. Myers and Ziv argue that this resulted in worse treatment outcomes or a prolonged lack of progress towards recovery, whereas being empowered to take authority over one's own experiences could lead to better outcomes (Myers and Ziv 2016). If the development of autobiographical power is one way that individuals living with mental illness are able to begin to gain control over their mental illness, then the ways that the performance of autobiographical power exists in shifting care contexts—is it encouraged or discouraged, and why—can shed light on the ways that relationships between care-providers and care-seekers subvert or reify hierarchical power structures in clinical settings. This is only one example. Surely, viewing facilitators and strategies for mental wellness from the point of view of assemblage theory is fertile ground for future research emphasizing political economics, the relationships between individuals and larger structures, and agency.

CHAPTER IV:

TOWARDS SUSTAINABLE FRAMEWORKS IN MENTAL HEALTH RESEARCH

In this thesis, I have examined barriers to mental health care access in Louisville, Kentucky, in the context of the recovery movement of mental health reform. Barriers to care occur at three inter-sectional levels: the individual, the institutional, and the environmental (Hines-Martin et al 2003). These three categorizations articulate in complex ways but can be conceptually understood as creating precariousness and uncertainty for mental health care providers and consumers who navigate them. The mechanisms by which barriers to care manifest in the lives of care-seekers, I argue, manifest this precariousness either as the experience of instability and access cycles or as an unwillingness or inability to take on risks, even in a care context which encourages upward trajectory. These are fundamentally disempowering experiences, fraught with concrete and symbolic defeats (Luhrmann 2007). The narratives of the recovery movement, as it is translated through institutional climates of care, are mitigated by notions of neoliberal responsibilitation and by insurance structures. In this context, mental health consumers will work through their treatment within community mental health care systems, supported by insurance, until they are able to leave these systems and self-manage their illness independently. However, I described in Chapter Two the ways in which barriers to care become accumulative and recursive and act to prevent that process. In Chapter Three, I picked up the thread of the primary argument

of this thesis: the project of recovery and seeking stability, where stability is often recursive with both mental health care systems and stability of care access or of external stressors in ones' social context, is undertaken via care assemblages by both care-providers and care-seekers, sometimes as a co-produced effort, and sometimes not.

Leading from the findings of this thesis, I propose that future directions for research into barriers to care surrounding mental health move towards examining the *process* of mental health management, within shifting care contexts, with a closer focus on the lived experience of individuals with mental illness themselves. I argue for a reframing of research focus towards both care access and illness management as ongoing projects intentionally undertaken by individuals, whose actions are constituted through shifting temporal, symbolic, experiential, and concrete contexts—that is, through assemblages.

Assemblage is a difficult concept to translate to applied approaches, despite its presence in social research and the clear utility of it to health research (Little 2012). The foundational question driving this work was purely descriptive: I was interested in the structures *preventing* care access. However, I began to rethink some of my central assumptions about "access" as I conducted this research. Care access is an ongoing project. It is not a singular occurrence, but a repetitive set of actions that is forced to change (as a person experiences barriers to access) or is intentionally retooled in response to those barriers, or in response to a care-seeker's desires and agency or a care-provider's response to a need. Interpreting the types of health-seeking behaviors individuals make as shaped by barriers to care should also be understood as modes of empowerment and disempowerment. They should also be understood as the "creative tools of the weak," the concrete and

symbolic development or repurposing of technologies and knowledges that would loan themselves to the practical development of short-term solutions for individuals residing outside of formal care systems (Guell 2010).

All sociological and anthropological research are questions of agency and structure; however, it's often difficult to mobilize data towards solving large-scale social structures which seem insurmountable to challenge. However, data focusing on "health at the margins" reveals strategies of the everyday, the short term (Guell 2010). Perhaps lines of questioning about health inequalities should not perpetuate descriptions of the ways in which individuals are marginalized and disempowered but find practicality in the strategies and modes of empowerment they creatively—and perhaps tragically—find to manage their health in the context of an individualistic, neoliberal context which so often creates intense difficulties for those living with chronic health conditions. In lieu of identifying structures as projects for long-term change while everyday individuals still struggle, could social research contribute to the development of more immediate strategies for wellness and empowerment? Further, what can questions of utilization and care assemblages tell us about these strategies, what they representant about our care systems and society at large?

As such, I believe that re-framing questions of "care access" to focus more wholly on "care maintenance" which consider the lived histories of mental illness is an important engagement for future research. The agency and intentionality of actions undertaken by individuals experiencing mental illness can reveal important processes of recovery. This is contingent on the inclusion of the voices and narratives of individuals living with mental illness through qualitative work. In addition to ethnographic research with mental health

consumers and individuals living with mental illness, another potential area of focus for ongoing research can be among peer supports. Across interviews with both care-provides and care-seekers, peer supports were lauded as filling a needed gap between institutions and individuals seeking care. The way that peer supports described themselves in my data raises further questions for research. Peer supports described themselves as "professional" friends, as examples of how mental illness can "work" in our society, or as embodying and transmitting messages of recovery while still being care-seekers themselves engaged in their own assemblages of care. In between the worlds of providing and receiving care, peer supports' experience can offer insight into institutional relationships with clients, the implementation of recovery models in theory and practice, and about the process of care miniatous itself.

The inclusion of these narratives of care maintenance, in which individuals describe tinkering, political-economic frameworks of decision making, agency, and a breadth of subjectivities between which they move based on care context, necessitates taking an assemblage-driven view of mental health. Mills characterizes the core conflict of mental health care research as an ongoing discourse about social drift and social causation theories (Mills 2015, citing Payne 2012). Mills is critical of how this question has been translated trough research and practice, saying that the burden of mental illness is often parsed as economic or productivity losses and that fixing mentally ill people is often viewed as a problem of individual brain chemistry rather than potentially reflective of patterns of inequality and marginalization. This is one half of her double-edged argument—the other is that, simultaneously, the stress of poverty itself as problematized as mental illness rather

than a true grievance about marginalization and the forces which cause it—but it is germane to my findings and reconciling social determinants with assemblage theory.

Precariousness, uncertainty, and instability were themes at the core of my data, with care assemblages forming as responses to such precariousness. But precarity is not equally experienced. This is an imperative line of questioning for future researchers to take on, as they inquire about health care provision and inequality, especially about mental health. There are important considerations in the ways that social context and structural inequalities may limit the resources available from which individuals can construct effective assemblages.

From the perspective of assemblages and agency-structure tensions, which I have attempted to capture throughout this thesis, it is apparent that the force of structural inequality is strong in shaping the everyday lives of individuals living with mental illness. Social marginalization and accumulated burdens can limit the choices available for individuals to make health-seeking decisions that have efficacy (Fletcher 2017). Within the question of care maintenance and care assemblages is real information about how agency is limited within our social systems. When agency is limited, what becomes of individuals' ability to create assemblages of care which allow them to break vicious cycles, to engage in the question of recovery, and to become empowered to contend with their mental illness? These are complex questions, but I believe that we can begin to answer them by engaging with the care-maintenance narratives of people living with mental illness, where maintenance itself is shaped by these social forces. This is also an important view to centralize agency in research about a population who has so often been spoken for. We can

dig deeper into how mental illness interacts with agency-structure tensions: when we look at social determinants, what else is there? When we look at measures of how mental illness impacts levels of education or vocation, for example, do we interpret that as a sign that people living with mental illness are inherently incurable, or do we interpret it as a difficult negotiation between an illness and society?

Basic access to community mental health care systems, by some means, was rarely a problem for care-seekers. Connecting with services could be as "simple" as becoming psychotic and being involuntarily hospitalized, taken to a drop-in center to stabilize, or arriving in a psychiatric hospital waiting room with suicidal intent. The ACA and Medicaid expansion could even remove the financial barrier from these interventions. But as my data analysis demonstrates, this does not ensure that individuals will be able to overcome other challenges in their life, related to their mental health care. Nor does it ensure that a person is empowered to grapple with the other components of their life. Kate said, during their interview, that being hospitalized

> "[...] is somewhat helpful, honestly, in terms of getting some stability because you have to get up at seven o' clock in the morning and you have to do these functional things. That routine is helpful, but without the structure of the hospital around you, how are you supposed to maintain that, especially when you come to the hospital with no self-care skills?"

This speaks to the importance of examining barriers and facilitators to care maintenance, beyond access alone. Throughout my interviews the specific barriers to meeting needs and the experiences of navigating complex circumstances and resources, and of stitching together solutions, were individuals attempting to determine just what makes a good mental health intervention.

If the ongoing project in the recovery mental health reform era is a trajectory through services to eventual independence, then questions of care access and care capacity must account for the strategies utilized by individuals when they are not connected with care systems. Rather than asking questions of how mental illness shapes marginalization or marginalization shapes mental illness, perhaps we should be asking a question that was ongoing through my interviews: why are some individuals able to recover when others are not? I believe that answering this question involves further investigation into the ways that individuals living with mental health care respond, or can respond, to social defeat or empowerment.

Mental illness presents real conflicts for how we think about illness and our society. Advocates often parse their experience not as an illness at all, but as differences of experience (The Icarus Project 2018), which rarely lines up with the ideologies of our society. Only in the last several decades have advocacy and activist activity drummed up within communities of individuals living with mental illness; similarly, only recently in health care delivery have attitudes begun to shift towards models of care delivery which recognize non-professional individuals living with mental illness as helpful caregivers, in the form of peer counselors and peer supports. When I asked Kate what had been the most helpful for them in their recovery, they told me:

> "Reading. Reading online. Reading the work from mental health advocates has been the most helpful thing, because I really didn't understand that I had worth or rights or the ability to recover. What the medical establishment will tell you, that you're permanently damaged and you're going to be dependent on these services for the rest of your life, is one of the most profoundly dis-empowering and shitty things that they do to crazy people."

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In that spirit, it's important that researchers contribute to the proliferation of work guided by the experience of individuals living with mental illness and the experience of recovery itself. Examining care assemblages and care-maintenance are perhaps the most revealing about system shortcomings and successes of different pathways to mental health recovery.

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ACRONYMS

The following acronyms appear in this text, and are explained in quotes, footnotes, or in synthesis.

ACA—Patient Protection and Affordable Care Act
APAC—Addiction Policy Action Committee
BHSO—Behavioral Health Services Organizations
BRFSS—Behavioral Risk Factor Surveillance System
CBT—Cognitive Behavioral Therapy
CCSS—Community Counseling and Supportive Services
CLOUT—Citizens of Louisville Organized and United Together
CMHC—Community Mental Health Care
CMHCO—Community Mental Health Care Organization
DBSA—Depression Bipolar Support Alliance
DBT—Dialectical Behavioral Therapy
MCO—Managed Care Organization
MIW—Mental Inquest Warrant
NAMI—National Alliance for Mental Illness
PAR—People Advocating Recovery
SMI—Severe Mental Illness
SNAP—Supplement Nutrition Assistance Program
SPMI—Severe Persistent Mental Illness
SSDI—Social Security Disability Insurance
SSI—Supplemental Security Income
TCM—Targeted Case Management

CURRICULUM VITA

NAME: Laura Drabelle Valentine

EDUCATION & TRAINING: B.A., Anthropology
                               University of Louisville
                               2012-2014

                               B.A., Broadcast Journalism with a minor in
                               Anthropology
                               Western Kentucky University
                               2010-2012

PROFESSIONAL SOCIETIES: Student member, Society for Applied
                               Anthropology, 2016-2017, 2017-2018

NATIONAL MEETING   Valentine, L. (2018) "Navigating Mental
PRESENTATIONS: Health Care Access in Louisville: An
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