Love in a Time of Madness: The Importance of Purpose and Belonging in Healing and Harnessing Madness

by

Laura Yakas

A dissertation submitted in partial fulfilment
of the requirements for the degree of
Doctor of Philosophy
(Social Work and Anthropology)
in the University of Michigan
2018

Doctoral Committee:

Associate Professor Damani Partridge, Co-Chair
Associate Professor Karen M. Staller, Co-Chair
Professor Holly Peters-Golden
Professor Richard M. Tolman

Laura Joy Jamie Connie Yakas

lyakas@umich.edu

ORCID iD: 0000-0002-4111-2338

ACKNOWLEDGEMENTS

This dissertation is a cumulative effort on such a scale that to do "acknowledgment" full justice is impossible. The truncated version must suffice. So firstly, I wish to acknowledge my committee: thank you for allowing me the freedom to create from my head *and* heart. I could not have done this any other way. And to the faculty and staff of the anthropology department who had me to themselves for my first few years here: thank you for believing in me, especially for the times when doing so meant not believing me. To the program directors and staff of the joint program: thank you for inviting me over from across the street and supporting my transition to our hybrid world of scholarship for social justice. To my fellow students in the anthropology department: you were my first friends here, and were put in the painful position of being my *only* friends (*and* recently acquired) during my darkest of times. The day I realized how much I owed you – for some of you, literally my life – was the day that I "grew up." And to my fellow joint students: you are my comrades, and I am honored to fight in this shit-pit beside you.

Beyond present academic acknowledgments, I also want to thank my undergraduate mentors: you gave me a hybrid gift-curse of a home in the social sciences. Though I would never wish to be again "blind," learning to "see" what others are socialized not to see is a burden we must carry together. Thank you for this gift-curse, and for literally inviting me into your family.

And to my family (inherited and chosen): thank you for making me, breaking me, passing time with me, laughing at me, and telling me when I suck.

And to the clubhouse community who opened their doors, arms, hearts, and heads to me: what I learned through and for you has fortified me beyond my wildest imagination.

I also offer an affectionate "pat" to the places my laptop rested upon: to the sticker-covered coffee shop tables, the Waipu bach, the Dargaville library, Blah's, the Raumanga whare, my Bowen haven and big sister's sewing table, and Foster's Home for Wayward Women.

And to my dear old laptop; you are an ergonomic nightmare, but you have unlocked me.

You (above) are the reason why I know what you (the reader) are about to read.

Thank you for loving the hate out of me.

PREFACE

"Three Mics"

Midway through my writing journey, Dr. Rich Tolman told me about a comedian who had used three different microphones as a creative tool during a performance. One he used for the segments that followed a "traditional" stand-up conversational thread, one for philosophical "confessional monologues," and the third he used for the one-liners that didn't fit elsewhere but, damn it, deserved to be delivered.[1] This "Three Mics" metaphor is the perfect tool to borrow as I attempt to write an authentic book on madness in which my many selves that have knowledge on the subject are heard and heeded.

My primary metaphorical microphone will appear on each page in Times New Roman 12-point font, 1.5-line spacing. With this microphone, my academic self will address fellow academicians in the more "traditional" tone.

My second metaphorical microphone will be daringly represented by the font Helvetica. These are my "confessional monologues," in which my full self will address your full self. Some will be longer, and stand alone but in relation to a chapter. Some will be shorter and embedded *within* a chapter, with the goal of introducing a new tone or layer (or song[2] – via YouTube link).

My third metaphorical microphone will appear as bold and italicized footnotes.[3]

---

[1] http://3mics.com/about.html

[2] In this I follow the beautifully blazed trails of anthropologists who have pioneered "antropoesía" (anthro-poetry), such as Renato Rosaldo (2013), as well as ethnographic songwriting (Jacobsen 2017).

[3] ***This is my one-liner mic, where I will share tangential funnies.***

TABLE OF CONTENTS

ABSTRACT

This is a vulnerable ethnography (Behar 1996) about the experience of Madness in a neoliberal-ableist society. In it, I combine ethnography with members and staff at a Michigan Psychosocial Clubhouse – a non-clinical strengths-based program that employs meaningful work and community building in order to meet the recovery goals of its membership, impoverished people diagnosed with psychiatric disabilities – with my own reflections as an "ex-patient." In order to present my varied knowledge on this topic, I employ three metaphorical "microphones"; one for the academic voice, one for the unadulterated self, and one for tangential comedy.

There is an inevitable darkness to this topic. Madness is a collective and neutral phenomenon that has been individualized, problematized, and reduced to "mental illness" or "psychiatric disability" to the detriment of justice. Additionally, the wider world we live in – the "current regime of neoliberal, white-supremacist, imperial-capitalist, cis-hetero-patriarchy" (Hedva 2016) – *makes* people Mad, and creates conditions in which social needs – like *purpose* and *belongin*g – are very difficult to meet (which *keeps* people Mad). However, my "findings" are far from dark, because in spite of all this, people who experience the injustice of such medicalization and marginalization – like the clubhouse community I grew to love – steadfastly live unlivable lives. They continue to centralize the fringe and challenge the center, and in doing so prove that oppression's power – though incontrovertibly destructive to our bodies/minds – need *not* extend to our souls, as it does not preclude the possibility of a rich and meaningful life.

In addition to contributing to the anthropological literatures on disability, work (as it relates to *purpose*), and kinship (as it relates to *belonging*), I make the following contributions; 1) I testify to the collective problems of trauma, oppression, medicalization, unmet social needs, and the fact that, in spite of intentions and successes, *the U.S. mental health system remains an insidious source of harm*; 2) I demonstrate that people – as individuals *and* collectives – *can* change for the better, and provide a toolkit for doing so on varying levels (i.e. strategies for healing and harnessing one's own madness, recommendations for people looking to be active agents for socially just change, and recommendations for clinicians who work with people

experiencing Madness/mental illness); 3) Because I creatively employ many of my voices – the interdisciplinary scholar, activist, musician (songs are included via YouTube links), ex-patient, Madwoman, anti-oppressive educator, and comedienne – I aim to not only reach readers with a variety of backgrounds and experiences, but also to model the vulnerability and authenticity I believe necessary for addressing a phenomenon as complex and existential as Madness, and to use my power (and the power of my intellectual ancestors) to make it easier for future scholars to do similarly integrated work.

CONFESSIONAL MONOLOGUE
It's not *You*, it's the *World*

I am *mad*.

I am *mad* because life is *hard*.

Humans have built a world that can shelter us from many hardships, but not from ourselves or from each other. I am *madder* because we have made life *harder* than it *has* to be.

This is in part because human minds need to limit conscious input and form categories to make sense of the world, without which we would be incapacitated by the chaos of infinite stimuli. It is therefore characteristically human to perceive and categorize difference, including human difference. But, the slope from different to inferior is slippery, and so – perhaps it happened gradually, perhaps abruptly, who could know? – humans began to *rank* human difference. We formed hierarchies. And because we are a cultural animal, we were duped by our ancestors' (mis)understanding of the world. Human-made social categories were mistaken for facts. We accordingly created a clusterfuck of self-fulfilling prophecies (#identities), and institutionalized the resultant inequality. This left us with a clumsily stitched, but durable, social fabric.

Isms were born.

At some point far, far down the line, I was born. I was born into a world that had a lot for me to learn. Men were men and did manly things like hunt and grunt. Women were

women and did womanly things like laundry and complaining about men. The Maori were lazy and didn't like to work. (Had I been born in the United States – where this book is situated – I might instead have learned that The Blacks were lazy and didn't like to work). Some people were beautiful and some were ugly. Some people were good and some were bad. Normal was better than not normal.

I learned that there were right and wrong ways to be human.

It is perhaps rare to find a child that challenges the whole notion of normal, since children are encouraged to trust their adults for such fundamentals. I was not a special child in that regard. And as a teenager, I fully accepted that adult doctors knew what a mental illness was – an *abnormality*, a *disease of the brain* – and I fully accepted that they were correct in surmising that I had (was) one.

From 18 to 26, I had (was) a Serious Mental Illness, and I did what I was expected to do (#SelfFulfillingProphecy) as someone with a Serious Mental Illness. I passively received "treatment." I swallowed an eclectic rotation of generic psychopharmaceuticals. I went to therapy and talked about why I hated myself. I pushed shards of broken glass into my thighs. I pissed in cups. I wanted to die. I tried to die. I drank. I tried not to. I realized that if I were thinner, everything would be OK! I witnessed the cinder blocks and nighttime screams of the psychiatric emergency ward. I fucked the clumsily sexist men in bars that no self-respecting woman would fuck. I had "meta-breakdowns" where I would break down because I was Seriously Mentally Ill and would be *forever* breaking down. I went to graduate school. I decided to leave because someone with a Serious Mental Illness couldn't do an ambitious stressful thing like a PhD.

I explained to my advisor that I was too broken of a human for this shit. He said, "nice try." My friends told me I had a "superiority complex about my inferiority." One said that no matter how many people I convinced, she would believe me whole even if she were the last person on Earth to do so. Another said to me, **"it's not *you*. It's the *world*."**

I found that impossible to digest. Not only had I grown up in a culture that favors the simplicity of black and white, but pain itself is a particularly insidious blinder that narrows the mind, making it impervious to nuance, impossible to inhabit the glorious grey zones that are in fact all there is. But seeds were planted. In *Pride and Prejudice*, Elizabeth Bennet says about her love for Mr. Darcy, "It has been coming on so gradually, that I hardly know when it began." Likewise, I cannot pinpoint the moment I began to slowly understand that they were right, that there was nothing wrong with **me** – and if there was (of *course* there was), it was because *I was in and of this* **world**. But I know that it happened because, in struggling to find a reason to finish my PhD, I decided to research mental illness. After all, I was already a certain kind of "expert."

I began to read. And go *deep*. And learn. And *un*learn. And one day it hit me like a freight train that I had been wrong(ed): reducing mental illness to "brain disease" was not only over-simplistic, it was *oppressive*. The view from Mad and Disability Studies and medical anthropology revealed that when it came to illness and disability, humans had done what humans *do*: noticed differences between humans, categorized them, and created a hierarchy of "better" and "worse" that was called "normal" and "abnormal," "health" and "illness," "sane" and "mad." Another ism was born. Like most isms, it was tricksy, cloaked in rhetoric about care and treatment and science and all good things. But the myth that there is a right way to be human was (is) reigning.

But they told me it was simple, that I had a diseased brain! They told me that my now much bought and beloved neat little label ("Bipolar Disorder Type II") was a fact they had uncovered, not created, and they told me that the best (*only*) life I could feasibly live was that of "psychiatric citizen!" (Rhodes 2010). No one told me it was possible to believe myself whole as I was, nor that there were alternatives to medical treatment. No one told me about the maddening corruption of Big Pharma. No one told me there was any disagreement in the field – streams of activists, practitioners, and researchers who challenge the medical model from countless directions. *No*. Everything was presented

to me as *fact*, not *perspective*. I spent years believing that I was broken – I damn near *broke* – because I did what vulnerable people often do: I trusted authority and doctrine. I went to the one place people are supposed to go when they can't live in this world, and they told me that there was something wrong with **me**. And it was so easy to believe, so very easy, because people – including myself (#InternalizedInferiority) – had been saying so all my life. That is the kind of **world** this is.

The bigger and deeper truth is that madness didn't happen *to* me, but *through* me. Mine was but a puny drop in a bucketful of human woe, and I was merely a particularly sensitive antenna for a brutal anxiety and anguish that pervades the very air we all breathe. And given that I was trained in the dark arts (#SocialSciences), trained to see what most are trained *not* to see, when I felt this anguish, it was never for myself alone. And crucially, though "it's not you, it's the world" was the spark to my awakening, it was also simplistic. This was no "either/or" situation. I was not *bad*, I was *wounded* (but still wonderful) in and by a wounded (but still wonderful) *world*, in which the wounded inevitably wound themselves and others. I needed to understand this bigger and deeper truth in order to take responsibility for and heal my soul-wounds. And so, I healed.

And by "healed" I mean that my life is my own, and I have learned how to bear my own awful and awesome madness. Mine is *not* a story of triumph over mental illness, mine is in many ways a story of triumph over the mental health system. I healed *in spite of* treatment, and only after divesting myself of "psychiatric citizenship." I healed because I was empowered by what Paulo Freire called "critical consciousness" – learning the ins and outs of this beautiful and monstrous world and being inspired to resist; facing the bigger and deeper truths, even though the view from there is chaotic and terrifying.

This is not to say that mental health treatment cannot heal. I know that for some, psychopharmaceuticals are miraculous, quieting their unique and intense minds so that they can live more peacefully in the world available to them. I know that a humane therapist can work wonders. I know that most practitioners (including those who hurt

4

me) *intend* to heal (#IntentVsImpact) – they do what they can with the tools they have. And most importantly, now that I have done it – done a PhD, in which I spent three years intensely enmeshed (first as a social work intern, then as an ethnographer) in a mainstream psychiatric rehabilitation program called a "clubhouse" – I am also aware that *within* the mental health system, there are many people, programs, and movements that are *retooling*, challenging the doctrine and renovating a deeply flawed system that **individualizes collective human problems**. There are people in "the system" that envision a world where difference – even the gritty, monstrous kind – is embraced, and where we stop the futile attempts to silence or explain away "deviants."

Yes, mental illness is an individual experience influenced by biology and patterns built over a lifetime (#biopsychosocial). It is **me**. But there is a palpable overemphasis on the individual (#neoliberalism) and overlooking of the general and collective madness of life in our unacceptably unjust **world**. When a person, say, an impoverished little part-Maori girl in rural New Zealand, incubates in such a contradictory and violent world, what does one expect to happen? Madness is more than a problem in a *person*, it is a feature of *people*. It is *integral* to humanity, not an *aberration* of it. It causes pain, some of which can and should be ameliorated through intervention. But also, *pain is integral to humanity, not an aberration of it*.

I know, from multiple positions – as ex-patient, practitioner, researcher, friend, and fellow human – that living with mental illness is hard. My hope is that people living with it meet someone who shakes them awake, who challenges them to see the value in their experience and to realize that ultimately it was not their *brains* that failed them, but the *world* that failed them, and yet there are people in the world who will *not* fail them. They are not everywhere, perhaps. But there is at least one Mad and proud anthropologist social worker who will tell you, no matter who you are, who wounded you, who you wounded, whether you are a bold intersectional feminist or a proud pussy-grabber:

It's not *just* you, it's the *world.*

CHAPTER ONE

Introducing a Book on Madness: Me, Myself, and My Book

Introducing the Introduction

In this dissertation[1] I task myself with writing a book on madness. I choose the word

"madness" in spite of the fact that this word has been all but replaced in professional and

common parlances with technical terms such as "mental illness" or "psychiatric disability." I use

these technical terms too,[2] but my reasons for keeping "madness" alive are many: firstly, unlike

these technical terms, madness is not always and necessarily a (medical) problem of an

individual person. Madness can describe problematic processes, places, peoples (collectives), as

well as individual persons. Secondly, madness is also not always and necessarily a *problem*.

Terms which include the words "illness" or "disability" by definition limit the scope to

problematic phenomena, but beginning with the a priori idea that madness is problematic (i.e.

unwanted, negative) is itself problematic. This is why "madness" is a reclaimed term among the

varied community of scholars, practitioners, artists, and activists like myself who identify with

the missions of *Mad Pride* and *Mad[3] Studies*. As the introduction to *Mad Matters: A Critical*

Reader in Canadian Mad Studies notes, for about five decades;

> Across a range of institutional and cultural contexts, activists, psychiatric survivors,
> academics, journalists, and dissenting practitioners have been challenging the
> conventional biological paradigm of "mental illness"; exposing the systemic and
> symbolic violence that lie at the core of the psychiatric system; constructing radically
> creative ways of thinking about matters of the mind; linking the struggle against
> biopsychiatry with other movements organized around gender, race, disability, social
> class, culture, and generation (Menzies, LeFrançois & Reaume 2013: 3).

---

[1] This is a dissertation, but henceforth I will call it a "book" – a choice both aesthetic and aspirational.
[2] As Margaret Price (2013) suggests, it is important to use culturally salient terms, but *consciously* and with *clarity*. By "mental illness" I mean the broad *diagnostic* label given to people who meet diagnostic criteria, and by "psychiatric disability" I mean the less inclusive *bureaucratic* label given to people who also meet criteria for welfare entitlements (such as my interlocutors).
[3] I will capitalize the words *Mad* and *Disability* when they are attached to the word *Studies*, as capitalization is a common strategy for reclaiming such terms as Identities (and Identity Studies).

Mad Studies is reactionary, intersectional, political, interdisciplinary (or as Richard Ingram [2016: 13] calls it, an "in/discipline"), and *resistant*. This book is, among many things, one of my platforms for mad resistance. My task in this book on madness is twofold:

1) To investigate the interplay between the madness of *humans* and the madness of *humanity,* and reveal the risks of a) **individualizing problems that are collective**, and b) **problematizing phenomena that are not only and always problems**.

2) To tell stories about people **centralizing the fringe**. I write about people who, due to their experience of psychiatric disability, find themselves on the fringe of the main stream of society – a neoliberal capitalist society in which paid employment is a key ingredient people use to feel *purpose* and *belonging* (which are social needs). Though such marginalization can mean people are denied opportunities to meet these needs, it doesn't *have* to: when people centralize the fringe, they seek or create a "micro-world" – in this case, a unique non-clinical psychiatric rehabilitation program called a clubhouse – on the fringe of the wider world, in which mainstream norms may be subverted and social needs met, such that their micro-world is brought to perceptual fore (centralized) and the fact that the wider world is inaccessible and harmful ceases to *matter* as much because it doesn't limit one's ability to live a meaningful life. In short, **when people meet their needs on the fringe, the fringe becomes their center, and the center their fringe**.

In this introductory chapter to my book on madness, I introduce **Me, Myself, and My Book**, through the following sections:

1) A broad description of my research that connects it to anthropology and social work.
2) An in depth description of my research methodology, which for this project necessitates
3) A review of the autoethnographic literature on mental illness.
4) An overview of the chapters in this book on madness.

1) My Book

"What?" and "Where?": My Project and Field Site

My project grapples with this puzzle: in the U.S., there is a tacit stigmatizing assumption that life with psychiatric disability must be worse than life without it, when in fact, living with psychiatric disability and living a self-defined good or meaningful life are *not* mutually exclusive. Psychiatric disability is undeniably challenging to experience, due not only to

diagnosable symptoms, but also the profound, complex, intersectional oppression faced by those who experience this particular kind of medicalization and marginalization (Menzies, LeFrançois & Reaume 2013). However, it is wrong to reduce those who live with psychiatric disability to "suffering subjects" (Robbins 2013), for that eclipses the diversity of lived experience, experience that includes joy and suffering, agency and lack thereof, ability and inability.

That being said, "suffering," powerlessness, and dependence have – for good reason – come to be dominant themes in scholarly attempts to understand madness and mental illness. Generally speaking, people have social needs. These needs include *love*, which I frame in terms of *kinship* and *belonging* (the subjective feeling of community/being affectively connected to a specific group of people), and *work*, which I frame in terms of *purpose* (the subjective feeling that one's life and labors are meaningful/matter). A significant body of interdisciplinary research has shown that unmet social needs have grave psychological and physiological consequences (Sapolsky 1998; Cacioppo & Hawkley 2003; Hawkley & Cacioppo 2010; Lieberman 2014; Mushtaq et al. 2014; Strecher 2016). Purpose and belonging *matter*, yet it is *precisely* such needs that are disproportionately unmet for people with disabilities living in "neoliberal-ableist" societies such as the U.S., which exclude and oppress people based on their in/ability to produce, accumulate and consume (Runswick-Cole, Lawthom & Goodley 2016). Stigmatizing ideology and isolation foreclose belonging, while limited options for economic and civic participation due to institutionalized inaccessibility foreclose purpose.

Or do they? This exclusion refers only to participation in the *main stream* of society, and people often resist exclusion by seeking or creating spaces in which they *can* participate. Repeatedly across time and space, people who have for varying reasons eschewed the main stream, have clustered together in what I call "micro-worlds."[4] For "psychiatric citizens"[5] of the

---

[4] This is similar to a "reality bubble," a term increasingly in use after the 2016 U.S. presidential election that refers to the insular worlds people live in, where not only values but versions of *reality* can be different. It is also similar to the concept of a subculture, "alternative community," or "intentional community" – small groups with shared values who choose to live alternatively (to the mainstream). Many micro-worlds arise because members are critical of wider society and seek like-minds with whom to share life. Some arise out of necessity as wider society will not have them. I am focusing on the latter.

[5] I encountered this term in Lorna Rhodes' "Dreaming of Psychiatric Citizenship: A Case Study of Supermax Confinement" (2010). "Psychiatric citizenship" means being labeled as someone with a mental illness or psychiatric disability, becoming a recognized "citizen" of the mental health system, entitled to its resources and protections. Rhodes found that for incarcerated peoples, to be labeled as mentally ill was a beacon of *hope*, as it spared them the worst aspects of incarcerated life (such as solitary confinement). This is a brutal twist: that my worst case scenario (psychiatric citizenship) is someone else's salvation.

U.S., there is a long history of resistance of this micro-world creating kind (Chamberlin 1978; 1990; Menzies, LeFrançois & Reaume 2013). Such micro-worlds become havens for those who live in them due to a collective process I call "centralizing the fringe." Though most people with psychiatric disabilities struggle to meet their social needs in the wider world, my field site was a micro-world on the *fringe* of the wider world in which the social needs of purpose and belonging were intentionally *targeted*, and hence that micro-world became the world that was *centralized.*

I conducted ethnography with a community of people living with psychiatric disabilities who defy the stigmatizing expectations underlying their label, and live self-defined meaningful and productive lives in spite of living in a society with minimal options to do so. My field site was a specific kind of psychiatric rehabilitation program called a clubhouse. Fountain House, the first clubhouse, was founded in New York City in 1948 by former psychiatric patients who sought to reclaim autonomy in their recovery after years of passivity within the mental health system (Glickman & Flannery 1996). Fountain House began attracting the attention of the wider mental health system in the 1960s due to both advocacy and efficacy research (Beard et al. 1963; 1978), and standardization and expansion began in the 1980s. There are now over 300 clubhouses internationally, with development and accreditation overseen by an organization called Clubhouse International, established in 1994.[6] The Clubhouse Model has 37 "Standards"[7] of practice that have been devised by consensus, and which offer members lifetime membership, meaningful work, and the opportunity to build relationships.

The Work-Ordered Day (WOD) is the primary rehabilitative method of the model, and refers to the daily process by which members and staff work side by side to operate the clubhouse (Doyle et al. 2013). Each day begins with a meeting where people sign up for work, encompassing administrative tasks (answering phones, tracking attendance, "outreach"/checking in with absent members), kitchen tasks (preparing lunch, operating a snack shop), maintenance (custodial work, landscaping), and advocacy (writing to legislators when relevant, participating in anti-stigma events). The WOD is explicitly framed as "meaningful work," and is viewed as therapeutic by itself for enabling purpose and self-efficacy. It can also serve as a stepping-stone toward other vocational goals, such as Transitional Employment (TE), a foundational invention of the Clubhouse Model. With TE, the clubhouse has part-time jobs in the community that

---

[6] http://clubhouse-intl.org/about-us/mission-history
[7] http://www.iccd.org/quality.html

members rotate through. Clubhouse staff train members, work with them while they build confidence, and take over if they are incapacitated. Clubhouse colleagues also support members who seek independent employment (Doyle et al. 2013).

Clubhouses are unique among mental health services due to their relatively egalitarian structure, reflected in the intentional terminology: "member," not client or patient, or "colleague," to avoid differentiating between "member" and "staff." Additionally, intimate relationships between staff and members are demanded, not deterred. Staff must engage members in work, which requires building close relationships in order to identify and develop their strengths. Staff must also be hands-on and enthusiastic. As Mark Glickman (1992: 2) – a member of Fountain House and board member of Clubhouse International – notes:

> If staff are passionate about the opportunities in the clubhouse, be they humble cleaning opportunities or working on the newspaper, a contagious enthusiasm will swirl around them… an important part of the staff's role lies in generating enough enthusiasm and sense of urgency about the club's needs to overcome the inertia and anguish which is a realistic part of mental illness.

In clubhouses, staff build close relationships, get their hands dirty (sometimes quite literally), and in so doing, undermine the inherent hierarchy in mental health settings.

Engagement in work also involves staff *believing in* members. Clubhouse director Andy Wilson said the ultimate rules for staff are "expect that everyone in your Clubhouse will have the ability and desire to be a leader" and "will get better" (2007). Psychological research on "expectancy theory" suggests that interpersonal expectations can significantly impact outcomes (for better and worse): that is, people are vulnerable to both positive and negative self-fulfilling prophecies (Rosenthal 2002). But interpersonal expectations are shaped by stereotypes and biases that mirror the culture one lives in, which means that the low or negative *societal* expectations attached to certain identities (such as "psychiatrically disabled") must be contributing to the *perpetuation* of said identities. According to clubhouse staff member Robby Vorspan (1999), staff must overcome deep unconscious prejudices if they are to *believe* in members, thus creating an environment where members feel genuinely needed. And it is "feeling needed" that many believe makes the model a success. As Jacqueline Peckhoff, a member/spokesperson, said during a 1989 conference address titled *Patienthood to Personhood*:

> I spend so much time at the clubhouse because I am doing real work, and know that I am expected and needed. To be needed, to me, means more than anything else in my life, and it also means that I am living a meaningful life (2).

This success, translated to/by efficacy research, is often[8] measured quantitatively via objective quality of life markers like rehospitalization or employment.

The first efficacy study was a two-year experiment with 400 recently released patients,[9] some who became members of Fountain House and some who did not. They found that clubhouse members were rehospitalized significantly less often and were employed at higher rates (Beard et al. 1963). Many studies have since demonstrated sufficient efficacy, such that the Clubhouse Model was accepted by the Substance Abuse and Mental Health Services Administration (SAMHSA) as an "Evidence-Based Practice"[10] in 2010. There is thus sufficient evidence that clubhouses yield positive objective outcomes in their membership. The dearth lies in, as Biegel and colleagues (2013) wrote, "ethnographic studies examining the interpersonal and support dynamic of the Clubhouse environment" (258). The nuances of people's stories within the clubhouse are important for those who seek to explore deeper questions about the experience of madness in neoliberal-ableist America.

"Why?": Connection to the Literature on Disability, Work, and Kinship

For decades, social scientists have blurred the reified, socially constructed distinction between normal and abnormal bodies/minds,[11] thus "resocializing desocialized phenomena"[12] (Canguilhem 1991[1966]; Szasz 1960; Foucault 2011[1976]); 1990[1978]; Kleinman 1991; Hacking 1999; Davis 2013a: 2013b). Furthermore, disability rights activists and scholars have dispelled the myth that life with disability is inherently less fulfilling (Johnson 2013) and re-envisioned disability as both a minority identity and a "universal aspect of human life" (Rapp & Ginsberg 2013a: 53), not a flaw in need of fixing. Rather than directing the focus on *individuals*, it is instead *society* and its layered upstream "structural violence" (Farmer 1996; 2004) that is

---

[8] There is also a recent body of qualitative research, reviewed in Chapter Three.

[9] This is attributable to the massive wave of closures of psychiatric hospitals occurring throughout the U.S. at the time, known as "deinstitutionalization." However, "deinstitutionalization" is a misnomer: people are *differently* institutionalized rather than *de*institutionalized. Sue Estroff, writing in 1981, suggested that "patients may be subject to as much social control as before, but in a different setting" (205). I very much agree: instead of a one stop shop institution that people can't escape from, people are mired and shuffled through several smaller "community based" institutions that they can't escape from.

[10] The Clubhouse Model's listing in the National Registry of Evidence-based Programs and Practices can be found here: http://legacy.nreppadmin.net/ViewIntervention.aspx?id=189

[11] I often use mind/body or body/mind to resist Cartesian dualism.

[12] This quote is from Paul Farmer's keynote at the 2017 American Anthropological Association meeting.

implicated in the persistence of inequality and oppression. ("It's not (just) *you*, it's the *world"*).
It is certainly not coincidence that poverty, violence, and oppression demonstrably worsen,
cause, and perpetuate disability, including psychiatric disability (Kleinman, Das & Lock 1997;
Hudson 2005; Murali & Oyebode 2004). This re-envisioning leads to calls for *structural* and
ideological changes necessary to disrupt the cycles of oppression, which historically manifested
in overt humiliation, exclusion, and eugenics, and contemporarily manifest in subtler
humiliation, exclusion, and eugenics (Chamberlin 1978; Sayce 2000; Menzies, LeFrançois &
Reaume 2013). But psychiatric disability has not been successfully re-envisioned as a different
but equally valuable way of life in the U.S. Not only is the dominant doctrine "seek treatment"
(i.e. let *the system* change *you*), but all of the five "I"s of oppression remain: interpersonal (i.e.
discrimination), intrapersonal (i.e. internalized inferiority or self-stigma[13]), institutional (i.e.
exclusion, inaccessibility, impoverishment), ideological (i.e. cultural values), and of course,
intersectionality (i.e. the way that mental illness interacts with other systems of oppression like
poverty, racism, or patriarchy).

It is thus difficult to research mental illness without emphasizing the "suffering subject"
(Robbins 2013), and easy for social discourse to continue framing life with psychiatric disability
as "unendurable" (Sayce 2000: 12). Ethnographic work on mental illness and homelessness
(Desjarlais 1997; 1999; 2010[1994]), incarceration (Rhodes 2004; 2010), and community
treatment (Estroff 1981; Scheper-Hughes 1987), poignantly depict and interpret the suffering of
people caught between this ravaging rock and hard place. My research breaks from this focus on
suffering. Although ethnographic research addressing mental illness from more neutral or
positive perspectives is (understandably) rare, there are notable exceptions. These include the
Belgian city of Geel where people with mental illnesses have been integrated into a unique
community care system since the 13th century (Roosens & Van de Walle 2007), and Bethel
House in Japan, a remarkable community approach to psychiatric rehabilitation that employs
work and community building in a similar way to the Clubhouse Model (Nakamura 2013).

---

[13] It is likely self-evident, but self-stigma negatively impacts well-being/recovery (Corrigan & Rao 2012).

Work and Disability

Through work, people simultaneously meet subsistence needs, forge affiliative relationships (Marx & Engels 1978; Durkheim 1984[1893]), and feel subjectively purposeful (Royce 1995[1908]). However, Karl Marx' (1978) noticed that far from being affiliative or purposeful, capitalist labor was "*alienating*" from self and other. Many have since joined in criticizing capitalism; for the oppressive techniques employed to make working bodies (Foucault 1990[1978]; 1995[1979]; Burawoy 1979; Ong 1991; Yanagisako 2002), the impacts on the exploited (Thompson 1966; Taussig 2010; Wolf 2010[1982]; Sahlins 2005), and growing social inequality, social unrest, boredom/ennui, and economic instability (Graeber 2012; Harvey 2014; Scott 2014; O'Neill 2017). In short, there are innumerable reasons why capitalism – especially the recent-to-current variation of *neoliberal-capitalism* (a pervasive, individualistic, privatized, and deregulated market-driven economic philosophy/practice [Harvey 2007]) – attracts criticism: the consequences in terms of avoidable human suffering have been and continue to be dizzying.

My research addresses what befalls people with bodies/minds that cannot or can no longer be rendered "workable." In a neoliberal-capitalist society, such as the U.S., where "paid employment" and "work ethic" (Weber 2002[1905]) are synonymous with value and adulthood, there are slews of people without "value" who become "bare life" (Agamben 1998) – depoliticized dependents who are infantilized, systematically excluded, and subjected to profound injustice. Or, *people with disabilities*.

And to complicate matters, though people with disabilities are framed as "not able" to work, there is ample evidence that they *can*, depending on how one views and practices work. Additionally, when efforts to include people with disabilities in economic activity are successful, working provides purpose and a sense that one is needed (Lynch 2012), and improves overall functioning (Essen 2012). Karen Nakamura's (2013) ethnography of the Japanese work-focused community program, Bethel House, demonstrated what is also evident in clubhouses: people with psychiatric disabilities *can* engage in subjectively fulfilling work. In clubhouses, members do not consider their work "alienating," referring to it instead as "meaningful work." For those who work in the kitchen to prepare lunch or operate the snack bar, the work might not be dissimilar to (potentially alienating) food service work in terms of actual tasks, but *menial* work is not *meaningles*s work in this context. Here, such work is undertaken alongside people with

whom one is close, products go back into one's own clubhouse, and one receives gratitude and remains aware of one's contribution to the whole.

My research gives an ethnographic account of work that is imbued with meaning due to the positive work environment and community fostered in the clubhouse. This deepens anthropological understandings about the role of work in social life: not all work is the same (even when it looks the same), or accomplishes the same thing. Rather, particular work is meaningful for particular people in particular contexts, and *work* is very often associated with deeper subjective experiences like *purpose* and *belonging*. For people with psychiatric disabilities who are socially defined by their *inability* to work in the narrow sense of paid employment, *their* understandings of the role of work in social life are worth listening to.

Kinship and Disability

I draw upon theories of kinship as a symbolic feeling of belonging (Schneider 1980; Sahlins 2013), as agentive and open to choice (Weston 1997), and as practice: kinship is "doing rather than being" (Holy 1996: 150), formed through both unusual events and "small, seemingly trivial or taken-for-granted acts like sharing a meal" (Carsten 2000: 18). The agentive practice of "kinning" – making kin out of non-kin – can also occur after relations are ruptured via "de-kinning" (Howell 2006), which is a common occurrence for people who experience mental illness, and was true for many of my interlocutors. In clubhouses, these ideas about kinship and kinning come into play in interesting ways. Interlocutors (my own as well as other qualitative researchers') express that the clubhouse is "their home" or "family," suggesting a symbolic sense of "mutuality of being" (Sahlins 2013: 37). I believe this occurs due in part to their engaging in "seemingly trivial" (Carsten 2000: 18) but subjectively meaningful work, and in part because they feel understood by others who have similar experiences. This phenomenon of bonding because of a shared affliction, illness, or related intense experience, has also been well demonstrated ethnographically (Rabinow 1996; Rapp & Ginsberg 2013a; 2013b).

"Why?": The Non-Academic Importance

My research connects the literatures on kinship, work, and disability by investigating how the interconnected processes of kinning and engaging in meaningful work provide a unique avenue for challenging the lack of ability presupposed by a diagnosis of psychiatric disability in

the U.S., and providing evidence that people with psychiatric disabilities *can* live meaningful lives, albeit on the margins of a neoliberal-ableist America.

This has import beyond the academic. Anthropologist, physician, and co-founder of international aid organization *Partners in Health*, Paul Farmer, spoke at the opening reception for the 2017 American Anthropological Association meeting on the new film about his work, *Bending the Arc*.[14] His work treating infectious diseases like HIV and drug-resistant tuberculosis in developing[15] nations led him to the pessimistic conclusion that "structural violence" (a term he famously coined in 1996) is the main reason why health inequity exists. No one believed it possible (or wanted to try and) treat *expensive* infectious diseases in such places until *Partners in Health* proved it could be done by *doing* it, using radical means like stealing medical supplies and pioneering the "community health worker" model where local people are trained to provide services. In mental health, well-known[16] psychiatrist (and Clubhouse Model fan[17]) Vikram Patel has pioneered a similarly successful program in which non-experts are trained to provide basic mental health services in resource-poor nations (Patel et al. 2011; Singla et al. 2017). People like Farmer and Patel who resist the metaphorical shrug of the shoulders, resist allowing impoverished "Third World" peoples to suffer in spite of the profound barriers to alleviating their suffering, inspire me to continue this pessimistic work of intervening in hopeless structural situations (Farmer called this "optimism of will, and pessimism of intellect").

The structures of our world are so distorted by inertia that they have not and will not change in time to help those who increasingly and more desperately need (and deserve) it. The power of just showing that *it can be done* – that impoverished people in rural Haiti can recover from drug-resistant tuberculosis, that impoverished people in rural India can recover from mental illnesses (Patel et al. 2011), or that impoverished people with psychiatric disabilities in Michigan can live meaningful and productive lives – cannot be understated. The fact that the structures and dominant narratives of the wider world are likely doomed to recreate inequities only means that we must fervently continue to (metaphorically?) steal medical supplies.

---

[14] http://bendingthearcfilm.com
[15] *AKA exploited*
[16] See his 2012 TED talk *Mental Health for All by All Involving All*: https://www.ted.com/speakers/vikram_patel
[17] Patel was the keynote at the 2017 Clubhouse International World Seminar.

CONFESSIONAL MONOLOGUE
Why 2.0: Contributions

At times I feel cynical about academic knowledge-production. So much of what I have (or *anyone* has) to say has already been said, and certainly, every problem I illuminate has already been illuminated. James Baldwin's *The Fire Next Time* (1992[1963]) for example, already called out institutional oppression and collective trauma. Foucault's *Madness* (2011[1962]) already identified the problem of power, of labeling, of medicalization, of marginalizing integral parts of the human experience, and allowing economic value to stand in for human value. Viktor Frankl's *Man's Search for Meaning* (1984) already identified purpose and belonging as crucial social/spiritual[18] needs.

But then I remember that *the point of knowledge-production is to take the gifts of past knowledge-producers and play with them*. Revisiting, reminding, replaying, and rethinking is how knowledge *grows*. Knowledge-production is a collective and cumulative effort. I am just one of *now's* voices.

And my voice is doing more than repackaging the wisdom of the past for an audience of now. The contributions I make with this book fall into three categories:

1) **Reminding readers that people change, and that it is *always* worth trying**: As I said regarding the work of Paul Farmer and Vikram Patel, without knowledge-producers (people with resources and clout) who are committed to challenging injustice, and capable of demonstrating that *it can be done*, much injustice would remain unchallenged.

2) **Reminding readers of what they *still* need to know:** Though I am not the first to identify (and testify to) the problems of trauma, oppression, medicalization,

---

[18] I will alternate between "social needs" or "social/spiritual needs" when discussing purpose and belonging, because social needs (i.e. needs that can only be met in relation to or by others) *are* spiritual in the broadest sense of being beyond the tangible realm of experience. This will become clearer in Chapter Five.

marginalization, unmet needs, or the crucial fact that *the mental health system remains an insidious source of harm,* it is also true that a) some of my readers may not already know this, b) for those who do, perhaps my wording will expose new layers, and c) the problems I identify (and testify to) *are still problems*, and until they are no longer problems, it will never be wasted energy repeating them.

3) **Using many voices to communicate knowledge:** In this book I use many of my voices – the scholar (of cultural [and a splash of biological] anthropology, psychology, philosophy, history, poetry…), the writer, the activist, the artist, the ex-patient, the Madwoman, the anti-oppressive educator, and the comedienne. What this means is that *nobody but Laura Yakas could have written this book.* And it also means that;

    a. My work will (I hope) reach readers on many levels: it will provoke questions, it will provide work-in-progress answers, it will provide practical tools, it will move them emotionally, and it will inspire change.

    b. My work will be accessible to people who learn in a variety of ways.

    c. I am modelling vulnerability and authenticity, and using my power (and the power of my intellectual ancestors) to make it easier for future scholars to do similarly integrated work.

These are my contributions, and they are valuable – to the academy and beyond.

---

2) Methodology: Research = Mesearch

"Seeking the Good"

When I began this project, I sought to discover what was "special" about "the mentally ill."[19] Though a categorical "insider," I was behaving like an old-fashioned "other"-seeking anthropologist. As Ruth Behar wrote in *The Vulnerable Observer* (1996), anthropology long ago progressed "toward viewing identification, rather than difference, as the key defining image of

---

[19] *Shameful sigh…*

our theory and practice [because] our classical dichotomies of Self and Other, Subject and Object, the West and the Rest [became] hopelessly inadequate" (165). I had alas missed that memo, and was seeking the "something special" that distinguished the "mentally ill" from the "not mentally ill" – the mysterious nugget of Truth that would mean I could maybe outsmart my broken brain and save myself. Luckily, I failed. I failed to find what was categorically unique about my fellow "psychiatric citizens," and instead found that what ultimately plagued my interlocutors was not substantively different to what plagued (or could plague) anyone else in this society: *purposelessness*, and a *lack of perceived belonging*.

I use the word "luckily" intentionally. As my opening confessional monologue conveyed, without the platform of my specific PhD program, I may never have unlearned what I needed to unlearn, or reframed the search such that I could find truths that actually *could* save me: for example, that life with an extraordinary or abnormal (formerly known as "broken") brain could also be a wonderful life. Both luck (random fortune) as well as privilege (non-random fortune) played a crucial role in the fact that I am writing this book on madness instead of having succumbed to it. Additionally, the discovery of my field site was luck. I knew someone who knew someone who knew of it. There, I discovered an inspiring intentional community in which the purposelessness and lack of perceived belonging so fundamental to the experience of psychiatric disability in the U.S. were countered through *work* – not the "paid employment" kind, but as I came to define it through my time there, *purposeful activity that builds belonging*.

This was "luck" in the positive sense, but I had my share of the reverse. It was, after all, my traumatic experiences within the mental health system that inspired me to begin this project. Therefore, in this book, I must achieve the delicate balance of confessing this trauma without overdoing it on the gratuitous grit. I must disclose that my experience as a "psychiatric citizen" harmed rather than healed me, ultimately leading to my decision to divest myself from the mental health system.[20] I do not identify as mentally ill. I concede to being Mad, to "meeting diagnostic criteria" every now and then, but I am not "mentally ill" and much about the mental health system would need to change before I *ever* acquiesced to being so-labeled again. I must confess these things because they very obviously shape my understanding of mental illness and the mental health system – two constructs that are omnipresent in these pages. It would be a

---

[20] March 2014 was my last month of psychiatric citizenship.

profound lie of omission not to frame this research as mesearch, to write anything about madness that did not include my own experience with it.

To achieve this delicate confessional balance, I turn to the advice of esteemed autoethnographer Carolyn Ellis (2007): "seek the good… be wise, but not cynical" (23) and remember that this work "should lead to positive change and make the world a better place" (27). Seeking the good does not mean only *reporting* the good. I will need to describe and analyze experiences and phenomena that are harmful. But I will commit to communicating such discoveries through a lens of nonviolence[21] and justice-seeking: what were the needs that were not met, why (and this is *always* convoluted), and what can be done to remedy it?

Autoethnography

A deceptive subtitle, for this is not autoethnography. Were this autoethnography, there would not be interlocutors, and there are. However, my personal experience and my distinctive voice featured prominently in the formation of the project, in the process of data collection, and in analysis and writing. More so than the average ethnography does. What I am doing is a hybrid of auto-and-ethnography, what Ruth Behar called "vulnerable" ethnography (1996).

Autoethnography – writing analytically about oneself as an agent in a specific society – emerged out of postmodern critiques that began in the U.S. in the 1970s and 1980s. Feminist and anti-colonial critiques of conventional research opened up the possibility that positivism was merely *one* way of knowing among many (Ellis et al. 2011), one that had been systematically "privileged" throughout the institutions of academia (Staller 2012). So-called "postmodern" thinkers questioned the unquestioned dichotomies that were at the root of social science research (*and* social inequality) – self and other, "West" and "rest," us and them. This process of questioning the fundamental tenets of scholarship was called the "reflexive" turn, because it involved scholars reflecting on themselves and their assumptions and practices regarding the production of knowledge. Autoethnography or similarly vulnerable writing became a tool for scholars to voice concerns about society (and academia) and to "treat research as a political, socially-just and socially-conscious act" (Ellis et al. 2011: n/p).

---

[21] The philosophy of nonviolence and practice of nonviolent communication (NVC) – which emphasizes focusing on the feelings and needs behind our words and actions – is integral to my work, and I will explain this in detail in Chapter Six.

As is often the case when change is demanded, there was backlash: this work was allegedly gratuitous and self-indulgent, better suited for the shelves of autobiography than scholarship. As Behar noted, such "criticisms of vulnerable writing stem from unwillingness to consider that personal stories can lead readers to serious examination of social issues" (1996: 14). Indeed, each criticism stemmed from, ironically (given the tenets of postmodernism), a reluctance to accept new or divergent ways of knowing, and a relentless commitment to convention which hinders the reshuffling of power. However, over the past few decades, proponents of autoethnography have staunchly resisted "epistemological privilege" (Staller 2012), and today it is an accepted (if peripheral) method of engaging with social issues.

There are many noted strengths of autoethnography, such as its ability to evoke empathy in readers, which can both deepen understanding and provide space for people to make sense of (and perhaps heal or change) similar experiences. Another strength of autoethnography is that social scientists – those most likely to write one – are uncannily well-positioned[22] to speak to the multi-faceted ways that social problems operate and thus "testify on behalf of an event, problem, or experience" (Ellis et al. 2011: n/p). Perhaps they will be biased (of course they will be), but a nice feature of postmodernism is that its adherents tend to own that *all* truths are biased and subjective, including their own. Autoethnographers tend to be self-consciously value-centered and rarely make pretensions to neutrality or objectivity.

There are also drawbacks specific to this mode of inquiry, such as the aforementioned risk of producing a gratuitous and masturbatory display of one's demons and opinions. Worse still if the writing isn't even good. One good reason why autoethnography is rare is that it is very difficult to do well. Behar (1996) notes that autoethnography

> doesn't require a full-length autobiography, but it does require a keen understanding of what aspects of the self are the most important filters through which one perceives the world, and more particularly, the topic being studied. Efforts at self-revelation flop not because the personal voice has been used, but because it has been poorly used, leaving unscrutinized the connection, intellectual and emotional, between the observer and the observed (13-14).

So the tremendous power that autoethnography has to be *good* – to be deep, engaging, moving, cathartic – parallels fairly its power to be *bad*.

---

[22] *As a woman* and *social scientist, I* really *know the patriarchy.*

But the most significant drawback to autoethnography is the risk of unintended ethical consequences. Carolyn Ellis' (2007) reflection piece on the ethics of writing autoethnography and ethnography provided me with the earlier-mentioned advice of "seeking the good." In this article, Ellis discusses research ethics. There are ethical issues that are accounted for by Institutional Review Boards (IRB) – for example, "procedural ethics," whereby one learns and follows, sometimes frustratedly, specific rules for conducting human research (e.g. it was prohibitively difficult for me to get approval to conduct interviews with people who were in adult foster care/not "legal adults"). There are "situational ethics," whereby one hones the skills of navigating unexpected situations in the field (e.g. how and when I chose to disclose my mental health history or push an interlocutor on their problematic beliefs). However, as Ellis came to learn through causing and experiencing pain with her writing, following the IRBs guidelines when it comes to procedural and situational ethics are not enough when it comes to the murky terrain of writing about yourself and intimate others. The IRB is not designed for research in which the researcher includes their own stories (which involve the stories of intimate others) or when the researcher develops friendships in their field sites (when interlocutors *become* intimate others). In other words, the IRB cannot offer guidance on the idiosyncratic complexity of what she calls "relational ethics." Which and whose stories to tell, and how to tell them?

Her article is designed to provide advice to somebody in exactly this conundrum. And as I mentioned earlier, her ultimate advice is to *seek the good*:

> most people want to do the right thing, the sensible thing. As human beings, we long to live meaningful lives that seek the good. As friends, we long to have trusting relationships that care for others. As researchers, we long to do ethical research that makes a difference. To come close to these goals, we constantly have to consider which questions to ask, which secrets to keep, and which truths are worth telling (2007: 26).

Such an endeavor demands relentless bravery and humility. The writer must show "warts and bruises as well as accolades and successes" (25) – their own and others'. When I tell the story of a man who stalks me in the woods, a husband who leaves me, a parent who hurts and humiliates me, or a doctor who looks right through me and says "what's the point of living? Forget it, you're just depressed," I am not trying to make monsters out of human beings. I am trying to tell you that life makes any and all people into momentary monsters, but it is never the whole story. To "seek the good" means acknowledging the climate of patriarchy and toxic masculinity which enabled this man to follow, grab, and attempt to rape me. To "seek the good" means

acknowledging that my ex-husband did his best to love me "in sickness" but did not know how, and that my parents broke me because they were broken (#IntergenerationalTrauma). To "seek the good" means acknowledging that this doctor was not trying to erase, explain away, or reduce me to ashes, he was trying to comfort me. As I said in my opening confessional monologue: *he was doing what he could with the tools he had.*

The depth and complexity of understanding made possible by seeking the good through exposing the bad is well worth the risks of exposure. I simply cannot write a "good" book on madness without describing how I became mad, and how I learned to harness and heal from it.

My Research/Mesearch Methodology

1) Data collection

I spent three years at an accredited clubhouse in Michigan with five staff and an average daily attendance of 25-30 members. Members were low-income, as this clubhouse only accepts members who receive services from the local Community Mental Health agency and who are on Medicaid.[23] I began as a volunteer, and then spent eight months as a social work intern working three days a week. When that ended, I returned as an ethnographer.

Foundational to ethnography are the methods of participant observation and interviewing (Bernard 2011). I was engaged in participant observation for 18 months, which involved working alongside colleagues: preparing meals, clerical tasks, attending meetings, etc. It also involved down-time: eating lunch, taking cigarette breaks and discussing the minutiae of life. As Ellis (2007) notes, throughout any long-term fieldwork, identities like researcher, friend, or colleague, become murky: I was always many things. As an ethnographer, I was always a former social work intern, and all that I had learned during that 8 months of everyday participating and observing informed what I learned in the following 18 months of IRB-approved[24] participant observation. In fact, it made this learning *possible*, and especially in regards to "situational ethics," provided me with the necessary skills to navigate this space. For example, I was also always a former psychiatric patient, about which I was forthright though rarely explicit.

---

[23] This clubhouse is funded through Medicaid. Obviously this membership limitation is problematic, as it violates the Clubhouse International "Standard" that any clubhouse should be available to anyone who experiences mental illness, but is not uncommon in the U.S., and is standard in Michigan. This I will discuss further in Chapter Three.

[24] IRB approval ID: HUM00097739

I did not, as Ellis (2007) did not, constantly remind people "I'm a researcher! I'm writing a book! Don't forget I'm participant-observing right now!" because to do so can be awkward and disruptive, though I did ensure that I explained myself fully to every new person I met (in such a dynamic setting, there were often new people to meet). Also, the community could not "forget" I was a researcher/anthropologist because I quite clearly stood out[25]: known as a deep and quirky reservoir of human-related musings and questions.

Between February and October 2016, I conducted interviews with three staff and eleven members, the recruitment of which was based on pre-existing relationships. Limiting myself to interviewing people I was already close with introduced a certain bias, but given the intimacy of the topic as well as my interview style, it was important that the interviewee and I had a trusting relationship. My interview style drew upon what Ellis and Patti (2014) call "compassionate interviewing" – a dialogic process in which both parties listen, share vulnerably, and reflect, often with the goal of care and catharsis. I would begin by asking how the person came to the clubhouse, and then delve into their experiences with mental illness and the mental health system, family and community, and the clubhouse. I asked them what they thought of as a "good" or "meaningful" life, and sought to understand if and how they had made this happen for themselves. In several interviews, tears were shed, unexpected similarities were uncovered, and two interviewees told me they had never felt this heard or seen.

To ensure that my research met accepted standards of rigor in qualitative social work research, I followed several strategies outlined by Deborah Padgett (2008). I maintained an audit trail by keeping raw field notes and documents in which I conducted analysis, and also sought the support of faculty mentors, especially regarding research ethics. Lastly, my prolonged engagement in this community – as the bedrock of ethnography – means that interlocutors were likely genuine with me, just as I am now genuine in my attempt to represent their lives.

2) Analysis and Writing

I transcribed my own interviews. For the sake of narrative flow, I took occasional liberties regarding paraphrasing and cutting out redundancies and fillers/speech disfluencies. My

---

[25] Though for obvious reasons – chiefly to be a good fit in their space – I was not my full Mad self.

empirical evidence – consisting of copious typed field notes and these interview transcripts, plus a small selection of members' creative work – was analyzed inductively.

For the purpose of protecting interlocutors' privacy, many ethnographers use composites, pseudo-fictional interlocutors based on details from a variety of interlocutors. I did not employ this technique, because for the situations in which there would be any reason to – i.e. the more detailed descriptions of people and their stories – the loss of specificity defeated the point of retelling the story. My strategy was instead a careful consideration of "necessariness" akin to "good-seeking" autoethnography: "which questions to ask, which secrets to keep, and which truths are worth telling" (Ellis 2007: 26). With the help of readers and reviewers, I strove to avoid gratuitously gritty (or identifying) detail about my interlocutors. Additionally, all interlocutors were aware that I would use pseudonyms and would not locate the clubhouse beyond the State (Michigan) it is in. However, they were also informed that due to the size and intimacy of their community, people who know them may identify them in my publications, and that if someone *really* wanted to know, combining their logical skills with Google could lead them to hazard a very good guess as to which of Michigan's accredited clubhouses I worked in.

As for the finesse of writing about "intimate others" (Ellis 2007) – both those from my life before and outside of the clubhouse, as well as the clubhouse community members who are now my friends – I have two points to add: 1) Because I am "seeking the good" (23), when I report the bad, I do so with nuance and purpose. 2) Because I am "assum[ing] everyone in [my] story will read it" (25), I am upfront about my work and share it with those involved.

CONFESSIONAL MONOLOGUE
The Making of: Madness Monologues

This is a kind of "fourth mic" moment, or breaking of the metaphorical "fourth wall," inspired by a question from one of my committee members: how had I decided where to place my confessional monologues? Was there a rhyme or reason to the timing of my mic switches? I wish I could give a clear answer to this question, because as this

committee member correctly noted, if I could, it would make life easier for folk who may wish to emulate. I don't know if this is such an answer, but here is what I can say:

The three monologues that stand alone do so chiefly because they are too long to be a break within a chapter. *It's not You, it's the World* began in 2016 as an essay inspired by a creative magazine's call for submissions of work about mental illness. When I eventually decided that my dissertation would include such personal reflections, I knew *It's not You, it's the World* would be the opener, as it tells the long, long story of how madness came to be a medical problem, how *I* became a medical problem, and how I undid that becoming through research that became critical consciousness that became power. *Talking Across Borders* is a meta-monologue (like *this* one) about creating this work, specifically, why and how I navigated the joint program in social work and anthropology. Its placement between Chapters One and Two is in part because it clarifies the purpose of Chapter Two, and in part because it develops points made in Chapter One regarding scholarship that is also activism. The other stand-alone monologue, *Never Again,* was inspired by writing Chapter Two (hence its placement right afterwards). Chapter Two explores the history of madness and its ties to other forms of oppression, and the entire time I was writing it, I was thinking, "yes, I can speak to that. *And* that." In fact, there was nary a sentence that did *not* provoke the memory of a personal example. And if I had written that chapter with the intention of weaving monologues throughout, I would have… but when I was writing it, the intention was only to *get through it*, as it was the chapter I found most difficult due to its depth and breadth. Once it was done, and I was satisfied that it cohered, I began journaling about the stories it brought to the surface. From that journal entry, *Never Again* was born.

The shorter monologues within chapters are each preceded by a segue. For example, *Loneliness and Belongingness* addresses the concept of "belonging" (and its opposite, loneliness), and falls after I have introduced the frames of "purpose" and "belonging" in Chapter Five. *Unbreachable Worlds* addresses the potential for isolation and mutual

unintelligibility between people's mad worlds, and falls after a section in Chapter Four describing the "Multiple Worlds" that we sometimes share and sometimes *cannot* share.

This is my best attempt at describing my process for weaving *Madness Monologues* into this book. But beyond placement rationale, I think it helpful to provide reflection on my writing *style*. Firstly, their title as "monologues" demands elaboration: I have been a long-term fan of Eve Ensler, who wrote the world famous *Vagina Monologues* as well as the less well-known but, to me, very impactful set of monologues about body image and "beauty," called *The Good Body*. I decided to call my confessional pieces "monologues" because – like Ensler's – they are written to be spoken. Another point of mention is the idea of "seeking the good" put forth by Carolyn Ellis (2007). Moreso than my traditional mic writings, my monologues began with a *lot* more grit than made it through the edit-filtrations (thanks to peer readers and my committee). This process was cathartic, as I was able to frame and reframe and reframe until I had distilled dark stories to their "good" bones. It also enabled creative development, as I became a much more confident and competent writer. Lastly, it made me *braver*, as I suffered, stressed, and sought support through the intimidating task of laying bare my life at its darkest (that which happened to me *and* that which I made happen).

My last point of reflection explains why this question was so difficult to answer, and why at the beginning of this monologue I expressed concern that my answer may not be a great guide for those who wish to emulate: I don't entirely *know* "how" or "why" I wrote and placed these pieces. In answering this question, I am called to retroactively self-analyze a process that was, for lack of a better word, *natural*. About my songs, I have also been asked, "why did you do it that way?" and had no answer other than, "I don't know… it just… happened?" I was not trained to sing, or to write songs, so I suppose it came with practice and something like osmosis via listening to a great many singers and songs.

This feels like a similar situation. I was not trained to write,[26] so I suppose it came with practice (both as a student and a daily journal-er) and something like osmosis via reading a great many writers and writings.

---

3) Autoethnographies of Madness

In order to better situate my own vulnerable book on madness, I will now review a selection of autoethnographic works on mental illness, trauma, treatment, and the academy.

Madness in the Academy

Barbra Jago's *Chronicling an Academic Depression* (2002) focuses on stigma and inaccessibility in the academy. She notes that compared to other professions, academia is extremely competitive, high pressure, and demands a lot of emotional and intellectual investment. Stress, anxiety, self-doubt, these are all *normal*, at times worn as a badge of *honor*. But this environment undoubtedly worsened her depression.[27] She describes in great detail – complete with visceral openness about self-injury, alcohol abuse, and medication side effects – an incident where things got so bad that she had to leave midway through a semester. Afterwards, the dean was hesitant to allow her to return, and Jago recalls the moment as cold and humiliating. She also writes about the review process for this article, and in addition to standard content criticism, one reviewer warned of the potential career consequences of exposing herself thus and suggested she reconsider publication. The dean and the reviewer, as representatives of the university and the journal (as representatives of academia), were hesitant and hurtful when it came to accommodating a colleague experiencing mental illness. In reading this, I wondered: are there professions that are just "not a good fit" for someone like Jago, or like me? (As I wrote: *I decided to leave because someone with a Serious Mental Illness couldn't do an ambitious*

---

[26] I have not been trained in creative writing, or, for that matter, academic writing. There were times I felt the latter point was a graduate school failure: that we are not trained in the nuts and bolts of writing, but that it is assumed anyone who arrives will either already know due to prior academic training, or will osmosis it via reading. I think this perpetuates disadvantages that "minority" scholars arrive with, however, I don't feel this is my battle, as I am lucky enough to have "natural" talent as a writer, and so have not myself been disadvantaged by this.

[27] This blog post about depression in graduate school, written by a fellow University of Michigan student, makes a similar argument: https://www.rackham.umich.edu/blog/my-story-depression-grad-school.

stressful thing like a PhD). Or *can* academia be home to the mad? These are crucial questions to consider in light of the postmodern call for more diverse and vulnerable voices in the academy.

In her journey toward recovery, Jago emphasized how important it was to go beyond the "canonical story of depression" (2002: 746) as a "chronic illness" necessitating medication for life, reducible to brain chemistry, and fundamental to one's identity. Eventually, she embraced this side of herself as *valuable*, not to be explained away but understood and validated:

> Depression offers me an opportunity to glimpse a reality beyond…the paramount reality of everyday life, to become more acutely aware of the ways in which we craft lived experience into meaningful and livable stories, to take the blinders off (756).

Treatment Stories

Because of their relevance to my project, I have chosen three pieces that address the interface between people experiencing mental illness and different forms of treatment, both clinical and non-clinical. Behar (1996) and Smith (1999) describe encounters with clinicians, and Martin (2009) provides an account of support groups for people diagnosed with bipolar disorder.

I will begin with Emily Martin's *Bipolar Expeditions* (2009), which is divergent here as it is marketed as *ethnography* and does not include much of Martin's personal story. But as she makes clear, her own experience with bipolar disorder fueled her interest in the topic and facilitated her research. She was not out of place in these support groups. She was also open with interlocutors about her experience, and they likely opened up to her in ways they may not have had they not shared such experiences.[28] Martin's main argument in the book is that while depression is pathologized and quelled, many of the qualities of mania are *lauded*, because in the U.S. – with values centered on capitalist hyper-productivity – mania can be *harnessed*, but the lethargy of depression is not *useful* here. A stout argument for how cultural (and economic) values shape what counts as *good* and *bad* deviance. Her secondary argument is for the importance of collective identity in support groups as an antidote to stigma and isolation;

> Support groups can be seen as a kind of enclosed social space that allows particular forms of intimate sociality. Under the impact of the stigma of mental illness, people often have to accept many social losses: a less well-paying and satisfying job; less continuous support from family members and friends; less ability to maintain relationships of all kinds. The continuous presence of the support group – even with its loose and changeable membership – can serve as a softly furnished haven (147).

---

[28] This is conjecture based on experience. I was regularly told that as someone who understands the experience of patienthood, interlocutors were more comfortable sharing their experiences with me.

28

Bret Smith's *The Abyss: Exploring Depression through a Narrative of the Self* (1999) does a lot in 15 pages. His writing is evocative and heartbreaking. Comparing his mind, his thoughts, his existence to a "swamp," an "abyss," conjuring imagery of darkness and desolation, he takes us through his journey through depression, alcoholism, and a suicide attempt. And as a typical autoethnography, he connects this to wider social forces. Gender: that as a man socialized into a specific form of (British) masculinity, self-stigma was extremely difficult to surmount. Medicalization: that the cloaking of his experience in disembodied clinical language hindered rather than helped his growth toward self-acceptance and recovery. His description of his first (as a *first* experience, this is crucial) encounter with clinical help-seeking is striking:

> The memories of the humiliating "drop in" with Dr. Paul send shivers down my spine. I recollect the questions that were reeled out as if he were a factory machine. His smug and condescending attitude increased my shame. Like the others, he "looked down" on my "diseased" body. *Another body eating into the budget. Another person who can't handle life. A little stressed maybe. As if I haven't got anything better to do with my time*, I heard him think. *I'll prescribe him some Sexorat or Prozac and refer him to a psychiatrist*, he politely insisted (274).

This dismissiveness and lack of compassion is not unique, but ubiquitous. I have experienced it myself. *Every depressed person thinks their existential woes are real, but it is just* chemistry[29]... *It is important to accept that you will need treatment for life…*

Another important contribution that Smith's piece offers is the warning, also mentioned in other sources (e.g. Tillman-Healy 2002), against stories of suffering that have happy and transcendent endings. Not everyone survives. Not everyone *can*, and not everyone *should have to* in order for their story to be valid and meaningful. Smith notes that "I am no Phoenix who heroically and cleanly rises out of its own ashes" (274), but that his struggles are continuous and changing. And lastly, Smith discusses the importance of *narrative* in the reconstruction of self that must follow serious mental illness. A major reason why I believe that stories like his are crucial is because they provide tools that others can use to "repair his or her narrative wreckage"

---

[29] Similarly, Kay Jamison (1997) wrote that "like most people who get depressed, [I] felt that my depressions were more complicated and existentially based than they actually were" (54), which is far from validating the experience. Her memoir of manic-depression/bipolar disorder is an exception to what I found to be the rule in the works I read: in over 200 pages, she did not implicate society in the construction or perpetuation of mental illness. I would not categorize it as autoethnography, but memoir, because it does not meet the criteria I believe to be most important: wider social awareness or criticism. This is not wrong, nor is it surprising, for she wrote from the perspective of a clinician who believes mental illness is a brain disease (and in the 1990s, when the brain disease model was at its most virulent).

(276) and begin making sense of their story in empowering ways.

Ruth Behar's *The Girl in the Cast*, one of the essays in *The Vulnerable Observer* (1996), is a poignant and dramatic account of a horrific car accident (with multiple fatalities), which rendered her cast-bound and immobilized for almost a year of her childhood. In her tale, she critically examines the cultural tropes that exacerbated her pain and prevented her psychological healing from this trauma for decades. Firstly, she was discouraged from feeling pity for herself – for grieving her loss – because she had not died (and others had). This is an oft-used strategy, to discourage pain because it is trivial compared to others' (Jago [2002] also described feeling guilt for being depressed for "nothing" when a friend had just lost his wife). Gender norms about femininity and modesty exacerbated her trauma, as her body was regularly surveilled and invaded during the rehabilitation process. Decades after the accident, Behar suddenly developed panic attacks – specifically around using her legs and driving.

When she sought help, her physician told her that her body was "physically depressed" (Behar 1996: 122) and prescribed anti-depressants. When this made no difference, and the doctor proved dismissive, she contacted an emergency help-line and the respondent said that based on her situation – an inexplicable inability to leave her room – she should research agoraphobia. So she did, and because she is a deep-thinking cultural critic, she was able to connect agoraphobia to feminism, to the fact that women in a patriarchy are *always* in a state of anxiety and unsafety – "The girl in the cast grows up to be the woman in a cast" (130). Such deep reflection enabled her to grieve her childhood trauma so that her adult self could move on. She self-taught exposure therapy, and eased her way into leaving the house, driving, using her legs again with confidence. She took matters into her own hands, as the mental health system had failed her.

Trauma and Madness

Behar's piece is a nice segue into a deeper examination of how mental illness is connected to trauma – both collective (i.e. patriarchy) and individual (i.e. abuse), though the two are inseparable, for individuals manifest culture. (*Madness didn't happen* to *me, but* through *me*). In *My Father's Shoes*, Kiesinger (2002) exposes the trauma of childhood abuse. She uses painfully descriptive language, and intriguing subheadings: "Hating" in which she describes her hatred for her father, "Unbucklings" in which she chronicles her beatings, "Invisible" in which she describes how she became silent, believing that if she were invisible she would be safe. She

foreshadows her adult life by noting that "years later, I continue to link pain with love" (98). She talks about feeling suicidal, and how she coped with drugs and sex. The details she provides are breathtaking; how he hits her "from room to room" and how she always checked her mouth afterward, fearing that she would someday lose her teeth.

She describes how the narrative she held onto for years – of he the monster and she the victim – impeded her recovery and froze in stone agents who were in reality nuanced. There are no monsters here, only humans. Yet she had "accounted for [her] life as an arduous journey" that she was "barely surviving," and in this story "there was no room for joy, happiness, and most of all, peace" (2002: 103). Healing began once she learned her father's story. One day she paused as she looked at a pair of his shoes, and it hit her how far he must have walked in them. She began to be curious about his life, and when she started to dig she discovered that he had been repeatedly sexually abused as a child. Behind his rage, the rage that sent her bleeding "from room to room," was "a terrified, seven year-old child, pretending to sleep, as a grown man – reeking of smoke and hard liquor – invaded his body and crushed his child spirit" (106).

Through unpacking *his* baggage, she could contextualize her *own* baggage, and forgive him, love him "not as a daughter loves her father, but the way one human being loves another when she realizes how the other has suffered, persevered, and tried to live a reasonably good life despite deep inner wounds" (104). Hers was merely a chapter in a *long* story of intergenerational trauma. This work reveals the importance of "narrative reframing." Painful and inexplicable events are rattling, and "stimulate one's narrative need" to make them fit into a wider life story that is "coherent, intelligible, and meaningful…Reframing our story in ways that empower rather than victimize does not mean that we deny painful or abusive experiences, nor does it mean that we excuse others for the ways they have hurt or violated us" (2002: 107-8). But to heal, we must release narrative frameworks that don't serve, and reclaim agency as authors of our lives.

Tillman-Healy's goal in *A Secret Life in a Culture of Thinness: Reflections on Body, Food and Bulimia* (1996) is to demystify the lived experience of bulimia and to challenge the dispassionate clinical literature with evocative text. Her style is exquisite. She begins with "I invited bulimia to come live with me. She never moved out… this is our story" (76), personifying[30] the "disorder" and approaching it with intimacy and respect. The technique she

---

[30] As you will later see, some of my interlocutors use "personification" of their diagnoses in their stories.

employs to tie in the academic literature on bulimia is similarly engrossing – "most research on bulimia has been conducted by physicians and therapists. This is their story" (78). She reviews this literature, and notices that it all focuses on *causation* – things related to one's *individual* environment like abuse, *individual* characteristics like body dissatisfaction or depression – and *treatment*. There is nothing about *what it means to people*, and nothing addressing *broader collective issues* like oppressive size-ist beauty ideals: "My story implicates the family and cultural stories that encourage young women (and, increasingly, young men as well) to relate pathologically to food and to their own bodies" (81). For example, in one vignette she describes watching her mother squeezing her stomach in the mirror and sighing, and in another she describes hearing other girls "fat talk."[31] But the most fascinating thing about this piece, for me, was the way she revealed how easy the slope from fine to demonstrably-not-fine really is. One day, you have never purged, never cut yourself, never had sex with a stranger whilst blacked out… and in what seems like no time, these things are as habitual as brushing your teeth.

Her healing – as is becoming the pattern – came from critical consciousness. From realizing that bulimia was "not an illogical choice" (104) in a culture that frames beauty as synonymous with thinness. It was not *her*, but the *world*, that was illogical.

In Summary: More Mad Autoethnographies, Please

My specific project demands the use of autoethnographic techniques. My research is also mesearch. But I also feel that mad autoethnography and other "survivor-produced knowledge" (Sweeney 2016) should be far more widely produced and consumed in academia than it currently is. The fact that this literature is so sparse speaks to the profound barriers to openness that people who experience mental illness in academia live with, made plain in Jago's (2002) piece. Beyond obvious interpersonal discrimination, there are conventions and an overarching culture that is *not accessible* to people who experience life in this way. But autoethnography about mental illness – especially what it is like to experience treatment – *must* happen, and must be heeded as equal to other methods of research about this topic conducted by people who witness but do not experience it. All of the authors I reviewed here resisted having their experience invalidated, fought deep pain, and shared that with the world in order to tell their audience (academics and

---

[31] "Fat talk" refers to the normalized way that girls and women in the U.S. talk about their own and others' bodies. For example, "do I look fat in this?" "I feel so fat today." "She is too fat for that outfit."

professionals) – in *their* language (academic and professional language) and with *their* tools (academic research methods) – something *important*: **the mental health system causes harm**.

The beautiful and crucial contribution that autoethnography (and ethnography) make to the literature on mental illness is the vulnerability and deep cultural analysis necessary for the *empowerment* of stigmatized peoples. Only then will sustainable systemic change be possible. As the saying goes, "Nothing about us, without us."

<u>**4) Overview of this Book on Madness**</u>

In the next chapter, *The "Other and Oppress" Propensity and the Making of Mental Illness*, I first describe what I call the "other and oppress" propensity – humans create meaningful social categories, and then (alas) mistake them for natural facts, and then (alas!) create oppressive hierarchies. I then contextualize this general propensity by reviewing theories from medical anthropology and Mad and Disability Studies which argue that one of modern medicine's projects is *to assert and reassert what is "normal,"* and that people with psychiatric disabilities are not flawed people, they are *othered and oppressed* people in a flawed world. In doing so, I unpack the historical construction of the medical category of "mental illness" from the broader experience of "madness," revealing the deeper roots of this process, as well as the present lay of the land in terms of the U.S. mental health system and critical alternatives to it.

In Chapter Three, I elaborate upon *The Clubhouse Model: History and Efficacy* by delving into the complex history of the Clubhouse Model and reviewing the body of efficacy research that has resulted in the model's acceptance as Evidence-Based Practice. Throughout the historical tale, I reflect upon the tension between professionalism and radicalism – or the sacrifices and consequences of professionalizing movements that begin *in reaction to* professional services (a process called "cooptation") – and also reveal that the history of the Clubhouse Model intersects with the history of the development of *strengths-based practice* in social work in intriguing ways.

Chapters One-through-Three provide historical context for the ethnographic material presented in Chapters Four and Five. In *What is Madness? And what is it like to be Mad in Michigan?* I build upon what was accomplished in earlier chapters by portraying what madness is, means and does for my interlocutors (and myself). I discuss "Madness Genealogies," or the complex ways that members (and myself) account for the origin of our own madness in order to

make *meaning* of our experiences, and I also present some of the struggles of life as a "psychiatric citizen" (Rhodes 2010) in Michigan. Then, in *"Work is Love Made Visible": Purpose and Belonging in the Clubhouse*, I explore the deeper meaning of "work" from the perspective of people socially defined by their *inability* to work. In doing so, I explore the deeper meanings of *work* and *kinship*, distilling these concepts to the *social needs* beneath them – *purpose*, and *belonging*. In the clubhouse, a space with a *positive work environment* designed to meet these needs, "dis-ability" becomes a misnomer as members show remarkable "ability." In this work environment, members come to feel needed and valued, countering common feelings associated with psychiatric disability such as dependence and a lack of self-efficacy. Consequently, members *centralize the fringe* by living self-defined meaningful lives in their clubhouse micro-world and paying little mind to the wider world beyond.

Chapter Six – *Accommodating Madness: Tools for Building a World to Belong to* – is where I put into practice the goal of "seeking the good" by exposing the bad (Ellis 2007). The goal of the chapter is threefold; firstly, I provide a multifaceted toolkit for accommodating one's own madness, which simultaneously relays my personal journey of change and emphasizes the paramount importance of *critical consciousness*. Secondly, I describe the importance of anti-oppressive allies in the collective struggle for liberation, and provide a toolkit for becoming (and creating) Mad allies. Finally, I address clinicians with a tools to enable them to better accommodate their client's madness.

In my concluding chapter, I close with a confessional monologue that reprises the underlying theme of interdependence – which I phrase as *"It's not (just) you, it's the world."* I summarize the key arguments made throughout the book; that "madness" is a collective and neutral phenomenon that has been individualized, problematized, and reduced to "mental illness" to the detriment of justice; that the wider world we live in – the "current regime of neoliberal, white-supremacist, imperial-capitalist, cis-hetero-patriarchy" (Hedva 2016) – *makes* people Mad, *makes* people sick, and creates conditions in which social needs are very difficult to meet (which *keeps* people Mad and sick); and that in spite of all this, every day people are out there living unlivable lives, centralizing the fringe, challenging the center, and proving that oppression's power – though incontrovertibly destructive to our bodies/minds – need *not* extend to our souls.

CONFESSIONAL MONOLOGUE

Talking Across Borders

Like *The Making of: Madness Monologues*, this is a meta-monologue inspired by two pieces of feedback. The first was a question posed by a committee member, who identified my overall knack for making disparate voices communicate with one another,[32] *and* the specific capacity I have developed for making anthropology and social work communicate with one another, and then asked; "how can anthropology and social work talk to one another, especially about madness?" The second was a push from another committee member to lead each chapter – especially the *contextual* chapters (like Two and Three) that are susceptible to information overload – with an *argument*, to be clear about *why* I say what I say, rather than just saying it.[33]

This monologue – which, as is my wont, comes in the form of a tale – is my attempt to wrestle with these connected questions: **how can anthropology and social work talk to one another about madness**? And perhaps more centrally, *why* **should they**?

I began graduate school in 2011 in the Michigan department of anthropology. There were many reasons why I struggled in those early years, most of which were personal – it coincided with my divorce and descent into tainted madness. But I also struggled to justify to myself the many-year climb toward doctor-hood, as I quickly determined that a

---

[32] Perfectly enough, this resonates with my overall life purpose *and* the purpose of this book: to teach people how to talk across – and perhaps someday dismantle – borders (internal borders, borders between people, borders between "peoples").

[33] Upon reflection, it seems my style is to tell stories and provide information, all of which have arguments (or "whys") embedded within and unfolding throughout, but which are rarely delineated in the first paragraph.

life of scholarship for scholarship's sake was not for me. I felt that; A) if I were to create scholarship of this (PhD level) magnitude, I wanted it to break hearts[34] and also *heal* them; and B) this would be challenging in a non-applied academic anthropology department like the one I was in. In short, I considered becoming an anthropologist a worthwhile endeavor, provided the anthropology I did had positive consequences in the realm of social justice. The most accessible path for me to achieve this end was to transfer to the joint program in social work and anthropology, which necessitated a quick walk across South University Avenue, and a not-so-quick Master's in Social Work (MSW) and additional set of preliminary examinations.

This joint program is notoriously difficult to navigate, in large part due to the divergent aims of each school. Whereas social work is a profession that draws upon a variety of academic disciplines (primarily the social sciences)[35] in order to make the world a more just place, anthropology is an academic discipline that seeks only to know the/a world. Social work is pragmatic, anthropology is heady. Whereas social work aims to change the world for the better, anthropology asks "what *is* "better," and who decides?"

On most days, I identify as an anthropologist more than I do a social worker, because anthropology is fundamentally **deep and heady**,[36] and so am I. Social work, though it

---

[34] On the final page of *The Vulnerable Observer: Anthropology That Breaks Your Heart,* Ruth Behar (1996: 177) writes; "call it sentimental… but I say that anthropology that doesn't break your heart just isn't worth doing anymore." I consider myself a great mind that thinks alike.

[35] Within social work there is debate about this issue: is social work a profession that uses social science, or is it a social science? What are the benefits and drawbacks of marrying social services and social sciences? Kirk and Reid's *Science and Social Work* (2002) addressed this issue, and there has since been much discussion in social work journals. My view is, as I just expressed, that social work is not itself a science, but a *profession* that *uses* science – however, this does not mean that social *workers* cannot also be scientists. The border is between the two games, not the *players*, who can (as I and many others do) elect to crisscross.

[36] By "deep," I mean that one keeps digging through space and time (i.e. with a seemingly simple problem like "obesity," one could go back in time to the agricultural revolution that altered human diet, and spatially take it to a global scale by examining the ways that "first world" exploitation of the "third world" shapes the food systems of all). By "heady," I mean that one explores related connections and tensions (i.e. one could connect obesity to poverty, or patriarchal and racist/size-ist beauty ideals, and sit with the uncomfortable tension that in

strikes a chord in terms of its clear orientation toward socially just change, generally lacks in depth and headiness, which means that many interventions operate in the superficial realm (*applying bandages to the gangrenous*), and much research is shallow. There is nothing inherently wrong with this. Not every problem needs to be heavily deconstructed or traced back to the beginning of time. Not every researcher needs to be deep and heady in order to make significant contributions. **But for some problems – especially madness – I believe there is no way save deep and heady.** This is precisely the "why" – the "why must anthropology and social work be in conversation with one another about this?" – because the majority of social work (and related professions like psychiatry and clinical psychology) research on madness/mental illness is dangerously lacking in depth and headiness. But madness *is* deep, *and* heady, and to tackle it one *must* have the tools to navigate such ambiguous and challenging terrain.

This is why Chapter Two was by far the most difficult to write[37] (as noted in *The Making of: Madness Monologues)*. As footnote 36 elucidates, when one is examining a social phenomenon – even one that appears simple – one can theoretically begin from the Big Bang. My aim was to write about madness, and this society's means of addressing it (the mental health system in the United States, of which the Clubhouse Model is a part), but… where/when to begin? I chose *deep*. I began with basic human cognition and how our social evolution contributes to what Rogers Brubaker (2006) calls "groupism," and I call the "other and oppress propensity" – our tendency to create the borders that I am, it seems, now skilled at talking across. By taking something finite – like the construction of mental illness and the mental health system – and sending it to this infinitely deep and heady place, I was able to understand that we live in a culture (one which transcends national borders) that is sick and sickening. I was able to understand that this culture oppresses difference, and fears fear, and I was able to understand why and how this came to be. I was able to see how and why madness became (and remains) an unjustly

---

making "obesity" a target of intervention, one is simultaneously improving people's physical well-being *and* suggesting the world would be improved if obese people were no longer part of it).
[37] **I referred to it as "chapter poo" for a period.**

feared and persecuted manifestation of humanity's potential. I was able to understand what madness is, means, and does, in terms of people's everyday lived experiences. *And* I was able to learn how to heal and harness it.

So, if the underlying argument is ever unclear in my context-providing "information overload" chapters (such as Two and Three), this is what you need to know: **I am sharing these stories and analyses so that you understand how *serious* it is that the mental health system has been what it has been, and is what it is**. It is a truly monstrous thing that people created under monstrous cultural circumstances. That is just the nature of the beast. And being monstrous, it has created monsters of a great many kind; from the dehumanized and disempowered patients[38] to the equally dehumanized and disempowered clinicians and bureaucrats who yearn to *heal*, but whose blind-spots and insufficient tools too often *harm*. In short, what was true for me is true for *all* agents: **it's not just *you*, it's the *world*.**

It is deeply ironic, and, for lack of a better word, *sad*, that America(ns) has(ve) tried so very hard to live by and create values around *freedom*, and instead live(s) bound by the chains of entrenched oppression, doomed to create and recreate borders that we habitually do not talk across. And when we do not talk across borders, we lose the *ability* to. And when we *cannot* talk across borders, not only can we not heal the wounds inflicted across borders, but we cannot stop inflicting further wounds.

Anthropological training gave me the tools to see, *deeply* see, the phenomena of madness and oppression, and as a creative discipline that affords flexibility in presentation (one can write according to the formula, but one can also write something like *this*), it also enabled me to speak it in as many voices as I needed to. However, the gifts of anthropology would by no means have been sufficient, and not only because of the aforementioned issue of finding adequate support for social-justice-oriented

---

[38] I believed myself a monster, and can assure you that belief did much more harm than did the raw materials of my "abnormality."

research in a non-applied program. It was in the school of social work that I was given necessary tools in interpersonal practice (like non-violent communication and dialogue facilitation), and as a profession committed to social justice, it was in social work that I learned to be unabashedly political and vulnerable.

Combining the tools and goals of both social work and anthropology has been a challenge. As the first-mentioned committee member correctly said in the preamble to her question, "most students struggle to make this program work,"[39] and her question of "how?" was designed to encourage me to think about how to advise other students in this specific joint program, as well as anyone else out there doing strange hybrid heady activism scholarship. So, *how* does one do it – make social work and anthropology talk together about something inherently deep, heady, and strange, like madness? I can only answer for myself, but I hope it is relatable: depth, vulnerability, humility, and hope.

<u>Depth</u>: As I have said, depth and headiness are necessary for adequately exploring topics that are deep and heady. Regarding madness, one must go deep enough to understand how oppression and its self-perpetuating consequences have shaped what "mental illness" looks like today, such that we treat it as a **social justice issue,** *as well as* a biopsychosocial issue. Throughout this book, my depth and headiness is quite apparent, particularly in defining my key frames. Like "disability" – what does that even mean? Unable? Unable to do *what* exactly, and *where* exactly, and *when* exactly? This "going deep" also uncovered the book's crucial frame of "unmet social needs," as I distilled "work" and "kinship" to reveal the fundamental social/spiritual needs beneath them. The point of depth and headiness is this: **deep problems require deep solutions**. Of course, "deep solutions" are pipe dreams – we are no closer to solving racism than we are to transcending the laws of thermodynamics – but the more that people learn to think and feel deeply about deep problems, the easier it is for positive momentum to offset the omnipresent toxic momentum.

---

[39] Context: the median "years to PhD" for the anthropology department is between eight and nine years, and it is generally longer for joint students.

Vulnerability: I see no use for research on madness that doesn't address sentimentality. We must know and communicate what is observable, but we must also know and communicate what is *felt.* To talk genuinely and openly about feelings, needs, and the deep yearning for a "better" world, is tough on two counts. Firstly, our society has a long-standing habit of conflating vulnerability with weakness, such that it demands profound bravery to be vulnerable – especially when it is published and thus subject to unknowable scrutiny. (Fortunately for me, my experiences with madness have desensitized me to the harsher consequences of vulnerability such as shame or exclusion). Secondly, it is tough to do this in any discipline that calls itself a science. (Science and Art = Another useless border). But as my work and the work of my trail-blazing intellectual ancestors demonstrates, it has been, is being, and can be done. It may be work that sits for now on the fringes… but *fringes only wait to be centralized*.

Humility: As I frequently say to people when facilitating "wokeness workshops"[40]; "take a bite, and remember that you will be chewing forever." What this means, generally, is that in order to survive wokeness, one must release attachment to being "right" and "good" and embrace tension and ambiguity. (On *every* side of the arc of justice, there are people who believe they are "right" and "good"). What this means in terms of being a producer of hybrid scholarship is that you must find the people and places in which your work fits, and respect that this will not be everyone/everywhere.[41] All academics, and especially we who are unconventional, would benefit from embracing the fact that some will believe our work "wrong" and "bad" – and this is *fine*. I advise students and other early scholars (without the power of tenure) to do as I did, and be choosy about whose feedback we seek and heed. For example, I chose committee members based on two criteria: kindness and unconventionality. There were faculty who were better fits

---

[40] One of my passions is facilitating anti-oppressive programming in which I provide people *knowledge* about oppression (what, how, why), and the *skills* of non-violent communication, empathy, increased tolerance for ambiguity/tension, and conflict resolution, which are necessary if one is to *do* anything constructive with said knowledge. I discuss this more in Chapter Six.
[41] For example, I published an article last year (which Chapter Five is derived from), and then entered it into a paper competition at the school of social work, and found that what was appreciated and published in one space, was rather unkindly reviewed in another.

in terms of topical expertise, but who were not kind communicators or open to my strangeness. Of course, these are borders that can be crossed with finesse – but Laura three years ago was not yet an adept border-crosser, and only became so *because of the support that came from finding people who were already on the same side*.

Hope: Though I don't imagine many self-identified cynics gravitate toward a life of heady activism and hybrid scholarship, my last "how" is *hope*. Oppression is here to stay, but that fact is not the finale to the grand story of life, it is merely context. This world is brutal and scarring, and because of the way brutality and scarring operate, there is something indelible about it. But as I repeatedly say throughout this book: this need not cause despair. We have the power to accept what is unacceptable, to be intentional (as opposed to habitual) in our everyday behavior, and to learn, grow, heal from, and harness this madness. Oppression is a collective problem, and *individual* choice is both the barrier and key to its solution. You – one person – can resign yourself to the default of complicity, or you can choose consciousness and compassion, and in doing so overhaul your micro-world and each and every micro-world you ever touch.

CHAPTER TWO

The "Other and Oppress" Propensity and the Making of Mental Illness

> As long as we cannot up-level our "thinking" beyond Us and Them, the goodies and
> baddies, it will go on and on. The only possible end will be when all the goodies have
> killed all the baddies, and all the baddies all the goodies, which does not seem so difficult
> or unlikely since, to Us, we are the goodies and They are the baddies, while to Them, we
> are the baddies and They are the goodies. Millions of people have died this century and
> millions more are going to, including, we have every reason to expect, many of Us and
> our children, throttled by this knot we seem unable to untie. It seems a comparatively
> simple knot, but it is tied *very, very* tight - round the throat, as it were, of the whole
> human species. But don't believe me because I say so, look in the mirror and see for
> yourself.
> - R.D. Laing, *The Politics of the Family, and Other Essays* (1969: 124)

Almost as soon as any budding anthropologist is introduced to the discipline, they learn about a general and basic human characteristic I call the "other and oppress" propensity. Step one, humans perceive human variation; step two, humans make meaningful categories about these differences; and step three, humans take the foolhardy leap toward reifying and ranking the categories, resulting in a world that is *unsafe* for human difference (to paraphrase Ruth Benedict[42]). The first two steps of this propensity are universal (though anthropologists today don't like to speak of such things): across time and space, human worlds have been rife with social categories such as gender, race, religion, age, ethnicity, class, caste, clan, profession, sexuality, and nationality, to name but a few. Step three cannot be confirmed universal, though it is certainly pervasive if one takes but a cursory glance at the world today.

In the first section of this chapter I briefly describe the "other and oppress" propensity, and in the second section I apply this to the social construction of madness, arguing that when

---

[42] Ruth Benedict is often quoted as having said; "The purpose of anthropology is to make the world safe for human differences" (cited in Haviland et al. 2013: 134), however I could not locate the source of her words directly, and found a scathing Reddit entry decrying it as an unsubstantiated quote: https://www.reddit.com/r/Anthropology/comments/5debjg/stop_this_ruth_benedict_misquote_the_purpose_of/ However, I *like* the quote, and would correctly cite whoever it was that *did* say it if I could.

"sane" and "mad" – later to become "normal" and "mentally ill" – were created as opposing categories, it was yet another instance of "other and oppress."

The "Other and Oppress" Propensity

> If the doors of perception were cleansed every thing would appear to man as it is – Infinite. For man has closed himself up, till he sees all things through narrow chinks of his cavern.
> - William Blake, *The Marriage of Heaven and Hell* (1790)[43]

The "other and oppress" propensity refers to the process by which "isms" are created. Humans notice and make categories about human differences, and then reify and rank these categories so that the oppression of one group by another appears "natural" to all involved. Social constructionists, like myself, challenge *essentialism* – the supposed "naturalness" of social categories – and illuminate the underlying processes by which people construct and use social categories to forge identities, as well as to organize and divide, exclude and include, the people with whom they share the world.

These underlying processes are many, complex, and intertwined. Firstly, the "other and oppress" propensity begins with "othering," which has roots in basic cognition: humans perceive the world *categorically*. This is an advantageous time saver – one need not relearn what a car is each time one encounters an unfamiliar car, nor is one stumped by pugs because they are similar enough to other creatures one has learned to call "dogs." For humans, the formation of categories – and stereotypes[44] about these categories – is necessary in order to simplify, and thus comprehend and navigate, the world. This goes for cars and dogs as well as for ourselves. According to Sperber and Hirschfeld (2004), all humans have "folk sociologies" – the "capacity to sort conspecifics into inductively rich categories, membership in which is based on (supposedly) shared intrinsic natures" (41). Not only is this a byproduct of basic cognition, but some believe it *adaptive* as it enables in-group cohesion and the survival benefits that go along with it (Sperber & Hirschfeld 2004). Simply put, humans are wired to create groups, to create the "others" to our "us." But the authors' parenthetical "supposedly" is very significant.

---

[43] http://www.blakearchive.org/work/mhh

[44] Stereotyping is a type of "heuristic," which is "defined as cognitive shortcuts or rules of thumb that simplify decisions [and]… lead to cognitive biases." https://www.behavioraleconomics.com/mini-encyclopedia-of-be/heuristic/

If the purpose of category-formation is simplifying the perceptual stimuli we receive from the world, the conundrum is quite clear: the world is *not simple*. The world is chaotic, unpredictable, and dynamic. We are in the unfortunate plight of, by necessity, **applying categorical thinking onto *spectral* and *fluid* phenomena**. And unless we are *aware* of this, it is a very slippery slope toward step three of the "other and oppress" propensity, where we *reify* and *rank*, mistaking social categories for Truth and justifying the inequities that follow this Truth. It will not *matter* if a social category is flawed; whether **the boundaries between categories are clear, or the differences between them exaggerated, or outliers marginalized/overlooked.[45]** A social categorical system can be so absurdly full of holes – such as 19th century racial categories in the U.S. (Baker 1998) – and *still* be accepted as Truth, due to what Pierre Bourdieu (1972) calls *misrecognition*: a "misrecognition… of the arbitrariness on which they are based… [such that] the world of tradition [is] experienced as a 'natural world' and taken for granted" (164). As Sperber and Hirschfeld suggest, the "shared intrinsic natures" people have with group-mates is "supposed"[46] (2004: 41) – but what we *suppose* matters greatly.

Suppositions about social categories become deeply embedded in language, "institutions, practices, material interactions with things and other people" (Hacking 1999: 31), operating largely under the radar, self-perpetuating through cultural inertia and self-fulfilling prophecy. When people *suppose* that "there are girls and there are boys and that is it," and the whole fabric of society rests upon that assumption, from banalities like public bathrooms to fundamentals like marriage and family, calling gender a "social construct" – or a "prevalent and compelling social fiction" (Butler 1988: 524) – is like spitting into the wind. People tend to suppose "social construct" means "not real," and react with skepticism. In *The Social Construction of What?* (1999) Ian Hacking challenges this black and white reasoning, stating that "there need be no clash between construction and reality" (1999: 29). For example, race is not a valid biological category in humans, but that does not negate the real biological and social consequences of *racism*. In this sense, race is very real, and it is ***powerful*** (consequential), and ***power-full***

---

[45] These three flaws are common to all social categories.
[46] Benedict Anderson uses the word "imagined" to a similar effect in *Imagined Communities: Reflections on the Origin and Spread of Nationalism* (2016[1983]). The argument is that the connection people feel to those who share their national identity is *imagined* – we imagine that we share a bond, that we share understandings about the way the world does/should work, etc.

(distributes and reinforces power relations). In *The Social Construction of Reality* (1967), Berger and Luckman made this astute observation about power and worldview;

> The appearance of an alternative symbolic universe poses a threat because its very existence demonstrates empirically that one's own universe is less than inevitable… The confrontation of symbolic universes implies a problem of power – which of the two conflicting definitions of reality will be "made to stick" in the society. Which of the two will win, however, will depend more on the *power* than on the theoretical ingenuity of the respective legitimators (108-109).

The Making of Mental Illness

In taking on a constructionist argument, Hacking (1999) has this advice: "insist that the metaphor [of construction] retain one element of its literal meaning, that of building, or assembling from parts…Anything worth calling a construction has a history. But not just any history. It has to be a history of building" (49). With this in mind, allow me to unpack the building of the medical category "mental illness" from the broader experience of "madness." As this is an expansive topic, this section is divided into three subsections: in "Roots" I outline factors which are deeper and further-in-the-past. In "Stems" I describe the current lay of the land in psychiatry and resistance to psychiatry (i.e. the "brain disease" versus critical alternative models). And in "Withering and Withered Leaves" I describe and decry the ways in which the U.S. mental health system (its categories and its cures) fails in helping and succeeds in harming.

1) Roots: Deeper Historical Factors

Building "Normal" and "Abnormal": Medicine as Powerful and Power-full

> The condition of alienation, of being asleep, of being unconscious, of being out of one's mind, is the condition of the normal man. Society highly values its normal man. It educates children to lose themselves and to become absurd, and thus to be normal.
> - R.D. Laing, *The Politics of Experience* (1967: 24).

Before I can focus on the building of mental illness, I must first describe the building of the categories of "normal" and "abnormal." In the introduction to the *Disability Studies Reader* (2013a), Lennard Davis points out that the "idea of a norm is less a condition of human nature than it is a feature of a certain kind of society" (1). In fact, the word/idea of "normal" only came into being around 1840, and "norm" in 1855. Until then, ideals were mostly godly and

unattainable, but through developments in population statistics, the "average" came to be the new ideal. The norm was born, and with it, the abnormal.

In Georges Canguilhem's *The Normal and the Pathological* (1991[1966]) – his transgressive medical school thesis – he argued that the categories of "normal" and "pathological" are flawed, and that *suffering* should indicate disease rather than normative measurements, as human lives are *dimensional*. (Again, the plight of applying categorical thinking to spectral/fluid phenomena). Canguilhem's mentee, Michel Foucault, later developed a prolific theory of power that implicated the idea of the "norm." In *Discipline and Punish* (1995[1979]) he describes how categorizing and hierarchizing people – in schools, prisons, workplaces, and hospitals – both "punishes and rewards" (181), using (crude but effective) behavioral reinforcement to force people into normative boxes. In *History of Sexuality Volume I* (1990[1978]), he states that such disciplinary techniques result in the "taking charge of life, more than the threat of death, [and give] power its access to the body" (143). This he calls "biopower," the purpose of which is to keep the living bodies of ever-larger populations under control without requiring active force. People are then dominated "not by law but by normalization, not by punishment but by control" (89). It is *far* more effective and efficient to create and disseminate ideology that has people monitoring *themselves* and *each other*, than it is to have authorities monitoring them.[47] Medicine, Foucault argued, was not just about returning the ill to health, but was a link between "scientific knowledge [and] political intervention-technique with specific power-effects" (2003[1976]: 252). The "medical gaze," a term he developed in *The Birth of the Clinic* (1994[1973]), served to reinforce these "power-effects" by turning suffering people into "patients" – scrutinized, surveilled, and normalized by medical professionals.

Medicine may appear neutral or even beneficent – especially when cultural ideology frames it as such – but as Kleinman, Das and Lock (1997) note in the introduction of *Social Suffering*, "There can be little doubt that technologies applied today purportedly to reduce suffering… are often at the same time designed to create or reassert the normal" (xix).

---

[47] A recent article in the leftist U.S. magazine *Jacobin* discusses this very issue: neoliberalism encourages competition and the development of a destructive "perfectionism" whereby we excessively (and about pointless things, like what we look like or what we own) judge and scrutinize ourselves and others – this, the authors note, can be linked to rises in certain mental illnesses, especially anxiety, eating disorders, and depression. https://jacobinmag.com/2018/01/under-neoliberalism-you-can-be-your-own-tyrannical-boss

Building "Mental Illness": individualizing collective problems, plus rampant problematizing

> The clustering of substance abuse, street violence, domestic violence, suicide, depression, posttraumatic stress disorder, sexually transmitted disorders, AIDS, and tuberculosis among people living in disintegrating communities…defeats categorization of such issues as principally psychological or medical and, therefore, *individual*. Instead, it points to the often close linkage of personal problems with *societal problems.*
> - Kleinman, Das & Lock, *Social Suffering* (1997: ix, emphasis mine)

> The recognition that enables one to say, "This man is mad," is neither a simple nor an immediate act. It is based on a number of earlier operations and above all on the dividing up of social space according to the lines of *valuation and exclusion*. When the doctor thinks he is diagnosing madness as a phenomenon of nature, it is the existence of a threshold that enables him to make such a judgment. Each culture has its own threshold, which evolves with the configuration of that culture; since the mid-nineteenth century, the threshold of sensitivity to madness has considerably lowered in our society; the existence of [psychiatry] is evidence of this lowering in that it is an effect as well as a cause of it.
> - Michel Foucault, *Madness: The Invention of an idea* (2011[1962]: 129, emphasis mine)

Michel Foucault undertook the "history of building" of mental illness in two influential works; *Madness: The Invention of an Idea* (2011[1962]) and *Madness and Civilization* (1988[1965]). *Madness and Civilization* is the more well-known, and provides a rigorous historical account of the varying and changing ways madness had been conceptualized and managed in Western Europe and North America. The book is amazing, but it was the earlier book, *Madness*, that shook me with its raw humanism and profound theorizing. The goal of *Madness* was to show that "the root of mental pathology must be sought not in some kind of "metapathology" [i.e. biological cause] but in a certain relation, historically situated, of man to the madman and to the true man" (2). To productively understand madness, one must shift focus from the *individual* to the *collective*, and remain connected to its historical social context.

It is simple enough to see the "relativity of the morbid" (Foucault 2011[1962]: 100), with countless examples of behaviors being valued in one space and shunned in another. It is also simple enough to see the logical flaw in making normal and abnormal the touchstone of understanding madness: the fact that human personality is so relentlessly variable that there is no clear definition of "normal" to oppose. But further than acknowledging its relativity and flaws in classification, Foucault identifies the *root* of the "problem" of madness in the West: not only have we *individualized problems that are collective,* but we have *problematized phenomena that*

are not always and only problems. He notes that "if American psychologists have made deviancy and departure [from the norm] the very nature of mental illness, it is no doubt because… *our society does not wish to recognize itself in the ill individual whom it rejects or locks up*" (104, emphasis mine). When a culture silences certain elements of the human experience, unable to acknowledge them as valid or integral parts of life, it creates profound contradictions. And this tendency toward polarizing black and white reasoning is *cultural*. Psychologist Richard Nesbitt (2003) argues that it is typical in cultures influenced by ancient Greek logic, in which one thing cannot be another. People in Western cultures are thus primed to be hesitant and resistant toward ambiguity – and madness is a wildly ambiguous phenomenon. It is therefore unsurprising that, as Foucault wrote, Western society "cannot offer a solution to the contradictions it has given rise to… and cannot acknowledge its madness" (2011[1962]: 137).

Along with its conceptualization, Foucault traces the history of the *treatment* of madness. "Generally speaking [before the mid 17th century], madness was allowed free rein; it circulated throughout society, it formed part of the background and language of everyday life, it was for everyone an everyday experience that one sought neither to exalt nor to control" (2011[1962]: 112). Then there was a period of "great confinement." The mad, the poor, the old, the sick – the miscellaneous unwanted who were "not fit to belong in society" (113) – were interned in workhouses, and came to be seen as moral inferiors without which the world would be better (a precursor to eugenics rhetoric). *Differences noticed, differences categorized, differences ranked*. Workhouses employed forced labor, not only to make their operation viable, but because;

> the compulsion to work also had the role of a sanction, of moral control. In the bourgeois world then being constituted, the major vice, the cardinal sin in the world of trade, had been defined; it was no longer, as in the Middle Ages, pride or greed, but sloth. The common category that grouped together all those interned in these institutions was their *inability to participate in the production, circulation, or accumulation of wealth* (114, emphasis mine).

Here we see how morality and a budding capitalism came into play. The world was becoming such that to be incapable of producing, circulating, or accumulating wealth meant that one had no place in society. Moral ideology changed to mirror and reinforce the economic shifts which demanded the exclusion of so many: there became a valuing of "reason" and devaluing of "madness" that would be "made to stick" (Berger & Luckman 1967: 109). Erasing the *people*

that manifested madness then became paramount, because the presence of madness, in a world that eschews ambiguity and so values "reason" and "productivity,"

> places the Other world on the same level as this one, and on ground level, as it were. As a result, no one knows whether it is our world that is duplicated in a fantastic mirage; or whether, on the contrary, it is the other world that takes possession of this world; or whether the secret of *our* world was to be already, without our knowing, the *other* world... [it is an] ambiguous experience that allows strangeness to reside at the very heart of the familiar (Foucault 2011[1962]: 127).

In the middle of the 18th century, the "great internment" ended because of social and political pressure relating both to morality (i.e. growing awareness about the conditions in these institutions) and the fear and mystery they garnered. However, the release of society's misfits back into the world did not extend to the mad. It was in this period that the insane asylum was created, and madness became of interest to medicine. Early asylums used a combination of surveillance and punishment in order to "cure" the mad. In the process they were infantilized – which Foucault acknowledged also requires the construction of "child" and "adult" categories – and rendered totally dependent. Contemporary experience is inextricably linked to this history of infantilizing and forced dependence: **dependence and a lack of adult personhood are integral to the experience of psychiatric disability today**.

2) Stems: Recent-to-Contemporary Psychiatry and Resistance to Psychiatry
The "Medical Model" and the "Social Model"

Once madness was reduced to "mental illness," it was susceptible to the same trends that general medicine was going through; positivism, reductionism, and turning toward biological causes and cures for the ever-increasing array of human experiences being medicalized. In seeking to understand the lay of the land when it comes to mental illness and the mental health system charged with understanding its cause and cure, one hence arrives at another dichotomy of sorts: the *medical* model and the *social* model.

The medical model, or "brain disease model," is the logical outcome of the medicalization of madness. It proposes that mental illnesses are chemical-biological diseases, with chemical-biological causes and chemical-biological cures, and was the dominant model for many decades. As Bradley Lewis (2013), who wrote about the history of *Mad Pride*, noted;

> The last thirty years have seen a "scientific revolution" in psychiatry that primarily values quantitative, positivistic protocols for research. The emphasis on "objective" data has

created a preference for neuroscience and genetics at the expense of an array of cultural and humanistic styles of inquiry. This new scientific psychiatry, working in tandem with pharmaceutical funding, has gone on to create today's dominant clinical model of psychiatry, "biopsychiatry" – whose emphasis is almost exclusively biomedical style diagnoses and pharmacological treatments (122).

Lewis's mention of the partnership between practitioners, researchers, and pharmaceutical companies is paramount. Investigative journalist Robert Whitaker exposed the hidden sides of being *Mad in America,*[48] and in *Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America* (2010), implicated the sinister skewing of clinical trial evidence[49] and profit-mongering of pharmaceutical and insurance companies[50] who have an interest in making mental illness something that requires "drugs for life" (Dumit 2012: 6), that *perpetuates* disability rather than countering it. As the editors of *Mad Matters: a critical reader in Canadian Mad Studies* note: "Big Pharma and profiteers in the psychiatric system and academy make a living labelling and medicating that which they cannot imagine or tolerate" (Menzies, LeFrançois & Reaume 2013: 2). In many ways, the dependence of psychiatric citizens on the system is *mutual*. Anthropologist Sue Estroff cleverly asks; "Who is dependent on whom?" (1993: 267), highlighting the fact that the mental health system employs hordes of professionals, all dependent on the existence of "patients" for their living.

Mistrust in the dogma and motives of the mental health system resulted in reactionary movements. In the latter half of the twentieth century in the U.S., many oppressed groups – such as women, and sexual and racial minorities – began questioning norms and challenging their oppression. In the 1980s, people with disabilities and their allies began a similar movement, and the *social model* of disability was born during this period. The social model of disability shifts

---

[48] Whitaker's book *Mad in America: Bad Science, Bad Medicine, and the Enduring Mistreatment of the Mentally Ill* (2010[2002]) inspired a justice-focused movement with an online forum called "Mad in America: science, psychiatry and social justice." https://www.madinamerica.com

[49] Whitaker presents an overwhelming array of information on the dubious dealings between Big Pharma, the US Food and Drug Administration (FDA), and influential psychiatrists/researchers: e.g. a systematic review of anti-depressant trial evidence between 1987-2004 that showed only 50/50 efficacy of FDA approved drugs (not nearly enough to meet accepted criteria of "clinical significance"), as well as exhaustive detail about money individual doctors/researchers received from Big Pharma.

[50] I would be remiss if I did not include the gloriously ambiguous fact that people who work for such companies are not monsters counting cash and cackling over the sleeping bodies of homeless Madpeople. As Emily Martin (2006) wrote in *Pharmaceutical Virtue*, based on research with pharmaceutical sales representatives, many employees "live surrounded by the growing public vilification of the industry as rapacious and profit hungry and yet find ways to make their jobs meaningful and dignified" (157).

focus and responsibility from the *individual* to the *collective*, and proposes a distinction between impairment (limitations of the individual body/mind) and disability (societal oppression), arguing that disability is a *cultural* – not a *natural* – category, and that people with disabilities are not flawed, but oppressed (Shakespeare 2013; Davis 2013a: 2013b). As for the *psychiatrically* disabled, the "anti-psychiatry" movement within the academy, and the "mental patients' liberation movement" (later called "c/s/x," shorthand for "consumer/survivor/ex-patient," a term designed to include people from varying positions on the radical spectrum[51]), created reactionary traction (Menzies, LeFrançois & Reaume 2013; Lewis 2013).

The "Anti-psychiatrists": Intellectual Resistance to Psychiatry

In order to understand the gravity of the psychiatric oppression which necessitated "anti-psychiatry," one must understand "expectancy theory." In psychology, "expectancy effects" refer to self-fulfilling prophecies whereby interpersonal expectations impact behavior and outcomes (Rosenthal 2002). This can go in both positive and negative directions: the positive self-fulfilling prophecy (where high expectation yields high performance) is named the "Pygmalion effect," and the negative self-fulfilling prophecy (where low expectation yields low performance), the "Golem[52] effect." Expectancy theory was stumbled upon accidentally in the mid-1950s when Robert Rosenthal tainted his dissertation research via the "observer-expectancy effect."[53] He then capitalized on his blunder and decided to *research* expectancy effects. Students in his lab were assigned rats and instructed to put them through mazes, with some told their rat was particularly adept at maze navigation, and others told nothing. The rats whose humans had been told they were adept navigated the mazes significantly faster than the ordinary unspecial rats did (Rosenthal & Fode 1963).

His next step was to explore this phenomenon in humans, specifically school children: "If rats became brighter when expected to, then it would not be far-fetched to think that children might become brighter when expected to by their teachers" (Rosenthal 2002: 842). Students at a Californian elementary school were given a standard intelligence test, though teachers were told

---

[51] People who identify as "consumers" are not as anti-system as those who identify as "survivors" (which voices systemic trauma) or "ex-patient" (which voices a severed relationship). I identify as an ex-patient.
[52] These names come from appropriate mythical characters.
[53] There was already awareness that researchers could alter their experimental results by unconsciously conveying their expectations, hence the development of the "double blind" method (Hock 2004).

it was a special test designed to measure a child's potential to bloom – to have an intellectual growth spurt in the next year. Students were then divided randomly into two groups – those with bloom potential, and those without – and teachers were given these (false) results. At the end of the year students were given another test, and there *were* statistically significant differences: those who had been randomly assigned to the bloom group had improved scores. And in addition to test scores, teachers were asked to review their students, and "bloom" students were described as more curious, motivated, intelligent, and friendly (Rosenthal & Jacobson 1966). After several studies with similar results, it became clear that expectancy effects reliably existed, so researchers turned their attention to *mechanisms*. This research found that nonverbal (often unconscious) behaviors of expecters towards expectees had significant impacts – such as tone of voice, eye contact, facial expression, and proximity (Babad et al. 1982; Chaikin et al. 1974).

This literature on expectancy effects provides amazing food for thought: might social categories impact expectations and become self-fulfilling prophecies? The person who wrote the Wikipedia entry on the Golem effect noticed this, saying;

> There is something to be said about Golem effects towards disenfranchised and stigmatized demographics in society such as the homeless, intellectually disabled, and other groups often looked down upon. Due to the low expectations often cast upon individuals in these groups by society as a whole, there is reason to believe that such individuals suffer from Golem effects in a truly significant and crippling manner.[54]

Though the researchers in experimental psychology did not address this, Ray Rist did in his landmark article "Student social class and teacher expectations: the self-fulfilling prophecy in ghetto education" (2000 [1970]), based on ethnographic research in a predominantly black urban school. Early on, he found that teachers created a "caste system" (267), rendered visible via seating arrangements cemented after only *eight days* of knowing the new kindergarteners. The children who lived in poverty sat furthest from the teacher and chalkboard (in some cases, facing *away*). He also noted teachers' verbal and non-verbal behavior, much like the experimental studies did. Toward the students who were wealthier and deemed "fast learners," they were warm and encouraging. The children who were poor were often ignored or subjected to punishment. But the major finding was that *student performance corresponded to teacher treatment*. Those deemed "fast learners" did better each year, as the "slow learners" did worse.

---

[54] https://en.wikipedia.org/wiki/Golem_effect (accessed 3-23-2018)

The gap widened, not unrelated to the spatial arrangement separating students. Rist determined that self-fulfilling prophecies *were* at play, that "teachers themselves contribute significantly to the creation of "slow learners" within their classroom" (293) and that "the common positive treatment accorded to all within the [high class] group by the teacher may have served as the necessary catalyst for the self-fulfilling prophecy whereby those expected to do well did so" (296). His results suggested that schools *reproduce* existing class and race relations: "the system of public education in reality perpetuates what it is ideologically committed to eradicate – class barriers which result in inequality in the social and economic life of the citizenry" (300).

My understanding of expectancy effects compels me to amend this famous bootstrapping Henry Ford quote one can find printed on bright canvas in the home decorating section of Target: "whether you think you can, or you think you can't, you're right" – and whether *they* think you can, or *they* think you can't, *they're* also likely to be right. This is *so* important for understanding the experience of mental illness and psychiatric disability and why people from so many walks of life believe the mental health system to be a cause of further harm to weakened spirits.

The goal of this subsection is to describe the concerns expressed by academics and professionals who fall under the poorly named[55] moniker of "anti-psychiatrist." Sociologist Erving Goffman was one of the first to do ethnographic research with U.S. mental patients. In *Asylums* (1961), he argued that it was *socialization* – not inherent qualities or symptoms – that made *people* into *mental patients*. Through a complex process of total confinement, dehumanization, inactivity, and timelessness (without any structure, the experience of time disintegrates), mental patients were removed from the social world and subsequently lost any ability to function in it.[56] It was also clear to Goffman that the professionals responsible for treating people with mental illnesses did not believe in their humanity or dignity, let alone their now-withering strengths. In a similar vein of implicating *society* over the *individual*, Scottish psychiatrist R.D. Laing believed that "the mad" were merely manifesting the madness of modern society – "a sane response to a mad society" (Shorter 1997: 276) – an idea also articulated beautifully by Foucault in *Madness* (2011[1962]):

---

[55] I think "anti-psychiatry" is a misnomer. Many so-called (and *not* self-defined) anti-psychiatrists pointed out criticisms that could and should have been *useful* to psychiatry. It also sets up another false binary.
[56] Rehabilitative programs like clubhouses do the very opposite, helping people to *develop* such abilities.

When a man remains alienated from what takes place in his language, when he cannot recognize any human, living signification in the productions of his activity,[57] when economic and social determinations place constraints upon him and he is *unable to feel at home in the world*, he lives in a culture that makes schizophrenia possible (138, emphasis mine).

Laing was an influential presence in the movement, for many reasons. Firstly, he truly valued and *validated* the psychotic experiences that fall under the label of schizophrenia, believing that these experiences could be understood and made meaningful if one sought the tools to *listen*. One of his more famous quotes expresses his belief in the potential of psychosis to facilitate the widening of the "cavern chinks" that William Blake (quoted earlier) wrote of;

If the human race survives, future men will, I suspect, look back on our enlightened epoch as a veritable age of Darkness. They will presumable be able to savor the irony of the situation with more amusement that we can extract from it. The laugh's on us. They will see that what we call "schizophrenia" was one of the forms in which, often through quite ordinary people, the light began to break through our all-too-closed minds (1967: 107).

Secondly, Laing rejected the medical model of mental illness and believed in the power of self-healing through validation and existential analysis of mad experiences, combined with *community*. In developing alternatives to psychiatric treatment, Laing formed an organization called the Philadelphia Association[58] in 1965, through which the practice of "Therapeutic Communities"[59] was pioneered. The first was Kingsley Hall, a house in which people with schizophrenia could be "treated" without drugs or restraints. Through living together, participating in domestic activities and the like, with the support of compassionate and open-minded staff/facilitators, he believed that people could reduce psychological distress, heal soul-wounds, and live meaningful lives, without psychiatric practices he deemed harmful. Since the development of the Kingsley Hall Therapeutic Community, the Philadelphia Association has run over 20 such houses in the U.K., with two still in operation.[60]

---

[57] This sounds as though it might have been influenced by Marx' theory of alienated labor.
[58] https://www.philadelphia-association.com
[59] The Laing Society has a list of Therapeutic Community resources: http://www.laingsociety.org/colloquia/thercommuns/index.htm One of the links is this "Consortium for Therapeutic Communities," an informational directory for people looking to access a Therapeutic Community (which are tailored to different needs, such as addiction, personality disorder, criminal behaviour, trauma, etc.) in the U.K. (and to a lesser extent the U.S.): https://therapeuticcommunities.org
[60] https://www.philadelphia-association.com/houses

The 1960s in the U.S. saw two very similar alternatives. Psychologist George Fairweather began the Fairweather Lodge Program in California based on learning that people with serious mental illnesses required less psychiatric hospitalization when they lived and worked together as a community, or "family" (Fairweather et al. 2008[1969]). Today, the Fairweather Lodge program (similarly to the Clubhouse Model) is a standardized program supported by The Coalition for Community Living, with 90 lodges in 16 of the United States.[61] Influenced by both Fairweather and Laing, psychiatrist Loren Mosher started the Soteria Project in 1971. Soteria was designed to be a drug-and-restraint-free therapeutic environment for people with schizophrenia. As Mosher wrote;

> the Soteria method can be characterized as the 24 hour a day application of interpersonal phenomenologic interventions by a nonprofessional staff, usually without neuroleptic drug treatment, in the context of a small, homelike, quiet, supportive, protective, and tolerant social environment. The core practice of interpersonal phenomenology focuses on the development of a nonintrusive, noncontrolling but actively empathetic relationship with the psychotic person without having to do anything explicitly therapeutic or controlling. In shorthand, it can be characterized as "being with" … The aim is to develop, over time, a shared experience of the meaningfulness of the client's individual social context – current and historical (1999).

Mosher's own research provided evidence that the Soteria method was effective at reducing hospitalization and medication reliance, and *more* effective than hospitalization or medication at creating lasting change in residents. And a recent systematic review concluded that "the Soteria paradigm yields equal, and in certain specific areas, better results in the treatment of people diagnosed with first- or second-episode schizophrenia spectrum disorders (achieving this with considerably lower use of medication) when compared with conventional, medication-based approaches" (Calton et al. 2008: 181). But though Mosher was an active and influential psychiatrist and researcher throughout the 1970s and 1980s, founding the journal *Schizophrenia Bulletin* and becoming the first chief for the NIMH Center for Studies of Schizophrenia (1969-1980)[62] in addition to developing the Soteria Project, he became disenchanted with the direction of the American Psychiatric Association, and resigned publicly in 1998.[63]

---

[61] http://www.theccl.org/FairweatherLodge.aspx
[62] http://www.moshersoteria.com
[63] I highly recommend reading his resignation letter, of which my favorite excerpts are: "The major reason for this action is my belief that I am actually resigning from the American Psychopharmacological Association. Luckily, the organization's true identity requires no change in the acronym." And his advice

Related closely to "expectancy theory," Thomas Scheff (1966) introduced *labeling theory*, which proposed that mental illness was merely the labeling of deviance turned self-fulfilling prophecy. He believed that when society views behaviors as deviant, and labels them as mental illness, people with that label are influenced by societal expectations to continue to meet criteria. Moreover, he argued that a diagnosis of mental illness says less about the labeled *individual* than it does about *society's* inability to accommodate the individual. And in a more recent paper titled *The Impact of Illness Identity on Recovery from Severe Mental Illness*, Yanos and colleagues (2010) argue that illness identity – accepting and identifying as "mentally ill" – very often *does* lead to worsened symptoms and diminished subjective and objective quality of life. The authors' model for this process aligns with expectancy theory:

> We propose that accepting a definition of oneself as mentally ill and assuming that mental illness means incompetence and inadequacy impact hope and self-esteem, which further impact suicide risk, coping, social interaction, vocational functioning, and symptom severity (73).

Through the process of self-stigma and negative expectations of oneself – which cannot be separated from *societal* stigma and negative expectations – a form of self-fulfilling prophecy whereby no motivation or hope for recovery precludes the possibility of recovery. Similarly, in Davidson's (2003) work on "recovery," he notes that;

> Many of the stories told by consumer/survivors suggest that…early messages [during diagnosis and treatment] of hopelessness and despair have a destructive impact far beyond the initial shock, disbelief, or discouragement they elicit. Pessimistic pronouncements and the offer of poor prognoses, along with societal stigma and other social consequences of the illness, appear to compound the loss of self brought about by aspects of the illness (49).

Beyond criticisms of psychiatry centered around the causation and treatment of mental illness – whether the onus is on *people's* broken brains and maladjusted being, or on *society* and the *mental health system* that labels and socializes people into the mad/sick role[64] through isolation, degradation, low expectation, drugging, and forced dependence – there were also

---

to "Get out of bed with NAMI and the drug companies. APA should align itself, if one believes its rhetoric, with the true consumer groups, i.e., the ex-patients, psychiatric survivors etc."
http://www.moshersoteria.com/articles/resignation-from-apa/

[64] The "sick role" was coined in *The Social System* (1951) by sociologist Talcott Parsons. He argued that sickness is "sanctioned deviance," an unproductivity that disturbs the status quo and is therefore policed by the medical profession. Being "sick" is hence not a *natural* fact but a specific social role/relation to others, with its own set of obligations (such as seeking/accepting treatment from professionals).

criticisms on *epistemological* grounds. Psychiatrist Thomas Szasz attracted a radical following by attacking the "myth" of mental illness. In his argument, mental "illness" was at best a metaphor, and a poorly applied one at that. Instead, he framed such experiences as "problems in living" (1960: 113) rather than medical diseases with knowable discrete causes (which there was no evidence for). And, alluded to in the "Roots" subsection, there was also epistemological criticism pertaining to the *relativity* of madness as evidenced by its diversity across time and space. The way mental illness is defined and interpreted is "not the gradual discovery of the true nature of madness, but simply the sedimentation of what the history of the West has made of it for the last three hundred years" (Foucault 2011[1962]: 116). And as Hacking (1999) argues, such changes are "not the result of a better classification of individuals as pure beings-in-themselves, but reclassification of individuals in the light of how those individuals had altered, in the light of a previous classification and because of the theories, practices, and institutions associated with that classification" (112). Psychiatric categories are not *discovered*, they are *created*, and once created, these categories alter the categorized.

David Rosenhan's (1973) notorious study where "sane" research assistants faked hallucinations in order to gain admission to psychiatric hospitals, highlighted key flaws in the system's practices of *knowing* and *identifying* "mental illness." As I mentioned in section one, there are three flaws common to social categories; the boundaries between them are unclear, the differences between them are exaggerated, and the outliers are minimized. Rosenhan's study demonstrated that outliers – such as the fact that the "insane" study participants showed no symptoms and behaved "normally" the entire time – were completely overlooked. Once they were mad, they were mad. Their differences – the fact that they had purportedly hallucinated – were exaggerated, and as a result, their entire being was filtered through their newly acquired label of "mentally ill." Rosenhan's ultimate conclusion was that the boundaries between sane and mad are porous, that "the normal are not detectably sane" (252) and that "the insane are not always insane" (254). Madness, as an array of diverse experiences, is obviously a *spectrum*. And yet, mental illness – due to its current formulation as a set of discrete categories – cannot be treated as spectral. This is a serious bind.

Intellectual resistance would not have been possible without the coincidental *political* resistance of people who had experienced the mental health system from the inside. *Mad Pride* is a term that describes diverse movements around the globe in which people have resisted psychiatry due to an experience-driven conviction that the medical model 1) erases the legitimacy of madness as a human experience, 2) pathologizes emotional, psychological and behavioral variation in an act of psychic hegemony, and 3) is coercive and harmful. As Bradley Lewis (2013) – an interdisciplinary MD/PhD scholar who writes in Mad and Disability Studies – notes, *Mad Pride* is "an international coalition devoted to resisting and critiquing clinician-centered psychiatric systems, finding alternative and peer-run approaches to mental health recovery, and helping those who wish to do so minimize their involvement with current psychiatric institutions" (115). Similar to the coincidental disability rights movement[65] proposing the new "social model of disability," *Mad Pride* proponents believed the problem was that "rather than adjust *social* environments to meet different needs, medical interventions seek to cure the *individual*" (116, emphasis mine). And as members of the disability rights movement adopted the term "ableism" to name their oppression, *Mad Priders* adopted "mentalism" and "sanism" (coined by Judi Chamberlin [1978]) to name theirs.

The 1970s and 1980s were fertile decades for this resistance. The *Insane Liberation Front* was formed in Portland (OR) in 1970, the *Mental Patient's Liberation Project* in New York City and the *Mental Patient's Liberation Front* in Boston in 1971, and the (still active) *Network Against Psychiatric Assault* in San Francisco in 1972[66] (Lewis 2013; Chamberlin 1990). These organizations had radical goals for liberty, autonomy, and a post-psychiatry world. They held conferences and shared news through the *Madness Network News*, a newspaper covering the ex-patient movement worldwide (Chamberlin 1990). And, just as it was for Fountain House (described in Chapter Three), the mental health system took notice. As Judi Chamerlin (1990)

---

[65] Lewis (2013) notes that the disability and *Mad Pride* movements have not been collaborative, as may have been expected given their shared struggle against medicalization and inaccessible social environments. There are probably complex reasons why this is so, but Lewis' research suggests that two factors contributed to this separation: that many people with physical disabilities had "sanist" beliefs, and that many people with mental illnesses did not wish to identify as "disabled." ***One could perhaps call this MAD, or Mutually Assured Discrimination…***

[66] http://networkagainstpsychiatricassault.org (this website marks 1974 as the founding year, but I will keep 1972, based on Bradley Lewis and Judi Chamberlin's publications).

wrote, the *National Association of Psychiatric Survivors* (founded in 1985)

> was formed specifically to counter the trend toward reformist "consumerism," which developed as the psychiatry establishment began to fund ex-patient self-help. Ironically, the same developments which led to the movement's growth and to the operation of increasing numbers of ex-patient-run alternative programs, also weakened the radical voices within the movement and promoted the views of far more cooperative "consumers." The very term "consumer" implies an equality of power which simply does not exist; mental health "consumers" are still subject to involuntary commitment and treatment and the defining of their experience by others (333).

When Chamberlin wrote this article about the history of the ex-patient movement in 1990, her view on "where the movement stands now" was a combination of hopeful and cynical that is very familiar to me. *Cynically:* she acknowledged that – as was true for me at first – most people with psychiatric diagnoses did not know about *Mad Pride* organizations or alternatives. Psychiatry was (already) too dominant, present in all major social institutions (courts, schools, etc.), with its co-opting[67] clutches on the ex-patient (now "consumer") movement via funding and professionalizing programs developed by ex-patients[68] and promoting advocacy through organizations like the *National Alliance for the Mentally Ill* (NAMI) – a medical model touting anti-stigma organization founded by family members of ex-patients. *Hopefully*: she acknowledged that the movement was still growing[69] and becoming more intersectional through alliances with groups fighting homelessness, poverty, and other forms of structural ableism.

Emblematic of meta-backlash – or as Menzies, LeFrançois & Reaume (2013: 6) call it, the "sulfurous odour of counter-revolution" – then came the 1990s, the "Decade of the Brain,"[70] as President George Bush said. In 2002, he championed what Bradley Lewis (2013: 125) called

---

[67] Penney and Prescott (2016) define co-optation as "a process by which a dominant group attempts to absorb or neutralize a weaker opposition that it believes poses a threat to its continued power" (35).
[68] Including the Clubhouse Model, as Chapter Three will show.
[69] That same year (1990), a coalition was formed to peacefully protest the annual meeting of the American Psychiatric Association in New York City, and this coalition became the active international radical human rights organization *MindFreedom*, "one of the very few totally independent groups in the mental health field with no funding from or control by governments, drug companies, religions, corporations, or the mental health system." (http://www.mindfreedom.org/who-we-are) Also of note, the still active Hearing Voices Network (HVN), established in 1988, was developed as an alternative, in which providers and patients strive to validate and make meaning of "auditory hallucinations." (https://www.hearing-voices.org/about-us/)
[70] "The Library of Congress and the National Institute of Mental Health sponsored a unique interagency initiative to advance the goals set forth in a proclamation by President George Bush designating the 1990s as the Decade of the Brain: "to enhance public awareness of the benefits to be derived from brain research."" https://www.loc.gov/loc/brain/

the "Bush Triple Play" – 1) Sally Satel, a biopsychiatrist and critic of c/s/x run alternatives, was appointed to head the National Advisory Mental Health Council, 2) many peer run services were defunded, and 3) the New Freedom Commission on Mental Health[71] was formed in order to fund and conduct brain-based research. Between 1990 and 2000, the U.S. pharmaceutical market expanded by 683% (Rose 2006) as more and more behaviors were medicalized, more and more people became "mentally ill," and pills were promoted as the ultimate "magic bullets" (Whitaker 2010) – not just for illnesses, but any imperfections that stood in the way of one's "optimization," for "biology was [no longer seen as] destiny, but opportunity" (Rose 2006: 51). Electroshock treatment "rose from the ashes of denunciation to become "respectable" again"[72] (Menzies, LeFrançois & Reaume 2013: 7), and "deinstitutionalization" was blamed for the continued social inequities experienced by people with mental illnesses, "rather than the long-standing systemic prejudices that led to chronic underfunding of social supports that were supposed to go along with the release of ex-patients from institutions" (7).

In 2003,[73] a small but passionate group of *Mad Pride* activists in Pasadena, California, staged a hunger strike. Their motives were simple: researchers within the mental health system did (and still do) not agree on simple questions like "do medications work?" and "are the safe?" (as Whitaker's *Anatomy of an Epidemic* [2010] would later elucidate), nor had (or have) they produced any direct evidence that mental illnesses are in fact "brain diseases" despite this being the ubiquitously accepted doctrine. The hunger strikers simply challenged NAMI and the American Psychiatric Association (APA) to provide evidence for their claims. The APAs response was; "brain science has not advanced to the point where scientists or clinicians can point to readily discernible pathological lesions or genetic abnormalities that in and of themselves serve as reliable or predictive markers of a given mental disorder" (Lewis 2013:

---

[71] https://www.federalregister.gov/documents/2002/05/03/02-11166/presidents-new-freedom-commission-on-mental-health

[72] I was surprised to discover during my fieldwork that an interlocutor younger than I was had received electroshock treatment, for I had (naïvely) believed the method a thing of the past.

[73] Also in 2003, the radical intersectional anti-oppressive organization "Icarus Project" was founded in San Francisco. Their goal is to create and disseminate survivor-produced toolkits for self and community healing, aimed at being a resource for oppressed peoples. They train providers and peer supporters in how to engage in anti-oppressive therapeutic work. Like myself, "Icarus has always had an analysis of mental health and distress as being directly linked to experiences of social oppression and trauma, asking questions like, "What does it mean to be crazy in a world gone mad?""
http://theicarusproject.net/welcome-to-the-icarus-project/origins-and-purpose/

124). It had not "advanced to the point" where they could prove what they nevertheless allowed (and encouraged) the public (*and* the President) to believe.

"Biopsychosocial": An Attempt at Bridging a False Dichotomy

> Today, all explanations of mental pathology must "pass through" the brain and its neurochemistry – neurons, synapses, membranes, receptors, ion channels, neurotransmitters, enzymes, etcetera. Diagnosis is now thought to be most accurate when it can link symptoms to anomalies in one or more of these elements. And the fabrication and action of psychiatric drugs is conceived of in these terms. Not that biographical effects are ruled out, but biography – family stress, sexual abuse – has effects through its impact on this brain. Environment plays its part, but unemployment, poverty, and the like have their effects only through impacting upon this brain. And experiences play their part – substance abuse or trauma for example – but once again, through their impact on this neurochemical brain.
> - Nikolas Rose, *The Politics of Life Itself* (2006: 220)

In *Of Two Minds: an Anthropologist looks at American Psychiatry* (2001), Luhrmann presents her "studying up"[74] ethnography, and reveals that the binary of "psychoanalytically" and "biologically" minded psychiatrists is *false*. Psychoanalysts did not disagree that biology was relevant, nor the reverse, it was about 1) *degree*, and 2) the manner they felt destructive traits could be most effectively *changed* (i.e. treatment). Medication, or psychotherapy? Today, the standard answer is "both."

Having recently completed my Master's in Social Work in Interpersonal Practice and Mental Health, I can attest that the "brain disease" angle has weakened since the failed "Decade of the Brain." Today, the ubiquitously accepted doctrine is that mental illnesses are "biopsychosocial."[75] Whereas the medical model implicated the brain, and the social model implicated society, the biopsychosocial model seemingly plays the "middle ground" card. It is now believed that there are biological explanations (genes, chemicals, synapses, lesions), psychological explanations (behavioral reinforcement, personality), and social explanations (life experience and context), that combine to produce "mental illness." However, as the quote opening this subsection suggests, there is still a brain-focused orientation to this model.

---

[74] Referencing Laura Nader's (1969) call for anthropologists to "study up," or research the powerful as often as they do the disempowered.
[75] See this article for full definition and history of the model:
https://www.sciencedirect.com/topics/neuroscience/biopsychosocial-model

Moreover, it is still an *individualizing* approach, which means that its treatments do nothing to further a "collective identity" that could ameliorate the effects of stigma and isolation (Mandiberg & Edwards 2013) or facilitate consciousness-raising (Chamberlin 1978; 1990). In short, the "social" in biopsychosocial does not address the systemic oppression of people labeled with mental illnesses, nor does it include the voices of people – like myself – who cannot move past the entrenched violence of psychiatric diagnosis and treatment.

To me, the "cause" and "cure/treatment" arguments are not particularly interesting. In 1993, Sue Estroff argued that it was time to stop expending effort asking whether mental illnesses were real, and what caused them, and to focus instead on why *outcomes* between people with like diagnoses were so variable. Why one person with schizophrenia has a job and family, and another is homeless. As Evelyn Fox Keller (2010) wrote in *The Mirage of a Space Between Nature and Nurture*: "Let us ask not how much of any given difference… is due to genetics and how much to environment, but rather how malleable individual human development is" (84). Sure, mental illnesses are biopsychosocial, but that neither adequately explains or addresses the fact that many people with mental illnesses are "withering and withered leaves," nor does it give hope to those who want to believe individual (and collective) change possible.

3) Withering and Withered Leaves: How Psychiatric Categories and Cures Cause Harm
Being "Mad in America": Ethnographies of Mental Illness and Trauma in the U.S.

In 1981, Sue Estroff published *Making It Crazy*, an ethnography of Assertive Community Treatment (ACT) clients in Wisconsin, many of whom were formerly patients in asylums similar to the one Goffman (1961) had examined. The book is a deep and humane depiction of the lives of people "making it" while "crazy." In her analysis she argues that rather than being a problem of individuals, mental illness is a collective phenomenon: "We all make this lifeway a crazy one, not only by defining it as pathological but by contributing to its perpetuation with this very act of treatment *qua* definition" (40). We *all* make mental illness the nightmare that it is, and in a later publication (1993) devoted solely to theorizing the *chronicity* of mental illness – or why an experience with psychological suffering becomes a lifetime sentence – she takes this further. In addition to the *ideological* warfare related to low expectations[76] and the pigeon-holing that

---

[76] "Clients are told constantly in multiple ways that they need meds, probably for the rest of their lives…told that they will never "get well"" (1981: 109).

enables "chronicity [through] a fusion of identity with diagnosis" (251), she implicates *institutional and structural* issues: "among the factors contributing to chronicity are: (1) the growing number of and demand for jobs by mental health professionals; (2) (fueled by) ardent public and political advocacy and espousal of medical models of mental illness among family members[77]; and (3) income maintenance resources that are illness-tested and bound to deservedness through disability"[78] (251). And yet, people in these settings do have *agency*. They learn how to navigate this flawed system. They "make the best of it" (Estroff 1981: 110). Similarly, in Carr's (2010) work with addiction treatment clients in the Midwest, she notes how there is a formulaic "script" that is *expected*, and yet in being socialized to meet this expectation, many are actually "flipping the script" – playing along with what is expected of them disingenuously in order to access resources. "People can act politically by strategically reproducing – rather than simply resisting – ideologies of language" (19).

Many other ethnographic works have paid attention to *socially mediated* problems of life with mental illness. Corin (2010) worked with people with schizophrenia and found that the unstructured time and lack of expectation for them to be anywhere or do anything, created a world in which seemingly trivial routines become crucial: that they eat at the same diner every day, visit the same parks, and are "skillful at developing a position on the margin of our common world" (113). Desjarlais (2010[1994]) similarly noted in his research with the "homeless mentally ill" that rather than "experiencing" life – a concept that demands narrative flow to a life story – they merely "struggle along." Without the structure and purpose of social participation, there are no "experiences," just a *timelessness* akin to what Goffman (1961) noticed in *Asylums*. People mentioned that their memory didn't work for this reason: "I never learned how to use my memory like most people do" (2010[1994]): 169). People don't remember details or events – *experiences* – when there is no reason to, when time collapses in on itself and a good day isn't a day that something *good* happens but a day that *nothing* happens. He too notes that this is a social, not an individual, problem: "While the disabling troubles of mental illness surely play a

---

[77] She is referring to NAMI, which as noted earlier was founded by family members of people with mental illnesses, and is still geared toward ally (rather than patient-focused) advocacy.
[78] "Being a full-time crazy person is becoming an occupation among a certain population in our midst. If we as a society continue to subsidize this career [through welfare entitlements], I do not think it humane or justifiable to persist in negatively perceiving those who take us up on the offer" (1981: 255-6).

role here, it is a set of political, social, cultural, and environmental forces, rather than any inherent will or disposition, that leads people to either experience or struggle along" (171).

<u>In Conclusion: Disrupting the Layers of Suffering</u>

In concluding this subsection – and this chapter – I briefly turn to "intersectionality" (Cho, Crenshaw & McCall 2013; Collins 2000) to better understand the *layering* of suffering experienced by people diagnosed with mental illnesses. People with mental illnesses are *people*, with various other oppressive experiences that create a feedback loop with their diagnoses: mad women's experiences and needs are divergent from men's, gender non-conforming folks from cis-folks, heteronormative from non-heteronormative folks, people of color from white folks, immigrants from citizens, people of one faith from another, and perhaps most significantly and intersecting, *the poor from the non-poor*.[79] And within the large and diverse group of people who share the label "mental illness" – and the even larger group who share the experience of "diagnosable (but no thank you) madness" – there is *great* diversity. Menzies, LeFrançois, and Reaume (2013) remind us that even among *Mad Priders* and *Mad Studiers* there is "no consensus of a post-psychiatric world" (17). And certainly, it is not the mission of Mad Studiers to invalidate people who do not identify as "survivors" or "ex-patients" but as willing "consumers" or active "partners" – as do the majority of my interlocutors. "Mad Studies is steadfastly arrayed against biomedical psychiatry, at the same time as it validates and celebrates survivor experiences and cultures" (13), no matter how much our views about the *helpfulness* or *harmfulness* of mental illness/psychiatry as an ideology/practice differ. At the end of the day, most (if not all) of us who live and work in this realm share a similar overall goal: to disrupt the layers of suffering. We may disagree about *how*, but we want to see changes that mean people are no longer "unable to feel at home in the world" (Foucault 2011[1962]: 138).

I believe that the current mental health system is not only incapable of achieving these ends, but is a *barrier* to them. In her piece for the edited volume *Searching for a Rose Garden: Challenging Psychiatry, Fostering Mad Studies* (2016), ex-patient, activist, and peer supporter Mary O'Hagan writes;

> Despite my best attempts to be fair and measured, I have reached the conclusion that psychiatric harm is routine and widespread. It is not something that just happens as a

---

[79] I will take this further in Chapter Three.

result of poor performance or ethical lapses committed by a few. It is ingrained in the fabric of psychiatry – against a backdrop of community stigma and discrimination – by mental health legislation, narrow funding allocations, Big Pharma, professional vested interests and harmful practices committed by many. After 30 years I know enough to say with some certainty that psychiatry does more harm than good[80] (12).

Alternatives are desperately needed – and they *are* out there if one knows where to look – and moreover, the *hope* for alternatives continues to be a beacon. As Menzies, LeFrançois, and Reaume (2013) note;

> For those who inhabit the margins of our 21st century civilization – the armies of lost and outcast people facing a broken system[81] that serves up chemical cocktails and institutional constraints as a hollow substitute for care, compassion, human contact, and the basic requirements for a dignified life – Mad Studies will have little meaning if it cannot offer some sense of an alternative, some measure of hope that the present can be endured and overcome (17-18).

There is no singular theory or practice that can tell us how to conquer the fundamental human tendency to "other and oppress," nor how to heal the cumulative and compounding wounds that oppression has left on our individual and collective bodies and souls. However, as Howard Zinn (2002) wrote in his famous autobiography *You Can't be Neutral on a Moving Train*:

> To be hopeful in bad times is not just foolishly romantic. It is based on the fact that human history is a history not only of cruelty, but also of compassion, sacrifice, courage, kindness. What we choose to emphasize in this complex history will determine our lives. If we see only the worst, it destroys our capacity to do something. If we remember those times and places – and there are so many – where people have behaved magnificently, this gives us the energy to act, and at least the possibility of sending this spinning top of a world in a different direction. And if we do act, in however small a way, we don't have to wait for some grand utopian future. The future is an infinite succession of presents, and to live now as we think human beings should live, in defiance of all that is bad around us, is itself a marvelous victory (208).

For my part, I am here to "seek the good" (Ellis 2007) through exposing the bad, and revealing the ways that people live *good* lives in spite of (even because of) all the *bad* around them. I do hold onto hope for widespread social change – be it dramatic and abrupt (like Robert

---

[80] I concur, and in the next confessional monologue will explore my personal reasons for doing so.
[81] But as is oft-said in social justice circles (i.e. Ta-Nehisi Coates' views on criminal justice, see https://www.theatlantic.com/notes/2015/09/i-think-our-criminal-justice-system-is-working-as-intended/404725/?page=1&oldest=true) - The system is not *broken*, it was designed this way.

Sapolsky's baboons[82]), or a gradual back and forth of revolution and "sulfurous counter-revolution" (Menzies, LeFrançois, & Reaume 2013). But the metaphorical arc of justice is too long to be my *only* hope, so I intentionally narrow my focus (centralizing the fringe, if you will) toward my micro-world and the micro-worlds of my fellow mad comrades who refuse to "sleepwalk wrapped in this flimsy and unobservant fabrication" (Pinkola-Estés 1996: 277). In our micro-worlds, madness is just one of life's many "keys."

The Key

Your heart and mind opens
when you accept the key
to open the doors
not just to agony and pain
but to beauty wonder and peace
- Charles Tenaglia (published in Fountain House's Spring 2017 zine)

Figure: Front cover of "The Fountain Pen," the aforementioned zine.

---

[82] Robert Sapolsky (2004) witnessed something scientifically crucial that one could never ethically orchestrate: He was researching *stress* in baboons – a notorious species for violently enforced social hierarchy. Because alpha males never share with subordinates, when they got wind of a meat stash in a nearby resort, only (and all) alpha males partook in the revelry. Unfortunately (fortunately?), the meat was tainted and they all died, leaving a troop devoid of alpha males. The beta males, who had spent their lives perfecting the affiliative behaviors necessary for surviving the lower rungs of the social ladder, were launched into dominance. Within a generation, this troop was no longer violent, demonstrating that this was cultural behavior not intrinsic to the species. This research received public attention: https://www.nytimes.com/2004/04/13/science/no-time-for-bullies-baboons-retool-their-culture.html

CONFESSIONAL MONOLOGUE
Never Again

I recently had a curious clinical moment where my "mental health" intersected with, of all things, dermatology. I have psoriasis. I say my skin and my soul are the battle sites on which played out the cumulative violence I experienced, witnessed, and was not taught soon enough how to heal from. According to the Adverse Childhood Experience[83] study, auto-immune diseases (like psoriasis) are common consequences of the continued stress one Experiences in an Adverse Childhood. Through Adversity, my body, like my soul, learned to self-attack. I phrase it as self-cannibalization – *"I wish my body would stop eating itself"* – which is also an apt metaphor for what I did to myself spiritually in my young adulthood through a relentless and consuming self-hatred.

A few months ago, I began "flaring," as they say. Within weeks, 40% of my body was "lesion." It was debilitating enough to tip me over the trauma-addled threshold that keeps me steadfastly away from all things clinical. Begrudgingly, I accepted that I could not bear it, I could not heal it, and I did not have the energy to seek alternatives. I was hospitalized. And just as I had expected, I was flooded with painful memories. When they told me I couldn't leave the clinic during treatment hours, I remembered how it felt knowing I couldn't leave the Ward until a doctor deemed me discharge-able.

I was a psychiatric "inpatient" only once, for *one* night, in my many years of constant clinical visits. I went because I was dangerously suicidal and no one wanted me alone

---

[83]https://web.archive.org/web/20151227092712/http://www.cdc.gov/violenceprevention/acestudy/index.html

with myself. It was truly transformative. I left, and not only did I not kill myself, but I have neither set foot in a mental health clinic nor been mentally ill since.

Myself and the people I met in that world were not on the same page about some serious fundamentals, and I had been blind to this until that night in the Ward. It felt like waking from a cult. It felt like a part of me died right there. The "patient"? The "person with a mental illness"? The last of my ability to trust that the mental health system was a safe home for me? Whatever it was, I felt hollow without it. I had needed, so badly, for my experience to make sense, and had gladly drunk the "mental illness" Kool-Aid only to find myself (metaphorically) puking pink while those around me "ascended." This was not going to work for *me*. The buy-in was gone. I was empty, anchorless, and lost.

But there is something liberating about loss of this magnitude. I was *free*. I could refill. Rest, and then fortify. I was not afraid, because the worst had already happened.

When I left the Ward I stopped taking my prescriptions immediately (with mild concern for the recommended tapering). I held myself together through the following eerie and dark times as Sirius Black did (#HarryPotterFan): he reminded himself he was innocent in order to keep hope whilst imprisoned. I reminded myself I was no longer imprisoned in order to keep hope whilst newly liberated but without a new anchor.

I found new anchors. I fortified. And in the bustle of time passing, I forgot. I had comparatively little voice as a writer back then, through which to remember. In the scribbled notebook that came with me to the Ward, I vent about my fellow patients, decry the selection of "books" in the "library" and the fact that I (arrogantly but not wholly without foundation) believed myself more intelligent and interesting than the doctors in control of my sanity, and I repeat the phrase "*never again*."

Never again.

But in the dermatology treatment center, I was brought there again (in a sense), inspired to reflect and write about the **iatrogenic effects**[84] the mental health system had upon me personally, how being mired in clinical encounters drove me mad(der than I already was) by facilitating my total surrender to believing myself sick, bad, and weak.

How did clinical encounters contribute to my **disempowerment** and **internalized inferiority**? I thought you'd never ask…

Feeling Invalidated: By this I am referring to the way professionals use diagnostic language to cloak and coopt the interpretations of the person having the diagnosable experience, whilst simultaneously believing they are both *right* and *helpful*. "That's not you, that's not real, that's mental illness." Fellow *Mad Studier* Maria Liegghio (2016: 122) calls this "a denial of being," a form of "epistemic violence" akin to the erasure of indigenous peoples through colonial invalidation of their worldviews.

You begin to chronically doubt yourself the more you speak truths to people who invalidate them. I acquiesce that I have since seen invalidation used kindly and effectively (like gently reminding someone that the fear they feel at the contents of a delusion is unfounded). Nevertheless, it is at minimum disempowering, and has potential for great spiritual violence. I was told I was not *fat*, I was *Anorexic*. I was told I was not *worthless and unlovable*, I had a *Complicated Grief Disorder* due to my divorce (plus *Unresolved Trauma* due to my Adverse Childhood Experiences). I was told that my existential concerns – that life was brutal and meaningless – were just symptoms of *Clinical Depression*. For the first two, the challenge to my truth was justified, if poorly executed. Sometimes it seems there is little else to say but "no, that's not at all true," and were I in the same position, I might also say it (or better, "I can see why you feel

---

[84] This specific topic means that I am not dedicating much space in this monologue to the people I *did* connect with in the system, or the facets of treatment that *were* healing. Such people and facets did exist, but were enough of a minority that this monologue is still the truest representation of my overall experience that I can currently muster.

this way, but that's a harmful narrative and I urge you to select another"). However, the third and by far most frequent of my invalidating experiences, I cannot justify – and I will devote energy in Chapter Six to addressing practitioners with a plea to develop skills to deal with the existential concerns of their patients. When someone asks you "but what's the *point* of it all?" you need an *infinitely* better answer than "stop overthinking things, and let me do my job."

Feeling Unseen: The "medical gaze" is more than a theory about the ways medicine reduces people to patients. It is a concrete lived interpersonal moment. I've seen it and been unseen by it. The way someone looks at you with such separation, as if through the glass of a fish tank or the bars of a cage, with no trace of awareness that "*there but for the grace of God (and Privilege) go I.*" During my recent dermatological hospitalization, I had an encounter – which the first sentence of this monologue alluded to – that well encapsulated this kind of concrete lived interpersonal moment.

One of the doctors asked me how I was feeling, and in the moment that he asked, I was "feeling ambivalent, both skeptical and hopeful about the improvement so far, and ultimately exhausted by the weight of being stuck and sticky under fluorescent lights for so long. I mean, it really is horrible, this experience."[85] Toward the end of my monologue I began to cry. The roomful (two nurses, the doctor, a resident) seemed stunned, and I responded with "well, you asked how I was feeling." The resident quickly said "yes, thank you for sharing" and tried to hand me a tissue, to which I said "leave it. I'm covered in goop anyway." She was of course being nice, but things are never that simple, and I felt that for as much as she was being nice, she also wanted not to have to look at my pained and wet face (and I thus stubbornly[86] wanted it to remain both pained and wet). The doctor met my (still wet) eyes, perhaps in just the way it instructs to in the

---

[85] This begs some clarification: my treatment involved two weeks of daily attendance in which I received phototherapy (high intensity UVB radiation), was twice smeared in a half-inch layer of steroid cream, then sprayed with water and put in a plastic "sauna suit" to trap it all in.
[86] This grumpy stubbornness is likely "soul padding" (protection) that I have developed through disempowerment.

manual on how to respond to a patient who is crying, and gave an awkward "I'm so sorry" and asked if I were "following up with a therapist." I told him I was not, that I had the realm of my ebbs and flows of emotion quite under control (thank you). He then asked me if I, "umm," ever thought of "hurting myself." I smiled and I sighed (deeply). I thanked him for being responsive to my emotional distress, told him I quite understood his impulse to respond in *this* particular way, to cover *this* particular base, and that I appreciated his thoroughness, but no, I was merely expressing entirely valid emotions shared by, I'd be willing to bet, every patient he has *ever* seen here. No I am not thinking of hurting myself. I am hurting (and being hurt) quite enough as it is.

This "medical gaze" almost reduced me not to a *dermatology* patient, but a *mental health* patient. Of course, I am now sufficiently empowered that I was unrattled. I knew exactly what I needed when I spoke my truth to him – simple empathy – and I also knew when and how to relinquish that objective and satisfy myself with a gracious departure (and subtly clever last word). For a moment I wondered, "it is really protocol to give a robotic self-injury risk assessment when a patient cries?" and then I remembered I was talking about American medicine, and that was a silly question.

Feeling Misplaced: The mental health system is a behemoth, and thus I suppose it rash to claim there is no "place" for me in it. But I can at least say that I was very much *misplaced* within it. To explain, I must backtrack to my arrival in Michigan.

When I came to Michigan, I already believed myself mentally ill. I had seen many school-based counselors and physicians for my varied "problems in living," and though I had never seen an actual psychiatrist, I had been diagnosed and medicated for "bipolar disorder" for four years.[87] When I moved to Michigan, I understood that, as someone "in my condition," I needed to be someone's patient, so I contacted the university's department of psychiatry. Based on my understanding of the system, I figured I needed

---

[87] Which sounds (*is*) sketchy, but unsurprising in an age where *dogs* are prescribed Prozac.

a new therapist (someone to connect with and see regularly) and I needed a new drug-dispenser/doctor (someone to see occasionally for ten minutes and then forget). However, though I was reasonably stable for the initial meetings with my New Doctor and New Therapist, within six months of the move, my now-ex-husband decided to end our marriage – and could not avoid mentioning, when pressed, that my mental health was one of his reasons for believing our match poorly made. Though I now believe he was correct in deeming our marriage unsustainable, at the time I felt that a) I was losing my purpose, my home in the world, and b) it was *because* I was mentally ill. The "mentally ill but under control" narrative I had expressed to my New Doctor and New Therapist unraveled, and they saw for themselves just how sick their New Patient was.

And now comes the juicy part of the tale: now that I was sick, slicing and screaming and starving and not playing the role of "mentally ill but under control" a jot, they began to *heed* me. And though my underlying (and in their 100% correct opinion, dubiously acquired) diagnosis was a "mood disorder," my "comorbidities" – my "Psychiatric RAP Sheet" – was *impressive.* I was piling on the diagnosable "problems in living" like it was my business. This made it difficult for them to know how to proceed – What to address first? What was most critical? The self-injury, or the eating disorder? The cognitive traps[88] or the unstable moods?[89] Alas, my New Doctor (a mood disorder specialist) decided it was *drugs*. Once he caught a whiff of "unprescribed mood-altering substance," it overrode all else like a diagnostic one-drop rule. I was shuffled to a *New* New Doctor in the substance abuse center. And the hilarious thing, truly hilarious, is this: I was merely a run-of-the-mill Pot-head with no more of a claim to "drug addict"

---

[88] ***AKA the total bullshit beliefs about myself that I was clinging to.***
[89] This is a good opportunity to balance out my "iatrogenic effects" monologue with an aside: during this time, I did seek help outside of the university system. My ex-husband (who was not at the time legally my ex-husband) had great insurance, which paid for a private out-of-network partial hospitalization program for people experiencing depression and complicated grief. I found that experience very healing – group therapy, art therapy, psychoeducation, and then home to sleep in one's own bed. Alas, it was tainted after-the-fact because one of my fellow patients (a man twice my age) slipped a note in my pocket confessing his attraction to me, and then Googled me and found my email so that he could repeat the sentiment (#MeToo).

than the rest of my graduate school cohort. For as much as I was a stoner – someone who used marijuana daily – I was also *functional* on it (you will hear more on this subject). The notion that the most appropriate place in the system for me was the substance abuse center was laughable. Yet, that became my institutional "home." This misplacement had profound and negative consequences for me. Especially in

Feeling Threatened: Until I was in the substance abuse center, I had not felt threatened in clinical settings. I had been accustomed to viewing clinicians as sometimes kind and wise, sometimes boring and wrong, but never as *threatening*. But here, it was constant. Sometimes it was subtle: "you will not get better if you continue to smoke marijuana." By framing it in this way, they make my betterness my choice (and my fault), whilst at the same time claiming expertise beyond me: that they *know* any and all unprescribed drugs are bad, bad barriers to betterment. Sometimes it was not as subtle: "you are an addict, and you *cannot* use any substances or there will be *serious* consequences." (Allow me this brief pause to laugh at the riotous conflation of Pot-head with "addict"[90]). Beyond words, there is something about being forced to piss in a cup every time you visit a place that makes it feel threatening, especially when you are reminded that the purpose of the piss is to make sure you are behaving yourself, and that the piss is in many ways a more believable entity than you, the pisser.

This entire time I repeatedly told them, "this piss will tell you exactly what I will tell you: that I was high yesterday, the day before, and the day before that, and have no intention of not being so today, and tomorrow, and the day after that." Yes, the entire time I was a twice-weekly outpatient at the substance abuse center, amounting to around two years, I told them I was "using" and had *no desire or intention not to*, and regularly wondered aloud whether I was in the appropriate place. I was stubborn (see?) and resistant (hardly surprising reactions to feeling threatened). Of course, because I was also Invalidated, Unseen, and Misplaced, my resistance only exacerbated matters. There

---

[90] In a later confession monologue (Chapter Four) I will further explore cannabis and addiction.

was so much tension, so much stubbornness (on both sides), and it spiraled such that I eventually took pleasure in their displeasure. Every narrow-eyed purse-lipped sigh gratified me beyond measure.[91] And this dance led to my

Feeling Bad: I don't mean having feelings that feel bad (well yes, that too), but feeling as though one *is* bad. I came to feel baaad, rotten to the core, toxic, irreparably broken. (The "brain disease" angle they fed me only made it seem immutable, truer than true. It made me think "fuck it – I'm *bad*").

There is something so corrupting about the realization that one can never again use any (unprescribed) mood altering substances, especially when one has grown to rather *trust* a particular substance (as I had marijuana). The prospect of life without it, and the assertion I kept receiving that this was the *only* option,[92] made me feel like a *monster* because I didn't want it. *I didn't want to be good if good couldn't include marijuana*. But after being outnumbered for so long, I eventually acquiesced that I was indeed a drug addict, *and* a very bad person for wishing to remain so. Mine was the only voice, among so many powerful voices, that questioned whether "Cannabis Use Disorder" was a real thing. I repeated that "it was the only substance that ever helped. Hadn't I been on psychopharmaceuticals for longer and had no relief?"[93] "Yes, but because you are ruining their efficacy with your drug addiction." "Oh, of course." So I agreed to stop smoking pot so that I could be *good* again, because feeling *bad* felt *too bad*.

---

[91] There is a version of myself I (during grief counseling with a *wonderful* therapist) learned to call "Stray Dog Laura." This was who I became in this space, precisely because I felt threatened. And I have known "Stray Dog Laura" all my life, because she is the same snarling dead-eyed creature my mother would meet when she made me feel threatened.

[92] From their perspective/worldview, this is true. But this doesn't mean I was wrong, it means that, as I said earlier, *we were not on the same page about some serious fundamentals.*

[93] One of my interlocutors, Marian, had a similar story. She identified as a Pot-head, and told me that she has so much difficulty accessing it because her psychiatrists won't authorize it; "for me, it works better than my meds actually. I have argued with many psychiatrists about this. I'm not ashamed to admit I am a Pot-head."

Once I believed that I was an addict, and started to practice abstinence and restriction – a slippery slope for someone with a history of disordered eating, someone for whom abstinence and restriction was already part of a pattern of self-punishment – things rapidly worsened. Within two months of ridding myself of the "evil" of marijuana, Laura – two-drink-drunk Laura – had become *Drunk* Laura. Of course, the fact that I had replaced one substance with another confirmed that I was an addict after all. And alcohol was, let it be known, much more destructive. Rather than sitting alone watching Scrubs reruns with Cheetos crumbs scattered down my naked chest (#Cheeto-tits), I was waking up once or twice a week surrounded by the chaos of blackout-sex-last-night. It was this catastrophic slide that precipitated my night in the Ward.

Feeling Humiliated: I know things are relatively "better" than they were when psychiatric patients could be stripped naked and blasted with cold water, however, hospitalization is still humiliating enough to cause lingering spiritual wounds. When I arrived for my one night in the Ward, the first thing I remember happening is being stripped of my belongings. I had not expected this. I presumed that I would be asked (but not forced) to wear a hospital gown, but I had not expected them to take my phone, laptop, wallet, *everything*. I immediately felt like a prisoner, and when I demanded to know why, was met with a dissatisfying list of bureaucratic reasons followed by a list of faux-therapeutic reasons that were intellectually insulting (e.g. their assertion that, without technology to distract us, we can take fuller advantage of the magnanimous resources at hand). To make matters worse, patients who are there because of Suicidal Behavior are singled out – everyone knows who we are, because we never, for one second, have any privacy. I remember thinking (foolishly, in hindsight), that I could at least shit in peace, only to discover that I was also to be accompanied in my ablutions.

There is also something *vicarious* and *collective* about humiliation in a place where it is so omnipresent. I had come of age in a community (a liberal university) where stigma was not as voracious, so I had not felt ashamed to share the label of "mentally ill" with others. But suddenly I was sharing a room with a middle-aged woman surrounded by

dolls who never spoke but would periodically scream, and outside of our room, I was doomed to wander the halls desperately seeking a space – any patch of floor – where the man who breathed loudly and stared intensely would not follow me.[94] I felt humiliated, not just for myself because I was a "Suicidal" wearing sagging brown scrubs and a tampon someone watched me insert, but for *all* of us, even the someone who had watched me insert said tampon. I was humiliated for the doll-surrounded woman who did not deserve a cruel witness to her degradation – I was humiliated by *her* humiliation. I was also humiliated by the *fact* that I was humiliated by her humiliation, and the fact that I had *projected* humiliation upon her.

There I was, surrounded by people who shared the label of "mentally ill" with me, and I could find no common ground, nothing that made me feel we were "one" aside from our collective humiliation. To me, we were all monsters – myself the worst of all of us, a shortsighted clown squandering her considerable mental prowess on self-flagellation. I have since seen the power of "collective identity," and I know that when people feel "one" with others who share these experiences, it is magical. But the Psychiatric Emergency Ward – where people are at their (humiliating) worst – did not foster such oneness for me. It was more *misplacement*, and if there *were* a place within the mental health system where I could have found what I needed in that moment, perhaps I would not have left determined only to *never* return *again*.

Feeling Cold: Institutional settings have a certain feeling about them, and I am not the first to skewer such physical spaces for their coldness and inhumanity.[95] Crisp shirts, uniforms, fluorescent lights, linoleum, square ceiling panels filled with little holes, white cinder blocks, women's workplace make-up faces, people smiling workplace smiles, PA systems, rows of computers, food served on plastic trays, plastic nametags on lanyards.

---

[94] Unlike the man from the partial hospitalization program, this man began making his advances (verbally and physically) while we were *still* in the hospital.

[95] Robert Murphy, an anthropologist who became paralyzed due to a spinal cord tumor and then wrote the foundational *The Body Silent* (1990: 21), wrote; "The hospital has all the features of a bureaucracy, and like bureaucracies everywhere, it both breeds and feeds on impersonality."

Spaces that combine enough of these features – airports, offices, clinics – seem to me intentionally designed to make people feel disempowered and anxious. Of course, it is just as likely that these materials are simply *cheap*, and their unholy coldness a mere byproduct, but I must still decry the inherent ableism: these spaces are barriers to human connection and belonging. They are certainly not spaces that heal.

Feeling Weak: In Social Work today there is much emphasis on empowerment, because we are aware of the serious consequences that arise when a person believes themselves weak or broken. When people are disempowered, they can lose their sense of agency, self-efficacy, and eventually their sense of dignity and humanity. This negatively impacts their health and wellbeing. And the reverse is also true, that when people are empowered, when they believe that their choices and actions matter, it positively impacts their health and wellbeing. In my experience, the mental health system sends various subtle and unsubtle hints that you have little power.

The recent shift in medicine toward treating "patients" as "consumers" does little to offset this power imbalance. As Annemarie Mol (2008) argued in *The Logic of Care*,[96] providing patients (excuse me, *consumers*) with a menu to select from does not level the power dynamic. Perhaps some consumer-patients enjoy this as agency, but more often (as it was for me), consumer-patients are seeing provider-doctors because they *do not know what to do*, and are looking for someone who *does*. We people who are sick and suffering are encouraged to believe that clinicians will know what to do, and will be strong for us while we are weak, guiding us back to strength with care and compassion. We choose to continue to believe this, for where else is there to go?

---

[96] Care is an ambiguous term, as practices that are called "care" can be beneficent and empowering, but can also serve to control or govern, as Foucault's theory of "biopower" (described in Chapter Two) suggests.

What was I to do when I could believe that no longer? What was I to do when I realized that instead of guiding me to strength, the practices of the clinicians I interfaced with were weakening me?

Flee. Rest. Fortify. And never let it happen again.

Never Again.

CHAPTER THREE

The Clubhouse Model: History and Efficacy

In this chapter I detail the history/ies of the Clubhouse Model and review the research on its efficacy/ies,[97] making two associations: firstly, I link the development of Fountain House to the development of strengths-based practice in social work, revealing that Fountain House's distinct strengths-focused philosophy and practices were precursory to the "strengths perspective" movement. Secondly, I link it to the overarching tension within social work of the balance between radicalism and professionalism: to what extent does professionalization preclude the radical systemic and ideological changes that many – including myself – believe necessary for adequately bending the metaphorical arc of justice? What was sacrificed when Fountain House became the Clubhouse Model?

From "Fountain House" to the "Clubhouse Model"

Fountain House was founded by discharged patients from Rockland State Hospital in New York who sought peer support (Glickman & Flannery, 1996). The founders met during hospitalization, and continued to meet once discharged – initially in public spaces like the library – calling themselves "We Are Not Alone" (WANA). A wealthy former aide at Rockland State was instrumental in purchasing the house on West 47th street in Manhattan that became the group's headquarters in 1948.[98] A house with a fountain. A Fountain(ed) House.

In 1955, the members and volunteers of Fountain House recruited a social worker named John Beard to be the first director of the club, as many[99] felt the need for practical expertise in managing and developing the steadily growing organization (Glickman & Flannery 1996; New York Times 1955). According to Mark Glickman (a long time member of Fountain House and

---

[97] I write "history/ies" and "efficacy/ies" just this once, in recognition that there are multiple and contradictory voices in any history, and multiple and contradictory ways something can be efficacious.
[98] https://www.fountainhouse.org/about/history
[99] Not everyone felt this way, which will become clear later in the chapter.

current board member of Clubhouse International) and health reporter Mary Flannery[100] – who together published a history of Fountain House in 1996 – John Beard was specifically recruited because of his prior work with psychiatric patients in Detroit.

John Beard trained as a social worker in the Wayne County General Hospital in Detroit. Collaborating with psychologist Victor Goertzel[101] and psychiatrist Arthur Pearce, Beard developed a program called Activity Group Therapy (AGT), where patients with schizophrenia were engaged in group tasks. They published a study in the *International Journal of Group Psychotherapy* (Beard et al. 1958) showing that "chronically regressed" patients "confined to custodial wards, with poor prognosis… and a marked degree of social isolation" (123) undergoing AGT had social capacities restored. This supported their hypothesis that schizophrenia did not disable *every* facet of a person, and inexplicitly (perhaps inadvertently) revealed the iatrogenic effects of the treatment they were receiving.[102] Though also inexplicit, it is possible that with this discovery, they may have felt frustration at the system for giving up on people who were *not* beyond help.[103] Beard's career trajectory – including his skepticism of the mental health system (Glickman & Flannery 1996) – indicates that he did.

Shortly after the success of AGT, Beard expanded the sphere of his work with the Wayne County patients. If they could do group activities, why could they not also do activities that counted as "work"? To test this blossoming theory, he convinced a local warehouse to let him trial his patients at working there, and yes, together, they *could* do the work (Glickman & Flannery 1996). This was a groundbreaking precursor to the now well-established Supported

---

[100] https://www.kff.org/other/press-release-announcing-the-selection-of-1997-2/

[101] Goertzl later assisted Beard with research at Fountain House (i.e. Beard et al. 1963).

[102] Remember that at this stage, Erving Goffman had not yet released *Asylums* (1961), in which he would argue that it was not schizophrenia that sapped people of their social capacities, but the effects of "total institutions" (complete with "marked social isolation" [Beard et al. 1958: 123]) that deprived them any development of social skills through neglectful and in some cases abusive treatment.

[103] An analogy to Paul Farmer's work, reviewed in Chapter One: Farmer refused to believe it impossible, and through his work proved that people in "third world" nations *could* be successfully treated for HIV and drug-resistant tuberculosis, and any resistance to doing so was because people in power did not *want* to fund it, not because it *couldn't* be done, as was formerly the doctrine. Beard and his colleagues refused to believe it impossible, and through their work proved that people in "first world" nations *could* successfully rehabilitate from "serious mental illnesses," and any resistance to doing so was because people in power did not *want* to fund it, not because it *couldn't* be done, as was formerly the doctrine.

Employment (SE) model in vocational rehabilitation, which includes these core components: job placement, job training, and ongoing follow-up.[104]

Beard's work attracted the attention of Fountain House, and he was hired as director in 1955. By this time, Beard knew that with appropriate supports people with psychiatric disabilities could work, and set out to hone the practices that would provide such support. During his early years, Beard transformed Fountain House – until that point a peer support social club – into a work-focused rehabilitation program. The Work-Ordered Day (WOD) – where members and staff work side-by-side to operate the clubhouse – became the primary rehabilitative practice of the program. And building on his "warehouse" experiment, he developed the Transitional Employment (TE) Program, now fundamental to the Clubhouse Model.

With TE, the clubhouse holds part-time entry-level jobs which members rotate through, usually for 6-9 months. TE differs from SE in one significant respect; the job is the *clubhouse's*, not the individual member's. Clubhouse staff manage the job – they train new members, work alongside them while they build confidence, check in once they are working alone, and take over if they are unable to work (Beard et al. 1964; Goertzel et al. 1960). Aside from the last element (shift coverage), TE and SE are identical, and it is the last element that provides support to both the member *and* the employer, incentivizing the employer's participation at a time where there was no legislation mandating the hiring of people with disabilities (Anthony & Blanch 1987). Apparently, the earliest TE employers found the relationship gratifying. According to a 1960 article in the New York Times titled *Mental Patients Guided Into Jobs: Social Agency Places Them – Employers Are Pleased with Their Work*:

> Lane Bryant and the five other companies that have been providing temporary jobs for members of Fountain House share a pride of achievement that almost equals that of the people who are learning to work, many for the first time in their lives (Harrison 1960).

---

[104] SE operates on the theory that "*all* people – regardless of the severity of their disability – can do meaningful, productive work in normal [i.e. not sheltered workshop] settings, if that is what they choose to do, and if they are given the necessary supports. "Failures" are due not to the disability itself but to inappropriate job selection or to inadequate supports" (Anthony & Blanch 1987: 7). SE originated in the 1980s with legislation and activism surrounding the integration of people with developmental disabilities (at the time "mental retardation"). But in outlining the history of SE for people with *psychiatric* (as opposed to developmental) disabilities, Anthony and Blanch (1987) credit "a number of successful independent, transitional work programs for the mentally ill" (9) – including Fountain House.

In addition to developing these work-focused rehabilitative practices, Beard was a proactive fundraiser. In the New York Times archives, there are several articles advertising large-scale fundraising events (New York Times 1959; 1965; 1966). He was also involved in well-funded efficacy research almost as soon as the program was in full swing. For example, the study by Beard and colleagues (1963) sponsored by the National Institute of Mental Health (NIMH). Later in the chapter I will review the efficacy research, but for now, suffice it to say, Fountain House's growing success – demonstrated by research and positive media coverage – resulted in a demand for standardization so that its practices could be implemented elsewhere. In 1977, the NIMH awarded Fountain House a multi-year grant to develop a training program, which also received congratulatory New York Times coverage:

> The program has become the model for a dozen others like it across the country and a Federal grant is bringing groups of social workers here from various cities to study the methods for possible duplication elsewhere. It should be noted that its success, built from private charity money [i.e. Beard's aforementioned fundraising prowess] and only minimal Social Security payments of club members, is finally being recognized at a time when a new government-subsidized program of "community care" – Medicaid-styled along industrial lines of large "group care" residences of 25 or so former mental inmates – is spreading in the state. The latter is fueled by the profit motive, which is clearly not the preeminent force at Fountain House, where the coin of the realm is the triumph of ordinary people over ordinary tasks (Clines 1977).

This quote reveals a disgruntled attitude toward mainstream "community care" and the author's strong differentiation between *that* and Fountain House.

The 1980s yielded continued expansion of the model, along with the death of John Beard in 1982 (Anthony & Lanoil 1983; Beard-Eddy 1983). His successor was Kenneth Dudek, a long-term staff member. Glickman and Flannery (1996) note that when Dudek replaced Beard, that was the chance for the model to become mainstream. Whereas Beard had been "wary of the mental health establishment, Kenn recognize[d] that the clubhouse model can flourish only by reaching out to those working and teaching in the field of psychiatric rehabilitation" (165). In 1989, official "Standards" for what was now called "The Clubhouse Model" were formed – about which Rudyard Propst, another staff member, said "Probably [John] would have loved the idea, but he also might have thought it was dogmatic" (175).

In 1994 the International Center for Clubhouse Development – recently renamed "Clubhouse International" – was developed as a coalition hub for organizing and overseeing the

expansion of the model.[105] In 2010, the Clubhouse Model was recognized by the Substance Abuse and Mental Health Services Administration (SAMHSA) as an Evidence-Based Practice.[106] This trend of recognition continued, with Fountain House becoming the first mental health program to ever win the Hilton Humanitarian Prize, "the world's largest humanitarian award…presented to organizations judged to have made extraordinary contributions to alleviating human suffering" in 2014.[107] The Clubhouse Model today is gargantuan, spanning 320 accredited clubhouses (many more if one counts unaccredited and on-the-path-to accredited clubhouses) in 34 nation-states.[108] And from what I learned at the 2017 World Seminar – a biannual international clubhouse conference – there is much interest in further expansion, and in partnership between movers and shakers in Global Mental Health such as Dr. Vikram Patel (the Seminar keynote), who, as mentioned in Chapter One, aims to make mental healthcare more accessible globally through decentering "experts" and following a community health worker model.[109] Patel sees potential in the Clubhouse Model precisely because it is a low-cost program that is not reliant on experts.

Clubhouse Michigan

I worked in a clubhouse in Michigan. Michigan is perhaps one of the most "system-married" states in terms of clubhouses, due to its reliance on Medicaid. In the early 1990s, Medicaid awarded funding to a host of day programs and drop-in centers in Michigan under the condition that they become clubhouses – that they instate work-focused rehabilitation practices and adhere to the Clubhouse International Standards. For this reason, Michigan has one of the highest numbers of clubhouses in any state: there are 47, 12 officially accredited.[110] All accredited clubhouses are Medicaid funded, and Medicaid has requirements that *contradict* Clubhouse International Standards. Specifically, the second of the 37 Standards: "The Clubhouse [must have] control over its acceptance of new members. Membership is open to anyone with a

---

[105] http://clubhouse-intl.org/about-us/mission-history/
[106] http://legacy.nreppadmin.net/ViewIntervention.aspx?id=189.
[107] https://www.hiltonfoundation.org/humanitarian-prize/laureates/fountain-house-club-house-international and https://www.hiltonfoundation.org/humanitarian-prize
[108] http://clubhouse-intl.org/what-we-do/international-directory/
[109] http://ghsm.hms.harvard.edu/person/faculty/vikram-patel also *Where there is no Psychiatrist* (2003).
[110] These numbers/this information comes directly from a presentation I attended on the history of clubhouses in Michigan at the September 2017 World Seminar in Detroit: http://clubhouse-intl.org/clubhouse-international-announces-world-seminar-2017/

history of mental illness, unless that person poses a significant and current threat to the general safety of the Clubhouse community."[111] But Medicaid funded clubhouses have membership limitations: all members must be recipients of Medicaid and clients of whichever local Community Mental Health agency oversees their case management.

"Clubhouse Michigan" is the coalition of Michigan clubhouses, officially recognized by Clubhouse International in 2012. The goals of Clubhouse Michigan are: 1) to support the development of new clubhouses and support unaccredited clubhouses on their path to accreditation (the "goal" is for all Michigan clubhouses to receive accreditation), 2) to collaborate with the National Alliance on Mental Illness (NAMI), Clubhouse International, the Michigan Department of Health and Human Services (MDHHS), and universities, in order to gather and disseminate efficacy research, 3) to work with MDHHS to secure funding for expansion, and 4) to promote clubhouses and engage in political advocacy.[112]

The first and second goals demand elaboration. Firstly, the goal that all clubhouses become accredited: I put scare quotes around the word "goal" because it is not an aspiration – the MDHHS has *mandated* that all Michigan clubhouses become accredited by December 2018.[113] The stated reason is *fidelity* – and clubhouses that are not accredited and do not follow the Standards are often looked down upon as "using the famous name without doing the actual *work* of a clubhouse," according to a Clubhouse Michigan member. Secondly, the goal of producing and disseminating efficacy research: since 2010, there has been an annual survey conducted by the Michigan Department of Community Health (in collaboration with Michigan State University) which provides a quantitative evaluation of all accredited clubhouses.[114] Additionally, due to the influence of Dr. Esther Onaga at Michigan State University and Dr. Francesca Pernice at Wayne State University, Michigan clubhouses have been involved in much of the efficacy research (especially qualitative) to come out of the U.S.

---

[111] https://clubhouse-intl.org/resources/quality-standards/
[112] http://www.mi-clubhouse.org
[113] http://clubhouse-intl.org/what-we-do/mental-health-advocacy/
[114] http://www.mi-clubhouse.org/new-page-1/

"Strengths-based Practice" in Early Fountain House: John Beard's Unconventional Understanding of "Psychiatric Disability"

John Beard's early work in Detroit taught him a crucial lesson that he carried to Fountain House: psychiatric disability was not as permanent or all-encompassing as was generally assumed. He knew that people with psychiatric disabilities could be reached, and their social functioning restored. They could even *work*. This led him and co-authors to write:

> The basic philosophy [of Activity Group Therapy] was derived from the concept that the mental hospital patient was disabled in the use of social tools, either as a result of his illness or as a result of a total life experience (Fisher et al. 1960: 296).

Though not explicitly stated, this "total life experience" included the neglect and isolation endemic to standard psychiatric interventions. This sort of language was not common at the time – the "social model of disability" that implicates culture and institutions in the creation and perpetuation of disability was still at least a decade away. However, in a piece co-authored by Beard and one of his staff fifteen years later, they wrote about employment barriers thus:

> At Fountain House we believe that the vocational disability of the psychiatric patient should not be viewed as a condition solely within the patient. In many instances, the disability is due to factors not related to the patient's ability to work productively. For example, personnel departments are often set up to exclude people with many of the characteristics inherent in the psychiatric patient (Bean & Beard 1975: 254).

In this later publication the language *is* explicit, perhaps influenced by the growing disability rights movement: "the disability is due to factors not related to the patient's ability" but rather from accepted practices that "exclude" them. About Fountain House, Beard and colleagues (1982) later wrote, in the *Psychosocial Rehabilitation Journal*;

> The goal is to establish a foundation for better work habits, enriched social skills, and a more helpful view of the future. Many discover that although they are viewed as disabled, there are many ways they can still be constructive, helpful, and needed. In time, this newly discovered sense of self-awareness can be translated into a more rewarding, nondisabling way of life, free of financial dependency and perpetual patienthood (49).

This passage also reveals an unconventional understanding of disability: rather than "although they are disabled," the phrase is "although they are *viewed as* disabled," which subtly calls into question the immutable "fact" of psychiatric disability, *and* implicates the systemic "financial dependency and perpetual patienthood" eclipsing people's abilities.

Embedded in this unconventional view of disability is a shift in focus toward people's *strengths*. In a piece published in *Mental Hygiene* in 1964, Beard and colleagues wrote;

> The staff worker…acquires a very intimate and extensive understanding of the many facets of a member's personality and difficulties, his strengths and capacities. The worker utilizes the work environment for the purpose of enabling the member to establish a relationship characterized by those qualities which typify more normal interpersonal relationships. We believe that in this way, the patient's perception of himself is gradually modified (16).

Not only does this passage highlight what I will address in the next section – the unique *professional identity* of clubhouse staff – but it distinctly states that staff engage with "strengths and capacities" in order to combat emphasis on "difficulties." This language sounds ordinary today, but given that "strengths-based practice" was not codified in American social work until the late 1980s (Saleebay 1992; 1996; Kim 2013), it is quite remarkable. The precursors to the "strengths perspective" in social work are surely variable – including, as I am now suggesting, Beard and his colleagues – but the term "strengths perspective" was not coined until 1989 (Weick et al. 1989) in the journal *Social Work*, with the first edition of *The Strengths Perspective in Social Work Practice* close behind in 1992.[115] The basic components of strengths-based practice are 1) all people and communities have strengths, 2) trauma, illness, and hardship are injurious, but also provide potential for growth and resilience, 3) people and peoples *can* change, and 4) collaboration is more effective than service (Saleebay 1992; 1996; Kim 2013).

Viewing the language in Beard's early co-writing as precursory to codified strengths-based practice is illuminating. For example, in the very first paper Beard co-authored about Activity Group Therapy (Beard et al. 1958);

> [The study] demonstrated that the schizophrenic patient will reveal ego strengths that can be utilized in the activity structure of the group. It is our conviction that when these rudimentary capacities of the patient are regarded as insignificant and extraneous only to be dropped and forgotten, then the patient as a person feels himself dropped and forgotten. Only if his responses, limited as they are, can be made an essential part of the groups' activity structure, does the patient himself become a meaningful, positive participant. The initial activities of the group were thus consistent with the capacities of

---

[115] According to Kim (2013) it began in 1982 when a University of Kansas School of Social Welfare faculty/doctoral student duo (Charles Rapp and Ronna Chamberlain) were funded to develop a new case management program, and decided to focus on the strengths of their clients – people with psychiatric disabilities. As their work continued, it influenced other members of the department such as Ann Weick and Dennis Saleebey, cited in this paragraph. I think it interesting that, though the strengths perspective is *now* used in various areas of social work, the movement *began* with people with psychiatric disabilities.

each individual, thereby permitting constructive participation. Although there was a wide range of activities, none was prearranged (133).

…Regardless of the degree of pathology, there remains in the patient a core of essential ego strengths. These ego strengths can be utilized therapeutically through the establishment of an activity group structure, provided the activities are relevant to these strengths. Because the requirements of the activities do not surpass the patient's ego capacity, he is enabled to participate effectively in a social relationship. For the institutionalized schizophrenic who has lost his relationships to his environment, a first step toward rehabilitation is taken (136).

This language is shockingly anachronistic. In 1958, we have three professionals[116] – a psychiatrist, a psychologist, and a social worker – saying that not only do patients have "strengths" and "capacities," but that to overlook them as "extraneous" is tantamount to "dropping" and "forgetting" the person. Moreover, they argue that what the *patients* care about is relevant, and that coming in with a "prearranged" curriculum might not be best. Instead one might (gasp!) tailor the program to be "relevant to the[ir] strengths" such that they can be "meaningful, positive participants" on their own terms, "participating effectively in a social relationship," a "first step toward rehabilitation." In short, they advocate for "*meeting the person where they are*" – a common value in *contemporary* social work – and argue that *no one* has too high a "degree of pathology" to take steps toward rehabilitation.

This idea of human malleability is key. Beard believed that no matter how dysfunctional the behavior, or how negative the self-conception, nothing was *immutable*. Strengths could be found and built upon. Self-conceptions could be "gradually modified," new ways of seeing oneself "discovered" and "translated into a more rewarding, nondisabling ways of life" (Beard et al. 1964: 16). People, even "pathological" people, can change – *and* change is more likely when people's strengths and wishes are centralized and when the rehabilitative work is done together.

John Beard was not a naïve optimist, nor did he object *philosophically* to the idea of "mental illness" as did the contemporaneous "anti-psychiatrist" critics reviewed in Chapter Two. Beard's understanding of mental illness – as *socially mediated* and *changeable* – came from direct experience: he had seen enough people experts had assumed were lost causes transform through simple interventions. What stood out about Beard was not what he *knew* about mental illness or treatment, but that he *questioned* what was "known." He was open to the possibility that people with psychiatric disabilities not only *had* strengths, but were as *valuable* as anyone

---

[116] *All men, but of* course.

else. His obituary in the *Psychosocial Rehabilitation Journal* lauded his achievements not only in terms of his renown as "the most prominent international figure in the psychiatric rehabilitation movement" (Anthony & Lanoil 1983: 1), but his kindness and belief in equality:

> My dad liked people. All people. I believe this is one of the most important things he shared with me – that there is beauty and value in everyone... What is important is the similarities in people, not the differences. And that it is important to really hear, touch, and to be with each other (Beard-Eddy 1983: 5).

Professional Identity in Early Fountain House

Because of John Beard's unconventional understanding of psychiatric disability, and his personal attributes – open-mindedness, humility, and a belief in equality – his understanding of the role of staff and member/staff relationships in Fountain House was quite divergent from mainstream social work. This was clear from the non-hierarchical terms used: "members" rather than patients or clients (earliest mention in Beard et al. 1964). But what kind of professional identity did John Beard look for or instill in Fountain House staff?

As noted in the prior section: it did not take "expertise" to discover or put into practice what John Beard did. As Glickman and Flannery (1996) said about the model, "its methodology was so down-to-earth that people outside the psychiatric community could understand how it worked" (74). This de-emphasis on expertise is perhaps why there were/are problems reconciling the role of staff at Fountain House with the professional identity of a social worker. The plenary from the 2013 World Seminar addressed this with an anecdote:

> An incident occurred at Fountain House a number of years ago that triggered our inquiry into *community* as the defining notion of what a clubhouse is. Graduate degree students attending Fountain House on their field work placement were returning to their classes in social work reporting they spent their time watering plants or peeling potatoes. Their professors were perplexed, some infuriated. We at Fountain House were engaging their students in blatantly mundane activities unworthy of a professional. Social work as practiced at Fountain House seemed to fly in the face of their efforts to invest their students with a professional mantle, that of an expert (Doyle 2013: 1).

This highlights the disconnect between clubhouse practice and the conventional ideas of professionalism within social work often inculcated into students. As an MSW student who also trained in a clubhouse, I can attest to this disconnect. It did feel strange to be doing "menial" tasks until I learned that the tasks themselves were not the point, not the skillset I was building.

Jerry Dincin worked at Fountain House from 1958 to 1964,[117] and wrote an article on "Utilization of Professional Staff in Psychiatric Rehabilitation" for *Social Work* in 1965. In this article, the skillset I was developing during my field placement was described in detail.

Dincin's (1965) primary point was that, contrary to clinical settings, the role of Fountain House staff is not to talk things through with people, but to actively "reach out" (51) to members and take the initiative in seeking and engaging with their strengths. To do this, staff need to build genuine and "informal" relationships based on "friendship" (53), and actively work on tasks *with* members: "the best way to reach a member is to involve him in a constructive activity in which the worker himself is involved" (54). Failure to do so is detrimental;

> Professionals cannot be effective if they are passive or neutral. They must be active, involved people deeply committed to the development of a rehabilitative relationship… It is too easy for a worker, under the guise of maintaining his professional status, to reject the client (53).

He then wrote a set of nine necessary skills for clubhouse staff:

1. Strong professional desire to influence the member
2. Ability to develop a feeling of "Dynamic Hopefulness" in a member
3. Creativity to enable the worker to use the setting constructively and do whatever is necessary to help a member.
4. Professional tenacity in the face of symptoms, regression, hostility and resistance.
5. A genuine ability not to be fearful of the member's illness.
6. Great frequency of interpersonal contact.
7. A deep-seated interest in all areas of members' current life situations.
8. Accent on and development of the healthy portion of the personality. The pathological background of the member's illness is not dwelt on.
9. Informality. The center wants to break down the barriers to communication often created by stereotyped hierarchical roles (54).

All nine of these skills are important, but in terms of differentiating between *clubhouse* and *clinical* professional identity, the most interesting are the first and last: "influence," and "informality." These skills are the most difficult for clinically trained social workers to achieve. Two illuminating quotes from the article pertain to *informality*:

> Professional informality without loss of professional identity is an important and helpful factor. Mental patients are at the bottom of the pecking order in the hospital… It is refreshing for them to be treated as equals and with respect for their intrinsic worth…

---

[117] http://www.fountainhouse.org/blog/memories-jerry-dincin

The usual status of a social worker in a professional agency cannot get in the way of a client's needs… He must be able to get to the level on which the member is operating (56).

These excerpts emphasize the *humility* necessary for "professional informality." Fountain House sought staff who were comfortable being "level" with members and could genuinely "treat [them] as equals." This is what made the model *work*.

In "The Role of Staff at Fountain House," published in a 1985 edition of Fountain House's newsletter, Stephen Anderson addresses similar issues through describing his own professional journey. He had trained as a clinical social work counselor, and thus entered Fountain House believing the role of a social worker was to "help people sort out their values" and unpack their problems, but *not* to "try to influence them" as that was an "infringement of that person's freedom" (1). This is very different to Dincin's first necessary skill: a "strong professional desire to influence the member" (1965: 54). Anderson describes *unlearning* this clinical mentality via learning that his role was to engage members in work in order to show them that they are needed and valued – which cannot fail to influence them.

Both of these skills – the ability to positively *influence* members, and to be *informal* – are highlighted in the last article Beard co-authored, published posthumously in 1982:

In designing a program in which staff and members *work together*, Fountain House has brought about a *major change in staff role* from the role assigned in other, more traditional day programs. Role change necessitates attitude change on the part of staff, specifically, that staff come to appreciate the members, to respect their contributions. In more traditional day programs, the patients frequently respect and appreciate staff, but staff rarely have the experience necessary to appreciate and respect their patients (48, emphasis mine).

What stands out here is the conviction that for effective rehabilitation to occur within the clubhouse context, the onus of change falls on *staff* as much as it does members.

Based on my discussions with the director[118] of the clubhouse I worked in, there is still tension between the desire to hire professionals *with* skills and knowledge pertaining to psychiatric rehabilitation, but *without* typical qualities of clinicians that make it difficult for them

---

[118] She has been involved in the clubhouse movement for almost 20 years – as staff here in Michigan as well as in Fountain House, as a director, and as one of the founders of Clubhouse Michigan.

not to pathologize or separate themselves from members. As she said; "Most of the time, the clinically trained social workers don't last. And in truth, the best staff I've had were not MSWs."

> Me: in your opinion, what makes a good staff?
> Director: It is a demanding job that requires an expansive skillset. They must be a tremendous communicator – particularly a good listener – and extraordinarily patient. They must be self-aware and reflective, but also they have to be able to see outside of themselves and see what other people see. They have to be socially engaging, someone that people like to be around, but also – there are so many opposing concepts and contradictions! – you can't be so dynamic and magnetic that you pull all the energy towards *you*. It is like the back-up dancer, leading from behind.

Social work as a profession is self-aware of the "balancing acts" and "opposing concepts and contradictions" that make this work so difficult. There is rarely one right answer, it is rarely possible to follow rules and regulations wholly (especially when rules and regulations are problematic), and one rarely feels like one's work is "done." But it seems that, in spite of how diverse social work is – and how especially different clubhouse practice is as social work – there is an overall agreement that a social worker should strive to play the "back-up dancer, leading from behind." That is what empowerment looks like.

The State of the Clubhouse Efficacy Research

As noted, the Clubhouse Model is recognized as Evidence-Based Practice, which means there is a significant body of efficacy research. This research focuses intensively on *outcomes*, framed in terms of both objective and subjective quality of life (QOL). Subjective QOL refers to "life satisfaction" and objective QOL refers to observable "participation in activities and interpersonal relationships"[119] (Narvaez et al. 2008: 202).

Objective QOL

The first efficacy study published by Beard and colleagues (1963) involved a two-year experiment with 400 recently released patients divided into an experimental group who became members of Fountain House, and a control group referred to other services. After two years they found that the experimental group was rehospitalized significantly less – 46% versus 64% – and

---

[119] Interestingly, the two do not always correlate as researchers expect them to: many people like their lives though they have poor objective QOL, and many hate their lives in spite of being functional in terms of objective QOL markers (Narvaez et al. 2008).

were employed at higher rates (though rehospitalization impacted this: the rate of employment was similar between non-hospitalized control group members and clubhouse members). A follow-up study published in 1978 evaluated "outreach" (checking in with absent members) in relation to rehospitalization. There were experimental groups who received different degrees of outreach, and a control group of non-clubhouse members. Rehospitalization was significantly higher in the control group than in the clubhouse members, at least initially. However, the study took place over nine years, and though outreach did make a difference – members who received more outreach were delayed in rehospitalization longer – eventually, most members *were* rehospitalized. Rehospitalization was "delayed" rather than "prevented" (Beard et al., 1978: 626), though clubhouse members who were rehospitalized did spend less time in the hospital than the control group, and it was usually voluntary and with the support of the clubhouse.[120]

Over the years, more outcomes research confirmed what Beard and colleagues (1963; 1978) found. Warner and colleagues' (1999) study in Colorado evaluated an experimental group of regular clubhouse users (defined as four days of attendance per month) and a matched (for age, gender, diagnosis, psychiatric history) control group of people in a neighboring community *without* access to a clubhouse, and found that clubhouse members were hospitalized less often. Masso and colleagues (2001) conducted a study in North Carolina that involved 117 randomly selected members, and sought to evaluate the effect of attendance rates[121] on members' rates of employment and hospital recidivism. As hypothesized, they found that members with higher attendance had higher employment than members with low attendance, and the members who attended more often had lower rates of rehospitalization.

Several years later, two studies were conducted that focused specifically on employment. McKay and colleagues (2005) examined the employment outcomes of several clubhouses in Massachusetts using self-report surveys, and found that in spite of the oft-mentioned risk of jeopardizing benefits,[122] many more members were working: between 1998 and 2001 there was a 20% increase in job placement. Schonebaum and Boyd (2012) then specifically sought to

---

[120] This was true in the clubhouse I worked in. When a member and/or their support network felt hospitalization was necessary, clubhouse colleagues visited and stepped up outreach in the weeks after they were discharged.

[121] The authors do note that *attendance* does not necessarily reflect *active participation*, and acknowledge that this as a limitation in their study design.

[122] An issue I heard about first hand, addressed in Chapter Five.

determine whether *active participation* in the Work-Ordered Day (WOD) of a Massachusetts clubhouse impacted employment. They conducted a longitudinal study (135 weeks) following an experimental group of clubhouse members and a control group of participants in an Assertive Community Treatment (ACT) program. Unlike the other studies (i.e. Masso et al., 2001, who tracked attendance only), they tracked members' active participation in the WOD, and found that on average, a one-hour increase in clubhouse work led to a 2.3-week increase in employment. They also found that participants with more WOD participation had significantly longer average employment than other participants, even when accounting for prior work history.

Subjective QOL

Every qualitative study that has addressed subjective QOL has examined *community*. For example, Biegel and colleagues (2013) found that 60% of their interlocutors believed their "participation had resulted in an increase in social relationships, friendships, or social support" (255), and the study (described earlier) by Warner and colleagues (1999) found that clubhouse members more often said they had close friends (92% versus 62%) and someone to rely on when they needed help (100% versus 63%) than people in the control group. Perhaps more illustrative than mentioning friendship and support is the fact that Carolan and colleagues (2011) heard members describe clubhouses as "feeling like home" or serving as "surrogate families" (131), just as Staples and Stein (2008) noted "the strong sense of community, becoming almost like a second family, [which] promotes self-esteem, increased self-efficacy, and a sense of hope" (187). That there are members – including many I worked with, as I will show in Chapter Five – who feel familial connection, who feel at "home" at their clubhouses, suggests an intimacy unheard of in mental health settings, and sorely lacking in their lives.

Biegel and colleagues (2013) sought to examine the social support networks of clubhouse members in Michigan.[123] Using a specially designed social network interview, they interviewed 126 members and assessed the following dimensions: "frequency of contact, perceived availability of support (concrete, emotional, or informational), perceived closeness to network member, perceived criticalness from network member, importance of the network member, and satisfaction with the relationship" (52). The key findings were that the average social network

---

[123] As noted, a great many studies have been done in Michigan, and the scholars I mentioned earlier are co-authors on all the Michigan-based articles reviewed in this section.

size was eight (range 1-25) and comprised mainly of family and service providers (including the clubhouse), and that 84.9% of their participants said that their life had changed since they became a member, with 56.1% of those members attributing this to an increase in social support and friendships and 27% to support with employment. This is unsurprising given that clubhouses specifically target these areas of a member's life.

In a similar study, also conducted in Michigan, Carolan and colleagues (2011) aimed to understand the role of the clubhouse in facilitating social support. Unlike the above study, they conducted open-ended interviews, and in their analysis found these recurring themes: that clubhouses provided a place to be, a place to facilitate personal growth, and a place to connect with others. Some of the ways the clubhouse facilitated these feelings were: being with people who have similar experiences, having positive role models with experience coping with mental illness, and flexible meaningful work that enabled them to develop skills and feel needed and helpful. As one participant said, "Helping others helps me not to think about my problems. I feel like I have a purpose and can help others. It feels nice to do that when you are usually the one who needs help from others" (129).[124] Another study, conducted in Australia, that used open-ended interviews to understand social support, found similar themes: participants felt that shared *purpose* and shared *suffering* contributed to the development of intimacy, which improved self-esteem and life satisfaction. As one participant said;

> My roles are receptionist, editor, helper. I see myself as a contributor by coming... I contribute to the functioning of the house and to other members. We give and we receive ... It all gives me a sense of purpose, self-esteem and you feel like you're not just a vegetable. You're actually doing something worthwhile (Coniglio et al. 2012: 157).

Conclusion: Clubhouses **are** *effective… but* **why***?*

According to my review of the efficacy research, clubhouses are effective at improving the subjective life satisfaction of members as well as their objective QOL markers. A recent systematic review similarly concluded that clubhouses yield positive impacts on membership employment and rehospitalization, and subjective quality of life (McKay et al. 2016).

---

[124] This idea of helping as helpful was also noted by the authors of a similar article: "people with mental illness think of themselves as takers rather than being in reciprocal relationships, but being a part of networks of exchange and reciprocity is an important feature of human societies" (Pernice-Duca & Onaga 2009: 2).

However, the literature is almost exclusively focused on *outcomes*, and heavily skewed toward *objective* outcomes. This is unsurprising given the economics and politics of healthcare in the U.S. As Masso and colleagues (2001) wrote, "Clubhouse programs are relatively inexpensive due to their deliberate understaffing philosophy…Despite the low cost, managed care companies must be provided with some measure of outcome in order to demonstrate the program's effectiveness" (25). It is fair that insurance companies and funders are more interested in economically relevant statistics than they are subjective life satisfaction: is money being saved (i.e. reduced hospitalizations)? Are people becoming contributors rather than dependents (i.e. achieving paid employment and reducing reliance on benefits)?

These considerations are obviously important. However, it is equally important to *deemphasize* clinical definitions of recovery that focus on objective outcomes, and *centralize* humanistic understandings of recovery as "a lifelong process that involves an indefinite number of incremental steps" including "redefining the self and accepting illness…overcoming stigma; renewing a sense of hope and commitment; resuming control over and responsibility for one's life; exercising one's citizenship; managing symptoms; being supported by others; and being involved in meaningful activities and expanded social roles" (Davidson 2003: 44-45). To be "in recovery" can mean accepting that regular paid employment might not work for you, or that hospitalization may be an occasional, routine part of one's life. As one of my interlocutors, Wendy, told me when asked "what does mental illness mean to you?"

> I feel like my brain is outside of my control. I can do things to manage it: take medicine, sleep, exercise. But there is an element of no control, and even when I do those things sometimes it goes haywire. About a month and a half ago I was doing all those things – going to doctor, eating healthy, taking my medicine – and the weather changed and I had a manic episode and I had to go to the hospital. I was so mad. I have never been so mad. I yelled at my mom, at my doctor, "you cannot put me in the hospital, I am doing everything right!" but they said for my safety I had to go. And that is part of mental illness, that no matter what I do, sometimes it just happens.

In addition to ensuring that clinical definitions of recovery are not overly centralized in outcomes research, I believe it important to transition in focus from *outcomes* to *mechanisms*. *How* and *why* do these changes occur? Outcomes research has resulted in the Clubhouse Model achieving recognition as Evidence-Based Practice, but without a deeper understanding of the

combination of forces *leading* to these outcomes, it does not follow that compliant/high fidelity clubhouses will be necessarily more effective than noncompliant/low fidelity clubhouses.[125]

As I conveyed in Chapter One, people within the clubhouse community have identified what they believe are the keys to the model's success – that members feel needed, expected, accepted, and loved. Many of the qualitative studies I reviewed also uncovered these factors: for participants in these studies, having positive role models was important, feeling as though they were needed (that they were in reciprocal rather than dependent relationships) was important, friendship was important, hope was important. Within group social work, there is the concept of "common therapeutic factors" – the underlying mechanisms that cause change/growth in people in various group settings (Corey et al. 2010; Schwartz & Waldo 1999). Practicing social skills, having positive role models, having shared experiences of suffering, feeling accepted and not judged – these have all been identified as common therapeutic factors that operate in successful groups. As the qualitative research shows, these factors are present in clubhouses.

In a special edition of the *Journal of Self-Help and Self-Care*, the Clubhouse Model was connected to the self-help, mutual aid, and recovery movements. James Mandiberg and Michael Edwards (2013) noted (as I have) that clubhouses have been proven effective, and yet are *still* "considered non-mainstream" (20). They argue that this is because, in the U.S., there is more emphasis on (and money in) *individualized* approaches such as interpersonal therapy and medication. As Masso and colleagues (2001) note, "Clubhouse programs are relatively inexpensive" (25), and though it feels cynical, I agree with Mandiberg and Edwards: of *course* clubhouses are "non-mainstream," they don't make professionals, insurance companies, or pharmaceutical companies any *money*. Like Vikram Patel's work, clubhouses do not rely on (high earning) experts. Like group social work, clubhouses de-center the individual and instead

---

[125] This is an opportune moment to mention the critiques of the "Evidence-based Practice" phenomenon. As Mullen and Streiner (2004) write in "The Evidence For and Against Evidence-Based Practice" the framework has limitations, such as; overemphasizing objective QOL markers, randomized clinical trials, and meta-analyses of clinical trials (which are not appropriate ways of "measuring" the efficacy of every intervention); deemphasizing the expertise of clinicians in favor of what they call a "cook-book" approach; not attending to the preferences or needs of patients; and being an "ivory-tower concept" (114). And as (my heroine) Karen Staller (2006), notes, Evidence-based Practice "should be reframed to focus on practice-based evidence(s) (PBE). Doing so changes the nature of debate, highlights the practitioner role, recognizes practitioner agency in evaluating evidence, focuses on real-world situations (thus embracing complications), and honors the notion of multiple and competing evidence sources" (503).

foster "collective identity" (Mandiberg & Edwards 2013), which is both inexpensive, *and* impossible to achieve in (expensive) individualized expert-provided treatments.

And yet, it is precisely the formation of "collective identity" – through being and working with one another – that seems to drive clubhouse *outcomes*. There is significant evidence from many stigmatized groups (e.g. the LGBTQ community) that positive collective identity buffers the negative impacts of discrimination and marginalization (Mandiberg & Edwards 2013). "Pride" groups exist for a reason: because people realize "it's not (just) *you*, it's the *world*" and *resist* the world together. In such groups, one *could* say people are **centralizing the fringe**. I propose framing the *mechanisms* of clubhouse outcomes in terms of the social needs of *purpose* and *belonging*[126] that marginalized peoples can only meet on the fringes of American society, and that are met through therapeutic factors common to *any* group practice aimed at healing soul-wounds.

Reflections on "Radicalism" and the "Strengths Perspective"

The strengths perspective arose as backlash to the dominant problem-focused approaches. In Chapter Two I showed some of the ways in which problem-focused approaches were, well, *problematic*, not the least of which was the label-as-self-fulfilling-prophecy issue. If humans are impressionable enough to internalize the ways that wider culture defines them – and we are – then problem-focused definitions like psychiatric labels should be handled with care. But the strengths perspective, though a step in the right direction for social work, still has problems to be aware of. The strengths perspective still focuses on *individuals* rather than *the system*, and no amount of developing people's strengths and resiliency is going to address the structural violence that will repeatedly weaken them. As Grey (2011) says, "the theory of social capital and community development, and the strengths and empowerment approaches they entail, are a weak antidote to the calculative individualism of contemporary neoliberalism" (10). Additionally, the strengths perspective has been accused of being "Pollyanna-ish" – "overly optimistic about the strength of social capital, community, and community development" (10). Some wounds won't heal, and some wounded people/s won't stop wounding themselves and others.

---

[126] These needs are filtered through a specific cultural context, in this case, neoliberal-ableist America.

In clubhouses, the strengths perspective is central, and understandably but also problematically, problems are steadfastly deemphasized, and at times, actively deterred. I have witnessed members attempt to introduce darker topics, who are then discouraged by someone citing clubhouse principles: "I was raped by my father." "I'm sorry to hear that, but at the clubhouse and during the work-ordered day is not the right place or time to talk about that – would you like to work on something to take your mind off things?" As I will argue in Chapter Six, this seems a necessary practice in order to maintain a positive *collective* space in this context, however I also acknowledge that the practice can make an *individual* feel silenced.

Another example comes from a training workshop involving people from varying clubhouses, in which I entered into a polite debate with a member I had just met who was adamant that when members promote the clubhouse, they must avoid talking about grit from their pasts and present themselves "normally." He seemed to be decrying what Summerson Carr (2010) critiqued in *Scripting Addiction*: the "script" that positions a person as the transformed victim: "That happened and then *this* and *then* I found the clubhouse, and if it weren't for the clubhouse I don't know *where* I would be!" (cue violin music). Such testimonies are used for fundraising and awareness-raising, and yes, they are very scripted and rehearsed. And I agree that the script, and the victim-to-saved-to-spokesperson trope, is troubling. But I also think that the "competent in spite of" or "passing as normal" trope is troubling. This member (and he was not alone) was encouraging members to *compartmentalize and conceal their grit as a means for challenging stigma*. Someone then told an anecdote – "remember when we were at a conference with a bunch of mental health practitioners and John Doe got up and spoke and it took them 10 minutes to realize he was a *member* because he was wearing a tie and looked just like everyone else? Wasn't that a great lesson?" I raised my hand and asked whether anyone had heard the phrase "respectability politics" and almost no one said "yes," so I briefly explained:

> "Respectability politics" refers to the unjust idea that oppressed peoples should behave "respectably" in order to protect themselves from danger or discrimination, in a context where the group that defines what is "respectable" is the group doing the oppressing. For example, when a black teenager is shot by the police and someone responds, "well if he wasn't wearing a hoodie and his pants weren't around his ankles, if he had been dressed respectably, this might not have happened." True, it *might* not have, but obviously, the root problem is *racism*, not teenage fashion choice. The reason why I am bringing this up is because I don't think that people with mental illnesses should have to wear ties or hide their scars in order to speak out and fight stigma.

An overcorrecting has happened. In order to resist the sensationalizing and tokenizing of the Mad, some are shouting "but we can be normal!" But I think this is as oversimplified as the stereotypes it is attempting to overthrow, and stems from what Foucault (2011[1962]) noticed – *our current societal values foreclose embracing the gritty side of madness*. And this will *not* change so long as we continue to allow madness – especially the gritty kind – to remain hidden.

I asked the people in the room what they thought about this idea of "respectability" – are we not silencing those who cannot or refuse to "pass" (Goffman 1963)? Are we not asking for acceptance and inclusion on the condition that we behave ourselves according to mainstream values, the same values that oppress our community to begin with? There were some nods, but the member I was addressing, while acknowledging my view, insisted that representatives should tidy themselves up – their story, their style – lest more stigma be generated. I, in turn, acknowledged this members concern. I understand that sometimes it is *easier* to (over)simplify matters, and that if the end result is inclusion – even inclusion upon unjust condition – that is better than continuing to feel marginalized. I have to respect people who believe in respectability. Besides, it is far too easy for me, someone who not only effortlessly "passes" but holds many privileged identities (like whiteness and a PhD) to say "don't hide – Resist!" In any case, such disagreements are *productive*: they keep us all thinking.

"Kind of Radical?"

The director of the clubhouse I worked in told me "clubhouses are a *kind* of radical social work. They don't overtly challenge the system, they work within it, butting heads but maintaining the interface." I understand that "radical social work" is somewhat paradoxical, as social work is a federally recognized profession, not a revolution. As Reisch and Andrews note in *The Road Not Taken: A History of Radical Social Work in the United* States (2002), there is a palpable "tension between radicalism and professionalism" (8), but to foreclose the possibility that professional social work can be "radical" is shortsighted. One should think of radicalism as a *spectrum* with multiple meanings and foci, but an underlying understanding that *systemic inequity is the foundation upon which other inequities rest, and of which helping professions are inevitably a part*. Related to this is Park's (2008) refusal of the dichotomy between social service and social control: "Such a dichotomy occludes the discomfiting possibility that social control may be immanent in all well-intentioned social service practice" (475).

If all it takes to be "radical" is *awareness* of the deeper ideological and institutional causes of a problem, then indeed, clubhouses are on the spectrum. But awareness is not action: in what ways are clubhouses *acting* upon awareness? Firstly, through the non-clinical and egalitarian structure of the program, clubhouses are pushing back against very problematic hierarchies that have fueled ableist dichotomies like "server and served," "helper and helped," "professional and client." Secondly, clubhouse staff are not necessarily *social workers* (and as mentioned, the director I worked with believes clinical training can be a *hindrance*), which means that clubhouses are spaces where more diversely educated/experienced people can work, further reducing the reliance on clinical expertise. Thirdly, clubhouses challenge neoliberal-ableist ideology through 1) refusing to believe that people with psychiatric disabilities cannot participate in the mainstream of society and 2) creating a supportive environment that proves their belief right.

But to parallel these points, in what ways are clubhouses *failing to act* on awareness or revealing a *lack* of awareness? Firstly, the hierarchy may be flat in theory, but I have never been in any clubhouse where it was not obvious who was staff and who was member (even though not being able to tell the difference is one of the models key features), and in cases of uncertainty it is usually resolved by "so, are you staff or member?" And this is saying nothing about the directors, executive directors, and other positions of power within Clubhouse International. In short, clubhouses *do* have hierarchies. Secondly, many clubhouses, including Fountain House, have begun to *only* hire people with MSWs, so though clubhouse staff are *currently* diverse in professional background, this is changing. Thirdly, though clubhouses *do* challenge neoliberal-ableist ideology by 1) refusing to believe that people with psychiatric disabilities cannot participate in the mainstream of society and 2) creating a supportive environment that proves their belief right, they *fail to question mainstream society*. In fact, clubhouses *reproduce* hegemonic ideologies and practices surrounding mental illness and social participation. They promote medical understandings of mental illness, and their benchmark of successful rehabilitation is still the same old 1950s era *American Dream* of a "normal life" – a job, someone to marry and reproduce with, property ownership, and above all, "independence."

Clubhouses are very good at providing people who are marginalized, poor, and lonely with a place to meet their social needs of purpose and belonging, and a path to meeting their life goals. This is *fantastic*. But clubhouses do not try to instill in members a critical consciousness

about the broader social conditions that are directly *responsible* for their marginalization, poverty, and loneliness – such as white supremacy, classism, neoliberal capitalism, patriarchy, and most critically, *ableism*. This is perhaps understandable, as clubhouses are psychiatric rehabilitation programs, *not* conscious-raising programs. But that said, consciousness-raising is an utterly *crucial* element in empowering *anyone* about *anything* (Chamberlin 1978; 1990).

In this community, I expected to see a lot more awareness of the ableism intrinsic to the mental health system, but in clubhouses, diagnoses are *deemphasized*, not *challenged*. The "brain disease" model is accepted by almost everyone I have ever met in a clubhouse – barring some notable exceptions, like the woman I overheard telling a NAMI representative;

> I don't buy the "busted brain" hypothesis. That's why I don't like the word "disability." I prefer *diff-ability – different* ability.

In fact, Clubhouse International's "fact page" about mental illness opens with: "Mental illness is a highly prevalent, life-threatening *disease* that affects millions of people around the world" and "has a significant impact on human *productivity*, causing as *many lost days of work* as cancer, heart attacks, or back pain" though "people can recover from mental illness with good treatment."[127] I italicized a few key words: "disease" (diagnostic brain disease language) and the conflation of "productivity" with "days of work" (wage labor). *Not* radical, *quite* ableist. Also, I can guarantee that "good treatment" means psychiatric evaluation, pharmaceuticals, case management, and individual therapy. This is not a guess – Alan Doyle, Director of Education and Training at Fountain House, told me that "Clubhouses are not anti-psychiatry, they are partners with it." They *must* be, in order to ensure that members get integrated and decent care.

It was naïve of me to expect to see radical understandings of mental illness in clubhouses. I hold my beliefs because I am educated in a deconstructive discipline. To expect to see radical anti-system mentalities in impoverished people who are deeply reliant on the system was foolish.[128] To expect to see radical mentalities in staff was also foolish – frankly, their job doesn't ask them to deconstruct "mental illness," so why would they? Additionally, and perhaps most importantly, *the current system of which clubhouses are a part relies on people believing there is something wrong with them that they need expert support for*. Consciousness-raising is

---

[127] http://clubhouse-intl.org/our-impact/about-mental-illness/key-facts-about-mental-illness/
[128] It was also foolish of me to project my own threshold of "radical" onto clubhouse members. Among the disempowered, rebellion looks very different than does the rebellion of the more powerful. See James Scott's *Weapons of the Weak: Everyday Forms of Peasant Resistance* (1987).

unlikely to happen in places where people's faith in experts is necessary for its continued existence. The radical move that clubhouses make is not to deconstruct mental illness or the mental health system, but to say "ok, these folks are ill, but that doesn't mean they don't get to have their needs met, and it doesn't mean they can't get better, so let's meet those needs and get them better." I think clubhouses are a "humanistic mental health program," which, like "radical social work," is to me paradoxical, but nevertheless the case. And clubhouses reach *many* more people who are desperately in need than anti-establishment alternatives do.[129]

And now to turn to the ways that clubhouses reproduce problematic values and practices *beyond* the definition and treatment of mental illness. Firstly, let me discuss this in relation to staff. If you remember the list I reviewed earlier of qualities that staff must possess, I have here three cynical additions:

1) To be fine with little to no career mobility or pay raises. This is unfortunate but also necessary. The environment would be polluted by hierarchy if staff were earning six figures while members were impoverished.

2) To be fine with antiquated gender stereotypes. As clubhouses do not practice consciousness-raising, they are as patriarchal as anywhere else where people are not particularly "woke." This means people routinely express gender normative values. "This is ladies work, this is man's work." And this includes the objectification of women, from compliments to comments about why we are unmarried or without children "at our age." Additionally, the demands of *affective labor* in clubhouse staff (who are usually women) are high – you are expected to be committed, enthusiastic, and loving, at all times. As one staff said, "you must learn to self-regulate, to fake a good mood if you must, because the clubhouse can make room for *member's* dips, but the same doesn't go for us." This is necessary – and if you can't bring love to this work, it probably isn't your work – but it is still gendered labor that is often unacknowledged and not remunerated.

---

[129] As Chamberlin (1990) noted, most people don't *know* about alternatives to conventional treatment.

3) To have enough of a life outside of the clubhouse that it doesn't drive *you* mad. As one staff said, "this job is unpredictable and chaotic. This is a good thing for me, as it draws me out of my shell, but it also drives me, and my husband who has to listen to me, *crazy* sometimes." And another, "if it wasn't for my commute – the hour I get to sing, cry, or whatever I need to decompress – and the little guy waiting for me at home, I don't know if I could sustain this."

In the end, I cannot reconcile the painful tension between "seeking piecemeal improvements in the ways things are done" or tackling "fundamental challenges in the name of reason to the current way of doing things and to the avowed or hidden assumptions on which it rests" (Carr 1967: 207). Yes, clubhouses reproduce oppressive norms, but they also reveal how those who are marginalized by such norms adapt to and resist them. And by refusing to be separatist – through their Transitional Employment (TE) program, encouraging people to strive for independent employment, social recreation in the community, engaging in activism and advocacy[130] – clubhouses *do* succeed at making the mainstream more inclusive by showing that people with diagnosed psychiatric disabilities can, do, and will continue to be a part of it.

At their most successful, clubhouses enable members to reproduce the norms of the society that has rejected them, suggesting that *helping people take pride in feeling normal takes precedence over challenging the inequities that normality generates and masks*. However, I believe that clubhouses can, and should, expend effort to raise consciousness amongst members. I have already witnessed rustlings of this. For example, during my fieldwork, the clubhouse formed consensus-based rules for appropriate workplace conduct in reaction to women's complaints about flirtation. Though letting people know that saying "you look pretty" is not appropriate in a workplace is reactionary (rather than proactive) and surface-level (rather than deep), it is a good starting place. I believe that clubhouse members have the right to understand that they could choose not to identify as "ill" or "disabled," to choose instead to be "differently abled." Who is going to tell them this,[131] if not the clubhouse? This issue – the absence of

---

[130] Including voter registration: 77% of members in my clubhouse were registered to vote in 2015.
[131] In one of my interviews, I challenged a member to start thinking about mental illness in terms of difference rather than wrongness: Her: I knew something was wrong but didn't know exactly what.
Me: What do you mean by wrong?
Her: Well, I couldn't keep still, and I kept getting so depressed… I always felt alone, like I was different.
Me: So by "wrong," do you mean different?
Her: Yes, different.

consciousness-raising programming – forms the basis of my recommendations for improving the model, to be addressed toward the end of this book.

And the "broken eggs?"

There are already so many "buts," *but*, I have another. The Clubhouse Model has improved a lot of lives, but eggs have been broken for the sake of this colossal omelet, and it is now time to examine these broken eggs.

As many of the works I referenced in this chapter pointed out, the tension between professionalism and radicalism was present in the history of Fountain House. John Beard was known for his "war[iness] of the mental health establishment," and only after his death did standardization take off because his successor "recognize[d] that the clubhouse model can flourish only by reaching out to those working and teaching in the field of psychiatric rehabilitation" (Glickman & Flannery 1996: 165). This transformation has meant a lot of good things – the model reaches more people, has a clear and replicable philosophy and practice, and is even accepted by the mainstream mental health system in spite of its philosophy and practices being contrary to that main stream. However, in marrying the system as it has, there have been sacrifices, such as the membership limitations instated by Medicaid, not to mention the total reliance on unstable government funding subject to cuts based on what creed of politician has power at the time. I happened to be in the field when this issue came to a head.

In 2015, the Community Mental Health (CMH) agency in the county I was in faced a huge and well-publicized budget deficit of almost five million dollars due to dramatically decreased General Fund and Medicaid funding.[132] It was not alone, all throughout the state cuts were being made and people were being shuffled from one program to another (e.g. from Medicaid to the "Healthy Michigan Plan"[133]). Around this time, the county's CMH agency decreed it would *only* see people on Medicaid (not formerly so) – and as a result, many members I knew not only lost their eligibility to be seen at CMH, but also to attend the clubhouse.

Because of the Clubhouse Michigan coalition, my clubhouse was in deep conversation with other clubhouses who were forced to actually dismiss members – an epic violation of

---

[132] I can't be explicit because it would be too easy to identify the clubhouse I was in, and the IRB does not wish me to do this… and though I can't share it, I do have a list of names of psychiatrists and administrators earning six figures at the time that the deficit was revealed.
[133] http://www.michigan.gov/healthymiplan/

Clubhouse Model principles, and deeply felt in their communities. This, luckily, did not happen in my clubhouse, but the fear was there. The strategy at my clubhouse, as well as others in the conversation, was to use an "honorary member" system, to defer to the very first Clubhouse Model Standard – "membership is voluntary and without time limits."[134] Basically, the people who had become members before this change happened would be allowed to attend, but they could not be "billed for." For some Michigan clubhouses this was a financial blow, but it was also a blow to morale, with members in this situation feeling like they were "not really members" or that they were a further burden to the already financially burdened program.

And even *before* this mess, there were problems with the Medicaid marriage. For example, on multiple occasions I witnessed members (two in particular) saying to staff things like "you should be thanking me for being here – for every 20 minutes I'm here, you all get paid, but what do *I* get?" And one director from another clubhouse (who I met during a coalition meeting) gave me the low-down on what she called the "crapshoot" of Medicaid eligibility:

> A lot of people who are really sick, sick enough to end up at CMH, are not really ready for clubhouse right away, but when they get well enough not to need CMH, they immediately lose their eligibility to be clubhouse members, right at the time they could benefit the most from it.

And yet, Clubhouse International touts the Medicaid marriage in Michigan as one of its great advocacy successes of 2015-2016:

> The Michigan Department of Health and Human Services (MDHHS) has seen dramatic improvements in member outcomes at those Clubhouses that have achieved Clubhouse International Accreditation. As a result, they have made Accreditation a requirement for all Clubhouse programs in Michigan. Clubhouse International, MDHHS and our Michigan Clubhouse Coalition are partnering to ensure success: we expect the number of Accredited Clubhouses in Michigan to double from 15 to 30 in two years, and grow to 40 by December 2018, which is the MDHHS deadline for full Accreditation of all Michigan Clubhouses.[135]

What they say is true, but an it is *also* true that the Clubhouse Model has partnered with the very same kinds of bureaucracies and deficit-focused systems that the original group in Manhattan – We Are Not Alone (WANA) – formed *in reaction to*. Indeed, the tension began *before* the Medicaid marriage, *before* the official standardization in 1989 that John Beard "might have

---

[134] https://clubhouse-intl.org/resources/quality-standards/
[135] http://clubhouse-intl.org/what-we-do/mental-health-advocacy/

thought dogmatic" (Glickman & Flannery 1996: 175), *before* Fountain House was funded by NIMH to begin expansion in 1977… and right back to when John Beard was hired in 1955.

Judi Chamberlin is famous in the *Mad Pride* movement, and her book, *On Our Own: Patient-Controlled Alternatives to the Mental Health System* (1978) has been widely read and cited in the Mad Studies community. It is one of the most beautiful books I have ever read, detailing the social construction of mental illness, the iatrogenic nature of psychiatric treatment, and the absolute *centrality* of critical consciousness. The book is designed to help people understand and connect with alternatives to the mental health system, and she describes several kinds of alternatives: 1) The partnership model, where professionals and patients work together. 2) The supportive model, where there are no professionals, and membership is open to both non-patients and ex-patients. 3) The separatist model, where only ex-patients can be involved. She believes that only the latter two can be "real alternatives," because there will always be hierarchy in programs that purport "partnership."[136] In elaborating upon this, she says;

> An excellent example of the workings of the partnership model is provided by Fountain House… The history of Fountain House clearly shows the limitations of this model. What is now Fountain House began as WANA – We Are Not Alone – a self-help group formed by several patients in Rockland State Hospital in the late 1940s. The group continued to meet in New York City after the patients were discharged, and attracted the attention of volunteer workers, who found them a place to meet but who also transformed the group from a self-help project to a new kind of psychiatric facility. A professional staff was hired and, in the early 1950s, most of the original founding group of ex-patients quit in disgust… Jordan Hess, who was a member of WANA, remembers how things changed when the group became professionally controlled. 'There was a feeling of solidarity and companionship in WANA that deteriorated when the professionals got involved. For awhile, the ex-patients continued to run the club. We raised our own money and we voted in new members. But eventually the administrators decided to take that power away from us. Instead of the members deciding who could join, when new people came in they were interviewed by staff, who decided if they were "suitable cases." WANA was unique because patients ran it – that was abolished when it became Fountain House' (87-88).

What makes this passage so eerie is that it begins almost exactly like the rosy Fountain House history one finds almost everywhere else, *including the beginning of this chapter*. But instead of "and then John Beard came and things got even better!" it says the *reverse*.

---

[136] In Carl Roper's "Is Partnership a Dirty Word?" (2016) he suggests that in looking at "partnerships in psychiatry [we must] start by acknowledging that they are not equal and [shifting] the focus away from equality to a commitment to articulating inequality… if this does not happen, there is a danger that those with less power will bear the burden of whatever is unspoken" (205).

Chamberlin visited Fountain House herself, and writes of that experience;

> During my visit to Fountain House, staff member Sheila Sherman told me that Fountain House is run by its members. This is the official ideology… but what it appears to mean in practice is that members do most of the work while professionals make most of the decisions… Director John Beard told me that one of Fountain House's main strengths is its flexibility. Members aren't expected to move through the program at a predetermined speed…and can drop out and come back any time. But the flexibility only goes so far. It does not allow members to question their need to be "rehabilitated" or to determine the suitability and qualifications[137] of the staff (89).

She also noticed that Fountain House had a harmful and unexamined problem: its membership was limited to the most disabled of ex-patients. Fountain House members had no role models of ex-patients who were "competent" or held "responsible, interesting, well-paid jobs" (Chamberlin 1978: 90). Their role models, and thus their aspirations, were limited to Transitional Employment (TE) positions in low-skilled wage work, and if they were lucky, they might be the ideal "success story" and move on to independent employment in the same realm.

It is shocking to see such an opposing account to the "official ideology" of the Clubhouse Model, a glimpse of its metaphorical "broken eggs." But in truth, I worried about these issues before reading this. I knew there must have been people who resented the professionalization. And most significantly, I had also noticed the fact that there is little room in the program for people with greater recovery ambitions than working in a supermarket. In my time, I saw one member return to a "responsible, interesting, well-paid job," and one member come in and almost immediately say "this isn't me, I went to art school, writing for some piddly little newsletter here isn't going to cut it." But most other members were exactly as Chamberlin described in early Fountain House: undereducated and impoverished. For a variety of reasons, including the way it is funded, the clubhouse I worked in serves a specific population: *the poor mad.* The intersectional messes, people who life has barreled with many "disadvantages," who might not have lofty ambitions even if they *didn't* happen to experience psychiatric disability.

In the end, when it comes to clarifying my view on the Clubhouse Model, I am most influenced by the members I worked with. As you will see in the next two chapters, there is a palpable gratitude for the clubhouse, because it separates them from the lives they had when they faced life with mental illness and poverty *alone*. I am irked by the imperfections, disconnects,

---

[137] I am certain it was *exactly* like this at the time she visited, but today, members are actively involved in hiring, from reading resumés to participating in interviews.

disappointments, and "broken eggs," but I can also see that the Clubhouse Model omelet is feeding an awful lot of hungry people. There are people with needs, desperately important needs, that are met through and by their clubhouse alone. Mental illness, especially at the grave level of psychiatric disability, is an awful and isolating experience, and there are so few places where people can find what they deeply need – not pills, not an hour-long appointment once or twice a week, not knitting circles or workshops about how to "cope" with your "symptoms," but just to feel purpose and belonging.

CONFESSIONAL MONOLOGUE
Rich Mad, Poor Mad

It only occurred to me halfway through writing it that my ethnography is not of *mad* people, but *poor mad* people. Clubhouses almost entirely cater toward the poor mad. Even in Fountain House, the freestanding and financially stable mother ship, the members are poor. Or "cheap," as one of the staff said, delicately, as he tried to convince members not to skimp on air conditioning lest they drop dead from heat exhaustion (as a member apparently had the summer before my visit).

In my clubhouse, members were so poor that I perceived poverty as their major disadvantage most of the time. It certainly got a lot more coverage in day-to-day complaints than mental illness did. And complaints about mental illness were usually just complaints about poverty in sheep's clothing: "Shit, I'm going to struggle to make these appointments because my car is threatening to die" (from one of the very few members who *had* a car – a really old, really decrepit piece of shit – who confided in me that other members enviously believed she must have "loads of money" because she had a car, "so were always asking for loans").

It is common to wonder about the evident link between mental illness and poverty – *chicken or egg*? Of *course* poverty, being a relentlessly stressful experience, can cause

or exacerbate mental illness. And of *course* mental illness, being an expensive experience that often drags one away from economic participation, can cause or exacerbate poverty. As the authors of *Poverty, Social Inequality, and Mental Health* wrote, "Money is not a guarantor of mental health, nor does its absence necessarily lead to mental illness. However, it is generally conceded that poverty can be both a determinant and a consequence of poor mental health" (Murali & Oyebode 2004: 217). Determinant *and* consequence. Chicken *and* egg.

Though I had my causation suspicions, I was doomed to the limbo of "correlation" until I stumbled upon a beautifully written article in the radical online forum *Mad in America*. Social worker Jack Carney wrote *Poverty and Mental Illness: You Can't Have One Without the Other*[138] in which he reviewed the correlation/causation research. He noted that the correlation between poverty and mental illness has been empirically and publishably evident since at least 1958 (i.e. Hollingshead and Redlich's *Social Class and Mental Illness: A Community Study*). Most recently, a 2005 article by Christopher Hudson appears to have laid the argument to rest: a study of epic proportion, conducted over six years with 34,000 subjects in Massachusetts, which found that 1) increased economic hardship in a community resulted in increased rates of mental illness and hospitalization, 2) socio-economic status accounted for 80% of the rates of mental illness in a community, and 3) economic drift, or "getting poor after diagnosis," was not statistically significant. Hudson concluded that there was "a remarkably strong and consistent negative correlation between socio-economic conditions and mental illness, one that supports the role of social causation in mental illness and cannot be accounted for by geographic or economic downward mobility" (16).

This confirmed my suspicion that poverty was more of a cause than an effect (though it was still both). I felt overwhelmed by the irony as I realized that the mental health system is (unwittingly) trying to solve a problem (poverty) that it absolutely cannot solve.

---

[138] https://www.madinamerica.com/2012/03/poverty-mental-illness-you-cant-have-one-without-the-other/

I remembered what I had learned from Foucault – that modern "madness" began as a stand-in for "someone without economic value" – and thought about all the steps that took us from there to the place where "mentally ill" is still a fair synonym for "poor."

Here in New York City, where I currently write, I don't have to go very far to find someone who is experiencing poverty and mental illness. The poor mad are very obvious. There is literally someone who fits this bill "living" on every street. They may be marginalized, background noise to the very-important matters of the passers-by, but they are still obvious. But though poverty demonstrably causes mental illness, it is clearly not the only cause, so… *where are the rich mad*?

As a millennial, I obviously asked Google first. Google informed me that there are a variety of "Luxury Psychiatric Treatment Centers," and that the "highly trained professionals at inpatient luxury psychiatric facilities are equipped with the skills and knowledge it takes to get you through even the roughest states of recovery."[139] A little ways down the search results page was an NPR article titled "How therapy became a hobby of the wealthy, and out of reach for those in need"[140] – which describes how more and more clinicians have stopped accepting insurance because they can more easily make a living providing therapy to people who can pay for it out of pocket.

I then found countless articles claiming that *wealth,* just like poverty, *causes* mental illness: apparently, "Children of rich parents [are] suffering increased mental health problems: The unrealistic expectations being placed on children by wealthy parents is leading to mental health problems, according to the latest research."[141]

[139] https://www.recovery.org/topics/luxury-psychiatric-recovery-centers/#finding-the-best-luxury-psychiatric-treatment-center
[140] http://www.npr.org/sections/health-shots/2016/06/30/481766112/how-therapy-became-a-hobby-of-the-wealthy-out-of-reach-for-those-in-need
[141] http://www.telegraph.co.uk/education/10439196/Children-of-rich-parents-suffering-increased-mental-health-problems.html

So, the poor rich mad were possibly to be found in luxury hospitals, or paying 400-dollars-an-hour out of pocket to a therapist, or fighting stigma by speaking out like these "55 celebrities"[142] are?!?

I closed the computer. It was late, and I was too tired to handle this new set of revelations and questions. As I stood up, I caught a glimpse of myself in the full-length mirror (which corroborated that I was indeed too tired), and it hit me: *I* am rich mad.

I am not *wealthy*, but I am certainly not poor, and in terms of social capital (i.e. education and social connections), I am *very* wealthy. Therefore, everything I have to say about madness, I say as someone who once knew (childhood) poverty, but not anymore (#UpwardlyMobile). This does not invalidate my musings on madness, but it is absolutely necessary that I remain conscious of it: I am rich mad, and through fieldwork have come to know poor mad, and I have learned that madness is not nearly enough of a unifying experience to overcome the chasm of class.

I do believe – based on evidence, experience, and hope – that whatever ones' layers of intersectional disadvantage may be, one can still heal soul-wounds and accommodate madness (or learn to roll with the strengths and limitations of one's own body/mind). But healing soul-wounds and accommodating madness is *expensive*. Incalculable material *and* immaterial costs to ourselves and those we lean upon.

I fear that "sanity" is becoming a luxury fewer and fewer can afford. The apocalyptic-sounding "1 in 5"[143] is, I believe, the sneaky result of overdiagnosis *and* over-medicalizing *and* keeping mental-health-system-ers employed. But I also believe it signifies how spiritually inhospitable the world is and how burdened we all are by the

---

[142] http://www.glamourmagazine.co.uk/gallery/celebrities-talking-about-depression-anxiety-and-mental-health
[143] https://www.nami.org/Learn-More/Mental-Health-By-the-Numbers

accumulation of manmade[144] suffering. In our culture it is hard to feel good about yourself, or others, or humanity. It is easier to hate yourself, to be fearful and anxious, and to teach children that strangers are monsters rather than as-of-yet unmet friends. Rich or poor, the steep cost of sanity in a mad world renders it near unreachable.

I think about these oft-quoted words of Audre Lorde; "Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare" (2017: 130).

Accommodating madness and healing soul-wounds in this totally mad world may be the costliest act of resistance one ever does.

---

[144] Ordinarily I would amend this to "human-made" to be gender inclusive, but let's be real, if we are talking transhistorically about oppression, we *are* talking about men.

CHAPTER FOUR

What is Madness? And what is it like to be Mad in Michigan?

In this chapter I further define and describe what madness is, means, and does. In the first section, "What is Madness?" I explore the multiple and contradictory ways that myself and my interlocutors view "mental illness" – both the *term*, and the *experience*. In the second section, "Mad in Michigan," I describe the practicalities of "psychiatric citizenship" in Michigan.

***

The day that I said goodbye for the last time, Anna, who I had been sitting and chatting with a while, blurted out "you're so lucky, you don't have a mental illness."

"I don't?"

"You don't look *like you do."*

"And what should someone with a mental illness look *like?"*

"Oh. I guess you're right."

I wandered toward the reception desk, where I had worked for most of my internship. Rena was standing there holding her usual overlarge McDonald's soda cup. "Don't forget to eat," she said to me, sipping slowly. I assured her that I wouldn't, for the hundredth time. To be thin[145] in

---

[145] Since readers know that I have experienced disordered eating, I must clarify that this was no longer the case during fieldwork. I was/am still "thin" by cultural standards, but not underweight, and I definitely ate in front of people (including Rena) all the time.

a sea of people uncomfortably overweight due to the insidious mix of psychiatric medications[146] and poverty, meant that my body was regularly commented on. I gave her a farewell card, and she smiled and said, "I want to stay in touch with you." "Of course", I said, "we can text any time."

"No, spirituality*," she clarified. "But you have to understand, it means we will feel each other's pain, and happiness."*

"Isn't that what friendship is?"

She grinned, hugged me, pressed her forehead to mine, and went back to her soda.

Jen, who had been studying her bible silently nearby, asked me if she could visit me in New Zealand. "Of course you can," I said. And even as I was saying it, it occurred to me how absurd the notion was. Not only would she never, ever be able to afford it, but as a person living with schizophrenia, whose wellness requires more support than I could ever imagine, the idea of her embarking on any trip alone – never mind a 20-hour trek from Michigan to New Zealand – was the maddest thing I would hear that day.

I entered the clerical unit, and found Sophie sitting quietly at a table. Sophie rarely says much, and has some complex cognitive degeneration that means much of what she does say, she has said already, but she has a distinct and pleasant personality, and gives the strangest compliments I've ever heard ("What a lovely shaped nose you have!"). As I entered the room, she lifted her gaze to me and said, "you're leaving, aren't you?"

"I am."

"Well, you will be missed. By the clubhouse as a whole, and by me in particular."

---

[146] A significant body of literature shows that psychiatric medications – mood stabilizers, anti-depressants, and anti-psychotics – cause weight gain (Schwartz et al. 2004; Shrivastava & Johnson 2010). This is also discussed beyond scientific journals, i.e. https://www.scientificamerican.com/article/many-psychiatric-drugs-have-serious-effects-on-body-weight/

Her tone was formal. I hid my tears by giving her a hug.

Then Hope, dear Hope, my close friend and fellow reception desker, pulled me into one of her classic, and very awkward, minute-long (at minimum) hugs. Anna sauntered toward us and sat on a desk nearby. She regaled us with tales of her group home housemate, her floor-pissing glass-smashing porn-watching group home housemate. Hope had a cold, and wondered aloud whether it was because of some eggs she had eaten. I assured her that was unlikely. I loved conversing with Hope. She is gentle, and asks a lot of very odd questions which are fun to answer. She also has the highest pitched voice I've ever heard, and a laugh to match, a laugh which often inspires Anna to mimicry (to the chagrin of anyone who can't bear the sound – so, everyone*). Anna announced that we should be proud of her, because she had banished her tumor. "I told you to pray for that! Well done Anna!" Hope exclaimed. I relished in the moment, in the strange and otherworldly discussion of things that were –* here *– totally ordinary. It tore at my heart to think that, soon, I would be without such strangeness.*

When we said goodbye, I thanked Hope for being my friend and for helping me so much throughout my internship and research. "You helped me too," she said. "You helped me by being my friend, and made me realize that I am not strange because of my mental illness."

"Not because *of your mental illness, no," I said, chuckling.*

"I'm strange as well," Peter chimed in.

"Yeah, me too," said Fred, who had been standing silently nearby.

"We're all *strange. There's no such* thing *as strange here," laughed Jen.*

CONFESSIONAL MONOLOGUE
Bothersome Terms

One carefully crafted question I asked everyone I interviewed was **"what does mental illness mean to you?"** I settled upon this question because I believed it was worded to yield more idiosyncratic (and deep) responses than "what is mental illness?" or "what do you know/think about mental illness?" Though I frame my own thoughts (and this book) using my preferred term, madness, I did not use it during fieldwork because it was not part of the local lexicon, and besides, I wanted to deemphasize *terms* and focus on *lived experiences*. But no matter how hard I resisted, I found myself defining and categorizing internally (damn categorical mind). So I relented. What follows is what I wrote when I asked myself the same question, for each bothersome term in turn.

Madness…

…is **strangeness.**

…is a space of **potential** between the cracks of the world we think we share with others (between the "chinks of man's cavern" that William Blake wrote of).

… is the **break from shared reality** (accompanied by consciousness that multiple realities must exist) that happens when one cracks the "cavern" walls or lifts the perceptual veil[147] and glimpses an infinity that can never be unglimpsed, so the reality one formerly shared (or believed one shared) with others may never again cohere.

…is the **inability to "feel at home in the world"** (Foucault 2011[1962]), having nowhere for your soul to "land."

…is the **"existential vacuum"** Victor Frankl (1984) wrote of, in which life's meaning is obfuscated (perhaps by pain, the ultimate blinder).

…is the **mind-blowing paradoxes** of human life, such as: structure and agency (realizing you have no control over things you wish you had control over, or feeling overwhelmed and indecisive in the face of choices you *could* make about things you

---

[147] As Barbra Jago wrote, "to take the blinders off" (2002: 756).

could control), or knowing about not-knowing (fear of the unknown, and/or becoming aware of the profound limits of human awareness which makes most of what "is" unknowable), or that you feel most alive when you most don't *want* to be.

…is love, and **"love is merely a madness"** (#Shakespeare). Or as Gabriel García Márquez wrote in *Love in the Time of Cholera,* "his examination revealed that he had no fever, no pain anywhere, and that his only concrete feeling was an urgent desire to die. All that was needed was shrewd questioning... to conclude once again that the symptoms of love were the same as those of cholera" (2007[1988]: 62).

…is both suffering *and* ecstasy (though we often reduce it to the former), and learning there is no limit to either – **there is no floor to hell or ceiling to heaven***.*

…is learning what humans (and humanity) are (is) capable of (**#misanthropology**).

…is crossing a threshold (different for each person) of **intensity in emotion** that seems new, even if it isn't new, because it so powerfully captivates (like when a pain feels like the worst pain or a need feels like the only need, or when you are blinded by rage or passion. Renato Rosaldo used the phrase "high voltage"[148] to describe the shocking intensity of crossing such a threshold in emotion).

…is an **opportunity for authenticity**. When you accept and embrace madness, you accept and embrace raw humanity. Gone are pretensions to normality or OK-ness as you realize that no one is normal and no one is OK.

…is **marginalized (and coopted) by capitalism.**

…is not an enemy in the journey towards human liberation and peace. It is at least a necessary precursor, and at most, just necessary. Our ability to crack and then re-form, the bravery we learn because we have to, is **liberatory** if we allow it to be.[149]

…*can* fuel diagnosable mental illness, but is *not* reducible to it.

…thus broadly conceived is simply **a part of the human experience** – it might *feel* lonely, but most of us experience it before we die.

---

[148] He used this phrasing in an interview for the NPR podcast *Invisibilia*: https://www.npr.org/templates/transcript/transcript.php?storyId=530727323
[149] See my song "Epic Sigh" – a song about learning to "roll with all the punches that come between bliss": https://www.youtube.com/watch?v=CyUbNNnkXkQ&t=4s

Mental Illness…

…is *not* something most of us experience before we die. Depending on the measure, it is something **one in five** people in the U.S. experience in a year.[150]

…is a collection of specific **diagnostic criteria** that has been cumulatively created, informed by social and economic values.

…falls under the purview of a **mental health system** – a set of connected institutions created to manage (or cure/treat) it, such as public or private hospitals and clinics, insurance companies, and welfare programs.

…is treated by **mental health professionals** – psychiatrists, direct care workers, social workers, psychologists, case workers, nurses, peer support workers – who practice (ideally evidence-based) **therapies** (options include pharmacological therapy, individual psychotherapy, and group therapy, each with diversity therein).

…is **biopsychosocial**, or the result of a complex interplay between the social world that one is reared in, psychological idiosyncrasies formed over one's lifetime, and neuronal/chemical operations that happen beneath one's consciousness.

… is **created (and caused) by capitalism**. Hear me out! Not only was the *idea* and *practice* of "mental illness" created by a capitalistic medical system, but capitalism (as it has panned out in America) results in poverty, loneliness, and traumatic violence, which are all "causes" of mental illness (#SocialDeterminants). I fear that mental illness will continue to be pervasive, and will continue to account for a significant (the current estimate is 32.4%) slice of the total global "years lived with disability,"[151] so long as poverty, loneliness, and traumatic violence continue to be pervasive.

…is *not* **a brain disease** (I should not need to say this, but as I still encounter the brain disease model, it seems it is still an "error" in need of "killing"[152])

---

[150] https://www.nami.org/Learn-More/Mental-Health-By-the-Numbers
[151] http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(15)00505-2/abstract
[152] I am referencing this Charles Darwin quote: "to kill an error is as good a service as, and sometimes even better than, the establishing of a new truth or fact" (http://charles-darwin.classic-literature.co.uk/more-letters-of-charles-darwin-volume-ii/ebook-page-229.asp)

Serious Mental Illness…

…is everything that mental illness is except rarer (**one in twenty-five**), and **serious-er** ("substantially interferes with or limits one or more major life activities"[153])

Psychiatric Disability…

… is everything that mental illness is, plus the person meets the **legal definition** of "disability" and qualifies for **welfare state entitlements** (in the U.S. this means Social Security Disability Insurance [SSDI] – for people who were formerly employed and earned sufficient credits to qualify – or Supplemental Security Income [SSI] – for people who were never employed or did not earn sufficient credits to qualify for SSDI.[154])

*Note: any and all terms may apply to any and all people. One can identify as mad *and* mentally ill *and* psychiatrically disabled, if one meets criteria for all. This exercise has helped me better understand the separation between Madness and Disability as identities (and Studies), and why "sanism" was created to describe mad oppression rather than including it under "ableism." One can be mad, one can even be mentally ill, without meeting criteria for or identifying as having a disability.

What is Madness?

In this section, I relay mine and members' reflections on mental illness through the following sub-sections: "What does mental illness mean to you?" – Members' Madness Genealogies; "There's no such thing as strange here"; Multiple worlds; and Sick, or Dick?

"What does mental illness mean to you?" – Members' Madness Genealogies

In the clubhouse, I saw different understandings of mental illness, but despite diversity, there was one commonality: everyone thought about mental illness **genealogically**. What caused it? What is the origin story? How far back does it go? The universality of such questions

---

[153] https://www.nami.org/Learn-More/Mental-Health-By-the-Numbers
[154] https://www.ssa.gov/redbook/eng/overview-disability.htm

suggests that in any attempt to make meaning of (or cope with) experiences diagnosed as mental illness, it is necessary to understand its genesis and incorporate it into the narrative of self.

As noted in Chapter Three, people in this community generally understand mental illness to be a medical condition. And although the "brain disease" model is subsumed by the "biopsychosocial" model amongst up-to-date practitioners, many of my interlocutors still referred to it as a "brain disease." Pamela was an elderly woman who had lived a very full life spanning the ministry, homelessness, marriage, goat farming, and much more, with the only common thread being that nothing stuck for very long. In our interview, she told me;

> I didn't know why I couldn't keep still, why I kept feeling the need to move, why I kept getting so depressed, why I became who I was. I could look back at childhood for answers, but I didn't connect it to mental illness… when I look back on my life the mental illness limited me in gaining strong relationships, in staying with any job, staying with any place I lived. They were things I just couldn't do. Now I understand it was the bipolar… I have a brain disease. It's not my fault I am bipolar. It is like having diabetes – I have diabetes, and I do things for it – same thing as mental illness. It is a disease and I do things for it.

In describing her mental illness genealogy, Pamela uses three interesting linguistic devices. One device, common in brain disease model proponents, is to liken mental illnesses to physical illnesses. As Nikolas Rose (2006) notes, proponents "embrace a conception of mental disorders as diseases with a genetic component and argue that this recognition will reduce stigma associated with such conditions…[because] once located within the brain, mental disorders can…escape from the stigma of madness, and become simply diseases like any other" (216). But as I showed in Chapter Two, this is not only dangerously simplistic, but has failed to yield widespread social acceptance. With "*Now I understand*," Pamela reveals her (legitimate) buy-in to this rhetoric – something I also had (and found valuable), before I lost it – which helped her understand herself in productive ways, and also contributed to her ability to seek community with others who have similar experiences.

The second linguistic device is demonstrated in the statement, "It's not my fault I am bipolar." Sue Estroff (1993) describes the difference between "I have" and "I am" illnesses, noting that some diagnoses – such as mental illnesses – are more readily incorporated into one's identity ("I am") than others ("I have"). For example, "I *have* colitis" versus "I *am* bipolar." And yet, the third linguistic device Pamela used seems to counter the identification expressed in her "I am" statement: she also *separates* herself from "the bipolar." I witnessed several examples of

this separation of self from illness, such as when the director informed everyone that a valued member was in the hospital because "the depression has been kicking his butt lately," or when a group of people, in an attempt to comfort a member who was experiencing a distressing hallucination, assured her that it was "just the mental illness," it was "not real."[155] The most literal (and creative) instance I encountered was with Wendy – a smart and sassy young woman who wrote and illustrated[156] a children's book about a woman plagued by a tempestuous dragon, a dragon that is hard to tame, but with the support of loved ones, proves tame-able. The dragon, she informed me, represents "her bipolar."

This strategy of separating the self from the illness is a feature of certain clinical practices, especially postmodern meaning-centered practices. For example, in *Narrative Therapy* – which encourages reframing the "narrative" of the self in a way that centralizes one's values – this process of separating the self from the problem or illness is called "externalization."[157] In *Acceptance and Commitment Therapy* (ACT[158]) – a mindfulness-based therapy that similarly emphasizes values-driven living – it is called "cognitive de-fusion"[159] (i.e. reversing the process of fusing your identity with your thoughts or concepts).

Returning to the theme of understanding mental illness **genealogically**: thus far, I have described people who use depersonalized words like "illness" or "brain disease" to account for the origins of their experience, who at times identify with the label, and at times separate it from themselves. The following vignette provides a more personal and existential genealogy.

***

---

[155] This is the example of effective "invalidation" alluded to in the confessional monologue "Never Again." By "real," I believe they meant "shared" – the comforters are saying that they are not also experiencing this hallucination in hopes of reassuring her that whatever threat it contains is unlikely to manifest in "real" (as in "tangible") danger.

[156] Similarly, Ellen Forney's graphic novel "Marbles" is about life with bipolar disorder (https://marblesbyellenforney.com) and Toby Allen's project "Real Monsters" depicts different mental illnesses as cartoon monsters (http://www.zestydoesthings.com/realmonsters).

[157] http://jstinstitute.com/2017/03/narrative-therapy-practice-externalization/

[158] The "wonderful therapist" who helped me separate myself from "Stray Dog Laura" – which I reference in "Never Again" – practiced ACT.

[159] https://contextualscience.org/cognitive_defusion_deliteralization

"If I can look at my life and say 'nobody was able to break me, as much as they tried, not even myself,' and if I can see that I helped others, that my story helped a girl in foster care feel empowered, showed her that even the abandoned are somebodies... then my life will have been worth something."

This was by far the most rattling of my interviews. Of course I had known bits and pieces of her story from months of working together, but being with her alone, having her bear her most ravaging moments to me over the whir of a ceiling fan, was almost unbearable. Abuse, poverty, abandonment. Old friends to us both. And yet, after unspeakable violence, after strange beds in strange houses and the hopeless imprisonment of being a 'ward of the state,' what had destroyed her was love. *The loss of the little girl who she nannied from infancy until her tragic death by car accident at age five.*[160] *"When she died, I lost my purpose in life. Caring for her was my purpose and I felt like God had placed her in my life to save me. Though she has been gone for years, I am not over it. I'll* never *be over it."* So it goes, *I thought, remembering that my own unspeakable violences had paled, been totally eclipsed, by a run-of-the-mill heartbreak.*

To think, we both had endured extraordinary pain, yet our undoing had been the most ordinary thing of all! Heartbreak. The everyday tragedy. The all-time ultimate blood spiller.[161]

"No one understands this,"[162] *she said ruefully, "and you probably won't, and I don't really care because it makes sense to me.* Cutting helps. *One moment I'm raging, and one little cut later I*

---

[160] Before this, Clarice had not been hospitalized in a decade. Afterwards, it was "like a rotating door – I was in and out. I spent about 9 months of that first year in some sort of hospital or halfway house."

[161] See my song "all time ultimate blood spiller": https://www.youtube.com/watch?v=q_HZRaan4k8

[162] A sad indication that Clarice had not discovered how many people really *do* understand this. Not only myself, but many others who challenge the stigmatizing belief that self-injury is "mutilation," only significant in terms of its relation to suicide risk. In "Deciding to be alive: self-injury and survival," Clare Shaw (2016) centralizes the narratives of people who experience self-injury (including herself), and shows that "self-injury is about survival. The majority of people who self-injure do so in order to survive. Not die... self-injury is about distress and suffering, [but] it's also about hope, strength, choice, and self-determination" (78). She also frames it as a *coping strategy*, and amasses several functions of self-injury from the perspective of experiencers: it brings calm, comfort, distraction, a sense of control, relief from pain or guilt, and is a means of self-expression and feeling alive… Clarice and I are far from alone in finding solace in self-injury, nor are we alone in refusing to hide the scars that help tell our stories. See my song "frontal lobe farewell" – a song about trauma, stray dogs, and self-injury: https://www.youtube.com/watch?v=-mqGjgHTWlg

feel calm. And I don't look at it as mutilation. Each scar is a part of me. People ask why I don't wear long sleeves, and I say 'I have nothing to hide.' These are my Maggie scars."

I lowered my voice, though we were alone, and adjusted my skirt to reveal part of my thigh. "These are my Mark scars."

"Huh. We are more alike than I thought."

Yes*, I thought.* But… *After the unmasking of unexpected similarity, there is usually a beat where we lock eyes and I think, 'don't you see? I am like you.' Then guilt washes over me like a flash flood because I am* not*, because I am on the cusp of a PhD while she spends her life on an endless rotation of visits to doctors, case managers, and pharmacists, fiercely pinching pennies in the days before each social security check clears.*

<center>***</center>

This vignette comes my interview with Clarice. Though only a couple of years older than I am, Clarice's narrative is overwhelmed by trauma. She grew up in foster care, has been violated in almost every way a person can be violated, and yet has become a passionate advocate for foster children. With her, I felt a deep connection and shared more of my self than I did with anyone else. As the vignette illustrates, to both of us, it was not the *presence of bad things* that we perceived as the straw that broke our camel-backs, but the *absence of a very, very good thing*. Someone we loved with everything we had. This was not unique to the two of us. Marian, an older member – vivacious and tenacious – had an eerily similar story. Foster care, sexual assault, poverty, difficult jobs, difficult relationships, and yet it wasn't until she lost her husband – the only person who ever made her feel at home in the world – that she broke: "When I lost him, my whole world fell apart. I didn't have anything to live for." This idea – that loss of love is more torturous than torture – is not a new discovery (though for me it was), it is a theme that has dominated human stories for a very long time (e.g. Achilles and Patroclus).

One quote I will always remember is from Shakespeare's comedic romance, *As You Like It*: "Love is merely a madness."[163] I don't mean to argue that it is insane to love,[164] I only mean to argue that love and madness are intertwined. In the *social needs* framework, "love" – meaning relationships with intimate others – is a major source of *purpose* and *belonging*. Both Clarice and Marian explicitly said that their loved ones brought them purpose and belonging, which shattered in their wake. I believe this kind of loss is especially grave for people who experience madness and mental illness. Within the disability justice community, there is something called "access intimacy,"[165] which is the feeling you get when you (all of you) *belong*. It describes a space or person that is accessible to *you*. You don't even need to ask for accommodation because the space or person already accommodates you. Access intimacy is rare, and for people who experience mental illness – who are vulnerable to feeling like outsiders, whose strange souls struggle to find spaces to land in the world around them – it can be blissful to find someone(s) with whom we feel such belonging. This book is titled "Love in a Time of Madness" – a clever hat-tip to García Márquez, and a way of alluding to the fact that love (broadly conceived as purpose and belonging) is what saves us from the bad madness that surrounds us. But just as love *saves us* from destructive madness, so can love *become* destructive madness (Love in a Time of Madness…Love *is* a Time of Madness…). Though there may theoretically be more "fish" in the

---

[163] The whole excerpt is delightful (*Act 3 Scene 2*): "Love is merely a madness, and, I tell you, deserves as well a dark house and a whip as madmen do, and the reason why they are not so punished and cured is that the lunacy is so ordinary that the whippers are in love, too." Just as I said – "*everyday tragedy*."

[164] Though if I *were* to follow the farcical footsteps of Richard Bentall – who proposed adding "major affective disorder: pleasant type" to the DSM in his 1992 article *A proposal to classify happiness as a psychiatric disorder* – I could do the joke justice. Much of what passes as "normal" loving or romantic behavior could be convincingly "diagnosable" in terms of delusion, obsession, anxiety, risky behavior. I could even call it a "biopsychosocial" condition, for is it not also influenced by biology (pheromones, genes), psychology (personality, learned patterns), and the social environment (gender/sexuality norms)? In this semi-jocular assertion, I am joined by Helen Fisher, an anthropologist who researches romantic love. In a recent interview for the National Public Radio Podcast, *On Being*, she and the interviewer discussed love, lust, obsession, and madness. The interviewer quoted from a novel (a quote which mirrors the earlier Shakespeare quote); "Lust, that state commonly known as 'being in love,' is a kind of madness. It is a distortion of reality so remarkable that it should, by rights, enable most of us to understand the other forms of lunacy with the sympathy of fellow-sufferers." Fisher laughed, and agreed that "in fact, parts of the brain associated with decision-making begin to shut down when you're in love… romantic love evolved for that reason, to enable you to overlook everything in order to be with this human being." https://onbeing.org/programs/helen-fisher-this-is-your-brain-on-sex-apr2017/

[165] https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/

sea, *access intimacy* is so rare that for madly grieving[166] people like Clarice, Marian, or myself, the sentiment is empty. In an email I wrote to my ex-husband after our separation, I said "the adage that it is better to love and lose than never to have loved should me amended… for some of us, it is better not to know what we were (and will now be forever) missing." I no longer feel this way,[167] but Clarice does. I hope not forever, but she easily could. Maggie's death was a trauma to the very depths of her soul, far more personal and existential than the many traumas to her body/mind that she has already surmounted.[168] And though this is unbelievably sad (and to write it without weeping, impossible), it is also *beautiful*. Of all the maddening forces in this world, I am honored to be (and bear witness to others) toppled by love.

> Love has no other desire but to fulfill itself
> But if you love and must needs have desires, let these be your desires:
> To melt and be like a running brook that sings its melody to the night.
> To know the pain of too much tenderness.
> To be wounded by your own understanding of love;
> And to bleed willingly and joyfully.
> - Kahlil Gibran, *The Prophet*

Clarice conceived of her overall journey with mental illness through the lens of **trauma**, focusing on what *happened* to her rather than what was *wrong* with her. Like many others do, she described its impacts using brain-oriented language;

> Sometimes your brain just doesn't click, things aren't connecting. I feel wrong. Different. I hate to use the word normal, because normal is relative, but for me something feels off. I accept that I will always struggle with this, and need medications, but I can see it now, when my brain isn't clicking, and I know what to do, what questions to ask myself, in order to return to clarity.

But she also acknowledged that this doesn't just *happen*. *Trauma* makes it happen.

> People often think of mental illness as scary, like you are a time bomb. That's not it. It's just about things *not connecting*. Mental illness can be managed, yet people look at us as if we are damaged…It's not OK. I think of it as victim, to survivor, to thriver. You start out as a victim. When you are a survivor, you have survived but the trauma still has a

---

[166] See "Breaking Open the Bone: Storying, Sanism, and Mad Grief" (Poole & Ward 2016), which complicates the clinical "grief" framework and focuses on narratives that embrace grief as transformative.
[167] In my song "there you aren't," I describe how I have come to view grief as an opportunity for growth: https://www.youtube.com/watch?v=8eNBSVLbXqs
[168] In her own words; "I would go through sex trafficking, having boiling water poured over me, being chained to beds, any and all of it, if I could just have her back."

hold on you. When you are a thriver it means you have let go to the point where the person, or event, doesn't have a hold on you anymore. With mental illness, people can be thrivers… They may always have times when the brain doesn't click, and medicine may help or it may not, but I think talk therapy helps, and trauma-informed body work. Talk therapy helps you metabolize and process things mentally, but it is not head to toe. Trauma is stored in the body, so the body also needs work.

Clarice identified that trauma – being a "victim" of violence – is a common trigger of mental illness, which she views as things (such as thoughts) "not connecting" or "clicking." But she was also adamant that this is not the end of the journey, and that people are not easily damaged beyond repair ("*Nobody was able to break me, as much as they tried, not even myself").* It takes intensive work to metabolize trauma, integrate into an empowering "thriver" narrative, and use the experience to empower others, but it can be done.[169]

Another woman who centralized trauma in her narrative was Dorothy – a woman who knows multiple intersecting oppressions, as she not only experiences mental illness, but a variety of physical disabilities, as well as poverty, and being black.

> Dorothy: Mental illness is something in the brain, sure, the brain doing its own thing. The chemicals all those people talk about. But it also comes from trauma. I was molested when I was young, I was raped several times, maybe that was it. Both my mum and dad used drugs, maybe it was that. Or physical abuse. Look at my son… he was a normal healthy baby, and after what I did to him… I'm not trying to make excuses, but I need to explain. When my mum was dying I told her I forgave her, for doing this to me (she shows me a giant scar that wraps around her forearm, one that I'd seen before but had never asked about). She tied me to my crib and left me there, the rope dug in all the way to the bone. It was 6 or 7 days. My brother's teeth were all rotten when he was little because she didn't care for him. She was… she was…a "bad mom."

> Me: A woman struggling, who didn't have her shit together, like you were?

> Dorothy: Yes. Exactly. It was just so messed up. Incest, physical and emotional abuse… just… sickness. You have to break the cycle. That's why I eventually moved and took my son away. I knew I needed to change something. I regret that he is in the system, I regret that I damaged him, I regret so much, but I don't regret leaving the hood.

---

[169] In "The haunting can end: trauma-informed approaches in healing from abuse and adversity," Beth Filson (2016) reiterates the well-known fact that trauma *causes* mental illness, and introduces the trauma-informed narrative frame of "what happened to you?" (not "what is wrong with you"). Like Kiesinger (2002) and Smith (1999), she centralizes the power of *narrative coherence* – being able to tell an integrated life story – and *reclaiming authorship* – telling one's story in one's own words.

Dorothy highlights the uncomfortable truth that trauma is *intergenerational*, often becoming a "cycle" that is difficult to "break" (but not unbreakable). And though not included in this excerpt, the two of us also discussed the *collective trauma* her enslaved ancestors experienced, and the related fears she has for her son, who lives in a world where his big black body is constantly under siege. Her madness genealogy begins with ancestral enslavement, and ends (she hopes) with the violence she committed against her son, now in prison – today's enslavement.[170]

The last member whose tale begs telling in this sub-section on **madness genealogies** is Rena – a woman in her forties with the telltale look of someone whom life has ravaged: few teeth, wild white hair, fierce eyes, and sagging skin.

> What does mental illness mean to me? I guess because of what we've been through, evil fucks us up worse. There are reminders, things that trigger, bringing paranoia and pain. And people around us – people who don't know evil – don't understand. We are *all* a little messed up by life, but once it starts building up, evil has the chance to mess us up even more. Do you know what I mean by evil? The devil. People who cut throats. Bad energy plus action. I don't trust anyone in this world. There is so much, we could never cover all the evil there is in this world… There are people who are evil, people who do terrible things and get called mentally ill, giving the rest of us a bad name. Mental illness means people have been to hell, and now Earth no longer makes sense. I am not crazy; I have been through shit. Evil can capsize each and every one of us, and to stay afloat, sure, I do need medication. To keep calm in the face of everything I can't change. I'm a bitch in the morning. Let me get my coffee, pop my pills, and then I can face you all.[171]

Several points stood out to me in Rena's words. Firstly, that she has a very astute view of things: that it is *life* that "messes people up" (though unequally) – that *collective* problems contribute to *individual* madness. Secondly, the confident way she accepts her reality, and the role that medications play in keeping her "afloat" "in the face of everything she can't change." Hers was one of the few stories in which I felt favorably toward *psychiatric medications* – a topic about which I feel ambivalent, as I must *validate* their importance to many people in spite of profound,

---

[170] By this I mean that 1) prison, like slavery, strips people of liberty and rights, and 2) I am referencing the body of work (most famously Michelle Alexander's *The New Jim Crow: Mass Incarceration in the Age of Colorblindness* [2012]) that suggests that contemporary prisons have replaced Jim Crow laws, which replaced slavery, as the primary institution that oppresses black people in the U.S.

[171] As mentioned in Chapter One, I edited interview transcripts for clarity. But for this excerpt, I must be more open, as it went beyond ordinary editing. I rearranged things: brought something she said at the end to the beginning. I also wrote the sentence "mental illness means people who have been to hell, and now Earth no longer makes sense," because she spoke (without clarity) about hell, and people on Earth not "getting" it, and I wanted to create a powerful image out of this powerful idea.

preoccupying *skepticism*. The third point that impacted me was the idea that "mental illness means people have been to hell, and now Earth no longer makes sense." This is an idea I have often expressed myself – including in the first confessional monologue of this chapter. It is a difficult and layered concept, but for some, mental illness truly feels like a break from shared Earthly reality, one that is hard to un-break. And the last (and most painful) point I took from Rena was this: that her profound words could so easily fall on ears that would immediately invalidate them as "symptomatic."

"There's no such thing as strange here"

Though said in jest, Jen's words at the end of the vignette that opened this chapter were illuminating: *"there's no such thing as strange here."*[172] In spaces meant for society's "strange," what use does the idea have? And what is "normal" in spaces where dwell the "strange"?

One example of strange-but-normal behavior was how readily psychiatric language was incorporated into everyday speech, especially in what I call "Mad Humor" – the humorous use of psychiatric language. I once witnessed an elderly member sobbing over her stressful living conditions, who finally sighed and said, "I better stop this crying. We're about to head to the hospital,[173] and knowing my luck, they'll *keep* me there." And once, over lunch, I heard one member say to another, "this drama is boring, I'd rather listen to the voices in my head!" (This same member told me he enjoyed engaging in "witty banter" with his more critical inner voices). I even heard one of the staff say (without any members present), about an insurance agent she was dealing with, "I was so pissed, I almost went borderline on his ass" – referencing borderline personality disorder, a diagnostic category that describes people known for outbursts of rage. And once, while working in the kitchen, the staff member I was working with began to sing along to Michael Jackson's *Billy Jean*, complete with jazz hands. One of the members working with us exclaimed, "looks like Katie forgot her meds today!"

Initially, I found Mad Humor to be an unnerving indication of *colonization* by psychiatric rhetoric. But with time, I came to see it as an indication of *agency* – like Summerson Carr's (2010) "script-flippers," members were using this colonial-esque language for their own

---

[172] As one staff member told me; "the clubhouse is like the twilight zone sometimes. I have to say, since I started working here, I've felt surrounded by love and gratitude, *and*, I've never had stranger dreams."
[173] To give a presentation about the clubhouse for interested patients – a regular occurrence.

purposes, turning "serious" words into playthings. Additionally, it confirmed that for this community, psychiatric language was *normal.* This normalization of psychiatric language – as well as the experiences and practices this language describes – was not always humorous. At times it was mundane, like when I was small-talking with a member at the reception desk, and she casually said, "I got my groceries, then went to get a Haldol[174] shot, and then got my bangs trimmed – it only cost five dollars!" Or when the director told us Marian was in the hospital again because "she's been dealing with feelings of not wanting to live" – one of the most *humanistic* descriptions of "suicidal ideation" I have ever heard. In the clubhouse, such hospitalize-able experiences are included in "normal."

Multiple worlds

The member who most inspired this idea of "multiple worlds" was Anna. It took profound patience to connect with Anna. She was exuberant, unfiltered,[175] and had a tendency to speak in non-linear riddles. In my notes I often described Anna as "in her own world," and it wasn't until late in my field experience that I heard her say so in her own words. We were discussing the candidates for the 2016 presidential election – a surprise in itself, as she rarely concerned herself with current events – and she told me her views on Donald Trump;

> Anna: I don't like him. It seems crazy that a man like that is running for president. But I guess I don't know that much about it. To be honest, I am in my own world, most of the time.

> Me: I think we are all in our own worlds sometimes. Maybe I enter the world everyone else is in more often than you do, but it is all a matter of degree.

I was speaking truth, but I was also being *tactful*. Though it *is* all a matter of degree, Anna's position on the spectrum is extreme: she is regularly lost in "delusion." In *Madness,* Foucault (2011[1962]) describes the inherent isolation of delusionary worlds thus; "others cease to be partners in dialogue or task…and become, in this depopulated world, strangers" (87). Not only does isolation occur in this phenomenological deep-in-the-bones sense, but because our society is ableist, it is compounded by stigma and exclusion. One of Anna's common responses to the delusions that isolated her, was to invite others into her world.[176]

---

[174] Haldol is an anti-psychotic medication.
[175] ***For readers who know me, I am sure that hearing me describe another as "unfiltered" is riotous.***
[176] Not unlike the member who was "effectively invalidated" whilst experiencing a hallucination.

Anna's world can be jarring to invitees – it is a world where worms can enter and control human minds – and her world demands a unique set of navigational skills. She has mastered the art of double-checking, plainly asking someone else what they think. When invited into her world through her questioning, most people would say "no, that isn't real," invalidating her reality. Anna was so accustomed to this, that she would immediately accept it, and accept their invitation to return to the shared world where the table needs to be set for lunch.

"Do you think I am being controlled by brain worms?"

"I don't."

"Then you must be right. It's just my mind trying to frighten me again,[177] isn't it?"

"Yes, I think so. Now, will you help me set the table?"[178]

"Oh, right, yes, let's get back to that."

It is this constant re-invitation to the shared world of the clubhouse that prevents Anna from getting lost (and challenges the patience of whoever is attempting to remain connected with her).

One of the staff members who worked hard to keep Anna connected to the shared world of the clubhouse called her "mindfully delusional" – capable of noticing when something in her world seems delusional, double-checking, and rejoining the shared world. I was not able to discern where Anna learned this skill, though I suspect she had help: many people with schizophrenia participate in support groups, such as the Hearing Voices Network,[179] where they are encouraged to speak to (and seek *meaning* to) voices so they can be managed.[180] Psychiatrists R.D. Laing and Loren Mosher, introduced in Chapter Two, similarly believed that if we take pains to *decipher* the messages of madness, it becomes manageable.

---

[177] Another example of "externalization."

[178] This is a classic example of using the work-ordered day as a way to redirect members' attention from suffering/symptoms.

[179] https://www.hearing-voices.org

[180] At Bethel House, the program in Japan that shares similarities with clubhouses, they have a ritualized practice of respecting and creatively naming voices. As Nakamura writes, "every year they hold an annual festival where the highlight of the festival is the Hallucinations and Delusions Grand Prix. Here, the best hallucination or delusion is celebrated. The twist is that "best" means the [one] that brings together the most people or has the most community involvement/" (82). The extent of Bethel's ability to make room for voices means that many "would miss their voices if they were gone" (83).

The multiplicity of worlds is not the problem; the problem is mutual *intelligibility* between worlds. In truth, many people (with or without mental illnesses) struggle to consistently understand each other's worlds, but when the distance between worlds is magnified by the extraordinariness that characterizes the inner world of the mad, it can be nigh impossible.

Anna will always struggle to understand others and be understood by others. She will always struggle to find access intimacy – a smooth landing pad for her world in the world of another. I was incapable of providing such a space of belonging for her, simply because of how hard I had to work to understand her – for me, such intense intellectual engagement precludes empathic connection. Sadly, it doesn't prevent me from projecting my own experience upon her, and pitying the loneliness I presume anyone would feel at realizing there is nowhere to land.

CONFESSIONAL MONOLOGUE
(Un)breachable Worlds

I well know the loneliness that comes from having spent too much time in my own world, and too little time in worlds I share with others. For a long time, I would glimpse shared worlds (at school, at the store) and feel lost and terrified because I'd forgotten the rules of conduct. I stopped being capable of eye contact. I forgot how to touch or be touched. My ability to connect with other humans seemed to be made of stuff that could atrophy.

I was ashamed of my world, and of myself for creating it. Somewhere inside, I knew the ends didn't meet. I knew my stories (*myths*) lacked rigor, rhyme, and reason. I knew I was full of shit – that I was not worthless or doomed to eternal loneliness, and that if I passed my life thus it would be because I gave up trying *not* to. There were clear signs that my madness was a mystery that, once unraveled, would cease to disable me. One sign was the steadily increasing number of myths being busted by friends, mentors, and the one wonderful therapist I encountered (she practiced Acceptance and Commitment Therapy, which is how I first discovered a clinical tool I could connect with). Another sign was the fact that, when my mind was distracted from the task of myth-based self-

hatred, I became both competent and charismatic… my spirit was perishing and my body seemed not far behind,[181] yet I was not underperforming in a challenging doctoral program, and was still someone many called "friend."

In spite of these signs, I was terrified to leave my world, so much so that I instead tried to force others to join me in it. Nobody did. Nobody wanted to board the Kill Laura Yakas Express. No matter how hard I attempted to convince or prove to people that I was shit (rather than that I was *full* of shit), friends remained. They waited it out because whatever I was when I was not *that* was worth the wait.

With time, and great effort[182] (a dissertation's worth…), at long last all myths were metabolized and harmful habits broken (which demanded a release of any and all fixities: I went "vagabond" in a radical attempt to deprive myself of habits that connected me to Hate-Full-of-Shit Laura). I became open again, and started experiencing the kind of love that brings people into shared worlds. I re/developed muscles that enabled me to share worlds, cross worlds, and make disparate worlds communicate with one another.

This journey, along with literature research and my experiences in the clubhouse – the shared world there, as well as the glimpses into the private worlds of people with whom I became intimate – has led me to conclude that the most destructive consequence of madness is its tendency (especially when occurring in an inaccessible wider world) to banish a person to an unbreachable inner world. When worlds – when *people* – become isolated to this degree, it goes so far against the nature of a belonging-hungry animal that there is simply no surviving it spiritually. This abject loneliness – of being "unable to feel at home in the world" (Foucault 2011[1962]: 138), of finding nowhere for your soul to land, no mutual intelligibility or points of connection – is what starves and destroys the mad, sending them further and further into a cold and unbreachable world.

---

[181] There were times I looked "near death," underweight with empty eyes and falling-out hair.
[182] Sit tight for Chapter Six, where I describe the journey of comprehending my madness.

And so, our task – the task of those who seek to accommodate madness in the world – is to find or create tools to breach unbreachable worlds. Such tools are not intuitive, nor (alas) are they pervasive or of cultural priority, but they do and can exist. As I wrote in Chapter Two, there have been (atypical) practitioners who have endeavored to develop such tools – like Loren Mosher and R.D. Laing, and the Scandinavians who developed Open Dialogue Therapy (an effective practice for addressing psychosis which "emphasizes listening and collaboration and uses professional knowledge with a "light touch" – rather than relying solely on medication and hospitalization[183]"). What connects these clinical tools is a commitment to *understanding* a mad world by using one of the oldest of human tools – *language,* and the empathy that is enabled when one *listens* with curiosity and patience. Beyond the clinical realm, there are places like clubhouses, "Therapeutic Communities," and "Fairweather Lodges," which, rather than focusing on making an individual's madness comprehensible so they can again enter shared worlds, actively *invite* people into a specific shared world.

After all this effort to understand madness, I consider myself a connoisseur. And yet, in spite of how hard I have worked to be able to traverse the mad-erected walls between people, I am not always able to. In the clubhouse, I confronted the fact that there are (and will always be) worlds I cannot breach. There were members who I just *could not* connect with. And these were not people I could not connect with because I felt them toxic and unpalatable (you will hear about people who fit this description once I return to the traditional microphone), they were people whose words I simply could not follow, people who tended to lose me somewhere along the way.

Anna was like this. I adored Anna and felt she was a kind and talented[184] person, and yet I was constantly perplexed by her tangential way of speaking, and it was equally apparent that she did not always understand *me* (there is a way about the eyes... I know it well, the look of *Laura Not Landing*). And this intensely charismatic and joyful

---

[183] http://www.dialogicpractice.net/open-dialogue/about-open-dialogue/
[184] Anna and I sang together on many a karaoke social recreation night.

older man, Carl… I *so* wanted to get him. I *so* wanted to follow his strange and cryptic words as they bounced about, faster and faster as he became more and more excited. Once, I asked him what he thought a meaningful life entailed, and he told me that;

> a good life is where you see life. Money can't respect – (sung) R E S P E C T, find out what it means to me!
>
> Me: So, respect is important, and not to focus too much on money? Sorry to ask so many questions, you're a bit hard to follow sometimes.
>
> Carl: (rapped) I don't like being nickled and dimed dimed.
>
> Me: Me either.
>
> Carl: Pain, anxiety, depression, crying spells, stress, if you suffer from any of these illnesses, please come to Northville. We will fix it. We will make things better.
>
> Me: How?
>
> Carl: A little bit of time. Therapy. We know your time is valuable, but sacrifice some with us... What to *do* about the price of tea in China?
>
> Me: I don't know. What do you suggest?
>
> Carl: (sings) Amazing grace, how sweet the sound
>
> Me and Carl: (sing) that saved a wretch like meeeeeee.

I tried to keep up – and possibly even succeeded in periodically making him believe I was with him – but I was *lost*. He lost me to his own world. I am not prepared to try to interpret or analyze his words.

I still get lost in my own world sometimes, times when connecting with others, sharing a mutually intelligible reality with them, is too difficult. The way I accommodate this is simple (*difficult*): I use language (albeit sweating and staring at the floor).

"I am struggling to connect. Please wait for me."

Breached.

Sick, or Dick?

This book wrestles with the overall question "Sick, or *Different*?" In this sub-section, I deal with the more difficult and ethically ambiguous question "Sick, or *Dick*?" Where is the line (if any) between difficult behaviors that count as mental illness, and run-of-the-mill assholery? This question was inspired by my encounters with members who identified as having *personality disorders*, defined as "a way of thinking, feeling and behaving that deviates from the expectations of the culture, causes distress or problems functioning, and lasts over time."[185] Personality disorders are unique amongst mental illnesses. In fact, the DSM used to contain five "axes" that its disorders fell under[186] which clearly distinguished between *mental disorders* (axis 1) and *personality disorders* (axis 2[187]). The concept of personality disorders has always distressed me, because the "distress" they cause is in many cases not the *person's* – that is, a personality disorder diagnosis can violate one of the foundational DSM criteria for any mental illness, which is the subjective experience of suffering by the diagnosed.[188] Personality disorders often describe people who *cause* rather than *experience* suffering. The framing of the question "Sick, or Dick?" is also inspired by comedian Louis C.K, who said "it's not up to you if you're an asshole or not. It's up to everybody else."[189] Personality disorders, like "assholes" (or "dicks," the synonym I chose for the rhyme), are also decided by "everybody else" – the members of the "culture" from which the person's "way of thinking, feeling and behaving" deviates.

There are many kinds of personality disorder in the DSM, such as antisocial personality disorder (otherwise known as sociopathy), schizoid personality disorder (having little to no

---

[185] https://www.psychiatry.org/patients-families/personality-disorders/what-are-personality-disorders
[186] This multiaxial system was removed in 2013 with the release of the DSM-5: http://tpcjournal.nbcc.org/the-removal-of-the-multiaxial-system-in-the-dsm-5-implications-and-practice-suggestions-for-counselors/
[187] During my MSW training, I learned from a clinical professor that "axis 2" became a shorthand amongst his colleagues for "clients to be cynical about or avoid."
[188] The authors of the article "Mental Suffering and the DSM-5: a critical review" (Vanheule & Devisch 2014) suggest that this is also true for mental illnesses diagnosed in children, which tend to be based on external observation (especially ADHD).
[189] https://www.youtube.com/watch?v=18y6vteoaQY

impulse to form relationships), narcissistic personality disorder (exaggerated self-importance and little empathy), and borderline personality disorder (mood swings, outbursts, unstable identity, and often self-injury).[190] In the clubhouse, there were two members who, in common knowledge, were "borderline" – which, as Clare Shaw (2016) wrote, is often "the medical way of stating that, for now and forever, this person is… a 'total cunt.'"[191] I would regularly hear staff venting about members,[192] and these two "borderline" women, Jessie and Frances, in particular. On one occasion, after an outburst in which Jessie had verbally abused another member[193] to tears, a staff member said, "the clubhouse is just not right for people who are borderline. They can't change, and all they do is bring drama that disrupts other people's recovery." As someone who felt uncomfortable with personality disorders due to the fact that someone can "have" one because "everybody else says so" (and a psychiatric label like "borderline" carries with it consequences that "asshole/dick/cunt" does not), I wanted to feel differently. But…

Jessie and Frances also challenged my belief that anyone can be reached. There were times when I really liked Jessie. She was funny, talented, and devoted to her friends. But she did seem to create, attract, and seek, drama. In my years of knowing her, she; accused the staff of stealing from the café; accused me of being a spy for the staff[194]; created a vociferous backlash when the clubhouse changed the way that meals were served; regularly said insulting and inflammatory things about people behind their backs; regularly said insulting and inflammatory things to people's faces. Frances was even more difficult for me personally, as she attended less often and I did not have much opportunity to get to know her more positive sides. In the brief times that I spent with her, she; demanded constant reassurance that I liked her (even on the day we met, at which point I didn't *know* her); regularly began to cry without clear provocation; regularly disrupted a scene with a sudden declaration of something dark (e.g. I was with

---

[190] https://www.psychiatry.org/patients-families/personality-disorders/what-are-personality-disorders

[191] Shaw is quoting personal communication with Louise Pembroke, a fellow "borderline diagnosee" and author of *Self-Harm: Perspectives from Personal Experience* (1996).

[192] This was not done maliciously, and never in the presence of members. I believed it a palliative and necessary means of releasing frustration and creating camaraderie and understanding with those who most closely understand the difficulty of this work. As one staff told me, "it is challenging to find time and space to be with the other staff during work. We aren't supposed to have staff only spaces or times, but the reality is that members don't know my job like the others who have it do. So we sneak that time together to vent and support one another in quiet moments, or outside of work."

[193] It was Hope, which exacerbated the staff's anger because, like me, they really loved Hope.

[194] ***Interns spying for the staff… Damn, I thought I was subtle!***

members at the reception desk taking down names for lunch, and out of nowhere she said "did you hear I have cancer?" which the director reassured us was not true).

In experiencing Jessie and Frances, I was rent with existential frustration: I found myself thinking and feeling things that I did not *want* to, or know I *could,* think or feel. I applied moralistic judgments (*Liar. Bitch*). My belief that every person has value and deserves a space to belong wavered (*I wish they weren't here. They don't belong here*). My belief that the stigma of borderline personality is unfounded wavered. (*They really* are *'total cunts'*). In short, I began to create a self-focused category of "we" and "others" within the clubhouse: those who may be "sick" sometimes but who I liked and believed in, and those who were just "dicks."

Luckily for me, Jessie and Frances were not the only "dicks": I also resented Harry and Thomas, older men who often expressed patriarchal ideas (*I won't do dishes, that's ladies work. Sweetheart, how beautiful you look today*), and avoided Brian for his crass innuendo and intentional passing of gas both noisy and noisome.[195] When I say "luckily," I mean that this fact resolved my existential frustration. By realizing that my personal category of "dick" was not exclusively occupied by people diagnosed with personality disorders, and by remembering that Clarice, who was *not* a "dick," *was* diagnosed with borderline personality disorder, my concern that I was conflating personality disorder with "dick" abated. In fact, I realized that the question of "sick or dick?" was flawed, because this was no either/or situation. There are people who meet criteria for mental illness who also meet criteria for "dick," and though the two (obviously ludicrous) categories (sick/non-sick and dick/non-dick) overlap and intersect in confusing ways, they are not the *same* category.[196] With Jessie and Frances, the issue was not that they were "borderline," the issue was that we could not *connect* – like I wrote in **Multiple worlds**, our worlds were not *mutually intelligible. I simply could not read (or meet) the needs they were attempting to communicate through their behavior, nor could they read (or meet) mine*. In Frances's world, everyone else is a dick. And for "everybody else," Frances is a dick.

---

[195] The director had words with him about this – "you cannot fart like that here, it is inappropriate."
[196] In wider society, mental illness and assholery are often conflated, especially in recent months as Americans wrestle with the drama surrounding President Trump: is he sick, or a dick? We must resist this conflation. Donald Trump meets criteria for "dick" because he meets criteria for "violent and abusive," "white supremacist" and "misogynist," not because he meets criteria for a mental illness. https://www.theguardian.com/commentisfree/2018/jan/07/donald-trump-dangerous-psychiatrist

The world is full of "dicks" – or people *behaving* like dicks, so-labeled by those around them because their behavior is hurtful.[197] I believe that "dick" clubhouse members were more challenging for *me* to deal with than everyday "dicks" because, in my position – as an intern turned ethnographer – *I could not reject or exclude them from my community*. In a clubhouse, staff (and interns) must engage with and continue to believe in *all* members – even those they perceive as "dicks." And each staff member (and intern) handled hostile or disruptive behavior in their own way. Depending on the nature of the behavior, some refused to engage with it: my strategies included a well-placed "drama-free zone" sign at the front desk, or a "why are you telling *me* this?"[198] But when the behavior could not be deflected, staff were forced to expend (or as one said, "waste") energy resolving interpersonal drama (and in more serious cases, this would fall on the director). As one staff member who had been there over five years told me, "inappropriate behavior is a sucky part of this job, and I do *not* accept mental illness as an excuse for rudeness. It used to hurt my feelings, but my skin has thickened a lot, and now I just tell people, "you might get away with that here, but in the real world, you won't be so lucky." Other settings will not tolerate behavior that is tolerated here, and we need to prepare people for that."

Mad in Michigan

My interlocutors lived in adverse conditions. All were impoverished. Many lived in group homes, where abuse and neglect is routine; I have seen this in academic literature (Post et al. 2010; Ramsey-Klawsnik et al. 2007; in Michigan, Zhang et al. 2011), regional news, and firsthand. Most struggle to navigate the bureaucracies that provide necessary resources. Some valued their therapists, case workers or physicians, while others were overwhelmed by the magnitude of clinical encounters. Older members could recollect abuse in hospitals prior to "deinstitutionalization," though some had *recent* recollections. Finally, all lived in a world of constant discrimination. Their disadvantages, in short, spanned from the material and structural to the symbolic and ideological. Anna's statement – *"you're so lucky you don't have a mental*

---

[197] See professor of social work Jane Gilgun's *On Being a Shit: Unkind Deeds & Cover-Ups in Everyday Life* (2012) for comedic theorizing about the shitty things people do to each other. Importantly, it isn't a theory of "shitty people," it is about people *behaving* like shits.

[198] This was a trick the director taught me for when people bitched behind others' backs. For example, if someone were to say, "I am so sick of X, they keep doing Y and Z," I would say, "why are you telling *me* this? I can't do much about it. Might not X be the more appropriate audience?"

illness" – in this chapter's opening vignette is unsurprising. As Rena told me, "it's a real bitch being crazy." In this section, I describe what it is like to be Mad in Michigan in three sub-sections: Interactions with care workers; The Hospital; and Bureaucracies.

Interactions with care workers

"Care worker" refers to a variety of related professionals that people with psychiatric disabilities must interface with. I will be focusing on group home staff and direct care workers – those who do home visits to assist with errands, hygiene, and medication delivery.

I was close with three members who lived in **group homes**. These were members who experienced more severe disabilities and were therefore not able to live independently, and either had no family, or their family could not manage their daily care. Anna I have already described, and her group home complaints centered around roommates she didn't like. But Karen's complaints were much more serious. I knew Karen quite well because she and I regularly worked the reception desk together. (It was she who said "I better stop this crying. We're about to head to the hospital, and knowing my luck, they'll *keep* me there"). Over the course of our relationship, I heard about many troubling experiences. From invasions of privacy such as staff opening her mail or watching her dress (not *assisting*, just watching), to being denied food and other privileges, being told when to eat, shit, and even when she was allowed to *cry*, and having the house manager express disbelief in her physical pain and insinuate that he could prevent her having the necessary corrective surgery if she didn't "behave." She regularly expressed feelings of humiliation and hopelessness, and made comments like "I wish I could move," or "they think I am gone (mentally), but I understand *everything*."

Mike never complained about his group home himself – in fact, I never heard him complain about *anything*. He was cheerful and hardworking, and was affectionately known as "the president" of the clubhouse because he was one of its longer-term members. But I heard many stories from the staff about his group home experience: the manager there had been known to punish him by denying him his right to attend the clubhouse if he "misbehaved." On one occasion, "misbehavior" meant throwing away the wrong shirt.

I once met a group home manager who came in with one of his residents who was touring the clubhouse as a potential new member. He was friendly, but when I asked if he lived on site, his reaction was "God forbid!" followed by what I felt were offensive remarks about people with

mental illnesses who "don't want to better themselves or get jobs, but just want to sit around all day and smoke cigarettes." I wanted to say "right, because the world is *so* full of opportunities to do otherwise," but I said nothing. He was not wholly wrong. Many people with psychiatric disabilities do spend a lot of their lives inert and aimless (hardly shocking given the side-effects of many medications), and some of them may even "want to" – and who am I to judge that choice? But regardless of "wants," the entire reason why clubhouses *exist* is because opportunities for social and economic participation are so limited.

People with psychiatric disabilities who are capable of living independently won't be found "sitting around" a group home. They will have their own (or shared) apartment in a low-income housing estate, and be visited regularly by a **direct care worker**. Well before I began this project, I befriended two people who were direct care workers. I didn't know what a direct care worker was, and when I asked, was told "in theory, we care for people – take them to the shops, make sure their hygiene is up to snuff – but really, we are drug dispensaries." Though my friends put in effort – getting to know their clients, playing chess with them, and "you know, giving a fuck" – they told me that most of their colleagues did little more than make sure the pill was swallowed and then disappear into their cellphones.

During my internship, I went to a Recipients' Rights Training (RRT) – a mandatory training on the rights of mental health consumers[199] – where everyone else in attendance was a newly hired direct care worker. Though I didn't talk to anyone, what I overheard was that direct care was an "easy" minimum wage job (with high turnover) that "anyone" can get.[200] This was corroborated by my friends. Because of this, few direct care workers do the job because they "care," and most do it because they, like their clients, have limited options for social and economic participation (such as impoverished women of color, who predominated the RRT).

---

[199] Judi Chamberlin (1978; 1990) might instead write "consumers" in scare quotes.
[200] This article describes the situation well: "Starting pay for direct patient care workers in Michigan's beleaguered behavioral health system averaged $8.69 per hour in 2015 with a turnover rate that averaged 40 percent and could be as high as 58 percent." Authors also note in this context, those who *do* care and remain doing this work struggle to make a living, often having to hold several jobs at once. http://www.crainsdetroit.com/article/20170925/blog010/640151/family-members-patients-speak-out-about-impacts-of-low-pay-on-mental

In a system that attracts and creates (though weak training, underpayment, and overwork)[201] direct care workers who don't *care*, neglect and abuse are rampant. As my friends told me, neglect is widespread, and "care worker" a thinly veiled substitute for "drug dispensary."

I only knew one clubhouse member who had a direct care worker. One day, his girlfriend – another clubhouse member – arrived fuming because she had just visited him, and had found bruises all over his arms from what he had said was "rough play" with his care worker. It was the fourth care worker he had had since they started dating, and he felt they were friends.

The Hospital

Clarice and I met for coffee after I learned she had just been released from the hospital. Whilst decorating the Christmas tree at the clubhouse, she had become manic, describing a feeling of flying and whirring and being unable to stop. The director had suggested she call her case manager at the Community Mental Health agency (CMH). Her CMH team – case manager, therapist, and psychiatrist – have the ultimate goal of keeping her out *of the hospital. All CMH agencies have this goal, and view hospitalization as an expensive last resort. This was a "last resort" kind of day, though Clarice told me she had been sliding for a while, and if she had gone sooner, perhaps the "break" might have been less intense.*

She had been to this hospital once before. The last time, she had been injured by a staff member, who had dragged her off the dresser – yes, she had climbed onto the dresser – causing her to fall. She was concussed. He was fired. She was predisposed to feel unsafe at returning.

"The staff there are rough. They don't care for the patients. I think they hate their job and are

---

[201] In the literature, work stress and lack of job support are known sources of dissatisfaction (Delp et al. 2010) and high turnover (Gray & Muramatsu 2013). And though dated and conducted in the context of nursing homes, in *Direct-Care Healthcare Workers: You Get What You Pay For*, Dawson and Surpin (2001) write; "The long-term-care system in the United State long ago structured itself on the presumption of a seemingly endless supply of low-income individuals (usually women, and disproportionately women of color) willing to work as certified nurse's aides, home health aides, and personal care attendants. Both providers and consumers presumed that these workers would always be available to offer care… despite being low-quality jobs that kept them working, but poor."

primed to treat us like animals. I asked if I could switch rooms because my roommate was snoring and I knew I needed to sleep because it had been days since I had. They said no. I argued. I am often argumentative in hospitals because the environment just brings out such rage. (I remember that, the impulse to resist everything and everyone). *And then they said, "yeah, you can have another room, but it's a* special *room, loads of people go there, and they never come out." I became frightened. They said "come on, time to go," and I was like, no way, so I climbed onto the dresser – like last time – and one of them dragged me down. He restrained me, and someone else gave me a shot of something, but I had a moment of clarity and said, "just because you are angry with me doesn't give you the right to hurt me." I still have bruises!* (She showed them to me. They looked just like fingers). *I wanted to file a report, and they were such dicks about it. They kept delaying taking photos, and I was like, "no, you have to take them before the bruises fade, it's evidence." In the end, the manager of the unit believed me, but she still didn't transfer him from my unit, so I had to keep seeing him, and he was even meaner afterwards."*

After this traumatic act of abuse, routine professional incompetence stepped in to twist the knife. "They seem to have a go-to med for everything (this often happens, thanks to Big Pharma). *They gave everyone the same thing, but we are not all the same, and for me the meds didn't feel right. I felt wiped out, I still do a little, like I'm in a fish bowl with the world outside watching me."*

I wanted to be shocked, but I had seen, heard, smelt, and felt too much to be surprised. I said something along the lines of "well, we both know the mental health system is a joke. I mean, Big Pharma and insurance companies pollute it from the top, endless paperwork and pointless confusing hoops fuck it up in the middle, and on the ground we have fuckers who do shit like that*"* (I pointed at her bruises).

"Yes! I wish there was something I could do. *But I have already been a spokesperson about the foster care system, and it is so exhausting, even though it's empowering, to be always fighting such huge battles. And now, I have to be careful, because I'm on court ordered medication. They'll be stuffing me with shots that make me fat zombie – and I just lost a bunch of med weight! I hate this. It's like prison without the bars."*

Toward the end of our conversation we found ourselves reeling with laughter due to another unexpected similarity: she was also told she needed substance abuse treatment after a drug test revealed she had smoked pot. "When they told me they were adding Cannabis Use Disorder to my psych RAP sheet, I was like, 'WTF that is not a thing you just made that up!'"

"I KNOW, RIGHT?"

"It's so ridiculous. I hardly ever smoke pot, and also, it has never *fucked with me like some of the shit they have given me. It's not even addictive! Do you know how many prescribed drugs I am technically "addicted" to?"*

"Well, as long as people keep buying *them, they'll never run out of labels, or label-makers."*

<center>***</center>

Clarice's story seems from another era, like it would not be out of place in Goffman's *Asylums* (1961). I knew three members old enough to have experienced psychiatric hospitals in the 1960s-80s, and who shared their recollections with me. Dorothy shared this painful tale;

> Back in the 80s people were really getting abused in those hospitals – I was one of them. My first struggle was when I was in a big state institution for kids, at 11. I was there nine months. I saw kids bound and dragged down the hallways, I remember seeing staff kick kids, I remember them being stripped butt naked and thrown in quiet rooms alone, or being dangled from the ceiling in restraints. Some of these kids were just normal kids. Nothing was wrong with them, they were just kids whose parents didn't want them or who had nowhere else to be. I would talk to them. There were four of us in a room and I talked to them, and they didn't need to be there, not compared to what I was going through – I was really unwell. One girl actually said she faked having mental illness to *escape* abuse, cos her dad was molesting her. I said, "tell a staff" and when she did, no one believed her.

And Pamela told me;

> The hospitals back then treated you like you were a rat in an experiment, you couldn't make calls, they told you where to go and what to do, your opinion didn't count. I had some idiot come in and wake me up with his noise, and then say "it isn't time to wake yet, go back to sleep" – things like that. It was just horrid. Terrible experiences. Over the years it got better. My last hospitalization was five years ago at a local hospital, and by then it was excellent. I felt respected. Things have changed a lot in my lifetime, *a lot.*

Pamela's reflection on her recent hospitalization was favorable, and I was glad to hear this juxtaposition of hospital-then and hospital-now, because for the most part it reflects a greater truth: things are "better." But better does not mean *acceptable*. Clarice's recent experience reveals that hospitalization can be just as traumatic today.

Lara was also critical of her recent hospital experiences. Over the past ten years she has experienced soul-crushing invalidation, had her foot broken due to staff-inflicted violence, and been both *denied* medications and sent into excruciating withdrawal, and *filled* with enough medication to stupefy. Her deepest chagrin has been having her "body ruined by drugs." Like many Mad Priders and Mad Studiers have, Lara has developed critical consciousness about the role of pharmaceutical companies in oppressing people with mental illnesses: her life story is one of the many failed tales of medications. When she read me her current list of medications, we both cringed: lithium as a mood stabilizer, but also an anti-psychotic called Depakote which is supposed to do the same thing, plus two anti-depressant/anti-anxiety/catch-all "go to" selective-serotonin reuptake inhibitors (SSRI). Like I and almost every other contemporary psychiatric patient I have ever known, she has been given a little bit of everything over the years. Worst of all, she recently began meeting with a (rare but existent) holistic psychiatrist in private practice, one who is also critical of Big Pharma, who has confirmed Lara's suspicion: she probably never needed medication to begin with. Her first breakdown 20 years ago was in response to a deeply traumatic event (on the tailwind of the dull-ache traumatic life of any black woman). She had needed emotional support and trauma-work. But now, her "body is ruined"[202] – the degree of dependence is such that she will never be off psychiatric medications.[203] I cannot imagine this

---

[202] Most of my interlocutors repeated to me the standard doctrine when it came to medication: they accepted needing it, accepted the side effects (weight gain being the most commonly mentioned), and believed it helped. Lara, and one other older member who believes long-term (non-voluntary) Haldol shots "disabled" him, were the only two who believed medication had damaged them.

[203] See Whitaker's *Anatomy of an Epidemic* (2010) for similar stories of medication failure far beyond side-effects. Side-effects are bearable provided medications also have the *desired* effects, but many noted that medications have not cured or corrected any chemical balances that have improved their lives, leading Whitaker to argue that medications *create* the chemical imbalances they supposedly counter, leading to dependence. Also see this recent New York Times article (March 2018) which reviews a comprehensive study that suggests anti-depressants are underwhelmingly "modest" in their efficacy: https://www.nytimes.com/2018/03/12/upshot/do-antidepressants-work.html
And this New York Times article (April 2018) about addiction and withdrawal with anti-depressants: https://www.nytimes.com/2018/04/07/health/antidepressants-withdrawal-prozac-cymbalta.html

intensity of injustice: when I got "woke" I was still young enough that my body was capable of auto-correcting.

CONFESSIONAL MONOLOGUE
Self-Diagnosis, Self-Medication

I am presently a proud, prescription-less ex-patient. With ample foundation, I do *not* trust psychiatric medications – or more pointedly, the system that researches, makes, markets, and (over)prescribes them. Because of this mistrust, and as alluded to in *Never Again*, I have practiced *self-medication* throughout my Mad life.

The "self-medication hypothesis" of addiction was proposed in 1985 by E.J. Khantzian, and consisted of the following observation: most people who become physically addicted to drugs are *self-medicating*, or seeking to quell pain that psychiatrists would call "mental illness." Khantzian's theory of self-medication changed the way addiction was viewed by introducing the question "what does the drug do for you?"[204] therefore granting agency to people who experience addiction. *It is a choice made for a reason.*

Since then, self-medication for mental health issues has received much attention, with the overall message being one of *risk*. Self-medication is viewed as risky for two major reasons; **firstly,** because of its association with addiction.[205] If one self-medicates, one

---

[204] This is a 2017 article by Khantzian describing the history of the theory: http://www.psychiatrictimes.com/addiction/theory-self-medication-and-addiction
And this blog post by a clinical psychologist also frames self-medication in terms of trauma (i.e. most people who experience trauma subsequently experience intense emotional distress that they then quell with substances – he cites the Adverse Childhood Experience Study as evidence of this trend): https://www.psychologytoday.com/us/blog/addicted-brains/201208/addiction-self-medication

[205] For example, this article in the Huffington Post written by a clinical psychologist, warning about "dependence" (on alcohol or pot) as a result of self-medicating anxiety and depression: https://www.huffingtonpost.com/dr-tian-dayton/self-medication_b_3236724.html

might become "addicted." Addiction is a complex phenomenon, and the American Psychiatric Association defines it as a "brain disease" (hmm) that occurs when brain chemistry adapts to a substance such that a person becomes incapable of functioning without it.[206] However, they also note that people become addicted to substances (or behaviors, like gambling or sex) that are not physically addictive, and this is called "behavioral addiction" – habits that are as tough to break as physical addiction.[207] And **secondly**, though less explicit, self-medication is viewed as risky because the distressed "self" is presumed to be a less trustworthy medicator. Self-medication is not *expert*-medication, and the U.S. mental health system thrives on cultural messaging that frames "professional treatment" as the best – and least *risky* – choice.

I am skeptical on both counts; **firstly,** addiction (or "dependence") is neither positive nor negative in essence (#GreyZone), but entirely *dependent* (ha) on the situation and substance/behavior in question. The fact that Americans generally feel that coffee nuts,[208] Austen fanatics, and people in love, are *different* from "heroin addicts," "gamblers," and people addicted to prescriptions like benzodiazepines or OxyContin,[209]

---

[206] https://www.psychiatry.org/patients-families/addiction/what-is-addiction

[207] Alavi and colleagues (2012) write; "Behavioral addiction such as internet addiction is similar to drug addiction except that in the former, the individual is not addicted to a substance but the behavior or the feeling brought about by the relevant action. In addition, the physical signs of drug addiction, are absent in behavioral addiction. Others have stated that behaviorally addicted individuals have certain symptoms and will undergo the same consequences brought about by addiction to alcohol and drugs as well as other obsessive behaviors."

[208] Funnily enough, shortly after coffee was introduced to the United Kingdom, Coffee Houses attracted moral panic and resulted in a proclamation by Charles II: "it is most apparent that the multitude of Coffee-houses of late years set up and kept within this Kingdom…have produced very evil and dangerous effects: as well for that many Tradesmen and others, do therein misspend much of their time, which might and probably would otherwise be imployed in and about their Lawful Callings and Affairs; but also, for that in such Houses…divers False, Halitious and Scandalous Reports are devised and spread abroad, to the Defamation of His Majestie's Government, and to the disturbance of the Peace and Quiet of the Realm; His Majesty hath thought it fit and necessary, That the said Coffee-Houses be (for the future) Put down and Suppressed." http://www.herbmuseum.ca/content/proclamation-suppression-coffee-houses

[209] Incidentally, the Big Pharma companies that made and marketed them *lied outright* about their physical addictiveness. With benzos, Whitaker (2010) exposed the decades-old lie that did much damage, and OxyContin is a much more recent (aka currently the talk of the town) issue: http://time.com/4542105/john-oliver-opioids-last-week-tonight/

suggests that there is a tacit spectrum of "harmless-to-harmful" with respect to addiction, one that I would gladly accept (I am not a total relativist, I get that heroin is more harmful than Jane Austen) were it not clouded by moralistic and underhanded oppressive bullshit like the *War on Drugs*. And **secondly**, though the "self" might not be particularly trustworthy, *the same goes for experts*. In fact, *all* self-prefixed practices – self-care, self-discipline, self-governance, self-medication, and of course, self-*diagnosis* – are neither positive nor negative in essence, but *entirely dependent on the self in question*. (I would apply this to self-injury too. As I have already explored, it is not only-and-always a destructive act. Sometimes it is a way to express the self,[210] or soothe the self, or *save* the self).

Self-medication is indeed *riskier* when the self in question is desperate, or lacking in (self-)awareness. This is why I practice and promote *self-diagnosis*. In Bethel House, the fascinating Japanese intentional community with eerie similarities to clubhouses (#ConvergentEvolution) – about which Karen Nakamura wrote the stunning ethnography *A Disability of the Soul* (2013) – they have developed a rigorous and beautiful practice of self-diagnosis called "self-directed research." (Perfectly enough, this English translation misses something of the Japanese term, as it refers to "research on yourself as part of an affected class" [173] – a *political* act). The steps of "self-directed research" involve; 1) differentiating between the person and the problem (called "externalization" in Narrative Therapy), and 2) exercising one's creativity to determine an empowering (and if possible, comical) "self-diagnosis" that one has ownership over. For example, I experience a variety of mads: Sad Mads, No Filter Mads, Stray Dog Mads, Weepy Cut Cut Mads, etc. One is also called to 3) journal extensively in order to identify "patterns and processes of your problems" (174) and devise "concrete ways that you can help or protect yourself and scenarios where you can practice them" (174). One then 5) practices the devised tools in order to "verify your results" (174).

---

[210] On this note, I have a photographic series titled "Sc(Art)" – beautiful and stylistic images of my scars (sometimes still as fresh wounds) – which I created as a way to resist the small-minded notion that they are ugly, bad, shameful, or pitiable.

In Chapter Six, you will see the product of my own self-directed research – my Madness Genealogy and toolkit for accommodating my particular Mads.[211] Because I have labored intensely to develop a deep understanding of and respect for my Mads, I feel confident in my ability to self-medicate effectively, and my experience (#NeverAgain) has led me to believe that it is by far the less *risky* route. It would be ideal if circumstances were such that I could trust (and encourage others to trust) experts and the systems they work within, but, dear readers, these are not such circumstances.

I have self-medicated primarily with Pot, and Pot is a fascinating substance/medicine for a few reasons; firstly, and most importantly, until very recently it was totally *illegal*, so could *only* be self-prescribed. Now, it is medically legal in most of the United States[212] and can thus be prescribed by someone claiming expertise (though the reputability of Pot-prescribers varies widely). Secondly, though cannabis is frequently behaviorally addictive, only in rare and extreme cases is it *physically* addictive.[213] Thirdly, being a Pot-head (or whichever moniker one prefers) is not always (or only) medicinal: it can also be an identity and/or connection to counter culture and community.

Pot played an integral role in my recovery, for I believe that without it, I would no longer exist. I tried many prescribed substances to address my Mads, but I no longer

---

[211] Note: unlike my Madness Genealogy, Bethel does not emphasize metabolizing trauma or other past-oriented activities. And unlike the Clubhouse, or perhaps any program that could flourish in the U.S., a society that valorizes optimism/ambition, Bethel does not promote self-directed research as a means to become "better" or "normal." Bethel promotes "pessimistic realism" – embracing a "life of descent" rather than striving for a "life of ascent" (110).

[212] See this map of cannabis laws by state: https://thecannabisindustry.org/state-marijuana-policies-map/ Also bear in mind that cannabis is not (for now) *federally* legal, and therefore the entire project of medical marijuana exists in an ambiguous state by state grey zone.

[213] See this research report/literature review on cannabis addiction: https://www.drugabuse.gov/publications/research-reports/marijuana/marijuana-addictive

remember what any of those drugs "did for me."[214] But I do remember that when it came to the endless ocean of grief and madness, Laura + Pot swam to shore.

Mind over matter,[215] as they say in the mental health world, can only do so much. When chemistry intertwines with mind, one cannot just will one's way to balance. If, as was often the case for me when my madness was at its most intense, your mind is moving so fast that you can neither sleep nor cohere yourself into a self (*Overexposed Mads*), or you are emptied to the point of nigh-catatonia (*Sad Mads*), or your perceptual filtration system is letting in more than you can process and letting out more than others can receive (*No Filter Mads*), there is likely a chemical component. And there may be a chemical cure (or at least, a bandage). Here, a chemical cure is called a "medicine."

Many medicines yield side-effects[216]: Laura + Pot has missed trains, left doors unlocked, burned dinners, lost phones, and gotten lost (literally and metaphorically). Many medicines yield discrimination: Laura + Pot has pretended to be just *Laura*. Many medicines yield ethical ambiguity: Laura + Pot has wondered about her exemption from rules applied to *recreational* Pot-heads – Should she go to work thus, for example?

---

[214] I believe a major reason why I cannot remember if/how these drugs helped me, is because I remained terribly Mad whilst taking them. But this may have less to do with the chemical effects of the drugs, and more to do with how monstrous and broken I believed myself to be whilst I was a "psychiatric citizen" (Rhodes 2010). I could try pharmaceuticals now that I am fortified against the soul-crushing disempowerment I experienced when I was younger, weaker, and less woke, and see how they *now* impact my Mads. But as I have been prescription free for the most stable and productive of my years to date, it seems an unnecessarily *risky* experiment.

[215] I highly recommend my friend Shira Erlichman's poetry about medication. Her series is called *Ode to Lithium*, and I found it tender, nuanced, and thrilling. This one is called "Mind Over Matter" (http://www.boaatpress.com/ode-to-lithium-75-mind-over-matter/) but see also: http://psychologytomorrowmagazine.com/ode-to-lithium-erlichman/ http://muse.jhu.edu/article/632164 https://preludemag.com/posts/ode-to-lithium-0/

[216] This article reviews some of the clinical literature on marijuana's side-effects (i.e. lung damage = negligible, cancer = ditto, memory impairment = short term yes, long term not really): https://www.nytimes.com/2018/05/07/upshot/its-time-for-a-new-discussion-of-marijuanas-risks.html

In spite of the side-effects, discrimination, and ethical ambiguity, I have chosen in the past to live as Laura + Pot because Pot reliably addressed my Mads. It has successfully soothed the intensity of Sad Mads and force-quit the violent intensity of Stray Dog Mads. It has also helped ameliorate the overwhelm of my extra-normative perceptual filtration system, or No Filter Mads. For many, Pot is a filtration-system interrupter, a *mind-opener* (#CavernChinks), so to speak. But during peak No Filter Madness, the effect it had on me was *reversed*. It slowed me down and sucked me in, enabling me to enter what I called a "Laura Day" – a solitary timeless zone in which I could *intensely feel* and *metabolize* what I was otherwise *hyper-experiencing*.[217] This timelessness was crucial in my recovery,[218] so I am grateful that I was introduced to Pot. It was a lifeboat that could carry my weight while I carried the weight of the world.

Bureaucracies

It was mid-spring, and I was at the reception desk with Hope. She hadn't seen me in a month, and asked how I had been. I was truthful, and told her that my heart had just been broken, my

---

[217] A typical Laura Day involved guitar-singing and re-watching movies or shows, so there was some stimulation and release without there being any new material or experiences to take in.

[218] This is a fascinating juxtaposition with Robert Desjarlais' (2010[1994]) work described in Chapter One: for his interlocutors, people experiencing homelessness and mental illness, timelessness was a profoundly dehumanizing phenomenon. He goes as far as to interpret them as people who do not "experience" life – because "experiences" demand a trajectory, a coherent story with points of variation – but when every day is the same, and the same in a *bad* way, rather than experiencing, one "struggles along." This is bad timelessness (and many of my interlocutors know it, as you will see in the next chapter). So it is very interesting to unearth through my own self-examination that there are *good* kinds of timelessness. A Laura Day was timeless in very much the same way Desjarlais discussed: I didn't "experience" things, and any one "moment" could have been seamlessly exchanged with another. But because I was otherwise "hyper-experiencing" life, I needed to balance it with days where I *didn't* experience. This complication of timelessness is amazing – it is productive to understand the ways something unwanted can become wanted (like Lorna Rhodes [2010] work cited in Chapter One – i.e. for incarcerated people, "psychiatric citizenship" affords rights that are liberatory, but for me and my fellow self-defined ex-patients, it does the reverse). And what seems to separate the *bad* timelessness of Desjarlais' and my interlocutors from the *good* timelessness of a Laura Day is precisely the factor of *choice*. Timelessness was not foisted endlessly upon me, but was something I was privileged enough to be able to seize when I needed to.

partner was leaving, and I was shattered and afraid that of what grief lay ahead – would it be easier or harder this time? She looked me dead in the eyes and told me that even if I couldn't see it, things were working themselves out. Things always dip and rise, and in dips, one learns their deepest lessons. "What lessons have dips taught you?" I asked.

"Well, the biggest dip I had was homelessness. A lot of people with schizophrenia end up homeless at some time in their life, and so did I. Being homeless taught me how hard it is to not *be homeless when you have schizophrenia, and how much support it takes to stay afloat. But the support is there, if you know how to look for it, and I learned how to look for it. Now I have a case manager and case management team, and I have the clubhouse, and so the responsibility to stay on top of all the things – appointments, paperwork for SSI, taxes, school stuff* (she is a part time student at the local community college due to clubhouse staff support), *food stamps, making sure that if I work I don't earn too much – it isn't all my own.*

<center>***</center>

Embedded in Hope's reflection on the lessons from her "dips," is a very serious and often overlooked reality for people with psychiatric disabilities: the bureaucratic morass they must navigate in order to survive is extremely complex, almost *impossible to manage without support*. Even in the best case scenario, with a competent community of carers like Hope has, one is still met with the inadequacy and inefficiency of these bureaucracies. Whether it is literal insufficiency – represented in one member's tearful testimony during a legislator visit[219] about how often she has "gone hungry" due to cuts in food stamps – to the hurdles placed on people receiving Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI).

As noted earlier, SSI is need-based: it is an asset and income tested program, which means that those who are entitled to SSI are people with legal disabilities who meet criteria of need (in terms of income and assets), and are not eligible for SSDI (i.e. they were either never in in the workforce, or not in the workforce long enough). Because SSDI is considered to be earned, rather than need-based, people on SSDI have no asset limitations (though they do have income limitations) – that is, they are entitled to receive benefits no matter what wealth they

---

[219] The clubhouse often engages in advocacy work, including visiting legislators in the state capitol.

accumulate. But for SSI, as it is need-based, there are strict asset limitations of no more than 2000 dollars.[220] To continue to receive SSI, you have to remain poor.[221]

Perhaps the most frustrating thing about SSI and SSDI is how difficult it becomes to return to fulltime employment for those who are more temporarily disabled. In awareness of the fact that people with disabilities often *can* and *want to* work, the Social Security Administration (SSA) does provide "work incentives" to facilitate the transition: one can continue to receive benefits, so long as one doesn't earn more than the "substantial" amount (in 2018, this is $1,180 per month[222]), and so long as one reports everything under the sun. Understandably, the SSA needs to know this information, because it would be ineffective to dole out limited resources without understanding who is most in need. However, it has taken me – a late-stage PhD candidate – *hours* of flipping pages and frowning just to write this paragraph. As user-friendly as I am sure the SSA aims to be, it is, as are most large-scale bureaucracies, very complex. Without support, many find the hoops a deterrent to trying.

---

[220] https://www.disabilitysecrets.com/page7-5.html
[221] It seems perplexing: what if someone on SSI did amass too much wealth? They'd be denied SSI, and then spend their assets, and become poor again, and then qualify for SSI…
[222] https://www.ssa.gov/planners/disability/dwork2.html

CHAPTER FIVE

"Work is Love Made Visible": Purpose and Belonging in the Clubhouse

In this chapter[223] I explore the ways that the clubhouse meets its members' social needs of purpose and belonging, enabling them to **centralize the fringe**. After the introduction, the chapter is divided into three sections; one devoted to *purpose*, one to *belonging*, and one to the *positive work environment* that facilitates the meeting of these needs.

<u>On Work</u>

You work that you may keep pace with the earth and the soul of the earth.
For to be idle is to become a stranger unto the seasons, and to step out of life's procession, that marches in majesty and proud submission towards the infinite.
…
Always you have been told that work is a curse and labour a misfortune.
But I say to you that when you work you fulfil a part of earth's furthest dream, assigned to you when that dream was born,
And in keeping yourself with labour you are in truth loving life,
And to love life through labour is to be intimate with life's inmost secret.
…
You have been told also that life is darkness, and in your weariness you echo what was said by the weary.
And I say that life is indeed darkness save when there is urge,
And all urge is blind save when there is knowledge,
And all knowledge is vain save when there is work,
And all work is empty save when there is love;
And when you work with love you bind yourself to yourself, and to one another, and to God.
…
Often have I heard you say, as if speaking in sleep, 'He who works in marble, and finds the shape of his own soul in the stone, is nobler than he who ploughs the soil.
And he who seizes the rainbow to lay it on a cloth in the likeness of man, is more than he who makes the sandals for our feet.'
But I say, not in sleep but in the overwakefulness of noontide, that the wind speaks not more sweetly to the giant oaks than to the least of all the blades of grass;

---

[223] Note: Much of the analysis in this chapter also appears in an article I published in the Disability Studies Quarterly special edition on Work and Disability (Yakas 2017).

…
Work is love made visible.
And if you cannot work with love but only with distaste, it is better that you should leave your work and sit at the gate of the temple and take alms of those who work with joy.
        - Kahlil Gibran (abridged by myself)

Introduction

"On Work (and Disability)": From "Work" to "Purpose"

I discovered Kahlil Gibran's *The Prophet* (1923) at a critical moment of my graduate program: whilst deciding whether to *finish* it. His reflections "On Work" soothed and inspired me, reinvigorating my research as well as my will to *do* it. I was already determined to study madness, but what drove me to explore "psychiatric disability" through the lens of "work" was the awakening afforded me by this poem, which deepened my understanding of the relationship between work and disability.

Gibran alluded to several truths about work to which early social theorists also attended. For example, that *work is a social act:* "When you work with love you bind yourself to yourself, and to one another, and to God." Of course there are material issues at play – work is required to meet subsistence needs – but work, especially the sharing of work, has been viewed as social glue for well over a century. As Émile Durkheim noted, one function of the "division of labor" is "to create between two or more people a feeling of solidarity" (1984[1893]: 17). Gibran also notes that through work, *we maintain connection to our environment*, avoiding "becoming a stranger unto the seasons." I appreciate this acknowledgment that "solidarity" applies not only to the people we are bound to, but also to the place(s). And of particular relevance to the concepts of work and disability today, Gibran wrote:

> Often have I heard you say, as if speaking in sleep, "He who works in marble, and finds the shape of his own soul in the stone, is nobler than he who ploughs the soil. And he who seizes the rainbow to lay it on a cloth in the likeness of man, is more than he who makes the sandals for our feet." But I say, not in sleep but in the overwakefulness of noontide, that the wind speaks not more sweetly to the giant oaks than to the least of all the blades of grass.

Here, Gibran speaks to the way that *acts and products of work come to be valued differently in socially (and materially) meaningful ways*, and cautions readers against the uncritical over and undervaluing of work and workers.

Such advice is generally unheeded under neoliberal capitalism. Not only do we consistently overvalue (and overcompensate) certain work/workers and undervalue (and undercompensate) others,[224] we have also thinned our understanding of what work *is*. The word – the most general word for "doing something/something done" – has come to refer to "paid employment" (Williams 1976: 335), both deed and site. We go to work at work, and using prefixes like "home" or "house," or words like "hobby," we differentiate between "work" and the rest of what we do with our energy.[225]

This thinning in the meaning of work, and the over and undervaluing of its different possibilities, contributes to what critical Disability Studies scholars call "neoliberal-ableism." The idea that the neoliberal capitalist world – its ideology, its institutions – oppresses people based on their in/ability to produce, accumulate and consume. Runswick-Cole, Lawthom and Goodley (2016) describe it thus: "Under neoliberal-ableism, the rationality of the market is paramount; the ideal citizen is an adaptable citizen, indeed he is an able individual (note the deliberate gendered/ableist positioning of the subject here) who is caught up in and complicit with the demands of late capitalism" (257). Critical Disability Studies, through identifying and interrogating such phenomena, "aims to understand and challenge exclusionary and oppressive practices associated with disablism and to consider the ways these intersect with other forms of marginalisation" (258). In this book, I contribute to this mission by highlighting the oppressive neoliberal capitalist view on work as *rankable* and *remunerative*, and showing how a community of people with psychiatric disabilities have adapted to and challenged that reality.

However, though I began with the frame of "work," my data ultimately led me to "purpose." It became apparent that I was not so much theorizing work and disability as I was people's subjective experience of fulfilment (and its opposite) in *relation* to work and disability. Irrespective of oppressive labels and systemic barriers to social and economic participation, my interlocutors had similar worries that I and many I knew did: What do I need, and what do I need to *do*, to feel fulfilled? Their answers may be complicated by the caveat that they experience a

---

[224] E.g. the astronomical difference in pay between a bank CEO and a direct care worker

[225] The relationship between the words "work" and "energy" is significant: in terms of physics/the laws of reality as we mere humans understand them, *work* refers to whatever happens to transform one form of energy to another.

psychiatric disability that excludes them from work-as-paid-employment, but the essence transcends the division between "disabled" and "not-disabled": the need is for *purpose.*

Humans are interdependent social animals with social needs, and purpose is one such need (Royce 1995[1908]; Strecher[226] 2016). As Friedrich Nietzsche wrote: "If we possess our why of life, we can put up with almost any how" (1990[1896]: 33). The notion that purpose has the power to make or break a person was championed by psychiatrist and Auschwitz survivor Victor Frankl. Through experiencing one of the most senselessly destructive of human phenomena – identity-based genocide – Frankl glimpsed a profound truth about humanity: **people need a reason to live**. This is true at the "best" of times, as he notes that modernity has yielded an "existential vacuum" that "manifests itself mainly in a state of boredom,[227] [which now brings] to psychiatrists more problems to solve than distress" (1984: 129), especially in terms of addiction and depression.[228] "People have enough to live *by* but nothing to live *for*; they have the *means* but no *meaning*. To be sure, some do not even have the means" (165, emphasis mine). But it is even more gravely evident at the *worst* of times. Those who survived the camp – in the literal as well as the spiritual sense (for many who "survived" became as oppressive as their oppressors) – were infallibly those who remained connected to a higher *purpose* or sense of *belonging*. For Frankl, this was the wife he was not sure was still waiting for him (she was not), and his life's work that remained to be published.

His powerful and influential memoir/treatise, *Man's Search for Meaning* (1984), introduced the world to logotherapy, which guides people toward purposeful living. The foundational tenets of logotherapy are: 1) the primary motivational force in humans is to find meaning in life, reflecting the truth that people need a reason to live; 2) all life has meaning, even

---

[226] Victor Strecher is a professor of public health whose research demonstrates the positive health impacts of purposeful living (see https://www.vicstrecher.com and https://sph.umich.edu/purpose/).
[227] As I will later show, "boredom" is relative, especially in terms of privilege (O'Neill 2017).
[228] "Fifty years ago, I published a study devoted to a specific type of depression… I called "unemployment neurosis" [which] originated in a twofold erroneous identification: being jobless was equated with being useless, and being useless was equated with having a meaningless life… whenever I succeeded in persuading [them] to volunteer…their depression disappeared though their economic situation had not changed… The truth is that man does not live by welfare alone (1984: 167). He links this to the problem Foucault identified in *Madness*: Western society conflates *value* with *usefulness*, "blur[ring] the decisive difference between being valuable in the sense of dignity and valuable in the sense of usefulness" (178), which makes possible the oppression (even genocide) of the "useless."

seemingly senseless suffering[229]; and 3) meaning is relative, something people have the power to determine for themselves. Frankl argued that though our environments shape us, there is always *agency*. No matter how damaging the environment – be it the eviscerating agony of Auschwitz, or the dull ache of the "existential vacuum" – **people have the power to resist**.

> I speak of a tragic optimism, that is, optimism in the face of tragedy and in view of the human potential which at its best always allows for: (1) turning suffering into a human achievement and accomplishment; (2) deriving from guilt the opportunity to change oneself for the better; and (3) deriving from life's transitoriness an incentive to take responsible action (162).

The need for purpose is urgent, so the fact that *work*, freed from the shackles of "paid employment," is a *subjective* concept – that what one calls work, another might call frivolity – is potentially liberating. It enables people who are/feel oppressed by narrow neoliberal definitions of work to say, "what I do is work, and my work has value." However, it also enables people to *disagree* with such a claim. And in truth, it is not enough to cry "relativity" when one feels worthless/(workless). Society is such that "paid employment" is a significant means by which people feel purposeful and connected to a whole larger than the sum of its parts. Whatever anti-capitalist idealists like myself may wish, not having a career/capitalistic endeavor is tantamount to "step[ping] out of life's procession" in this society. It may be complicit with ableism to want paid employment, but as Goodley (2016) points out;

> Equating all things associated with the ability to achieve and enact specific ambitions and aims as always ableist (and therefore wrong) is problematic… A critical ableist approach need not inevitably lead us down an ignorant path where we refuse to acknowledge the importance of normative, perhaps even ableist, ideals (197) … Human practices which might be deemed as deeply normative (working, earning money, shopping, marriage) remain desirable for many people (disabled or not disabled). Being poor and wanting more money might smack of a neoliberal-ableist subjectivity to [some]. To others it is a matter of life and death (201).[230]

In short, it is important to interrogate oppressive norms, and the complex reasons why people buy into them. However, is it equally important to remember that striving to be "normal" is not

---

[229] He believed that suffering is transcended when one makes meaning out of it. This is not the same as rationalizing violence. The Holocaust was 100% a collective act of meaningless violence, but this does not mean that the *suffering* was meaningless. Meaning in this context can be as simple as the internal decision to view one's suffering as a sacrifice and to bear it with grace.

[230] This was so helpful in enabling me to take sincere pleasure in member's successes that were "deeply normative." For example, when a young man named Bevan excitedly declared that he had gotten his dream job – bussing tables in a pizza franchise – I said "that is amazing, congratulations," and I *meant* it.

simply ignorant and complicit, but a way of ensuring that one's needs are not in jeopardy, primed by having witnessed widespread oppression of the "abnormal."

Beyond this focus on (oppressive) social context, my interest in the relationship between work and psychiatric disability was intensified by contradictory phenomena. For example, I discovered that employment was purportedly associated with improved mental health, conjuring circuitous questions: Do people not work because they are disabled, or are people disabled because they do not work? Fortunately, the intellectual heavy-lifting required to settle this issue had been done. In their critical analysis of Individual Placement and Support, the major form of vocational support in mental health, Essen (2012) concluded that though having a job is associated with improved mental well-being (in people who meet diagnostic criteria, *and* people who don't), it is *not* associated with improving symptoms of mental illness. And if it *were*, it would be fallacious to assume it was the job that was responsible. Yes, jobs provide structure, and reduce economic hardship, both of which aid in recovery. But "the meaning of work for service users is very often intimately tied up with the renewed embodiment of a 'mainstream' identity, achieved through an integrative process of 'normalization'" (Essen 2012: 234). It is not the job, but what the job signifies – *normalcy* – that fuels improvement. And again, *normalcy must be seen as a valid goal* in light of the consequences of abnormalcy.

The second contradiction was the simple fact that though people with psychiatric disabilities are by definition "not able" to work, they *could*. This I learned through encountering the Clubhouse Model. And so, I sought to discover what a clubhouse could teach me about work.

But I was strangely drawn to Gibran's words, "work is love made visible." If work could be distilled to "purpose," what was "love"?

On Love: From "Kinship" to "Belonging"

In my research proposal, I pitched exploring the connection between "work," "disability," and "kinship" in the clubhouse. I drew upon anthropologists who had questioned assumptions about what kinship is (and is not) (Sahlins 2013), and shown that it was another social construct – and a very useful one for making sense of and learning to navigate our social worlds. I was moved by these words of Robert McKinley, which remind us that what constitutes kinship is

variable, but that forming meaningful relationships is essential: "no matter how people count their relatives, relatives always count" (2001: 149).

When seeking kinship in the clubhouse, I turned to theories of kinship as a **symbolic feeling of belonging** (e.g. Schneider 1980; Sahlins 2013), as **agentive**, something people make conscious choices about (e.g. Kath Weston's [1997] "chosen families" in the LGBTQ community, or Signe Howell's work on adoption and coining of the terms "kinning" and "de-kinning" to signify the creation and rupturing of kin bonds), and most importantly, as **practice**. Kinship is "doing rather than being" (Holy 1996: 150). Kinship is action, created and recreated through "small, seemingly trivial or taken-for-granted acts like sharing a meal" (Carsten 2000: 18), as well as sharing non-trivial experiences like a goal (i.e. "shared intentionality" [Sahlins 2013: 37]) or an illness (e.g. Rayna Rapp and Faye Ginsburg's work on kinship and disability [2013a; 2013b] or Paul Rabinow's "biosociality" [1996]).

With this lens, I saw kinship everywhere. Many members felt a sense of symbolic belonging in the clubhouse. Phrases like "the clubhouse is my family" were commonplace. Most would spend Thanksgiving and Christmas together, national holidays associated with family. There was also plenty of de-kinning, due to stigma, violence, and the simple fact that people grow apart. However, when it came time to analyze this data, I realized that just as "work" had necessarily distilled to "purpose," it transpired that "kinship" also needed to be distilled. Yes, in clubhouses, relationships can be productively theorized as kinship, so I do so when appropriate. But it is not the key frame. The *category* of relatedness is not what matters. What matters is *mattering* – that people "count" (McKinley 2001: 149) to each other. At root, **my research addresses the consequences of oppression on people's ability to meet social needs**. "Work" (i.e. paid employment) is not the *need*, it is simply the most common way people *meet* the need. The need is *purpose*. Similarly, "kinship" (i.e. a family) is not the need, it is simply the most common way people *meet* the need. The need is *love*.

Well, *almost.* In David Lynch's trippy television series *Twin Peaks*, the character Major Briggs, when asked about his greatest fear, responds with "the possibility that love is not enough."[231] Love is a loaded and elusive term, and one I have wrestled with as intensely as I

---

[231] Season 2, episode 20: https://en.wikiquote.org/wiki/Twin_Peaks#Episode_27_[2.20]

have "madness." One definition that resonates is that of psychologist Barbara Fredrickson; "love is not a category of relationships," it is a "micro-moment of warmth and connection that you share with another living being" (2013: 10). Love can pave the way for complex feelings and categories of relationship (such as family, friend, lover), but love cannot be *reduced* to complex feelings and categories of relationship[232]. This is as potentially liberating as untying the knot of "work" and "paid employment": it means that one can recognize love, even when one lacks a stable source of it (such as family, friend, lover). But just as the earlier analogy went, it is not enough to cry "relativity" when one feels loveless. Micro-moments of connection feel *great*, and learning to see love in something as simple as a stranger's smile is a well-worn path to inner peace. But though such present-mindedness is beneficial, human lives are *not* micro-moments. Most people remember pasts and imagine futures, and for Americans, having people one can call family – people we remember in the past and imagine in the future – is important. It is through this cross-temporal sense of connectedness that we come to feel *belonging*. Family, friends, and lovers are not the need, *love* is the need. But love's flashes of fading warmth are "not enough" in and of themselves. Strung together across space and time, these micro-moments create the longer-lasting feeling of belonging. *Belonging*[233] is the deeper need, without which we are plagued by loneliness, a consequential psychological and physiological stressor (Sapolsky 1998; Cacioppo & Hawkley 2003; Hawkley & Cacioppo 2010; Lieberman 2014; Mushtaq et al. 2014).

If work distills to purpose, and love distills to belonging (through kinship), then
"Work is love made visible" distills to
"Purpose is belonging made visible"
Through purpose we belong, and belonging is itself a purpose.

---

[232] Just as madness can pave the way for mental illness, but cannot be reduced to it.

[233] "Love and Belonging" are combined on Maslow's well-known hierarchy of needs, a five-part pyramid that covers physical needs for shelter and food, social needs for love and belonging, and individual needs for esteem and self-actualization (Maslow 1943). Though the needs Maslow identified are ethnocentric – social needs vary by social context, especially in relation to the collectivism-individualism spectrum (Hofstede 1984) – and the idea of a *hierarchy* not compelling or helpful, the focus on "needs" in understanding human behavior (and mad human behavior) is extremely valuable.

Purpose and belonging are interconnected, and together create the feeling that one, and one's work, *matters to and in a specific group of people*. This is why my data-driven and context-specific definition of "work" became **purposeful activity that builds belonging**.

CONFESSIONAL MONOLOGUE
Loneliness and Belongingness

Loneliness[234]: the feeling of sadness due to a perceived lack in social connection. (Juicy paradox: loneliness is unifying. *Everyone* is vulnerable to it, because of)

Belongingness (psychology): the innate human motivation to form bonds of intimacy as well as the need to belong to a collective greater than the self.

I just referred to loneliness as a "consequential psychological and physiological stressor." Indeed, loneliness has been called a "killer"[235] and an "epidemic"[236] in op-eds and news articles (even the American Psychological Association succumbed to the trend in their press release "So Lonely I could Die"[237]), and for good reason – there is *plenty* of evidence for it. Notably and recently the work of Julianne Holt-Lunstad, whose article (2018) – presented to the U.S. Senate Aging Committee – ominously concluded;

---

[234] Caveat: loneliness is not the same as being alone. As Eric Klinenberg's work shows, today many people in the U.S. live alone (28%), often by *choice*, because; a) modern technology enables connection without proximity; b) modern life is "hyperconnected" and many people choose to balance this with a space for solitude; and c) changes in social norms surrounding gender and marriage mean that being single and living alone is becoming less of an "oh no, poor thing" situation, and more of a "oh, of course, you do you" situation. https://www.smithsonianmag.com/science-nature/eric-klinenberg-on-going-solo-19299815/
[235] https://www.huffingtonpost.com/guy-winch-phd/the-danger-of-loneliness_b_3816494.html and https://www.theguardian.com/commentisfree/2014/oct/14/age-of-loneliness-killing-us
[236] https://www.nytimes.com/2018/02/09/opinion/sunday/loneliness-health.html
[237] http://www.apa.org/news/press/releases/2017/08/lonely-die.aspx (the American *Psychiatric* Association has a blog-post on the same topic, though without allusions to death in the title: https://www.psychiatry.org/news-room/apa-blogs/apa-blog/2017/01/loneliness-a-growing-health-concern)

There is now substantial evidence documenting that being socially connected significantly reduces risk for premature mortality, and lacking social connection significantly increases risk, even more than the risks associated with many factors that currently receive substantial public health attention and resources (e.g., obesity, physical inactivity, air pollution). Further, social isolation influences a significant portion of the U.S. adult population and there is evidence the prevalence rates are increasing. With an increasing aging population, the effect on public health is only anticipated to increase. While many U.S. health organizations have been slow to recognize this, the World Health Organization explicitly recognizes the importance of social connections. Indeed, many nations around the world now suggest we are facing a loneliness epidemic. The challenge we face now is what can be done about it. Sustained efforts,[238] attention, and resources are needed to adequately address this important issue (130).

Beneath these superficial truths about loneliness – that it is a "feeling of sadness due to a perceived lack in social connection," a "consequential stressor," a "killer," an "epidemic" – there lies a very deep truth: *the unmet need for belonging.*

I focus so fixedly upon "unmet social needs" because I have concluded that this must be one of the deepest roots of all manifested human misery. When an animal's needs are unmet, the animal can still survive, albeit with consequences – adaptations, coping mechanisms, all perfectly "natural." But with long-term transgenerational undernourishment, the consequences become impossibly complex. Where does coping end and living begin? When is a limp simply locomotion? Humans have been experiencing spiritual undernourishment for as long as humans have been divided, and humans have been divided for longer than any human knows. And since spirits are nourished *only* through meeting social needs like purpose and belonging, I belabor "unmet social needs" because I believe there is no hope for stemming the tides of human misery without addressing them.

---

[238] In the U.K., "sustained efforts" at "addressing this important issue" are underway: there is a National Campaign to End Loneliness (https://www.campaigntoendloneliness.org/about-loneliness/) and the prime minister very recently appointed a *Minister* for Loneliness (http://time.com/5107252/minister-for-loneliness-uk/).

Brené Brown[239] is one of the most well-known current academic activists addressing belonging. Her work on vulnerability, bravery, shame, and belonging has circulated through TED talks,[240] news articles,[241] magazines,[242] and podcasts.[243] I was lucky enough to discover her work right when I needed it. During my post-*Never-Again* recovery, I saw her TED talk on the power of vulnerability, and it gave me a new and empowering way to define myself. I had believed my vulnerability – my sensitivity to being rattled and my inability to hide being rattled – was a shameful weakness (#neoliberalism[244]). But with a few tweaks – a splash of surrender, a dash of intentionality – those same qualities became badges of bravery.

Brown's work also showed me the immense nuance of belonging. **Belonging is**…
…a **spiritual experience**, a belief in something greater than any and all of us which connects us across time and space. This is why I referred to a lack in belonging as "spiritual undernourishment" (and it is also why the neoliberal disavowal of mutual interdependence and connection creates spiritual starvation).
…something that humans are so desperate for that they often sacrifice themselves for it. That is, when **people mistake being "normal" with belonging**, it leads to the soul-crushing half-life of inauthenticity. And paradoxically, as Brown said in her *On Being*

---

[239] https://brenebrown.com
[240] https://ideas.ted.com/finding-our-way-to-true-belonging/
[241] https://www.cbsnews.com/news/author-brene-brown-social-scientist-new-book-braving-the-wilderness/
[242] http://www.oprah.com/spirit/life-lessons-we-all-need-to-learn-brene-brown
[243] https://onbeing.org/programs/brene-brown-strong-back-soft-front-wild-heart-feb2018/
[244] As Lynne Layton (2014) shows in her article "Some psychic effects of neoliberalism: Narcissism, disavowal, perversion," one of the hallmarks of neoliberalism is that **vulnerability is rendered shameful**, because 1) people are socialized to be competitive and self-interested, 2) mutual interdependence is disavowed, 3) vulnerable social distinctions (such as "poor" or "homeless") are reified, and 4) strategies to address these "problems" are market-based and invoke individualistic subjectivity (i.e. personal responsibility). In extreme cases, people may come to believe that "there is no such thing as society, [only a] living tapestry of men and women and people and the beauty of that tapestry and the quality of our lives will depend upon how much each of us is prepared to take responsibility for ourselves" (Margaret Thatcher 1987 https://www.margaretthatcher.org/document/106689).

podcast interview, "fitting in is a hollow substitute for belonging," and "what we do to ensure we fit in makes true belonging impossible." True belonging does not force inauthenticity or complicity with things (however "normal") that counter one's values. (Juicy paradox: sometimes true belonging demands standing alone). No. "Your level of true belonging is only as high as your willingness to be authentically yourself" and your ability to maintain the belief that you are connected to all people (such that when you encounter difference, you lean in to seek common ground rather than turning away).

…**not the same as shared identity**. In fact, the "other and oppress" propensity responsible for shared identities is a *barrier to belonging*. When we feel belonging at the expense of others not-belonging, when the thing that binds us is not shared passion or purpose but shared hatred, this does not nourish the spirit, it further starves it.

…something we experience in **layers**, and sometimes in **hierarchies**: in Western societies, belonging with or to specific intimate others generally matters more than belonging to society at large, just as the love we feel for specific intimate others is generally more intense and long-lasting than the love we feel for abstract humanity[245] (the glow one feels when connected to strangers, e.g. at a concert, a religious service, or other such moment of what Durkheim called "collective effervescence").

…**not the same as feeling happy**. It can be as much a source of frustration and obligation as a source of happiness. (Juicy paradox: happiness is *not* a need, and the cultural preoccupation with happiness is a "trap"[246] that stymies meeting *actual* needs).

If belonging is a need, though, the question is *to what end*? The abatement of loneliness is one answer: **we need belonging to avoid loneliness**. Another is the abatement of fear: **we need belonging to avoid fear (of not belonging)**. And another, to me the most compelling, is the abatement of violence: **we need belonging to avoid violence**. Hannah Arendt called loneliness "the common ground of terror" and believed that the

---

[245] Another "psychic effect of neoliberalism" is "amoral familism" – a "retreat into an individualistic private sphere and a tendency to extend care only to those in one's family and immediate intimate circle" (Layton 2014: 168).
[246] One of the key texts for ACT is *The Happiness Trap*, by Russ Harris (2008).

violence of "totalitarian domination…bases itself on loneliness, on the experience of not belonging to the world at all, which is among the most radical and desperate experiences of man."[247]

Loneliness thus conceived can only happen once certain wheels have been set in motion: the "other and oppress" propensity ignites, neoliberalism fans the flames, and it becomes possible for people – no matter their privilege or lack thereof – to believe that **they do not belong to the world**. The idea that vulnerability is weakness acts like gasoline. Rather than admitting to ourselves or each other that we are lonely and terrified to the core, this pain is transformed into hate. We need to belong so badly that we chase its shadow, attaching ourselves to the false idols of identity and normality until all we know are love's shadows, and the world is so terrible that *none of us* belong to it.

This is the consequence of transgenerational spiritual undernourishment. Unmet social needs + time = **a world that none of us can belong to**.

Must things be thus? Is it possible to find peace in lasting belonging? Brené Brown believes it possible. In fact, she believes it "is not what is *possible*, it is what is *true*." The work is not to make belonging happen, but to remove the barriers to it. This means reclaiming the power of vulnerability. We must embrace our pain and yearning and connect with others' pain and yearning. *This* is why I wrote earlier that "madness is not an enemy in the journey towards human liberation and peace, it is at least a necessary precursor." Madness is vulnerable. Madness is a portal to raw authenticity. And no one who experiences "vulnerability" of the kind Brown promotes, gets there *without* experiencing madness.

---

[247] https://www.brainpickings.org/2016/12/20/hannah-arendt-origins-of-totalitarianism-loneliness-isolation/

Purpose

Structure versus Timelessness

"Paid employment" is normative, so it is unsurprising that members talked a lot about jobs. Many claimed to want one (though as Essen [2012] noted, this doesn't mean they actively sought one), and yet I heard the common refrain that there weren't many jobs, least of all fulfilling ones, for "people like us." As Dorothy said;

> Sure some find a job, if they are lucky. But they always give low end jobs to people like us, with mental illness. I want more than that. People with mental illness deserve the same opportunities as everybody else, not offered the work no one else wants to do while the employers pat themselves on the back.

Dorothy also discussed her "hurdles" to employment, such as stigma, health issues, racism,[248] and companies that wouldn't "work with her" (provide disability accommodations). In spite of this, she wanted a job; "it hurts me not to be contributing to society. I *want* to work."

Of course, material considerations are a factor since, as one jocular member told me, "disability [SSDI/SSI] barely covers the cheeks of my ass." But money was infrequently emphasized when members described why employment mattered most to them. It was *purpose*: that one feels like one is "contributing to society." In examining this further, it became clear that the *feeling* of purpose came in part due to *structure*. As one staff said, "you need a reason to get out of bed, you need structure, to be expected somewhere." And Dan, an older member, mused that "if you're disabled, it is tough, but you gotta do something. You have to work. If you don't, well, I don't know what to say. It's just, you gotta do *something*. You can't *sleep* 24 hours a day." In this sub-section, I juxtapose the *structure* of work – that there is a specific time and place that one is expected to be, specific tasks to do, and specific people to whom one is accountable – with the *timelessness* of unemployed disability.

By timelessness, I am referring to what researchers have witnessed amongst people marginalized by homelessness or institutionalization. For example, in *Asylums*, Goffman (1961) noticed that when nothing begins or ends or changes, the experience of time disintegrates. And Robert Desjarlais (2010[1994]) noted that amongst people experiencing homelessness and mental illness, many lost the ability to remember events or construct cohesive life stories. As Rena said offhandedly when I asked how long she'd been a member: "I don't know. You know I

---

[248] I often thought about intersectionality, but though people sometimes discussed ableism, other "isms" were rarely mentioned. Dorothy, a black woman, was the only person to discuss this with me in depth.

have schizophrenia and we don't keep track of time." Goodley (2016) reminds us that "we rethink temporality through disability" (195), and timelessness is an unsettling extreme.[249] In many members' tales of life before the clubhouse, timelessness was a recurrent theme.

Andy – a jubilant man one would find operating the clubhouse's snack shop – described the years he spent living alone in a small apartment with an air of sadness, saying he would lose track of time (the day, the week, the month) because "I only left my room when nature called."

> Andy: Now, instead of being at home all day with nothing to do, I come here and work. I spent years doing nothing, bored and inactive and unproductive.
>
> Me: So before you came here you had trouble finding structure, staying occupied?
>
> Andy: Structure, you've said the magic word, structure… These days I have a great routine. I have a TE position, twice a week. Then I come here two days a week, and the other day I use to do my running around. Getting my blood drawn, seeing doctors, getting meds filled. You know.
>
> Me: Keeping busy.
>
> Andy: Yes, I gotta keep busy and structured. When I am a bad boy that's when I'm not active enough! So I try to keep myself active and my mind preoccupied.

Similarly, Clarice decried the inactivity and purposelessness of unemployment as an exacerbating force;

> Clarice: When I started coming here I *really* found it helpful. Helpful because I was doing something, I wasn't just sitting at home, I wasn't thinking about suicide, I wasn't thinking about her (the child who died) constantly. I had something to *do* with my time.

Andy and Clarice remind us that the proverb of idle hands (or as Gibran wrote, "step[ping] out of life's procession") serving as the devil's workshop has truth to it. Idleness can

---

[249] In *Man's Search for Meaning* (1984), Frankl connects the timelessness of concentration camp life to the timelessness of unemployment and explains how it leads to purposelessness: "A man who could not see the end of his "provisional existence" was not able to aim at an ultimate goal in life. He ceased living for the future…Therefore the whole structure of his inner life changes; signs of decay set in which we know from other areas of life. The unemployed worker, for example, is in a similar position. His existence has become provisional and in a certain sense he cannot live for the future or aim at a goal. Research work done on unemployed miners has shown that they suffer from a peculiar sort of deformed time – inner time – which is a result of their unemployed state. Prisoners, too, suffered from this strange "time-experience." In camp, a small time unit, a day, for example, filled with hourly tortures and fatigue, appeared endless. A larger time unit, perhaps a week, seemed to pass very quickly… a day lasted longer than a week" (91-2).

be experienced along a spectrum, from exhilarating freedom to excruciating timelessness. It depends on perspective and context. Impoverished people with psychiatric disabilities who live in timelessness do not do so by choice,[250] and this does not feel like *freedom*, but *boredom*[251] (O'Neill 2017). And for people who have experienced trauma – which goes hand in hand with mental illness (and often, the mental health system) – having nothing but endless time and one's own mind to disappear into can be perilous.[252] Clarice was hospitalized several times for suicidality, which she explicitly linked with "just sitting at home" ruminating on her grief. Both Andy's and Clarice's lives were considerably worsened by the *boredom* so fundamental to timelessness. Life improved dramatically when they found opportunities for structure, for "keeping busy," in the clubhouse.

I find it fascinating that structure can be both means *and* end. Through structuring one's time – as I will elaborate upon in the final section – one can more easily set and work toward goals. But structure can also *be* the goal.

CONFESSIONAL MONOLOGUE
Structure and Timelessness, Stasis and Growth

Though it is easy to think of structure and timelessness as an either/or, or a good/bad, it is not so simple. Structure and timelessness are poles on a spectrum, and for each person, the optimal threshold varies. Some thrive with little structure, and in a space of timelessness arrive at wondrous productivity. Some thrive with more structure, and in a space of timelessness arrive at bored inaction. For some, freedom – another word for

---

[250] *Choice* is what separates their experiences of timelessness from my "Laura Days."

[251] In *The Space of Boredom: Homelessness in the Slowing Global Order* (2017), Bruce O'Neill theorizes *boredom* as a pervasive sense of timelessness, of being left behind in an increasingly globalized capitalist world in which all sociality is filtered through accumulation and consumption. Though that world is fast-paced, when one is displaced from it, "life slows down" (3). Boredom thus conceived is not a term to use lightly, very different from the "boredom" of the understimulated masses, "acknowledged as a troubling but also trite burden of privilege… When theorized from the perspective of poverty, however, boredom… becomes something chronic (rather than passing) and cruel (rather than petty)" (15-16).

[252] A point also noted by Essen (2012): "for some, work even provides a distraction away from the 'symptoms' or personal distress that they experience" (235).

"nothin' left to lose" (#JanisJoplin) – is opportunity. For others, all they *want* is something to lose. Some resent rules, others need rules. Some resent being busy, others need to be busy. Some are one way today and another way tomorrow.

But when psychiatric disability is involved, structure becomes *necessary*, as the self-motivational skills one needs in order to play in timeless zones have atrophied. Give a box of crayons and a blank sheet of paper to someone who has never drawn, and they may be lost. Replace the blank sheet with the page of a coloring book, and there is a structure to play within. With structure, it is easier to reignite the flame of self-motivation. And self-motivation is one of the first casualties when mental illness slides to psychiatric disability. This is why structure is so key in psychiatric rehabilitation: it can ground an unmoored being for just long enough that they find their feet.

Once they have their feet, a journey of self-discovery begins. They can uncover where they truly are on the spectrum, how much structure they need when they are not ascending from rock bottom. They can also discover where they are on the closely related "stasis-growth" spectrum. Some people are content with stasis, preferring a mossy life without much vertical movement. Some are more restless, and thrive when they are growing, growing, ever closer to the sun.[253]

---

[253] *All* people benefit from some degree of growth, and its inherent tension. As Victor Frankl wrote (1984), "Mental health is based on a certain degree of tension, the tension between what one has already achieved and what one still ought to accomplish, or the gap between what one is and what one should become. Such a tension is inherent in a human being [and] it is a dangerous misconception of mental hygiene to assume that what man needs is… a tensionless state" (127). Nakamura (2013) had a similar insight at the Japanese psychiatric rehabilitation program Bethel House, noting that people actually *need* worries and stressful experiences. "Hospital environments are designed to take away all of your problems… You assume the sick role, the hospital manages everything else. In contrast [Bethel House] felt that people should be given back their problems and worries. The ability to worry represented a step toward real social rehabilitation and social participation" (109) … "Recovering their lives also meant recovering their struggles. A life without struggle is not one worth living" (153).

The last step of the journey is discovering what *motivates* their position on the spectrum. Do I seek stasis because I thrive in stasis, or because I fear growth? Do I seek growth because I thrive in growth, or because I have not yet found the right stasis?

To clarify, let me offer myself as an example: accounting for the fact that I sometimes need more structure to ascend a madness-pit, I am one who can arrive at wondrous productivity in timeless times. Accounting for the fact that I may not have found my "stasis" yet, I am a *grower*. Frequently restless, motivated by the joy of *mastering*, destined to be forever studying, forever practicing, thriving on the high of worthwhile sacrifice. I know this, so now my concern is *balance*. I sometimes feel at risk of sliding off the edge of an ever-quickening fulfilment-treadmill.[254] Once, writing a song could fulfil me for weeks. Now it is days… So, excessive growth is managed in two ways – by a strategic denial of resources, or by pruning. Sometimes I force myself into the shade. I resist the restlessness and elect to rest. As for pruning, well, I needn't worry about that. Life itself has proven to be more than capable of cutting me back to seedling size.

Menial does not equal Meaningless

The element I found most intriguing in exploring "purpose" was that whether or not something *feels* purposeful is context dependent. I quickly learned that without the clubhouse, members' need for purpose would remain unmet: each member I interviewed told me in one way or another that they would be lost without the clubhouse. Yet I wondered about clubhouse work. Initially, I would watch people doing tasks that seemed by all accounts to be menial, the same

---

[254] My notion of a "fulfilment-treadmill" is based off the psychological theory of the "hedonic treadmill," or "hedonic adaptation," which refers to the "reduction in affective intensity of favorable and unfavorable circumstances" (Frederick & Loewenstein 2003). In other words, humans adapt to the "good" and "bad" of life such that we do not necessarily become happier the more "good" things come our way (though individual differences complicate this general trend [Lucas 2007]). The treadmill metaphor suggests that one must keep moving forward (having more and more "good") just to stay at the same level of happy. In proposing a "fulfilment-treadmill" I am applying this metaphor to purpose rather than happiness.

"low end jobs… no one else wants to do" that Dorothy decried. I would be doing such work – cleaning bathrooms, for example – and I would *not* feel purposeful.

My "ahaa" moment came when the director said she wasn't surprised I was struggling to feel purposeful by focusing on the tasks themselves, as the point of my job was *not* the tasks themselves. It is not *what* you work on, but *how, why*, and *with whom* (as one should never work alone in a clubhouse). As Clarice remarked:

> When I first came here I thought [the clubhouse model] was just about getting tasks done, but now I see that it is really about creating a meaningful community as well as learning skills that could help you get back to work.

Later in our interview, she elaborated:

> My goal here, what makes me feel productive here, is not just tasks…my goal is can I empower my friends? Can I empower other members to see themselves not as a person with a mental illness, but a *person?...* And you know, I want people to see that this is not just busy work. It is not just doing stuff to keep you busy. We are trying to teach you skills, to be productive, to stay on task, that we need help and *you* are needed.

Post "ahaa," once I knew what I was seeing, I saw this – that *the point of clubhouse work is collaboration that facilitates shared purpose* – daily. For example, when Marian said from behind the reception desk, "come on back honey, I need all the help I can get!" to Sophie, sitting idly nearby. Or when Pamela patiently sat beside a member with dementia and had her highlight each name on the attendance sheet after she entered it into the database.

I came to understand the true *relativity* of meaning, and that *menial does not equal meaningless*. Even toilet-cleaning, the shittiest (pun intended) work, can be imbued with meaning when viewed as shared purpose. In my initial reaction, I was (alas) channeling the neoliberal belief that work is rankable, and that "He who works in marble…is nobler than he who ploughs the soil," forgetting that "the wind speaks not more sweetly to the giant oaks than to the least of all the blades of grass." But the wind speaks just as sweetly to the woman who slowly and shakily highlights names as it does to the Ph.D. student who watches.

Belonging

Relationships – "knots we can hold on to"

The former section focused on how work comes to feel *purposeful,* and embedded in each scenario was *relationships*. In fact, intrinsic to the Clubhouse Model is the *interdependence*

of work and relationships.[255] In this sub-section, I delve into the sense of community I witnessed, heard about, and came to feel myself. As one member poetically described clubhouse relationships; "They help tie a knot that we can hold on to when life is tearing us down."

I am not the first clubhouse researcher to hear a member say "this is my family." As Chapter Three showed, many qualitative researchers have witnessed this. However, I may be the first anthropologist to do so (and thus the first to deconstruct the assertion). As I said in the introduction to this chapter, clubhouse relationships can be validly theorized as kinship: from the "shared intentionality" (Sahlins 2013: 37) of "seemingly trivial" (Carsten 2000: 18) but subjectively meaningful clubhouse work, to the excellent analogy of "chosen families" that form between people who share an oppressed identity (Weston 1997), to the kinship of shared disability (Ginsburg & Rapp 2013a: 2013b). However, what I believe to be most relevant is not the language – for every member that said "family," another said "friend" – but the sentiment expressed. The germane truth is that members feel connected, supported, moved, and obligated. They matter, and others matter to them. That clubhouses enable and encourage this degree of intimacy makes them quite rare amongst mental health programs. It also means the clubhouse is meeting a need – *belonging* – that would be otherwise unmet.

When asked about the major difference between life before and after he came to the clubhouse, Andy said:

> I have a community. It is a family almost. You know, everybody supports and helps each other, works together, there's no prejudice, nothing that rubs me the wrong way, we are all tolerant of each other and help each other out, whether it is with work or just talking. I am grateful for that.

Similarly, for Marian, who had just explained the complicated reasons why she had no relationship with her children or siblings;

> Anyway, I'm not alone. We are like extended family. [The director] even cat-sits for me.

And Trish, a wonderfully funny member who co-supervised my internship;

> The clubhouse is one of the only places I feel like a *person*, not a burden. I am treated with respect… some people here even *like* me.

---

[255] As Robby Vorspan (1999) wrote: "you can't have a clubhouse with great relationships and a weak work-ordered day" (2), or vice versa.

I was deeply moved by the strong sense of connectedness at this clubhouse. I participated in joyous celebrations, and tearful goodbyes as colleagues moved on. I sat on hiring committees, and heard someone say "we take this so seriously[256] because we are inviting them to join our family" – and I was told by one staff member that they accepted the job because they felt "something special" during the hiring process. I witnessed members fall in and out of love with one another. I spent Christmas and Thanksgiving participating in the inevitably stressful bustle of feast preparations. I was drawn into inside jokes, delighting in their comforting repetitiveness (for example, due to the frequency with which I consume it, Sophie would unfailingly ask, whenever she saw me, "have you had enough peanut butter today?"). I even found myself participating in the kinds of inside jokes that went too far (for example, I once burped, and before I could stop myself, said "excuse me" in the *exact* tone that an elderly, rather gassy, member often used to excuse herself[257]). Of course the environment was not without its interpersonal drama – as is true in *any* community – but the majority of members were grateful to be together. As Dorothy said:

> I am very grateful to have the clubhouse because it became the backbone I didn't have. The support system. It is a family I can talk to. People here *know* [i.e. share the experience of mental illness]. We have a bond. We are just like a family. Family argue, family have problems, but at the end of the day we know where we stand as a group of people, as a family.

Respite from Stigma and Loneliness

Though many felt content in their lives within the clubhouse, *before*, as well as *outside* of it, they experience/d profound stigma and loneliness. Many had no other people in their lives. Whilst interviewing Rena, she told me that she didn't know why, but aside from her father she "only spends time with clubhouse people." As I urged her to think through it, she mused, "I guess outside of this place, people think I'm a weirdo." We both laughed, some combination of laughter-from-humor and laughter-from-pain.

Me: You're right. A lot of people with mental illness are made to feel like 'weirdos.'

---

[256] Hiring consists of an interview conducted by a panel of members and staff, and then a half-day where interviewees participate in the work-ordered-day to get a sense of their fit in the space.

[257] It is a mark of the truly unique professional identity in this space that, when I confessed this to the director, I was told, "don't worry, you are human. That was taking it too far, but since the clubhouse is more like a family, ambiguous moments like this are quite normal."

Rena: Yeah, but most of what makes us act weird is from the shit that happens. We are all a little bit messed up by life, and once it starts building up, we get messed up even more.

Rena's words were astute; mental illness is influenced by shit happening, and life/shit messes *everybody* up. She also shed light on the main mechanism by which people with psychiatric disabilities find themselves isolated and lonely: *stigma and exclusion.* Not a single member I spoke to failed to mention this reality, nor that the clubhouse was a much-needed respite.

Beyond the unkindness of strangers policing "weirdness," stigma contributed to de-kinning. As Hope said, "I felt rejected by my family, especially when I was homeless. They wrote me off as crazy. I kind of had to figure out how to get help alone." Hope was not alone in finding her family – her first line of defense when things got difficult – an insufficient support network. Marian's children had "given up on her"; Jackie was excluded from family gatherings because "no one wanted to have to take care of me"; Dan's father did not want a "psycho" for a son; and I could fill another book with Clarice's familial woes, as her father was sexually violent, and her step-mother is responsible for a fair few of the scars she wears with pride. I was not surprised to hear her say, "family is not blood. I tell people that all the time. Family is who you choose, who supports you, who loves you."

In addition to the disappointments of *existing* family, I also learned how difficult it is for members to form new families, at least in the normative sense. Though many were in romantic relationships – sometimes with each other – none were married. And this is not because they have transcended the convention,[258] but because of the asset limitations imposed by SSI: when one has a spouse, their assets become your assets, and you are much more likely to lose your benefits. Additionally, two members told me, in colorful language, the reasons why they had not had children. Trish, now in her forties, told me offhandedly, as if it were nothing more than small-talk, "I was sterilized at 20. No one wants any more schizophrenic babies running around." Similarly, Victor told me that, though he had a partner with whom he lived, he would never consider procreating because "they would end up fucked up like me."

Clubhouse members are prevented – sometimes through institutional constraints, but mostly through everyday interpersonal (and internalized) stigma – from forming normative families. Fortunately, as I said earlier, people don't *need* families. They are wonderful when they

---

[258] ***This is what I tell myself I have done.***

are wonderful, but if one is not blessed with a wonderful family,[259] one can still meet the need of *belonging* by seeking or creating the right micro-world. As Pamela said;

> Because we share similar experiences, it is a deeper level of identifying with people. Last week we went to a museum as a group, and I realized that I'd had so little of that*, just being part of a group…* I don't feel as isolated as I did before.

The importance of *belonging* – of "just being part of a group" – cannot be overstated. It literally makes life livable.

CONFESSIONAL MONOLOGUE

Family and Madness

R. D Laing implicated *society* for creating the conditions that fuel madness, and argued that *parenting* played a role. In the *Politics of Experience* (1967) he wrote;

> From the moment of birth, when the Stone Age baby confronts the twentieth-century mother, the baby is subjected to those forces of violence, called love, as its mother and father, and their parents and their parents before them, have been. These forces are mainly concerned with destroying most of its potentialities, and on the whole this enterprise is successful. By the time the new human being is fifteen or so, we are left with a being like ourselves, a half-crazed creature more or less adjusted to a mad world. This is normality in our present age (49).

Laing was not saying that mental illness is caused by bad parenting by bad parents. He was saying that people who parent recreate in their children the same contradictory beliefs and behaviors that count as "normal" in a mad world, and this drives some to madness. Nevertheless, critics associated him with other mommy-blaming psychiatrists who proposed theories of parenting-to-madness in the 1950s-1970s, the most potent being the idea of the "schizophrenogenic mother."[260]

---

[259] Many members *did* have wonderful families. For example, Wendy's mother was extremely supportive – from big things like helping her get her career back on track, to little things like helping her sort her daily pills into pill-boxes at the beginning of every week.

[260] http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)60546-7/fulltext

One of the reactionary movements that sought to "kill this error" (#Darwin) began in California, as I learned through the documentary *When Medicine Got It Wrong.* "A small group of middle-class parents, in the 1970s, got sick and tired of being blamed for causing their children's schizophrenia. They built a grassroots movement and launched a multi-pronged rebellion… taking on doctors, politicians and the cultural fear surrounding schizophrenia."[261] Activists in this movement, such as Eve Oliphant,[262] were instrumental in the foundation of the National Alliance on Mental Illness (NAMI).

For obvious reasons, these activists were *enthusiastic* when biopsychiatry took off in the 1980s and 1990s (#DecadeOfTheBrain), and since its inception, NAMI has been married to the brain disease model. This explains why, in one of my social work classes, a representative from the local NAMI chapter who had come to speak to our class said, "it wasn't *my* fault. My son has a *brain disease.*"

I said nothing. Neither did anyone else. I began to furiously take notes:

> *Whoa, the speaker just dropped the brain disease bomb… and there's basically* crickets! *Why isn't anyone saying anything? Why am* I *not saying anything?*

I didn't say anything because I didn't know what to say other than "the 90s called and they want their reductive language back." But now, I do:

> *I am sorry you experienced self-blame, and glad you found a way to move past it. It is awful that mental illness is so stigmatized that blame has to be assigned at all. However, I was troubled by the phrase "brain disease." The current understanding is that mental illnesses are not simple brain diseases, but are complex biopsychosocial illnesses.*

And though I probably wouldn't say it:

---

[261] http://www.whenmedicine.org/MedW/Story.html
[262] http://www.miwatch.org/2010/06/eve_oliphant_cal_activist_died.html

I know it is harder to wrap the mind around "biopsychosocial." Not only is it complex, but it means we cannot hide behind the "brain" anymore. We have to take responsibility for the ways that we cause harm without meaning to, and think about deep dark social problems that make the world a harmful place. It is challenging, but also liberating. There is no need for "blame" when we all *accept responsibility. Families do not cause mental illness – it is far bigger than families – but our families influence all we become. The good, bad, and mad.*

<div align="center">

Positive Work Environment:

"Clubhouses work for people with mental illness because they work for *people*"

</div>

In order for a clubhouse to provide opportunities for *work* – purposeful activity that builds belonging – to be rehabilitative, a conducive work environment is demanded. Many work environments under neoliberal capitalism are, as Marx put it, "alienating" (Marx 1978). What makes clubhouses un-alienating, and accessible? The director had this to say: "Clubhouses work for people with mental illness because they work for *people.*"[263] In her view, clubhouse work is not particularly tailored toward people with psychiatric disabilities, it is rather a commonsense approach to making people feel *positive* in their work. Clubhouse colleagues have spent 70 years honing intentional practices that foster a work environment in which people feel positively about themselves, their work, and their community. In this section, I describe some of these practices.

Collaboration and accountability

A big part of purposeful productivity is *accountability*: an awareness of one's responsibility to others. As Frankl (1984) showed, a sense of freely chosen responsibility is integral to purpose: "Freedom is only part of the story and half of the truth. Freedom is but the negative aspect of the whole phenomenon whose positive aspect is responsibleness" (156). This accountability adds pressure to be sure, but pressure is integral to collaboration, and to purpose.

---

[263] She went on to say; "People with mental illness experience social isolation a lot more than the general population, but *everyone* could benefit from a positive working environment like this. If more of the world operated on the clubhouse model philosophy, I think the world would be a much better place."

Lunch preparation was a good example. The individual tasks that, when combined, would result in the urgent transformation of "no lunch" to "lunch," would be broken up, and people would work side-by-side in the open kitchen, directly witnessing their task contribute to the whole. Andy told me why he liked this:

> We work together as a team, and it feels good. You go into the kitchen and someone is like 'wanna help with dishes? And someone has to sweep the floor!'… it is a good feeling to know that you are needed, but that you have backup.

In the kitchen Andy felt *needed*. He was motivated by that pressure, but also secure because he had "backup," so he wouldn't be overwhelmed. Another reason why lunch preparation didn't feel overwhelming is because it was broken into chunks, emphasizing the value of

"Baby steps"

In rehabilitation, "baby steps" are fundamental. As Mark Glickman suggests, "just as physical rehabilitation begins with light weights and simple, gentle stretching, so psychiatric rehabilitation and recovery begin with easy-to-accomplish tasks both in the clubhouse and then in the community, through paid jobs in transitional employment" (2012: 1170). Wendy, who sought to outgrow the clubhouse once she found her feet, described her journey thus:

> When I am well I cook, and when I am unwell I don't. So [when I first joined] I started in the kitchen because a goal was for me to get back to cooking. And I met Katie (a staff member) and paired up with her. I was so shy and she was so sweet to me, and she helped me go in toes first. Do a little bit and then a bit more. Within a month I was back to cooking at home… I really believe people thrive when they can build on successes. The first thing I was successful at here was chopping an onion. Katie taught me how, and I did it, and I was successful… And as I was successful with one thing, I moved on to other things. Setting up the salad bar, making the entrée, building the new website. Increments. And by the time I was thinking about applying for a job, I was like "why wouldn't I apply for a job, I just made a website!" … I had a lot of support in looking and applying for jobs. I now work 15 hours a week. My plan is to work and go to school part time at the same time and see how that goes, because I'll keep my SSDI… see the thing that is hard about getting off SSDI is that you *can't* do it in increments, so there is a risk. This way I will go up to full time, but with school, which won't impact my benefits.

Wendy illuminated many important points about rehabilitation; she emphasized support and encouragement – Katie showing her the steps, colleagues helping her apply for jobs; she also highlighted the importance of "increments" and building on prior successes – she built toward employment as a behavioral analyst technician from the humble (and tearful) task of onion-

cutting; and she pointed to a systemic barrier – in spite of the necessity of increments, there is no way to incrementally wean off of SSDI and onto fulltime employment.[264]

Andy also provided key insight. When we interviewed, he had been a member for six years, and was nine months into a Transitional Employment (TE) position. After discussing how his life had changed since he became a member, I asked what he thought inspired such a change:

> Andy: Probably just getting out and exploring… It makes me feel like I am getting out there, getting my feet wet, I am not closed off, not holding back. I'm not really a social person usually.
>
> Me: Yes, it sounds like you were shy and withdrawn, and being here helped you participate in the world a bit more.
>
> Andy: Yes. In baby steps.
>
> Me: Was it scary to go back to work?
>
> Andy: Yes! I hadn't had a job in over ten years. I've been there nine months now. It went so fast!
>
> Me: It is a miracle what we can do with just small steps.
>
> Andy: That's right, like I said, little baby steps. And I never took the initiative, I might never have, so having staff here give me that extra push, ask me directly if I was ready for a TE, I needed that. That's why I feel good today that I did it, that I didn't pull back. I went for it.

The "baby steps," as well as the "push" – that others believed in him, held him accountable, and understood but refused to heed his fear of growth – enabled Andy to "go for it."

Appreciation, encouragement, and acceptance

In the clubhouse, people are regularly thanked and complimented for their contributions and skills. In fact, morning meetings begin with "affirmations," where people are publicly acknowledged. On the topic of the clubhouse work environment, Pamela told me:

> After I started coming, a lot of things fell into place... They taught me new skills, I entered information into the database – I never thought I would be doing anything like that on a computer!... But it was kind of fun and I felt like I was doing something, because everyone was so appreciative. That's one good thing about being more involved – getting a lot of kudos, a lot of support, and encouragement… [And at first] I would hide

---

[264] Noted by McKay and colleagues (2005), reviewed in Chapter Three.

[whilst symptomatic], but now I come in and get the positive feedback I need to keep going. People are sensitive to days when people are not all there and can't do what they normally can. All of that is OK here. That helps recovery. You know you can be yourself whether you're up, down, or in between.

Pamela not only illuminates the importance of appreciation and encouragement, but of *acceptance*: that whether one is having a good or bad day, whether one can or can't, "all of that is OK here."[265] It is this sense of acceptance that has facilitated *commitment*, a novel experience for her. At 70, she has never spent more than two years in one place or with one pursuit. That is, until she moved here and began attending the clubhouse:

I've been [here] 5+ years now, the longest I have been anywhere since 1964. Hahaha, I finally settled down! I'm 70 years old, and finally kinda settled.

Ensuring the work feels meaningful

As Clarice mentioned, "this is not just busy work." Because of the commitment to *meaningful* work, colleagues regularly do an inventory to ensure that no tasks are superfluous. Sometimes, this involves getting rid of tasks, like when they did away with paper in favor of electronic records. Sometimes, this involves creating new tasks, such as the decision to switch to table service from a lunch buffet. And sometimes, this involves *reframing* tasks. During my internship, I was responsible for devising a "mission statement" for the reception desk, which would allow members to see their contribution to the whole. Rather than simply, "we greet people, we answer phones, we answer questions," Hope and I agreed that the reception desk was "the face of the clubhouse, and the informational hub." By explaining how our role contributes to a positive work environment, Hope and I showed our desk colleagues how necessary they were to the smooth operation of the clubhouse.

To tie this to the idea that "menial does not equal meaningless," the key point is that *meaning rarely comes from the task itself*. It matters less what the task is or which of our skills it engages. Meaning in this context comes from our *perceiving a task as urgent or helpful to people*

---

[265] With the caveat that this is not always true. People are redirected ("that is not appropriate here") or asked to take time away if they are instigating or exacerbating negativity that impacts the group. In some ways, as I said in Chapter Three, this is a kind of *silencing*, revealing that the full self (including all grit) is not welcome in this space. However, this is true of many communities (*and* families). Love and belonging are not fixed, and not unconditional. Additionally, as I return to in Chapter Six, in order for the clubhouse to continue to be a healing *collective* space, this necessitates deterring *individual* darkness.

who matter to us. That the work feels meaningful is crucial in a positive work environment, and only demands intentional framing of each task in relation to the whole.

Motivation, not Manipulation

This point follows from the last insofar as when work feels meaningful, people *want* to do it. It is crucial – written into the "Standards" – that clubhouse work is *voluntary*. Members must not feel *forced* to work, so there is much emphasis on *engagement*: the goal is to motivate, not manipulate. This is particularly important due to the history of coercion and exploitation in spaces such as sheltered workshops or moral treatment facilities (Ernst 2016).

Ideally, all colleagues endeavor to engage newcomers in work, but the ultimate responsibility is with staff. As one member of staff described;

> There is a fine line between engagement and coercion. It is important that we are not making it seem, in our tone or whatever, that someone *has* to help. But it is hard to know the difference between a member who needs a bit more encouragement because they have so little confidence in their abilities, and a member who just straight up doesn't want to work.

Interestingly, the director pointed out that sometimes, *refusing* to work is a member's way of exercising agency in a world where they often feel powerless. They don't get to say no to medication[266]; they don't have control over the bureaucracies that determine their benefits; and for those who live in them, they don't get to say no to the staff in their group homes who tell them when to sleep, dress, shower, and shit. They *do* get to say no here.

That said, clubhouses are work-focused programs, so past a certain point, members who treat the clubhouse as a place to socialize draw frustration from colleagues who feel, justifiably, taken advantage of. It is one of Marian's pet peeves;

> I can't *stand* it when folk just sit and drink coffee and eat lunch and never lift a finger. This is a work-focused program! If you just want to socialize, go on down to [the drop-in center].

---

[266] Sometimes literally (i.e. forced medication regimes), but even without direct force, medication is not viewed as optional for psychiatric patients in the U.S., and people are urged to take "responsibility" for their health via "medication compliance." This coercive self-governance helps explain the fact that I have yet to meet anyone (in person) in the U.S. who, like me, has been diagnosed with a "serious mental illness" but does not take prescribed medications.

There is ambiguity here: is it appropriate to use the clubhouse only to socialize? Who decides? In the end, staff handle this by continuing to engage and being transparent about why;

"We could use an extra hand in the kitchen. Wanna set the cutlery?"

"I told you no. Stop hassling me!"

"I know you did, and I'm sorry to hassle, but we really need the help, and you know, I'm *supposed* to include you in the work-ordered-day."

The hope is that each member will gravitate to some task(s). There are some who don't, but for the most part even those less inclined to work have tasks to which they are drawn. For example, one man refused almost everything except facilitating meetings. In such moments, whether or not the staff saw this as problematic – a *man* almost exclusively occupying leadership roles – they'd likely say "thanks, you're a great facilitator!" (appreciation and encouragement).

I felt conflicted when staff overlooked sexism, or used problematic gender tropes in their engagement strategies (e.g. "we need a *man* for the grill"). But the Clubhouse Model's success rests upon staff's ability to make members feel needed – and alas, gender sometimes played a role. Connecting with the clubhouse mission helped me reconcile this: Clubhouses are not intended to smash the patriarchy, they are intended for psychiatric rehabilitation.[267]

Accessible Communication

By this I mean two things: 1) inclusive language, and 2) transparency and clarity. A commitment to inclusive language means that staff must be, and must encourage members to be, careful to avoid oppressive language. This is not easy *anywhere*, but in a community comprised of disenfranchised, under-educated people, many of whom are quite unfiltered, it is a particular struggle. The way this is handled is context-dependent, so I will provide an example. Victor once nonsequitously said to myself and two women staff, "ladies need to be treated with respect, talked sweet to." One of the staff replied, "true, but don't you think this goes for *all* people?"

Achieving transparency and clarity means *meetings*. As Karen Nakamura (2013) noticed in Bethel House – a very similar program – in the clubhouse, there are *a lot* of meetings. Daily

---

[267] *Engagement is not without its nefarious undertones, but I cannot in good conscience belabor the presence of patriarchy in the clubhouse when the nation-state it exists in elected a self-proclaimed proud pussy-grabber as president.*

meetings, weekly meetings, bi-weekly meetings, monthly meetings. There are even *meta-meetings*, meetings about how to hold better meetings. But for such a transient workplace, it is important that everything is communicated clearly – *and* repetitively. The director explained;

> The importance of communication in this setting is twofold: it means everything is more likely to run smoothly, and also means that newcomers – and there are always newcomers, as new members join, or members who haven't been in for while come in – are clued in to what is going on. Things change here so much. They have to. It is the nature of a dynamic workplace. We do our best with predictable routines, but we also have to adapt to who is here and what needs to be accomplished. A place like this could only function with a real dedication to communication. Even when it becomes flogging a dead horse, that is better than someone feeling lost.

Conclusion: Centralizing the Fringe

When asked "what does it mean to you to live a good life?" I received a litany;

> Wendy: "Being surrounded by people who love you, giving back to society, and some occasional fun of course."

> Clarice: "If I continue to grow as a person and help others, my life will have been good."

> Rena: "Being able to live comfortably and have good relationships."

> Hope: "Being able to achieve the goals I set."

> Andy: "To me it means family and friends, being healthy, and going through life doing better as a human being. Being responsible, treating people the way you wanna be treated no matter what."

> Pamela: "Having meaningful work to do. Having relationships. Having the feeling of a future, as well as a legacy, being remembered when I'm gone."

> Dan: "If you're happy, but not because of something you swallow, smoke, or drink. It takes people, you gotta have people. Money helps too. It is too bad, but you gotta have it to survive. And then work. You gotta *do* something. And try to avoid negativity when you can."

Their understandings of what constitutes a good and meaningful life resemble the ingredients proposed by Frankl (1984): "we can discover meaning in life in three different ways: (1) by creating a work or doing a deed; (2) by experiencing something or encountering someone; and (3) by the attitude we take toward unavoidable suffering" (133). Like Frankl, my interlocutors realize the "meaning of life" lies in *work* and *love*. This is why I am captivated by the phrase

"work is love made visible" whenever I revisit *The Prophet*. It encapsulates my understanding of work as *purposeful activity that builds belonging*.

In the clubhouse, I discovered the power of *purpose* and *belonging* in rendering oppression *less* powerful. Life in an oppressive society is no picnic for those holding the shorter end of the privilege-stick. Yet, this home for impoverished people with psychiatric disabilities was neither dark nor depressing. Moreover, I stumbled upon a surprising truth: unlike me, **most of my interlocutors were not particularly perturbed by the fact that society is inaccessible and harmful to them**. At first I was tempted to account for this as ignorance, but that didn't work because though I wouldn't characterize the clubhouse membership as "woke," they were not living beneath rocks. Then, I realized they had **centralized the fringe**. Though their lives epitomize marginalization, *this has not prevented them living meaningful lives*, as they have found a micro-world in which their social/spiritual needs are met, and support in meeting material needs provided. And because their needs are met on the fringe, the fringe has become their center, and the center their fringe. In a sense, this is a kind of *amoral familism* (Layton 2014) in response to oppression: their concerns center around their micro-world rather than the (oppressive) wider world.[268] And though this insularity surprised me, it should not have: insularity is hardly surprising when one is surrounded by stigma (remembering Rena's words, "I only spend time with clubhouse people... I guess outside of here people think I'm a weirdo"), and not caring/thinking much about an abstract "society" is hardly surprising when one has spent one's life on its fringes.[269]

Admittedly, part of my surprise was *judgmental*: insularity is not something I generally approve of, as it counters what I believe to be crucial to living an anti-oppressive life – critical consciousness (being "woke"), and social/civic engagement. But another side of my surprise was *awe*: I am sincerely awed by the human capacity to create and connect with micro-worlds of "matters" that are one's own, especially when it so powerfully reflects resilience in the face of exclusion. This is what purpose and belonging are all about: knowing that you, your work, and

---

[268] Caveat: this is a generality, not a universality, and it is based on my own observations (a limitation as I was not always there). There were of course some members – such as Wendy and Clarice – who were engaged in other communities, who maintained an interest in current events and politics, etc. However, the majority appeared – in terms of conversation and habits – quite insular/clubhouse-centered.

[269] *If the world of narrow-minded normality dubs you inferior and marginal, never fear – it is possible for the feeling to become* **mutual.**

your successes and setbacks, matter to *specific others*, *not* a vague "imagined community" (Anderson 2016[1983]).

Clubhouses meet the needs of purpose and belonging by decentering the individual and fostering "collective identity" (Mandiberg & Edwards 2013). As one Fountain House staff member said, quoted by Glickman and Flannery (1996);

> So many times we hear about the special needs of the mentally ill. But lots of what we need isn't special. Is it a special need that you want friends? That you want an intimate relationship? A social life? A job? A home? Food? A little bit of money in your pocket? (161).

The mainstream mental health system, with its emphasis on individualized problem-focused practices, *cannot meet these utterly crucial "unspecial" needs*. Clubhouses *can*.

And as I opened this chapter with a poem, it seems fitting to close with another;

Ode to Fountain House

Fountain House is, at last
where I belong
Not merely because I suffer from mental illness
but because it reflects my Marxist values
people-members and staff-
working side by side
with mutual respect
for a progressive cause
it's not about money, not about power, not about fame
it's about fulfilling, ethical work
work that heals the mind and nourishes the soul
it's about a loving, supportive community
in which a mentally ill writer and activist
can find a place for himself and his writings
Fountain House is a people's place, not a place for the rat race
It would be blessed by Marx… and is probably blessed by the Lord
himself.
   - Craig Bayer (published in Fountain House's Spring 2017 zine)

CONFESSIONAL MONOLOGUE

Psychiatry Rehumanized…

When I read *Man's Search for Meaning*, I was entranced. So entranced that, when the spell broke, it was rather *stark*.

The spell broke (temporarily) when I reached page 156, part of the 1984 addendum – "The Case for a Tragic Optimism" – to what was otherwise written in the 1940s.

> PSYCHIATRY REHUMANIZED
>
> For too long – for half a century, in fact – psychiatry tried to interpret the human mind merely as a mechanism, and consequently the therapy of mental disease merely in terms of a technique. I believe this dream has been dreamt out. What now begins to loom on the horizon are not the sketches of a psychologized medicine but rather those of a humanized psychiatry (156/7).

About the human condition, Frankl could not have been more on point.

About this, however, he was *too* optimistic.

CHAPTER SIX

Accommodating Madness: Tools for Building a World to Belong to

There is great fear and stigma attached to madness in America, but fear and stigma cannot withstand the power of *critical consciousness* coupled with the *tools* to act upon it. To that end, the purpose of this chapter is to momentarily divert from my mission of deconstructing madness in order to explain how and why a fringe-centering movement like the Clubhouse Model came to exist, and *provide a practical toolkit for accommodating madness into everyday life.*[270] My use of the word "accommodate" is intentional. Not only is "accommodation" the word used by disability rights proponents and policy-makers to refer to the interventions that facilitate the integration of people with disabilities into mainstream environments, but its literal meaning refers not only to adaptation or amendment, but the act of "housing" or "providing sufficient space for."[271] This is precisely what I propose: that we *make space* for madness, inviting it back into the realm of everyday life.

This chapter is especially important in light of the difficult truth that *much of one's suffering with "mental illness" comes from unjust forces beyond one's control*: systemic issues like awkward bureaucracies, insufficient social welfare, and dehumanizing clinical contexts, and societal issues like discrimination. Though I participate in and promote collective efforts to chip slowly away at such systemic and societal issues, *my purpose in this chapter is to describe tools designed for personal application, so that we may embody and radiate the changes we wish for the world*. We cannot control society, but we *can* control ourselves as agents in society.

The most painful of my recovery-epiphanies was that *I had harmed myself and others, manifesting further violence in the world*. It was not intentional, and it was even explicable (#Trauma #WoundedWounder), but that did not make it excusable. *I needed to change*, and the first section of this chapter, "Accommodating Our Madness," describes the tools I discovered

---

[270] A *Western/American* everyday life: these tools are based on specifically situated assumptions.
[271] https://www.merriam-webster.com/dictionary/accommodate

through that journey. The second section, "Becoming an Ally," describes interpersonal tools we can implement in order to become (and create) better allies, and in the final section, "Becoming a *Clinical* Ally," I provide tools for clinicians to better accommodate their clients' madness.

Accommodating Our Madness: How to Heal and Harness Madness

However *diagnosable* one's madness, its effects are less *disabling* when one applies tools for *healing* and *harnessing* it. By healing I mean *identifying the wounds and treating them*, and *identifying the needs and meeting them*. By harnessing I mean attaining a particular power that comes from triumphing in a world built for you to fail in, developing a depth and bravery that enables you to navigate a wilderness not everyone can navigate, and becoming a source of guidance to others who also tread the wild path – harnessing means *collective liberation*.

This section describes the tools I sought when I realized that I had two essential routes for addressing my diagnosable "bipolarity": I could take the dominant route and seek to *quell* the intensity of my fluctuating moods and energy (something I attempted without success), or I could *pack for the poles*, arming myself with the tools to bear these full-force fluctuations with grace. Through this retooling I learned that the source of my *disability* – what made my madness unbearable – was neither the fluctuations nor the intensity, but the way I had been socialized to handle them. I was trapped in a vicious cycle in which I would first experience an intense mood, and then misinterpret it, and then communicate and react to it violently such that it became both more intense and more violent. A depressed mood would hit; I would think "something must be wrong" and begin searching for wrongness; I would *find* wrongness, usually in myself (I'm fat/slutty/broken/bad), and attack it. I call this "tainted madness," to be distinguished from "pure madness." Madness is "pure" when accommodated, embraced, and handled with compassion. Madness is "tainted" by violence. For me, "pure madness" is painful, but also creates opportunities for growth. "Tainted madness," like all violence, only recreates itself.

What follows derives from my own "madness toolkit," a deceptively unremarkable folder on my computer desktop titled "Get your shit together, girl."[272] In this folder there are tools, carefully assembled by my well self to guide my unwell self out of any hole she stumbles into. I

---

[272] This comes from an *Oasis* song ("The girl in the dirty shirt").

began crafting this toolkit after I divested myself from the psychiatric establishment, and will continue to tinker and tailor it as my understanding and experience of madness changes.

The Toolkit

1) The first item in my toolkit is the "**Emergency Steps**," the document I open when I am leaning toward self-injury or suicide (the mental health realm has many pre-made "distress tolerance" resources, and I include some in Appendix A). This personalized document instructs me on how to handle the space I am in, and is framed using the CARESS technique, which I learned from a therapist who practiced Acceptance and Commitment Therapy (ACT). CARESS is an acronym; "CA" stands for "Communicate Alternatively," that is, reframe your experience nonviolently (you did not "fail again, *loser*," you "experienced a hurdle"), or use some other medium than words to communicate it (draw it, dance it, sing it). "RE" stands for "Release Endorphins," or in other words, trick your body. Yes, you are deeply distressed, and it is everything, *BUT*, you are also an animal with reasonably predictable physiology. If you dance (I have my favorite songs ready), or hold an ice cube in your hand (so your body recognizes "pain" and reacts accordingly), your body will release endorphins, which is *exactly* what it must do when in pain (yet often fails to do with emotional pain – one reason why self-injury can de-escalate is because the body releases analgesic endorphins). And the final step is to "Self-Soothe." This is where one takes deep breaths, compresses the chest (weighted blankets are often used to calm children on the autism spectrum – I use a microwaveable wheat bag), laughs (I have a list of infallibly hilarious videos), takes a long hot shower, or cuddles a warm someone.

2) To supplement the "**Emergency Steps**" document, I have a folder titled "**Your Life**" that contains photographs and videos which I have selected for their power to remind me of my best self and what matters to me.

3) My "**Non-suicidal Suicide Note**" is a strange tool that demands explanation: given that I have experienced suicidality often over the years, I have drafted many a suicide note from a space of desperation, and upon reflection, each was woefully inadequate (pain *is* a powerful blinder). Then I discovered this poem, posted to Facebook by a dear friend (shared with her permission):

> there has to be a space to talk about suicidal ideation
> and forget a space with no judgment.

i don't lie to myself that most of us are over the baggage attached to
suicide or anything related to it.
and if you're not over it then you just aren't.
but despite that a space is needed.
because i think if we can mine thoughts of suicide we can come to a clear
understanding of how hard it is to remain alive.
how challenging it is being human in this time and place.
and we can understand how hard it is for people across boundaries.
we can recognise how people feel they're chasing a wheel that will always
be one mile ahead of them on an empty stomach with no shoes.
for decades.
and how a body wears out and a soul gets weary and people just need to
stop
and anything can look like a rest
anything can look like a way out of a system where you're socially
engineered to never be enough
and trauma is your starting point for engaging life
if we could discuss this thing without the words weak or failure then maybe
we could realise how many of us are exhausted and looking for some break.
and maybe that break could be some kind of equally permanent but less
final change.
i don't know
i'm just thinking.
so many people can't be thinking of ways out without it being a sign that
there's problems with where we are.
-    Carla Moore

This poem moved me profoundly, and I realized that were I to decide to fare well the brutal world, I would want to speak truth to power as she did. I would want to be legitimated. In short, I would want a *non*-suicidal suicide note, one written by my best self from a space of clarity, that is capable of communicating my departure in a way that *destigmatizes and demedicalizes it.*

Many people who feel suicidal avoid help-seeking: "Suicidal people, like everybody else, do not want to lose their liberty and be assaulted by medical violence, so we find that mental health services are being deliberately avoided by the very people they are supposed to help" (Webb 2016: 89). This was written by David Webb, the first known suicide-survivor to write a PhD (turned book) on suicide.[273] This resonates with my experience, and though I have not studied suicidology, I trust Webb's assertion that the literature does not include the voices of people who experience suicidality, and concur that this is because *suicide is so medicalized that*

---

[273] https://thinkingaboutsuicide.org

it cannot be viewed as anything but an irrational symptom of "mental illness." And when *suicide* is medicalized, so will be suicide *prevention*, which creates spaces like the emergency psychiatric ward that I experienced, justifiably a place to "deliberately avoid" (#NeverAgain). (Though I must add that suicide prevention is broader than hospitalization, and I *have* found empathic support in volunteers at Samaritans.org, an online crisis counseling service).

Webb encourages his "suicidal soulmates" to "honour and respect [their] suicidal feelings as real, legitimate, and important" (93), and provides a **"rose garden"[274] for suicide prevention** (see Appendix A) – a list of tips for creating healing discourses and practices around that pesky problem of people deciding to die. These tips include: demedicalizing suicide so that we can discuss it holistically as a "crisis of self" and get at its roots; prohibiting psychiatric violence deemed suicide prevention; fostering healthy communities in which suicide is less likely *and* can be openly addressed without shame or fear; creating safe spaces for people who are suicidal; and centralizing the voices of survivors in academic research.

In an attempt to "honour and respect [my] suicidal feelings as real, legitimate, and important," I wrote myself a non-suicidal suicide note in which I pitch my departure as an act of *protest*, and speak truth to power.[275] I offer this idea as a tool to fellow "suicidal soulmates," as I found it comforting to write the hypothetical final chapter of my story without the threat of it being the *literal* final chapter of my story. It was also a productive way to wrestle with my complex feelings about suicide. On the one hand, I respect the decision to die, and like Carla, fully comprehend that *society creates the conditions that make people decide to die*. On the other hand, I understand that most people who take their lives do not do so from a space of clarity, but from a space of pain-blindness. My hope, and my goal as a suicidal soulmate, is not to deter people from a valid choice, but to ensure that their choice does not come from a place of tainted madness that can still be healed or harnessed. *I don't want to see anybody die because they lacked the tools to accommodate madness*.

---

[274] A play off the famous auto-biographical novel by Joanne Greenberg, *I Never Promised You a Rose Garden*. It is also the title of the edited volume this chapter is in – *Searching for a Rose Garden: Challenging Psychiatry, Fostering Mad Studies*.

[275] Suicide as a form of protest has a long history, especially amongst communities that practice Buddhism: http://content.time.com/time/world/article/0,8599,2043123,00.html

4) I have an extensive "**Quote Wall**." It is literally a wall plastered in hand-written quotes, but one could also create a document. There are countless deep and glorious humans who have written words that could unfurl the first spring flowers. Why have blank walls when you can have wisdom instead? "Sage" becomes background to your life. "Misery is wasted on the miserable"[276] is where your eyes flit as you look in the mirror. You have to lean over "You learn to love the place somebody leaves behind for you"[277] or Kahlil Gibran's poem "On Pain" to fluff your pillows. When you reach for clothes, you might see William Blake's "Doors of Perception," and if you are wearing earrings today you will see Rumi's "Things are such" and the last line of Ehrmann's "Desiderata." As you grab your backpack, Bukowski's "If we take-" will be the last thing you see before going about your day. Appendix A features the quotes mentioned here, as well as others that can move me when I am too mad to function.

5) "**You are Loved**" is yet another folder, this one containing copies of notes which remind me that I am integral in other people's lives. Emails or letters sent by friends, family, mentors, and students become ammunition against the idea, bound to return, that I am expendable.

6) My "**Gratitude List**" is another document. Gratitude lists are common in contemporary self-help/self-care, and the practice derives from mindfulness meditation (which derives from Buddhism). Mental health professionals have researched mindfulness and dubbed it an evidence-based practice,[278] and it has been integrated into various interventions, from Mindfulness-Based Stress Reduction (MBSR) to Mindfulness-Based Cognitive Therapy (MBCT), Dialectical Behavioral Therapy (DBT), and Acceptance and Commitment Therapy (ACT). In ACT and

---

[276] This is a quote from Louis CK's show *Louie* (Season 4, Episode 10).
[277] This is a quote from Barbara Kingsolver's *Prodigal Summer* (p. 73).
[278] http://www.apa.org/monitor/2012/07-08/ce-corner.aspx and
https://www.sciencedirect.com/science/article/pii/S0924933813775072

DBT[279] (which I have experienced), gratitude lists are encouraged in order to ground oneself in the present moment[280] and direct one's attention to the proverbial sunny side of the street.

7) The component that took the most time and effort is my comprehensive "**Madness Genealogy**." Not everybody can invest as much in self-study and self-diagnosis as I have, but I believe some undertaking imperative. As I said in Chapter Four, I have yet to meet anyone who has experienced madness and not sought its origin – and without an *empowering* origin story, one's madness easily falls prey to the "taint" of violence. In my "**Madness Genealogy**" – which takes the form of a letter to myself – I accomplish the following:

- **Metabolizing Trauma**: Your life, along with any life, has incurred trauma. Your own, or that which you experience vicariously by simply existing in a profoundly traumatizing world (which, due to present trends in social media use, is difficult to hide from[281]). *This trauma must be metabolized,* as unmetabolized trauma is grave and costly.[282] Trauma-informed/metabolizing practices do not ask "what is wrong with you?" but rather, "*what*

---

[279] As a strangely perfect analog to my toolkit: DBT – a program aimed at addressing the erratic moods and behaviors associated with borderline personality disorder (BPD), which combines psychotherapy with training in intrapersonal and interpersonal skills such as emotional regulation, distress tolerance (see Appendix for a distress tolerance worksheet), and mindfulness – was created by a woman named Marsha Linehan who had experienced BPD. Like my toolkit, DBT was created after a personal journey with the problems being tackled. Linehan spent her teens and twenties in the throes of a dark and destructive tainted madness, which she overcame through what she called a "radical acceptance" of who and how she was (similar to my realization that it wasn't *me*, it was the *world*) and a discovery of *tools* that made everyday life easier. She is now a clinical psychologist, and her story and career are largely responsible for changes in the way BPD is viewed (both within the mental health system and in the public eye). Once an indelible sign that one is, as I quoted in Chapter Four, "a total cunt" (Pembroke 1996), there is now a more nuanced understanding of BPD. And crucially, there is an evidence-based practice that helps people recover from the pain and harmful habits that earn them the label. In short, she rescued the world from the stigmatizing and bullshit belief that BPD was "untreatable." (Linehan's personal story: https://www.nytimes.com/2011/06/23/health/23lives.html Information and evidence for DBT: https://linehaninstitute.org and https://behavioraltech.org/resources/faqs/dialectical-behavior-therapy-dbt/)

[280] In Chapter Five I discussed the "hedonic treadmill" that results in people becoming desensitized to their progress/pleasure such that they constantly feel as though they are chasing an ever-moving target of contentment. Gratitude lists are a good tool for stepping *off* this treadmill.

[281] This article describes the impacts of social media on diagnosable mental illnesses (especially anxiety disorders) in youth, and links it to factors like cyber-bullying and hyperconnectivity (i.e. FOMO/Fear Of Missing Out on everyone's awesome lives, and also feeling intensely aware/worried about widely publicized dangers/tragedies). https://www.nytimes.com/2017/10/11/magazine/why-are-more-american-teenagers-than-ever-suffering-from-severe-anxiety.html

[282] This is true on an individual level (e.g. the Adverse Childhood Experience/ACE Study mentioned in *Never Again*), but also on a collective level (e.g. the consequences of oppression).

happened to you?[283]" I do not recommend answering this alone, because unmetabolized trauma is difficult to detect (as it is *normalized*) and its consequences mean one likely has a skewed sense of self (i.e. with childhood abuse, one often internalizes untruths like "I deserved it"). I fortunately had an amazing therapist and friends, without whom I could not have tackled this gargantuan task. So, I urge you to reach out and speak your pain. With the answers to the question of *what happened to you* laid bare, you can digest the trauma via *compassionate scrutiny*: face all the things, break them apart and see the threads and linkages, and do so with the goal of "seeking the good" (Ellis 2007). And I reiterate: *this must not be done alone.* None of us can or should be sole authorities on ourselves. We need others' insights and judgments, especially since, as the Dunning-Kruger effect[284] suggests, we cannot recognize our most serious flaws or blind-spots. I was unbelievably lucky to have people who knew and loved me enough to call my bullshit out for what it was, to remind me that I was not the only person entitled to define myself (especially important in cases of madness, like mine, that involve self-hatred). But it is *imperative* that the people you share this with are "amazing,"[285] by which I mean open-minded and *capable of receiving what you have to share.* I have made the mistake of believing that any ear is better than no ear, but this is far from true. If, for example, you need to say the S word (the I want to die word) and you say it to an unamazing person, you may find yourself surrounded by cold cinder blocks and mansplained to by a crisp shirt with a name tag (#NeverAgain). But if you say it to an amazing person, you might hear "been there" and instead receive a cuddle or a cookie and the next day a dear friend might show up with a "break glass in case of emergency" box with a letter inside reminding you of how much you'd be missed. If you do not have access to an amazing therapist or friends at present, there are three books I recommend: Cheryl Strayed's *Tiny Beautiful Things*, Eve Ensler's *In the Body of the World*, and Clarissa Pinkola Estés'

---

[283] In Chapter Four, I showed that this language featured in Clarice's "madness genealogy," suggesting that she has experienced trauma-informed therapeutic interventions.

[284] https://www.scientificamerican.com/article/the-psychology-of-the-breathtakingly-stupid-mistake/

[285] Amazing is perhaps hyperbole, as I am often surprised by how ubiquitous people like this are. I think one of the greatest pieces of generic advice I can offer anyone is: if you don't have your shit together, build bonds of community with (amazing) people who *do* (but once did *not*) and can show you how to together your shit. And if you are someone whose shit is now together but once wasn't, *advertise that shit*, as I am here doing: **strategically wearing hearts on sleeves is integral to accommodating madness**. How else will the world know what we can offer it? How else will fear, silence, and shame be trampled?

Women who Run with the Wolves (see Appendix A). These books explore the deepest and most traumatic places the human spirit can go, and somehow manage to convince you that these places are not only beautiful, but that *you can return from them stronger than you would have been had you stayed always in the light*.

- **Getting Over Myself**: This is a byproduct of "metabolizing trauma," but deserves special mention because it is a common roadblock, and was one of my toughest challenges: what to do without victimhood/mental illness to define me? I had spent *years* defining myself and being defined in this way, and had fused "self" with "struggle." By the time I was 26 and taking stock, I was a bipolar-substance-abusing-self-harming-disordered-eating-ex-wife-abandoned-daughter-damsel-in-distress. Then, one of my amazing friends laid this hard truth on me; "you've made this bed you're lying in, but you *can* get up. You have a superiority complex about your inferiority, and you need to get over yourself." She was correct: *I needed to get over myself*, to stop thinking I knew everything there was to know about me, to stop expecting a perfectly integrated "Laura" to emerge (it is common, and *fine*, to have conflicting versions of oneself – such as my "Stray Dog Laura"), and to stop clinging to the victim narrative as though it were a lifeboat rather than the very thing dragging me under. Though it is difficult to get over oneself (we are, after all, ego wrapped in skin), it is not impossible. It takes only humility and an amazing friend.

- **Humanizing My Demons**: In addition to getting over yourself/self-conceptions, you also need to get over *others*, to stop defining them as "someone who broke me." *You must humanize the people who have wounded you*. If you can see them in complexity and context, as the wounded and flawed humans that they are, you will realize this helpful truth: *violence isn't personal, particular, mysterious, or rare*. People who wound are not demons, not otherworldly, they are *human*, made in and of this world. Of *course* my mother was violent: she is a Maori woman (#Colonialism) who was raised in a violent and impoverished home. Learning her story, taking wonder in her whole person and allowing her to be more than just the woman who beat and humiliated my child self, enabled forgiveness (which is entirely for the sake of the forgiver's peace of mind[286]) and the development of an open and fulfilling adult relationship.

---

[286] Forgiving is not condoning, just as explaining is not excusing. The intergenerational/cyclical nature of violence is an explanation, not an excuse, and I forgive without condoning it.

- **Choosing My Label**: I gave much time and thought to choosing my label/s. I am mad, eccentric, wild, and many other things, but "mentally ill" I am not. As my interlocutors Wendy and Pam did (in Chapter Four), you may find that a diagnostic label meets your needs – it may help you understand yourself or cope better, and may even be a window to community. However, *it is not neutral to identify as mentally ill*. Therefore, if this is the label you choose, I suggest that you do so consciously and not as a default. The language we use has political significance, and people who experience mental illness are not simply sick, but *oppressed*. Disability justice activist Johanna Hedva says "it's important that I also share the Western terminology that's been attached to me – whether I like it or not, it can provide a common vocabulary: "This is the oppressor's language, Adrienne Rich wrote in 1971, "yet I need it to talk to you.""[287] Diagnostic language, no matter the intentions of those who use it, is the "oppressor's language," so *use it consciously*.

- **Choosing My Medicine**: One major difficulty in devising this toolkit, aimed to be of use to others, is the challenging terrain of self-medication and my profound and as yet unshakable skepticism of psychopharmaceuticals. As I wrote earlier, I am prescription free, and have practiced self-medication. As Derrida noted in *Platos' Pharmacy* (1983), the ancient Greek term "pharmakon" denotes both medicine *and* poison, accounting for this ambiguous fact of mind/body-altering substances: their effects (and people's desires regarding their effects) are relative. What acts as medicine to one may act as poison to another, and moreover, what is en masse considered "poison" – or to use the more contemporarily relevant distinction of "medicine" and "drug" – what is en masse considered a "drug" versus a "medicine" is culturally relative and by no means aligns with what such substances actually *do*. This is a long-winded way of saying that the "war on drugs" was not a war on "poison" but a war on *people* manifesting an undesirable side of being human. But the fact cannabis has been made medically legal, and that psychopharmaceuticals (and Big Pharma) are have become objects of widespread scrutiny,[288] means that the cultural tide is shifting, and we can begin to openly discuss the ways that "drugs" are *also* medicinal, and "medicines" are *also* poisonous. And so, I urge

---

[287] http://www.maskmagazine.com/not-again/struggle/sick-woman-theory
[288] I included these articles in Chapter Four, but they are again relevant:
https://www.nytimes.com/2018/03/12/upshot/do-antidepressants-work.html
https://www.nytimes.com/2018/04/07/health/antidepressants-withdrawal-prozac-cymbalta.html

you to *interrogate your views on the substances people choose (or are* coerced *into choosing) to address madness*. Understand that just because a substance is prescribed, approved by the FDA, and legal, does not necessarily make it safer/superior to substances that are not prescribed, approved by the FDA, or legal. In short, *try to avoid allowing moralistic societal beliefs to limit your options as you explore available substances in search of the configuration that best meets your needs.* I will not "yuk anyone's yum" (or denigrate another's preference). Though I am skeptical, I will believe (and celebrate with) anyone who tells me that prescribed medications work for them, if they have entered into the relationship with a critical eye.

- **Critical Consciousness**: As Mark Tappan (2006) notes in his exploration of Paolo Freire's theory/practice of "critical consciousness," its purpose is *liberation from oppression* (which is viewed as a *mutual struggle to free both oppressed and oppressor groups*, a point which I will elaborate upon later in this chapter as well as the next), and its site of intervention is the *internal world*[289] of the peoples in question. That is, critical consciousness promotes critical *thinking,* which ideally leads to *action*. And the reason why critical thinking is the *necessary* initial target is because oppression is by its nature a complex phenomenon that operates in what I call "The Five Is" (ideological, institutional, interpersonal, intrapersonal, and intersectional), which means it is thoroughly *normalized* and thus takes much cognitive effort to see, let alone challenge.[290] Of the Five Is, critical consciousness most explicitly targets the fourth – intrapersonal, or as it is otherwise known, "internalized oppression/domination" (see footnote 289). When one is engaged in consciousness-raising, one is essentially on *a mission to uncover the ways that one is trapped by oppressive ideologies and practices without realizing it*, such that one can

---

[289] This is why, as Tappan (2006) suggests, people who theorize and practice critical consciousness-based interventions have become stuck on descriptive terms that emphasize *individual* psychological processes: "internalized oppression" is the common term denoting the way oppressed people internalize the dominant narrative of inferiority and come to view inequality as "natural," and "internalized domination" is the reverse process for groups with power. Tappan pushes against this individualized understanding and suggests an alternative terminology of "appropriated oppression/domination," because the word "appropriation" better reflects the fact that agents are *appropriating* these ideologies, or "master[ing] and [taking] ownership of cultural tools that transmit oppressive ideologies, messages, and scripts" (2127). In this book, I will continue to use "internalized oppression/domination" as these terms currently have more salience to my audience, however I acknowledge and appreciate Tappan's theoretical contribution.

[290] *Collective* trauma (i.e. racism/enslavement) is so incredibly difficult to heal from and harness precisely because *almost everyone around you is in the same boat.*

develop a nuanced and healing/harnessing understanding that "it's not (just) you, it's the world." To demonstrate how this process worked in my journey, here is an example of a concrete way that critical consciousness moved me beyond deeply embedded diagnosable patterns: I used to experience body dysmorphia, and as a result behaved unconscionably – starving, vomiting, counting everything that came in and out, "meeting criteria" for almost every eating disorder under the sun. For years I attempted to overcome this using a combination of cognitive-behavioral therapy and metabolizing trauma (i.e. researching the link between childhood abuse, sexual assault, and eating disorders[291]), but never quite managed to. What ultimately broke the spell was an amazing friend informing me that regardless of the complexity of the issue, I needed to own that my behavior was *size-ist* and *harmful to others*. I resisted at first – how could I be hurting others when it is *myself* that I hate/hurt? – but eventually the message landed: *it does not matter where one intends to send violence, for it always radiates*. I was *of course* behaving oppressively, and once I could see this – and see that it contradicted my values – the path to releasing these behaviors was illuminated. However, critical consciousness as a path to healing/harnessing madness is not always as simple as this instance, so I will provide another example. People who experience madness in America are subject to *internalized ableism/sanism*, a destructive inner script that conflates difference with illness and illness with inferiority – or as a dear friend calls it, "the asshole in my head."[292] This inner ableist asshole is decentered as long as one is in a state of relative wellness, but when one begins to slide, one is met with harmful asshole/ableist notions that one has "failed" and is in a "useless" zone in which one is "not as one *should* be."[293] In order to counteract this, one may be lucky enough – as I was in the earlier example – to have an amazing friend call out the inner asshole, and have it utterly burst the bubble. But more likely, it will be a gradual process of reminding and re-reminding oneself, which becomes quicker and more effective with practice. In my case, when I begin to "go low" (enter a more

---

[291]https://www.nationaleatingdisorders.org/sites/default/files/ResourceHandouts/TraumaandEatingDisorders.pdf
[292] This process of personifying/naming a harmful version of oneself in order to diffuse its power, is promoted by ACT, and as mentioned in Never Again, forms the basis of "Stray Dog Laura."
[293] In Chapter Three, I relayed an instance where Wendy was hospitalized due to a manic episode, and in her reaction to it – anger and shock because she had been "doing everything right" – there appeared mild "inner assholery," though expressed in Wendy's characteristically polite manner.

depressed configuration of mood and energy), the inner asshole invariably makes an appearance, but I almost immediately retort, "I hear you, but I shan't heed you." And now, before I move on from critical consciousness, there is a final caveat: *it is very easy to become "imprisoned by isms" – utterly overwhelmed by the seemingly insurmountable ways that oppression has baked into our bones*. This is why it is crucial that one does not stop at *awareness*, but moves on to *action*. As James Baldwin said, "in order to change a situation one has first to see it for what it is… [but] To accept one's past – one's history – is not the same thing as drowning in it; it is learning how to use it" (1992[1962]: 81). The first step of action, as Baldwin suggests, is *acceptance* (which instantly disempowers the source of oppression). From there, one can move toward healing and resistance.

- **Seeing the Bigger Picture**: What I mean by this is *we are all in this together*. Trauma, oppression, violence, all the forces which can make us doubt whether life is worth living, are as much a part of the human experience as joy, love, art, all the forces which can make us wonder what we could have possibly done to deserve this gift. Whoever and wherever you are, you are part of something massive, a collective cumulative human experience in which there is no floor to hell, and no ceiling to heaven. The weight of cumulative trauma is heavy. If you are a poor woman, you are a poor woman in a long, long, line of poor women (the weight of which is experienced intergenerationally[294]). If you are in love, you are a lover in a long, long, line of lovers. As Martin Luther King Jr. said, "whatever affects one directly, affects all indirectly,"[295] and though we are each unique, it is also true that no feeling or experience is new. It *has* all been done before, the unimaginable pain and unimaginable joy. *You are not alone*. And for those who know the hell of diagnosable madness, I believe you are *lucky*: once you understand that hell hath no floor, only endless quicksand, it is possible for you to live without *deep fear* (i.e. existential rather than tangible fear, like fearing death versus fearing spiders). The most earth-shattering thing I learned was that each of my deep fears was *founded*. Deep fears

---

[294] This is called "intergenerational phenotypic inertia." Biological anthropologist Chris Kuzawa coined this term based on his research on development and maternal/infant health. Its essence is that cumulative maternal stresses (i.e. the mother's entire lifetime, not just her pregnancy) shape the development of infants throughout *their* entire lifetime. Therefore, health disadvantages are inherited in a very complex and long-term sense, and interventions to ameliorate them – usually being short-term – do not make much difference intergenerationally (Kuzawa & Fried 2017).

[295] https://www.africa.upenn.edu/Articles_Gen/Letter_Birmingham.html

may be wider world fears: the world is broken, I am broken, everyone is broken, nothing and everything matters, and we are all going to die and the sun is going to explode. Deep fears may be micro-world fears: this love won't last, I will lose this or run out of that, there is something really wrong with me. *Yes, to all of it*. Every source of wisdom I have turned to has taught me that when one accepts pain as integral to life, and stops resisting it, viewing happiness as "normal" and valorizing a life in which you "laugh, but not all of your laughter, and weep, but not all of your tears,"[296] one is freed from the fear that prevents you from growing through it. "Seeing the bigger picture" enabled me to outgrow these understandable fears – and I write this because the big picture is hard to see and few can see it without a guide, and as per my "**Life Mission Statement**," my purpose is to do such spiritual heavy-lifting so that others don't have to.

8) As I just alluded to, I have a "**Life Mission Statement**." This is quirky, as I am neither school nor non-profit. But why do organizations have mission statements? So that they can first determine, and then connect and reconnect to, their *purpose*.

The wider world bombards us with confusing, shallow, and contradictory messages about what matters in life: how much we earn, what our job is, what we look like, etc. As an existentialist-minded liberal, I am all for the multiplicity and relativity of "matters," and would never tell anyone that what they think matters doesn't matter. But I also know that we are being manipulated to focus on matters that cause us harm, and I think that marketers prey on the fact that there *are* things that deeply matter to us. We are not buying anti-wrinkle cream, we are buying the promise of "beauty," which we are manipulated to believe will buy us belonging. Writing my mission statement was an attempt at organizing myself around deep matters, so that surface-level distractions would no longer take over my attention and therefore my life.

> My purpose is to expose and accommodate that which is marginalized and silenced. The darkest and most feared extremes *cannot* be separated from the full human experience. Therefore, I must be open about my own darkness (sacrificing my pride and privacy willingly), encourage others to do the same, and not allow the sheltered to remain so. In short, my purpose is to wake people up, and provide them with tools to *use* their wokeness for justice. My secondary purpose, deeply intertwined with the first, is to

---

[296] Paraphrasing a section of Kahlil Gibran's poem "On Love" from *The Prophet*.

commit to authentic, humorous,[297] and nonviolent connection with others. To *laugh* and *love*. For only from a place of love can waking be a success.

Regarding the logistics of a mission statement, I suggest: 1) Find a sweet spot between specific and vague. You'll notice that my mission statement does not specify exactly how or in what context I am lovingly waking, which means that I have flexibility. I lovingly wake in everyday conversation, with research, with writing, with music, and if I am ever working a tedious 9-5, I'll find a way to do it there too. 2) Make it deep (i.e. not "to be the best at X"), and something that can't end (i.e. not "finish my dissertation"). 3) Keep reworking it as you keep growing.

9) A copy of Martin Luther King Jr's six "**Principles of Nonviolence**"[298] reminds me of my commitment to nonviolence: 1) nonviolence is courageous (whereas violence is cowardice); 2) nonviolence yields connection (whereas violence yields division); 3) nonviolence defeats injustice, not people, recognizing that hurt people hurt people (whereas violence casts blame); 4) nonviolence accepts pain and believes it transformative (whereas violence resists pain); 5) nonviolence yields love (whereas violence yields violence); 6) nonviolence believes that "the universe is on the side of justice" – that *love trumps hate*, as they say… This reminder of my commitment to nonviolence is crucial. As I mentioned, by far the biggest struggle for me in this journey to heal and harness madness was wrestling with the fact that *I was a violent person* and *I radiated violence into the world.* I had been ignorant of this (#DunningKruger) because a) my society has not acknowledged or addressed its inherent violence, b) people often take "violence" to mean "*physical* violence," and c) violence is subject to desensitization, so the fact that I had grown up in a violent home meant that my threshold for noticing it was set very high. From my perspective, shooting vitriolic barbs at hapless customer service folk was not a big deal, nor was making others around me feel bad when I felt bad. But it *was* a big deal. Not only did I hurt others, but my unwittingly violent default patterns of thought and behavior,[299] coupled with the intensity of my fluctuating moods, was *disastrous* for my mental health.

---

[297] Humor is a key tool for turning awareness into action. Humor is restorative, palliative, connective, and enables us to more easily metabolize trauma. The Association for Applied and Therapeutic Humor (AATH) is a community/resource for people seeking to practice this: https://aath.memberclicks.net
[298] http://www.thekingcenter.org/king-philosophy
[299] Cognitive-behavioral therapy (CBT) is a tool that can be used to address this issue, as its essence is rewiring harmful/violent thoughts in order to alter behaviors.

This changed when I discovered Marshall Rosenberg's program of Nonviolent Communication[300] (NVC). Based on the principles of nonviolence, and the assumptions that a) humans are compassionate until they *learn* to be violent, and b) humans share basic needs that motivate our behavior, NVC trains people to communicate nonviolently by expressing (and listening[301] for) *feelings*, *needs*, and *clear requests*. For example, "it is disrespectful when you come late, and I feel like you are always late" may appear nonviolent because it does not contain any typically violent words,[302] but this phrase casts blame (you are disrespectful), extrapolates beyond the instance (you are always late), and makes no attempt at resolution. The nonviolent way to communicate this would be "when you are late, I feel disrespected, and I need to feel secure with you, so I ask that you respect me and my time."

Now that I have embraced the *principles* of nonviolence, and learned the *tools* of NVC, my madness is more "pure" than "tainted," and thus I can bear it gracefully. Moreover, I have learned how to communicate my madness in such a way that *it can be accommodated by others*, and this has two benefits: firstly, it enables me to meet my goal of inviting madness back into everyday life. It is crucial that madpeople expose the world to madness, as exposure disrupts fear and stigma.[303] (Though this is less true for "tainted" (violent) madness.) Secondly, it spares me the loneliness of self-isolation. Allow me to demonstrate this with an autoethnographic vignette:

> *I often feel regret for all the possible moments of connection thwarted by my inability to connect. Where goes my open heart when I am sad mad? Must low mean lonely?*
>
> *Yesterday I had a breakthrough: I was grocery shopping (the sad mad also need food), and when the cashier began the perfunctory small-talk, it occurred to me that I had two*

---

[300] https://www.cnvc.org (Note: this is not just an American/Western practice, it has been successfully translated all over the world and has been used in volatile contexts such as Israel/Palestine: https://www.cnvc.org/connect/cnvc-projects-overview.html and https://www.cnvc.org/about-Israel-Palestine-9-day-training)

[301] A key point of NVC is that one can use it even when one is communicating with someone who is *not*, by *listening* for the needs/feelings/requests that bely what they say. For example, if someone were to say to me the hypothetical phrase about lateness, I might say "I am hearing that you feel frustrated at my lateness, and maybe that it shows disrespect whereas you need to feel respected?"

[302] I wish to add that *swearing* – using words that are socially constructed as "offensive" – is not tantamount to *violent language*. This hypothetical phrase is far more violent than "that show was fucking great!" I am committed to nonviolent communication, but anyone who knows me is well aware that I am *not* committed to not swearing. I find swearing cathartic, humorous, enjoyable, and emphatic, and I believe that fear of swear-words (as opposed to fear of violent words) is shortsighted.

[303] To this end, I have a song titled "please mind the gap," where I communicate my madness through the metaphor of the London Tube's famous phrase: https://youtu.be/AwKUDsgT8YY

options: my go-to strategy of coldly keeping my eyes to the ground, grunting, and clearly conveying my disinterest, OR, speaking my truth. "I am sorry, but today I am so sad that I am having trouble connecting and this interaction is difficult and scary, which has nothing to do with you, obviously, but if you could give me space that would be amazing." There it was, me requesting a "disability accommodation," demanding a place in the shared world even though its conventions (such as the ability to connect with others) were momentarily out of reach. The cashier simply said "sure thing, feel better soon," and that was that. And I realized how incredibly powerful it made me feel, but also, it drove home the fact that **madness without openness does not yield openness to madness**. *I always thought that people were afraid of my sad madness, but I was wrong; people were afraid of my* tainted *sad madness, a sad madness that became synonymous with rudeness, which perpetuated my isolation, which both perpetuated my sadness* and *kept me on the fringes of the world.*

In concluding the presentation of this **toolkit**, I wish to make two final points. Firstly, I wish to stress that *it is a work in progress*, just as I, the toolmaker, am. These tools will not be universally useful (they are particular to me in spite of efforts to make them relatable), nor do they universally prevent me from descending into madness. But that isn't the point: the point of this toolkit is to prevent my descent into *tainted* madness, so that I can gracefully tread the path to *and* from hell.[304] And of course, tainted/pure madness is not a dichotomy, but a spectrum; so I aim for purity, fall short, and keep aiming.

Secondly, I have chosen to share this toolkit, along with the history of its making (and maker), for a reason: because I had to overcome serious odds in this journey to transform from hateful to nonviolent, from lonely to loved, from burdensome (an open acknowledgment of how many people worried for and about me) to sought-after. And yet, *the fact that I surmounted the seemingly insurmountable does not make me special*. I am resilient, yes, and savvy, certainly, but I am not special, nor do I come from a particularly privileged position that would render such tools inaccessible to the majority. Therefore, I share this toolkit in hopes that it will be *useful* to others, both as evidence that people can change against remarkable odds, and as a guide for *how*.

---

[304] My song "what a lovely place" is about this journey to and from hell, and the fact that once one knows the path, they need not fear becoming lost upon it: https://youtu.be/GwRna4KEtPg

A Caveat: Self-Care (and Privilege)

Though my toolkit focuses on psychological/spiritual interventions, the whole being – body/mind/spirit – needs attention, so I will briefly describe my holistic self-care needs. But before I do, I must draw attention to the valid criticisms of contemporary self-care rhetoric. As feminist freelance writer, Nashwa Khan, writes; "No one wants to fight such a beautiful and needed practice, but in the same instance, a lack of critical engagement with self-care practices can leave it vulnerable to corporate and neoliberal tendencies that progressive circles supposedly challenge and dismantle."[305] Though self-care is "beautiful and needed" – and as many[306] (myself included) argue has potential to be a liberatory anti-capitalist move – it is also co-opted by neoliberal capitalist discourse such that self-care has become entangled with *superficial* and *classed* activities like spa days and yoga retreats. In short, *one must ensure that one's self-care practices are* really *self-care practices and not expensive bullshit, and one must acknowledge that one's privilege impacts one's access to resources that facilitate the care of the self*.

To acknowledge my privilege here is necessary. Though I just finished saying that "I do not come from a particularly privileged position that would render such tools (in my toolkit) inaccessible to the majority," I must elaborate upon this to clarify my meaning. My toolkit represents a *very* privileged access to resources: *my graduate program was my connection to stable income, health insurance, flexible working conditions, and most importantly, the people capable of directing my attention to these tools*. However, my position as a graduate student in this program does not come from privilege: I am first generation to finish high school, and grew up in poverty in a rural community in which tertiary education was not emphasized. Therefore, I am clearly privileged in class and education, but of the (increasingly rare) "upwardly mobile" variation, which means that *my toolkit is not designed with only the "privileged" in mind.*

However, to add another messy aside, I must also own that beyond class, my racial privilege has deeply impacted my ability to accommodate my madness. Rachel Gorman's (2016) *Thinking through Race, Class, and Mad Identity Politics* warns against allowing "mad identity" to represent a "white middle-classed narrative" (269), and speaks truth to the uniquely oppressive

---

[305] http://gutsmagazine.ca//self-care-and-justice-for-all
See also *Life-Hacks of the Poor and Aimless: On negotiating the false idols of neoliberal self-care*:
https://thebaffler.com/latest/laurie-penny-self-care?src=longreads#

[306] This includes Johanna Hedva in *Sick Woman Theory*, which I will describe in Chapter Seven:
http://www.maskmagazine.com/not-again/struggle/sick-woman-theory

experiences that communities of color have with institutions like psychiatry, which dramatically alter the way people of color *today* engage with such institutions.[307] I am acutely aware that were I not a *white* woman (with an accent Americans find "adorable"), my ability to accommodate madness here would be complicated on two fronts; firstly, my initial trust in the system's beneficence and the way I behaved in clinical settings would have been very different; and secondly, it would have been much harder to transform my public persona from "scary mad" to "quirky mad" with the heavy legacy of racial stereotypes to also contend with.

This caveat sub-section on "self-care and privilege" is odd in that it is mostly preamble. All I have so far said is intended to preface the daily resources, beyond the toolkit, which enable me to accommodate my madness: **access to nourishing foods, eight-to-nine hours of uninterrupted sleep, suitable space in which to exercise and meditate, safe access to marijuana, and plenty of flexible *time* to reflect, decompress, have "Laura Days," and experience joy through consuming and creating art**.[308] It costs a great deal to keep myself well, and without my considerable class privilege, I would struggle to meet these needs and my strategies for accommodating madness would need to change.

Becoming an Ally

This section contains tools for accommodating (healing and harnessing) madness that is *not one's own*. I am creating and sharing these because *to heal oneself demands healing others*. This has double entendre: a) one's healing requires Healing Others (others to help you heal), and b) one's healing demands and develops the skills required to help *others* heal, which also furthers one's *own* healing. In short, *becoming an ally is a logical byproduct of needing allies*.

Before presenting these tools, however, I must interrogate the word "ally," for though it is the word I use, it is not without valid criticism. In seeking the origin of the term, I discovered an honors thesis on the topic by an undergraduate in anthropology and women's and gender

---

[307] For example, Jonathan Metzl's (2011) *The Protest Psychosis: How Schizophrenia Became a Black Disease,* reveals the ways that racism and understandings about mental illness combined to produce a trend during the Civil Rights era of overdiagnosis of black people (especially men) as schizophrenic.

[308] I believe that outlets for such enjoyment are paramount. For me, the major outlet is singing. When I sing, it is uniquely spiritual: I feel one with the universe. It is a form of escapism to be sure, but as Ursula LeGuin writes, "As for the charge of escapism, what does escape mean? Escape from real life, responsibility, order, duty, piety, is what the charge implies. But nobody escapes to jail. The direction of escape is toward freedom. So what is 'escapism' an accusation of?" (2017: 83).

studies at Wesleyan University,[309] in which I learned that feminist social justice scholar Janet Jakobsen proposed a politics of "alliance" in 1998. As this galvanized young scholar writes;

> Jakobsen suggested an alliance politics in which both sides are *allied to each other*, in order to form mutual goals and create nonhierarchical spaces in which different people can interact in new ways. She mentions alliances between various marginalized groups, rather than simply between a center and periphery on a single axis of difference. "Alliances are not the outcome of connections across pre-determined units of 'difference,'" she writes, "but are the constitutive subject matter of activity located within diverse and complex social relations" that must be "mobilized to challenge dominating power relations (Jakobsen 1998: 21, cited by McGrory 2014: 1).

McGrory goes on to implicate *neoliberal cooptation* as the source for the current failure of ally politics in yielding social justice. And in *A Critique of Ally Politics*,[310] the (anonymous) author explicitly identifies the reasons why such "ally politics" fail; firstly, because allyship is embedded in contemporary "identity politics" discourse, it operates on the assumption that there are fixed "identities" of oppressed peoples – such as "black people" – whereas *there is no unified mass of "black people."* Secondly, it assumes that oppression is best overthrown when "the privileged" become "allies" to "the oppressed," deferring to "their" leadership and acting upon "their" behalf, whereas *there is no unified mass of "oppressed" people for "privileged" people to defer to or act on behalf of* (and in practice, "allies" often amplify the voices of tokenized "oppressed peoples"). Finally, ally politics has been coopted by neoliberalism and is therefore practiced individualistically, with people policing interpersonal behavior rather than addressing structural issues: a quintessential "ally" spends more time self-flagellating or tone-policing than working toward reparations. In short, ally politics of the kind this author interrogates, *fails to view anti-oppressive resistance as a collective struggle for mutual liberation*.

But it *is* a collective struggle, so my usage of the word "ally" refers to being an accomplice in the shared battle for liberation from identity-based oppression. Therefore, when I say "becoming an ally is a logical byproduct of needing allies," underlying this is a belief that *we all need allies*. In saying "we all need allies," I acknowledge that discussing the collective pain and longing that results from oppression is an ambiguous and challenging task. On the one hand,

---

[309] https://wesscholar.wesleyan.edu/cgi/viewcontent.cgi?referer=https://www.google.com/&httpsredir=1&article=2159&context=etd_hon_theses

[310] https://radicalwashtenaw.org/2015/02/07/a-critique-of-ally-politics/ This article is excerpted from *Taking Sides: Revolutionary Solidarity and the Poverty of Liberalism*, published in 2015 by AK Press, an anarchist publishing house: https://www.akpress.org/takingsides.html

people who are not typically "privileged" in America (white, straight, able-bodied men) are clearly those who suffer most overtly: they are largely those whose bodies are under siege. But, *they are not the only ones whose spirits/souls are incurring damage.* They are not the only ones trapped by a toxic and deprived set of rules for relating to others. In short, I posit that "privilege" exists only in the tangible realm. Therefore, to become an ally, as I see it, means to take seriously the unequal way that oppression hurts, but to nevertheless view an anti-oppressive struggle as a collective struggle for mutual liberation, one which must and will have equalizing consequences in the tangible realm, but is ultimately a struggle for an intangible something deeper: the soul.

In order to be an ally to mad liberation, one must accommodate madness on two fronts: one must be able to *witness* and make space for it without fear or judgment, and one must be able to *intervene* appropriately when called to. Therefore, this section is broken into two sub-sections, one with tools for witnessing, and one with tools for intervention.

How to Witness

1) **Validate their pain:** Many witnesses with good intentions try to soften or trivialize pain. "It could have been worse." "I'm sure they didn't mean to." Such remarks may serve *later*, as you try to prod the person toward a broader perspective, but they are *terribly* invalidating openers.

2) **Share *your* pain**: When you give of yourself, you accomplish much; you show the person that they are not alone, you make the conversation more of a dialogue than a confession, you reassure them that you are not afraid, and you enable empathy. It is a very powerful move to blur the line between "witness" and "witnessed" in this way.

3) **Ask questions**: Asking questions demonstrates that you are really present, interested, and open to hearing. Sometimes, a person *needs* to be asked searching questions in order to discover their story. And sometimes, in order to guide someone toward their discoveries, the question need not be "searching" at all, as this autoethnographic vignette reveals;

> *Not too long ago I lay shuddering next to my sister wincing*
> *"I really am mad, aren't I? After all this, I really am mad!?"*
> *And all she said was*
> *"So?"*

4) **Contextualize**: It can be very helpful to push someone to view their story from another (or a broader) perspective. You can do this by asking questions that shift the direction of the dialogue ("could you tell me more about your father, beyond how his actions impacted you?"), or by…

5) **Checking the bullshit**: *Not all invalidation is harmful.* When someone is sharing pain – especially whilst also experiencing it – they may be dropping hyperbole, oversimplification, and skewed truths left right and center. You are doing a service by (kindly) calling them out on it, as the ethnographic vignette on the next page demonstrates.

6) **Thank them**: Acknowledge what they have shared and what it meant to you to receive it.

7) **When necessary, withdraw kindly**: Sometimes you won't be capable of witnessing, and must communicate this in a way that is clear, kind, and validating: "I appreciate your wish to share this with me, but I think we should talk about this later/somewhere else" (something I frequently said to clubhouse members who began telling intense stories in inopportune moments or places). "I would like to support you right now, but I am struggling myself today and I don't think we can both support each other. Is there anyone else you can talk to?"

The following autoethnographic vignette demonstrates the application of these tools;

> *I was recently in conversation with my mother, and was floored by how well I felt we navigated the challenging topic of childhood abuse. This was not our first time discussing the matter, but it was the first time I felt I handled it according to my values and skills (why is it so much harder to practice this with our intimates?!). At one point, she said; "well you complain about how I was as a mother, but you have no idea what it was like to live with* my *mother. She was so frightening that I slept with a knife under my bed… and now I'm crying. How pathetic." And I responded with; "No, Mum, crying is a brave and cleansing thing, I do it all the time. And thank you so much for trusting me enough to share this, it really helps me make sense of things. Of course I cannot possibly know your suffering, but you know that you are not the only one of us who was frightened of their mother. I am sorry that you missed the opportunity to break the cycle, and I am also*

> *sorry that I have not acknowledged your strengths as a mother enough. How on Earth did*
>
> *you manage to raise four girls alone?*

I validated her pain (*"crying is brave"*) and shared mine. I contextualized (*"the cycle"*) and I checked the bullshit (*"you are not the only one/you missed the opportunity"*). I thanked her and I asked questions.

This ethnographic vignette from the clubhouse provides another example, this time in a professional context, and without the heightened intimacy of the parent/child relationship;

> *Today I had an opportunity to practice kindly checking bullshit. Clarice and I were*
> *discussing her latest horrifying hospitalization, and she told me that what she hated most*
> *about the whole thing was the "med weight" that has rendered her "fat" and "gross."*
> *Now, we have known one another a while, and we have talked about our shared history*
> *with eating disorders, so she knows my stance on the topic. This is why I felt comfortable*
> *(and compelled) to say, "listen, I understand where you're coming from, I really do, it is*
> *terrible to feel like your body is out of your control like this. But I'm disappointed to hear*
> *you talk this way. You are not fat, not gross, and even if you* were *unhealthily overweight,*
> *I would not tolerate you or anyone else saying so with those offensive words.*

I validated her pain, but I also checked the bullshit – in much the same way that an amazing friend once checked *mine*.

How to Intervene

In the social justice realm, we emphasize "Bystander Intervention,"[311] the moment when an ally intervenes rather than overlooks a moment of injustice. The following are tools for those seeking to intervene in such moments.

1) **Educate yourself/critical consciousness**: You must understand the history of the construction of "mental illness" and the oppression of people who experience it.

---

[311] The term "Bystander Intervention" was developed specifically regarding sexual assault prevention, and utilizing the psychological theory of the "Bystander Effect" – which refers to the fact that in moments of risk/harm, the more people that are present, the less likely any one of them is to intervene as they assume someone else will. https://www.psychologytoday.com/us/basics/bystander-effect

2) **Own your privilege/take responsibility**: You must acknowledge your privilege and humbly accept without defensiveness any criticism related to your tacit participation in oppressive practices. Sanism/ableism is not your *fault*, but it is your *responsibility*.

3) **Take care with your cares**: As I said in my Life Mission Statement, I willingly sacrifice my pride and privacy for the greater purpose of accommodating madness in the world. This, coupled with the details of my own prior madness, means that I have a high tolerance for social sanction, so it is easier for me to *take care with my cares* – to care about (expend energy on) only what is *worth* caring about, according to my deeper principles. However hard it may be to achieve, *the ability to be intentional with one's cares is very important for protecting the sanity of anyone attempting to be an anti-oppressive ally*. Not only does it mean one has more energy to expend on what one deeply cares about (which one can solidify through a Life Mission Statement), but it means that empty and unproductive criticism (which we rabble-rousers attract much of) is promptly released (for the ego is not called to action), sparing oneself corrosive resentment and self-critical spiraling. Life becomes less awkward the more unafraid of awkwardness one becomes, so I recommend increasing one's tolerance for social sanction in baby steps.

4) **Baby steps and small bites:** You can't call attention to everything all the time, so you will need to take baby steps and small bites. "Baby steps" refers to the fact that incorporating any new habit into your life is most effectively done incrementally. You will not be "good" at this straight away. When I first started calling out catcalling, I could barely manage more than a sweaty-palmed "fuck off!" Nowadays I'll calmly say "I understand that you find me attractive, but your opinion on my looks is not important to me, and I don't appreciate this attention." "Small bites" refers to the fact that the general problem of injustice and oppression is too big to handle, so you must take small and specific bites. It is easier and more effective to focus on specific issues at specific times than to attempt to do everything all at once.

5) **Clarify *before* you judge**: It is important to give people the benefit of the doubt. Most of the time when someone uses ableist/sanist language, they are unaware of behaving oppressively. If you simply ask, "what do you mean by psycho?" you may be able to engage them in a dialogue

that gently informs them of the consequences of their language ("when I hear the word psycho, I am reminded of the way words are used to make people ashamed of who they are").

6) **Approach with compassion**: When practicing anti-oppressive intervention, I believe nonviolence is the only effective way. The goal is not to shame or blame, but to compassionately educate or de-escalate. As an example, I was recently riding the Subway with a man who was intoxicated and loudly vocalizing his romantic prowess, inquiring (rather vulgarly) as to whether any of the "bitches" present would like to benefit from his considerable "gifts." As expected, the surrounding people were uncomfortably ignoring him (#BystanderEffect). I turned toward him and said, "sir, I think you should stop this." He became defensive, and asked "are you trying to tell me to shut up?" To which I responded, "No, it is not my place to do that, but I ask that you understand how uncomfortable you are making people feel, and that you respect this shared space." He was ruffled, but as I was providing him with no retaliation, he became quiet.

7) **Trust in change**: It is difficult not to feel defeatist at the extent of oppression, but people can and do change, and you must trust this lest you lose motivation and hope.

8) **Be patient with yourself**: Every ally feels they "aren't doing enough." This is understandable in light of the hugeness of the issue, but as I said: *small bites*. Understand and honor the fact that this takes time, you can't do everything, and you will mess up and make situations worse. We all do. Learn from it. *Take your small bites, and embrace the fact that you will be chewing forever.*

9) **Accept discomfort and lack of resolution**: Part of what makes allyhood so difficult is, as was mentioned at the beginning of this section, *there is no consensus about the ideal future*. When it comes to mental illness/madness, I have shown (particularly in Chapters Two and Three) that there is *great* variety in people's needs and wishes. Depending on where one sits on the spectrum of "anti-system" to "system-married," there will be diverse views on how society should move forward. Some will believe that being an ally means to promote the brain-disease model and advocate for funding and research in that arena, and some will believe it means spreading the oppositional message of *Mad Pride*. Wherever you are, *you must accept that you co-exist with others whose views are different but whose intentions are similar*.

Becoming a Clinical Ally

This section provides extra tools for clinicians to better accommodate madness, and is necessary due to the ubiquitous experiences of clinical harm that I have described throughout this work. **The issue, as I see it, is a pervasive failure to understand (and act as if one understands) that whatever else it may also be,** *mental illness is a social justice issue*. When social workers – clinical or otherwise – are charged with intervening in social justice issues, they (ideally) approach it as *allies*; they are *aware* that the problem is deep and complex, that 1) certain voices and narratives are amplified while others are silenced, that 2) there will be internalized oppression/domination to contend with, and 3) they must *dig* in order to unearth the deeper roots of the surface-level problem (in this case a diagnosable mental illness) they are addressing. I will focus on the "digging" tools, as this is the *action* (whereas the *awareness* side of things is a personal journey for the clinician).

Clinical Tools for Accommodating Madness

Integral to accommodating madness, and to the role of a clinician, is *healing.* As I have defined it, healing involves two interconnected steps: identifying the wounds and treating them, and identifying the needs and meeting them.

1) **Identifying and treating the wounds**: In order to adequately address trauma (wounds), one needs the tools of *trauma-informed practice.* As noted earlier, the essence of any trauma-informed practice is a shift in the question from "what is wrong with you?" to "what happened to you?" which the post-modern clinical tools I have already introduced – such as narrative therapy and ACT – are capable of addressing. Beyond this, the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) defines a trauma-informed practice as one which promotes *awareness* – of its quasi-universal prevalence, as well as its harmful impacts and how to address them – as well as *action* – being able to integrate this awareness into practices that heal and resist "re-traumatization."[312] There are several specific clinical practices which meet SAMHSAs criteria (see the last footnote for the link to that list), and I also suggest the Trauma Informed Care Project,[313] an Iowa-based organization with many resources, as well as this article in *Social*

---

[312] https://www.samhsa.gov/nctic/trauma-interventions
[313] http://www.traumainformedcareproject.org/index.php

Work Today[314] which relays the essential components of trauma-informed practice for a specific social work audience (in great detail, from organizational policy to the components of a non-traumatizing physical space).

However, due to the U.S. mental health system's longstanding emphasis on problem-focused diagnoses and treatments, I imagine that *identifying and treating wounds* is something any clinician is already poised to do, just not always at the necessary *depth*. In order to meet my criteria of a trauma-informed practice/practitioner, *I demand the depth of critical consciousness*: not stopping at "what happened to you?" but pushing forward to "it's not (just) you, it's the world." And just as importantly, trauma-informed practice must not stop at identifying and treating wounds, because an equally crucial element of healing is…

2) **Identifying and meeting the needs**: The issue of *unmet social/spiritual needs* is perhaps the bedrock of this book: my interest in and appreciation for the Clubhouse Model comes from knowing that *clubhouses expressly meet the essential needs of purpose and belonging*. Therefore, I urge clinicians to *take these needs seriously,* and *to incorporate tools into their practice which enable clients to identify and understand these needs so that they can be met*.

- **Taking the needs seriously**: My major reason for emphasizing this is because of how often these needs are *not* taken seriously. Underlying my depressed ramblings about there being "no point to life" was a valid attempt at expressing the fact that my need for purpose was unmet. So, when my doctor told me to just calm down and let the medicine take such worries away, it was very invalidating and counterproductive. If he had instead said, "well, that is valid, but what I am hearing is not so much that 'life is meaningless,' but that *you* are struggling to find meaning in life right now. Can you remember times when you felt your life did have meaning? What was different then?"[315] perhaps I would have left feeling curious rather than disengaged.

- **Incorporating tools that enable clients to identify and understand their needs so that they can be met**: Once again, I will highlight narrative therapy and ACT, as well as logotherapy. ACT encourages people to identify and live by their values; narrative

---

[314] http://www.socialworktoday.com/archive/exc_012014.shtml

[315] Note that I have structured this hypothetical doctor response using the tool of nonviolent communication. For clinicians wishing to learn these valuable skills, there is a free training on YouTube: https://www.youtube.com/watch?v=O4tUVqsjQ2I

therapy is similarly designed to facilitate a clear understanding of both one's values as well as the skills needed to live by them (thereby promoting resilience); and logotherapy is explicitly designed to help people make meaning out of existence. In short, the tools for helping people identify their social/spiritual needs are out there, and once people are empowered to understand that 1) they *have* needs, and 2) their needs are valid, and do not make them weak or needy, but *human*, they are in a better position to find ways to *meet* these needs. In fact, as I will elaborate upon in the next and final chapter, I believe (along with Frankl [1984]) that the spiritual/social needs of purpose and belonging can be met by *anyone,* and in *any* context, no matter the degree of oppression and suffering. And this deep and unshakable power is what *harnessing* madness is all about.

3) **Be humble**: The final tool I have for clinicians is *humility.* Own when you are out of your depth. It does not reveal weakness or deficiency in your expertise, it reveals bravery and a commitment to what I hope is your actual professional goal – *healing,* not *being an expert*. Along these lines, do not react defensively when people express frustration or skepticism about you, your profession, or the mental health system. *It is valid*.

<u>Conclusion: A World to Belong to</u>

I wish to close this chapter with two final points: Firstly, implementing these tools will not result in systemic change, and thus will not make the wider world one to belong to: what it *will* do is enable you to build such a micro-world within and around *you*.

Secondly, I want to contextualize this chapter in terms of the Clubhouse Model, because I believe clubhouses are a kind of space where madness *is* accommodated. Clubhouses accommodate madness by creating a space in which people can meet their social/spiritual needs of purpose and belonging, which facilitates healing. Of course, clubhouses do not also "treat the wounds," as their philosophy involves deemphasizing the wounded side of a person. Arguably, this creates a contradiction in that not *all* madness is invited into the space. However, most members I knew formed intimate relationships with one another that left the space, relationships which *did* provide "access intimacy" (i.e. invited the whole self, wounds and all). And also, each time I witnessed staff deter members from expressing madness, it was *tainted* madness. I never heard anything remotely like "don't cry," or "you're hearing voices? Better go home." People

were only deterred from introducing violence that created a toxic environment for all. In short, clubhouses have plenty of room for pure madness, but because of the centrality of a positive and healing *collective* space, clubhouses cannot also house *individuals'* tainted madness.

But though clubhouses occasionally uninvite tainted madness, they also create conditions in which madness can be purified. In fact, I believe what unites clubhouses with programs like R.D. Laing's "Therapeutic Communities," Loren Mosher's "Soteria House," George Fairweather's "Fairweather Lodges" (described in Chapter Two), and Bethel House in Japan (Nakamura 2013), is *that they foster an environment in which people can* change *via purifying their madness, because madness is approached with curiosity and compassion by Healing Others who are* also *changing.*[316] They don't *need* to make room for tainted madness, as when people start coming to this world they can belong to, their madness starts to lose its taint.

Accommodating madness is to purify it so that it can be harnessed – not toward normality, but freedom.

---

[316] In my journey, I have changed, grown, and learned *a lot*, but only because my community has changed, grown, and learned *with* me. See Reima Maglajlic's "Co-creating the ways we carry each other: reflections on being an ally and a double agent" (2016) for an example of the ways that *mutual* change facilitates the accommodation of madness. Also, recall from Chapter Three that one interesting feature of early Fountain House professional identity was the explicit call for change in staff mentality.

CHAPTER SEVEN

Concluding a Book on Madness

This is textbook bittersweet. Here I sit, remembering what I once heard about readers remembering (sometimes *reading*) only the beginnings and endings of texts, and tingling with that pressure. Tying a ribbon on a piece my soul and releasing it into the world is a strange grief. The time has come to let go – I *must* let go before it buckles me – yet I will ache for missing it.

My traditional microphone has served me well, but as I stand on this metaphorical stage, I find that I need only one microphone from here on. So picture me standing firm, rooted in place, eyes ahead, voice sporadically cracking, addressing you, human to human.

CONFESSIONAL MONOLOGUE

It's not (just) *you*, it's the *world* 2.0

> "We are all born mad. Some remain so."
> - Samuel Beckett, *Waiting for Godot* (1954[2011]: 91)

In this book, I have shared many sides of myself. The scholar, the artist, the madwoman, the social worker, and the hippie bleeding heart. I have taken you on an intense journey, inviting you to know what I have known and feel what I have felt, and I am so grateful to you for accompanying me.

On this journey, I have shown you that…

… "madness" is a collective and morally neutral human phenomenon that has been individualized, problematized, and reduced to "mental illness" to the detriment of justice: *we lack a just and liberatory dominant narrative of madness*. I explored the why and

how, unearthing many factors; from the general "other and oppress" propensity, to the Western tendency to black-and-white thinking, to the advent of a narrow "normal" as "ideal," to the influence of neoliberal capitalism in reducing human value to one's ability to produce/accumulate/consume and making healing/helping cold and commercial.

… people have social needs for purpose and belonging, which are hard to meet even for those with privilege, let alone the intersectionally disadvantaged. Why? Because the "other and oppress" propensity has resulted in rigid lines of division (and often mutual unintelligibility across lines of divisions) that we now call "identities," and *identity is limiting*: identity is a box, and in that box we can often access belonging, but we can also be prevented from outgrowing or transcending the box when necessary. When is it necessary? When identity fuels oppression (so it is well overdue). Why? Because oppression creates conditions that starve people of purpose and belonging (#ViciousCycle #SpiritualStarvation).

… the contemporary U.S. mainstream mental health system descends from oppressive practices, and in spite of successes and good intentions, remains a harmful source of epistemic, emotional, and physical violence.

… people with disabilities are oppressed, and the nature of their oppression – which depends on *exclusion* – prevents many from meeting their social needs in mainstream society. However, when people centralize the fringe, they find or create a micro-world where these needs *are* met, demonstrating resilience in the face of adversity.

…Clubhouses are micro-worlds that meet these needs, and though they do not challenge oppressive normality and the history is not entirely rosy (#BrokenEggs), the movement has illuminated important truths about madness and disability. Firstly, that the box is porous: the mad/disabled are not always mad/disabled, and the stairway to madness/disability is one that almost anyone can descend/ascend. Secondly, that the descent/ascent depends in large part on the ability to meet social needs: people are inclined to descend when they do not have a reason to live or a world to belong to, and ascend when they do.

The sum of these challenging truths is; **it's not (just) you, it's the world.**

This is another way of saying **we are all in this together** – **"Nobody's free until everybody's free"**[317] – which many in critical Disability Studies call **interdependence**.

Interdependence

Writer, organizer, and queer disabled woman of color, Mia Mingus, says this on interdependence;

> Our communities and movements must address the issue of access. There is no way around it. Accessibility is concrete resistance to the isolation of disabled people… We must, however, move beyond access by itself…We must understand and practice an accessibility that **moves us closer to justice, not just inclusion or diversity**. As organizers, we need to think of access with an understanding of disability justice, moving away from an equality-based model of sameness and "we are just like you" to a model of disability that embraces difference, confronts privilege and challenges what is considered "normal" on every front. We don't want to simply join the ranks of the privileged; we want to dismantle those ranks and the systems that maintain them… This work is about shifting how we understand access, moving away from the individualized and independence-framed notions of access put forth by the disability rights movement and, instead, working to view access as collective and interdependent. With disability justice, we want to move away from the "myth of independence,"[318] that everyone can and should be able to do everything on their own. I am not fighting for independence... **I am fighting for an interdependence that embraces need and tells the truth: no one does it on their own and the myth of independence is just that, a myth.**[319]

---

[317] This is the title of a speech given by Civil Rights organizer Fannie Lou Hamer. http://oxfordindex.oup.com/view/10.14325/mississippi/9781604738223.003.0017

[318] Though tangential to my work, there are people who take this "myth of independence" further and argue that our experience as individuals, as "selves," is also illusory. Human cognition creates the perception that we are coherent and separable beings, but there is much evidence (most of it in neuroscience) that we are not as bounded as we believe ourselves to be. As Sam Harris (author of *Waking Up: A Guide to Spiritualty Without Religion*) writes; "There is no discrete self or ego living like a minotaur in the labyrinth of the brain. And the feeling that there is – the sense of being perched somewhere behind your eyes, looking out at a world that is separate from yourself – can be altered or entirely extinguished. Although such experiences of "self-transcendence" are generally thought about in religious terms, there is nothing, in principle, irrational about them. From both a scientific and a philosophical point of view, they represent a clearer understanding of the way things are." https://samharris.org/books/waking-up/

[319] https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/

Scholar and editor of the *Disability Studies Reader* (2013b), Lennard Davis, uses the

term **dismodernism** to a similar effect:

> The dismodern era ushers in the concept that difference is what we all have in common. That identity is not fixed but malleable. That technology is not separate but part of the body. That dependence, not individual independence, is the rule (273) … In a dismodernist mode, the ideal is not a hypostatization of the normal (that is, dominant) subject, but aims to create a new category based on the partial, incomplete subject whose realization is **not autonomy and independence but dependency and interdependence**. This is a very different notion from subjectivity organized around wounded identities; rather, ***all* humans are seen as wounded. Wounds are not the result of oppression, but rather the other way around** (275).

And artist, activist, and queer disabled woman of color, Johanna Hedva, calls this the

Sick Woman Theory;

> Sick Woman Theory maintains that the body and mind are sensitive and reactive to regimes of oppression – particularly our current regime of neoliberal, white-supremacist, imperial-capitalist, cis-hetero-patriarchy. It is that **all of our bodies and minds carry the historical trauma of this, that it is *the world itself* that is making and keeping us sick**… The Sick Woman is an identity and body that can belong to anyone denied the privileged existence... The Sick Woman is all of the "dysfunctional," "dangerous" and "in danger," "badly behaved," "crazy," "incurable," "traumatized," "disordered," "diseased," "chronic," "uninsurable," "wretched," "undesirable" and altogether "dysfunctional" bodies belonging to women, people of color, poor, ill, neuro-atypical, differently abled, queer, trans, and genderfluid people, who have been historically pathologized, hospitalized, institutionalized, brutalized, rendered "unmanageable," and therefore made culturally illegitimate and politically invisible... **The Sick Woman is who capitalism needs to perpetuate itself**. Why? Because to stay alive, capitalism cannot be responsible for our care – its logic of exploitation requires that some of us die. "Sickness" as we speak of it today is a capitalist construct, as is its perceived binary opposite, "wellness." The "well" person is the person well enough to go to work. The "sick" person is the one who can't. What is so destructive about conceiving of wellness as the default, as the standard mode of existence, is that it *invents illness as temporary.*[320] When being sick is an

---

[320] The conversation about temporality is important. In common parlance, "sick" usually refers to a temporary affliction, something one catches and then releases. "Disability" or "injury" connotes a more permanent affliction. Sicknesses are "healed," and disabilities and injuries, "rehabilitated" – the latter acknowledged to be a "recovery" process that takes time and effort and does not necessarily have "normality" as the end goal, the former something that can be as simple as a pill. This temporality is tied to oppressive values and practices. Not only are people with disabilities or "chronic illnesses" discriminated against precisely because of the perceived

abhorrence to the norm, it *allows us to conceive of care and support in the same way...* **The most anti-capitalist protest is to care for another and to care for yourself.**[321] To take on the historically feminized and therefore invisible practice of nursing, nurturing, caring… To protect each other, to enact and practice community. A **radical kinship, an interdependent sociality, a politics of care**. Because, once we are all ill and confined to the bed, sharing our stories of therapies and comforts, forming support groups, bearing witness to each other's tales of trauma, prioritizing the care and love of our sick, pained, expensive, sensitive, fantastic bodies, and there is no one left to go to work, perhaps then, finally, capitalism will screech to its much-needed, long-overdue, and motherfucking glorious halt.[322]

This world – the "current regime of neoliberal, white-supremacist, imperial-capitalist, cis-hetero-patriarchy" – is **sickening** and **inaccessible**. Consequently, there are many of us (*any of us*) who know the feeling of **"not belonging to the world at all."**[323]

And so, our work – perhaps the most important work of our lives – is to find or create the tools for building a world we *can* belong to.

Tools for building a world we can belong to

---

permanence of their afflictedness, but as Hedva notes, presumptions about temporality feed into a politics of not-enough-care. When care is viewed as temporary (and abnormal) because sickness is viewed as temporary (and abnormal), we fail to appreciate that constant care/healing is already well overdue because we are all, in one way or another, "sick."

[321] Hedva defines "care" as I do: building communities that accommodate (heal and harness) madness/sickness. This conception of care is indeed anti-capitalist, for capitalism cannot accommodate madness/sickness (rather, it *creates* it). However, care by another definition (e.g. Foucault's "biopower") could be a tool of capitalism – returning a mad/sick body/mind to a "workable" state. This is not the care Hedva or I practice or promote. Reflecting upon my necessary self-care practice of "Laura Days" is illustrative: guess what Laura cannot do on a "Laura Day"? "Work" in the sense of "being productive according to a capitalist definition of productivity." "Laura Days" are, in this sense, "sick/disability days," and on the surface, a Laura Day is an "unproductive day." This notion haunted me for a long time, and it took serious de-programming to quell the shame of not "being able" so often. Once I realized that "Laura Days" are only "unproductive" to the American economy – but are profoundly productive for me, and for my community who need me – I promptly released all guilt, because *fuck capitalism*.

[322] http://www.maskmagazine.com/not-again/struggle/sick-woman-theory

[323] https://www.brainpickings.org/2016/12/20/hannah-arendt-origins-of-totalitarianism-loneliness-isolation/

As the purpose of this book was to "seek the good" (Ellis 2007) amidst the gory – and further, **to disrupt the suffering that results from lacking the tools to process and surmount the violence of oppression** – it became my mission to identify and communicate concrete tools for building worlds we can belong to.

In Chapters Five and Six I presented these tools. I spoke of creating positive work environments, metabolizing trauma, developing critical consciousness, centralizing the fringe, practicing non-violence, and prioritizing care of ourselves and others. Underlying these practical tools is this profound truth: **carrying oppressed identities need not prevent you from living a meaningful life.**[324] As Victor Frankl (1984) showed, meaning is *always* accessible. *Purpose* and *belonging* – the required tools for a life of meaning – cannot be stolen. The violence of oppression destroys bodies/minds, but it does *not* inevitably destroy the spirit, because what nourishes the spirit is indelible, existing on a deeper plane than tools of oppression can penetrate.[325]

In sealing this book, I have the following summative recommendations:

Dear Clubhouse Community,

I stumbled into your world looking for pain (wounds) and longing (unmet needs), expecting to make a grand argument about how terrible the wider world is and how terrible it is that people are doomed to lives of pain and longing on its margin. That is no longer my argument. In your world I found pain and longing, but I also found the secret to a meaningful life that can transcend pain and longing. I knew the odds that you were up against, and now I know that you had already beaten them before I stumbled in.

---

[324] My interlocutor Dorothy is an excellent example. She is a poor black single mother with psychiatric and physical disabilities (that's a *lot* of oppressed identities) who believes her life joyful and meaningful, is strong and insightful, laughs often, and offers warmth to others.

[325] As Mahatma Gandhi famously said, "You can chain me, you can torture me, you can even destroy this body, but you will never imprison my mind."
http://www.bbc.co.uk/worldservice/learningenglish/movingwords/quotefeature/gandhi.shtml

Knowing that this nation (and beyond) is being slowly populated by your strange little homes for society's misfits brings me hope: not only because I know that more pained and longing people will be able to find a world they can belong to, but because I know that if I am ever again disabled by madness, you would welcome me with open arms.

You do wondrous work, but I must ask more of you. Integral to your mission is empowerment: you aim to restore people's power and heal their wounded spirits through everyday practices that remind them that their lives have purpose and they are not alone. But empowerment cannot stop at everyday practices. In order for lasting empowerment at the deepest of levels, critical consciousness is necessary. To this end, **my recommendation is to develop and practice a consciousness-raising program that enables your community to understand that it's not (just) you, it's the world**. *I fully believe this doable, and have discussed this with people in your world already. It is my intention to work with you to bring this to pass.* [326]

Dear Clinicians (in America),

In seeking the good by exposing the harmful, I have had to paint an unflattering picture of people who share your profession as well as the whole system in which you work. I acknowledge this, and hope that the nuance of my words has landed – I know it's not (just) you, it's the world. And though I cannot abide the mental health system as a whole – its dogmatic labels, its individualism, its commercialism, and its pervasive harms – I know that within that whole are many clinicians who truly heal and empower themselves and others. Though it is true that a person in pain can come to a clinician and leave with fresh wounds, and it is true that for me (and many I have read and interviewed) this was by far the norm, *it is also true that the next door one knocks upon may open to a clinician who truly heals and empowers themselves and others. As my mother said while we were discussing my work, "there is no better time to be mad." For all the unacceptableness, I agree that today we have a better set of clinical tools than ever before to process and surmount madness. Acceptance and commitment therapy*

---

[326] I have already discussed with the director what a consciousness-raising program in this setting might look like.

(ACT), narrative therapy, and logotherapy are examples of such (evidence-based[327]) tools. **These tools empower people by unlocking their ability to meet their deeper spiritual/social needs**. Other common tools – like cognitive-behavioral therapy (CBT), or dialectical-behavioral therapy (DBT) – teach people to rewire toxic patterns of thought and behavior and develop coping skills, which is crucial, but does not necessarily address deeper needs.

My recommendation to you is this: **treat madness/mental illness as a social justice issue, because it is, and take seriously the social/spiritual needs of every client, because whatever else you do to intervene will fail as long as they are unmet.** Whatever your tools of choice may be, you must connect with the person on which you are applying your tools. You must know what happened to them, what matters to them, and what they believe is wrong. You must take seriously the tough existential questions they have (such as "why bother?" – a common question due to the pervasive "existential vacuum" [Frankl 1984] in which we live). And if you do not have answers, all you need to do is apologize, own that you are out of your knowledge and comfort zone, and help them find the next door to knock upon.

Dear "Imagined Community,"

I am not certain who exactly I address here. Benedict Anderson (2016[1983]) uses "imagined community" to refer to fellow nation-state citizens, people one has never met but feels connected to because of (presumably, though not assuredly) shared meaningful assumptions and experiences that mean one can communicate from a place of common ground rather than across an (equally imagined) divide. To whoever fits that description, I have a fourfold recommendation. Firstly, **get woke** – drag society's

---

[327] Like the Clubhouse Model, ACT is also on SAMHSAs national registry of evidence-based practices: https://nrepp.samhsa.gov/Legacy/ViewIntervention.aspx?id=191
For an interactive list/review of efficacy studies on narrative therapy, see:
https://dulwichcentre.com.au/narrative-therapy-research/
For a recent systematic review of research on logotherapy, see:
https://pdfs.semanticscholar.org/5ba0/afe61eebefd553444428f021606f84db760c.pdf

ideological filth to the surface and expose it to the harsh light of critical consciousness –
*as this paves the way for lasting empowerment. Secondly, **introduce nonviolence into***
***your life**, as violence demonstrably causes pain (wounds) and longing (unmet needs).*
*Thirdly, **centralize the fringe whenever you need to** (Meet. Those. Needs), but do not*
allow an unbreachable distance to form between your micro-world and others, as siloing
*is a known source of division. And fourthly, I invite (implore) you to **expand your***
***attitude toward pain**. For too long, we shortsighted pain-fearing Westerners have been*
suffering (= prolonged pain) the consequences of resisting what must always be*, and*
what must always pass: *pain. Ours is a society which views pain as an unwelcomed*
guest, and happiness (or "wellness") as homeostasis. Let me be clear that I do not
protest efforts to reduce and relieve pain, and am glad that much human ingenuity has
been expended to vanquish vanquishable woes. But in medicalizing and problematizing
emotional and existential pain, we have made a world where such pain is routinely
invalidated, misunderstood, misidentified, and unaddressed. And if anything, such pain
has increased *in prevalence, in spite of efforts to vanquish it.*

But the worst is worsened when we fear and resist it. So, Dear World, I must
*conclude that **cowardice is the ultimate sickness in this society, and bravery is***
***therefore the cure**. Bravery manifests in many ways, so I cannot advise exactly how to*
be brave, save what I have already said: expand your attitude toward pain. Understand
that the cycles of death and renewal necessitate one another, and if you can roll with
the punches that come between bliss – enjoy joy when it is your turn, and embrace pain
when that is your lot – then you can be vulnerable and authentic, take risks on behalf of
yourself and others, grow, and be pummeled by life while continuing to return for
second and third helpings. You will not be afraid of pain, because you already know it is
coming, and you are ready for it.

*   **You are ready for it***

I describe myself as an "intensity chaser." I gravitate toward intense experiences – the
joyful and painful – and tend to skip the placid middle-ground. This means I am primed

to be "ready for it" on the occasions where "it" is intense (and not so much when "it" is not). These are the raw materials I have to work with (at least for now), and I have embraced this: I am suited to the life of a warrior. My purpose is therefore to fortify myself and others so that we are "brave enough"[328] to face what must be faced, resist what must be resisted, and grieve what must be grieved.

My bravery, the bravery I promote, is a nonviolent and compassionate bravery that can only be communicated through a tale.

Most of the personal stories I have shared in this work have been about the pain of *intimate* violence – violence between people who are somehow connected. I don't believe dichotomies are the best methods for argument-making, but I notice a distinct difference in the pain that comes from devastation (the presence of something harmful), versus the pain that comes from deprivation (the absence of something needed). And I also notice a difference between violence that is intimate and violence that is not, with the former more often collapsing the devastation/deprivation dichotomy: intimate violence is notorious for devastating and depriving in one fell swoop. My divorce, for example, was devastating beyond belief, and also deprived me my sense of belonging and purpose, which would have made the devastation less devastating. My reaction to that experience was resistant and violent, in part because I was not yet who I am now, but also in part due to the nature of intimate violence: it is much more difficult not to take it personally, and it is much harder to weather devastation from a space of deprivation. But I can see, as I have since had another partnership blossom and die, that I do have much sharper tools to process and surmount such experiences. I am "ready for it," ready for life – for work and love – to delight *and* disappoint me.

---

[328] I have a song called "brave enough" that describes the life of we empathic "hippie bleeding hearts" who feel the full weight of the world, and feel it even more forcefully the more we love: https://www.youtube.com/watch?v=Tn-awhskivM

But what of the pain of non-intimate violence – violence between people who have never met and which is almost entirely due to identity-based oppression? Until a year ago, I could not name a pure instance of this. There were impure instances – experiences that were *almost* non-intimate violence, but not quite. An unwanted sexual encounter with someone I knew – an act of patriarchal violence to be sure, but an intimate one. Being viewed as crazy and broken by friends, family, and clinicians – instances of sanist violence to be sure, but intimate ones.

Then a year ago, I wrote this:

I am an avid solo hiker, and feel deep peace and security in the woods. Yesterday I was followed by a solo hiking man, who passed me (from in front and behind) five times, on a loop trail (revealing an intention to circle me). Each time, I acknowledged him with a nod or a smile. I did not feel unsafe, for I am not the type to see strangers (or strangeness) as suspicious, but when I saw him the fourth time, I confess it was chilling. I allowed him to pass me, this time from behind, and go on ahead. When I looked up shortly afterwards, and saw him again approaching me from the front, I already knew what was about to happen. I was not surprised when he darted at me, put his hands around my waist, leaned his body into mine and said "I think you are beauuutiful" (elongating and grunting the word in a truly unforgettable manner).

Because he had grabbed my waist, my hands were free. I placed them on his shoulders and pushed his body back far enough that I could see his face, and said, slowly, loudly, firmly, "you will not *touch me." His stunned pause emboldened me, and my next move was to remove my right hand from his shoulder and use it to pry his right hand off my waist. With his hand in mine, I looked him in the face, shook the hand I was holding, and said "my name is Laura, by the way. It's nice to meet you."*

He let go instantly and ran away.

Blindly, I ran in the opposite direction. I did not stop until I saw another person – alas not *a person, but a group of school children and their teacher. He took one look at me and told them to hang back. I collapsed into his arms and explained what had happened. Calmly, he told his students that it was time to return, and – leaving enough*

distance that I could go through what I needed to in privacy, but that I could still hear them – they escorted me out, a shield of youthful chatter keeping me company for the agonizing thirty-minute trudge.

I have had so many confusing and conflicting questions since. How would this have played out had I reacted – understandably, and certainly expectedly – with fear? If I had screamed, or asked him to "please don't touch me"? How premeditated was this – was he out looking, or did he simply see something beauuutiful and decide to seize it spontaneously? And most significantly, did I really just save myself from being raped and thrown off the side of a mountain with a firm handshake?

This tale of almost-rape was my first pure experience of impersonal identity-based violence. I was not Laura (at least not until I demanded he know my name) – I was a pussy there for the grabbing. And through this experience, I learned my answer to a question that many women (and other holders of sexually oppressed identities) ask themselves: *what would I do if…? Am I "ready for it"?*

I *was* ready for it. I can honestly say that I have never been more sure of myself than I was in the brutal aftermath of this almost-rape. Instead of isolating myself, I reached out. I told and retold the tale until I had exhausted every angle, and allowed myself the unhumble conclusion that I was a total badass: I was *brave.* Life presented me a moment in which I could be nothing but my truest self, raw Laura, and I found that my instinct aligned with my values – I was not violent, I simply firmly demanded and offered respect (whereas many friends suggested *their* instinct would have been: punch testicles first, shake hands second). I even managed a splash of sardonic.

Moreover, I found myself, for the first time, experiencing *pure* madness. I was mad – trauma is trauma, and one does not experience devastation without consequences – but it was not tainted by the usual suspects: violent thoughts like blame (of him or myself), or resistance to the pain. I was sweating and writhing and weeping and vomiting, but I was entirely present for it. I was experiencing and calmly observing

madness simultaneously.

And what I discovered was *breathtaking*. From this space of pure madness, I instinctively "sought the good" amidst the devastating, and found that **I had never felt less alone**. The hatred of one stranger was confronted with the kindness of countless others. The support from the community I have cultivated was immediate and lasting, and I felt honored to call myself their fellow warrior. I also felt connected to a profound and universal realm of the human experience, which considerably deepened my empathy reservoir. I felt one with *everybody*. Even him. Indeed, the most breathtaking of my discoveries was that I neither resented nor blamed him. I could hold ambiguity in my hands without desperately seeking a simple story. I did not believe him a monster or reduce him to "rapist," but understood that he was a complex and wounded man seeking something he may never find. Like all "monsters" (including America's 45th pussy-grabber), he was made in and by this world – and this world and its humans are as monstrous as they are beautiful.

This world and its humans are as monstrous as they are beautiful

> Let everything happen to you
> Beauty and terror
> Just keep going
> No feeling is final.
> -   Rainer Maria Rilke (tr. Barrows and Macy), *Book of Hours: Love Poems to God* (1997: 88)

To prefer beauty and fear pain is understandable, and I do not envision a world where all pain is embraced. Pain that results from violence – as opposed to pain that results from the cycles of loss and renewal – is a beast I would like to see slain. *Violence begets violence.* As champion of nonviolent resistance, Mahatma Gandhi, said, "I object to violence because, when it appears to do good, the good is only temporary; the evil it

does is permanent."[329] **In advocating for accommodating pain and madness into the full human experience, I aim to heal and empower myself and others to lean into *cycle*-pain whilst unwaveringly resisting *violence*-pain.**

This goal, and the journey it has taken me on, is not only mine. It would never be enough for myself alone to invite madness back into the realm of everyday human experiences. But I am *not* alone.

And on some level, that is what this whole book has been about. Its title, "Love in a Time of Madness," refers to the role of *love* – of work, purpose, friendship, kinship, belonging – in healing from and harnessing the madness within and the madness that surrounds (though are they really separate?). It is a play on Gabriel García Márquez' *Love in the Time of Cholera*, a novel demonstrating that love – howsoever one defines it – transcends and underlies all of life's journeys. One of the protagonists, a man who falls in love young, whose lover's path diverges from his own until they are both elderly and finally united, is described as having "courage [that] did not come from the need to survive, or from a brute indifference inherited from his father, but from a driving need for love, which no obstacle in this world or the next would ever break."

I believe that we are all driven in some way by this need. And it is a bittersweet belief.

Bitterly, I survey the world around me, trying to maintain a sense of (tragic) optimism (#Frankl), succeeding only some of the time. How grueling was this task, then, to write a book on Love in a Time of such *terrible* Madness[330] – a time when a hateful man came to lead the nation, when shameless white nationalism resurfaced, xenophobia and

---

[329] http://www.mkgandhi.org/nonviolence/phil7.htm

[330] My song "book on madness" is about the unique challenge of writing this book at *this* time and place (the U.S. during Donald Trump's presidency). Of course, the bad madness (oppression) I write of is timeless (it is always "a Time of Madness"), as timeless as the tools to heal from and harness it (purpose and belonging) … however, the past two years have been *brutal* to experience: https://www.youtube.com/watch?v=8eNBSVLbXqs

terrorism ran wild, and the Earth itself seemed to sigh "enough" and rattled communities with disaster after disaster. At times it was so debilitating just to be conscious and of this world, that I was paralyzed. Johanna Hedva's Sick Woman Theory began with one simple question: "How do you throw a brick through the window of a bank if you can't get out of bed?"[331] On so many days, I could not (cannot) get out of bed, for no other reason than "everything hurts." Because it is my lot to witness and bear the weight of what I so wish were not so: that **it is already too late.** To imagine a harmonious humanity in which violence is vanquished and all people treat life (not only human life) with love, is impossible. The evil that violence has done is permanent (#Gandhi). There is no reversing it. There will be no post-violence world. *This* is the world that we inherited, and *this* is the world that will be passed on and on until the inevitable day where it is no longer hospitable to animals that need air and water to survive.

But **sweetly**, I survey the world around me and I see people going on, working together, accepting the unacceptable.[332] I see people centralizing the fringe, and confronting the center. I see activists galvanized, and people who were not activists become so (*misanthropy loves company*). I see people falling in love, and having babies, refusing to live as if there is no future here. I see people firm-handshaking haters, saying "I do not fear you, I do not believe this wounded version of you that hates and hurts… a handshake? I would hug you if I could." In short, **I see hope**. I see the world's "Good Bones."[333] And I am forced to confront the ambiguous fact that **the world is already inhospitable… and yet we live here**.

Of course, this hope – this glorious sign of tenacity, resilience, and movement – is born because there is something to hope *for* and something to hope *against*. Perhaps there

---

[331] http://www.maskmagazine.com/not-again/struggle/sick-woman-theory
[332] "Accept the unacceptable" is the title of one of my songs, not yet recorded: the idea is that though the world is terrifying, and "we're moving along, almost 8 billion strong, injustice baked into our bones, calling ourselves home in a world that has no room for us," we can still find peace by accepting that unacceptableness is a part of life and resisting what must be resisted.
[333] This is the title of one of the poems included in Appendix A.

would be no beauty without the contrast of monstrosity, and no love without the contrast of hate. Who could ever say?

So my final words to you are: **cling to hope**. Seek your purpose, cultivate your community, and hold on for dear life, for the seas are choppy and the forecast is bleak.

APPENDIX:
Additional Resources for Accommodating Madness

<u>Excerpts from Books and Articles (on my Quote Wall)</u>

"It seems to me that everything is good – death as well as life, sin as well as holiness, wisdom as well as folly. Everything is necessary, everything needs only my agreement, my ascent, my loving understanding…it was necessary for me to sin… to experience nausea and the depths of despair in order to learn not to resist them, in order to learn to love the world, and no longer compare it with some kind of desired imaginary world, some imaginary vision of perfection, but to leave it as it is, to love it, and be glad to belong to it."
      Herman Hesse, *Siddhartha*, p. 116

"You learn to love the place somebody leaves behind for you."
      Barbara Kingsolver, *Prodigal Summer*, p.73

"Discovering more joy does not, I'm sorry to say, save us from the inevitability of hardship and heartbreak. In fact, we may cry more easily, but we will laugh more easily, too. Perhaps we are just more alive. Yet as we discover more joy, we can face suffering in a way that ennobles rather than embitters. We have hardship without becoming hard. We have heartbreak without being broken."
      Desmond Tutu, *The Book of Joy*, p. 12

"Body acceptance means, as much as possible, approving of and loving your body, despite its "imperfections", real or perceived. That means accepting that your body is fatter than some others, or thinner than some others, that your eyes are a little crooked, that you have a disability that makes walking difficult, that you have health concerns that you have to deal with – but that all of that doesn't mean that you need to be ashamed of your body or try to change it. Body acceptance allows for the fact that there is a diversity of bodies in the world, and that there's no wrong way to have one."
      Golda Poretsky, http://everydayfeminism.com/2013/06/real-deal-on-body-acceptance/

"If the doors of perception were cleansed every thing would appear to man as it is, infinite. For man has closed himself up, till he sees all things through narrow chinks of his cavern."
      William Blake, *The Marriage of Heaven and Hell*

"Nothing bad could happen to me, I thought. The worst thing already had."
      Cheryl Strayed, *Wild*, p. 59

"A generous heart is always open, always ready to receive our going and coming. In the midst of such love we need never fear abandonment. This is the most precious gift true love offers - the experience of knowing we always belong."
    bell hooks, *All About Love: New Visions*, p. 164

"To love a person is to learn the song that is in their heart and to sing it to them when they have forgotten."
    Arne Garborg (found on Facebook – no amount of Googling can uncover its origin)

After the characters' run-in with a terrible nurse talking about her hospitalized sisters' 'lack of cooperation': "Imagine a psychiatrist sitting down with a broken human being saying, I am here for you, I am committed to your care, I want to make you feel better, I want to return your joy to you, I don't know how I will do it but I will find out and then I will apply one hundred percent of my abilities, my training, my compassion and curiosity to your health…if I fail it will be my failure, not yours. I am the professional. I am the expert. You are experiencing great pain right now and it is my job and my mission to cure you from your pain…I know you are afraid. I love you… Imagine a doctor calling you in an important meeting and saying listen, I'm so sorry to bother you but I've been thinking really hard about your problems and I'd like to try something completely new. I need to see you immediately!"
    Miriam Toews, *All My Puny Sorrows*, p. 176-7

"She told me that the brain is built to forget things as we continue to live, that memories are meant to fade and disintegrate, that skin, so protective in the beginning because it has to protect our organs, sags eventually – because the organs aren't so hot either – and sharp edges become blunt, that the pain of letting go of grief is just as painful or even more painful than the grief itself. It means goodbye."
    Miriam Toews, *All My Puny Sorrows*, p. 314

"Sorrow allows us a freedom happiness does not"
    Roxane Gay, *Bad Feminist*, p. 114

"It's hard to be told to *lighten up* because if you lighten up anymore, you're going to float the fuck away."
    Roxane Gay, *Bad Feminist*, p. 189

The following quotes are from Eve Ensler's *Insecure At Last,* in which she chronicles her journey as a journalist/playwright/writer and witness of violence and atrocity, and how this helped her overcome her own traumatic life experiences.
    "I came to understand why we block out the pain and atrocities of others. That pain, if we allow it to enter us, makes our lives impossible. It forces us to examine our values and reality. It insists that we be responsible for others. It thrusts us into the messy world where there are no easy solutions or reasons, only struggles and questions. It creates great fissures in the landscape of our insulated, so-called safe reality. Fissures that, once split open, can never close again. It compels us to act" (p. 17-18).

After a man, who had just escaped torture and death, collapsed and wailed in her arms: "it was as if I were holding the secret story of men in my lap. Centuries of male sorrow and loss, centuries of unexpressed worry and doubt, centuries of pain. I suddenly understood violence and war. I understood retaliation and revenge. I understood how deep the agony is and how its suppression has made men into other things. I understood that these tears falling down Agim's face would have become bullets in any other case, hardened drops, of grief and rage directed toward a needed enemy. I saw how, in fighting to live up to the tyranny of masculinity, men become driven to do anything to prove they are neither tender, nor weak, nor insecure. They are forced to cage the feminine within their own beings and consequently in the world" (p. 25).

"I was starving and there was nothing to eat. There was nothing that would make this better. Unless we were start over again as a species, we able to admit that we had spun off in the wrong direction. Were able to just stop. But I wondered if even that would make things better, would remove the mark of cruelty, the stain of violence, in the cellular structure – this stain that now directed and redirected everything. We are products of violence, each and every one of us. We are its outcome and its creation" (p. 43).

"My experience has led me to believe that only by wholly entering, wholly feeling, wholly inhabiting other people and experiences, are we brought to any happiness and security. Only by allowing ourselves to see what we already see and know what we already know are we freed from depression and ennui" (p. 77).

"We all know and hold the pain around us whether we realize it or not" (p. 80).

When she performed her play Good Body (about body image): "I stood on a platform and felt how deeply distracted Americans were by their corporate-induced self-hatred, by their sense that they were not enough… [who had surrendered] to the rich and Ivy Leagued and powerful who convinced them that they need to consume product after product… that somehow this consumption would ultimately lead to their security… I felt the isolation that this pursuit has engendered. I felt the exploitation of the world's peoples and resources through this ravenous pursuit. I felt the unexpressed guilt in the people who knew they were being manipulated and still they could not stop consuming… Americans are deeply kind, good, and thoughtful people. It is not aggression or hatred… It is not even apathy or lack of caring. It is a paralysis that comes from malignant self-hatred. It is the frozenness that comes from a suffocating loneliness. It is a story in the center of the culture that there are those who are beautiful and smart and rich. They are good, and the rest of us are pathetic, lost, worthless, and not enough… I wanted to throw myself on the stage as in a Greek drama and wail and wail and pull my hair out and scream: This is not accidental what you feel. This is not personal. There is a plan to make you feel ugly and powerless, insignificant and insecure. There is a plan to make you feel like someone or something is coming to fix and rescue you. Give up illusions of security! There is no one coming to take death or aging or sickness away. There is no solution. There is no reason to fix it. No one is smarter or better or on top. You are already enough. Enough. Each and every one of you. Enough. Enough" (p. 165-7)

"We have all been wrongly manipulated, misguided to believe we are longing for security, when really it is kindness we are after" (p. 190).

<u>Poetry</u>

We were Emergencies

We can stick anything into the fog and make it look like a ghost.
But tonight let us not become tragedies.
We are not funeral homes
with propane tanks in our windows
lookin' like cemeteries.
Cemeteries are just the Earth's way of not letting go.
Let go.
Tonight, poets, turn your ridiculous wrists so far backwards
the razor blades in your pencil tips
can't get a good angle on all that beauty inside.
Step into this
with your airplane parts
move forward
and repeat after me with your heart:
I no longer need you to fuck me as hard as I hated myself.
Make love to me
like you know I am better than the worst thing I ever did.
Go slow.
I'm new to this,
but I *have* seen nearly every city from a rooftop
without jumping.
I *have* realized that the moon
did not have to be full for us to love it,
that we are not tragedies
stranded here beneath it,
that if my heart
really broke
every time I fell from love
I'd be able to offer you confetti by now.
But hearts don't break, y'all,
they bruise and get better.
We were never tragedies.
We were emergencies.
You call 9 – 1 – 1.
Tell them I'm havin' a fantastic time
  Buddy Wakefield, http://buddywakefield.com/2009/01/

Good Bones

Life is short, though I keep this from my children.
Life is short, and I've shortened mine
in a thousand delicious, ill-advised ways,
a thousand deliciously ill-advised ways
I'll keep from my children. The world is at least
fifty percent terrible, and that's a conservative
estimate, though I keep this from my children.
For every bird there is a stone thrown at a bird.
For every loved child, a child broken, bagged,
sunk in a lake. Life is short and the world
is at least half terrible, and for every kind
stranger, there is one who would break you,
though I keep this from my children. I am trying
to sell them the world. Any decent realtor,
walking you through a real shithole, chirps on
about good bones: This place could be beautiful,
right? You could make this place beautiful.

     Maggie Smith, http://waxwingmag.org/items/Issue9/28_Smith-Good-Bones.php

Instructions for a Bad Day (spoken word)

There will be bad days. Be calm. Loosen your grip, opening each palm slowly now. Let go. Be confident. Know that now is only a moment, and that if today is as bad as it gets, understand that by tomorrow, today will have ended. Be gracious. Accept each extended hand offered, to pull you back from the somewhere you cannot escape. Be diligent. Scrape the gray sky clean. Realize every dark cloud is a smoke screen meant to blind us from the truth, and the truth is whether we see them or not – the sun and moon are still there and always there is light. Be forthright. Despite your instinct to say "it's alright, I'm okay" – be honest. Say how you feel without fear or guilt, without remorse or complexity. Be lucid in your explanation, be sterling in your oppose. If you think for one second no one knows what you've been going through; be accepting of the fact that you are wrong, that the long drawn and heavy breaths of despair have at times been felt by everyone – that pain is part of the human condition and that alone makes you a legion. We hungry underdogs, we risers with dawn, we dissmissers of odds, we blessers of on – we will station ourselves to the calm. We will hold ourselves to the steady, be ready player one. Life is going to come at you armed with hard times and tough choices, your voice is your weapon, your thoughts ammunition – there are no free extra men, be aware that as the instant now passes, it exists now as then. So be a mirror reflecting yourself back, and remembering the times when you thought all of this was too hard and you'd never make it through. Remember the times you could have pressed quit – but you hit continue. Be forgiving. Living with the burden of anger, is not living. Giving your focus to wrath will leave your entire self absent of what you need. Love and hate are beasts and the one that grows is the one you feed. Be persistent. Be the weed growing through the cracks in the cement, beautiful – because it doesn't know it's not supposed to grow there. Be resolute. Declare what you accept as true in a way that envisions the resolve with which you accept it. If you are having a good day, be considerate. A simple smile could be the

first-aid kit that someone has been looking for. If you believe with absolute honesty that you are doing everything you can – do more. There will be bad days, Times when the world weighs on you for so long it leaves you looking for an easy way out. There will be moments when the drought of joy seems unending. Instances spent pretending that everything is alright when it clearly is not, check your blind spot. See that love is still there, be patient. Every nightmare has a beginning, but every bad day has an end. Ignore what others have called you. I am calling you friend. Make us comprehend the urgency of your crisis. Silence left to its own devices, breed's silence. So speak and be heard. One word after the next, express yourself and put your life in the context – if you find that no one is listening, be loud. Make noise. Stand in poise and be open. Hope in these situations is not enough and you will need someone to lean on. In the unlikely event that you have no one, look again. Everyone is blessed with the ability to listen. The deaf will hear you with their eyes. The blind will see you with their hands. Let your heart fill their news-stands, let them read all about it. Admit to the bad days, the impossible nights. Listen to the insights of those who have been there, but come back. They will tell you; you can stack misery, you can pack despair, you can even wear your sorrow – but come tomorrow you must change your clothes. Everyone knows pain. We are not meant to carry it forever. We were never meant to hold it so closely, so be certain in the belief that what pain belongs to now will belong soon to then. That when someone asks you how was your day, realize that for some of us – it's the only way we know how to say, be calm. Loosen your grip, opening each palm, slowly now – let go.

Shane Koyczan, http://www.shanekoyczan.com/instructions-for-a-bad-day/

Each time

There is not a flood in all the worlds
that can douse a sacred flame in me,
that builds, that rises even higher, each
time I slay another fear.

Rumi, *The Purity of Desire: 100 poems of Rumi (tr. Daniel Ladinsky)*

A voice that calms

A voice that calms, movements that calm,
eyes that quiet – dreams that also do the
same, and enliven too…

Be a precious donor of peace and hope.
Give love to all you meet,

for so many in this world are being torn
apart.

Rumi, *The Purity of Desire: 100 poems of Rumi (tr. Daniel Ladinsky)*

Things are such

Things are such, that someone lifting a cup,
or watching the rain, or petting a dog,

or singing, just singing – could be doing as
much for this universe as anyone.
        Rumi, *The Purity of Desire: 100 poems of Rumi (tr. Daniel Ladinsky)*

Desiderata

Go placidly amid the noise and the haste, and remember what peace there may be in silence. As far as possible, without surrender, be on good terms with all persons.
Speak your truth quietly and clearly; and listen to others, even to the dull and the ignorant; they too have their story.
Avoid loud and aggressive persons; they are vexatious to the spirit. If you compare yourself with others, you may become vain or bitter, for always there will be greater and lesser persons than yourself.
Enjoy your achievements as well as your plans. Keep interested in your own career, however humble; it is a real possession in the changing fortunes of time.
Exercise caution in your business affairs, for the world is full of trickery. But let this not blind you to what virtue there is; many persons strive for high ideals, and everywhere life is full of heroism.
Be yourself. Especially do not feign affection. Neither be cynical about love; for in the face of all aridity and disenchantment, it is as perennial as the grass.
Take kindly the counsel of the years, gracefully surrendering the things of youth.
Nurture strength of spirit to shield you in sudden misfortune. But do not distress yourself with dark imaginings. Many fears are born of fatigue and loneliness.
Beyond a wholesome discipline, be gentle with yourself. You are a child of the universe no less than the trees and the stars; you have a right to be here.
And whether or not it is clear to you, no doubt the universe is unfolding as it should. Therefore be at peace with God, whatever you conceive Him to be. And whatever your labors and aspirations, in the noisy confusion of life, keep peace in your soul. With all its sham, drudgery and broken dreams, it is still a beautiful world. Be cheerful. Strive to be happy.
        Max Ehrmann, http://www.desiderata.com

On Pain

Your pain is the breaking of the shell that encloses
your understanding.
Even as the stone of the fruit must break, that its
heart may stand in the sun, so must you know pain.
And could you keep your heart in wonder at the
daily miracles of your life, your pain would not seem
less wondrous than your joy;
And you would accept the seasons of your heart,
even as you have always accepted the seasons that
pass over your fields.
And you would watch with serenity through the
winters of your grief.

Much of your pain is self-chosen.
It is the bitter potion by which the physician within
you heals your sick self.
Therefore trust the physician, and drink his remedy
in silence and tranquillity:
For his hand, though heavy and hard, is guided by
the tender hand of the Unseen,
And the cup he brings, though it burn your lips, has
been fashioned of the clay which the Potter has
moistened with His own sacred tears.
   Kahlil Gibran, *The Prophet*

On Joy and Sorrow

Your joy is your sorrow unmasked.
And the selfsame well from which your laughter rises was oftentimes filled with your tears.
And how else can it be?
The deeper that sorrow carves into your being, the more joy you can contain.
Is not the cup that holds your wine the very cup that was burned in the potter's oven?
And is not the lute that soothes your spirit, the very wood that was hollowed with knives?
When you are joyous, look deep into your heart and you shall find it is only that which has given
you sorrow that is giving you joy.
When you are sorrowful look again in your heart, and you shall see that in truth you are weeping
for that which has been your delight.
Some of you say, "Joy is greater than sorrow," and others say, "Nay, sorrow is the greater."
But I say unto you, they are inseparable.
Together they come, and when one sits alone with you at your board, remember that the other is
asleep upon your bed.
Verily you are suspended like scales between your sorrow and your joy.
Only when you are empty are you at standstill and balanced.
When the reassure-keeper lifts you to weigh his gold and his silver, needs must your joy or your
sorrow rise or fall.
   Kahlil Gibran, *The Prophet*

If we take-

if we take what we can see-
the engines driving us mad,
lovers finally hating;
this fish in the market
staring upward into our minds;
flowers rotting, flies web-caught;
riots, roars of caged lions,
clowns in love with dollar bills,
nations moving people like pawns;
daylight thieves with beautiful

nighttime mives and wines;
the crowded jails,
the commonplace unemployed,
dying grass, 2-bit fires;
men old enough to love the grave.

These things, and others, in content
show life swinging on rotten axis.

But they've left us a bit of music
and a spoiked show in the corner,
a jigger of scotch, a blue necktie,
a small volume of poems by Rimbaud,
a horse running as if the devil were
twisting his tail
over the bluegrass and screaming, and then,
love again
like a streetcar turning the corner
on time,
the city waiting,
the wine and the flowers
the water walking across the lake
and summer and winter and summer and summer
and winter again.
        Charles Bukowski

Articles

Augusten Burroughs, *How to Live Unhappily Ever After*
https://www.wsj.com/articles/SB10001424052702304746604577379891905861390

Hunter S. Thompson, *On Finding Your Purpose*
http://www.businessinsider.com/hunter-s-thompson-on-finding-meaning-2014-5

Recommended Books

Eve Ensler (2014) *In the Body of the World: A Memoir of Cancer and Connection*, Picador

Cheryl Strayed (2012), *Tiny Beautiful Things: Advice on Love and Life from Dear Sugar,* Vintage

Clarissa Pinkola Estés (1996), *Women Who Run with the Wolves: Myths and Stories of the Wild Woman Archetype*, Ballentine Books

Russ Harris (2008), *The Happiness Trap: How to Stop Struggling and Start Living*, Trumpeter

Kahlil Gibran (1923), *The Prophet*, Alfred A. Knopf, Inc.

Everything is Awful and I'm Not Okay: questions to ask before giving up
Copyrighted by Eponis Sinope, 2015

Are you hydrated? If not, have a glass of water.
Have you eaten in the past three hours? If not, get some food — something with protein, not just simple carbs. Perhaps some nuts or hummus?
Have you showered in the past day? If not, take a shower right now.
If daytime: are you dressed? If not, put on clean clothes that aren't pajamas. Give yourself permission to wear something special, whether it's a funny t-shirt or a pretty dress.
If nighttime: are you sleepy and fatigued but resisting going to sleep? Put on pajamas, make yourself cozy in bed with a teddy bear and the sound of falling rain, and close your eyes for fifteen minutes — no electronic screens allowed. If you're still awake after that, you can get up again; no pressure.
Have you stretched your legs in the past day? If not, do so right now. If you don't have the spoons for a run or trip to the gym, just walk around the block, then keep walking as long as you please. If the weather's crap, drive to a big box store (e.g. Target) and go on a brisk walk through the aisles you normally skip.
Have you said something nice to someone in the past day? Do so, whether online or in person. Make it genuine; wait until you see something really wonderful about someone, and tell them about it.
Have you moved your body to music in the past day? If not, do so — jog for the length of an EDM song at your favorite BPM, or just dance around the room for the length of an upbeat song.
Have you cuddled a living being in the past two days? If not, do so. Don't be afraid to ask for hugs from friends or friends' pets. Most of them will enjoy the cuddles too; you're not imposing on them.
Do you feel ineffective? Pause right now and get something small completed, whether it's responding to an e-mail, loading up the dishwasher, or packing your gym bag for your next trip. Good job!
Do you feel unattractive? Take a goddamn selfie. Your friends will remind you how great you look, and you'll fight society's restrictions on what beauty can look like.
Do you feel paralyzed by indecision? Give yourself ten minutes to sit back and figure out a game plan for the day. If a particular decision or problem is still being a roadblock, simply set it aside for now, and pick something else that seems doable. Right now, the important part is to break through that stasis, even if it means doing something trivial.
Have you seen a therapist in the past few days? If not, hang on until your next therapy visit and talk through things then.
Have you been over-exerting yourself lately — physically, emotionally, socially, or intellectually? That can take a toll that lingers for days. Give yourself a break in that area, whether it's physical rest, taking time alone, or relaxing with some silly entertainment.
Have you changed any of your medications in the past couple of weeks, including skipped doses or a change in generic prescription brand? That may be screwing with your head. Give things a few days, then talk to your doctor if it doesn't settle down.

Have you waited a week? Sometimes our perception of life is skewed, and we can't even tell that we're not thinking clearly, and there's no obvious external cause. It happens. Keep yourself going for a full week, whatever it takes, and see if you still feel the same way then.
You've made it this far, and you will make it through. **You are stronger than you think.**

PDF available here: https://drive.google.com/file/d/0B6A2F5ky9SELU0Zfd05YMEpyNUk/view

DISTRESS TOLERANCE
Practice Exercise 2: Due Date_____
Self-Soothe

Write down at least 2 specific SELF-SOOTHE Skills to practice during the week when you feel upset:

SELF-SOOTHE WITH THE 6 SENSES:
VISION_____
HEARING_____
SMELL_____
TASTE_____
TOUCH_____
MOVEMENT_____

Briefly describe the stressful situations you were in when you chose to practice your skill:
1)_____

_____

2)_____

_____

Did using this skill help you to (1) cope with uncomfortable feelings and urges and/or (2) avoid conflict of any kind? Circle YES/NO

If YES, please describe how it helped: _____

_____

_____

If NO, please describe why you believe it did not help: _____

_____

If you did not practice this skill, please explain why: _____

_____

_____

A rose garden for suicide prevention

Most of the key elements of my rose garden vision for suicide prevention seem rather obvious to me, but they need to be stated because many of them fly in the face of the current thinking and practices of mainstream suicidology.

1. **Prohibit psychiatric violence – stop beating us up**
   Legally sanctioned psychiatric force is the primary source of the stigma against suicide and suicidal people. It also does not work as a suicide prevention strategy. On the contrary, psychiatric violence can make a suicidal crisis more severe and can even trigger suicidal feelings in someone who has previously never been suicidal. Real progress with suicide prevention cannot commence until the current reliance on psychiatric force is abolished.

2. **Demedicalise suicide**
   The second major obstacle to progress with suicide prevention is the inappropriate and excessive medicalisation of suicide. Suicide prevention requires a whole-of-person, whole-of-community, holistic approach, which is not well served by the current medical dominance of suicidology and suicide prevention.

3. **Rethinking suicide as a crisis of the self**
   Hand in hand with the demedicalising of suicide must come a rethinking of suicide in non-medical terms. The concept of psychache is useful here, but thinking about suicide as a crisis of the self is also proposed.

4. **Mentally healthy communities**
   The purpose of mental health policies and programmes needs to shift away from the treatment of mental illness (including so-called prevention

94

BIBLIOGRAPHY

Agamben, G. (1998). *Homo Sacer: Sovereign Power and Bare Life*. (D. Heller-Roazen, Trans.). Stanford, CA: Stanford University Press.

Alavi, S. S., Ferdosi, M., Jannatifard, F., Eslami, M., Alaghemandan, H., & Setare, M. (2012). Behavioral Addiction versus Substance Addiction: Correspondence of Psychiatric and Psychological Views. *International Journal of Preventive Medicine*, *3*(4), 290–294.

Alexander, M., & West, C. (2012). *The New Jim Crow: Mass Incarceration in the Age of Colorblindness*. New York, NY: The New Press.

Anderson, B. (2016). *Imagined Communities: Reflections on the Origin and Spread of Nationalism*. London: Verso.

Anderson, S. (1985). The Role of Staff at Fountain House. *The Fountain House Annual, 3*, 1-3. http://www.fountainhouse.org/sites/default/files/ftp/articles/the-fountain-house-annual-december1985.pdf

Anthony, W. A., & Blanch, A. (1987). Supported employment for persons who are psychiatrically disabled: An historical and conceptual perspective. *Psychosocial Rehabilitation Journal*, *11*(2), 5–23. https://doi.org/10.1037/h0099582

Anthony, W.A., & Lanoil, J. (1983) Editorial Tribute. *Psychosocial Rehabilitation Journal, 6*(4), 1.

Babad, E., Inbar, J., & Rosenthal, R. (1982). Pygmalion, Galatea, and the Golem: Investigations of biased and unbiased teachers. *Journal of Educational Psychology*, *74*, 459–474. https://doi.org/10.1037/0022-0663.74.4.459

Baker, L. D. (1998). *From Savage to Negro: Anthropology and the Construction of Race, 1896-1954*. Berkeley: University of California Press.

Baldwin, J. (1992). *The Fire Next Time*. New York, NY: Vintage.

Bean, B. R., & Beard, J. H. (1975). Placement for Persons with Psychiatric Disability. *Rehabilitation Counseling Bulletin*.

Beard, J. H., Malamud, T. J., & Rossman, E. (1978). Psychiatric Rehabilitation and Long-term Rehospitalization Rates: The Findings of Two Research Studies*. *Schizophrenia Bulletin*, *4*(4), 622–635. https://doi.org/10.1093/schbul/4.4.622

Beard, J. H., Schmidt, J. R., Smith, M. M., & Dincin, J. (1964). THREE ASPECTS OF PSYCHIATRIC REHABILITATION AT FOUNTAIN HOUSE. *Mental Hygiene*, *48*, 11–21.

Beard, J.H., Goertzel, V., & Pearce, A. J. (1958). The Effectiveness of Activity Group Therapy with Chronically Regressed Adult Schizophrenics. *International Journal of Group Psychotherapy*, *8*(2), 123–136. https://doi.org/10.1080/00207284.1958.11508807

Beard, J.H., Pitt, R. B., Fisher, S. H., & Goertzel, V. (1963). Evaluating the effectiveness of a psychiatric rehabilitation program. *American Journal of Orthopsychiatry*, *33*(4), 701–712. https://doi.org/10.1111/j.1939-0025.1963.tb01018.x

Beard, J.H., Propst, R.N., & Malamud, T.J. (1982). The Fountain House model of psychiatric rehabilitation. *Psychosocial Rehabilitation Journal, 5*(1), 4-53.

Beard-Eddy, M. (1983). In tribute to John H. Beard. *Psychosocial Rehabilitation Journal*, *6*(4), 3–6. https://doi.org/10.1037/h0099729

Beckett, S. (2011). *Waiting for Godot: A Tragicomedy in Two Acts*. New York, NY: Grove Press.

Behar, R. (1996). *The Vulnerable Observer: Anthropology That Breaks Your Heart*. Boston, MA: Beacon Press.

Bentall, R. P. (1992). A proposal to classify happiness as a psychiatric disorder. *Journal of Medical Ethics*, *18*(2), 94–98.

Berger, P. L., & Luckmann, T. (1967). *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. New York, NY: Anchor.

Bernard, H. R. (2011). *Research Methods in Anthropology: Qualitative and Quantitative Approaches* (5th edition). Lanham, MD: AltaMira Press.

Biegel, D. E., Pernice-Duca, F., Chang, C.-W., & D'Angelo, L. (2013). Correlates of peer support in a clubhouse setting. *Community Mental Health Journal*, *49*(3), 249–259. https://doi.org/10.1007/s10597-012-9502-5

Bourdieu, P. (1972). *Outline of a Theory of Practice*. (R. Nice, Trans.). Cambridge, UK: Cambridge University Press.

Brubaker, R. (2006). *Ethnicity Without Groups*. Cambridge, MA: Harvard University Press.

Burawoy, M. (1979). *Manufacturing Consent: Changes in the Labor Process Under Monopoly Capitalism*. Chicago, IL: The University of Chicago Press.

Butler, J. (1988). Performative Acts and Gender Constitution: An Essay in Phenomenology and Feminist Theory. *Theatre Journal*, *40*(4), 519–531. https://doi.org/10.2307/3207893

Cacioppo, J. T., & Hawkley, L. C. (2003). Social Isolation and Health, with an Emphasis on Underlying Mechanisms. *Perspectives in Biology and Medicine*, *46*(3), S39–S52. https://doi.org/10.1353/pbm.2003.0049

Calton, T., Ferriter, M., Huband, N., & Spandler, H. (2008). A Systematic Review of the Soteria Paradigm for the Treatment of People Diagnosed With Schizophrenia. *Schizophrenia Bulletin*, *34*(1), 181–192. https://doi.org/10.1093/schbul/sbm047

Canguilhem, G. (1991). *The Normal and the Pathological*. (C. R. Fawcett, Trans.). New York, NY: Zone Books.

Carolan, M., Onaga, E., Pernice-Duca, F., & Jimenez, T. (2011). A place to be: the role of clubhouses in facilitating social support. *Psychiatric Rehabilitation Journal*, *35*(2), 125–132. https://doi.org/10.2975/35.2.2011.125.132

Carr, E. H. (1967). *What Is History?* New York, NY: Vintage.

Carr, E. S. (2010). *Scripting Addiction: The Politics of Therapeutic Talk and American Sobriety*. Princeton, NJ: Princeton University Press.

Carsten, J. (2000). Introduction: Cultures of Relatedness. In J. Carsten (Ed.), *Cultures of Relatedness: New Approaches to the Study of Kinship* (pp. 1–36). Cambridge, UK: Cambridge University Press.

Chaikin, A., Sigler, E., & Derlega, V. (1974). Nonverbal mediators of teacher expectancy effects. *Journal of Personality and Social Psychology*, *30*, 144–149. https://doi.org/10.1037/h0036738

Chamberlin, J. (1978). *On Our Own: Patient Controlled Alternatives to the Mental Health System*. Haworth Press.

Chamberlin, J. (1990). The Ex-Patients' Movement: Where We've Been and Where We're Going." *Journal of Mind and Behavior*, *11*(3), 323–336.

Cho, S., Crenshaw, K. W., & McCall, L. (2013). Toward a Field of Intersectionality Studies: Theory, Applications, and Praxis. *Signs*, *38*(4), 785–810. https://doi.org/10.1086/669608

Clines, F.X. (1977, September 6) About New York: A Different Route on the Road Back. ProQuest Historical Newspapers: *The New York Times* with Index pg. 37.

Collins, P. H. (2000). *Black feminist thought: knowledge, consciousness, and the politics of empowerment /* (2nd edition). New York, NY: Routledge.

Coniglio, F. D., Hancock, N., & Ellis, L. A. (2012). Peer support within Clubhouse: a grounded theory study. *Community Mental Health Journal*, *48*(2), 153–160. https://doi.org/10.1007/s10597-010-9358-5

Corey, M. S., Corey, G., & Corey, C. (2010). *Groups Process and Practice* (8th edition). Belmont, CA: Brooks/Cole.

Corin, E. (2010). The Thickness of Being: Intentional Worlds, Strategies of Identity, and Experience Among Schizophrenics. In B. J. Good, M. M. J. Fischer, S. S. Willen, & M.-J. D. Good (Eds.), *A

Reader in Medical Anthropology: Theoretical Trajectories, Emergent Realities (pp. 108–120). Malden, MA: Wiley-Blackwell.

Corrigan, P. W., & Rao, D. (2012). On the Self-Stigma of Mental Illness: Stages, Disclosure, and Strategies for Change. *Canadian Journal of Psychiatry. Revue Canadienne de Psychiatrie*, *57*(8), 464–469.

Davidson, L. (2003). *Living Outside Mental Illness: Qualitative Studies of Recovery in Schizophrenia*. New York, NY: NYU Press.

Davis, L. J. (2013a). Introduction: Disability, Normality, and Power. In L. J. Davis (Ed.), *The Disability Studies Reader* (4th edition, pp. 1–16). New York, NY: Routledge.

Davis, L. J. (2013b). The End of Identity Politics: On Disability as an Unstable Category. In L. J. Davis (Ed.), *The Disability Studies Reader* (4th edition, pp. 263–277). New York, NY: Routledge.

Dawson, S., & Surpin, R. (2001). Direct-Care Healthcare Workers: You Get What You Pay For. *Generations*, *25*(1), 23–28.

Delp, L., Wallace, S. P., Geiger-Brown, J., & Muntaner, C. (2010). Job Stress and Job Satisfaction: Home Care Workers in a Consumer-Directed Model of Care. *Health Services Research*, *45*(4), 922–940. https://doi.org/10.1111/j.1475-6773.2010.01112.x

Derrida, J. (1983). *Dissemination*. (B. Johnson, Trans.). Chicago, IL: University of Chicago Press.

Desjarlais, R. (1999). The Makings of Personhood in a Shelter for People Considered Homeless and Mentally Ill. *Ethos*, *27*(4), 466–489.

Desjarlais, R. R. (1997). *Shelter Blues: Sanity and Selfhood Among the Homeless*. Philadelphia, PA: University of Pennsylvania Press.

Desjarlais, R. R. (2010). Struggling Along: the Possibilities for Experience among the Homeless Mentally Ill. In B. J. Good, M. M. J. Fischer, S. S. Willen, & M.-J. D. Good (Eds.), *A Reader in Medical Anthropology: Theoretical Trajectories, Emergent Realities* (pp. 160–174). Malden, MA: Wiley-Blackwell.

Dincin, J. (1965). Utilization of Professional Staff in Psychiatric Rehabilitation. *Social Work*, *10*(1), 51–57.

Doyle, A. (2013). Creating Community: Changing The World of Mental Health. Plenary Presentation at Clubhouse International Seminar, October 19-24, 2013.

Doyle, A., Lanoil, J., & Dudek, K. (2013). *Fountain House: Creating Community in Mental Health Practice*. New York, NY: Columbia University Press.

Dumit, J. (2012). *Drugs for Life: How Pharmaceutical Companies Define Our Health*. Durham, NC: Duke University Press Books.

Durkheim, É., & Halls, W. D. (1984). *The Division of Labour in Society*. New York, NY: The Free Press.

Ellis, C. (2007). Telling Secrets, Revealing Lives: Relational Ethics in Research With Intimate Others. *Qualitative Inquiry*, *13*(1), 3–29. https://doi.org/10.1177/1077800406294947

Ellis, C., Adams, T. E., & Bochner, A. P. (2011). Autoethnography: An Overview. *Forum: Qualitative Social Research*, *12*(1). Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/1589

Ellis, C., & Patti, C. (2014). With Heart Compassionate Interviewing and Storytelling with Holocaust Survivors. *Storytelling Self Society An Interdisciplinary Journal of Storytelling Studies*, *10*, 389–414. https://doi.org/10.13110/storselfsoci.10.1.0093

Ensler, E. (2014). *In the Body of the World: A Memoir of Cancer and Connection*. Picador.

Ernst, W. (Ed.). (2016). *Work, psychiatry and society, c. 1750-2015*. Manchester: Manchester University Press.

Essen, C. (2012). Does individual placement and support really "reflect client goals"? *Journal of Psychiatric and Mental Health Nursing*, *19*(3), 231–240. https://doi.org/10.1111/j.1365-2850.2011.01769.x

Estés, C. P. (1996). *Women Who Run with the Wolves: Myths and Stories of the Wild Woman Archetype*. New York, NY: Ballantine Books.

Estroff, S. E. (1981). *Making it Crazy: Ethnography of Psychiatric Clients in an American Community*. Berkeley, CA: University of California Press.

Estroff, S. E. (1993). Identity, Disability, and Schizophrenia: the Problem of Chronicity. In S. Lindenbaum & M. M. Lock (Eds.), *Knowledge, Power, and Practice: The Anthropology of Medicine and Everyday Life* (pp. 108–128). Berkeley, CA: University of California Press.

Fairweather, G. W., Sanders, D. H., Cressler, D. L., & Maynard, H. (2008). *Community Life for the Mentally Ill: An Alternative to Institutional Care*. New Brunswick, NJ: Routledge.

Farmer, P. (1996). On Suffering and Structural Violence: A View from Below. *Daedalus*, *125*(1), 261–283.

Farmer, P. (2004). An Anthropology of Structural Violence. *Current Anthropology*, *45*(3), 305–325. https://doi.org/10.1086/382250

Filson, B. (2016). The haunting can end: trauma-informed approaches in healing from abuse and adversity. In J. Russo & A. Sweeney (Eds.), *Searching for a Rose Garden: Challenging Psychiatry, Fostering Mad Studies* (pp. 20–24). PCCS Books.

Fisher, S. H., Beard, J. H., & Goertzel, V. (1960). Rehabilitation of the Mental Hospital Patient: the Fountain House Programme*. *International Journal of Social Psychiatry*, *5*(4), 295–298. https://doi.org/10.1177/002076406000500405

Foucault, M. (1988). *Madness and Civilization: A History of Insanity in the Age of Reason*. New York, NY: Vintage.

Foucault, M. (1990). *The History of Sexuality, Vol. 1: An Introduction*. New York, NY: Vintage.

Foucault, M. (1994). *The Birth of the Clinic: An Archaeology of Medical Perception*. New York, NY: Vintage.

Foucault, M. (1995). *Discipline & Punish: The Birth of the Prison*. (A. Sheridan, Trans.). New York, NY: Vintage Books.

Foucault, M. (2011). *Madness: The Invention of an Idea*. New York, NY: Harper Perennial.

Frankl, V. E. (1984). *Man's search for meaning: an introduction to logotherapy*. Pocket Books.

Frederick, S., & Loewenstein, G. (2003). Hedonic Adaptation. In D. Kahneman, E. Diener, & N. Schwarz (Eds.), *Well-Being: Foundations of Hedonic Psychology*. New York, NY: Russell Sage Foundation.

Fredrickson, B. (2013). *Love 2.0: Finding Happiness and Health in Moments of Connection*. New York, NY: Plume.

Gibran, K. (1923). *The Prophet*. New York, NY: Alfred A. Knopf.

Gilgun, J. F. (2012). *On Being a Shit: Unkind Deeds & Cover-Ups in Everyday Life*. CreateSpace Independent Publishing Platform.

Ginsburg, F., & Rapp, R. (2013a). Disability worlds. *Annual Review of Anthropology*, *42*, 53–68. https://doi.org/10.1146/annurev-anthro-092412-155502

Ginsburg, F., & Rapp, R. (2013b). Enabling Disability: Rewriting Kinship, Reimagining Citizenship. In L. J. Davis (Ed.), *The Disability Studies Reader* (4th edition, pp. 185–201). New York, NY: Routledge.

Glickman, M. (1992). What if nobody wants to make lunch? Bottom line responsibility in the Clubhouse. Adapted from paper presented at 5th International Clubhouse Seminar, St Louis, MO. http://www.fountainhouse.org/sites/default/files/Glickman%20-what%20if%20nobody%20wants%20to%20make%20lunch.pdf

Glickman, M. (2012). Personal Accounts: My Recovery: A Long, Winding Yellow Brick Road. *Psychiatric Services*, *63*(12), 1169–1170. https://doi.org/10.1176/appi.ps.631201

Glickman, M., & Flannery, M. (1996). *Fountain House: Portraits of Lives Reclaimed from Mental Illness*. Center City, MN: Hazelden.

Goertzel, V., Beard, J. H., & Pilnick, S. (1960). Fountain House Foundation: Case Study Of An Expatient's Club. *Journal of Social Issues*, *16*(2), 54–61. https://doi.org/10.1111/j.1540-4560.1960.tb00949.x

Goffman, E. (1961). *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. New York, NY: Anchor Books.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Upper Saddle River, NJ: Prentice Hall.

Goodley, D. (2016). *Disability Studies: An Interdisciplinary Introduction* (2nd edition). London, UK: SAGE Publications Ltd.

Gorman, R. (2013). Mad Nation? Thinking through Race, Class, and Mad Identity Politics. In B. A. LeFrançois, R. Menzies, & G. Reaume (Eds.), *Mad Matters: A Critical Reader in Canadian Mad Studies* (pp. 269–280). Toronto: Canadian Scholars' Press Inc.

Graeber, D. (2012). *Debt: The First 5,000 Years*. New York, NY: Melville House.

Gray, J. A., & Muramatsu, N. (2013). When the job has lost its appeal: Intentions to quit among direct care workers. *Journal of Intellectual & Developmental Disability*, *38*(2), 124–133. https://doi.org/10.3109/13668250.2012.760728

Gray, M. (2011). Back to Basics: A Critique of the Strengths Perspective in Social Work. *Families in Society: The Journal of Contemporary Social Services*, *92*(1), 5–11. https://doi.org/10.1606/1044-3894.4054

Hacking, I. (1999). *The Social Construction of What?* Cambridge, MA: Harvard University Press.

Harris, R., & PhD, S. C. H. (2008). *The Happiness Trap: How to Stop Struggling and Start Living: A Guide to ACT*. Boston, MA: Trumpeter.

Harrison, E. (1960, July 10). Mental Patients Guided Into Jobs: Social Agency Places Them – Employers Are Pleased With their Work. ProQuest Historical Newspapers: *The New York Times* with Index pg 61.

Harvey, D. (2007). *A Brief History of Neoliberalism*. Oxford: Oxford University Press.

Harvey, D. (2015). *Seventeen Contradictions and the End of Capitalism*. Oxford: Oxford University Press.

Haviland, W. A., Prins, H. E. L., McBride, B., & Walrath, D. (2013). *Cultural Anthropology: The Human Challenge* (14th edition). Wadsworth Publishing.

Hawkley, L. C., & Cacioppo, J. T. (2010). Loneliness matters: a theoretical and empirical review of consequences and mechanisms. *Annals of Behavioral Medicine: A Publication of the Society of Behavioral Medicine*, *40*(2), 218–227. https://doi.org/10.1007/s12160-010-9210-8

Hock, R. R. (2004). *Forty Studies that Changed Psychology: Explorations into the History of Psychological Research* (5th edition). Upper Saddle River, NJ: Prentice Hall.

Hofstede, G. (1984). The Cultural Relativity of the Quality of Life Concept. *The Academy of Management Review*, *9*(3), 389–398. https://doi.org/10.2307/258280

Hollingshead, A. B., & Redlich, F. (1958). *Social Class and Mental Illness: A Community Study*. John Wiley & Sons.

Holt-Lunstad, J. (2018). The Potential Public Health Relevance of Social Isolation and Loneliness: Prevalence, Epidemiology, and Risk Factors. *Public Policy & Aging Report*, *27*(4), 127–130. https://doi.org/10.1093/ppar/prx030

Holy, L. (1996). *Anthropological Perspectives on Kinship*. London, UK: Pluto Press.

Howell, S. (2006). *The Kinning of Foreigners: Transnational Adoption in a Global Perspective*. New York, NY: Berghahn Books.

Hudson, C. G. (2005). Socioeconomic status and mental illness: tests of the social causation and selection hypotheses. *The American Journal of Orthopsychiatry*, *75*(1), 3–18. https://doi.org/10.1037/0002-9432.75.1.3

Ingram, R. A. (2016). Doing Mad Studies: Making (Non)sense Together. *Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice*, *5*(3), 11–17.

Jacobsen, K. (2017). Songwriting as Ethnographic Practice: How Stories Humanize. In M. Cahnmann-Taylor & R. Siegesmund (Eds.), *Arts-Based Research in Education: Foundations for Practice* (2nd edition, pp. 115–127). Routledge.

Jago, B. J. (2002). Chronicling an Academic Depression. *Journal of Contemporary Ethnography*, *31*(6), 729–757. https://doi.org/10.1177/089124102237823

Jamison, K. R. (1997). *An Unquiet Mind: A Memoir of Moods and Madness*. New York, NY: Vintage.

Johnson, H. M. (2013). Unspeakable Conversations. In L. J. Davis (Ed.), *The Disability Studies Reader* (4th edition, pp. 507–519). New York, NY: Routledge.

Keller, E. F. (2010). *The Mirage of a Space between Nature and Nurture*. Durham, NC: Duke University Press Books.

Kiesinger, C. (2002). My father's shoes: The therapeutic value of narrative reframing. In A. P. Bochner & C. Ellis (Eds.), *Ethnographically Speaking: Autoethnography, Literature, and Aesthetics* (pp. 95–114). Walnut Creek, CA: AltaMira Press.

Kim, J. S. (2013). Strengths Perspective. *Encyclopedia of Social Work*. https://doi.org/10.1093/acrefore/9780199975839.013.382

Kirk, S., & Reid, W. (2002). *Science and Social Work*. New York, NY: Columbia University Press.

Kleinman, A. (1991). *Rethinking Psychiatry: From Cultural Category to Personal Experience*. New York, NY: Free Press.

Kleinman, A., Das, V., & Lock, M. M. (1997). Introduction. In A. Kleinman, V. Das, & M. M. Lock (Eds.), *Social Suffering* (pp. ix–xxv). Berkeley, CA: University of California Press.

Kuzawa, C. W., & Fried, R. (2017). Intergenerational Memories of Past Nutritional Deprivation: The Phenotypic Inertia Model. In G. Jasienska, D. S. Sherry, & D. J. Holmes (Eds.), *The Arc of Life: Evolution and Health Across the Life Course* (pp. 7–20). New York, NY: Springer-Verlag.

Laing, R. D. (1967). *The Politics of Experience*. Pantheon Books.

Laing, R.D. (1969). *The Politics of the Family, and Other Essays*. London, UK: Tavistock Publications Ltd.

Layton, L. (2014). Some psychic effects of neoliberalism: Narcissism, disavowal, perversion. *Psychoanalysis, Culture & Society*, *19*(2), 161–178. https://doi.org/10.1057/pcs.2014.5

Le Guin, U. K. (2017). *No Time to Spare: Thinking about what Matters*. New York, NY: Houghton Mifflin Harcourt.

Lewis, B. (2013). A Mad Fight: Psychiatry and Disability Activism. In L. J. Davis (Ed.), *The Disability Studies Reader* (4th edition, pp. 115–131). New York, NY: Routledge.

Lieberman, M. D. (2014). *Social: Why Our Brains Are Wired to Connect*. New York, NY: Broadway Books.

Liegghio, M. (2013). A Denial of Being: Psychiatrization as Epistemic Violence. In B. A. LeFrançois, R. Menzies, & G. Reaume (Eds.), *Mad Matters: A Critical Reader in Canadian Mad Studies* (pp. 122–129). Toronto: Canadian Scholars' Press Inc.

Lorde, A. (2017). *A Burst of Light: and Other Essays*. Mineola, NY: Ixia Press.

Lucas, R. E. (2007). Adaptation and the Set-Point Model of Subjective Well-Being: Does Happiness Change After Major Life Events? *Current Directions in Psychological Science*, *16*(2), 75–79. https://doi.org/10.1111/j.1467-8721.2007.00479.x

Luhrmann, T. M. (2001). *Of Two Minds: An Anthropologist Looks at American Psychiatry*. New York, NY: Vintage.

Lynch, C. (2012). *Retirement on the Line: Age, Work, and Value in an American Factory* (1 edition). Ithaca, NY: ILR Press.

Maglajlic, R. A. (2016). Co-creating the ways we carry each other: reflections on being an ally and a double agent. In J. Russo & A. Sweeney (Eds.), *Searching for a Rose Garden: Challenging Psychiatry, Fostering Mad Studies* (pp. 210–220). PCCS Books.

Mandiberg, J., & Edwards, M. (2013). Collective Identity Formation in the Mental Health Clubhouse Community. *International Journal of Self Help and Self Care*, *7*, 19–39. https://doi.org/10.2190/SH.7.1.c

Marquez, G. G. (2007). *Love in the Time of Cholera*. (E. Grossman, Trans.). Vintage.

Martin, E. (2006). Pharmaceutical virtue. *Culture, Medicine and Psychiatry*, *30*(2), 157–174. https://doi.org/10.1007/s11013-006-9014-2

Martin, E. (2009). *Bipolar Expeditions: Mania and Depression in American Culture*. Princeton, NJ: Princeton University Press.

Marx, K., & Engels, F. (1978). *The Marx-Engels Reader*. (R. C. Tucker, Ed.) (2nd Revised). New York, NY: W. W. Norton & Company.

Maslow, A. H. (1943). A theory of human motivation. *Psychological Review*, *50*(4), 370–396. https://doi.org/10.1037/h0054346

Masso, J. D., Avi-Itzhak, T., & Obler, D. R. (2001). The clubhouse model: An outcome study on attendance, work attainment and status, and hospitalization recidivism. *Work*, *17*(1), 23–30.

McKay, C., Johnsen, M., & Stein, R. (2005). Employment outcomes in Massachusetts Clubhouses. *Psychiatric Rehabilitation Journal*, *29*(1), 25–33.

McKay, C., Nugent, K. L., Johnsen, M., Eaton, W. W., & Lidz, C. W. (2016). A Systematic Review of Evidence for the Clubhouse Model of Psychosocial Rehabilitation. *Administration and Policy in Mental Health and Mental Health Services Research*, *45*(1), 28–47. https://doi.org/10.1007/s10488-016-0760-3

McKinley, R. (2001). The Philosophy of Kinship: A Reply to Schneider's Critique of the Study of Kinship. In R. Feinberg & M. Ottenheimer (Eds.), *The Cultural Analysis of Kinship: The Legacy of David M. Schneider* (pp. 131–167). Urbana: University of Illinois Press.

Menzies, R., LeFrançois, B. A., & Reaume, G. (2013). Introducing Mad Studies. In B. A. LeFrançois, R. Menzies, & G. Reaume (Eds.), *Mad Matters: A Critical Reader in Canadian Mad Studies* (pp. 1–22). Toronto: Canadian Scholars' Press Inc.

Metzl, J. (2011). *The Protest Psychosis: How Schizophrenia Became a Black Disease*. Boston, MA: Beacon Press.

Mol, A. (2008). *The Logic of Care: Health and the Problem of Patient Choice*. New York, NY: Routledge.

Mosher, L. R. (1999). Soteria and other alternatives to acute psychiatric hospitalization: a personal and professional review. *The Journal of Nervous and Mental Disease*, *187*(3), 142–149.

Mullen, E. J., & Streiner, D. L. (2004). The Evidence For and Against Evidence-Based Practice. *Brief Treatment and Crisis Intervention*, *4*(2), 111–121. https://doi.org/10.1093/brief-treatment/mhh009

Murali, V., & Oyebode, F. (2004). Poverty, social inequality and mental health. *Advances in Psychiatric Treatment*, *10*(3), 216–224. https://doi.org/10.1192/apt.10.3.216

Murphy, R. F. (1990). *The Body Silent: The Different World of the Disabled*. New York, NY: W.W. Norton & Company.

Mushtaq, R., Shoib, S., Shah, T., & Mushtaq, S. (2014). Relationship Between Loneliness, Psychiatric Disorders and Physical Health ? A Review on the Psychological Aspects of Loneliness. *Journal of Clinical and Diagnostic Research : JCDR*, *8*(9), WE01–WE04. https://doi.org/10.7860/JCDR/2014/10077.4828

Nader, L. (1969). Up the anthropologist - perspectives gained from studying up. In D. H. Hymes (Ed.), *Reinventing anthropology* (pp. 284–311). New York: Pantheon Books.

Nakamura, K. (2013). *A Disability of the Soul: An Ethnography of Schizophrenia and Mental Illness in Contemporary Japan*. Ithaca, NY: Cornell University Press.

Narvaez, J. M., Twamley, E. W., McKibbin, C. L., Heaton, R. K., & Patterson, T. L. (2008). Subjective and objective quality of life in schizophrenia. *Schizophrenia Research*, *98*(1–3), 201–208. https://doi.org/10.1016/j.schres.2007.09.001

New York Times (1955, December 8). Heads Fountain House Unit. ProQuest Historical Newspapers: *The New York Times* with Index pg. 13.

New York Times (1959, October 30). Fountain House To Be Assisted At Party Jan. 14: Showing of 'Sound of Music' will benefit rehabilitation unit. ProQuest Historical Newspapers: The New York Times with Index pg. 30.

New York Times (1965, April 25). Fete Champetre May 4 to Benefit Fountain House. ProQuest Historical Newspapers: The New York Times with Index pg. 109.

New York Times (1966, April 8). Fountain House Will Benefit From Fete Champetre May 3. ProQuest Historical Newspapers: The New York Times with Index pg. 34.

Nietzsche, F. (1990). *The Twilight of the Idols and the Anti-Christ: or How to Philosophize with a Hammer*. (M. Tanner, Ed., R. J. Hollingdale, Trans.). New York, NY: Penguin Classics.

Nisbett, R. E. (2004). *The Geography of Thought: How Asians and Westerners Think Differently...and Why*. New York, NY: Free Press.

O'Hagan, M. (2016). Responses to a legacy of harm. In J. Russo & A. Sweeney (Eds.), *Searching for a Rose Garden: Challenging Psychiatry, Fostering Mad Studies* (pp. 9–13). PCCS Books.

O'Neill, B. (2017). *The Space of Boredom: Homelessness in the Slowing Global Order*. Durham, NC: Duke University Press.

Padgett, D. K. (2008). *Qualitative Methods in Social Work Research* (2nd edition). Los Angeles, CA: SAGE Publications, Inc.

Park, Y. (2008). Facilitating Injustice: Tracing the Role of Social Workers in the World War II Internment of Japanese Americans. *Social Service Review*, *82*(3), 447–483. https://doi.org/10.1086/592361

Parsons, T. (1951). *The Social System*. Routledge & Kegan Paul.

Patel, V. (2003). *Where There Is No Psychiatrist: A Mental Health Care Manual*. London, UK: RCPsych Publications.

Patel, V., Weiss, H. A., Chowdhary, N., Naik, S., Pednekar, S., Chatterjee, S., … Kirkwood, B. R. (2011). Lay health worker led intervention for depressive and anxiety disorders in India: impact on clinical and disability outcomes over 12 months. *The British Journal of Psychiatry: The Journal of Mental Science*, *199*(6), 459–466. https://doi.org/10.1192/bjp.bp.111.092155

Peckhoff, J. (1989). Patienthood to Personhood. Paper presented at 5th International Clubhouse Seminar, St Louis, MO. https://www.fountainhouse.org/sites/default/files/ftp/articles/patienthood-to-personhood.pdf

Pembroke, L. R. (1996). *Self-harm : perspectives from personal experience* (Rev). London, UK: Chipmunka Pub.

Penney, D., & Prescott, L. (2016). The co-optation of survivor knowledge: the danger of substituted values and voices. In J. Russo & A. Sweeney (Eds.), *Searching for a Rose Garden: Challenging Psychiatry, Fostering Mad Studies* (pp. 35–47). PCCS Books.

Pernice, F., & ONAGA, E. (2009). Examining the Contribution of Social Network Support to the Recovery Process Among Clubhouse Members. *American Journal of Psychiatric Rehabilitation*, *12*, 1–30. https://doi.org/10.1080/15487760802615566

Poole, J., M., & Ward, J. (2013). "Breaking Open the Bone": Storying, Sanism, and Mad Grief. In B. A. LeFrançois, R. Menzies, & G. Reaume (Eds.), *Mad Matters: A Critical Reader in Canadian Mad Studies* (pp. 94–104). Toronto: Canadian Scholars' Press Inc.

Post, L., Page, C., Conner, T., Prokhorov, A., Fang, Y., & Biroscak, B. J. (2010). Elder Abuse in Long-Term Care: Types, Patterns, and Risk Factors. *Research on Aging*, *32*(3), 323–348. https://doi.org/10.1177/0164027509357705

Price, M. (2013). Defining Mental Disability. In L. J. Davis (Ed.), *The Disability Studies Reader* (4th edition, pp. 298–307). New York, NY: Routledge.

Rabinow, P. (1996). Artificiality and Enlightenment: From Sociobiology to Biosociality. In *Essays on the Anthropology of Reason* (pp. 91–111). Princeton, N.J: Princeton University Press.

Ramsey-Klawsnik, H., Teaster, P. B., Mendiondo, M. S., Abner, E. L., Cecil, K. A., & Tooms, M. R. (2007). Sexual Abuse of Vulnerable Adults in Care Facilities: Clinical Findings and a Research Initiative. *Journal of the American Psychiatric Nurses Association*, *12*(6), 332–339. https://doi.org/10.1177/1078390306298576

Reisch, M., & Andrews, J. (2002). *The Road Not Taken: A History of Radical Social Work in the United States*. New York, NY: Routledge.

Rhodes, L. A. (2004). *Total Confinement: Madness and Reason in the Maximum Security Prison*. Berkeley, CA: University of California Press.

Rhodes, L. A. (2010). Dreaming of Psychiatric Citizenship: A Case Study of Supermax Confinement. In B. J. Good, M. M. J. Fischer, S. S. Willen, & M.-J. D. Good (Eds.), *A Reader in Medical Anthropology: Theoretical Trajectories, Emergent Realities* (pp. 181–198). Malden, MA: Wiley-Blackwell.

Rilke, R. M. (1997). *Rilke's Book of Hours: Love Poems to God*. (A. Barrows & J. Macy, Trans.). New York, NY: Riverhead Books.

Rist, R. (2000). Student Social Class and Teacher Expectations: The Self-Fulfilling Prophecy in Ghetto Education. *Harvard Educational Review*, *70*(3), 257–302. https://doi.org/10.17763/haer.70.3.1k0624l6102u2725

Robbins, J. (2013). Beyond the suffering subject: toward an anthropology of the good. *Journal of the Royal Anthropological Institute*, *19*(3), 447–462. https://doi.org/10.1111/1467-9655.12044

Roosens, E., & van de Walle, L. (2007). *Geel Revisited: After Centuries of Mental Rehabilitation*. Garant.

Roper, C. (2016). Is partnership a dirty word? In J. Russo & A. Sweeney (Eds.), *Searching for a Rose Garden: Challenging Psychiatry, Fostering Mad Studies* (pp. 201–209). PCCS Books.

Rosaldo, R. (2013). *The Day of Shelly's Death: The Poetry and Ethnography of Grief*. Durham, NC: Duke University Press Books.

Rose, N. (2006). *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century*. Princeton, NJ: Princeton University Press.

Rosenhan, D. L. (1973). On Being Sane in Insane Places. *Science*, *179*(4070), 250–258. https://doi.org/10.1126/science.179.4070.250

Rosenthal, R., & Jacobson, L. (1966). Teachers' expectancies: determinants of pupils' IQ gains. *Psychological Reports*, *19*(1), 115–118. https://doi.org/10.2466/pr0.1966.19.1.115

Rosenthal, R. (2002). Covert communication in classrooms, clinics, courtrooms, and cubicles. *The American Psychologist*, *57*(11), 839–849.

Rosenthal, R. & Fode, K. (2007). The Effect of Experimenter Bias on the Performance of the Albino Rat. *Behavioral Science*, *8*, 183–189. https://doi.org/10.1002/bs.3830080302

Royce, J. (1995). *The Philosophy of Loyalty*. (J. J. McDermott, Ed.). Nashville, TN: Vanderbilt University Press.

Runswick-Cole, K., Lawthom, R., & Goodley, D. (2016). The trouble with 'hard working families.' *Community, Work & Family*, *19*(2), 257–260. https://doi.org/10.1080/13668803.2016.1134153

Sahlins, M. (2005). Cosmologies of Capitalism: The Trans-Pacific Sector of "The World System." In *Culture in Practice: Selected Essays* (2nd edition). New York: Zone Books.

Sahlins, M. (2013). *What Kinship Is-And Is Not*. Chicago, IL: University of Chicago Press.

Saleebey, D. (1996). The strengths perspective in social work practice: extensions and cautions. *Social Work*, *41*(3), 296–305.

Saleebey, D. (1992). *The Strengths perspective in social work practice*. New York, NY: Longman.

Sapolsky, R. M. (1998). *Why Zebras Don't Get Ulcers: An Updated Guide to Stress, Stress Related Diseases, and Coping* (2nd edition). New York, NY: W. H. Freeman.

Sapolsky, R. M., & Share, L. J. (2004). A Pacific Culture among Wild Baboons: Its Emergence and Transmission. *PLOS Biology*, *2*(4), e106. https://doi.org/10.1371/journal.pbio.0020106

Sayce, L. (2000). *From Psychiatric Patient To Citizen: Overcoming Discrimination and Social Exclusion*. Houndmills: Palgrave Macmillan.

Scheff, T. J. (1966). *Being Mentally Ill : A Sociological Theory*. Chicago, IL: Aldine de Gruyter.

Scheper-Hughes, N. (1987). "Mental" in "Southie": individual, family, and community responses to psychosis in South Boston. *Culture, Medicine and Psychiatry*, *11*(1), 53–78.

Schneider, D. M. (1980). *American Kinship: A Cultural Account* (2nd edition). Chicago, IL: University of Chicago Press.

Schonebaum, A., & Boyd, J. (2012). Work-ordered day as a catalyst of competitive employment success. *Psychiatric Rehabilitation Journal*, *35*(5), 391–395. https://doi.org/10.1037/h0094499

Schwartz, J. P., & Waldo, M. (1999). Therapeutic factors in spouse-abuse group treatment. *The Journal for Specialists in Group Work*, *24*(2), 197–207. https://doi.org/10.1080/01933929908411430

Schwartz, T. L., Nihalani, N., Jindal, S., Virk, S., & Jones, N. (2004). Psychiatric medication-induced obesity: a review. *Obesity Reviews: An Official Journal of the International Association for the Study of Obesity*, *5*(2), 115–121. https://doi.org/10.1111/j.1467-789X.2004.00139.x

Scott, J. C. (1987). *Weapons of the Weak: Everyday Forms of Peasant Resistance*. New Haven, CT: Yale University Press.

Scott, J. C. (2014). *Two Cheers for Anarchism: Six Easy Pieces on Autonomy, Dignity, and Meaningful Work and Play*. Princeton, NJ: Princeton University Press.

Shakespeare, T. (2013). The Social Model of Disability. In L. J. Davis (Ed.), *The Disability Studies Reader* (4th edition, pp. 214–221). New York, NY: Routledge.

Shaw, C. (2016). Deciding to be alive: self-injury and survival. In J. Russo & A. Sweeney (Eds.), *Searching for a Rose Garden: Challenging Psychiatry, Fostering Mad Studies* (pp. 77–85). PCCS Books.

Shorter, E. (1997). *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac*. New York, NY: Wiley.

Shrivastava, A., & Johnston, M. E. (2010). Weight-Gain in Psychiatric Treatment: Risks, Implications, and Strategies for Prevention and Management. *Mens Sana Monographs*, *8*(1), 53–68. https://doi.org/10.4103/0973-1229.58819

Singla, D. R., Kohrt, B. A., Murray, L. K., Anand, A., Chorpita, B. F., & Patel, V. (2017). Psychological Treatments for the World: Lessons from Low- and Middle-Income Countries. *Annual Review of Clinical Psychology*, *13*, 149–181. https://doi.org/10.1146/annurev-clinpsy-032816-045217

Smith, B. (1999). The Abyss: Exploring Depression Through a Narrative of the Self. *Qualitative Inquiry*, *5*(2), 264–279. https://doi.org/10.1177/107780049900500206

Sperber, D., & Hirschfeld, L. A. (2004). The cognitive foundations of cultural stability and diversity. *Trends in Cognitive Sciences*, *8*(1), 40–46.

Staller, K. M. (2006). Railroads, Runaways, & Researchers: Returning Evidence Rhetoric to Its Practice Base. *Qualitative Inquiry*, *12*(3), 503–522. https://doi.org/10.1177/1077800406286524

Staller, K. M. (2013). Epistemological boot camp: The politics of science and what every qualitative researcher needs to know to survive in the academy. *Qualitative Social Work*, *12*(4), 395–413. https://doi.org/10.1177/1473325012450483

Staples, L., & Stein, R. (2008). The clubhouse model: Mental health consumer–provider partnerships for recovery. In M. Goldner & S. M. Chambré (Eds.), *Patients, Consumers and Civil Society* (Vol. 10, pp. 177–196). Bingley, UK: Emerald Group Publishing Limited.

Strayed, C. (2012). *Tiny Beautiful Things: Advice on Love and Life from Dear Sugar*. New York, NY: Vintage.

Strecher, V. J. (2016). *Life on Purpose: How Living for What Matters Most Changes Everything*. New York, NY: HarperOne.

Sweeney, A. (2016). The transformative potential of survivor research. In J. Russo & A. Sweeney (Eds.), *Searching for a Rose Garden: Challenging Psychiatry, Fostering Mad Studies* (pp. 49–58). PCCS Books.

Szasz, T. S. (1960). The myth of mental illness. *American Psychologist*, *15*(2), 113–118.

Tappan, M. (2006). Reframing Internalized Oppression and Internalized Domination: From the Psychological to the Sociocultural. *Teachers College Record*, *108*, 2115–2144. https://doi.org/10.1111/j.1467-9620.2006.00776.x

Taussig, M. T. (2010). *The Devil and Commodity Fetishism in South America* (2nd edition). Chapel Hill, NC: The University of North Carolina Press.

Thompson, E. P. (1966). *The Making of the English Working Class*. New York, NY: Vintage.

Tillman-Healy, L. M. (1996). A secret life in a culture of thinness: Reflections on body, food and bulimia. In C. E. U. of S. Florida & A. P. Bochner (Eds.), *Composing Ethnography: Alternative Forms of Qualitative Writing* (pp. 76–108). Walnut Creek, CA: AltaMira Press.

Vanheule, S., & Devisch, I. (2014). Mental suffering and the DSM-5: a critical review. *Journal of Evaluation in Clinical Practice*, *20*(6), 975–980. https://doi.org/10.1111/jep.12163

Vorspan, R. (1999). Clubhouse relationships need work! Paper presented at 10th International Clubhouse Seminar, Toronto. https://www.fountainhouse.org/sites/default/files/ftp/articles/clubhouse-relations-need-work.pdf

Warner, R., Huxley, P., & Berg, T. (1999). An evaluation of the impact of clubhouse membership on quality of life and treatment utilization. *The International Journal of Social Psychiatry*, *45*(4), 310–320. https://doi.org/10.1177/002076409904500410

Webb, D. (2016). Thinking (differently) about suicide. In J. Russo & A. Sweeney (Eds.), *Searching for a Rose Garden: Challenging Psychiatry, Fostering Mad Studies* (pp. 86–96). PCCS Books.

Weber, M. (2002). *The Protestant ethic and the "spirit" of capitalism and other writings*. (W. P. Baehr & G. C. Wells, Trans.). London, UK: Penguin. Retrieved from https://works.bepress.com/pbaehr/67/

Weick, A., Rapp, C., Sullivan, W. P., & Kisthardt, W. (1989). A Strengths Perspective for Social Work Practice. *Social Work*, *34*(4), 350–354.

Weston, K. (1997). *Families We Choose: Lesbians, Gays, Kinship*. New York, NY: Columbia University Press.

Whitaker, R. (2010a). *Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America*. New York, NY: Crown Publishers.

Whitaker, R. (2010b). *Mad in America: Bad Science, Bad Medicine, and the Enduring Mistreatment of the Mentally Ill* (2nd edition). New York, NY: Basic Books.

Williams, R. (1976). *Keywords: A Vocabulary of Culture and Society*. London, UK: Croom Helm.

Wilson, A. (2007). *The Science Behind the magic*. Keynote address at Michigan Clubhouse Conference (unpublished – I received this material through my training).

Wolf, E. R., & Eriksen, T. H. (2010). *Europe and the People Without History* (2nd edition). Berkeley, CA: University of California Press.

Yakas, L. (2017). "Work is Love Made Visible": Purpose and Community in Clubhouses. *Disability Studies Quarterly*, *37*(4). https://doi.org/10.18061/dsq.v37i4.6096

Yanagisako, S. J. (2002). *Producing Culture and Capital: Family Firms in Italy*. Princeton, NJ: Princeton University Press.

Yanos, P. T., Roe, D., & Lysaker, P. H. (2010). The Impact of Illness Identity on Recovery from Severe Mental Illness. *American Journal of Psychiatric Rehabilitation*, *13*(2), 73–93. https://doi.org/10.1080/15487761003756860

Zhang, Z., Schiamberg, L. B., Oehmke, J., Barboza, G. E., Griffore, R. J., Post, L. A., … Mastin, T. (2011). Neglect of older adults in Michigan nursing homes. *Journal of Elder Abuse & Neglect*, *23*(1), 58–74. https://doi.org/10.1080/08946566.2011.534708

Zinn, H. (2002). *You Can't Be Neutral on a Moving Train: A Personal History of Our Times*. Boston, MA: Beacon Press.