

# Dangerous Gifts: Towards a New Wave of Mad Resistance

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# Dangerous Gifts: Towards a New Wave of Mad Resistance

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# Abstract

This dissertation examines significant shifts in the politics of psychiatric resistance and mental health activism that have appeared in the past decade. This new wave of resistance has emerged against the backdrop of an increasingly expansive diagnostic/treatment paradigm, and within the context of activist ideologies that can be traced through the veins of broader trends in social movements.

In contrast to earlier generations of consumer/survivor/ex-patient activists, many of whom dogmatically challenged the existence of mental illness, the emerging wave of mad activists are demanding a voice in the production of psychiatric knowledge and greater control over the narration of their own identities. After years as a participant-observer at a leading radical mental health advocacy organization, The Icarus Project, I present an ethnography of conflicts at sites including Occupy Wall Street and the DSM-5 protests at the 2012 American Psychiatric Association conference.

These studies bring this shift into focus, demonstrate how non-credentialed stakeholders continue to be silenced and marginalized, and help us understand the complex ideas these activists are expressing. This new wave of resistance emerged amidst a revolution in communication technologies, and throughout the dissertation I consider how activists are utilizing communications tools, and the ways in which their politics of resistance resonate deeply with the communicative modalities and cultural practices across the web. Finally, this project concludes with an analysis of psychiatry's current state and probable trajectories, and provides recommendations for applying the lessons from the movement towards greater emancipation and empowerment.



# Contents

|          |                                                                |           |
|----------|----------------------------------------------------------------|-----------|
| <b>1</b> | <b>Introduction</b>                                            | <b>1</b>  |
| 1.1      | Participatory Paradoxes . . . . .                              | 3         |
| 1.2      | Medical Authorities . . . . .                                  | 9         |
| 1.3      | Transcending Dualities . . . . .                               | 12        |
| 1.4      | Creatively Maladjusted . . . . .                               | 18        |
| 1.5      | A Method to This Madness . . . . .                             | 21        |
| 1.6      | Projecting Forward . . . . .                                   | 26        |
| <b>2</b> | <b>Counterfactual Cures: Manufacturing Disease and Dissent</b> | <b>33</b> |
| 2.1      | Bad Pharma . . . . .                                           | 35        |
| 2.2      | Early-onset Misconduct . . . . .                               | 44        |
| 2.2.1    | Where Science Meets Hope . . . . .                             | 50        |
| 2.2.2    | Atypical Childhoods Lost . . . . .                             | 53        |
| 2.2.3    | Diagnostic Wormholes . . . . .                                 | 60        |
| 2.3      | Pathological Soothsayers . . . . .                             | 67        |
| 2.4      | Ferocious Attacks and Formulaic Defenses . . . . .             | 75        |
| 2.5      | Transcending Monocultures . . . . .                            | 79        |
| <b>3</b> | <b>Occupy Mental Health: Liberty Park Madness</b>              | <b>83</b> |
| 3.1      | owsmentalhealth: Emotional First Aid . . . . .                 | 87        |
| 3.1.1    | Joie de Vivre . . . . .                                        | 93        |
| 3.1.2    | Is There a Doctor in the House? . . . . .                      | 97        |
| 3.1.3    | Involuntary Treatment . . . . .                                | 99        |
| 3.1.4    | License to Support . . . . .                                   | 102       |
| 3.1.5    | Which 99%? . . . . .                                           | 105       |
| 3.1.6    | Vibe Checkers and Knife Wielding Psychotics . . . . .          | 107       |
| 3.1.7    | Coda: Post-Zuccotti Shelter and Support . . . . .              | 111       |
| 3.2      | Rising Up Without Burning Out . . . . .                        | 112       |
| 3.2.1    | Cacophonous Choruses . . . . .                                 | 115       |
| 3.2.2    | (In)Validating the mainstream . . . . .                        | 119       |
| 3.2.3    | Coercive Ideations . . . . .                                   | 123       |
| 3.2.4    | What is Radical Mental Health? . . . . .                       | 126       |
| 3.3      | Conclusion . . . . .                                           | 128       |

|                                                                           |            |
|---------------------------------------------------------------------------|------------|
| <b>4 APA 2012: Oppositionally Defiant Protestors</b>                      | <b>133</b> |
| 4.1 A Pivotal Moment . . . . .                                            | 135        |
| 4.2 Streets of Philadelphia . . . . .                                     | 139        |
| 4.2.1 The Friends Center . . . . .                                        | 140        |
| 4.2.2 Extreme Mental and Emotional Problems . . . . .                     | 147        |
| 4.2.3 Hey, Hey APA! . . . . .                                             | 152        |
| 4.3 Imagining a Different Future . . . . .                                | 154        |
| 4.4 Now in 3-D! . . . . .                                                 | 156        |
| 4.5 The Radical Caucus Ruckus . . . . .                                   | 159        |
| 4.5.1 A Pot Luck Parable . . . . .                                        | 162        |
| 4.5.2 Seats at the Proverbial Table . . . . .                             | 166        |
| 4.5.3 Involuntary Votes . . . . .                                         | 168        |
| 4.6 Conclusion . . . . .                                                  | 174        |
| <b>5 You Are Not Alone: The Icarus Project and Psychosocial Wellbeing</b> | <b>177</b> |
| 5.1 Preamble: Friends Make the Best Medicine . . . . .                    | 180        |
| 5.2 Discursive Snapshots . . . . .                                        | 196        |
| 5.2.1 Crooked Beauty . . . . .                                            | 197        |
| 5.2.2 Open Source, Open Minds . . . . .                                   | 214        |
| 5.2.3 The Problems in 'the' Movement . . . . .                            | 225        |
| 5.3 Addendum: Mad Maps . . . . .                                          | 231        |
| 5.4 Virtual Phenomenologic Interventions . . . . .                        | 233        |
| 5.5 Conclusion . . . . .                                                  | 237        |
| <b>6 Mad Horizons</b>                                                     | <b>241</b> |
| 6.1 Jonah Doe . . . . .                                                   | 243        |
| 6.2 Corrective Lenses . . . . .                                           | 245        |
| 6.3 Exploratory Salvos . . . . .                                          | 249        |
| 6.3.1 MADLOVE: A Designer Asylum . . . . .                                | 249        |
| 6.3.2 Understanding Psychosis . . . . .                                   | 254        |
| 6.3.3 Advancing Innovative Neurotechnologies . . . . .                    | 260        |
| 6.4 Mad Futures . . . . .                                                 | 265        |
| 6.5 #alternatives . . . . .                                               | 271        |
| 6.6 Conclusion . . . . .                                                  | 277        |
| <b>References</b>                                                         | <b>283</b> |

## Acknowledgements

**COMING SOON**



*In loving memory of Frank Moretti,  
eternal teacher, friend and spirit guide.*



# Introduction

“ I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect... I will apply, for the benefit of the sick, all measures [that] are required, avoiding those twin traps of over-treatment and therapeutic nihilism... I will not be ashamed to say "I know not,"... In purity and holiness I will guard my life and my art.

— Hippocrates  
Hippocratic Oath

In August 2007 *The Onion*, a satirical publication with a track record of clever and incisive socio-cultural observations, ran a story with the headline “Woman Overjoyed By Giant Uterine Parasite” (2007). The story described the patient’s happiness about the “golf ball-sized, nutrient-sapping organism embedded deep in the wall of her uterus”. It also describes how this “endoparasitic ailment” is a “disorder [that] strikes without prejudice across racial, ethnic, and class lines”, and its symptoms can include “nausea, vomiting, constipation, irritability, emotional instability, swollen or tender breasts, massive weight gain, severe loss of bone density, fatigue, insomnia”. The author sustains a pitch-perfect deadpan tone for over 500 words, and describes the clinical dark sides of the creature “writhing restlessly inside her... robbing her of her strength and stamina”. All this is juxtaposed with the patient’s exuberance over the “miracle” and her excitement over telling her parents about the parasite. The readers are left to figure out for themselves that she’s pregnant.

E.B. White famously claimed that explaining a joke is like dissecting a frog. “Humor can be dissected, as a frog can, but the thing dies in the process and the innards are discouraging to any but the pure scientific mind” (White, 1941). While we might kill this joke through serious examination, it brilliantly captures an essential issue at the theoretical heart of the controversies surrounding mental health and wellness. This *Onion* story is one of my favorite illustrations of the challenges we face when untangling facts from values. In purely factual terms, the *Onion*’s clinical description of pregnancy is accurate. However, the framing of the pregnant woman’s condition, and the cynical and deprecating attitude applied to the shared underlying facts, succinctly illustrate the power of the narrator and the dominant narrative. Most humans throughout history have greeted pregnancy as a cause for celebration, even though it carries some negative consequences, including, in pre-modern history, childbirth fever and early death for the mother. Healthy pregnancies are not typically categorized as “disorders”, even though the symptoms caused by pregnancy could very well be construed as such. Through humor, *The Onion* illustrates the power of language, and the ways which narratives shape and distort consensual reality.

The production of psychiatric knowledge currently shares many absurdities with the portrayal of pregnancy in *The Onion*. Psychiatry is wedded to an epistemology that is rooted in an outdated philosophy of science, clinging to a diminished conception of objectivity and wielding scientific authority as a trump card that the psychiatric-pharmaceutical establishment uses to shut down and short circuit debate. Psychiatry is wedded to an impoverished vocabulary, and refuses to acknowledge the validity of alternative descriptions and understandings of experiences. Psychiatrists insist that their

diagnostic language is the privileged or even the sole legitimate way to give an account of, and an explanation for, mental reality. Laboratory data in the forms of neuro-imaging, genetic sequencing and bio/blood-chemistry are offered as conclusive evidence that patients are broken and need to be fixed. These forms of evidence are wielded to bluntly assert the necessity of psychiatric diagnoses and treatment. The stakes here go beyond the binaries of illness or wellness—it is essential to acknowledge the real phenomena of emotional trauma, suffering, crisis and illness. The substantive controversies are about where these lines are drawn, who is involved in drawing them, and how we should decide what to call people on either side of the line?

This dissertation tells the story of an emerging wave of mental health activists, what I call the “mad resistance”, who challenge the assumptions underlying this drawing of lines. A new generation of mad activists is struggling to assert their right to substantively engage in the conversation around their own identities and self-care. They want to participate in the production of the knowledge that governs their diagnosis and treatment, and they are questioning the very language and narrative frames used to talk about their mental health and wellness. Their argument, embodied in their stories, represents a dramatic shift from the anti-psychiatry, psychiatric survivors, and consumer movements that preceded them.

## 1.1 Participatory Paradoxes

Over the past decade the politics and rhetoric of activists organizing around mental health issues have begun to shift dramatically. These shifts have been simultaneously

subtle and stark. Crucially, some elements of the movement have moved away from a purely oppositional, head-butting critique of the psychiatric-pharmaceutical alliance, and their demands have begun to focus on questions of voice. In the tradition of the disability rights movement, this new generation of the mad resistance has taken up the cry “Nothing about us without us”. James Charlton cataloged the centrality of this phrase to disability rights in his book *Nothing About Us Without Us: Disability Oppression and Empowerment* (1998). Charlton first heard the expression invoked by leaders of the South African disabled people’s group in 1993, who claimed to have heard it used earlier at an Eastern European international disability rights conference (p. 2). Two years later he saw a front page headline in the Mexico City daily about thousands of landless peasants marching under the banner “*Nunca Mas Sin Nosotros*” (Never Again Without Us), and adopted “Nothing about us without us” as the working title of his book.

Charlton quotes Ed Roberts, a leader of the international disability rights movement “If we have learned one thing from the civil rights movement in the U.S., it’s that when others speak for you, you lose” (Driedger 1989:28), and traces the impulse behind the expression “Nothing about us without us” to the civil rights era, embodied in works such as *Our Bodies, Ourselves: A book by and for women* (Boston Women’s Health Book Collective, 1973), and the widely used civil rights slogan “Power to the People”.

On the surface the proposition “Nothing about us without us” seems like a timid assertion, easy to satisfy. However, it has proven to be one of the most radical demands the movement can make. It has radical implications for the ways in which human conditions are investigated and addressed. It also challenges the binary distinction

between objectivity and subjectivity, and calls into question the possibility of objective knowledge devoid of context.

Mad folk have traditionally occupied a paradoxical place in public discourse. By definition they are branded “irrational” and are categorically precluded from having a voice in rational public debate. In an age when people of all sorts insist that their understandings of themselves and their problems matter, how can this constituency find their voices, sustain them, and make them persuasive? Who will accept their legitimacy and listen? This problematic has shaped mental health activism throughout its history, and this emerging wave of mad resistance has begun to confront this impasse directly.

In the first decade of the 21<sup>st</sup> century, mad activists reinvented psychiatric resistance with a politics that deeply resonated with trends in participatory culture and was supported by a new generation of communications technologies. The Icarus Project, a leading organization at the forefront of this shift, developed hybrid models of peer-support and direct action that were accelerated and amplified by new communicative possibilities. They mobilized around free and open-source communications platforms, and constructed architectures of participation that supported their existing commitments to access, advocacy, transparency, expression, engagement, and community building.

Challenging psychiatric methods and paradigms, questioning the validity of pharmaceutical research, and protesting the political processes that shape mental health policy is nothing new. Activists have struggled for decades (Crossley, 2006), if not centuries (Foucault, 1965; Whitaker, 2003), to resist the imposition of the category of mental illness for the maintenance of hierarchical societies. Even according to historians who contest Foucault’s simplistic account of madness in the Middle Ages, as presented in

*Madness and Civilization* (1965), the historical role of mad folk as society's outsiders subjected to the powerful, remains obvious. Erik Midelfort's *A History of Madness in Sixteenth-Century Germany* emphasizes the real trauma and suffering exhibited by the mad, and the benevolent care afforded them in hospitals modeled on monasteries (2000). His argument with Foucault over historical specifics does not undermine the general shape of Foucault's argument, namely the identification of "power" as the mechanism which determines who is mad, and who is sane, even if Foucault's portrayal of the period turns out to be a caricature. Though some of the mad surely suffered, some of those accused of demonic possession and witchcraft were surely undeserving victims. Foucault also recommends studying sites of resistance to better comprehend the machinery and contours of power, a strategy I adopt in this dissertation.

In the modern period, cultural theorists such as Brad Lewis and Jonathan Metzl have exposed the entrenched ideological and commercial interests that aggressively promote the hegemonic narratives that flatten minds into brains and reduce feelings to chemical reactions (Lewis, 2006; Metzl, 2010). In the 1990s, a wave of psychiatric resistance first self-identified as the "Mad Pride" movement emerged, advancing a more nuanced critique of mainstream perspectives on mental illness than earlier generations of anti-psychiatry activists and the consumer/survivor/ex-patient (c/s/x) movements (Coleman, 2008; Morrison, 2005; Crossley, 2006). This emergence marked a break from the orthodox psychiatric survivor movement that came before them.

Like the gay/queer pride movement, whose name and politics directly inspired them, mad pride activists focused more on identity politics than human rights discourses. As the second wave feminists argued, "the personal is political", and this reframing of the

issues opened up powerful new avenues of critique (Hanisch, 1969). This new wave of criticism did not entail any particular dogma around hospitalization, medication, or labels, but was rooted in challenging authority and the means by which knowledge is produced (DuBrul, 2012). What has opened up as a result is a whole field of linguistic contestation. The term “mad pride” is problematic, embraced by some and rejected by others in the movement it for reasons we will explore in Chapter 5. Currently, there is no recognized term identified with the new wing of the movement, aside from the generic “radical mental health” movement.

The radical epistemology captured in the mantra “Nothing about us without us”, succinctly represents this unnamed transformative shift (Charlton, 1998). Instead of simply resisting forced drugging and electroshock therapy, this new wave of mad resistance affirms an epistemology that diverges from the conventional medical model. They embrace liberation politics and stage direct actions that attempt to transform the language used to describe the mentally ill. They aspire to develop languages of compassion, celebrate their “dangerous gifts” through creative expression, and facilitate safe spaces for people to share their experiences and subjective narratives. Building on the work of earlier generations of activists who advocated for individual treatment choices and informed consent (Oaks, 2006), they encourage active participation in their healing communities, and insist that their voices and stories be heard and respected alongside those of experts and professionals.

The trope of patient empowerment was forced onto the mainstream agenda through the largely successful activism of the international direct action group, AIDS Coalition to Unleash Power (ACT UP)(Halperin, 1995; Gould, 2009). In the early 80s, when

the scourge of AIDS erupted in the United States, the government and pharmaceutical corporations were negligent in responding to the urgent needs of the afflicted. ACT UP formed to demand patient empowerment, and contingents within the group began conducting scientific research, drafting policies and protocols, and ultimately became leading experts on their own condition. They formed their own support groups, pooled their resources to collectively purchase experimental drugs that were not yet approved in the US, and staged vivid protests and direct actions, such as die-ins and the creation of alternative sexual education material. While ACT UP demanded new attention, research and drugs from pharmaceutical industry, and mental health activists are not especially interested in the development of new pharmaceuticals—one might say that they are demanding *less* attention—there are interesting parallels in the underlying ideology of their demands.

The transformational shift in this emerging wave of resistance can be construed as a shift from advocating for a particular ontology to advocating for a new epistemology. More than a discursive face-off disputing the nature of reality, the disagreement focuses on the question of how to approach controversies and establish consensus. For example, many anti-psychiatrists and psychiatric survivors in the 1970s have argued (and still continue to argue) that there is no such thing as mental illness. I argue that the newly emerging wave of mad resistance operates on a different plane. It is more concerned with ensuring that all of the relevant stakeholders have seats at the tables of power, where their voices can be included in the production of psychiatric knowledge. First and foremost is the primacy of their own voices in the understanding of their situation and

the co-creation of their stories. Crucially, their insistence on co-constructing their own identities and narratives underlies their platforms, critiques, and actions.

## 1.2 Medical Authorities

The psychiatric-pharmaceutical establishment rarely acknowledges these challenges to their authority, but their messaging reinforces and relies on the validity of a form of scientific objectivity that can definitely distinguish between sickness and health. Mainstream patient literature often explains mental illness by drawing an analogy between mental illness and diabetes, or other chronic ailments that require medical intervention (National Alliance on Mental Illness, n.d.). This comparison once again advances the notion that patients are sick and there is no lasting cure—only chronic treatments of symptoms requiring lifelong medication, despite many of the documented health risks that psychiatric drugs introduce (Whitaker, 2010).

The parameters of normal and illness are defined in the *Diagnostic and Statistical Manual* (DSM), a book published by the American Psychiatric Association (APA) whose influence extends far beyond psychiatry, throughout medicine, therapeutic services, insurance claims and health policy. There are important differences between the diagnoses in the DSM and classic physiological illnesses. First and foremost, many of diagnoses in the DSM lack consensus on whether the conditions described are *illnesses* deserving medical intervention or *patterns of behavior* that deviate from societal norms. Furthermore, psychological and emotional distress is incredibly complex and varied, and its causal roots are multivariate and remain shrouded in uncertainty. Many physiological disorders

have clearly defined symptoms, whose underlying causes are theoretically grounded in well established models, and can be directly measured. Others, such as Chronic Fatigue Syndrome (Institute of Medicine, 2015), Irritable Bowel Syndrome (Ohman & Simrén, 2010) or Morgellons Syndrome (Pearson et al., 2012) currently defy simple explanation, and Western medicine struggles to treat. Psychiatry's approach towards mental distress more closely resembles the treatment of these poorly understood syndromes than the treatment of the well-defined illness of diabetes. We still don't understand enough about mental distress to compare it with confidence to anything other than another mystery.

Diabetes is a metabolic disorder that is believed, with support from a variety of empirical observations, to be caused when the pancreas fails to create enough insulin to break down glucose, causing increased glucose levels in the blood (American Diabetes Association, n.d.). A network of beliefs and accompanying evidence has confirmed this interpretation of symptoms such as increased thirst, hunger, fatigue, blurred vision and headaches. Psychiatry, on the other hand, is still searching for a causal model, and the DSM's attempts to carve out analytic categories and constructs are regularly called into question. Some argue that many of the diagnoses in the DSM are actually “catch-all” categories. For example, the grab bag of symptoms associated with schizophrenic diagnoses arises from a variety of disparate causes, which may each benefit from differential treatments (Zimney, 2008). Despite investing hundreds of millions of dollars into decades of research, psychiatric researchers have yet to produce a test validating psychiatric diagnosis (Valenstein, 2002). In 2005 the president of the American Psychiatric Association, Steven Sharfstein, backpedaled on the profession's longstanding claim that mental illnesses are caused by chemical imbalances (Hickey, 2014) and admitted that

“brain science has not advanced to the point where scientists or clinicians can point to readily discernible pathologic lesions or genetic abnormalities that in and of themselves serve as reliable or predictive biomarkers of a given mental disorder or mental disorders as a group” (American Psychiatric Association, 2003). The use of the term “readily discernible” hedges the profession’s uncertainty about their lack of supporting evidence for the chemical imbalance hypothesis, without disavowing it entirely. As we shall see later, psychiatric researchers have begun to favor the language of “information processing errors” over “chemical imbalance”, reflecting the dominant metaphor for understanding brain functions as computations (Rabinbach, 1990). Hickey later wrote that “[psychiatry] must examine the fact that as a profession, we have allowed the biopsychosocial model to become the bio-bio-bio model” (2005).

The biomedical model of emotional distress attempts to definitively state the nature of this distress in objective terms. Many on the receiving end of these diagnoses feel that this claim of objectivity inhibits their ability to locate meaning in their condition by reducing it to a medical label. Despite the widespread claim that labels are purely instrumental, shorthand for doctors to communicate with each other, labels can deeply influence people’s identities. Diagnostic labels make some people feel powerless and objectified, like they are “a mood disorder with legs” (Rosenthal, 2010a). There are always elements of a psychological state that cannot be captured by physiological measures. Diagnostic labels often ignore individual and intergenerational trauma, structural oppression and inequality, and a range of social, cultural, political, spiritual and psychological lenses for understanding complex conditions. Some people I met described feeling that labels stripped them of their agency, absolving them of responsibility for behaviors

associated with their condition, or dooming them to fulfill their diagnosis. The objective authority of labels also discourages people from exploring alternative explanations for their conditions. Language matters in defining the reality of subjective states, and is central in the formation of identity and meaning.

Incorporating a range of diverse stakeholders in the production of psychiatric knowledge would help illuminate the narrowness of current assumptions and give voice to alternative ways to conceptualize and support existential diversity, suffering and crisis. This position does not amount to radical relativism, or endorse the idea that anything goes. Instead, it challenges monocultures of knowledge production and demands that diverse pluralities participate in the judgments that society enforces around values and norms. The systematic denial of the role of value judgments in the production of psychiatric knowledge needs to be interrogated and challenged. The pretense of atheoretical, “views from nowhere” needs to be exposed, laying bare its underlying biases and ideologies. To be sure, our capacity for reconciling difference is woefully lacking, but the precondition to begin this process starts with listening.

### 1.3 Transcending Dualities

Critics have engaged the controversies surrounding psychiatric diagnoses on multiple conceptual fronts, provoking debates about the integrity of the rhetoric, science and politics. The work of Stuart Kirk and Herb Kutchins, professors of social work, questions the science, statistics and proofs claimed by the small committee of psychiatric researchers who authored DSM-III and DSM-IIIR. *The Selling of DSM: The Rhetoric of Science in*

*Psychiatry* (1992), published by an academic press, and *Making Us Crazy: DSM: The Psychiatric Bible and the Creation of Mental Disorders* (2003), a trade book, expose the workings of these backroom proceedings, and describe their success in transforming psychiatry's central problem from one of "validity" to one of "reliability", the measure of multiple doctors agreeing on the same diagnosis. Reliability is a narrower, technical problem for researchers to solve, one that effectively redefines a diagnosis as valid if multiple doctors agree on the diagnosis. As Bradley Lewis shows in *Moving beyond Prozac* (2006), the discourses around psychiatric controversies encompass multiple perspectives beyond the rhetorical and scientific. The *rhetorical critiques* are theory-laden challenges to the ideological frames that are constructed and mobilized to describe the issues. The *scientific critiques* accept (or bracket) the dominant research paradigms and concentrate on questioning the validity of the research claims, on their own terms. Finally, the *political critiques* question governance and processes such as the construction of the research agenda, the voices involved in formulating policy recommendations, corruption, conflicts of interest and aggressive marketing practices that influence behavior and perception. These dimensions often overlap, and are difficult to disentangle completely in debate or analysis.

The political plane is where questions of diversity and inclusion are activated in the context of crafting a purposeful process for building consensus, resolving conflicts and constructing knowledge. The consideration of politics, in this sense, is largely absent from Kirk and Kutchins' work and is the operating beachhead for the emerging wave of mad resistance that I describe in this dissertation.

The new wave of activists which I profile often engage these controversies on all of these planes simultaneously, as the assertion “nothing about us without us” embraces a range of rhetorical, scientific and political moves. Their focus on enriching the language we use to define mental wellbeing and distress represents a deliberate effort to participate in the co-construction of their own reality. Their arguments are often motivated and amplified by dubious science, greedy corporations, and corrupt doctors and policymakers. The emerging wave of mad resistance is fundamentally about applying this political maxim to the full range of psychiatric discourse, and making explicit their demands for a participatory voice.

It is useful to contrast this emerging position with other strands of psychiatric resistance, which often leads to opponents butting heads with little chance for reconciliation. For example, the mind-body problem, a philosophical quandary about the nature of and relationship between the mental and the physical, is one site of rhetorical contention that stands between some psychiatrists and psychiatric survivors. Arguments on both sides of this debate effectively assume dualism, although these are rarely the explicit terms of debate. Dualism is the metaphysical position that postulates that physical and mental phenomena are distinct, though they somehow influence each other. Reductionist psychiatrists cast their arguments in terms implying that the flow of neurotransmitters and the firing of neurons uniquely determine states of mind, but not vice versa. Similarly, the arguments of orthodox anti-psychiatrists suggest that they deny the impact of biochemistry or neurophysiology on their minds, and they vehemently resist biological explanations of their behavior (with the notable exception of psychiatric drugs, which they blame for detrimental affects on their minds and bodies). These largely unexamined,

and, at times, incoherent positions creep into the discourse, even when the participants deny their dualistic dispositions.

A commitment to monism, a theoretical alternative to dualism, presents a substantive challenge to both the orthodox biomedical model of mental illness and orthodox anti-psychiatrists. Monism entails that all behaviors are correlated with corresponding states of mind, and similarly, changes in our brains are also correlated with changes in mind, so that mind and brain are dual aspects of the same phenomena. Unfortunately, the mind-body problem has remained unsolved for millennia, and adopting these positions results in untenable standoffs. Transcending dualism only addresses part of the conflict. To fully embrace a more democratic epistemology, we must also transcend the theoretical questions themselves and pragmatically consider their political implications, bracketing the theoretical frames, for now.

The act of categorizing a state of mind/brain and its corresponding behaviors as pathological is never devoid of subjective inflection and will always involve value judgments and interpretations of behavior that can never be isolated in a pure form. While an fMRI image may be used to demonstrate *correlations* between states of brain and states of mind (crucially, not the necessary consequences of these brain functions), an fMRI will never be able to conclusively demonstrate that a person suffers from a “psychiatric disorder”. The act of categorizing certain behaviors as deviant or pathological will always involve value judgments. Analytical distinctions carve up the world in particular ways, grouping data together and fitting them to preconceived patterns. Whenever something is counted, something else is omitted, and behavioral descriptions are forever imprisoned in language, comprised of words that are intrinsically bound

to shades of semantic senses, embedded in networks of meaning which are inherently social.

Psychiatric facts are inextricably woven among socio-cultural values. A patient, whether treated as a mind, brain, or unified whole, can never be diagnosed independently of our collective judgment of the subject's behavior and disposition. Both minds and brains exist in social entanglements, and divorcing the diagnosis of a patient from his or her psycho-social context effectively locates an individual's pathology inside their skull, without acknowledging the influence and impact of their environment. In theory, a full service treatment team might consider the patient's psycho-social context, but this contextualization is not typical in practice, as market forces, insurance codes and psychiatric cultural norms incentivize diagnoses that are devoid of context. Laboratory diagnostics will never be able to tell us what behaviors to pathologize or determine the threshold for "normal", since we as a society co-construct these values. Is the patient suffering from a uterine parasite, or blessed with child? Is the patient suffering a psychotic break or struggling to navigate his or her dangerous gifts?

The human condition is richly varied and there are limitless ways for us to find meaning in our experiences. To insist that there is only a single way to make sense of someone's life story requires generous helpings of arrogance and stubbornness (Fadiman, 1997). Once we recognize the inextricable coupling of psychiatric facts with socio-cultural values, the imperative to include more voices in the production of psychiatric knowledge ought to be self-evident. Under the status quo, a small group of primarily white, middle-aged men, most of whom have medical degrees from Western societies, are responsible for defining a normal range of human consciousness, what constitutes

healthy experiences, and how to support and treat people who are suffering (Kurt and Kutchins, 1992). Historically, the team that has drafted this defining document has omitted psychologists, psychoanalysts, social workers, philosophers, humanists, social scientists, patients, families of patients, as well as mental health activists of various stripes (Lewis, 2006). While DSM-IV and DSM-5 committees have made some gestures towards including more mental health professionals outside of psychiatry, as well as minorities and international representation, these additions have been ad-hoc, and not part of a deliberate philosophy of inclusion. It is easy to recognize the fundamental flaws in this arrangement and how diverse perspectives are essential for a more comprehensive and reliable understanding.

The moral imperative for diversity of input is not the only argument for inclusion. Recent sociological findings have demonstrated that diversity enhances organizational creativity and innovation, while homogeneity stifles it (Burt, 2004; Stark, 2009). Identifying and questioning assumptions, crafting compromises, and designing innovative alternatives are some of the reasons why diversity and inclusion are so important. The mere inclusion of diverse actors does not ensure a fair outcome, and processes and procedures must be deliberately adopted which maximize the possibility of fair outcomes. Sometimes positions are irreconcilable, and compromise a Faustian bargain, but the difficulty of achieving absolute fairness should not stop us from trying to improve the current situation.

## 1.4 Creatively Maladjusted

In the 1960s, the civil rights and anti-war movements challenged authority on multiple fronts, and Martin Luther King, Jr. famously called for his followers to stand maladjusted in order to reveal the madness of an unjust, self-destructive, and irrational society:

Modern psychology has a word that has become common—it is the word maladjusted. We read a great deal about it. It is a ringing cry of modern child psychology; and certainly we all want to live the well adjusted and avoid neurotic and schizophrenic personalities. But I must say to you this evening, my friends, there are some things in our nation and in our world to which I'm proud to be maladjusted. And I call upon you to be maladjusted and all people of good will to be maladjusted to these things until the good society is realized. I never intend to adjust myself to segregation and discrimination. I never intend to become adjusted to religious bigotry. I never intend to adjust myself to economic conditions that will take necessities from the many to give luxuries to the few, and leave millions of people perishing on a lonely island of poverty in the midst of a vast ocean of prosperity. I must honestly say, however much criticism it brings, that I never intend to adjust myself to the madness of militarism, and to the self-defeating effects of physical violence... Yes, I must confess that I believe firmly that our world is in dire need of a new organization – the International Association for the Advancement of Creative Maladjustment... Through such maladjustment we will be able to emerge from the bleak and desolate midnight of man's inhumanity to man, into the bright and glittering daybreak of freedom and justice. (King, 1962)

Widely read critical psychiatrists such as R. D. Laing (1967) and Thomas Szasz (1974) identified the language of “madness” as an instrument of oppression, and influential academics such as Erving Goffman (1961) and Michel Foucault (1965) wrote extensively about the institutions of psychiatry, their coercive power and histories of abuse. The counter-cultural movements of the 1960s embraced these societal diagnoses and psychiatric critiques that strongly reverberated with their messages of individuation, self-expression, and defiance of established forms of thought.

Over the ensuing decades, a diverse assemblage of organizations continued to actively resist psychiatry. Their positions varied, with an insistence on self-determination, individual freedoms, and a critique of coercion as their common denominator (Morrison, 2006). Some activists claimed that mental illness was a social construct and challenged psychiatry's ontological assumptions, while others accepted psychiatry's diagnoses, but advocated for health insurance parity and consumer rights. Some refuted the therapeutic value of any and all medications, and others struggled to reduce the stigma of mental illness by promoting its biological basis.

In a 2006 article published by the official journal of the American Psychiatric Association, Rissmiller and Rissmiller describe the collapse of the anti-psychiatry movement and its rebirth as the mental health consumer movement:

The formative years of this movement in the United States saw “survivors” promoting their antipsychiatry, self-determination message through small, disconnected groups, including the Insane Liberation Front, the Mental Patients’ Liberation project, the Mental Patient’s Liberation Front, and the Network Against Psychiatric Assault. The fragmented networks communicated through their annual Conference on Human Rights and Psychiatric Oppression (held from 1973 to 1985), through the ex-patient-run Madness Network News (from 1972 to 1986), and through the annual “Alternatives” conference funded by the National Institute of Mental Health for mental health consumers (from 1985 to the present)... The movement searched for a unifying medium through which to integrate. The growing Internet “global community” offered just such a medium. (2006:865)

Rissmiller and Rissmiller's article generated a strong reaction from the activists they purported to speak for, who contested the article's characterizations and misrepresentations (Oaks, 2006b). In particular, the “psychiatric survivors” did not appreciate being labeled with the marginalizing “anti-psychiatry” moniker, a term they associated with psychiatrists who were critical of psychiatry, and not how they chose to describe

themselves. They also refuted the overarching narrative of their movement's collapse in the face of psychiatry's so-called reforms. Rissmiller and Rissmiller exemplify the kinds of moderate, policy-oriented, mainstream activism that psychiatry was willing to engage. This kind of reform is characterized by organizations such as the National Alliance for the Mentally Ill (NAMI), whose lobbying and advocacy often aligns closely with the Pharmaceutical lobby.

NAMI's anti-stigma campaigns are good examples of this alignment. While reducing stigma around mental diversity is generally a positive development, NAMI's campaigns often come packaged in a suite of frames that promote disease models and pharmaceutical solutions. NAMI's anti-stigma campaigns denounce stigma, but in the same breath also reinforce the idea that patients are sick, there is no definitive cure, and they need to be treated with drugs for the rest of their lives. Their campaigns seek to medicalize mental distress, and are decidedly "on message" with Pharma's advertising campaigns. On the surface anti-stigma campaigns seem progressive, however, some of the practices they aim to de-stigmatize deserve closer scrutiny. Anti-stigma campaigns often whitewash and legitimize questionable practices under the guise of a progressive cause. Perhaps some conditions ought to be stigmatized? Perhaps prescribing anti-psychotics to toddlers is something that ought to carry some stigma? The psychiatric survivor movement was not satisfied with NAMI's kinds of reforms. They also denounced stigma, but rejected the language and categories that NAMI's campaigns endorsed.

During this same period, the American Psychiatric Association (APA) published DSM-III (1980), III-R (1987), IV (1994) and IV-TR (2000), grounding their ever-expanding diagnostic nets on what Lewis describes as "an amazingly idealized notion of" theory

neutrality" (2006: 1). Pharmaceutical companies introduced new therapeutic compounds (Barber, 2008; Whitaker, 2010), and marketed them directly to doctors and consumers on an unprecedented scale (Lane, 2008). Critics of the industry maintained that Big Pharma's business strategy was best understood as the manufacture and marketing of the chronic diseases for which they also sold the treatment (Mills, 2007).

Mindfreedom International (formerly called the Support Coalition International), an important activist watchdog organization dedicated to "a nonviolent revolution in mental health care" (2012), tracked these developments, and engaged in forms of protest using tactics such as civil disobedience, strategic litigation, and generating coverage in the mainstream media. Academic research communities, such as The International Center for the Study of Psychiatry and Psychology (renamed The International Society for Ethical Psychology & Psychiatry in 2011), were "devoted to educating professionals and the public concerning the impact of mental health theories on public policy and the effects of therapeutic practices upon individual well-being, personal freedom, the family, and community values" (2012).

## 1.5 A Method to This Madness

The controversies surrounding the psychiatric-pharmaceutical complex are tangled and emotionally charged. I do not intend to resolve them here. What I do insist, along with the new wave of mad resistance, is that the exploration of these questions and controversies should not be reserved to the medical establishment. The traditional human, social, and life sciences can and should bring the full force of their disciplines to

bear on these questions. Additionally, media and communications studies are positioned to offer unique and valuable perspectives on these issues (Peters, 2009). The media and communicative environments that we inhabit shape our experiences, perspectives, and behaviors (McLuhan, 1964; Ong, 1982). These environments are undergoing revolutionary changes, and correspondingly, so is identity formation and social interaction (Castells, 1996). James Carey writes that “communication is a symbolic process whereby reality is produced, maintained, repaired, and transformed” (Carey, 1992: 23). Both McLuhan’s and Carey’s interdisciplinary approaches for studying media and communications as culture suggest a powerful stance for interrogating the representations of pharmaceuticals and mental illness in advertising, popular culture, and the press. McLuhan believed that “ideally, advertising aims at the goal of a programmed harmony among all human impulses and aspirations and endeavors,” a claim that applies to psychiatry as easily as advertising (1964: 227). As more authoritative judgments are made through the interpretation of records gathered through institutional surveillance, diagnostic constructs and practices are subtly changing in response to this new form of scrutiny. Psychoactive drugs distort, deflect, and otherwise alter phenomenological experiences in ways that can be productively analyzed as a form of mediation. Just as traditional media mediate communications between senders and receivers, psychoactive drugs modulate cognitive and perceptual apparatuses, and effectively mediate experiences of reality. Like traditional media, these drugs shape our experiences, perspectives, and behaviors—our ways of seeing and being in the world.

Much like familiar elements of our mainstream media ecology such as advertising and the press, psychiatric diagnoses and psychotropic drugs directly mediate and shape

our experience of reality. They also, literally, mediate our behaviors, perceptions, desires, and expectations. An entire generation is growing up inhabiting a perpetually drugged-out existence, as their constitutive environment is regulated by drugs that sedate bodies and turn minds sluggish. Our youth's ways of seeing and being in the world are being actively shaped by diagnostic labels and mind-numbing drugs. Scholars, journalists, educators, and activists must work together to marshal all the methods at their disposal to comprehend and contain this burgeoning epidemic, where, by one measure, an astonishing 1 in 5 children are now considered mentally ill (Merikangas et al., 2010).

In this dissertation I tell the story of the emergence and transformation of a new wave of mad resistance. I do not attempt to reproduce the rich scholarship detailing the forms of psychiatric resistance that were prevalent in the second half of the 20<sup>th</sup> century (Morrison, 2005; Crossley, 2006). Rather, I summarize the salient characteristics of these historical movements in order to contrast them with emerging forms of protest and direct actions imagined and enacted by a new wave of mad resistance born into the networked society of the 1990s and the early twenty-first century.

Coming to terms with a complex domain is a daunting task, for which Plato suggests a concrete methodology: "First, the comprehension of scattered particulars in one idea... Secondly, there is the faculty of division according to the natural idea or members." (Plato, 1999). James Carey articulates a strategy that closely mirrors Plato's in preparation for his analysis of the effects of the telegraph (Carey, 2007). "Concentrate on the effect of the telegraph on ordinary ideas: the coordinates of thought, the natural attitude, practical consciousness... not through frontal assault but, rather, through the detailed investigation of a couple of sites where those effects can be most clearly observed." This

style of inquiry provides us with a basis for approaching the analysis of complexity which otherwise appear irreducible or intractable. Throughout this work I will investigate such sites in detail, where the effects I am describing can be most clearly observed.

I approach these sites through a variety of methods, emphasizing ethnographic and participant observer approaches consistent with the inclusive values advocated by the groups I study. Throughout the psychiatric medical literature, patient's voices are systematically omitted, or, at best reduced to survey responses or numerical statistics. Qualitative approaches address this gap in evidence and represent a powerful way to capture a diversity of voices through interpretation and analysis. In an era when "evidence-based" methods have become code for exclusively quantitative methods, it is important to assert and demonstrate the value of rigorous, qualitative social science. Ethnographies are not a substitute for the direct participation of diverse stakeholders in the co-construction of knowledge, but work like this signals an important step in that direction.

I also rely extensively on media content analysis, including mainstream, independent and grassroots. It is important to look at media representations about the activists, as well as ones that ignore or downplay them. It is also vital to learn about these issues and these communities through the stories that the activists themselves tell—about themselves and about the movement. My direct quotation, representation, interpretation, and synthesis of these stories form the core of my contribution to this discourse. My own voice is intermingled with the subjects I represent, in ways that I cannot fully separate. I attempt to indicate my own agendas and biases where possible, but this entire project should be read as my attempt to make sense of the current moment in the

psychiatric-pharmaceutical industries, and the counter-cultural movements that resist them. As someone who identifies as both an academic and an activist, I strive to be forthright about my assumptions and convictions. I hope to present an argument that is accessible and convincing beyond the choirs of cultural studies and mad activists.

Due to the sensitive nature of the subject matter, I rely heavily on publicly available primary sources. Despite the fact that many of these activists want to have their stories told, out of respect for their privacy, and in acknowledgement of the practical realities of stigma, I have decided to restrict myself to materials available publically on the web, including mailing lists and forums, unless otherwise noted. Many of the underground materials I draw upon are self-published, and their analysis is largely absent from the scholarly literature. This body of content is vast and difficult to navigate without the kinds of personal guidance and interactions I cultivated in my fieldwork. In each chapter I elaborate on the specific methods used for data collection and analysis. I open my conclusion by detailing my personal account of how I came to this research, and my own direct involvement as an activist within the movement.

Mad activists use communication technologies extensively, and I will consider their usage throughout this analysis as an important substrate of the transformation in mad identity and politics that I trace. James Carey defines “models of communication” as “templates that guide, unavailing or not, concrete processes of human interaction, mass and interpersonal” (1992: 31). The communication models and technologies adopted by a group reflect their strategic, organizing, and decision making cultures (Kavada, 2013). These tools leave traces that provide important clues about the groups’ politics and purpose. I do not argue for a causal relationship between these communication technologies

and the group's values and organizing principles. The relationship between changes in social movement organizing and the concomitant improvements in communications technologies is undoubtedly complex. In an attempt to avoid simplistic explanations, I will consider the socio-technical environment holistically, without privileging deterministic narratives, or making unwarranted causal claims. Although it is difficult to demonstrate how social movements shape, and are shaped by, revolutions in media and communications technologies, it is interesting and valuable to study how movements leverage technologies, both tactically and strategically.

## 1.6 Projecting Forward

In chapter 2, I set the stage for this transformation by illustrating dramatic expansions in psychiatry's diagnostic net and increasingly aggressive treatments. In the years leading up to the emergence of this new wave of mad resistance, the psychiatric establishment and the pharmaceutical industry were anything but idle. During this period, the rates of psychiatric diagnoses and treatments rose explosively, and psychiatric drugs became multi-billion-dollar blockbusters and household names.

In this chapter, I focus on the story of the explosive rise in pediatric bipolar diagnoses and the emergence of preventative, or prodromal, diagnoses in order to paint a detailed backdrop of the conditions that gave rise to a new wave of mad resistance. The public is vaguely aware of over-diagnosis and over-prescription, but is largely unaware of the extent of the growth in psychiatric diagnosis and treatment. The mainstream media struggles to tell stories about mental health for a variety of reasons, including their

exceeding complexity and perceived conflicts of interest with pharmaceutical advertising dollars. The psychiatric-pharmaceutical alliance grows relentlessly, and many of their most egregious over-reaches go unnoticed and unchallenged.

In the years leading up to the publication of DSM-5 in 2013, controversies raged around the diagnosis and treatment of behavioral issues in children. The rise of the pediatric bipolar diagnosis, and especially the associated prodromal, or predictive diagnosis, is a case study that exemplifies the ways in which psychiatric judgment has generated controversy among mental health professionals, journalists, activists, and the public. Has the behavior of American youth grown more irritable and defiant, or has the adult judgment of their behavior changed? How can we explain the variations in diagnoses around the globe? Why are similar childhood and adolescent behaviors diagnosed in some settings and not in others? If there is a dramatic shift in youth behavior, what factors and dynamics might be precipitating these changes? How can we effectively study and explain these dramatic transformations in judgment and behavior?

The case studies presented in Chapter 2 intend to provide a detailed examination of an area of dramatic expansion in psychiatric diagnosis and treatment as a window into the machinery of this process more generally. Other areas of diagnostic expansion, such as grief, shyness, anxiety, personality disorders, adult bipolar, psychotic risk, and other lifestyle disorders, vary in the particulars of their expansion, but display similar characteristic and trajectories. The lessons learned from the case of pediatric bipolar provides valuable insights to what is transpiring in the rest of the field.

Through the detailed case study of pediatric bipolar and prodromal diagnoses, Chapter 2 tells the story of the manufacture of a diagnosis and development of psychiatry's

alliance with the pharmaceutical industry during the decade leading up to the release of DSM 5. During this period, we also witnessed a pronounced transformation in mad activism, towards a new wave focused on asserting and demanding a voice. To demonstrate this trend I closely examine two separate sites where we witness non-credentialed stakeholders being systematically marginalized and silenced.

In Chapter 3 I present the fieldwork I conducted in Zuccotti Park during the Occupy Wall Street (OWS) protests. The first section of this chapter analyzes my experiences participating in OWS's "Support" working group, a group primarily composed of professional social workers, along with a few psychologists, psychiatrists, chaplains and others. Even among the liberal, progressive and radical activists in Zuccotti, radical mental health activists struggled to be heard. The non-credentialed peers faced systematic hurdles in voicing their concerns, and in many instances they felt silenced and marginalized by the professionals. In the second section of this chapter I analyze the collaborative production of *Mindful Occupation: Rising up Without Burning out*, a book that was the product of over fifty contributors, created by and for the Occupy Wall Street activists. I played a central role contributing to and organizing the production of this work and the contributors collaborating on *Mindful Occupation* included mental health professionals as well as radical mental health activists. The book's content, as well as the controversies that erupted during its editing clearly illustrate this new wave of mad politics, articulated through their approach towards consensus and conflict resolution. Taken together, the contrast between conflict resolution in the Support meetings and the editing of *Mindful Occupation* provide a thick study of authority and knowledge production around mental health in Zuccotti Park, and demonstrates the urgency for mad activists to advocate for

their right to participate directly in the creation of systems governing their classification and support.

Following a similar trajectory, Chapter 4 turns to the May 2012 American Psychiatric Association conference, held in Philadelphia. The conference previewed a draft of the controversial DSM-5, which was published the following year in 2013. A surge of activists and media converged on Philadelphia for the landmark unveiling of psychiatry's defining document. I attended activists' rallies and marches, official conference talks and poster sessions, and also witnessed a historic meeting of the Radical Psychiatric Caucus, whose members had invited activists and the media to participate in their yearly meeting. I closely analyze the speeches from the rallies, where I tease out evidence of the new wave of mad resistance, appearing side-by-side with its more orthodox c/s/x precursors. The two-hour meeting between the self-proclaimed radical psychiatrists and the mental health activists was filled with fire and vitriol. At one point, an activist slammed his hands on the table, donned a red clown nose, and rose to sing an anti-fascist protest song. Clearly, the constituencies were having great difficulty communicating. As with the professional mental health workers at Occupy Wall Street, even the "radical" psychiatrists had a difficult time truly listening to the mad activists—stakeholders without credentials.

After demonstrating in Chapters 3 and 4 that the mad resistance is desperately struggling to be heard, even among the most liberal, progressive and radical contingents, I turn to the question—What would we hear if we listened? What have they been saying for the better part of a decade? Aspects of this new wave of messaging appeared throughout chapters 2-4, but in Chapter 5 I knit together these threads to examine the history, culture and ideology of The Icarus Project, a pivotal grassroots organization

founded in 2002 that is at the forefront of reimagining community-driven mental health activism. The Icarus Project is the organization where my fieldwork was rooted, and both within and beyond the mad movement they are considered the avant-garde of mad activism. The Icarus project exists at the intersection of peer-support, activism, and media production and their birth coincided with the beginning of the Web 2.0 era, the rise of participatory culture and the popularization of digital networked activism. After twelve years of publishing books, films and artwork, hosting voluminous discussion boards and events, this chapter attempts to answer the question: What did The Icarus Project say? I attempt to answer this question by drawing on primary source materials. I examine the media that The Icarus Project and its membership have produced and published, alongside a detailed history of media coverage and an analysis of their communication infrastructure. I will describe how they have utilized digital media and web platforms to help diffuse stigma, redefine personal identity, and resist the relentless advance of the biomedical model of psychiatry. I will demonstrate that their evolving organizational model—whose genealogy can be traced through anarchism, punk, queer pride, harm reduction (“policies, programs and practices that aim primarily to reduce the adverse health, social and economic consequences of the use of legal and illegal psychoactive drugs without necessarily reducing drug consumption” (Harm Reduction International. (n.d.)) and permaculture (“a philosophy of working with, rather than against nature” (Mollison, 1997))—has informed their adoption of media and communication tools, and given rise to new forms of collective action.

I conclude by examining how mainstream psychiatry itself is under attack from forces within the scientific establishment who question the biochemical model of illness and the

utility of the DSM. This dispute poses a challenge for mad activism, too. The activists' messaging must adapt to these changes to remain relevant. Psychiatry is at a critical juncture, and many of the shifts underway challenge the mad movement's goals amid an extraordinary growth in psychiatric and pharmaceutical power. By studying cases that illuminate psychiatry's shifting boundaries we can gain more insight into the movement's ideology and recommend directions for future advocacy. We will see that the wave of mad resistance that I identify in this project is still nascent. It exists in an inchoate form, but has not yet been fully actualized. It is still searching for language and leadership to crystallize its vision, mobilize a broader constituency, and find solidarity with other anti-oppression movements involving, for example, prisoners, veterans, seniors, child advocates and the larger disability rights movement, all of which will be essential for the movement to flourish and prevail.



# Counterfactual Cures: Manufacturing Disease and Dissent

“Drugs! What’d they give you? Thorazine? Haldol? How much?  
Learn your drugs — know your doses. It’s elementary...”

— Jeffery Goines  
12 Monkeys

The transformation in resistance to the psychiatric-pharmaceutical establishment I describe in this dissertation is best understood against the backdrop of the expansive growth in psychiatric diagnosis and treatment witnessed globally over the past two decades (Angell, 2004a; Barber, 2008; Frances, 2014a). The statistics describing this growth tell a powerful and convincing story. To gain a more visceral appreciation of this period of growth it is also useful to closely examine a specific site of psychiatric-pharmaceutical expansion, the diagnosis and treatment of children. The tactics employed by the pharmaceutical industry around the marketing of these new diseases and treatments have become typical, and are employed with other populations—e.g., prisoners, veterans, and seniors—and, around other conditions, such as anxiety, shyness and attention. It is valuable to consider this example in detail to fully appreciate the machinations of this industrial golem.

In this chapter I describe the reinvention of the *pediatric bipolar* diagnosis, and consider the implications of *prodromal diagnosis*, also known as *psychotic risk syndrome*. A prodrome is a symptom, or group of symptoms, that appears shortly before an acute

attack of illness, and a prodromal diagnosis is intended to identify and prevent its full onset. These developments provoke a series of questions whose reach extends beyond the expertise of mental health researchers. Has the behavior of American youth grown more irritable and defiant, or has the adult judgment of their behavior changed? How can we explain the variations in diagnoses around the globe, and across racial and class lines? If there is a dramatic shift in youth behavior, what factors and dynamics might be precipitating these changes? How much risk should people tolerate to avoid potential outcomes? What is the relationship between contemporary media representations and madness? Are alternative explanations for purported shifts in the behavior of children and adolescents being adequately explored? How can we effectively study and explain these dramatic transformations in judgment and behavior? Whose voices and perspectives should be taken into account in deciding these questions?

The research agenda I have outlined demands that we draw upon multidisciplinary approaches using a diversity of methods to effectively explore with these subjects. A comprehensive investigation of this agenda is beyond the scope of this chapter, or even a single dissertation. The abbreviated snapshot I present here is intended to illustrate how complex these issues are, and the ways they intersect across a range of methods and disciplines. The methodological approaches I outlined in the last chapter are suitable candidates for studying these issues, and a mixture of methods including scientific literature reviews, content analysis of media, supplemented by ethnographic studies of the relevant stakeholders are all invaluable ways of knowing that can provide a more holistic and complete grasp of these concerns.

This chapter paints picture of the milieu that surrounds the ethnographic studies I conduct in the upcoming chapters three, four and five. These controversies set the stage for the lives of the activists and mental health professionals I interacted with. Stories like the ones I profile in this chapter are regularly passed around in mental health networks, among activists and professionals alike. In later chapters we will explore alternative explanations and narrations of these conditions neglected by most psychiatric researchers. To more fully appreciate these stakeholder's perspectives, it is essential to share this context.

## 2.1 Bad Pharma

Doctors, academics and journalists have written extensive accounts of disturbing trends in pharmaceutical expansion, and here I will only try to summarize this history in broad strokes. In 2004, Marcia Angell, an American physician, Harvard lecturer, and the first female Editor-in-Chief of the *New England Journal of Medicine*, published a book titled *The Truth about the Drug Companies: How They Deceive Us and What to Do about It* (2004). She described watching the drug companies stray from their original mission to discover healing drugs and become “vast marketing machines” with “nearly limitless influence over medical research, education, and how doctors do their jobs”. David Healy is an Irish psychiatrist and researcher who studies the relationship between antidepressants and suicide, as well as conflicts of interest between pharmaceutical companies and academic researchers. *Pharmageddon*, his most recent book, forcefully argues that drug companies’ drive for profits has led them to overhype the benefits of their products

and downplay their risks, often with deadly consequences (2012). Most provocatively, Peter Gøtzsche, a Danish physician and researcher, and former sales representative for AstraZeneca, convincingly compares the pharmaceutical industry to organized crime syndicates in his book, *Deadly Medicines and Organized Crime: How Big Pharma Has Corrupted Healthcare* (2013). Drawing on published studies and numerous anecdotes, he describes an “extraordinary system failure caused by widespread crime, corruption, bribery and impotent drug regulation”. These books are just a sampling from the long list of works detailing Pharma’s bad faith (Kassirer, 2005; Goldacre, 2012). Taken together they demonstrate the urgency for industry regulation to correct this behavior, and a complete reexamination of how psychiatric knowledge is assembled and evaluated; the lack of any meaningful policy reform helps explain the rise in organized resistance.

In 2002, Americans spent \$200 billion on prescription drugs, and this number has been growing at about twelve percent a year (Angell, 2004). The World Health Organization valued the global pharmaceutical market at \$300 billion in 2015, and expects this to rise to \$400 billion by 2018 (WHO, n.d.). The market is highly concentrated and the top ten pharmaceutical companies control over one-third of the market, with more than \$10 billion per year in sales and thirty percent profit margins (WHO, 2015). In 2010, psychiatric medications were the second-best-selling class of drugs that year, their sales amounting to a combined total of 50 billion dollars (Healy, 2012).

In the five years between 1996 and 2001, the number of prescriptions for psychiatric drugs increased twenty percent per year, resulting in an increase of 5.5 million Americans, and the numbers continue to climb (Zuvekas, 2005). In 2011 Medco Health Solutions published *America’s State of Mind* (2011), reporting that the number of insured Americans

taking medications to treat psychological behavioral disorders had risen to more than 1-in-5 by 2010, an increase of 22% since 2001. The report also showed that more women took drugs for mental health conditions than men, prescriptions to children and the elderly continued to rise, and the use of atypical anti-psychotics soared to 3-4 times its previous rates. In 2009, a study showed that poor children with Medicaid coverage were four times more likely to be prescribed anti-psychotics than a child with private insurance (Crystal, Olfson, Huang, Pincus & Gerhard, 2009).

According to the Roper Center's opinion polls about public attitudes towards mental health, the general population continues to perceive a stigma around mental illness (77% in 1978 compared to 82% in 2002, although in 2004, 55% claimed that the stigma around depression had been significantly lifted), and psychiatrists' reputation for honesty and integrity is significantly lower than other medical doctors, nurses, pharmacists and dentists (Roper Center, 2015). Many believe that, as a society, we are increasingly overmedicated, but the complexity of the political economy driving this expansion and the sophisticated ways this growth is instrumented are easily underestimated (Whitaker, 2010; Gøtzsche, 2013; Frances, 2014a).

This remarkable growth can be traced to the increasing market pressure to create "blockbuster" drugs, defined as drugs whose yearly sales exceed one billion dollars. Blockbuster drugs commonly treat conditions such as high cholesterol, high blood pressure, asthma, diabetes and cancer, and some of the biggest blockbuster drugs are psychotropic (Greenberg, 2008; Herzberg, 2008). Anti-depressants were the first psychotropic drugs to join the billion dollar blockbuster club, with the tricyclic Miltown (*meprobamate*) leading the charge in the 1950s, followed by Valium (*diazepam*) in the

1970s, and Prozac (*fluoxetine*) and Paxil (*paroxetine*) in the 1980s (Herzberg, 2008). The “off-label” use of these drugs contributed significantly to their spectacular success. The term “off-label” is applied to prescriptions made outside the range of FDA approved uses of a drug. Doctors are permitted by law to prescribe any medication they believe is medically appropriate, to anyone, for any condition; however, the FDA must approve a drug for a particular condition and population before the pharmaceutical companies are allowed to market that drug for that usage.

Blockbuster profits spur aggressive tactics for drug companies to expand their bottom line and they exploit the regulatory environment to continue this growth. Drug company charters do not contain anything like the Hippocratic Oath’s adage to “do no harm”, and their only obligation is to maximize shareholder value within the parameters of the law. They advertise to doctors and directly to consumers, pursue aggressive legal strategies to protect and extend their intellectual property, and manage sophisticated marketing campaigns that include funding research, journals, conferences and sponsorships (Huskamp, 2006; Peterson, 2008; Lane, 2008).

The role of advertising and mass marketing in the creation of blockbuster diseases and drugs has been widely investigated and researched, but is still under-appreciated. Melody Petersen, a New York Times reporter who spent over four years on the pharmaceutical beat, published a book in 2008 called *Our Daily Meds: How the Pharmaceutical Companies Transformed Themselves Into Slick Marketing Machines and Hooked the Nation on Prescription Drugs*. In *Our Daily Meds* she details a 17-fold increase in spending on prescription drugs (for all categories) between 1980 and 2003 (Petersen, 2008). In his book *Shyness: How Normal Behavior Became a Sickness* Christopher Lane documents the

sharp rise in disease and drug marketing, with many pharmaceutical product's marketing budgets dwarfing the marketing budgets of Hollywood blockbusters (Lane, 2008). The United States is the only country other than New Zealand where it is legal for pharmaceutical companies to advertise their branded products directly to consumers. Canada allows ads that mention the product or the indication, but not both, and the European Parliament has repeatedly rejected attempts to allow direct to consumer pharmaceutical advertising, even in the form of "information to patients" (Ventola, 2011). In New Zealand, the government is under intense pressure from consumers and professionals to ban the practice (Ministry of Health, 2006).

Direct to consumer advertising became legal in the US in 1985, and really took off in 1997 when the FDA relaxed the requirement to list all side-effects. A content analysis of television commercials in 2007 found that few ads (26%) described causes, risk factors or prevalence, some (18%) portrayed lifestyle changes as insufficient for change, and almost all (95%) included emotional appeals (Frosch, Krueger, Hornik, Cronholm, & Barg, 2007). The title of their paper captures the authors' argument: *Creating Demand for Prescription Drugs: A Content Analysis of Television Direct-to-Consumer Advertising*.

When it comes to mental and lifestyle illnesses, pharmaceutical companies seem to be in the business of manufacturing illnesses for which they also conveniently sell the cure. For example, the 2007 documentary *Does Your Soul Have a Cold?* tells the story of the aggressive, wholesale export of Western definitions of depression to Japan, a culture with alternative understandings and interpretations of social norms (Mills, 2007). Mike Mills, the film's director, traveled frequently to Japan and remembers feeling surprised when his Japanese friend shamelessly took an anti-depressant in front of him (Big Screen

Little Screen, 2007). Mills' film explores the effects of globalization on Japanese culture, which traditionally encouraged the acceptance of suffering and sadness, and frowned upon the pursuit of happiness.

Mills began researching the popularization of mild depression in Japan, spurred by a New York Times article titled “Did Antidepressants Depress Japan?” (Schulz, 2004). What he learned inspired him to create a film documenting the lives of five people living with “*kokoro no kaze*” (soul colds). “*Kokoro no kaze*” is a marketing slogan invented by GlaxoSmithKline to avoid the stigma of the word “*utsubyō*”, the clinical term for severe depression. According to Doug Berger, medical director of the Tokyo Meguro Counseling Center and a consultant to the Japanese pharmaceutical industry, Japan’s “lucrative market” was “significantly lagging” behind western countries in their introduction of psychiatric medications (Berger, 2005). Tooru Takahashi, a psychiatrist who worked for Japan’s National Institute of Mental Health for 30 years, explained, “Melancholia, sensitivity, fragility — these are not negative things in a Japanese context. It never occurred to us that we should try to remove them, because it never occurred to us that they were bad.” (Schulz, 2004). In her article, Kathryn Schultz interviewed Koji Nakagawa, a product manager for GlaxoSmithKline’s blockbuster antidepressant Paxil. Nakagawa explained that direct-to-consumer advertising was illegal in Japan, but the company exploited a loophole and relied on educational campaigns targeting mild depression. He elaborated, “People didn’t know they were suffering from a disease. We felt it was important to reach out to them.” GlaxoSmithKline formulated a simple message: “Depression is a disease that anyone can get. It can be cured by medicine. Early detection is important.” (Schulz, 2004).

The introduction of western norms around depression and sadness is not unique to Japan. Laurence Kirmayer, director of the Social and Transcultural Psychiatry division at McGill's Trauma and Global Health program, published a paper in the *Journal of Clinical Psychiatry* on cultural variations in depression and anxiety. He concludes:

In most parts of the world, people with symptoms related to depression and anxiety do not view their problems as psychiatric... Assuming that psychiatry does have something to offer such patients (this is not certain, but is at least worth testing), the clinician's task involves acquiring sufficient understanding of the patient's point of view and preferences... not only of a patient's ethnocultural backgrounds, but the structure of the health care system they find themselves in and the diagnostic categories and concepts they encounter in mass media and in dialogue with family, friends, and clinicians. (2001)

In the U.S., direct-to-consumer and direct-to-doctor advertising and marketing campaigns continue because they are unregulated, and they work. In countries outside of the U.S., health education and public service announcements are the most prominent forms of health communication. Within the U.S., where pharmaceutical advertising is unregulated, direct-to-consumer pharmaceutical advertising dominates the health communications that the American public encounters (Ventola, 2011). The pharmaceutical companies continue to innovate around peddling influence and persuasion with incredibly subtle and sophisticated marketing efforts. There is an urgent need for more research, regulation and literacy campaigns around the persuasive tactics employed in the marketing of disorders and blockbuster drugs worldwide.

Pharma's marketing campaigns extend beyond traditional blunt advertising, and are also designed to cultivate indirect influence. Pharma-funded speaking fees, research bounties and sponsored presentations generate influence and spawn serious conflicts of

interest. ProPublica, “an independent, non-profit newsroom that produces investigative journalism in the public interest” produces an ongoing transparency project called “Dollars for Docs” that tracks the flow of industry dollars to doctors and other health professionals (Dollars for Docs, n.d.). Launched in 2010, Dollars for Docs now tracks over 4 billion dollars in payments to physicians from over 17 companies. Psychiatrists dominate this database, and they receive more money from drug companies than any other specialty (Wood & Lowes, 2010; Jones & Ornstein, 2015).

To fully appreciate the financial motives behind the expansion into these new markets it is also essential to understand the role of intellectual property law in this information ecology. Pharmaceutical companies are granted patents on their discoveries, guaranteeing them a limited monopoly that is supposed to incentivize innovation. Putting aside the ethics of controlling potentially life-saving drugs, all of these patents eventually expire, falling off the so-called “patent cliff”, leaving drug companies with a gaping shortfall in profits (Hari, 2009). Expanding the diagnostic criteria for treatments extends the patent clock, and gives drug companies more time to reap bumper profits from their drugs. For example, pediatric bipolar diagnoses were popularized just as some ADHD drugs were coming off patent, meaning generic versions would cut significantly into drug companies’ blockbuster sales (DeRuiter & Holston, 2012). The popularization of this diagnosis helped make up for this shortfall by ushering in a surge of sales for atypical anti-psychotics. Anti-psychotics were still under patent, but in the late 1990s were prescribed primarily to the smaller population of schizophrenics. As anti-psychotics were approved to treat new disorders, like depression and bipolar, their patent clocks were reset, staving off the introduction of generic equivalents.

The mid-1990s also marked the beginning of a pattern where drug companies illegally promoted their products off-label using a variety of techniques to suggest that a drug could be used to treat conditions that had not received FDA approval (Peterson, 2008). The statistics of off-label use are not readily available, but a 2006 study estimated that over 20 percent of all overall prescriptions are made off-label, while the percentage of off-label use for specific drugs, including anti-depressants, anti-convulsants and anti-psychotics might range as high as 50 percent (Radley, Finkelstein & Stafford). The authors of this study report that very little is known about the frequency of off-label prescriptions, and their methods relied upon analyzing a statistically representative sample of physician reported diagnoses alongside their prescriptions. If some doctors reported diagnoses tailored to match their prescriptions, these numbers may under-represent the occurrence off-label prescriptions. Obtaining FDA approval is an expensive and lengthy process, involving multiple rounds of human trials. Off-label prescriptions are common, and often some research has been conducted on the safety and effectiveness of a drug when used off-label.

In 1996 David Franklin blew the whistle on Pfizer's off-label promotion of Neurontin (*gabapentin*), a drug approved to help control epileptic seizures that was being prescribed for bipolar disorder, post-traumatic stress disorder, insomnia, restless legs syndrome, hot flashes and migraines with sales of \$2.7 billion in 2003 (Angell, 2009). Pfizer paid academics to endorse off-label uses by attaching their names to journal articles where these uses were described, and by funding conferences where these off-label uses were presented. In a lawsuit filed in a Boston district court under the False Claims Act (2010), Pfizer settled for \$430 million.

The Neurotin case kicked off a string of lawsuits and record settlements: Bristol-Myers Squibb settled for \$515 million (The US Department of Justice, 2007), Pfizer settled for \$2.3 billion (The US Department of Justice, 2009), Eli Lilly settled for \$1.415 billion (The US Department of Justice, 2009), AstraZeneca settled for \$520 million (The US Department of Justice, 2010), Abbott Labs settled for \$1.5 billion (The US Department of Justice, 2012), GlaxoSmithKline settled for \$3 billion (The US Department of Justice, 2012), and Johnson and Johnson settled for \$2.2 billion (The US Department of Justice, 2013). These settlements all involved similar infractions around the off-label marketing of their products, including the psychiatric drugs Abilify (*aripiprazole*), Godeon (*ziprasidone*), Zyprexa (*olanzapine*), Seroquel (*quetiapine*), Depakote (*divalproex sodium*), Paxil (*paroxetine*), and Risperdal (*risperidone*), respectively. While the settlements were astronomical, they were dwarfed by the drugs' profits, and industry analysts are unsure if the fines will deter future infractions. They may simply be considered the price of doing business (Bobelian, 2013).

## 2.2 Early-onset Misconduct

Zooming in from these broad highlights on the workings of the pharmaceutical industry, this past decade has witnessed a profound shift in our collective judgment of behavior in children in the U.S., as childhood and risk itself are increasingly pathologized. The explosive rise in the controversial diagnosis of pediatric bipolar has received some coverage in the mainstream media, but these stories often serve to popularize the condition and neglect a deeper skepticism around its justification and treatment (Carey,

2007; Wallace-Well, 2009). Beyond prescribing kids Ritalin because they can't stop fidgeting, psychiatry has supplemented attention disorders with a more serious diagnosis and stronger, riskier treatments. With the profusion of bipolar diagnoses in children and its common treatment with powerful and dangerous atypical anti-psychotic medication, significant numbers of adolescents and teens are being chemically swaddled and sedated. Parents are under increasing pressure from teachers and other parents to "correct" their children's behavior with potent mind- and mood-altering drugs, often with devastating side-effects (Yan, 2008). Perhaps most worrisome is the growing tendency towards preventative treatment, and the call for earlier and earlier preemptive interventions before serious problems have manifested.

In 1995, a team of researchers affiliated with Harvard Medical School and Massachusetts General Hospital published a landmark paper arguing that early-onset bipolar was far more common than previously thought (Wozniak & Biederman, et al., 1995). Biederman and Wozniak, who helped redefine the disorder and were at the forefront of the popularization of early-onset bipolar, developed their hypothesis to help explain treatment-resistant children in Biederman's ADHD clinic. They noticed that many of the children who did not respond to standard ADHD medications exhibited anger issues, as well as child-parent interaction problems. The researchers wondered if these difficult to treat children were grappling with more serious mood disorders, not impulse control. These difficult cases did not respond to standard ADHD medications, but did respond to standard bipolar medications, leading the researchers to reconsider their diagnosis. Biederman characterizes the state of the children he treats as dire: "We need to treat these children. They are in a desperate state... It's not that somebody comes to me after

their child has a temper tantrum. They do things for years that are dangerous. These are things that profoundly affect the child,” such as putting at risk their academic record, substance abuse or even suicide (Allen, 2007).

Psychiatric literature dating back to the 1920s documented a very small percentage of adult patients diagnosed with bipolar who recalled manic symptoms dating back to childhood. Child-onset mania was considered extremely rare. Wozniak and Biederman argue that “juvenile mania may be common among referred children with severe psychopathology but that it may be difficult to diagnose”. They point out that “developmental variations” have been made to accommodate the diagnosis of major depression in children, but that no such accommodations had been accepted for childhood mania. They proposed that the clinical picture of mania in children overlapped with the symptoms of Attention Deficit and Hyperactivity Disorder (ADHD), and was “predominantly irritable and mixed, and the course was chronic [instead of episodic]”. They acknowledged that severe irritability was common in children, but differentiated “the type of irritability observed in our children with mania-like symptoms was very severe and often associated with violence... assaultive when irritable... resulting in throwing and breaking things, kicking down doors, and destroying property... ‘affective storms’”.

Prominent psychiatrists also advanced theories that went beyond the diagnosis of existing symptoms. With rationales that echo the prodromal theories I will return to later this chapter, leading researchers advocated for the treatment and prevention of *future* episodes. In 2002 Time magazine ran a cover story called “Young and Bipolar” (Kluger & Song) featuring Demitri Papolos, the research director of the Juvenile Bipolar Research Foundation and co-author of the bestselling book, *The Bipolar Child* (Papolos

& Papolos, 1999). Papolos, who believes a characteristic pattern in bipolar children is difficulty waking up in the morning, says, “if you don’t catch it early on it gets worse, like a tumor.” Kiki Chang, the director of the pediatric bipolar-disorders program at Stanford says: “We are interested in looking at medication not just to treat and prevent future episodes, but also to get in early and — this is the controversial part — to prevent the manic episode.” Chang explains the “kindling theory” of mania, as the justification for the urgency of prevention: “Once you’ve had a manic episode, you’ve already crossed the threshold, you’ve jumped off the bridge: it’s done. The chances that you’re going to have another episode are extremely high.” (Egan, 2008). From the start, pediatric bipolar has been closely associated with preventative treatment and has incorporated the logic of prodromal diagnoses.

The stakes of receiving this diagnosis are high. A psychiatric diagnosis is more than just an esoteric game of medical nosology. Bipolar is understood as a chronic, lifelong disorder, and children receiving this diagnosis are advised to continue pharmaceutical treatment for life. The first-line treatments for childhood bipolar are atypical-antipsychotics, drugs that have been shown to have dangerous side-effects including massive weight gain, metabolic disorders, *tardive dyskinesia*, and diabetes (Ücok and Gaebel, 2008; Yan, 2008). The first-line treatments for adult bipolar are the relatively safer mood stabilizers such as Lithium (*lithium carbonate*) or Depakote (*divalproex sodium*) (Kowatch, Strawn & Sorter, 2009).

Not all psychiatrists agree with Biederman and Woziak’s explanation. In a chapter titled “Bipolar in the Preschool Period” appearing in a definitive volume on the development and course of bipolar across the lifespan, the authors explain a central

disagreement about the diagnosis of mania in children (Luby, Belden & Tandon, 2010). Some psychiatrists believe that children need to manifest discrete episodes of mania, as seen in adults, to meet the formal criteria for the diagnosis. Others believe that the temporal dimensions of the disorder should be adapted for children, allowing for rapid or continuous outbursts to qualify as episodes. Finally, others accept Biederman's and Wozniak's assertion that the classic symptoms of euphoria and grandiosity are replaced with severe irritability in children. These nuances are frequently neglected in studies and practice, creating great uncertainty about the prevalence and application of this diagnosis.

Proponents of the diagnosis believe that the number of bipolar children has not grown in recent years, rather we have gotten better at diagnosing it (Kluger & Song, 2002). Critics point out that there is no evidence that children diagnosed with bipolar manifested the disorder when they grew up, and that many adults with bipolar diagnoses did not report having uncontrolled anger issues when they were young (Stringaris & Goodman, 2009). Nonetheless, the diagnosis of pediatric bipolar took off. Gabrielle Carson, a psychiatric researcher at Stony Brook University, characterizes the “bipolar controversy” as the question of “whether a broader definition of mania with less clear-cut episodes and more concurrent comorbidity [specifically, ADHD] represents a developmentally altered condition which will change in adulthood, or a condition which, because of its earlier onset, has a worse prognosis” (Carlson, 2011). She believes that labeling children bipolar became popular for non-scientific reasons. Carson thinks that many of the children diagnosed with bipolar used to be labeled with conduct disorders, a condition resulting from “bad parenting, lousy environment, poor supervision”, and one

that insurance companies will not reimburse (Spiegel, 2012). She thinks that when clinical psychiatrists were encouraged to think of these behaviors as “bipolar” they thought “Heck, if that’s what it is, we have a bunch of medicines that are supposed to be helpful for mania — maybe I can make it better.” Some parents also found the diagnosis somewhat liberating, since its biological nature was perceived to be context-independent and relieved them of blame for their children’s conduct.

There is evidence that other contributing factors may have influenced Biederman’s tireless efforts to promote the pediatric bipolar diagnosis. As part of a congressional investigation into potential conflicts of interest between academic researchers and pharmaceutical companies, Senator Charles Grassley uncovered that Biederman failed to disclose to his employer over \$1.6 million in consulting fees from drugmakers earned between 2000 and 2007 (Harris and Carey, 2008). Emails disclosed in a lawsuit, filed by parents who claimed Johnson & Johnson’s Risperdal caused injury to their children, reveal Biederman in conversation with marketing executives at Johnson & Johnson. These emails imply that Biederman submitted ghost written papers for publication in scientific journals, and accepted payments to participate in Johnson & Johnson’s Center for Education in the Study of Pediatric Bipolar (Harris, 2008). One email from Biederman assured Johnson & Johnson that *planned* studies “will support the safety and effectiveness of risperidone [Risperad] in this age group,” effectively guaranteeing the outcome of the study before it was ever conducted (Harris, 2009).

## 2.2.1 Where Science Meets Hope

In recent years one organization has tried to position itself at the center of this conversation, with a strong belief in the power of science and data to find an answer. The Child Mind Institute (CMI) was founded in 2009 by Dr. Harold Koplewicz, a psychiatrist and former NYU professor who is “committed to finding more effective treatments for childhood psychiatric and learning disorders, building the science of healthy brain development, and empowering children and their families with help, hope, and answers.” (Child Mind Institute, n.d.). CMI has raised hundreds of millions of dollars in donations and funding, without accepting donations from pharmaceutical companies. Kaplowicz also runs a twin, for-profit clinical consultancy alongside the foundation, which primarily treats the children of the power elite, for rates listed at \$1000 a session (Ellin, 2011). CMI’s gala fundraisers have featured politicians and celebrities including Hilary Clinton, former New Jersey Governor Jon S. Corzine, Robert De Niro, Jimmy Buffet, Dr. Ruth Westheimer and George Stephenopoulos (Ellin, 2011; Child Mind Institute, n.d.).

Koplewicz’s mission in life “is to remove any stigma from mental illness among children and teenagers, make it merely something to be managed and overcome as it was with dyslexia or attention deficit disorder before it.” (Ellin, 2011). He explains CMI’s philosophy and mission:

We have patients, in our case children and adolescents, who desperately need help. These children may be out of control, overwhelmed by anxiety, dangerously aggressive, disorganized in their communication, floundering in school. We need to help them. Medications, often along with behavioral therapy, can have a transformative effect... Furthermore, falling back on pure non-pharmacological treatment is not the

better alternative, since these treatments have rarely undergone objective evaluation.  
(Koplewicz, 2011)

The Child Mind Institute's messaging is consistently pro-medication, and their anti-stigma campaigns wrap this message in a veneer of upbeat packaging. In the same breath they argue against stigma, they simultaneously promote language and framing that endorses the biomedical model of children's suffering. CMI regularly runs print advertising campaigns to raise awareness and reduce stigma around childhood mental illness. In 2012 they rented a gigantic billboard outside of Penn Station, in one of the busiest intersections in New York City, depicting children frolicking in a park with a tagline proclaiming that CMI was where "science meets hope". A similar billboard campaign plastered New York's remaining phone booths depicting an adolescent girl on a stool, surrounded by a thought bubble of fantasies (e.g., "Travel to Fiji", "I want to be a designer", "Help my community"), with the tagline "Children's Mental Health Matters—help all children realize their potential". These messages are on the surface positive, or at worst, innocuous. It is easy to imagine why so many politicians, industry leaders, and celebrities have endorsed this feel-good cause.

CMI's "symptom checker tool", available on their web site and intended to help parents learn more about children's mental health disorders, reveals their bias. The tool presents parents with a checklist of behaviors, of the form "My child is..." Descriptors include: disobedient, impulsive or hyperactive, having problems in school, has sleeping problems, has trouble paying attention, has excessive fears, worries, or very unusual thoughts, etc. (Child Mind Institute, n.d.). Depending on your selections, more detailed behavioral descriptions follow, along with a chance to share your family's psychiatric

history. The branching paths all lead to additional information about a dozen different disorders, including major depressive disorder, somatic symptom disorder, conduct disorder, panic disorder, bipolar disorder, oppositional defiant disorder, and separation anxiety disorder. While the tool repeatedly encourages parents to seek the advice and diagnosis of a professional, none of the paths lead away from diagnosable disorders, and all paths through the survey lead parents to think about their children's behavior within the bio-medical model CMI promotes.

To complicate the story further, Koplewicz was one of the co-authors on the infamous "Study 329" (Keller et al., 2001), a clinical trial conducted between 1994 and 1998 to study the effectiveness of Paxil (*paroxetine*) in children. The article was ghost-written by an industry sponsored public relations firm, and was crafted to downplay the study's findings (McGoey and Jackson, 2009). It deceptively inflated the efficacy of the drug, which was no more effective than a placebo, and covered up side effects appearing in adolescent subjects such as suicidal thinking. This study prompted New York Attorney General Elliot Spitzer to file suit against GlaxoSmithKline for fraud, since they had selectively withheld evidence of unsuccessful trials and negative side-effects (Harris, 2004). This study later became central evidence in the \$3 billion federal settlement against GlaxoSmithKline (The US Department of Justice, 2012). One hopes that the "objective evaluations" Koplewicz wishes for non-pharmacological treatments conform to a higher standard than study 329.

Biederman and Koplewicz are two of psychiatry's leading voices promoting a reevaluation of how society judges and treats childhood behavior. They shroud themselves in the objectivity of science, and seem uninterested in the range of causes that may underlie

the irritability and behavioral misconduct they recommend treating pharmacologically. Systemic adjustments to children's nutrition, sleep, stress, poverty, oppression or education are not their primary concern. They are satisfied with biological and genetic explanations as the penultimate cause, and rarely explore environmental causal chains. The scandalous patterns of borderline-legal, conflicts-of-interest and cover-ups contribute to feelings of cynicism among activists. Psychiatrists' righteousness and self-confidence is especially troubling. From their writings, both Biederman and Koplewicz come across as true believers who genuinely want to help children and prevent suffering. Perhaps, if their teams were composed of interdisciplinary specialists alongside patients, peers and activists these star researchers might cede some of their objectivity-fueled confidence, and start paying more attention to the causes and implications of the treatments they promote. The treatments they trumpet create a great deal of misery and the outcomes of this cost-benefit analysis are far from clear.

### 2.2.2 Atypical Childhoods Lost

Challenging psychiatric methods and paradigms, questioning the validity of pharmaceutical research, and protesting the political processes of mental health policy, are nothing new. What is new here is the heightened focus on childhood behaviors and preemptive interventions. As a category, the diagnosis and treatment of children is a highly provocative topic. As with other human rights issues such as shoddy labor conditions, extreme poverty, disease and hunger, all suffering is deplorable; even more so when the sufferers are children. Children continue to be regarded as innocent, and without the ability to

fully consent to treatments the moral responsibility for their well-being falls on their parents, doctors and teachers. Children can never truly grant consent around any form of treatment, and their power to consent is entrusted to their parents or guardians. Our collective projections of our own failures coupled with the opportunity to redeem the next generation raise the ante around these issues.

Before presenting more facts and statistics about the rise of pediatric bipolar, I will introduce a few powerful anecdotes that vividly illustrate the human contours of this growing controversy. Consider the case of Rebecca Reily, a four-year-old girl in Boston who died on December 2006 after an overdose of the anti-psychotic *Seroquel*, administered by her parents (Creamer and Mishra, 2007; Couric, 2007). Her parents were both charged with murder and, at their trial, claimed they were following doctor's orders. They had obtained SSI benefits for the siblings and for themselves, to the tune of \$30,000 per year, and were applying for Rebecca's benefits when she died. Her mother was found guilty of second-degree murder, and her father was convicted of first-degree murder, and both were sentenced to life in prison (Lambert, 2014). Rebecca's psychiatrist, Dr. Kayoko Kifuji, diagnosed her with attention deficit and hyperactivity disorder and bipolar disorder whens she was just *two and a half years old*, and prescribed a powerful cocktail of psychotropic medications. Dr. Kifuji's license was not suspended, although she voluntarily suspended her practice pending the resolution of the outstanding civil and criminal charges (Wen, 2009). Her hospital has issued the statement: "The care we provided was appropriate and within responsible professional standards" (Creamer and Mishra, 2007). As we will see in this chapter, the appropriate professional standards for diagnosing and treating children's behavior have shifted dramatically this past decade.

However, even advocates for diagnosing adolescents and children with bipolar are skeptical about the validity of diagnosing toddlers with this condition.

Sadly, this case is not an isolated occurrence. Reports surfaced in 2006 about another three-year-old girl, Destiny Hager, who died in April 2006 of complications resulting from known side-effects of the antipsychotics *Seroquel* and *Godeon* (Carpenter, 2009). An autopsy of the 38-lb girl revealed “antipsychotic drugs present in concentrations considered therapeutic in adults” (Carpenter, 2009). Her psychiatrist, Vernon Kliewer, who had been practicing children’s psychiatry for over fifty years, was investigated by the Kansas Board of healing arts for his treatment of Destiny and five other children aged two to five years old. Kliewer negotiated a settlement that didn’t require him to admit any wrongdoing, and he has voluntarily stopped treating patients under age six (Carpenter, 2009).

In January 2008, PBS Frontline aired an hour-long documentary called *The Medicated Child*, profiling the lives of three children diagnosed between four to six years old with bipolar disorder (Garvilia, 2008). The children and their families were all struggling with devastating side-effects and complications, such as involuntary tics and spasms (*tardive dyskinesia*) and extreme weight gain, resulting from their treatment. The documentary argued that a massive public health experiment is currently being conducted on the nation’s youth, without anyone’s informed consent (Garvilia, 2008). In one segment a mother was feeding her son corndogs, Gatorade, Goldfish crackers, and cookies, while she complained on-camera about his erratic hyperactive behavior. For decades studies have suggested links between junk food and hyperactivity in children, and evidence continues to accrue that artificial food coloring causes ADHD symptoms (Arnold, Lofthouse & Hurt,

2012). The filmmakers probably included this shot to call attention to the irony of the son's diet, his mother's complaints about his behavior and the failure of his treatment team to explore these connections.

In one segment, a psychiatrist goads a young girl into sharing her violent fantasies, though the doctor fails to explore the connections to her father's trauma as an Iraqi war veteran. In another, a mother makes an appointment to reduce her son's medications but is told by their psychiatrist that drugs are the only therapeutic option. She leaves the office with an additional prescription for Xanax to relieve her son's first-day-of-school anxiety.

These anecdotes are not meant to imply that all children receiving diagnoses are grappling with superficial problems, or are being harshly punished for their misconduct. There are many reports of cases where children exhibit extremely violent and threatening patterns of behavior, including explosive rage, biting, punching, kicking and even knife wielding (Kluger & Song, 2002; Egan, 2008). Parents have banded together in online and in-person support groups, and report violent and aggressive behavior that includes violent threats, self-harm, and serious assaults (Papolos & Papolos, 2007). Some parents have exhausted alternatives to medication, feel genuinely threatened and unsafe, and are at a loss for how to help their children. However, these extreme cases mask the more common occurrence of the medicalization of misconduct and the role of drugs in punitive discipline. Just as mild depression was popularized by drug companies in Japan, childhood moodiness and irritability is being marketed as a medical condition in the U.S.. For the ordinary psychiatrist, school psychologist, social worker or foster parent in the

field, the spectrum of symptoms is confusing, and the reliability of diagnoses is known to vary tremendously (Egan, 2008).

In the course of my fieldwork, I met numerous people who felt they were wronged by psychiatry, their lives rendered miserable through side-effects and neglect. Many believe they are better off without psychiatric care, though many ambivalently continue to seek treatment, albeit at arm's length. Over my years of fieldwork, a disturbing trend I noticed was that people I met had entered the system at younger and younger ages. Many could not remember a time in their lives that they were drug-free. My observations corresponded with a nationwide surge in the diagnosis of children as mentally ill and dramatic increases in prescriptions of psychotropic drugs to treat them, which I detailed earlier in this chapter (Medco Health Solutions, 2011). The statistics tell an important story, but it was not until I met people unable to remember a time they were drug-free that I began to understand the full implications of these numbers on people's lives.

The atypical anti-psychotics prescribed for childhood bipolar are hardly innocuous. Common side-effects I have already mentioned include massive weight gain, metabolic disorders, diabetes, tardive dyskinesia. In November 2008 *The Wall Street Journal's* health blog reported on a class action lawsuit brought against Jansen (owned by Johnson & Johnson) for the side-effects of their antipsychotic *Risperdal* causing *gynecomastia*, or excessive male breast growth, in ten young boys (Mundy, 2008; Couric, 2009). Boys ranging from four to fourteen years old have been prescribed *Risperdal* for ADHD and bipolar disorder, and have developed female breasts that can only be treated with mastectomies.

These stories are horrifying, but they are not exceptions. In 2007 in Florida 23 infants under 1 years old were prescribed antipsychotics, prompting a perfunctory review process for all Medicaid prescriptions of antipsychotics to children under six (Hundley, 2009). Between 1994-2003 the diagnosis of bipolar in American children and adolescents has jumped 40-fold, or 4000 percent (Carey, 2007; Moreno, Laje, Blanco, Jiang, Schmidt, & Olfson., 2007). This statistic is somewhat misleading since the absolute number of children, ages 0-20 receiving this diagnosis in 1994 was small (25 out of 100,000, or a total of about 16,000), but the rate of increase was enormous (jumping to 1003 out of 100,000, or a total of about 725,000) (The United States Census Bureau, n.d.). The authors of this study based their estimates on a statistically meaningful sample (N=962) of the National Ambulatory Medical Care Survey. They lament that “[t]here is currently a dearth of information concerning national trends in the diagnosis of bipolar disorder among children and adolescents and the treatments that these young people receive.”

Since then, estimates of children's diagnoses have proven more challenging to discover, as researchers have begun tracking atypical-antipsychotics, prescribed for any indication, including ADHD, autism, bipolar, oppositional defiance disorder, and the newly coined Temper Dysregulation Disorder. The Medco report on *America's State of Mind* (2011) states that the number of 10-19 year olds prescribed anti-psychotics is now around 1% (or about 420,000 teens), double the number from a decade earlier, an increase of 106% for boys and 139% for girls (The United States Census Bureau, n.d.).

In an opinion piece published in the journal of *Child and Adolescent Psychiatry and Mental Health*, Gabrielle Carlson attributes this surge in diagnoses to increased coverage in the mainstream media. She cites books such as the bestselling The Bipolar

Child (Papolos & Papolos, 2000), which is now in its third edition and has sold over 200,000 copies, according to Amazon. The author's web site, bipolarchild.com, publishes a newsletter, sells accompanying DVDs and invites visitors to request consultations and referrals. Both Carlson and the authors of the 2007 study credit the 2002 *Time* magazine cover feature on "Young and Bipolar" (Kluger & Song, 2002) for a surge in public awareness. Finally, the authors of the 2007 study cite a 2003 *CBS Evening News* broadcast that profiled a child misdiagnosed with ADHD, whose situation greatly improved when he received his bipolar diagnosis, and switched from taking Adderall to Lithium (Holguin). These authors do not offer any specific evidence that this media coverage caused the surge in diagnoses, but they do report anecdotal evidence of parents citing these media sources, and others like them, when visiting psychiatrists and primary care physicians.

Psychologists such as Ross Green, author of *The Explosive Child* (2007) and Mary Kurcinka, author of *Raising Your Spirited Child* (1998) advocate for dealing with childhood misconduct by introducing alternative language, mediation styles and parenting techniques. Alternative explanations for irritability in children abound, as studies have shown that improved nutrition can reduce violence and behavioral unrest in prisons and schools (Laurance, 2008), and research demonstrates that sleep deprivation leads to hyperactivity and irritability (Brody, 2007). They do not rule out the use of pharmaceutical treatments, but believe they are being overprescribed, and are only one piece of a larger puzzle. Ultimately, no one really has a simple solution dealing with these troubled youth, and each case presents unique difficulties and challenges.

As Mary Kurchinka explains in *Raising your Spirited Child*, language and labels are extremely powerful (Kurcinka, 1998). We always have a choice to describe identical behaviors with words that carry different connotations. Are children acting: explosive/spirited, demanding/high standards, unpredictable/flexible, loud/enthusiastic, argumentative/opinionated, stubborn/assertive, nosy/curious, wild/energetic, manipulative/charismatic, impatient/compelling, anxious/cautious, explosive/dramatic, picky/selective, distractible/perceptive (Kurcinka, 1998)? These simple descriptive choices construct and perpetuate vastly different worlds. They communicate expectations as well as reinforce condemnation or support.

According to Lloyd deMause, a prominent psychoanalyst and historian of childhood, child abuse extends deeply and broadly throughout human histories and cultures, and is far more widespread than most of us are prepared to admit (DeMause, 1982). The notion that parents and teachers are receiving a blessing from medical authorities to “shut their kids up” is an important concern not to be dismissed out of hand. Similarly, structural biases such as racism, classism and oppression continue to correlate strongly with treatment practices and outcomes (Link & Phelan, 1995; Metzl, 2010, 2014; Linares, 2013).

### 2.2.3 Diagnostic Wormholes

During this period of rampant increase in the treatment of pediatric bipolar, it needs to be noted that the diagnosis did not exist in the then current version of the Diagnostic Statistical Manual, DSM-IV-TR, the official guide to mental disorders published by

the American Psychiatric Association. According to the DSM-IV-TR, bipolar was only recognized in patients older than 18. This period witnessed the manufacturing of a new disease, a common occurrence when releasing new versions of the DSM, but rare between editions.

The antipsychotics administered to these children were prescribed “off-label” (Shekelle et al., 2007). As the record-breaking court settlements described earlier indicate, drug companies have been involved in numerous scandals around marketing drugs for off-label uses. A 2009 study found that between August 2006 and July 2007, 37 percent of prescriptions for anti-psychotic drugs were written by family doctors—general practitioners, not psychiatric specialists (Morgan).

In summer 2008 the FDA legislated pediatric bipolar into existence so that clinical trials could proceed prior to the publication of the DSM-5 in 2013 (Dawdy, 2008). Philip Dawdy is an investigative journalist who worked as a staff writer for the Seattle Weekly until 2006, and won numerous awards for his mental health reporting, including an award from the National Mental Health Association in 2005-2006 (Dawdy, 2007). Between 2005 and 2010 he published *Furious Seasons*, a popular and influential mental health blog with a vibrant community and a readership in the thousands. In the summer of 2008, *Furious Seasons* was a major news hub in the mental health network, and the site brought together activists, mental health professionals, and industry experts. Dawdy regularly published multiple stories a day, sometimes critiquing mainstream Pharma coverage, and often publishing original reporting. The FDA evaded inquiries demanding a definition of the disorder, and finally supplied thin, circular evidence for its existence (Dawdy, 2008). In 2008, the FDA's press secretary, Sandy Welsh wrote an email to

Dawdy in an apparent response to an email campaign from his readers demanding an explanation:

The FDA does accept the validity of pediatric bipolar disorder. The FDA agrees with peer-reviewed journal articles, academics and clinicians that say that pediatric bipolar disorder can occur in children and adolescents and is a serious, chronic illness which causes shifts in a person's mood, energy, and ability to function.

The FDA, a science-based agency... according to the National Institute of Mental Health: Research findings, clinical experience, and family accounts provide substantial evidence that bipolar disorder, also called manic-depressive illness, can occur in children and adolescents. Bipolar disorder is difficult to recognize and diagnose in youth, however, because it does not fit precisely the symptom criteria established for adults, and because its symptoms can resemble or co-occur with those of other common childhood-onset mental disorders. In addition, symptoms of bipolar disorder may be initially mistaken for normal emotions and behaviors of children and adolescents. But unlike normal mood changes, bipolar disorder significantly impairs functioning in school, with peers, and at home with family. (Dawdy, 2008)

In her email, Welsh cites a narrow range of studies justifying the equivalent diagnosis of mania for children who manifest different symptoms than adults. They show that children and adults responded to the same bipolar medications, in this case, the anti-psychotics *Abilify* and *Risperdal*. In one longitudinal study she cites titled "Clinical course of children and adolescents with bipolar spectrum disorders", the researchers bootstrap the illness by presuming it exists, and then, designed studies to track its predictors and course (Birmaher et al., 2006). Welsh also cites a meta-study endorsed by the American Academy of Child and Adolescent Psychiatry (McClellan, 2007) which itself states:

[It is not] clear whether the atypical forms of juvenile mania and the classic adult form of the disorder represent the same illness. The debate and controversy over juvenile bipolar disorder are not whether there are a significant number of youths who are explosive, dysregulated, and emotionally labile or whether these youths suffer significant impairment or are at risk for a variety of adverse outcomes, including substance abuse. These difficulties and concerns are commonplace, especially in

community mental health settings and systems of care that deal with at-risk youths (e.g., juvenile justice, foster care). The debate is whether these problems in youths are best characterized as bipolar disorder and, more important, whether juvenile mania is the same illness as that classically described in adults. (McClellan, Kowatch & Findling, 2007)

Critics of the FDA's decision claim they based their decision on a relatively small number of trials whose lead authors were part of a "cabal" advocating for the recognition of pediatric bipolar, including Biederman, Wozniak and Carlson. It is no surprise that influential psychiatric researchers were cited in the studies—their labs are extraordinarily successful, and their papers are cited widely. What is most disappointing is that the meta-study did not adequately represent psychiatrists opposed to approving the disorder. Instead of calling for further studies, or a provisional approval pending clinical trials to proceed, the FDA pulled the trigger and approved the condition without further debate. As a reminder of the stakes, their own list of recommendations includes the warning that "Most Youths With Bipolar I Disorder Will Require Ongoing Medication Therapy to Prevent Relapse; Some Individuals Will Need Lifelong Treatment" (McClellan, Kowatch & Findling, 2007).

In 2007 the FDA approved Johnson & Johnson's *Risperdal* for use in children as young as ten, and the approval for Bristol-Myers Squibb's *Abilify* followed in 2008 (Office of the Commissioner, 2007). In 2009 an FDA advisory panel backed the expanded use of three commonly prescribed antipsychotic drugs for children—Lilly's *Zyprexa*, AstraZeneca's *Seroquel* and Pfizer's *Geodon* (Dawdy, 2009). As mentioned above, common side-effects for this class of drugs includes massive weight gain, metabolic disorders, *tardive dyskinesia*, and diabetes. Multiple class action suites are underway alleging

damages for their use (Ücok and Gaebel, 2008). The long-term effects on developing children are still unknown (Heavy, 2009).

Even within the psychiatric community, there is little consensus about pediatric bipolar diagnoses and treatments. All the way back in 2000, psychiatrist Dr. Lawrence Diller wrote the following in a story published by Salon.com. The situation has worsened dramatically since then.

Diagnosing bipolar disorder in children as young as 3 has become the latest rage. It justifies using a host of medications to treat very difficult-to-manage, unhappy children. The old-line drug, lithium [previously approved for children older than 12], has been replaced by newer, untested (in children) mood stabilizers like Neurontin or Depakote as a first-choice intervention for pediatric “manic depression.” Finally, a new class of anti-psychotic medications—the most popular these days is Risperdal—is heralded as the ultimately effective treatment for a number of diagnoses whose common features are not hallucinations or psychosis, but severe acting-out behaviors.

More than 200,000 children receive anti-psychotic medications, mostly to control unruly behavior rather than to treat hallucinations or other symptoms of schizophrenia.

No other society prescribes psychoactive medications to children the way we do. We use 80 percent of the world’s stimulants such as Ritalin. Only Canada comes close to our rates, using half, per capita, the amounts we do. Europe and industrialized Asia use one-10th of what we do. Psychiatrists in those countries are perplexed and worried about trends in America. The use of psychoactive drugs other than Ritalin for preteen children is virtually unheard of outside this country. (Diller, 2000)

A handful of academic researchers (Crystal et al., 2009), activists and independent journalists, such as Dawdy, have been closely following these developments. As we discussed above, mainstream media outlets lightly covered the controversy, often functioning more as cheerleaders from the sidelines. They have tracked and documented the dramatic increases in childhood diagnoses and prescriptions, and raised concerns over the long-term safety of these drugs due to their serious side-effects and known

developmental and metabolic issues. They have pointed out the discrepancies between American and international diagnoses (Lane, 2009), as well as the more aggressive prescription patterns for children covered by Medicaid versus those covered by private insurance (Martin et al., 2002). Despite this, the rates of diagnoses and prescriptions continue to surge (Wilson, 2009).

Pediatric bipolar is a disorder that never existed in DSM-IV-TR, does not exist as a distinct diagnosis in DSM-5, and is presented as a part of the main bipolar disorder entry as if it had always existed. In the years leading up to the release of DSM-5, the FDA approved clinical trials for the distinct ‘pediatric bipolar’ diagnosis, but it has since been folded into the criteria for ordinary bipolar disorder. The DSM-5 description of bipolar now includes caveats that only apply to children, such as the indications for depressive episodes:

Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad, empty, or hopeless) or observation made by others (e.g., appears tearful). (**Note:** In children and adolescents, can be irritable mood.)  
(American Psychiatric Association, 2013)

Or, the paragraphs explaining the differences in the ways mania presents in children:

In children, happiness, silliness and “goofiness” are normal in the context of special occasions; however, if these symptoms are recurrent, inappropriate to the context, and beyond what is expected for the developmental level of the child, they may meet [the criterion for a manic episode]... In children, overestimation of abilities and belief that, for example, they are the best at a sport or the smartest in the class is normal; however, when such beliefs are present despite clear evidence to the contrary or the child attempts feats that are clearly dangerous and, most important, represent a change from the child’s normal behavior, the grandiosity criterion should be considered satisfied. (American Psychiatric Association, 2013)

In another last minute play, the editorial board of the DSM-5 incorporated in their 2010 draft an entirely new childhood disorder: *Temper Dysregulation Disorder (with Dysphoria)* (TDD). It was proposed in response to the criticism of the over-diagnosis of bipolar in irritable children, meant to provide an escape valve for doctors who did not want to saddle a child with the stigma of a bipolar diagnosis. A number of psychiatrists published their concerns with the last minute addition to the manual:

We believe that currently there is insufficient scientific support to include TDD as a unique diagnostic entity. Furthermore, we believe that the inclusion of TDD will have an adverse impact on patient care, research, and the general public's perception of child psychiatry. (Axelson et al., 2011)

Their main criticisms were that the disorder “is a symptom, not a syndrome”. The diagnosis overlaps extensively with existing disorders, and the criteria do not provide any way to distinguish between TDD and the co-occurrence of severe explosive outbreaks in mood, anxiety, conduct and autism spectrum disorders. They feared that the media implied the diagnosis would lead to more psychosocial treatments, but they acknowledge the cynical likelihood that “the rationale that TDD will reduce the inappropriate use of medication in children and adolescents with temper outbursts also seems at odds with perceptions of how the pharmaceutical industry approaches the *DSM*.“ Given pharma’s modus operandi, TDD might begin as a way for children to avoid a bipolar diagnosis and the accompanying anti-psychotic treatments, but would soon have similar treatment recommendations. Finally, they demonstrate an awareness and concern over the reputation of child psychiatry in the media:

The media is rife with charges that psychiatry pathologizes normal behavior and turns misbehavior and character flaws into medical disorders, thereby absolving

individuals from responsibility for their actions. Skeptical and humorous reports have already surfaced in the media about how temper outbursts in children are now going to be classified as a disease and that the *DSM-5* will have a “temper-tantrum” disorder.

The 2013 publication of the *DSM-5* includes both Temper Dysregulation Disorder, as well as the updated bipolar criteria describing overlapping symptoms in children. I will return to the controversies around the publication of the *DSM-5* in Chapter 4 where I detail my visit to the 2012 American Psychiatric Association conference. To many of the protesters it seemed like psychiatry was unilaterally defining the parameters of normal childhood behavior, was manufacturing new disorders out of thin air, and was making it up as they were going along.

## 2.3 Pathological Soothsayers

If these trends are not sufficiently jarring, the future is even more disconcerting. Psychiatry continues to innovate, and is poised to push beyond pathologizing formerly normal behaviors by pathologizing *risk* with the growing rise of *prodromal* diagnoses, also known as *Psychotic Risk Syndrome*. The etymology of this word traces back to a Greek term *pródromos*, meaning “running before” or precursor (Prodromal, n.d.). An emerging trend in clinical psychiatry is the appropriation of this concept under the paradigm of “early intervention in psychosis” for “at-risk” patients.

Psychiatrists are starting to preventively diagnose mental illness and are treating people before they exhibit any behavioral symptoms. Children and adolescents are especially vulnerable to prodromal diagnoses, and much of the research and marketing is

directed at preventing children from developing mental illnesses later in life. We saw this tendency at work in the competing definitions for pediatric bipolar, and the emphasis on preventing “first breaks” due to the “kindling effect” hypothesis. The Papoloses explain this idea in *The Bipolar Child*:

Initial periods of cycling may begin with an environmental stressor, but if the cycles continue or occur unchecked, the brain becomes kindled or sensitized - pathways inside the central nervous system are reinforced so to speak - and future episodes of depression, hypomania, or mania will occur by themselves (independently of an outside stimulus), with greater and greater frequency. (Papolos & Papolos, 2000)

This logic, taken to its natural conclusion, led researchers to search for ways to identify and prevent first psychotic breaks before they occur. The Editor-in-Chief of the peer-reviewed journal *Current Psychiatry* identifies early diagnosis and intervention as one of the top six trends affecting all of psychiatry, not just child psychiatry:

#### *Earlier diagnosis and early intervention*

The past decade has witnessed a surge of progress in identifying individuals at high risk for psychosis or mood disorders. The “prodrome” has become a fertile area of research, with a focus on early “treatment” even before the clinical syndrome of schizophrenia or mania appears. The goal is to try to delay, modify, or ameliorate incipient serious mental illness by using both pharmacotherapy and psychotherapy. (Nasrallah, 2009)

Intuitively, preventative health care seems like a good thing. In the words of Benjamin Franklin, “an ounce of prevention is worth a pound of cure”, and a modern variation of the Hippocratic Oath includes the line “I will prevent disease whenever I can, for prevention is preferable to cure”. Western medicine is often criticized for primarily responding to acute crises, instead of proactively promoting health and well-being. However, the reductionist flattening of minds into brains leads to categorical

errors which pervert the Hippocratic principle to “do no harm.” Applying the medical paradigm to the treatment of risks, instead of disorders, stretches the dangerously elastic diagnostic net beyond the breaking point. Especially when many of the preventative treatments carry substantial risks of their own, the calculus of prevention is dangerously skewed. Many psychiatric patients feel their treatments are worse than their diseases; how much more so when the *possible risk* of a disease is being targeted?

Analogies between mental conditions and diseases of the body, such as diabetes, measles, or heart failure, are often the point of departure for proponents of prodromal treatment. However, these casual comparisons mask assumptions and disguise relevant differences. The pathologization of diverse mental states remains controversial, unlike life-threatening viruses or organ failures. Furthermore, there is currently no causal theory explaining why some people’s psychological experiences degenerate into crisis, or consensus on what constitutes an appropriate response to traumatic circumstances. Without a causal theory explaining transitions between mental states, all prodromal diagnoses of mental conditions are necessarily speculative explanations for correlations. It is unclear if such models are universally generalizable. Preventative treatment based on aggregates is highly questionable, especially considering the serious risks these treatments pose.

The roots of prodromal diagnosis of mental conditions can be traced back to work on the prodromal identification of schizophrenia:

What is needed is not the early diagnosis of schizophrenia, but the diagnosis of pre-psychotic schizophrenia. We must learn to recognize that state of mind which will develop into schizophrenia unless appropriate measures are taken to prevent deterioration. (Meares, 1959:55)

However, the identification of reliable predictors of schizophrenia has proven to be notoriously difficult and conceptually slippery:

Identifying symptoms or signs that reliably predict onset would obviously aid attempts to prevent mental disorders. Such specific predictors do not currently exist. In fact, one could argue that if any such risk factors were identified they would be conceptualized as early phenomena of the disorder itself... The nonspecific nature of these common features is notable. (Yung et al., 1996: 285)

Yung et al. describe the difficulties identifying prodromal symptoms for psychosis. The onset of psychosis is often “gradual” and “low-grade”. Also, unlike contracting the measles, an all or nothing proposition, psychosis exists on a continuum, involving degrees of clinical judgment. To detect the onset of psychosis, clinicians can be attentive to “attenuated” or “subthreshold” symptoms, but these precursor signs and symptoms quickly become symptoms for the disorder itself. Contenders for early indications of subsequent development of psychosis include: a) selective attention and perceptual abnormalities; b) a change in the sense of self and the world; and, c) suspiciousness.

The clinical gaze embodied in the pages of the DSM has always been rooted in the psychological theory of Behaviorism (Skinner, 1974)—the symptoms it defines are all observable behaviors, and are oblivious to the subject’s interior mental life. The trend towards prodromal mental diagnoses is flawed precisely because of the kind of power it cedes to an already arrogant apparatus, which, as we will demonstrate in upcoming chapters, fails to recognize interiority or listen to the voices of the people it purports to treat. In what could be interpreted as a form of humility, psychiatry’s reliance on observable behaviors acknowledges that doctors cannot know for sure what is going on in a person’s mind. However, psychiatry’s systemic dismissal of patient’s lived experience,

their reduction of minds into brains, and their insistence that their medical field claims a monopoly on defining “normal” is an arrogance on the verge of dramatic amplification. The risks of preemptive discipline and prescriptive moral judgment present a slippery slope which psychiatry has already begun to descend, and the dangers are simply too serious and damaging for this practice to continue. Patients, especially children, are being indicted on the basis of hereditary factors, thought crimes, and harmless deviant behavior. In a distinctly Orwellian twist, patients exhibiting symptoms are psychotic, while those that don’t exhibit symptoms, *yet*, are prodromal (Orwell, 1961).

Furthermore, the psychopharmacological treatments prescribed for these prodromal diagnoses are physically dangerous and psychologically damaging. As already discussed, the atypical antipsychotics that are often prescribed in these circumstances have been linked to excessive weight gain, metabolic disorders, and diabetes (Yan, 2008). The stigma attached to these diagnoses is also emotionally threatening. Advertising campaigns, such as the award-winning “Prescribe Early” poster, depicted an abandoned wallet, teddy bear and keys on a barren street. It targeted parent’s worst fears by invoking the terror of a missing child. It suggested this worst-case situation could be avoided with preventative pharmaceutical interventions, prescribed before it was “too late” (Rosenberg, 2009).

Children and teens often traverse intractable emotional terrain on their journey of self-discovery and becoming. Adult disapproval towards behaviors (smoking, drinking, inappropriate speech or activity, irritability) and appearances (fashion, body piercing, hairstyle) has increasingly taken the form of chemical discipline, with psychiatry’s permission and blessing (White, Anjum and Schulz, 2006). Defiant teenagers are

threatened with prodromal diagnoses based on their alternative fashion choices and misunderstood behavior. Smoking and substance abuse have already been associated with bipolar in teens, and are already being used as diagnostic criteria for the “illness” (Wilens et al., 2008). An article in the *American Journal of Psychiatry* introduces the following patient and explores if this teenage girl is prodromal for schizophrenia:

A 13-year-old girl, currently in the eighth grade and with a history of attention deficit hyperactivity disorder, was brought by her mother to a university-affiliated outpatient psychiatric clinic after a gradual decline in her academic performance was noted... She had tasted alcohol in the past but denied current use. She had also used marijuana a half-dozen times... her parents claimed that she had been withdrawn and had appeared sad and that at times they needed to prompt her to take a shower. She had a maternal aunt with bipolar affective disorder and a great uncle who had been institutionalized for unknown reasons... she was dressed in Goth attire, including a black T-shirt with images of letters dripping blood; she had dyed black hair. Her affect was blunted but was slightly more animated when her parents left the room. She denied thoughts of suicide. She reported occasionally hearing whispering voices calling her name and saying that she is worthless. She also reported the belief that her friends did not like her as much as they had... (White et al., 2006: 376)

I do not know anything more about this case than the short blurb presented at the beginning of this journal article. Clearly, this eighth grader seems to be experiencing a great deal of emotional pain, and has found cultural styles to express her anger. The whispering voices that she reports hearing may or may not be a cause of alarm, as many more people report hearing voices without negative consequences than is widely believed (British Psychological Society, 2014). Similarly, her disappointing academic performance may also be attributed to numerous factors, but White et. al. only consider one: “the presence of cognitive decline raises the possibility of a degenerative neurological disorder.” Of course, the entire framework for explaining this girl’s state of mind is clinical, but it is

still striking to read this language and consider all the competing explanations that are left unexplored:

The clinical vignette reflects these challenges. The early adolescent patient presents with a number of symptoms consistent with a schizophrenia prodrome, including a long-standing history of difficulties with attention, a recent history of cognitive decline, social withdrawal, and what appears to be psychotic symptoms. Yet these symptoms could also be explained in terms of major depression with psychotic features, bipolar affective disorder, substance use disorder, post-traumatic stress disorder (PTSD), or even an aberration in the maturation and solidification of personality structure. Furthermore, these diagnoses are complicated by their emergence within the developmental framework of the child, and thus developmental norms must also be taken into account.

There are many environmental factors that could explain the emergence of these “symptoms”, and ways to understand them as reasonable reactions, not a pathological disorder. Caring parents are often desperate to help their struggling children, and will try anything that might “fix” the problems they perceive. In my opinion, this girl needs more compassionate support, not a stigmatizing diagnosis. Just as there is slippage between onset symptoms and true symptoms, the lines between diagnosis of ‘schizophrenic prodrome’ and ‘schizophrenic’ is also blurred. The treatments are similar, the stigma is similar, and the impact on someone’s identity is likely similar as well. In this scenario, it is unclear if psychosocial support options have been exhausted, or the circumstances leading up to her visit to the psychiatrist. Situations like this scream out of the kinds of community oriented, peer-support structures that are advocated by activists and alternative mental health initiatives.

The trend towards prodromal diagnoses coincides with a parallel trend in society towards the auto-classification and prediction of citizen and consumer behavior (An-

drejevic, 2007). Governments and corporations have a strong interest in predictive behavioral models of every person they monitor (Stanley and Steinhardt, 2003). These systems are currently making their way off the lab bench, and into production systems (Robert, 2005). Already, algorithms to automatically classify human behavior based only on video streams have been deployed in nursing homes, casinos, the Olympics, and urban environments (IBM Smart Surveillance Solution, n.d.; Informedia Digital Video Understanding, n.d.). As computers scientists and engineers contend with the challenge of automatically classifying the full range of human behaviors, the DSM's ready-made ontology may prove too convenient to challenge. Just as code enacts law, diagnostic labels are on their way to being represented in software, where their embodiment will take on a life of its own—algorithmic diagnoses. When that occurs we will have seen the successful establishment of a new diagnostic environment; indeed, a system that opaquely collects, categorizes, interprets, and proffers definitions of illness similarly to the way Google defines news, or Facebook defines your status feed—that is to say, with what amounts to an arbitrary sort of logic and rigor.

Such a future for psychiatry would be quite disturbing. Prodromal treatment is the latest progression in an ever-constricting system of social control which purports to contain states of mind within definitional cages. Preventative psychiatric treatment hints at forms of control that raise legitimate questions about omniscient surveillance, and we can begin to glimpse how grotesque these practices might become in an era of pervasive surveillance and electronic medical records. As I describe in more detail in chapter 6, a study currently underway in Australia is attempting to predict the onset of manic episodes based on changes in Facebook use (The FAD Study, 2014). Pathologizing the

traumatically scarred and neurologically diverse is bad enough. Extending this attitude, and treatment, to those *at risk* of neurological diversity is ethically dubious and threatens our fundamental freedoms.

## 2.4 Ferocious Attacks and Formulaic Defenses

In the summer of 2011, Harold Koplewicz wrote column in the Huffington Post responding to Marcia Angell's favorable reviews of three books in *The New York Review of Books* (Angell, 2011). Angell, whose work we examined earlier in this chapter, is an American physician, Harvard lecturer, and the first female Editor-in-Chief of the *New England Journal of Medicine*. In 2004 she published a book titled *The Truth about the Drug Companies: How They Deceive Us and What to Do about It*, and she continues to command great respect and authority within the medical and scientific communities. Koplewicz, who we also encountered earlier this chapter, is a psychiatrist and former NYU professor, and is currently the director of the Child Mind Institute. Angell reviewed *The Emperor's New Drugs: Exploding the Antidepressant Myth* (Kirsch, 2010) written by a UK psychologist, *Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America* (Whitaker, 2010) written by an American journalist, and *Unhinged: The Trouble With Psychiatry—A Doctor's Revelations About a Profession in Crisis* (Carlat, 2010) written by a Boston psychiatrist.

In her review, Angell depicts the growth of mental illness as an epidemic, citing similar statistics to the ones I presented at the beginning of this chapter. She points out that “nowadays, treatment by medical doctors nearly always means psychoactive drugs,

that is, drugs that affect the mental state”, and that “the shift from ‘talk therapy’ to drugs as the dominant mode of treatment coincides with the emergence over the past four decades of the theory that mental illness is caused primarily by chemical imbalances in the brain that can be corrected by specific drugs.” She asks, along with the authors she reviews:

What is going on here? Is the prevalence of mental illness really that high and still climbing? Particularly if these disorders are biologically determined and not a result of environmental influences, is it plausible to suppose that such an increase is real? Or are we learning to recognize and diagnose mental disorders that were always there? On the other hand, are we simply expanding the criteria for mental illness so that nearly everyone has one? And what about the drugs that are now the mainstay of treatment? Do they work? If they do, shouldn’t we expect the prevalence of mental illness to be declining, not rising?

Angell characterizes the books’ arguments as documenting a “frenzy of diagnosis”, the overuse of drugs with sometimes devastating side effects, and widespread conflicts of interest. She wants us to stop thinking about “psychoactive drugs as the best, and often the only treatment for mental illness or emotional distress”, claims that our reliance on them “tends to close off other options”, and calls for more research studying alternative treatments and their inclusion in medical textbooks. Regarding problems with troubled children, often in “troubled families in troubled circumstances”, she recommends that “[t]reatment directed at these environmental conditions—such as one-on-one tutoring to help parents cope or after-school centers for the children—should be studied and compared with drug treatment.”

In the second part of her review Angell added the DSM to the list of books she reviewed. Discussing the upcoming release of DSM-5, she recognized the book’s “ex-

traordinary influence within American society.” She also reviewed the multiplication of diagnoses with each edition and extensive industry sponsorship.

Koplewicz calls Angell’s review a “ferocious two-part attack… on antidepressants, antipsychotics and, in general, medications to treat psychiatric disorders… she impugns both the medications and the motives of the psychiatric profession”. He accuses Angell of being a conspiracy theorist who sees “a conspiracy of psychiatrists and drug companies for their mutual benefit, with patient benefit only a distant concern”. Strangely, Koplewicz only responds directly to Angell’s critique, not to the authors she is reviewing, and demeaningly characterizes Angell’s take as “her story” and “her telling”.

Koplewicz presents a typical and formulaic defense for psychopharmacology. As the influential director of a multi-million dollar a year non-profit, his views are a model for psychiatrists across the field. He claims, “the drive for medication was fueled by the surprising observation that they were better treatments for mental illness than talk therapy or earlier sedative drugs.” This assertion is precisely the point that Kirsch, Whitaker and Carlat had questioned. Are these treatments really better? Koplewicz reiterates the myth of their efficacy without engaging, or even taking seriously, the possibility that they are not.

Regarding the DSM, Koplewicz rehashes the staid line that the DSM’s real value is in “promoting reliable clinical communication. . . . nothing in the DSM. . . ‘pushes’ medication — or any other form of treatment”. His denial of the real power of the DSM and diagnoses, beyond its use as professional shorthand, antagonizes those who attempt to engage psychiatry in good faith. Even the psychiatrists who opposed the addition

of TDD to the DSM-5 acknowledged “how the pharmaceutical industry approaches the DSM.” (Axelson et al., 2011).

Koplewicz makes a pragmatic argument that while more studies are needed, people are in need of help. While this position is laudable, his commitment to “objective evaluation” is confusing. On the one hand, he cedes that “objective research” has not caught up with “clinical realities”, but he still has faith in pharmacology, even in the absence of evidence demonstrating its effectiveness. On the other hand, “falling back on pure non-pharmacological treatment is not the better alternative, since these treatments have rarely undergone objective evaluation.” Koplewicz writes off non-pharmacological treatments on the grounds that they have not been subjected to “objective evaluation”, holding them to a stricter standard than he does to pharmacological treatments. Furthermore, he does not engage with the scientific evaluations that call into question the value of these pharmacological treatments, the basis for all three books that Angell reviews. Finally, regarding future risks Koplewicz writes: “As to the issue of psychoactive drugs actually harming patients by altering their brain chemistry over the long term, which Angell posits, here too data is lacking. It makes no sense to forego present benefit because of undemonstrated future harms.” The potential harm of psychoactive drugs is very well demonstrated, so Koplewicz’s defense rings hollow:

We try to weigh the risks of psychoactive drug treatment against the risks of forgoing treatment. That risk often includes academic failure, dropping out of school, substance abuse and even suicide. Unfortunately, the risks of avoiding demonstrated useful treatments are not something critics, like Angell, consider.

Angell does not avoid considering the risks to troubled youth. Koplewicz avoids acknowledging the full-blown impact of a diagnosis on a child, the demonstrated health

risks that psychoactive drugs pose, and categorically dismisses treatment approaches that cannot be objectively evaluated.

## 2.5 Transcending Monocultures

The volleys portrayed in this chapter, and others like it, continually antagonize mad activists and seed mistrust and disillusionment with the establishment. The evidence that children's behavior differs dramatically from prior generations is inconclusive. It is entirely plausible that our adult standards and judgments have changed, not their behavior. However, if we really are witnessing a rise in childhood irritability and behavioral misconduct, there are many important research questions we need to be asking, and different people who need to be answering them. If the dramatic increase in children's explosive outbursts are not illusory, we need to be looking for explanations beyond an individual's biology or brain chemistry. These outbursts may in fact be symptoms of society's ills, and it is essential to connect the dots between this epidemic in childhood mental illness and other pressing social issues like poverty, racism, educational reform and media consumption. These are questions that demand more study from social scientists, and psychiatry needs to collaborate directly with sociologists, anthropologists, and public health professionals. The field's isolation from the rest of the academy leaves them deprived of essential perspectives on their work and its impact.

The proponents of pediatric bipolar often rely on rhetorical sleights of hand to bolster their case by strategically framing the terms of the debate. They conflate instrumentally derived facts with value judgments, and wield these facts in an attempt to short-circuit

debate. They cite laboratory evidence such as neurotransmitter activity, brain imaging, genetic markers, and heredity as proof that patients are “sick” when, at best, this evidence signifies difference and diversity. This diagnostic strategy is decidedly one-sided, as spokespeople for the prevailing medical model claim an objective view from nowhere, but their vantage point is loaded with subjective value judgments. Many are so thoroughly immersed in the disease paradigm and a scientific worldview that they don’t even recognize the implicit subjectivity in these pronouncements. These flagrant distortions are most visible at the diagnostic boundaries, such as when moody toddlers and defiant adolescents are diagnosed as diseased.

All too often, purportedly neutral facts are loaded with value judgments, but presented as incontrovertible on the basis of their “factuality.” This perspective does not deny the possibility of varying degrees of confidence in different assertions, but we must demand recognition of the inevitable entanglement of subjectivity in our descriptions of a complex and contingent world (Alcoff, 1991). The real-world implications of the misuse of language and rhetoric are serious and potent (Davis, 1997).

To avoid the deadlock of epistemological paralysis, psychiatry must break free from its monoculture and listen closely to language and voices of the people they are trying to help. Humility and a genuine respect for people’s agency require that we take their stories and experiences seriously. These multiplicities of personal narratives demand reconceptualizations of mental health that defy the psychiatry’s mainstream messaging. As the mantra of the disability rights movement powerfully insists: “Nothing about us without us.” In recognition of the validity of this claim, we turn now to some of these stories, many of which include clear articulations of the earnest desire to be listened

to and heard. Through these narratives, we hear these activists demanding legitimate recognition, which goes beyond the condescension of paternalistic attention.



# Occupy Mental Health: Liberty Park Madness

“ …freedom, which only seldom—in times of crisis or revolution—becomes the direct aim of political action, is actually the reason that men live together in political organizations at all. Without it, political life as such would be meaningless. The raison d'être of politics is freedom, and its field of experience is action.

— Hannah Arendt  
What is Freedom?

When Occupy Wall Street erupted in Zuccotti Park, mental health activists were determined to “occupy mental health,” although initially there was little clarity around what this might mean. Many of those involved in mental health activism felt they had important knowledge and skills to contribute to the larger OWS movement. They wanted to talk with protesters and the media about the ways that psychiatry and big pharmaceutical companies contribute to social and economic injustice, and to emphasize the importance of tending to basic needs, such as eating and sleeping well, in order to avoid burning out. They especially want to explore how these two themes are related through the language we use to describe each other’s behavior. Would the movement unravel as Occupiers alienated and pathologized each other through what activists call languages of oppression, or would they unite and support each other with languages of compassion?

The OWS movement generally scorned turning to the criminal justice system to resolve conflicts, but there was no such consensus when it came to dealing with emotional crises and behaviors. Around the country reports began to surface of protesters being forcibly hospitalized and medicated, and many activists on the ground were desperate for training and educational materials that offered alternative perspectives towards handling emotional trauma and navigating crises. Even among the most progressive circles of activists, few were equipped with tools for dealing with these crises beyond the mainstream DSM—the Diagnostic and Statistical Manual—and the pathologizing gaze of the psychiatric biomedical model.

More and more stories surfaced in the media and in activist circles about protester burnout and emotional crisis at the occupations. Given the exacerbating conditions—lack of sleep, poor nutrition, exposure to the elements, topped off with violence and police brutality—it is unsurprising there were many frayed edges amongst the protesters. Many Zuccotti activists had travelled to New York City, or were displaced, homeless or otherwise struggling with their basic needs, and so lacked local support systems. Stress and trauma precipitated a range of emotional reactions and differences in the protester's mental states became the subject of misunderstandings and conflicts. Many protesters also brought their own emotional baggage with them to Zuccotti, and the community struggled to integrate neurological and behavioral diversity.

In Fall 2011 I conducted three months of field-work around mental health issues and Occupy. On one of my first nights in Zuccotti Park I met a young woman from the Pacific Northwest picking up trash around the camp and learned that she was part of the “Sanitation” working group. I was impressed by her commitment to support the

protest through the humble backstage labor of keeping the camp clean. A great deal of the media coverage of OWS focused on the outward messages that the movement communicated to the external world, but during the time I spent around the protests I learned about all the activity devoted to sustaining the physical and emotional well-being of the camp and its inhabitants.

I began participating in some of the New York City working groups who were devoted to supporting the safety and welfare of the protesters. Many of the radical mental health activists I knew believed strongly that the people involved in these efforts would be very receptive to their language and ideas, and were an important constituency for cultivating alliances. Some of the volunteers in these working groups were already sympathetic with the radical mental health movement while others were relatively new to their message. I was genuinely surprised at the resistance that radical mental health activists encountered from some of the mental health professionals working with OWS. The disability rights mantra “Nothing about us without us” may seem like an innocuous proposition, but my fieldwork helped me understand its radical underpinnings and how difficult it can be to apply this maxim in practice. Ultimately, I witnessed how much easier it is for many to critique various ‘isms’ (capitalism, consumerism, neoliberalism) and the external world than it is to flip the mirror in order to critique yourself and your own profession.

Together with some of the members of the local New York City “Support” working group, radical mental health activists from around the country began assembling a collaborative guide for activists titled *Mindful Occupation: Rising up without Burning Out*. The book’s concept excited radical mental health activists, as well as street medics

and mental health professionals involved in OWS working groups. Some wanted to create materials to support teach-ins and workshops, and others found the work itself to be liberating and therapeutic. We also saw the publication as a device for provoking important conversations about community, peer-support and mutual aid.

Many heated debates emerged around our work on *Mindful Occupation*, as well as my direct participation in the local ‘Support’ group. It was through these deliberative processes and exchanges that I rediscovered the promise of Occupy’s discursive “public space”. These exchanges also revealed the ideological contours and boundaries of different constituencies. The anecdotes and controversies I highlight in this chapter help bring the new wave of psychiatric resistance into sharper focus by exposing the entrenched biases of the mental health establishment. These biases are so entrenched that they surfaced among some of the most liberal and progressive voices of the establishment—the mental health professionals involved in volunteering and protesting at Occupy Wall Street. The encounters also revealed some of the entrenched biases among the radical mental health activists, and forced them to confront pragmatic realities around mental health, substance abuse, and the community’s capacity to provide the kind of the support they yearned for. Occupy Wall Street became a site where these opposing biases confronted each other face-to-face, where ideology met pragmatic necessity through the labor of on-the-ground support.

### 3.1 owsmentalhealth: Emotional First Aid

While most of the media coverage around Occupy Wall Street emphasized the protestors' message to the external world, a significant amount of energy and attention at Zuccotti park was focused inwards, in the forms of capacity-building, skill-sharing, and maintaining the health and safety of the protestors (Gitlin, 2012; Graeber, 2013; Mushett, 2013). A complex network of working groups formed in anticipation and response to the perceived needs of the group. Working groups formed to address physical needs such as food, waste removal, housing, and park planning. Safety, security and health were also primary areas of concern, and many of the working groups involved in these efforts coordinated their work under the umbrella of the “safety cluster” and the Medic groups.

A West Coast activist in his late twenties travelled to New York specifically to volunteer his emergency medicine skills to OWS, and joined the Medic group. He was familiar with The Icarus Project (see Chapter 5) from his encounter with *Friends Make the Best Medicine*, a popular zine published by Icarus in 2007. He personally reached out to the New York City Icarus chapter, inviting them to participate in the Safety Cluster meetings. He was concerned about the tone and direction he had observed in some of the Safety Cluster meetings, and requested supporting materials and allies that could provide alternative perspectives. He did not communicate his specific concerns in detail, perhaps challenged to articulate his vague sense of unease without a richer language to express his critique—a language and perspective he hoped that Icarus activists would bring to the meetings.

The “Safety Cluster” was an assembly of working groups that included people committed to mediation, non-violent communication, security and deescalation, as well as people committed to anti-oppression and reducing sexual harassment, who formed the “Safer Spaces” working group. Additionally, there was a working group calling itself “Support” that was operating as a subgroup of the “Medic” working group. The Support group was comprised primarily of mental health professionals — social workers, chaplains, psychiatrists, and a few non-traditional emotional support practitioners. Together, the safety cluster developed protocols for handling interpersonal conflicts in the park, and organized nightly “community watch” shifts, where members of the community organized to support protesters, and identify and defuse conflict. The Support group quickly assembled and distributed literature, where they described themselves as follows:

We’re a group of people providing mental health and emotional support at Occupy Wall Street. Some of us have formal training and others of us have lived experience, including peers and regular folks who just know a thing or two about how to support themselves and each other when things feel rough. We are a subgroup of the Medical Working Group. (Supporter05, 2011a).

They identified these issues that protestors were facing:

We’re seeing issues like post-traumatic stress, depression, anxiety, altered states, anger, and other things that understandably can come up when you’re sleeping outside and surrounded by police. Some might have issues related to drug or alcohol use, including staying sober while at the occupation. Folks are experiencing emotional distress related to social stigma/oppression, including people facing homelessness, LGBTQ people, people of color, people with disabilities and women, especially transgender women. (Supporter05, 2011a)

The support group quickly coordinated its efforts through a mailing list coupled with a Google Spreadsheet. They began organizing community patrols consisting of a pair of

Support volunteers walking through the park for 3-hour shifts between 6pm and 3am. During these shifts the Support volunteers wore orange armbands fashioned with a red heart made of duct tape. Shifts began at the medical tent, where the Support team would check in with the medics and other Support volunteers. A red log book for recording serious and ongoing issues was kept in the medic tent. Only first names were recorded in this log book, and illegal behavior was not supposed to be recorded. The community patrol team was then encouraged to make the rounds within the camp and among the working group meeting areas, walking around and checking-in where appropriate.

Many encounters focused on assisting people with their basic needs, such as finding a blanket, helping them calm their anxiety, and offering support to people who were struggling, especially after a conflict with another protester or the police. Some of the protesters would seek out the Support volunteers to discuss emotional issues or social services. Others might come to the medical tent “looking for someone to deal with a perceived physical issue (ie, breathlessness, feeling cold, believing that they have a rash/bugs/etc.) but it turns out to be emotional (ie, panic attack, altered state/perception).” Support was also part of the team that was called into deal with crises that had a mental health component, such as altered states, delusions or self-harm.

The community patrols began operating soon after the occupation’s establishment, on September 18th 2011, and ran all the way through the protesters’ eviction on November 15th. For almost two full months the Support working group successfully organized pairs of volunteers to patrol Zuccotti park, nine hours a night, seven nights a week. Most of the volunteers had full-time jobs, and insuring the continuity of the patrols was a significant undertaking. Some of the volunteers signed up for a one patrol

a week, but a few of the core participants in the Support working group did multiple patrols a week, in addition to regular organizer meetings and trainings. There were approximately 35-50 people participating in the community patrols. Since participation was fluid, and protesters within the Safety cluster often participated in more than one working group, it is difficult to determine the precise size of the Support group.

In addition to the community patrols, the Support working group convened weekly meetings, hosted trainings in order to orient volunteers on patrol procedures and Zuccotti security and deescalation protocols, and actively participated in many other working groups' meetings, including other groups in the safety cluster, the medic groups, and the general assembly. They also helped organize "Jail Support", where members of the Support group would meet arrested protesters upon their release. The support groups' mailing list was hosted on the Mayfirst.org's listserv, a long-time activist-friendly Internet Service Provider that provided free hosting to OWS working groups. The mailing list was very active throughout the occupation, providing a space for tactical as well as strategic planning.

From the outset the Support group struggled to negotiate a balance between theory and practice as practitioners from a diverse range of backgrounds came together for the purpose of supporting the overtly political OWS protest. As a part of a FAQ describing the group's identity and mission, the Support group organizers drafted the following statement:

Bring anti-oppression work into your practice: be aware of your own privileges (ie, race, class, having some place to sleep, or anything else) and how that may impact the people you are working with and their impression of who you are and what you're there to do. Some examples include: people of color have a long history

of experiencing oppression from white social workers; people with mental health histories may have been traumatized by engagement with psych hospitals; or, LGBTQ people may have had their identities pathologized by mental health professionals. Practice cultural humility by checking your own identity-based assumptions. Seek to listen to people's experiences from a place of openness and non-judgment, and help people to meet their needs as they define them for themselves rather than your own idea of what might be best. Also, try to coordinate responding to any incidents related to racism, homophobia, transphobia, sexism, etc. with the Safer Spaces [working group]. (Supporter05, 2011b)

Unsurprisingly, this collective statement of group identity generated some controversy. Some within the group wanted to elaborate on the oppressive features of the mental health system, and work to avoid them:

Supporter01: "I want to add one more thing: Work/be with the community in way that does not replicate, in any way, the oppressive models or behaviors of the system's social work/services. What do people think?" (2011a)

Supporter02: "Oppressive models? I think too vague. One persons oppressive model may not be another persons oppressive model." (2011a)

Supporter01: "I agree with you - it is too vague. Maybe we can give examples... For example, oppressive social work/services patterns: - collecting a lot of information from people, while worker doesn't share information about themselves;- use of professional language/jargon, such as diagnostic/DSM type of words, which may sound offensive or stigmatizing to people. Etc." (2011b)

Supporter02: "I will yield to the group but personally I have done good and non oppressive work with that model in the right context. The key is ones own sensitivity, starting where the patient is, and knowing what to use when and how. Some people thrive with a non reciprocal opportunity to talk and are put off by a support person's self disclosure. Some find diagnoses and medicines a liberating relief. I think we should remain flexible on modalities with this work in progress." (2011b)

A recurring theme surfaced around the appropriateness of this forum for critiquing language and the system versus focusing on the day-to-day practice of supporting the protesters:

Supporter03: "Let's not use this as the forum to critique our various disciplines but rather as a place to create something beautiful, with the hopes that our efforts will help to lead the systemic changes that are needed. I don't think this is the forum to debate diagnoses, disclosure etc. My understanding is that we are gathering to offer our unique experience and expertise to those who need our assistance. Let's focus on how we'll go about doing that and table these other challenges for the time being." (2011)

The question of critical engagement continued to surface, and some suggested spinning off a separate sub-group for more in-depth discussions:

Supporter04: "In addition, I propose that people who are passionate about creating a more in depth discussion about who we are and deal with some of the more nuanced dilemmas we are facing, would create a sub-working group for that. Also, concerns have been raised about the way we conduct our meetings, therefore I propose that we get more familiar with decision making, common meeting rules, and consensus process, as one possible way in which we handle our meetings as well as conflict." (2011)

The pressure to support the protesters created an understandable tension between tactical problem-solving and carving out a discursive space for reflection and critique. However, the proposal to spin-off a sub-group for critical discussions was interpreted by some of the participants as a way to marginalize or even dismiss difficult and controversial perspectives. At the heart of this disagreement were differing perspectives on the nature and goals of the OWS protest, layered on top of long-time controversies around the effectiveness of mainstream models of support. Some saw OWS as a platform for protesting inequality and the socio-economic system. Others took a more expansive view, and expressed their protest by prefiguratively modeling and enacting the kind of society they wished to inhabit. The Support group was caught in the middle, as many of the participants in the group were attempting to support the protesters using instruments

and tools that were also implicated in perpetuating the inequalities that constituted OWS's core concerns. Many in the group were acutely aware that certain support models could replicate the same power relations that OWS was resisting.

### 3.1.1 Joie de Vivre

In the early morning on Saturday, October 22nd Dylan Spoelstra, a 24 year-old Canadian OWS protester, scaled Zuccotti Park's "Joie de Vivre", a 70-foot tall, bright red sculpture composed of "open-ended tetrahedrons". Dylan remained on the sculpture for several hours until the police talked him down, handcuffed him, and sent him to Bellevue for a psychiatric evaluation (Baker, 2011). Dylan climbed the statue early in the morning and remained perched on a platform 30 feet above the ground for several hours. He demanded Mayor Bloomberg's resignation, and repeatedly requested a jacket and cigarettes throughout his dialogues with the Police Department's hostage negotiation unit. According to the police, "[h]e was not arrested, he did not get a summons, he'll just be evaluated psychologically." Dylan was subsequently committed to Bellevue's psychiatric unit, where he spent over 2 weeks as a psychiatric inpatient.

This incident sent waves through the support group, since this was precisely the kind of situation they wanted to intervene in, to handle with more gentleness and compassion than the NYPD. Supporter02 wrote:

Dear OWS support, I was at Zuccotti Park on Thursday at 6:30 pm for the first time and in my first five minutes had met the young man who climbed the sculpture on Saturday morning. Before he ran off, It was clear to me as I spoke with him that he was extremely psychotic, manic, and suffering and it was also clear to me that he could likely be helped in a relatively short period of time in a way that would not have involved danger, handcuffs, and press. By the time I left at 11:30, I was too

troubled by my experience with Support to return. I felt that the current structure was unsafe for volunteers and occupiers and I could not ethically participate in it as Support; nor could I engage in the time consuming process of organizing, when my goal had been to come in and do what I know how to do, which is to help people like Dylan. (2011c)

It is unclear precisely what treatment alternatives Supporter02 had in mind, or why he/she felt thwarted by the group's consensus process. Supporter02 is an experienced social worker who ran a small social work clinic in the Manhattan. When the support group first formed, Supporter02 offered to bring a psychiatric colleague to the park, and was one of the stronger proponents of the value of the diagnoses and psychiatric medication. He/she also made a case for supporters not disclosing their own personal history to supportees, since in his/her clinical experience some patients preferred to work with counselors operating with detached authority. Though Supporter02 minces his/her words in this email exchange, his/her frustration with the Support group's consensus model is clear.

We are left guessing at his/her's preferred alternative, but given Supporter02's other statements, it is likely that he/she would have steered Dylan to psychiatric support, and attempted to avoid police involvement at all costs. Afterwards, some of the mental health activists in the park that night discussed how they would have preferred to support Dylan by being together with him through his crisis, providing one-on-one, direct support. They conceded that they lacked the capacity to follow through on such an intensive support obligation. Ultimately, there is no clear-cut, correct solution for volatile situations such as Dylan's. While it is easy to second-guess the past, these situations are often chaotic and unpredictable. It is only after they have deteriorated that their impact and potential

danger becomes clear. Moreover, for every Dylan, there were many activists in Zuccotti acting erratically whose behavior never escalated to the point inviting police intervention. While everyone in the Support group was against police involvement, attitudes around coercion and forced hospitalization varied widely.

Supporter02 continued to vent her frustration with other participants in the Support working group:

I had entered the Occupation with humility and a wish to be of service and now I am suggesting that there should be greater humility on the part of all involved with Support. The expertise and years of experience of professionals who have worked on the ground in New York City with the homeless, the mentally ill, with addiction, with gangs, with domestic violence, with the hospital and entitlement systems, needs to be sought out actively and immediately. They are there for the asking. Respect specialization. I would not and could not presume to do anything outside of my ken. There is no time to argue about language or politics on the south side of the Park. Those debates can come later. Assume that anyone offering their service to the Occupation is like minded enough and ask them what they know and how best to proceed. It would be better to err on the side of that deference when addressing issues of immediate health and safety, and not with guiding the course of the movement." (2011c)

While Supporter02 would have most likely arranged a more compassionate intervention for Dylan than he received at the hands of the NYPD, the way he/she asserted his/her authority was triggering to some of the participants in the group. Supporter02 is clear enough in his/her writing to antagonize some, but did not persuade others to adopt his/her suggestions. It is unclear if the vagueness in Supporter02's writing is a function of his/her's frustration, lack of time, or if it was supplemented by face-to-face encounters. Supporter02 may have also constrained some of his/her language out of deference or fear of reprisal by the more radical contingents on the list.

Supporter02's claim that "There is no time to argue about language or politics on the south side of the Park. Those debates can come later." was met by the reaction that "arguing about language and politics is *exactly* what we are in the Park to do." Supporter02's insistence that the participants "respect specialization" provoked the response that "'specialists' [should] pay reciprocal respect to the experiences of those that they treat. We are all specialists in our own personal experiences, and these experiences need to be respected and validated by those who are trying to help—even if they are acting in good faith, and have the best of intentions." The tensions between the authority of credentialed expertise and experiential expertise were never resolved, and recurred throughout the occupation.

These sentiments were mirrored in face-to-face group meetings, leading to frustration and exacerbation. Some meetings ran so long that there was no time to complete the scheduled agenda, and participants who had waited patiently for over two hours to speak were never given the floor. On the other hand, face-to-face encounters sometimes led to reconciliation, especially in sidebars and personal conversations outside the formal meeting space where participants developed friendships and trust. Supporter05, shouldered an immense amount of responsibility, including organizing shifts, patrolling the park for multiple shifts per week, and facilitating trainings and meetings. His/her superb facilitation skills, dynamic inclusiveness and firm demeanor helped hold the meetings together, but eventually the stress of mediating conflicts became unbearable and Supporter05 suffered extreme burn out, choosing to step back from his/her core organizing role. Supporter05's stepping back closely followed the police raid on Zuccotti,

and had the occupation continued, it is unlikely the group had the capacity to sustain the level of services it was providing in the park through the winter.

### 3.1.2 Is There a Doctor in the House?

On a crisp autumn evening in early October, I attended an in-person Support-group meeting where a psychiatrist volunteering with the Support group introduced a motion to recruit more psychiatrists to spend time in the park and support the protester's psychiatric needs. The medic who had invited Icarus to OWS was present, in his wide-brimmed hat, along with two young social work students from Hunter College who had signed up for a community patrol that night, and other members of the Support group. The group was sharply divided on this action. Some argued against this recruitment, likening it to recruiting off-duty police officers to assist with security in the camp. They were visibly agitated, and angrily pointed out that psychiatrists have state sanctioned power to forcibly medicate or even institutionalize citizens against their will, and introducing this power dynamic to the community patrols would likely undermine trust. Others rationally countered that some of the protesters were already taking psychiatric medications, and would best be supported by not letting their prescriptions lapse. Also, there were some situations developing in Zuccotti that might benefit from psychiatric treatment, including anxiety, depression, panics, insomnia, and substance abuse. Although their points were largely rational, their tone was interpreted as patronizing and condescending. Those who favored recruiting psychiatrists were largely oblivious to the concerns of those who

were wary of direct psychiatric interventions, and the exchange was a warning for how provocative, and potentially counterproductive, psychiatric participation could become.

Strikingly, during this exchange, the psychiatrist present was belligerent and aggressive, dismissing the emotional significance of language and labels, while casually directing accusatory clinical diagnoses at other group members as well as activists. He did not yell, but spoke loudly, gesticulated wildly, and at one point, stood up and physically intimidated someone who disagreed with him. He exhibited an arrogance and lack of reflective awareness that disturbed many in the group, and demonstrated the very behaviors and attitudes that those against recruiting more psychiatrists were concerned about. This attitudinal pattern is common among physicians, especially psychiatrists, as we have already seen in Chapter 2. These outbursts illustrate the need for medicine to adopt what Sayantani DasGupta calls “narrative humility”, which she contrasts with medical curriculum’s claims of “cultural competence” (DasGupta, 2008). She sharply argues that culture is not something you can “master” in a two-week workshop, and this psychiatrist’s display of arrogant overconfidence was disconcerting and undermined trust. The group never succeeded in recruiting other psychiatrists to the park, and physicians associated with the Medical group operated an underground pharmacy, filling psychiatric prescriptions for the protesters.

The Support group acknowledged that they did not all share a common language, although they thought they largely agreed on their mission and goals. The group leadership encouraged the membership to be patient with each other, and give each other the benefit of the doubt.

Supporter05: And, one thing I'm encountering at many different meetings is that this really is the 99%. We're not all radical, and we're not all radical about everything. We don't all know or agree with the most politically correct or empowering or cutting edge way to talk about things. \*We also cannot demand that all of those approaches change overnight as a precondition to being able to work together.\* Meeting people where they're at doesn't just apply to others, it applies to us. This goes for the radical mental health folks but it also goes for the social workers: the radical mental health movement has been working very hard to change the language and culture of how we talk about these issues for a long time. It can be hard to be in a progressive space and hear some terminology that feels contrary to that. (2011c)

The cold, clinical language of psychiatry continued to trigger some of the radical mental health activists, and some members of the “Support” team made an effort to adjust their language after they began to understand its impact and learn some alternatives. Others however, insisted that this language was merely a value-neutral shorthand, jargon for professionals to communicate with each other more efficiently. While the debate about the impact of clinical labels on people’s identity has surfaced in numerous other contexts (Davis, 1997; Butler, 2004), the way it surfaced at Occupy Wall Street indicates how much work the mental health activists have ahead of them.

### 3.1.3 Involuntary Treatment

Conversations on the list also returned regularly to the topic of involuntary hospitalization. Supporter07, a chaplain who was working closely with the support group, first emphasized their deference to mental health professionals:

Chaplains... get training in mental health first aid, trauma, counseling and are taught to identify mental disorders and diseases etc... it is extremely important in our work as chaplains to call in the licensed professionals to handle as we are not qualified to do so. I do not claim nor am a mental health professional. Partnering

with them or MDs, psych classes and my own personal Jungian analysis sessions of the past neither makes me so. (2011).

He/she proceeded to explain his/her understanding of the relationship between the OWS Support group and the NY State mental health policy, as well as his/her understanding of patient rights.

... the logical part of me does feel that although we are really trying to do the right thing by being on the side of patient advocacy [and] it is vital... [we] are not an island devoid of state laws and mental and medical health policy and procedures... From what I do understand of the laws is that if an MD, PsyD or MSW suggests that a person be admitted to a facility... they are only in that said facility for a 3 day observation. They are not institutionally "locked" up indefinitely... there is an entire legal process involved to do that involving state legal agencies and it is limited to the criminals.... Although no law or policy is absolutely perfect, to prevent serious risk and/or possible loss, I do think it would be in our best interests to abide by the experience of the seasoned social workers, clinical psychologists and psychiatrists who are well versed in these systems and procedures. I humbly suggest that we set aside any preconceived notion or experience of "the system" to gain benefit from their work. Their experience in their field is vital to the movement. Perhaps what the situation calls for is... work[ing] to improve it not abolish it all together? (2011)

This textbook view of what actually transpires in cases of involuntary hospitalization was vehemently challenged by Supporter08:

Mental health professionals have been granted state-sanctioned power to forcibly detain (and toxically medicate!) citizens without any due process or legal recourse. 72 hour observation? Bullshit. Depends if you are voluntary or involuntary, and all it takes for someone to lose their constitutional freedoms is one psychiatrist with a wink to another.

Threat to yourself or to others? Maybe that's how people are admitted, but they won't be discharged until their behavior conforms to the norms as defined by their wardens. Or until their insurance runs out. Whichever comes last.

How bad can a few days or weeks or months in a psych ward be? Worse than jail? For some. Inpatient hospitalization often inflicts physical and emotional

abuse upon patients, with scars, and medical bills, that can last a lifetime. Once hospitalized, many patients are sucked into a revolving door of psychiatric care as their personalities are examined and pathologized under the gaze of the psychiatric magnifying glass. I know /many/ who would prefer to take their chances with the criminal justice system than ever set foot inside of a psychiatric ward again.

So, let's have a conversation about patient realities, from the subjective experiences of patients, rather than patient rights. Let's respect each others experiences and knowledge, and not ask for license numbers and credentials in order to be admitted to the conversation. (2011)

These claims were corroborated by a social worker with experience working in in-patient facilities:

Supporter09: i write here to give [Supporter08] support that no matter what the law states, the 72 hour observation period is not part of actual reality, certainly not in the hospitals i've worked in. first of all, patients—even voluntary ones—have to assertively write a 72-hour letter, which then starts the clock, and often the treatment team will indicate it may contest the letter in weekly court unless blah blah, so if the patient wants to hold their own completely they may have to wait until court, possibly seven days after being admitted, for instance.

Supporter08, i hear your frustration. i think a lot of us are frustrated—for a variety of reasons, or maybe a bunch of similar ones—and feeling belittled (no credentials? no patient experience? no street cred?) really sucks, especially when we're all working so hard and putting so much of our heart into this. i guess all this arguing, or dialoguing, or whatever, probably has to happen at some level because this movement does represent a fundamental shift in practically everything. (2011)

These encounters demonstrated the value of bringing together people from different backgrounds, including those with direct experiences within the psychiatric system. Although concessions and compromises were rarely made in writing, numerous participants in the Support group approached me offline to express the value they found in these exchanges. Although the primary interlocutors rarely gave much ground, many of the lurkers and listeners on the list reported that they learned a great deal about this

new wave of radical mental health, and how it differed from the dogmatic straw-man of anti-psychiatry they were familiar with previously. While it is difficult to tell if the presence and participation of the radical mental health activists within this group had a significant impact on its operations, it is clear from the mailing list that they succeeded in problematizing many assumptions that the professionals took for granted.

### 3.1.4 License to Support

Cracks continued to emerge, along with tensions between the professionals and the peer-supporters. At one point, one of the Support group members strongly proposed that Support members wear armbands displaying their credentials and professional license number:

Supporter06: "I've been talking with the medical people about a little more elaborate identification system. They have talked to me about problems they've been having with a fringe group 'Icarus' who have been acting at cross purposes with medical when trying to deal with psychotic/dangerous people in the park. According to the medics this group has been "encouraging" crazy behavior... mental health [should have] its own insignia on a sticker and/or big t-shirt that can be worn over outer clothing that identifies the person as an ows/zuccotti park mental health worker and has a number that can be written in. There can be a numbering system such as Sw# (for social workers), Pc# (for pastoral counselors), Psy# (for psychiatrists) The number is key because it means the person has had some \*vetting and orientation\*

All mental health workers can be vetted (ie. Their credentials checked\*) and be oriented to work in the park. Once this is done they can be given a number to write-in on their t-shirt or sticker. \*All workers in the park who see mental health workers with no number should refer them to a mental health point person for vetting and orientation\*. orientation including such things as - Procedure for dealing with psychotic/and or dangerous people in the park - Procedure for signing in and out - where the referral lists are and familiarity with what's on them. - a basic knowledge of the park and neighborhood service. - some idea on the limits of what we can provide vs. refer out. - How to proceed in a dangerous situation." (2011a)

The particular incident that spurred Supporter06 to recommend vetting the Support team was never fully elaborated or substantiated. There were over a dozen activists associated with The Icarus Project who were organizing in Zuccotti, participating in a range of working groups, including the Support group this email was addressed to. Supporter06's description of the "fringe" group Icarus suggests that he/she was unaware there were Icarus Project members participating in the group, or, was intentionally antagonizing them. As we will see in more detail in Chapter 5, The Icarus Project is a loosely structured network without a formal, hierarchical leadership structure. It is unclear if there were any individuals who identified themselves with The Icarus Project who the medics confused with a "group", but there was almost certainly no organized action by The Icarus Project to disrupt the medical tent.

In follow up conversations with the Medical group they explained that they wanted to fully "clear" their patients medically (e.g. physically) before turning them over to the Support group for emotional support. One radical mental health activist countered that in an era dominated by the reductionist biomedical model, all forms of emotional distress could be described in medical terms, ceding all authority to the Medical group when it comes to emotional well being. Was a chemical imbalance a physical condition, to be treated under the jurisdiction of the Medics? Where is the line between psychical and emotional ailments?

Soon after this exchange I got together for dinner and a drink at a nearby Irish pub with the head of the medical tent, a professional nurse who had shouldered the incredible responsibility of managing the life and death operations of the Medic group. His bandana-wearing golden retriever accompanied him, and he relayed his own personal traumatic

experiences with psychiatry, and his overmedication on attention deficit disorder drugs as a teenager. In the course of our conversation it became clear that his impression was that all psychiatric resistance conformed to the traditional mold of 1970s anti-psychiatry. His understanding of the radical mental activists was that they were categorically against all psychiatric medications, and did not believe that mental illness existed. He was unsure of which situation Supporter06 was referring to, but was very concerned that the entire medical operation would be held liable, and potentially shut down if it violated NY State standards around psychiatric evaluation and care. He saw the role of the Medic group as supporting OWS within the framework of the existing system, rather than re-imagining all social, medical and psychiatric services. Our conversation left him with a newfound appreciation for the more nuanced critique offered by the new wave of mental health activists, and he agreed to reconsider his extreme stance of wanting to bring in psychiatric authorities when faced with emotionally disturbed patients.

The issue of “vetting and orientation” continued to divide the group. Supporter10 responded to the armband proposal by questioning the underlying biases of the credentialing systems, as well as considering who would be excluded if this standard were enforced:

In regard to the “vetting and orientation” and the classification of who is qualified to provide what “support” services - this concerns me. I get how we want to have some idea of who is representing “support.” I just hope that this doesn’t turn into something that is based on “formal expertise” as opposed to informal, because the systems that formally recognize and confer expertise (i.e. licensing bodies, grad schools, etc.) are all inherently racist, classist, and other forms of oppressive. Given that these oppressions are at the root of a lot of the conflicts in the park, I want this group to consciously and purposefully recognize and include informal expertise at providing “support.” I know if we went to a system of only recognizing licensed/credentialed experts as being qualified to provide support, that would exclude most of the support

volunteers who have experience with issues of homelessness, drug use, radical mental health, and harm reduction (myself included). (2011a)

Supporter06 replied:

I agree with your larger point that one doesn't need to be credentialed to provide support, However, the problem I have is with people with no mental-heath or medical training setting policy regarding what to do and how to handle people in a psychotic, manic or dangerous episode.

Even thought Zuccotti park is a somewhat removed microcosm with its own ideals and mores, and they are trying to do things differently in regards to various 'isms' (not too successfully I might add) this does not strike me as a set of qualifications that then makes one able to determine 'best practice' on what to do and how to proceed with someone who is in a state of being a danger to themselves or those around them. Nor does having had an experience of being admitted to a psychiatric ward, or having a friend or relative admitted no matter how unpleasant the experience was. The whole situation of 'support' proceeding along these lines and making up new guidelines in these situations strikes me as dangerous and irresponsible. (2011b)

It is unclear what kind of training Supporter06 had in mind that would not provide credentials, but throughout the exchange he/she refused to demonstrate sensitivity to stigma and labeling, and insisted on dismissing the lived experiences and advice of people who had extensive experiences with the system. In the end, the group never adopted the resolution to wear armbands with identifying professional credentials, although some of the individuals in the group did so on their own.

### 3.1.5 Which 99%?

The questioning of credentials on the Support team was mirrored with a parallel questioning of the credentials of some of the protesters. OWS began as an inclusive movement with the intent of including all who wanted to participate. This principle became challenging to uphold as disruptions swept through the park, especially after the police

began directing the homeless and substance abusers to Zuccotti. The Zuccotti “Peace Council” tried to establish a protocol for asking people to leave the park, but the police maintained that, just as the police could not force the protesters to leave the park, OWS could not force anyone to leave either. Supporter02 describes another incident involving a couple who were well known to the Support group, and had been previously asked to leave the park after an incident where they had hit each other:

Note that on Monday night, both the methadone addict couple and the drunken punk rocker men railed endlessly amidst their noise and threats and chaos about how they were there for the movement and the cause, had been there since day two for that reason, and were not like these other self-entitled freeloaders all around them causing trouble. The language of this distinction is clearly part of the park culture and sadly, something the disease of addiction will readily try to co-opt. (2011d)

Supporter10 responded passionately:

I don't see how we can know that these claims were co-optation or insincere. Personally if someone told me that my political motivations were invalidated by my substance use, I would experience that as highly condescending and alienating and it wouldn't endear me to them. The fact that people use substances does not take away all of their agency or maturity or opinions. To be sure, it also doesn't excuse threatening or aggressive behavior. I'm really interested in changing the park culture that includes this language of distinction, rather than holding it precious and deciding who is qualified to make that distinction.

Again, just speaking for myself, but the revolution that I'm interested in participating in is the one that includes everybody and doesn't distinguish between worthy and unworthy protesters. Personally I feel that engaging and including everyone IS affecting systems of change. Some of the work that I'm doing with homeless/young/drug-using/gang-involved/etc. occupiers is exactly that. Talking to them about why they're there. And I don't mean challenging them, I mean listening to them...

Also, many people experience “addict” as a pretty stigmatizing label, especially when applied externally by someone else. Personally I don't use it unless the person I'm speaking with has self-identified that way. (2011a)

The issue of who was a legitimate protester, like the issue of who was a legitimate Supporter, was contentious and fraught. These issues provoked difficult questions about the identity and mission of the movement, and it is not surprising that within the Support group there were differing opinions around the value of inclusivity. Some felt strongly that the movement needed to accomplish specific political objectives, and that the protesters' activities should be organized according to these objectives. Others felt strongly that the work of creating an alternative society within the encampment was inherently political, and should not only be viewed instrumentally, as a means to an end. Rather, the creation of this alternative society was an end in itself, as well as a powerful performative expression of the group's principles. A policy of radical inclusion, even where it created some discomfort, was a strong political statement that defied the status quo, embodied the values the movement sought to advance, and was one way to effect change. At the same time, discomfort often leads to outright disruption, derailing meetings and undermining collective actions. Balancing these concerns while preserving coherence is a challenge that prevailed throughout Occupy, and an issue that recurs throughout activist organizing. The Support group often found itself in the crossfire of this conflict, mediating volatile conflicts and attempting to diffuse tensions before they erupted.

### 3.1.6 Vibe Checkers and Knife Wielding Psychotics

Although the threat of violence and sexual harassment in the park was real and immanent, some of the Support group participants began to question the group's incessant focus

on violence in their orientations and role-plays. They argued that the constant focus in role-plays on scenarios like a confrontation with a “knife wielding psychotic” primed the community patrollers, and helped perpetuate an atmosphere of fear, control and anger among the support staff. The mailing list was filled with examples of people imagining and responding to negative situations, but the Support group was not focused on improving this atmosphere by introducing positive energy to the park. These black and white examples also obscured the complexities of the far more common grey zones, like eccentric and annoying behaviors.

Countercultural events such as Rainbow Gatherings, Grateful Dead shows, and Burning Man feature “vibe checkers”, or people responsible for helping to insure that nobody is having a “bad trip”. Some of the radical mental health activists argued that the Support group’s community patrols felt more like policing than vibe checkers. In recent years, there have been numerous incidents where law enforcement has overacted when confronting mentally ill suspects, often with fatal outcomes (Krameddine & Silverstone, 2015; Friedersdorf, 2015). The Support group’s tactics were incomparable to law enforcement’s, as the community patrols were unarmed, empathetic, and focused on verbal de-escalation. Nonetheless, some of the group’s trainings and role play scenarios emotionally triggered some Supporters who had been on the receiving end of these kinds of authoritative interventions in their past. They expressed their desire for more nuanced role-play scenarios, and felt the black and white portrayals reduced their experiences to caricatures, and fostered exaggerated responses.

Being surveilled by the community patrols, a group that had begun to wield a distinct power within the community encampment, was a responsibility that most of the

Support group lived up to. However, as conditions in Zuccotti continued to deteriorate as the weather became colder and people set up tents, the patrols became more vigilant. The tents meant more private space, and more opportunities for mischief and strife to flourish. Some of the patrols carried their stress with them, and in some circumstances may have helped reinforce an atmosphere of fear and anxiety.

Supporter10: "In terms of the incident last night with the young man with the broken leg. I'm pretty sure that I've witnessed the disagreements and conflicts that lead up to that situation.... [T]his stems from some bigger issues than just that someone is "mentally ill" or "aggressive" or violent. I'm not trying to excuse or justify violence. I know these young people really well and I absolutely want nothing more than for them to be able to be safe.... [A] lot of the violence that is happening in the park is not random or isolated or happening in a vacuum. To adequately address and prevent it, we're going to need responses and interventions that take a lot of systemic injustice and inequality into account. I'm not saying I have the answer, or that there even is an answer that can be written up in a 5-step guide and distributed to different working groups. I'm just saying that these are big issues, that go much beyond a mental health diagnosis or whether or not someone is using substances. (2011b)

The incident that Supporter10 reports in this email, sent on November 14, the night before the police raid on Zuccotti park, captures the kinds of issues that Support grappled with in the latter days of the encampment. By this time, fatigue had set in, and the communication lines between Support members were fragmented. This incident Supporter10 writes about was not captured in the red log book, which was never consistently used, and the full background of this story was passed orally between Supporters directly involved in the intervention. Supporters who were not on-site that day relied on the mailing list for background information, and only received an incomplete account of the situation. Mailing list communications were often cryptic,

in part because of the effort required to compose a complete story, and in part since participants did not completely trust everyone else on the list.

I am unfamiliar with the full backstory behind this particular email, but I believe that it likely conveys a potent subtext, a communication sent to the wider list that was really intended for one or two specific individuals, the continuation of a conversation that began in person. Supporter10 was a social work student, studying community organizing, mediation, and de-escalation. His/her attempt to inject a consideration of the activist's history into their evaluation, and refutation of the group's ability to capture this approach in bullet points may have been a response to harsher proposals to eject the "troublemaker" from the park, and a critique of the effort to simplify the principles of mediation to a one-page flyer.

Faced with this range of differing and irreconcilable perspectives, a few members of the Support group migrated to other groups that better matched their understanding of support, and the kinds of assistance they wanted to offer the movement. They shared with me how they felt marginalized within the Support group structure, systematically silenced and ignored during meetings, and wanted to participate in a group more aligned with their values. Despite all of these conflicts and critiques, the Support group performed remarkably well, providing essential support services throughout the occupation of Zuccotti park, and extending their services through the winter as Occupy was dispersed throughout the city into makeshift shelters. Some of the differences people expressed with the Support group were based more on personality and style than on substantive ideological differences.

One of Occupy's strengths was catalyzing encounters between diverse perspectives, in relative safety. I want to emphasize that with all of the disagreements, the members of the Support group were all dedicated and passionate activists with good hearts and the best of intentions. Some of the demands of the Radical Mental Health activists were overly unreasonable, impractical, and disconnected from the harsh realities of suffering and risk on the ground. Overall the Support group was effective and cohesive, sustaining an active presence in the park throughout the period of occupied encampment. Radical mental health activists would most likely welcome the mainstream adoption of the intervention models developed and practiced by the Occupy Support group. Within the context of Occupy, the radical mental health activists held the Support group to a higher standard, in an effort to advance the discourse by challenging assumptions, unsettling conventions and provoking debate.

### 3.1.7 Coda: Post-Zuccotti Shelter and Support

Following the NYPD's violent eviction from Zuccotti park at 1am on November 15th, a few homeless shelters and churches opened their doors to the protesters. Many Zuccotti occupiers had come from out of town to the protests and needed shelter during New York's cold winter months. The Support group was pivotal in negotiating these arrangements, and essential in helping sustain these shelters in the months that followed. Conflicts between shelter dwellers and between the protesters and the shelter providers were more complex and difficult to manage than in the park. The Support group reverted to a more traditional model of support, as the shelter arrangement closely

resembled typical settings where social worker normally practiced. The group worked to provide information about government services, helped people secure food, clothing, and healthcare, and mediated conflicts with the shelter providers. The shelter organizers struggled to keep the peace, and many of the shelters formed their own governing structures. A few of the shelter organizers specifically asked the Support group to step back, as they felt that the Support members were more harmful than helpful. Overall, once the role of the Support group shifted to offering more traditional forms of Social Work support, the conversations around alternative mental health largely faded. While there was still plenty of urgency around engaging and questioning mainstream paradigms of mental health diagnosis and treatment, the occupation at Zuccotti helped foster the unique conditions for discussing these issues, *in situ*.

## 3.2 Rising Up Without Burning Out

Alongside my participation in the OWS Support group, I was simultaneously involved in a complementary project aimed at compiling, remixing and authoring materials aimed to support protesters and caregivers struggling with emotional crisis within the context of Occupy. The idea of working on this book excited radical mental health activists from around the country, as well as street medics and mental health professionals involved in Occupy working groups. Some wanted to create materials to support teach-ins and workshops, and others found the work itself to be liberating, defiant, and therapeutic. We also saw the publication as a device for provoking important conversations about community, peer-support and mutual aid.

I trace this project's inception to a number of other projects I had recently worked on which anticipated this publication. First, the summer preceding OWS I consulted with The Icarus Project on re-releasing new editions of their existing catalog of self-published books. We were trying to reimagine zine distribution for the 21<sup>st</sup> century through on-demand publishing and the release of the "source" files behind their publications to enable remixing and repurposing. Although the Icarus publications were already available under Creative Commons licensing, only the derivative, print-ready PDFs were distributed and not the underlying assets and layout files. The original source files were authored using Adobe's Photoshop, Illustrator, and InDesign applications, and were then rendered to the publishable PDFs. Reworking the PDFs is very difficult without these original source files, and this meant that remixing the materials for other purposes was legally permissible, but practically difficult. Second, I had also recently worked with the booki platform (later renamed BookType), an open-source wiki that is designed to create print-ready PDFs, as well as ebooks in a range of digital formats (Sourcefabric, n.d.). I was aware that this tool had been used to support "book sprints," in which teams would author a book in as little as a week. I myself had remotely contributed a chapter to *Collaborative Futures*, a book whose first edition was authored by five collaborators who locked themselves in a hotel room starting with nothing but the title, and emerged a week later with a complete first draft (Zer-Aviv et al., 2010). The *Mindful Occupation* project took longer than a week to assemble, but the inspiration came directly from prior booki projects, such as *Collaborative Futures* and *How to Bypass Internet Censorship* (FLOSS Manual Contributors, 2014). Finally, a friend of mine involved in OWS had recently launched a Kickstarter campaign for the creation and publication of *The 99%*'s

*Guide*, and I was inspired by this project to attempt something similar around mental health and Occupy (Mushett, Shah & Tang, 2011).

All of the labor on this project was completely voluntary, from the cover art, to the layout, to the [mindfuloccupation.org](http://mindfuloccupation.org) website and the fundraising video. We also made extensive use of prior materials that had been released under Creative Commons licenses. Since print remains an important medium of distribution and dissemination, we set up a Kickstarter project to help fund our print run and raised over \$3,000. We released a draft version of the hard copy in time for May Day 2012 and the May 5 occupation of the American Psychiatric Association conference in Philadelphia that I write about in the next chapter. The book was picked up for distribution by AK Press, an anarchist-friendly publisher and distributor, and to date has sold hundreds of copies.

The book brings together materials on emotional first aid, navigating crises, preventing and healing sexual assault, as well as facilitating peer-support groups and coping with stress. Many of the preexisting materials needed to be re-contextualized. For example, we would find a great resource within a PDF alongside material less relevant to Occupy. In this case, we wanted disentangled the relevant material on emotional first aid from the advice to local Icarus chapters on how to set up monthly peer-support groups. We did a lot of re-mixing and matching. When revisiting some older materials, we also found that some of it had aged poorly, and we reworked these portions with revised sensibilities. For example, a decade-old graphic from a poster titled “Taking care of the basics” was reworked to remove the portrayals of negative behaviors that offended some of the contributors. The original included depictions of unhealthy behaviors that some felt might offend the overweight, the poor, and to those with alternative lifestyles. The

occasion to reexamine legacy materials with a fresh, critical eye revealed ways which the project had matured over the years, and the resulting remix was well received. We also authored a great deal of original content, including the introduction, sections explaining radical mental health, and an effort to connect corruption in psychiatry and pharma directly to the core concerns of Occupy. We intended these sections to stimulate more discussion, analysis and action.

### 3.2.1 Cacophonous Choruses

By design, we selected a wiki-like platform to assemble and author the book. Anyone involved in the project could add or edit material online, and the system preserved the history of all our edits. We also set up a mailing list alongside the booki platform for planning logistics, developing content, and working through conflicts. The project attracted a diverse range of participants from a variety of backgrounds, all listed in the credits of the publication and on the website (Imai et al., 2012, p. 77). The project mailing list included over 40 contributors, the Kickstarter project attracted close to 80 supporters, and dozens of others contributed their skills, talent, and time to help produce this publication. Participants included mental health professionals, some of whom were involved with the Support group, long-time radical mental health activists, graduate students, and occupiers interested in mental health.

The project attracted contributors with varying perspectives and agendas. One of the key contributors, Contributor01, was a social worker and long time Icarus organizer.

On October 12th, he composed the following announcement, and circulated it within relevant communities:

The idea has come up to group-author a book/zine about mental health in direct action/protest situations that can be quickly compiled, printed and distributed at the occupy events around the country. . . If you want, please join in the authoring or reach out to others you know who might be able to help out, if you don't have time/energy to write anything, please please at least send on any topics/questions/concerns you hope could be addressed.

We quickly assembled a working title, *Mental Health and Activism: A guide to protesting sanely in a world gone mad* (later renamed *Mindful Occupation: Rising up without burning out*), and a tentative outline, including possible chapters such as: “1) *What is radical mental health?* Overview of radical mental health, critique of psychiatry, brief history of critical movements, why important; 2) *Rising up without burning out* self care, harm reduction, care for others, etc); 3) *Psychological First Aid for everyone* maybe separate chapter geared towards medics specifically?; 4) *Mental and Emotional Health at an Action Clinic* how to get providers on board, things to think about, supplies needed, etc; 5) *Just because you're paranoid doesn't mean they aren't out to get you* Special notes about dealing with mental health and the police state including how to care for people in jail, coming out of jail, how to keep paranoia in check, queer and trans legal support issues, etc.; 6) *Appendices*; 7) *Materials List*; 8) *Resource List*; 9) *Books/Websites to Read*”. This outline set the tone and direction for the project, and provided people interested in contributing with a clearer sense of the project’s intent.

In addition to the tentative outline, Contributor01 also posed some guiding questions they thought we should grapple with:

Some open questions: Someone is talking about killing themselves at the encampment, what do I do? (already happened in Mpls, and a probable suicide in San Diego) Someone is freaking out, what do I do? (Or why you shouldn't call the cops to deal with someone who is freaking out.) Dealing with trauma during/after an action or police brutality Having a self-care plan - also the movement doesn't need any heroes or martyrs Having some people with discreet access to marijuana and/or benzos to deal with extreme panic (good idea or bad idea) - general concerns about having RX drugs around in an action clinic, etc.

Initially, the group hoped to rapidly assemble relevant materials for publication, and quickly raise funds to print and distribute them where they were most needed. We quickly identified some great existing resources, such as the Activist Trauma Support site (Activist Trauma Support, n.d.) and Will Hall's *First Aid for Emotional Trauma* (2008), and obtained permission from the authors to republish their material. The author of a recent zine entitled *Stress, Anger, Depression, Anxiety: a Coping Skills Zine* also joined the effort (Contributor08), and offered access to all of his/her material. Some of the working groups in the safety cluster created handouts with important information and guidance, such as the "Safer Spaces Training Document" and these were incorporated as well.

As the project's scope and ambition grew, the hope for a quick turnaround was quickly dispelled. Although we repurposed large portions of content, we also committed to authoring some original content, aimed to contextualize the more generic support materials within the context of OWS. Additionally, Icarus Project materials have traditionally maintained relatively high production values, incorporating sophisticated layouts, rich graphics, and professional typography. This emphasis on a graphical style resulted in publications that were more readable and accessible than text-heavy counterparts,

and required more intensive, highly skilled labor. Finally, the material we were assembling included highly contentious topics, such as the use of coercion/violence, forced hospitalization, and psychiatric medication. Especially in the context of our inclusive collaborative authoring process, these factors all contributed to many rounds of edits, revisions, and debates. The contributors struggled with deliberative consensus building, endemic to OWS, and valiant efforts were made to forge a cohesive voice that everyone would be happy associating their names with.

The core contributors to the project were geographically dispersed, including participants from Minneapolis, Richmond, San Francisco, Pittsburgh, New Hampshire, and Ohio. A small concentration of participants lived in New York, which became the hub of organizing around this project. The group hosted in-person edit-a-thons, where contributors met in person, with some of the remote contributors participating in real-time on conference call or over Skype. Early on we reached consensus around our tentative outline, the number of pages we were aiming for (approximately 35-40 pages; the final publication was 80 pages), and that the book would not be branded as an Icarus Project publication. While many of the contributors were affiliated with the Icarus Project, and the Icarus Project would be appropriately credited, it would not be placed center stage. The group was determined to incorporate perspectives beyond the project, and to involve contributors from outside the radical mental health movement.

### 3.2.2 (In)Validating the mainstream

Some of the participants in the project were new to the radical mental health conversation. They expressed their concern about creating a publication that would be welcoming to mainstream audiences, and not alienate them with insults and accusations.

Contributor03: As a lurker on this list, I'd like to share some hopes and fears that have arisen for me as I've witness the development of *Rising Up without Burning Out*. I've long been committed to radical politics, but I'm just learning about radical mental health. Over the past couple of weeks I've closely followed this list... and attempted to both understand and explain this new (to me) and profoundly anti-oppressive conceptualization of "mental health."...

But, I've struggled. Both to clearly understand how I can contribute to the application of radical mental health on the ground as well as how to persuade friends and colleagues that radical mental health can play an important role in a non-violent movement. Many of the "support" volunteers (including myself) at Occupy come from pretty conventional health/mental health settings and have a more mainstream approach. At OWS, there has been an obvious tension between these individuals and others with a more radical perspective. It would be great if this publication could directly acknowledge this tension and attempt to provide a bridge between these groups.

Currently, some the language could be interpreted as blaming and exclusionary (e.g., "... Such mainstream approaches are therefore both product and tool of imperialism, capitalism, neoliberalism, and secularization; those very systems that Occupy is striving to undo...") and I worry it might serve to further divide the community, and not foster the goals of deepening understanding and acceptance.

So....my question: How can this publication be an open invitation to explore a more radical approach to mental health while still validating different perspectives and contributions? (2011a)

Contributor03's question was taken seriously, and received a number of thoughtful responses. Contributor07 acknowledged the need for clear language, quoted some of these responses, and summarized a plan to respond to contributor03's challenge:

Contributor07: [quoting Contributor06]: Complex problems demand holistic solutions, and psychiatry and pharma are an instrumental cog in the wheel of oppression. Have individual psychiatrists and particular medications helped people? For sure. But the system on the whole is broken and corrupt at multiple layers, probably beyond reform or repair. \*\*We are desperately struggling for conceptual revolutions that will foster paradigm shifts in ontology, epistemology, and ethics.\*\* When the underlying models are contested, communication can be stilted and awkward. Almost like we aren't speaking the same language. What assumptions do you think we have made that we can make more explicit? What kind of clarifying statements or disclaimers do you think we should add? How can you imagine us engaging and incorporating mainstream perspectives into our work? [end quote]

I'd love to hear response to these questions - I think it could really help our dialog and make this document we're working on so much more useful. It's easy to write to the already converted. We need to imagine this writing reaching all kinds of folks who aren't steeped in radical mental health rhetoric. My experience, after 9 (!) years of working on the Icarus Project, is that it is incredibly powerful and useful to actually open up spaces where, from the start of the conversation, we make it clear that people who use diagnostic categories to describe themselves and people who think all the categories are bullshit are welcome, and that people who use psych drugs and people who would never touch them are all welcome. I think it gets really tricky when we have "service providers" who've been trained in the DSM language but don't have their own personal experiences on the inside of the psych system trying to "provide services" to people who've been in and out of the psych system.... I sincerely hear you [Contributor03] when you talk about trying to contribute to radical mental health "on the ground.".... I think one of our most important roles has to do with education, and if that's the case, I vote for us trying to be as clear and compelling as we possibly can with the language we're using. (2011a)

Contributor03 replied, thanking Contributor07 for his/her thoughtful reply. He/she later followed up with a more thorough responses to these questions, which were directly incorporated into the final publication:

>>> *What assumptions do you think we have made that we can make more explicit?*

The shear volume of materials on the Booki is a little overwhelming. Much of it is very accessible and nuanced, but I think there is ambiguity that may trigger fear in some people. Particularly, I believe it is important to directly address the questions

that are the reoccurring points of discussion on this listserv and others: -what about meds? -what about hospitalization? -what to do if you believe someone is suicidal?

Also, it would be helpful if early on in the document there was a succinct communication of the main tenets of the radical psych. This document requires a fair amount of work on the readers' part. And while that might be your intent, it is hard to inform or persuade people if you've already lost them... [it] might help [to] engage people who aren't as informed or literate as you guys:

"1) the definitions around which behaviors are normal and abnormal is profoundly political 2) the primary goal of treatment should be empowerment and helping a person reach whatever their definition of healthy looks like rather than imposing a definition of health 3) many (most? all?) mental health issues are a response to trauma - personal trauma, familial trauma, social trauma, etc - and mental health must address the roots not only the symptoms 4) when it comes to consciousness and the brain, when it comes to neurochemistry and pharmacology there is so very much that we don't know, yet we treat people as if we did, and on a wider epidemiological level, we're making people worse. There is such a world of difference between humble questioning and informed consent and the current way the medical model plays out in real life - especially in institutional settings 5) consent and harm reduction are vital, not optional"

>>> *What kind of clarifying statements or disclaimers do you think we should add?*

I really like the existing disclaimer. I believe is also important to acknowledge upfront that this document does not reflect the perspective of all Occupy participants. And that there is an active debate on the ground about how to best provide emotional support to protesters.

>>> *How can you imagine us engaging and incorporating mainstream perspectives into our work?*

My previous comments were unclear, but my intent was not that you validate mainstream \*perspectives\*... those ideas have plenty of exposure, but that you validate mainstream \*people\*. That you recognize that there many people who work in mainstream mental health settings —some of whom are involved with Occupy— who are deeply committed to anti-oppressive practices, who are also end users of mental health care, who are also traumatized by working in profoundly unjust and under-resourced systems, and whose' goal is give to hope and support to very people most victimized by those systems. Yes we're cogs in a highly flawed system, but

we can also be potential allies in any systemic change. Currently, this document ignores us, which I fear could result in further division instead of community building (2011b).

Exchanges like these were emotionally demanding, and required a great deal of patience on all sides to work through diplomatically. Undoubtedly, the project could have published something much faster had we not insisted on running an inclusive process, but we believed that by including these disparate perspectives, the resulting document would be more accessible, relevant, and useful. The final publication incorporated most of the feedback that Contributor03 provided, including succinct primers and introductions, and a visual design that was welcoming and accessible. A sustained interest in the book and its usage across a variety of contexts such as workshops and college courses, speak to the bridges it succeeded in building across disparate communities.

The *Mindful Occupation* contributors dealt with conflict using an approach similar to Occupy's consensus-based decision making. As I will show in the next section, the difficulties inherent in this approach were exacerbated by the fact that most of the group's communication was conducted electronically, slowing down exchanges and making them more prone to misunderstanding. Building consensus was painstaking and onerous, and in rare circumstances, such as the section dealing with coercion, the group decided to eliminate content rather than publish a formulation that was disagreeable to some. In other circumstances the group was able to represent their conflicts explicitly, either by reformulating the material as a question to the reader, or by expressing multiple viewpoints within the text. The text was assembled as a guide, and many sections could be read independently. There was some redundancy between sections, as well as a

variety of voices represented throughout the book. Some disagreements were appeased by emphasizing alternate treatments in other sections of the book. Some contributors took issue with one chapter's emphasis on the biomedical model, but through a series of sidebars they agreed that we should include a shortened version of that chapter, since it portrayed a style of support that one of the contributors valued, based on their lived experience.

The contributor's commitment to consensus required more time and energy than many had hoped for. When the group first convened, they had originally hoped to publish materials quickly. The scope of the project grew, and the book's length, aesthetic aspirations and larger ambitions stretched the project from weeks to months. What began as a series of handouts, grew into a zine, and ultimately, an 80 page, independently published book—complete with a perfect bound spine, an ISBN number and a distributor. The contributors were uniformly satisfied with the final publication, which led directly to the OccupyAPA protests we will examine closely in the next chapter.

### 3.2.3 Coercive Ideations

Unsurprisingly, the sections relating to coercion, suicide, violence, medication, diagnosis, and hospitalization also generated tremendous controversy, which was challenging for the collaborators to navigate. In relation to a section outlining responses to a situation where someone might harm themselves, the issue of forced hospitalization surfaced. The draft in the booki read: “Coercion should only be used as a last resort, and to protect people from violence done by others, NOT to protect people from themselves.”

Contributor08 reacted forcefully, “Coercion should never be an option. I don’t agree with this last sentence” (2011). Contributor04 responded, attempting to defuse the standoff:

This is really seeming to me like a case of principle being privileged over people. Who benefits from allowing someone in crisis to commit suicide rather than be hospitalized? Who benefits from waiting until a person who’s posing a clear threat to others has harmed someone, and the situation becomes a police issue? As much as no one wants to be hospitalized against his or her will, the implicit assumption here that the criminal justice system is in any way less abusive is absurd. And once in the criminal justice system, odds are a person in crisis will end up spending some time in a really crap inpatient facility. It certainly isn’t benefitting him or her, nor does it benefit any larger community. I’m sorry, this just seems like a ridiculous position to take to me. (2011)

Contributor05, the original author of the booki draft replied:

@[contributor08]: I liked your edit as it’s a bit clearer to read than my 1st draft, although the last sentence does still present coercion as an option, just gets more specific on the types of coercion one might use, I don’t know if that was your intention. My basic idea was that coercion should only be used when it’s that or let someone seriously harm others in the space, and that it shouldn’t ever be used pre-emptively. (2011)

@[contributor04]: I AM SO FUCKING SICK AND TIRED of hearing this bullshit “concern” from those who say opposing forced treatment is “principle being privileged over people”. Guess what, a lot of us, I’d even say most of us, who are fighting against it aren’t doing so because of our abstract principles of respect for civil liberties, but because \*we have been victims of abuse by an abusive system\*. Who are you to say that to lock people up is always better than “to leave people to their own devices”, or more to the point, that it’s \*ever\* an either-or choice? (2011).

This exchange was just one example of many that mirrored intractable standoffs between different positions within the mental health activist movements. As a project that was attempting to represent and help bridge some of these perspectives, one of the project’s organizers wrote:

Contributor01: The debate about forced treatment has been ongoing for decades and isn't going to be resolved in this zine. Personally, i find that a lot of people use "not wanting to use coercion" as a way to duck the hard questions of what needs to be done when there is clearly violence/coercion being used already and/or used in weird ways (it's okay to call the police, but not EMS)… [R]ight now there are mental health folks involved in occupy that see nothing wrong with regularly using 72 hour holds etc and some of this attitude has filtered down to medics. I think the best we can do is problematize that and ask questions. We don't need to provide the answers… (2011)

This sentiment was echoed and reinforced by contributor07:

[I]t's the responsibility of folks like [us], who've been locked up against our wills to be good role models for the community and help people through crisis when we can with the skills we've developed from our own experiences going through the fire. but folks like us aren't always going to be there and i know for myself that i'm not always in a place to be able to help someone when they are desperate, especially if they're acting violent. once again, i find myself writing an email to a bunch of people i mostly don't know in real life, longing for the kind of intimacy where we know how to take care of one another when we're having a hard time. in the meantime, lets at least do our best to be respectful of each other's opinions and remember that we're all struggling together and hoping to put something out there in the world that's going to empower people. it's clear we're not going to agree on this issue, so lets expand our vision and get as creative about it as possible. (2011b)

Ultimately, the version we published, with everyone's consent, avoided making any absolute assertions. It also emphasized the importance of following up after the hospitalization:

If considering hospitalization or incarceration, take responsibility for your decisions and be clear about your motives—it'll make your presence more effective. Don't send someone to the hospital or call the police because it's "better than doing nothing." Let people know about community resources, and together figure out ways to meet their needs without harming others. Calling the police or sending someone to the emergency room for mental health concerns should be a last resort, after consultation with friends and allies. Consider first the potential ramifications including imprisonment, deportation/ loss of immigration status, increased depression, undue

medication, shame, a prison record, loss of custody/visitation rights, interruption of life, loss of anonymity, and health care debt, as well as further scrutiny of protests, police brutality, sensationalist media representations, and so on.

If someone is hospitalized or incarcerated, follow through by organizing visits and other communication. When they come out, help them process why the support team made the decisions they did. Try to be receptive to their critique and/or anger and/or gratitude. (Imai et al., 2012: 44)

Our decision to include a range of stakeholders from diverse backgrounds slowed our process down significantly, but also resulted in a more balanced document that captured and embodied our underlying message, emphasizing the importance of incorporating multiple perspectives into the formulation of these recommendations. It was very challenging to blend some of the most radical voices with more traditional and pragmatic ones, but the effort yielded a more nuanced guide that was sensitive to the concerns of all the contributors. In addition to confronting the hard question about how to handle an emotional crisis, we tried to emphasize the importance of follow up—visiting patients, supporting them after discharge, and teaching protesters about the devastating impact of mental health bills and shortcomings of insurance, even for those who are insured. The collaborators aspired to raise questions and consciousness, without necessarily providing all the answers.

### 3.2.4 What is Radical Mental Health?

There were also many sections offering concrete guidance and practical advice. The book opens with a description of these aims, the background of the contributors, and the relevance to Occupy.

What you hold in your hands is a rough toolkit of ideas and visions. It is meant to be shared, discussed and used for action as the Occupy movement evolves... The folks who put together this booklet come from different backgrounds, all involved with on-the-ground Occupy protests in various cities and towns. Many of us have been working on issues of radical mental health and activism for quite some time, involved with groups such as the Icarus Project, MindFreedom International, and the Freedom Center. Others are mental health professionals and street medics who have been involved in supporting the Occupy protesters on the ground. What binds us together is respect for each other's personal experiences, and our commitment to community-based approaches to emotional support.... There is an urgent need to talk publicly about the relationship between social injustice and our mental health. We need to start redefining what it actually means to be mentally healthy, not just on an individual level, but on collective, communal, and global levels. (p. 10)

The *Mindful Occupation* collaborators defined radical mental health through a series of concepts and associations, including interconnectedness, diversity, embodied expertise, options and politics. We emphasized the importance of not dividing people into “normal” and “pathological”, rather we try to see first a person, not a beaker full of neurotransmitters. We portrayed human experience as “a holistic convergence of social, emotional, cultural, physical, spiritual, historical, and environmental elements.” (p. 15) Strangely, the idea that healing is fostered by community, peer-support and mutual aid has not been widely adopted by the mainstream, neither as a complete solution, or even as an essential component of treatment plans. Some radical mental health activists assert that community and mutual aid offer a comprehensive alternative for supporting mental health (Burstown, 2015), but even the less extreme position emphasizing community as an essential part of healing is uncommon among mainstream psychiatrists. Psychiatry rarely critiques society and injustice, regularly transforms systemic social and political

ills into individual illnesses, and fails to incorporate an analysis of these dynamics into its explanations of trauma and suffering.

We proposed that one of the important ways to invent and enact the new language we advocate is by creating safe spaces for people to share their own subjective narratives with each other, without judgment. This process is evident in the publication that emerged from the dialog around this project, as well as in workshops and teachins that followed the publication of this book. This publication represents an incremental step towards the development of new ways of talking about mental health and well being.

### 3.3 Conclusion

My experiences participating in the OWS Support group alongside my experiences collaborating on the *Mindful Occupation* book were deeply transformative and helped solidify and clarify my understanding of the emerging wave of psychiatric resistance. Central to both projects was the question of voice—Who speaks, who listens, and who is involved in the production of knowledge? When I first began my fieldwork in Zuccotti I believed that if the mental health workers involved in Occupy were not receptive to the Icarus Project’s messaging about the need for a new language to discuss mental illness, the Icarus Project needed to revise their message. The Icarus Project was forged in activist contexts, and from the beginning they challenged the clinical and diagnostic language of DSM, advocating for the importance of community, peer-support, and the acceptance of alternative narratives around mental health and illness. My experiences

at Occupy provided me with a much clearer understanding of how difficult it can be to truly follow the disability right's mandate: "nothing about us without us".

To be clear, many of the mental health professionals at Occupy turned out to be strong allies with the mental health activists, but I was regularly surprised by the nature and degree of resistance by some of the mental health supporters to the perspectives and opinions of un-credentialed supporters like peers and former patients. As the exchanges above demonstrate, some of the professional social workers clung to their professional jargon, insisting it was simply innocuous professional shorthand, or that their patients preferred it. Others listened to the critiques, but rolled their eyes, looked restless and bored, or otherwise dismissed the concerns of the radical mental health activists as theoretical or esoteric. In the most extreme case, the psychiatrist who visited Zuccotti became visibly agitated and raised his voice in objection to the perceived attack on the legitimacy of his profession. The radical mental health activists involved in the *Mindful Occupation* project also had a very difficult time listening to and incorporating perspectives different from their own, and these standoffs helped bring into relief the difference between the previous wave and the emerging wave of mental health activism. Activists representing the new wave went to greater lengths to listen to perspectives outside of the own, and to entertain ideas outside of their comfort zones.

One important lesson to emerge from these interactions is that healing and education take a great deal of time and energy. There is no one-liner, however potent, that will alter entrenched habits and ideologies. Many of these beliefs are deeply ingrained, through years of professionalization or traumatic experiences. As with any belief that exists within a network of other beliefs, resistance to change is dictated by emotional valences

as much as rational deliberation. It is easy to imagine that when the professional social workers were thrust into a position of power, it was tempting for them to exercise this newfound superiority. Typically, in their institutional settings, social workers are at the bottom of the hierarchy, regularly looked down upon by psychiatrists and administrators. In psychiatric hospitals, psychiatrists, psychologists, and nurses earn higher salaries than social workers and command more respect and prestige. Social workers typically earn masters degrees, instead of MDs or PhDs, and though they may earn other certifications to practice counseling or therapy, many grapple with inferiority complexes comparing themselves to mental health professionals with terminal degrees. Similarly, when the radical mental health activists were given a setting where they could speak their mind to the psychiatric establishment, or at least a representative proxy for that establishment, it was tempting for them to disregard the individual people on the receiving end of their venomous attacks.

The radical mental health activists also learned how much work they have ahead of them in terms of spreading and popularizing their message. Many of the social workers were eager and receptive to learn more about radical mental health, and how they might apply its lessons in practice. However, even among the Occupy supporters, many had not heard of some of the leading Mental Health activist projects, and their primary association to psychiatric resistance was the caricature of resistance popularized by anti-psychiatry. Occupy provided an important stage to introduce these topics, as the event brought together a diverse cross-section of activists from a variety of backgrounds working on a diverse set of issues. In the course of these efforts it became clear how urgent and important it was to continue teaching and promoting these ideas. Occupy

attracted a range of social critics, but almost without exception, none of Occupy's leaders or theorists incorporated a critique of the psychiatric-pharmaceutical complex into their analysis of power and society. These issues were not broached in the stump speeches of Noam Chomsky, Naomi Klein, Cornel West, Slovak Žižek, or countless others, though as *Mindful Occupation* argues, the psychiatric-pharmaceutical complex plays a vital role in maintaining the socio-economic status quo, playing a vital role in supporting stigma and alienation, and contributing to social and economic inequality.

Our country has been in a social recession far longer than the financial one. It will take a long time to unlearn our self-defeating habits and embrace languages of compassion and liberation, instead of mistrust and fear. First, we need to believe in the future—vividly imagine it, talk about it and manifest it. This movement, and activism in general, is notorious for its cycles of energetic bursts of creativity, followed by a crash. We have to be self-aware of these patterns, and take better care of ourselves and each other. We need to be more honest with ourselves about what we can tackle, learn how to recognize our triggers, learn how to say no, and learn how and when to bottom-line, delegate and collaborate. We especially need to avoid replicating habits of exploitation and oppression in our day-to-day interactions. We need to actively build our support networks when we are well, and create wellness plans that our friends can use to help support us when we aren't. But, mostly, we need to re-learn how to breathe, share and trust.



# APA 2012: Oppositionally Defiant Protestors

“*The most intense conflicts, if overcome, leave behind a sense of security and calm that is not easily disturbed. It is just these intense conflicts and their conflagration which are needed to produce valuable and lasting results.*

— Carl Jung  
Collected Works

On May 5, 2012 over 10,000 members of the American Psychiatric Association converged on Philadelphia's Convention Center for their annual meeting (Burling, 2012). The official theme for 2012's annual conference was “integrated care”, but the unofficial theme dominating the conference presentations and media coverage was the formal unveiling of the DSM-5 draft. Since the publication of the first edition of the manual in 1952 (American Psychiatric Association), the DSM has been the subject of perpetual controversy, and the DSM-5 in particular has generated more debate than any of versions preceding it. Alongside the regular attendees, journalists flocked to the APA to cover this event, and mental health activists descended to express their dissatisfaction and outrage.

I traveled to Philadelphia to participate in the protests and observe the protesters' presentations. I also spent a full day attending the APA conference, listened to a few talks, visited the poster sessions, and explored the exhibition hall. I engaged in many conversations with protestors, journalists, researchers and psychiatrists about the DSM, focusing on the most controversial diagnoses like pediatric bipolar and psychotic risk

syndrome. I left Philadelphia with a newfound appreciation for the immense scale of the system the protesters were struggling against, and a fresh perspective for how many psychiatrists were also critical of the psychiatric-pharmaceutical complex.

I also witnessed confirmation of this dissertation's central contentions. First, there was an evident contrast between the established anti-psychiatry/psychiatric survivor movements and a new wave of mad activists. The contrast was at times subtle, as some activists with a history of advocating in a more traditional, dogmatic style had refreshed their rhetoric and nuanced their message to be more inclusive. At other times the contrast was quite stark. There were few sparks of contention between these two camps since their strategic interests intersected, however, their differences surfaced in their tactical priorities and were visible when their messages collided.

Second, the urgency of advocating for patient empowerment and a stronger voice in the co-construction of psychiatric knowledge was clearly visible in a dramatic meeting which included the protesters and a group of psychiatrists who self-identified as the "Radical Caucus". In the last chapter we witnessed how difficult it was for those without professional mental health credentials to assert their voices and be heard by mental health professionals. The mental health professionals organizing in Zuccotti Park are among the most progressive and liberal mental health professionals practicing in New York. Similarly, the psychiatrists who are members of the American Psychiatric Association's (APA) Radical Caucus self-identify as radical and, along with a few other groups (e.g. The International Society for Ethical Psychology & Psychiatry (ISEPP) and American Association of Community Psychiatry (AACP)), are ostensibly the most vocal critics of the psychiatry from within the US establishment. These groups are most likely

to be receptive to the needs and concerns of the protestors, and their negative reactions suggest how difficult it is for mad activists to find mainstream allies. Both in the Occupy Support group and the APA Radical Caucus the voices and concerns of the patients, peers, and non-credentialed advocates were systematically stifled and marginalized. If these actors are treated this way within sympathetic circles of allies, it is disconcerting to extrapolate the attitude of the mainstream psychiatric establishment.

## 4.1 A Pivotal Moment

The 2012 APA protest captured a pivotal moment in history of the mental health movement. The year leading up to this event witnessed a number of factors that increased participation and amplified the energy of the protests. In the months preceding the 2012 APA protest, the Occupy movement erupted, and activists, representing a range of causes, piggybacked on the movement's visibility and enthusiasm to mobilize support around their issues. As we saw in the last chapter, mad activists were among those energized by Occupy, and the language of Occupy spilled over to the APA protests, which were sometimes branded "Occupy APA".

The year also witnessed some high profile critiques of the profession of psychiatry, including Marcia Angell's favorable reviews of *The Emperor's New Drugs: Exploding the Antidepressant Myth* (Kirsch, 2010), *Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America* (Whitaker, 2010) and *Unhinged: The Trouble With Psychiatry—A Doctor's Revelations About a Profession in Crisis* (Carlat, 2010) in the *New York Review of Books* (2011). A number of documentary film projects

engaging the issues of mental health and corruption in the psychiatric-pharmaceutical complex entered production around this time, and some of these filmmakers documented the APA protests. In 2012 The Icarus Project turned 10, signifying the sustainability and staying power of the organization. And the APA protests in May 2012 would turn out to be one the last public protests led by David Oaks, the founder and longtime head of Mindfreedom and an important leader in the mad movement, for he would suffer a serious spinal chord injury in December 2012 that would severely limit his later capacity for organizing. The APA protest thus marks a changing of the generational guard.

Most significantly, the 2012 APA marked the release of the DSM-5 proposal, the culmination of 12 years of work following a process riddled with public controversy. With this release the APA switched from using Roman numerals to Arabic numerals in anticipation of the need to clearly indicate future versions and point releases. One of the most vocal and prominent critics of the DSM-5 included Dr. Allen Frances, the head of the DSM-IV task force. Frances received his MD from the Downstate Medical Center in 1967 and a certificate in psychoanalytic medicine from Columbia University's Center for Psychoanalytic Training and Research in 1978. He served as the chairman of the department of psychiatry at Duke University's School of Medicine and was the founding editor of two prominent psychiatric journals. Frances authored a series of articles starting in March 2010 on the *Psychology Today* blog called "DSM 5 in Distress" which later led to the publication in May 2013 of his bestselling book *Saving Normal: An Insider's Revolt Against Out-of-Control Psychiatric Diagnosis, DSM-5, Big Pharma, and the Medicinalization of Ordinary Life*. Mainstream media outlets in print (New York Times (Satel, 2013), the *Wall Street Journal* (Tavris, 2013), the *Washington Post* (Petri, 2013)),

radio (*NPR* (Flatow, 2013), and television news (*NBC* (Nash, 2013), *ABC* (Moisse, 2012), *CBS* (Jaslow and Castillo, 2013), *Fox* (Grush, 2013)) all covered the DSM's new release, and reported on the controversy surrounding it. Debates raged over topics such as the elimination of the bereavement exclusion for diagnosing clinical depression, the consolidation and tightening definitions around autism-related diagnoses, and the diagnosis of behavioral disorders in children such as pediatric bipolar, oppositional defiance disorder, and disruptive mood dysregulation disorder.

After DSM-5's unveiling at the 2012 APA, an open letter was drafted and endorsed by more than 50 Mental Health Organizations, and signed by over 15 thousand people, including psychiatrists, other mental health professionals, patients, and activists. The supporting organizations included numerous divisions of the American Psychological Association, alongside psychoanalytic and counseling associations. The signatories included strong representation from professional associations focused on minority issues, such as women, LGBT, African-American and Latino, as well as international support from associations in Britain, Denmark, India and Italy. The petition raised a number of concerns about the DSM-5 proposal relating to both the substantive content of the proposal as well as the process around its drafting.

Our three primary concerns in the letter were as follows: the DSM-5 proposals appear to lower diagnostic thresholds, expanding the purview of mental disorder to include normative reactions to life events; some new proposals (e.g., "Disruptive Mood Dysregulation Disorder" and "Attenuated Psychosis Syndrome") seem to lack the empirical grounding necessary for inclusion in a scientific taxonomy; newly proposed disorders are particularly likely to be diagnosed in vulnerable populations, such as children and the elderly, for whom the over-prescription of powerful psychiatric drugs is already a growing nationwide problem; and the increased emphasis on medico-biological theories for mental disorder despite the fact that recent research strongly points to multifactorial etiologies. (Coalition for DSM-5 Reform, 2012)

Regarding the drafting process, the letter also criticized the DSM-5 task force for delays, for cancelling field trials and forensic reviews, and for hiring a public relations firm to manage the brewing controversies. Most damning, the letter sharply criticized the task force for releasing a manual with such low reliability. Reliability is a statistical measure of different doctors' agreement on a diagnosis when presented with the same set of symptoms. Frances interprets and historicizes the papers published (Clarke, 2013; Regier, 2013; Narrow, 2013) by the DSM-5 leadership reporting the results of its field trial, in what he describes as a “distressingly misleading paper”:

According to the authors, 14 of the 23 disorders had “very good” or “good” reliability; 6 had questionable, but ‘acceptable’ levels; and just three had “unacceptable” rates. Sounds okay until you look at the actual data and discover that the cheerful words used by the DSM-5 leaders simply don’t fit their extremely disappointing results. The paper is a classic example of Orwellian ‘newspeak’. When DSM-5 failed to achieve acceptable reliability by historical standards, the DSM-5 leadership arbitrarily decided to move the goal posts in and lower the bar in defining what is ‘acceptable’.... DSM-5 cheapens the coinage of reliability by hyping these merely ‘okay’ levels as ‘very good’. Then it gets much worse.... 9 DSM-5 disorders... previously would have been considered just plain ‘poor’, but DSM-5 puffs these up as ‘good’. Then DSM-5 has the chutzpah to call acceptable the 6 disorders that achieved lousy, absolutely unacceptable reliabilities.... DSM-5 finally finds unacceptable... 3 diagnoses... (which is barely better than chance). (Frances, 2012)

The DSM-5’s release in 2013 also prompted the National Institute of Mental Health (NIMH), the federal agency which funds over \$1.5 billion yearly in psychiatric research, to disavow the work. In a press release issued on April 29, 2013, Tom Insel, the director of the NIMH, wrote that the NIMH would be “re-orienting its research away from DSM categories. Going forward, we will be supporting research projects that look across current categories – or sub-divide current categories – to begin to develop a better system.” (Insel, 2013). Insel continues to critique the reliability and validity of the DSM

with a surprising statement that ironically validates the longstanding position of many anti-psychiatrists. The NIMH's position sounds remarkably similar to the claim of activists and critical scholars that the diagnoses defined in the DSM are socially constructed:

While DSM has been described as a “Bible” for the field, it is, at best, a dictionary, creating a set of labels and defining each. The strength of each of the editions of DSM has been “reliability” – each edition has ensured that clinicians use the same terms in the same ways. The weakness is its lack of validity. Unlike our definitions of ischemic heart disease, lymphoma, or AIDS, the DSM diagnoses are based on a consensus about clusters of clinical symptoms, not any objective laboratory measure.

Insel has also gone on record validating another longtime contention of anti-psychiatry, questioning the scientific evidence for “chemical imbalance” as the causal mechanism underlying mental illness. In a front page story in the Philadelphia Inquirer leading up to the APA conference on May 5, 2012, Insel is quoted saying: “There is no biochemical imbalance that we have ever been able to demonstrate. What we think about are changes in circuitry and how the brain is processing information.” (Burling, 2012)

I will return to the implications of Insel’s declaration, on both psychiatry and the mad movement, in my conclusion. In this chapter we will focus on how these pent-up forces were unleashed in Philadelphia, in a moment that was primed for transformation and high drama.

## 4.2 Streets of Philadelphia

## 4.2.1 The Friends Center

At 10am on Saturday morning, a protest rally preceding the march was held in the Quaker-run Friends Center in downtown Philadelphia. Over a hundred protesters were seated in the pews of the chapel, surrounded by large signs with protest slogans arrayed along the walls. The morning talks were well planned and followed a printed program of speakers. A microphone was set up at the front of the room and Caitlin Belforti, an articulate college activist, actress and poet in her early twenties, introduced the speakers who were each given seven minutes to talk.

Protestors ranged in ages from teenagers to senior citizens, and came from across the United States. The march was organized my Mind Freedom International, based in Portland, Oregon, and a number of representatives from the Pacific Northwest had travelled to Philly to help organize the event. Jim Gottstein, a mental health advocacy lawyer and the founder of Psych Rights traveled from Fairbanks, Alaska to join the protest. He brought T-shirts and signs with an image of Lucy from Peanuts waiting idly for patients with a sign over her head reading: "Psychiatric "Help" 5¢ \$500", with the caption: "The doctor was A) Fooled B) Complicit". There were also many representatives from the North-East, including a full bus of activists from upstate New York who were involved in organizing around mental health and prison issues, a contingent from New England, where a growing community has formed around the popular blog *Mad in America*, named after Robert Whitaker's 2010 book investigating scientific cover-ups in the pharmaceutical industry and a history of the mistreatment of the mentally ill in 20<sup>th</sup>

century America (Whitaker, 2010). Activists also carpooled from the South, driving from as far as Virginia, North Carolina and Louisiana.

Belforti introduced most of the speakers by stating their ages, organizational affiliations, and for most, their earliest encounters with the psychiatric system. The majority of the speakers began their speeches by sharing their personal experiences with psychiatry and, in most cases, their disengagement from the system through the rejection of diagnoses and/or psychiatric medications. Many were also quite accomplished in their fields, and the speaker lineup included community organizers, lawyers, PhDs, and mental health professionals.

The theme of the rally was a critique of the DSM-5, and in particular the dehumanizing effect of labels and diagnoses. Popular rallying cries also included a shared outrage at forced drugging and electroshock treatment, along with the growing trend of diagnosing and drugging children. The morning speakers rarely formulated their critiques in the language of orthodox anti-psychiatry, and few categorically denied the existence of mental illness or condemned the use of psychiatric medications outright. The leadership of the movement went to great lengths to be inclusive of those who decide to take medication, and was deliberate about saying so. Nonetheless, at times their inclusiveness sounded half-hearted and condescending, with a tone that suggested to many activists that anyone who was fully informed would opt for alternatives.

The APA protest rally featured orthodox anti-psychiatrists and psychiatric survivors alongside the emerging wave of mental health activists demanding participation, empowerment, and authorship of their own narratives. The dogmatic sentiments of the old guard are evident in the writings of contemporary anti-psychiatrists such as Peter

Breggin (1991), Seth Farber (2013) and Bonnie Burstow (2015). Breggin, a practicing psychiatrist, has published numerous books and articles critical of psychiatry, and in particular, argues against the use of psychiatric medications and ECT under almost any circumstance. In the tradition of R.D. Laing, he blames patient's families for their suffering, and prescribes empathy and love instead of drugs. Farber is a psychologist who argues that mad folk are fundamentally misunderstood by society and represent the spiritual vanguard who will help usher in a messianic era. Burstow is a feminist therapist and on the faculty of education at the University of Toronto. She describes herself as an "abolitionist" and argues that the institution of psychiatry is fundamentally corrupt and beyond reform. She calls for replacing it with peer-to-peer social services, and condemns all psychiatric drugs as brain damaging, masking the very dysfunctions they create.

Organizations such as Mind Freedom International are strongly rooted in the politics of orthodox anti-psychiatry, denying the existence of mental illness and demonizing the entire field of psychiatry. Traces of these sentiments appear throughout the morning speeches. To my ears, the tension between the old and the new is audible whenever I encounter the categorical assertions condemning the entire practice of psychiatry, devoid of qualifications or context. When activists make normative claims about how other patients should narrate their experiences, they expose themselves to the same critique that the emerging wave of criticism has leveled against the psychiatric establishment. Specifically, the arguments for patient/consumer/survivor self-determination and empowerment apply equally to the forcefulness of both the psychiatric and anti-psychiatric establishments. Neither psychiatry nor anti-psychiatry can speak exclusively on behalf of the individual, construct their identity, or write their narrative for them. The kind of

participation that the new wave of mental health activists are advocating for includes demanding a voice, as well as listening to all of the actors involved in a controversy, and not obliterating their perspective by shouting over them or ignoring them. When anti-psychiatrists refute the positive experiences of people who find support in professional mental health treatment, they are guilty of privileging their own interpretation of reality and dictating other people's narratives.

Consider the speech of Laura Delano, a sharp, energetic young woman in her early thirties who identifies as a psychiatric-survivor, works as a peer-specialist, and is an active blogger and editor for *Mad in America*. Laura was diagnosed with major depression at 14, bipolar at 18, and was “struggling to manage life instead of living it” until 27, when she shed her labels and meds. Her speech at the rally was impassioned and authentic, and she choked back tears as she defiantly relayed her personal story of recovery.

The profound anger I have today for those still labeled, and those still trapped within the biomedical paradigm of psychiatry, is a healthy one that fuels me and motivates me to do whatever I can to make a change... It is one of the greatest existential insults to slap a biomedical label onto the experience of being an emotive human being, no matter how well intentioned the labeler may be... I respect your right to believe what you want and only ask that you keep an open mind and an open heart to what we have to say today. If you are here today and have freed yourself from psychiatric labels, I send you a deep and loving congratulations. If you are here today, still enslaved by your labels and the treatment they require, and want liberation, join this movement and find your path towards recovery. We are here waiting for you to walk together with you towards equality and justice for everyone, regardless of how uniquely each of us experiences this complicated and painful unbelievably beautiful thing we call life. (Delano, 2012)

Contrast Delano’s statement with that of Aki Imai. Imai is a 25 year old student of clinical psychiatry who collaborated on the *Mindful Occupation* zine, and also started the submission-based blog, “Life after Labels”. “Life after Labels” was modeled on the

very popular “It Gets Better” campaign, which encouraged LGBT adults to create short personal video messages of support directed at LGBT youth (It Gets Better Project, (n.d.)). The “It Gets Better” project was started in Sept 2010 by the syndicated columnist and author Dan Savage. Savage created a YouTube video to telegraph messages of hope to young people facing harassment after a string of LGBT bullying incidents. The video went viral and helped spawn a global movement, inspiring 50,000 video messages that have been viewed over 50 million times. Imai was inspired by this project and started “Life after Labels,” soliciting short, first person text or video accounts of recovery. In describing his motivation for creating this site, Imai explains:

I wanted to help people find hope... and present a challenge against DSM. The DSM steals authorship from our own life stories. Suddenly your story doesn't matter anymore. You are reduced into symptoms, and consequently a label... I'm not saying that the label itself is a bad thing. I don't have a problem if you like the label, or if you don't like the label... ‘When I want to know what misogyny is, I don't ask a man. When I want to know what racism is, I don't ask a white person. When I want to know what homophobia is, I don't ask a heterosexual. When I want to know what transphobia is, I don't ask a cisgender person. When I want to know what ableism is, I don't ask an able-bodied person. If you want to understand the experience of the oppressed, the conditions of oppression are best articulated by the oppressed.’ So, likewise if you want to understand experience of those with psychological distress, you do not ask people who are not experiencing psychological distress. You do not ask people who are trying to categorize personal experiences into cookie cutter definitions... This is also to make a statement that we do not need to rely on a hegemonic, aggressive system to manage us, but we can take care of each other. To take co-authorship in a movement, where we can take authorship of our lifestories back from the DSM, and back into our lives.

Although both Delano and Imai express similar sentiments, the difference between their arguments is both subtle and crucial. For Delano, “enslavement” comes with the diagnostic label itself, and labeling “the experience of being an emotive human”

with a “biomedical label” is an “existential insult”. For Imai, “oppression” comes from act of being labeled by an external authority, powerless to label yourself, even if you ultimately choose a label yourself according to the diagnostic categories of the DSM, and what is essential is taking “authorship of our lifestories”. For Delano, there is no true recovery or liberation within the paradigm of the biomedical model, while for Imai the essential question is one of “authorship” of one’s identity and life story. For Imai, someone who chooses to identify themselves with a DSM label is not oppressed while Delano believes DSM labels are inherently oppressive, regardless of who assigns them. These two speeches encapsulate much of the shift from orthodox anti-psychiatry to the emerging wave of mad resistance.

For years, critics of anti-psychiatry have expressed concern that the movement romanticizes suffering and doesn’t acknowledge the agency of those who self-identify as mentally ill (Jamison, 1997; Styron, 1992). Orthodox anti-psychiatrists argue that anyone who considers himself or herself sick is ignorant or deluded by the false paradigms promoted by psychiatry. Imai’s formulation captures an alternative position, one that emphasizes agency, empowerment, participation, and self-determination.

This position is also evident in the protest’s most visible direct action, the “label ripping” ceremony conducted Saturday afternoon in front of the Philadelphia convention center. Faith Rhyne, a co-organizer of the protest, described the action at the morning rally at the Friend’s Center. Rhyne lives in North Carolina and is a brilliant and prolific artist and writer, as well as a peer-counselor and mental health community organizer. Rhyne described the planned action:

We're going to do a ceremony today as we protest the APA and the DSM-5... We're going to rip up some labels. We've got labels that say "Not OK"... "Sick". "Chemically imbalanced". "Psychotic". "Schizophrenic". "Bipolar". "Borderline". "Depressed". We've got those labels. We've got about 500 of them... So, we're going to be rallying some folks up there at the protest — we can hand you some labels... and, we can tear them up. People are going to be filming. We encourage people to make a statement. Tear up the label that you were given, and state yourself as how you believe yourself to be. We all believe the most basic human right is the right to define our own experiences in ways that uplift us and nurture what is best and most true about ourselves, as we have identified it.

Notably, the pre-printed labels included DSM diagnoses as well as more generic labels like "Not OK" or "Chemically Imbalanced". These labels refute the clinical gaze and the act of labeling, in addition to specific DSM diagnoses. Crucially, the label ripping ceremony was followed by an assertive proclamation by the protestor of how they prefer to identify themselves, which was captured on video, posted on YouTube, and circulated on social media. Rhyne also described her experience with being labeled:

Philadelphia inquirer covered this event on their front page - the head of the APA responded... with the statement – "a label may save a life". That was not my experience. Nor has it been the experience of many, many people that I know love and support. What I found was that receiving my label when I did robbed me of my life. Robbed me of my potential of my understanding of myself. And I lived under those lies.

Without over-analyzing any particular formulation or turn of phrase, it is worth noting that Rhyne habitually "speaks from the I". Delano states: "It is one of the greatest existential insults to slap a biomedical label onto the experience of being an emotive human being", an argument formulated in a passive voice, which categorically applies to all of humanity. By contrast, Rhyne roots her argument in her own direct experience, and the experiences of her friends and loved ones. This pattern of speech is indicative of

the ideology that underlies the shift I am describing—a shift from universal imperatives and towards a recognition and respect for subjective experience and its bearing on knowledge.

#### 4.2.2 Extreme Mental and Emotional Problems

The speeches at the Friend Center rally engaged in many issues beyond identity politics, labeling, and the DSM. The movement's leadership illustrated some of the other concerns permeating the atmosphere. They raised policy issues including forced outpatient treatment, regulatory reform of the FDA and excessive drugging of prisoners and foster children. Overarching critiques of the system overlapped with critiques of an individual's choice to embrace the language and tools of psychiatry, since the policies are written using language inherently oppressive to many of the activists.

Lauren Tenney is a professor of environmental psychology at CUNY who was institutionalized at 15. She is now a leading human rights activist who identifies as a psychiatric survivor. In her speech she accused psychiatry of murder, torture and slavery. She characterized psychiatry's actions as "absolutely inhumane and torturous". Citing research that shows that psychiatric drugging can lead to a 25-30 year loss of life, she equated forced drugging with "murder". Finally, she argued that state-ordered treatment programs prevent people from working in their preferred job, forcing them to work in others, which she equated with "slavery".

Tenney's accusations captured the rage and frustration felt by many in the room towards the psychiatric establishment. She is a young organizer, in her early thirties, who

has devoted herself to the struggle against forced electroshock, drugging, and coercion. Her rhetoric is typical of a fiery protest speech, and was met with cheers and applause. It is worth noting the raw emotional outrage contained in these accusations, and the great chasm that was bridged when a group of psychiatrists invited these activists to their meeting later that weekend. Tenney was careful to blame organizations and structural forces, although she called for holding individuals accountable for these systemic human rights violations.

Jim Gottstein is an attorney, a psychiatric survivor, and founder of PsychRights. He is a long-time advocate for the mentally ill who regularly goes to court defending patients and prisoners in Alaska from forced psychiatric treatment. In 2008 he filed suit against then Gov. Sarah Palin seeking to stop the forced medication of children in foster homes and juvenile detention centers. The suit was dismissed a year later when the court decided that PsychRights lacked standing, but Gottstein has continued to champion the rights of children and prisoners. Gottstein lays out a series of structural and policy issues and demands reform and accountability.

Gottstein stressed the role of the movement in piercing the “veil of lies about [the psychiatric industry] practices and the great harm it causes”, and called on the crowd to spread the word about “the great physical carnage” psychiatry causes which prevents people from getting “their lives back on track”. He raised the issue of court-ordered shock therapy against the will of the patient, the “horror of the massive psychiatric drugging of poor children on Medicaid”, and the drugging of infants, which he claimed was mostly illegal. He called on the crowd to counter the “power of the psycho-pharmaceutical complex” by “exercising... the power of the people”. Regarding DSM-5, he argued that

“psychiatry uses dubious labels to drive up drug sales, lock people up, and force them to endure harmful counterproductive drugs and electroshock against their will.” He implored the protesters to “stand against this”, especially since the “prospective fifth edition of the diagnostic and statistical manual will make this even worse”. Gottstein concluded by acknowledging that the people at the rally are “the lucky ones” who are “not locked up by psychiatry”, unlike those “so debilitated by the drugs that [they] couldn’t come.” He charged the crowd with the task of speaking for those who are “so debilitated by the drugs that they can’t speak up for themselves.”

In the course of his systematic condemnation of psychiatry Gottstein pays lip service to respecting adults who choose to take psychiatric medications. “Now, I do know people who find their psychiatric medications helpful, adults, and they should be available to adults who want them. At the same time, they should be told the truth about them, including that there are other approaches that work for many people far better and without the tremendous harm caused by the drugs.” However, the tone of his delivery is grudging. His categorical condemnation of psychiatric drugs and the harm they cause is an attitude that continues to alienate many people struggling with emotional crises who choose to use psychiatric medication. The distinction between Gottstein’s position and more inclusive declarations is often subtle, and more a matter of tone than precise wording.

Informed consent is the standard that the Icarus Project clings to, but it is a difficult standard to meet. Information about the risks of psychiatric medication is hard to come by, and consent is hard to obtain from children, prisoners, and seniors with Alzheimer’s or dementia. However, contrast Gottstein’s phrasing with the more welcoming and

inclusive language of The Icarus Project. Icarus meetings always start with a preamble, which includes the following statement:

This is a space for people to come together and learn from each other's different views and experiences of madness. People who take psychiatric drugs are welcome here, as are people who don't take psychiatric drugs. People who use diagnosis categories to describe themselves are welcome, as are people who define themselves differently. The Icarus Project values self-determination and mutual support.

The Icarus Project and the Freedom Center has jointly published the *Harm Reduction Guide to Coming off of Psychiatric Drugs*, explaining that a “harm reduction” approach “means not being pro- or anti- medication, but supporting people where they are at to make their own decisions, balancing the risks and benefits involved.” (Hall, 2007). The horrors and abuses of the psychiatric system are very real, but the reaction to these horrors has created an environment that is sometimes hostile and stigmatizing to those who have chosen to incorporate psychiatric medications into their treatment regimen. Unlike orthodox anti-psychiatrists like Breggin or Burstow, Gottstein doesn’t reject psychiatric medications outright, but his tone and body language betray his sentiments, and helped foster an atmosphere that many who identify with the emerging wave of mad pride activists find discomforting.

Finally, David Oaks, the founder of Mindfreedom and one of the main co-organizers of the protest, spoke for more than ten minutes. He compared the movement to the anti-slavery movement and called for the creation of a modern-day underground railroad to save people from involuntary outpatient commitment and forced outpatient drugging. He spoke of the need for a “non-violent revolution” and claimed that the mad movement represented “the 100%” of humanity. Oaks regularly draws inspiration from the civil

rights movement, and has worked hard over the years to craft his message to be more inclusive. Oaks graduated from Harvard in 1977, where he was institutionalized five times during his undergraduate years (Neil, 1983). He wrote his senior thesis about the Mental Patients Liberation Front, and credits them with teaching him about “backpacking, friendship, anti-sexism, radical politics, community organizing, grant writing, press releases, dealing with the press, handling meetings, finding that trusted people can filch from the treasury” (p. 28). At the morning rally, he was greeted with loud applause and remarked:

We are unstoppable. We are the 100%. We are the human spirit... But really what we are saying is that this is about being human. This is about pathologizing being human. To be human is to have extreme states. To be human is to wrestle with overwhelm. To be human is not to have a grip on reality. To be human is to be unique and different. This is about the human spirit, and that's why we're going to win.... [The APA has] extreme mental and emotional problems.... We need to put some psychiatrists in prison.... We really are pro-choice. If you make the personal decision to take a substance as part of your recovery, that is your personal decision... Don't let them pigeonhole us, as in some kind of civil war between drugs and talk. Now, that's too simple.

Mindfreedom International, the organization founded by Oaks in 1990, includes many members who self-identify as psychiatric survivors and anti-psychiatrists. Over the years Oaks has actively modified and softened his language, and his position has shifted to become more inclusive, embodying the movement's emerging values. By 2006, Oaks was saying, “our social change movement must avoid the blind alley of fighting over an individual’s personal and private choices.” (Oaks, 2006a).

Many sub-networks of psychiatric survivors I encountered insulate themselves within ideological monocultures that mirror psychiatry's monocultures. It is hard for these

survivors to acknowledge that psychiatrists or drugs ever help anyone, and they systematically block out or refute all testimony to the contrary. These attitudes parallel the psychiatric monocultures that dogmatically deny psychiatry's harm, see biological sickness and disease wherever they look, and push pharmaceuticals as first line treatment. These positions may sound like straw man arguments, but they currently dominate too much of the debate.

The rally at the Friends Center was powerful and emotional, and set the tone for the rest of the weekend's protest. The format of the rally encouraged speakers to share their personal stories, and many opened their talks with intimate accounts of their experiences with psychiatry and emotional crises. The poignancy of their speeches helps us understand the tension and abrasive exchanges that developed in the Radical Caucus.

#### 4.2.3 Hey, Hey APA!

After the rally the protestors assembled in the Friends Center courtyard exchanging greetings, drawing last-minute protest signs and preparing for the march. One of my favorite signs read "Oppositionally Defiant Sign". One of the organizers distributed T-shirts with a dazed and doped cartoon figure, emblazoned with the word—Psychopharmacopia. On the back the term was defined:

Psychopharmacomania is a mental or emotional disorder caused by ingestion of too much end product of the psychopharmacological digestive tract. It results in permanent psychosis, intractable depression or brain damage, depending on which drug rep reaches your doctor first!

The protestors marched through downtown Philadelphia ending across the street from the conference center. A few curious conference attendees inquired about the

protestor's message and demands, although most deliberately avoided eye-contact and walked by without engaging. I struck up a conversation with a group of two medical students and their mentor, who were finishing their psychiatric residencies in New York. They explained to me that their only encounters with the mentally ill were in hospital settings, during acute crises. They never had the opportunity to talk to patients in any other context and were largely unaware of mental health rights movements, outside of a vague caricature of anti-psychiatry. The residents believed that all activists critical of psychiatry held naïve views about mental illness, and that anti-psychiatry denied the suffering and illness the residents witnessed daily. They shared a suspicion with the activists towards the profit motives of the Pharmaceutical industry, but were unaware of the range of beliefs and sophisticated critiques within the mad movement. An activist I later shared this exchange with remarked that it was easy to understand how these doctors' limited exposure to the lives of their patients outside of crisis restricts their ability to appreciate the long-term impact of their treatments. It was easy to imagine how this inhibited them from recognizing the toxic mixture of help and harm inflicted by their profession in the name of healing.

The protesters delivered more short speeches over bullhorns, and continued the chants and songs heard throughout the march:

“What do we want? Human Rights! When do we want them? Now!”

“Hey, Hey APA... How many shots did you force today?”

“Hey, Hey APA... How many kids did you kill today?”

The label ripping ceremony was embraced enthusiastically. Dozens of activists lined up holding pieces of paper with diagnostic labels, and one by one proclaimed independence from the labels and reclaimed authorship of their own identities.

“Fuck the labels!”

“This is not me!”

“I’m a patient, not a diagnosis. And, I have a voice!”

“I am not a label!”

“Label jars, not people!”

“I live, I love, I’m passionate, I’m a songwriter, I’m a singer, and I’m not a label!”

The action was filmed by activists, journalists and documentary filmmakers, but due to the location of the protest, few conference attendees witnessed the live ceremony. The complete rally, march and protest were published on YouTube on the PsychRights channel, and the label ripping ceremony was covered by the Philadelphia Inquirer (Burling, 2012) and incorporated by the BBC Newshour in their coverage of the APA (Marshall, 2012).

After the label ripping ceremony, the protest slowly dispersed. The organizers considered the day’s actions to be a phenomenal success. Organizers I spoke with remarked that the turnout was larger than anticipated, the media coverage more extensive, and the enthusiasm and participation was higher than an average APA protest.

## 4.3 Imagining a Different Future

A smaller number of activists remained in Philadelphia overnight, many of them planning to attend another event organized by mental health activists entitled “Imagining a

Different Future". This event was held on Sunday, May 6th and featured keynote addresses by Jim Gottstein, attorney and founder of the Law Project for Psychiatric Rights and Robert Whitaker, journalist and author of *Mad In America* and *Anatomy of an Epidemic*. The keynotes were followed by a question and answer session facilitated by Joseph Rogers, executive director of National Mental Health Consumers' Self-Help Clearinghouse. Gottstein's keynote repeated some of the information he presented at Saturday's rally, but his message was broader and included a call for the creation of more alternatives that would enable the courts to direct patients to services outside the mainstream. Without these alternatives, consumers and the justice system have very little choices for dealing with crises. Whitaker, who was not present for the rally or the march, presented his moving and informative stump speech that summarized many of the findings in his books. An award winning investigative journalist, Whitaker's most recent book was titled *Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America* which was awarded the Investigative Reporters and Editors (IRE) prize for the best investigative reporting book of 2010. Whitaker documents the worsening of long-term outcomes for mentally ill patients treated with medication. Through meta-studies and rich anecdotal data, he documents an "iatrogenic epidemic", one caused by the treatment itself. He finds damning evidence of the long-term detrimental effects of the new generation of so-called "atypical" anti-psychotics, called atypical due to researchers' initial beliefs about their reduced side-effects. Through a thorough review of meta-studies, Whitaker shows that patients who were taken off of this class of drugs have much better long-term prognosis than those who take them chronically. In partic-

ular, in poor countries with limited psychiatric services, the longitudinal outcomes for patients are significantly better than in countries where aggressive treatment of patients with antipsychotics is common. In countries like the US, where chronic treatment with antipsychotics is the norm, patients are more likely to experience relapse, brain damage, and reduced life-spans. They are also much less likely to reintegrate into society, as measured by employment and independence from social services. The *New Scientist* review of *Anatomy of an Epidemic* characterized Whitaker's argument as follows:

Whitaker wants us to believe psychiatry itself is to blame, and that scientific incompetence and corrupting self-interest have prevented reliable assessments of mental disorders and treatments alike. The author's belief that we could have got it so wrong seems far-fetched. Up close, however, his arguments are worryingly sane and consistently based on evidence. They amount to a provocative yet reasonable thesis, one whose astonishing intellectual punch is delivered with the gripping vitality of a novel. (Burch, 2010)

A few members of the APA's "Radical Caucus" attended these talks, and afterward they extended an invitation to the protesters to join the Radical Caucus' yearly meeting the following day.

## 4.4 Now in 3-D!

In addition to Sunday's event at the church, I also participated directly in the APA conference itself. One of the panels I attended was entitled "The Contributions of Brain Imaging to the Study of Psychosis", chaired by Raquel E. Gur, Professor of Psychiatry Neurology and Radiology at the University of Pennsylvania's school of medicine. The panel included talks exploring the use of brain imaging to differentiate schizophrenia and bipolar disorder (Keshavan, 2012), another presenting correlations between working

memory and prodromal psychosis (Seidman, 2012), and Gur's talk on brain function in psychosis-prone youth (2012). Notably, all of the panelists' presentations included their research on predicting and identifying prodromal risk, even though this aspect was absent from the panel's title.

Seidman's talk included a primer on "traits", a construct that researchers postulated that was meant to capture a predisposition for a certain behavior. The researchers affirmed the existence of traits regardless of whether the behavior had ever been exhibited, a suspiciously counterfactual definition. Traits are the ideal vehicle for "prodromal" diagnoses – they feel custom-made to explain the tendency or propensity for a disease that only exists in potential, and has never been expressed. I learned that despite the APA's insistence that prodromal diagnosis had been relegated to the appendix of DSM-5, research within this paradigm has proceeded for over a decade and the preventative trend is only growing.

In the exhibition hall, drug companies, medical equipment manufacturers and publishers hawked their wares and vied to leave memorable impressions. I have visited similar exhibition halls at technology conferences, and the extravagant opulence at this event made the tech expos look impoverished in comparison. Due to statutes banning gifts to physicians introduced in Minnesota and Massachusetts (Grande, 2010), the vendors were wary about the giveaways they could dispense, although it was left up to the attendees to self-identify as residents of the regulated states. At one lavish espresso bar, recipients of the espresso needed to sign a paper affirming that they did not practice in those states.

One prominent installation in the center of the hall continuously looped a three-dimensional educational film depicting a neurological reaction. Participants donned 3D glasses to watch the active pharmaceutical agent repair the broken brain chemistry, entirely devoid of the brain's host, or his or her context. Another vendor hawked psychiatric malpractice insurance. Dark humor abounded, as electroshock devices on display were hooked up to stuffed animals in a display of gross insensitivity.

One of the most notable experiences was the AstraZeneca installation. AstraZeneca, the makers of the anti-psychotic Seroquel (*quetiapine fumarate*), had a large pavilion. I signed up for a presentation that was delivered by a Key Opinion Leader, or KOL. KOLs are psychiatrists hired by the pharmaceutical companies to pitch their wares, a practice motivated by the assumption that doctors respond better to other doctors than to salespeople without medical degrees, a notion validated by studies (Elliot, 2010). KOLs are paid on average tens thousands of dollars per year (MarketWire, 2008; Dollars for Doctors, n.d.), and are often provided with precise scripts that they must read verbatim. During the presentation I attended, an AstraZeneca representative with a clipboard stood at the back of the small crowd scribbling extensive notes on a detailed checklist. The evaluator attentively monitored the performance, and the KOL regularly glanced his way, seeking approval. The presentation I attended started in one corner of the pavilion, and about half a dozen other doctors attended the presentation. The presenter talked for a few minutes over a slide show while we stood listening, asked us for questions, and then guided us to another corner of the pavilion where she resumed her presentation where she had left off. We made our way to all four corners of the pavilion, and I was left puzzled by the act of delivering the pitch from these four different locations. The

explanation for this format could be as simple as flow control, allowing multiple groups through the pavilion in parallel, but the experience of standing and then relocating to a new station also reminded me of medical grand rounds. I wondered if this resemblance was deliberate, meant to lend credibility and authority to the presentation through a subtle subconscious association.

My experience walking the halls of the APA reminded me of the system's vast resources and the challenges that reform faces. The sheer capital and marketing muscle was fully evident, as was the entrenchment around the paradigm and language. While there was a streak of skepticism among a small percentage of participants, too many accepted the status quo, and the few who acknowledged the protesters joked about them and dismiss their claims.

## 4.5 The Radical Caucus Ruckus

One immediate outcome of the weekend's actions was that a group of psychiatrists self-identified as the Radical Caucus invited the protestors to their annual meeting. The meeting was held during the APA in a conference room at a Courtyard Marriott, one block from the convention center. The meeting of the Radical Caucus was not part of the official APA program, but the group had been meeting for years on this occasion. The meeting was followed by an informal dinner at an upscale Cuban restaurant, and the activists were also invited to attend.

The Radical Caucus meeting was the culmination of the weekend protests. It offers a distillation of this dissertation's central contention that un-credentialed stakeholders

are systematically silenced, even by their purported allies within the establishment. The clash that followed encapsulates this dynamic, from agenda setting to solidarity around substantive issues, and demonstrates the deep rift in trust that decades of trauma and abuse have created. Although many of the psychiatrists in the room have published peer-reviewed papers advocating positions that are sympathetic to movement causes, actualizing those positions proved challenging in practice.

The meeting was recorded by a documentary crew working on a transmedia project called *Cause of Death: Unknown* (Hoel, in press). Andrew Grant, the film's producer, graciously provided me with complete footage of the meeting, which I used as the basis for this analysis. Grant and Anniken Hoel are working on a film that tells the story of Anniken's sister, Renate Hoel, who died suddenly and unexpectedly while under psychiatric treatment for a condition diagnosed as schizophrenia. The autopsy declared her cause of death unknown, and Anniken's investigation of her sister's death has led her on a decade long investigation of the global pharmaceutical industry. Their crew gathered footage at the APA protests and conference throughout the weekend.

The initial call for the meeting was focused on discussing the relationship between economic disparity and mental illness:

The Radical Caucus of Members of the APA invites everyone to a meeting to discuss how to make psychiatry and the APA more relevant to the people of this country... Although biomedical research is important, there is ample evidence that economic conditions account for much more of the “explained variance” in mental illness than any single genetic factor. This nation can do considerably more for public mental health if there are serious efforts to redistribute wealth through tax restructuring, providing foreclosure relief, creating jobs programs, and enhancing public investment. Let’s discuss what we can do. Please join us. Everyone is welcome.

Dr. Carl Cohen, a psychiatrist with a New York practice, distributed this invitation over email in the days before the conference, and facilitated the gathering. Cohen is a middle-aged New Yorker with a Brooklyn accent and a soft laugh. Cohen is intelligent and caring, with a warm demeanor in one-on-one encounters, but he was unable to command a strong presence once the meeting became contentious. His weak facilitation skills contributed to the confusion that unfolded.

According to Cohen, the Radical Caucus started in 1968, and was “organized in Miami around the anti-war protest in the late 60s”. When the anti-war movement died out, so did the radical caucus. It was reformed in 1979 in San Francisco where they “brought together a lot of people in the Bay Area to talk about radical perspectives on psychiatry.” For years, the Radical Caucus meetings were essentially dinners that a small number of like-minded psychiatrists attended. They did not publish statements or press releases, and were largely a footnote to the APA proceedings. Cohen continued to describe the group’s activity: “Periodically, we’ve done some various critiques of the biomedical approach in psychiatry, we’ve dealt with torture victims and immigrant populations, joblessness and various economic issues, consumer rights, global psychiatry, and I think most of the topics related to biological reductionism, consumer issues, psychiatric abuse, socio-economical and cultural issues. I think that about sums it up. We’ve been probably more intellectual than active, although many of us have been active on our own.”

Cohen spent about five minutes framing the meeting, explaining the agenda of the meeting was intended to “[deal] with the fact that psychiatry has typically been ignoring many of the severe economic problems in this country... [since] we know that income

disparities create problems in health and mental health, and as well as mortality.” Cohen hoped the group would “come up with some statements about it and then some action plans, either to present to the APA and beyond.” Cohen introduced Dr. Duncan White, a psychiatrist practicing in Maine, “who has been very interested in topics of economic disparity and economic inequality.”

#### 4.5.1 A Pot Luck Parable

White began talking, adopting the posture and tone of a university lecturer. His starting point was very abstract, as he laid out a thought experiment depicting the extreme wealth inequality in the global economy. White continued to explain the severity of wealth disparity and extreme poverty, without explicitly connecting these issues to mental health or psychiatry. He asked the room to imagine one hundred people sitting around a table having dinner representing the entire population of the world. “so 100 plates of dinner of the foods of the world is brought in and 56 of those dinners are placed beside this one man. One is placed in front of him, the next 39 get one dinner each, and the remaining 60 get a saucer about 4-inches in diameter with one spoonful of rice.” White explained two effects caused by this inequality. The physical effects of malnourishment leading to disease and death, and the emotional effects of shame and humiliation, elicited when people “are looked down upon, seen as not worthy of being spoken to, that their plight is their fault, that they are irresponsible lazy, all the things that describe poor people often.”

When I spoke to group participants after the meeting I confirmed that most were expecting a more interactive format, and I watched as many of the activists become visibly restless as the lecture continued. After about 10 minutes into White's lecture, David Oaks, who was noticeably frustrated by the format and substance of the meeting, interjected:

Duncan - can I put an asterisk in here? Because, obviously this end of the table is pretty distressed. They're on Prozac, Zoloft, Paxil, neuroleptics... very, very heavily drugged by the psych industry.... Suppose I was a 1-percenter here, and I announced that... I'm gonna hold a radical caucus that doesn't invite in the people from the most disempowered part. This meeting should be majority mental health consumer and psych survivor. The most radical thing... you guys could do as a radical caucus is to invite those people down from the other end of the table into the 1%-er and be allies, and work together and unite.

White appeared slightly flustered by the interruption of his thought experiment and tried to reassure Oaks that he was planning to get to the psychiatric interventions later. Oaks responded, "I think we just did." and started to explain that Cohen had appointed him the meeting leader when he walked in. Something about the exchange triggered Oaks to stand up and sing:

*Die Gedanken Sind Frei—my thoughts freely flower,  
Die Gedanken Sind Frei—my thoughts give me power,  
No scholar can map them, no hunter can trap them,  
No one can deny, [yells and pounds]  
Die Gedanken [pound pound] Sind Frei.  
I think as I please, and this gives me pleasure,  
my conscience decrees, this right I must treasure.  
My thoughts will not cater to duke or dictator,  
no one can deny, Die Gedanken Sind Frei...  
And if tyrants take me—yes, you down there at the end of the table—  
if tyrants take our people and throw them in prison,  
our thoughts will burst free, like blossoms in season,*

*foundations will crumble and structures will tumble,  
and free folk will cry: Die Gedanken Sind Frei!  
And that means, our thoughts are free. They can't be controlled.*

Several people at the meeting appeared disturbed by Oaks' electric performance. I overheard a psychiatrist sitting next to me crack a snarky joke to his neighbor that Oaks must have forgotten to take his Lithium that morning. Oaks continued:

You can't stop what I'm doing right here. Oppressed people are gonna be rising up... Please, if you are our allies, invite us in. You guys are professionals in emotions, deal with the anger of traumatized people... invite in the mental health consumers, invite in the psychiatric survivors... read about how a bunch of psych survivors were in front of the APA protesting. We had a few allies, but not enough... [puts on red clown nose] I am here for Patch Adams... he screens people for normality, and we are screening you for normality right now... Every single one of us is unique, different, unusual.... we are begging you guys to be our allies in the one-percent, cause you're one-percenter, like it or not. We are asking you to be a part of a non-violent revolution. No more reform at the APA... We've tried dialog. Help us with civil disobedience. With protest, with activism. Be our real allies.

Oaks' performance was seen by as counterproductive by some, and heroic by others. The intensity of the protesters' emotions was visible over the weekend, and the incongruity with the energy of the radical caucus was palpable. It is difficult to judge if Oaks' outburst was calculated or unrestrained. He was genuinely frustrated by the lack of urgency he perceived within the Radical Caucus, and especially by their tone deafness to the needs of the constituency he was representing. He also seemed to be driven by a need to perform as a leader in front of the activists present in the room. Ultimately, the mismatch in the tenor of the protests and the staid decorum of the Radical Caucus proved difficult to reconcile. The meeting will undoubtedly be remembered by all of the

attendees, and it is unclear how a gentler intervention would have changed the course of the conversation.

I spoke to Oaks later that night and he insisted his spectacle was spontaneous and was not premeditated. For years, Oaks has performed a routine at protests that involves dressing up in a white lab coat, donning a red clown nose and “scanning” people for normal using a rubber chicken. It is plausible that he happened to have his red nose with him during the meeting, from an action earlier that day. “Die Gedanken Sind Frei” is a traditional protest song, whose lyrics first appeared in pamphlets in the beginning of the 19<sup>th</sup> century. The song was taken up by anti-Nazi resistance movements, and in the 20<sup>th</sup> century was associated with groups opposing fascism (Melon, 2007). Oaks has sung this song in speeches before, and his selection of this song represents his defiance of the “thought policing” that characterizes the worst of psychiatry, and an accusation that equates psychiatric oppression with historical fascism. He implores the doctors in the room, who are “professionals in emotion” to “deal with the anger of traumatized people”. This plea, while not quite apologetic, surfaced the traumatic scars and raw emotions that must be processed and patiently tolerated for meaningful dialogue to proceed.

White accepted the outburst in stride, responding “I think, I appreciate your, I respect your passion with which you spoke, and I think there is actually quite a bit of common ground... I’ll speak for myself, that I’ve been trying to think for myself outside of the bounds of, conventional bounds of psychiatry, which is quite difficult. I think you brought in a justified sense of passion which is absolutely needed.” White then returned to the thought experiment he was explaining before the interruption. He invoked Marx and Gramsci, and touched on psychiatry’s role in defining social reality.

After another five full minutes of exposition, Oaks interrupted him again, asking—when will the workshop part of the meeting begin? White ignored the interruption and expounded on the idea that therapists reinforce the existing order, and they often “[discount] the social nature of your injury” and “turn the inequalities of the existing order into a series of personal problems.” He emphasized that changing individual practice is important, but doesn’t change the system.

As White wrapped up his thought experiment, Oaks again jumped in, imploring him to go around the room and ask people to introduce themselves. White replied that he would let Cohen decide what to do next and completed his lecture, a full 30 minutes into the meeting. Cohen took a moment to plug the *Liberatory Psychiatry* (2008) anthology he co-edited, and then tried to move the conversation to a discussion. Cohen agreed not to talk anymore and he asked Oaks not to talk for a while, at which point Oaks once again requested that people introduce themselves. “It’s like one of the most radical things you can do. Not to break domination, by having one, one individual run the meeting. Just go around and quickly say your names and introduce yourselves and say hi.” Cohen was concerned that introductions would take too much time, but finally relented and the participants introduced themselves.

#### 4.5.2 Seats at the Proverbial Table

The participant’s questions brought up issues relating to universal health care, corruption and greed in the insurance and pharmaceutical industries, and economic issues resulting in unemployment and the housing crisis. These issues all had an impact on society’s

mental health, and some of the meeting attendees wanted to call on the APA to take a public position on these policy issues. Like the mental health professionals in Zuccotti Park, they were prepared to critique the external forces of capitalism and policy, but had a very difficult time holding the mirror up to themselves, and critiquing their own profession and practices. The activists in the room thought the caucus was externalizing the problems and evading issues that psychiatry was directly responsible for.

A few participants tried to bring the focus of the conversation back to psychiatry's responsibilities. Frank Blankenship, a long-time Mindfreedom member, raised concerns about the "emphasis on the insurance company... given the amount of iatrogenic disease there is in the psychiatric field". He questioned the emphasis on insurance coverage instead of the damage that psychiatric drugs caused (he was also concerned that insurance companies would not cover the treatment for damage these drugs caused). Dr. Brad Lewis raised the issue of medicine becoming increasingly unaffordable, which in turn has pushed "more people off the insurance roles." He described how doctors have been complicit in designing practices and treatments that are unaffordable and unsustainable, and practitioners shared some of the responsibility for reduced access to services.

Andrew Grant, the documentary producer filming the meeting, prodded the audience: "How do you all feel about the proposed changes to the DSM, that are only going to classify more people in our society as mentally ill?" His question was applauded.

A young psychiatrist named Margaret Balfour responded:

I just finished my training a year ago... I started off as a researcher.... I used to think the DSM was very important and when people didn't stick to the criteria it annoyed me.... As I gained more experience, I found them to be less important... To label

everybody and diagnose it [is] not useful. . . . I don't think we've learned enough to have a whole new book, and it's probably not gonna be that useful in actual clinical practice. But it's gonna generate a whole lot of discussion and controversy and money.

### 4.5.3 Involuntary Votes

A member of the radical caucus tried to recognize and diffuse some of the tension in the room. He acknowledged the pain and trauma of some of the participants, and apologized to them on behalf of his profession. He then became quite defensive, and insisted that his practice was collaborative and not oppressive.

One of the psychiatrists described the tension in the meeting as disorganizing, and unhelpful. An activist responded that it has to be disorganizing, and that “there’s going to be tension because people are dying”. Another activist corroborated this sentiment, explaining that he was enraged since “we have people who have forced electroshock at the age of six, solitary confinement, tardive dyskinesia, still from the atypicals [anti-psychotics].”

Oaks jumped in and compared the APA to the Catholic Church, likening the cover-ups of psychiatric abuse to the Church’s cover-ups of child abuse. He expressed that he expected the radical caucus to “be able to handle the anger”, and was also “tired of hearing allies who say behind my closed doors ‘I’m so great with patients. . . things are getting better, and everything’. Where the hell is your letter to the editor about forced electroshock?” This stream of consciousness led to the meeting’s next twist, with Oaks calling for an impromptu vote on the opposition to involuntary electroshock:

If this place is truly a radical caucus, right now I ought to be able to say. . . that we are opposed to involuntary electroshock over the expressed wishes of the subject. . .

Are people opposed to involuntary electroshock over the expressed wishes of the subject? . . . The same position as the World Health Organization. . .

Dr. David Pollack began losing his temper, and started yelling over Oaks in a cross tone, “David, David, David you be quiet for a minute please!” Oaks accused Pollack of interrupting the vote because he was afraid to see its outcome, but Pollack insisted he was just trying to follow the meeting protocols. Oaks accused Pollack of calling his behavior “inappropriate”, a loaded clinical term that is often used when diagnosing psychotic behavior. Pollack denied calling Oaks “inappropriate”, but characterized his behavior as “rude”. Oaks volunteered to stop speaking after pointing out that “his silencing” began when he asked for a vote on “forced electroshock over the expressed interest of the subject”. Pollack replies to Oaks that he “appreciate[s his] position” but he “resent[s his] style”. Pollack went on to assert that “the psychiatrists who are here are the kinds of radical community based psychiatrists, who basically are in line with everything that you all have been saying.” He claimed he would have voted against forced electroshock, but he resented the process Oaks employed to initiate the vote. He defended approaching the issues from the vantage point of social and economic abstractions covered at the beginning of the meeting, since “these health systems that are extremely flawed to try to raise consciousness, improve things not in a piecemeal or patchwork way, but to it in a way that will hopefully lead to better results.” Finally, Pollack turned the tables on Oaks and asked him to respect the pain that psychiatrists struggle with: “We are limited in terms of our power, to do things in all the ways that we think we would like to. So, we have to struggle with that. We struggle with that pain that we feel, and we think that

you should respect in some ways that pain as well as we respecting the pain and the trauma that you've felt."

The meeting had devolved into bickering, and at stake were its substance, format, and especially agenda setting. The organizers of the Radical Caucus had made the mistake of starting out the meeting by "talking at" the activists they invited. The professionals had a difficult time listening to the activists' concerns and adjusting their program to address them. Instead, they largely replicated the doctor-patient power dynamic, setting the agenda, lecturing to the room, and relegating questions to a supplementary but secondary question and answer period. Their defensiveness was particularly off-putting to the activists. While the activists weren't accusing anyone present at the meeting of malfeasance or malpractice, they would have been more reassured by support and solidarity from within the establishment. Dr. Brad Lewis, cultural theorist and psychiatrist questioned the defensiveness of the psychiatrists present and called on them to work directly on developing alternative treatment models:

Why are the psychiatrists so nervous and defensive?... I try to do the best I can with my patients, but I'm not defensive that people are really mad about where psychiatry is going... Why does that make the radical people nervous?... I think that somehow they feel they're being blamed... We need alternatives to hospitalizations... we need mutual aid programs [and] opportunities, we need alternatives to the drugging... And once that begins to happen then you begin to start seeing the court start sending people there, and you also begin to see that changing people's mind.

One activist I spoke with referred to the psychiatrist who was proud of his practice and made the comment "I don't happen to be at that point when people wind up in that [psychotic] state. You all think that there's no such thing [as mental illness], but I don't want to go there". Here, the psychiatrist meant that he does not typically treat patients

undergoing acute emotional crisis in his practice, thereby avoiding situations that might warrant coercive treatment. Some psychiatrists avoid taking patients with more extreme case histories, and primarily treat patients with milder disorders. The activist found his aside—“You all think there’s no such thing”—to be particularly infuriating, since it was based on a flawed assumption that lumped together all opposition to psychiatry as orthodox anti-psychiatry, denying the existence of acute crises warranting psychiatric support or intervention. The way this assertion was formulated felt like it was intended shut down all debate, and was understood as a swipe at the legitimacy of the activists in the room.

As the meeting drew to a close, Cohen summarized the proceedings, and enumerated the issues the group had raised: 1) “The pharmaceutical industries, its connections with the economy, and the influence of that industry on psychiatry”; 2) “The insurance companies’... denial of care”, and the privatization of Medicaid and Medicare; 3) Concerns over the “national database for psychiatric patients”; 4) Advocating for a single payer system and universal health care; 5) Campaign finance reform; 6) Creating “change on an individual level”; 7) Working to create more treatment alternatives; 8) The “problem” of the DSM manual—“Should we be advocating just the abolition of classification systems altogether?”; 9) “The strained systems that we have and the reduced time for patients”; and, 10) Creating coalitions and alliances with activists and the UK’s Critical Psychiatry.

David Oaks responded once more, indignant that the question of forced electroshock was omitted:

I could have sworn that involuntary electroshock over the express issues of the subject came up... You need a different committee. You need an activist human rights committee... You're silencing me... Everybody is complicit when there's silence. Not just the abusers, the silencers are complicit... A laundry list isn't real activism. If you want a real action plan, take one thing to do. I think its time to start a new caucus.

The Radical Caucus is comprised of well-intentioned psychiatrists, trying in earnest to affect change in their profession and taking a stand against inequality. The deep miscalculation exposed at this meeting was the ways that both camps developed their priorities in isolation, and did not consult with the stakeholders at the other end of the prescription pad. If the Radical Caucus had attended the morning rally, or the label ripping ceremony, or opened the meeting with introductions and an open question around the most important issues one people's minds, the meeting would most likely have unfolded differently. Similarly, many of the activists were unaware of the existence of the Radical Caucus before that weekend, and had done little to research or understand their history or priorities. The issues raised by the Radical Caucus were important, and largely aligned with the activists' values, but not their priorities.

The tensions that surfaced at this meeting were disconcerting but unsurprising. Although the radical caucus had invited the protestors to their meeting, they were not invited as first-class participants, nor were the psychiatrists fully prepared to listen to their criticisms and acknowledge their pain without becoming defensive. The protesters also should have also arrived better prepared, with a better understanding of the Radical Caucus' membership and the agenda they had planned for the meeting. The clash of expectations around the presentation format exacerbated the tensions, and helped

lead to increased hostility and the breakdown in communication. Coming into the meeting, trust between participants was fragile, at best. This tension should have been acknowledged, and attempts to diffuse it instead of deny it could have led to a more productive exchange.

Analogous to psychiatry's tendency to command their patients' personal narratives and choose labels for them, the Radical Caucus asserted the agenda of resistance without consulting with the people subject to the brunt of forms of treatment they regard as oppression. They swooped in to address extreme poverty, and tried to make a compelling case for the relationship between poverty and mental illness, but neglected the immediate and pressing concerns of the protestors who had traveled from around the country to express their frustrations at the APA. The protesters also squandered an opportunity to cultivate allies, and allowed their mistrust and hostility towards the entire profession cloud their judgment. The meeting participants had far more in common with each other than the fireworks suggest, and all parties can learn a great deal from The Icarus Project's meeting agreements that we will encounter in the next chapter. In particular, everyone at this meeting should have listened more, paid more attention to repeating patterns and "listened like allies." The meeting would have greatly benefited from stipulating meeting agreements at the start, to help set more uniform expectations within the group over communicative protocols.

## 4.6 Conclusion

The 2012 American Psychiatric Association conference was a pivotal moment in the evolution of the mad movement. With the release of the DSM-5, the NIMH's shift away from the DSM and a growing surge of criticism of mainstream psychiatry, a new generation of activists took steps toward finding a new voice and a new message. This message is still being formulated and refined, but at its core it is a recapitulation of the refrain, "Nothing about us without us".

Although this argument was implied it was never explicitly spoken. "Nothing about us without us" is a formulation that is evocative and clear, but mad activists have yet to fully embrace this slogan as their own. Throughout my fieldwork, I uncovered no opposition to this slogan, or to greater solidarity with the larger disability rights movement. This slogan was not rejected, but remains neglected and largely unconsidered. Based on my extensive conversations with mad activists I believe they are still evolving the ways they theorize and conceptualize their positions. Instead of claiming the oppositional stance of anti-psychiatry, the new wave of mad activists demand participatory authorship over their identities and personal narratives. To me, this move closely echoes the demands of the disability rights movement, and the new wing of the mad movement is on the verge of arriving at this understanding and explicitly embracing these politics.

Elements of the mad movement are also starting to demand seats at various tables of power, including the tables of academia, the tables of public policy, and the tables where diagnosis is defined and treatment is determined. The meeting of the Radical Caucus shows how much work lies ahead in overcoming these divides. Many of the doctors

at the meeting believed themselves to be good people, trying their best to help their patients. They differentiated themselves from the “bad” psychiatrists, whom they vilified as greedy and corrupt. As a group, they externalized the problems in the system by blaming the forces of government regulation, insurance and pharmaceutical corporations and structural inequality. They had difficulty recognizing their own power within the APA, and understanding how their daily practice might help improve conditions through the creation of alternatives to mainstream treatment. The activists struggled to be heard, throwing a veritable tantrum when they did not get the attention they wanted, and practically inviting themselves to be ignored as a result. Their demand to be involved in agenda setting, and to participate in setting priorities is reasonable. However, their tactics may have been counter-productive and to be taken more seriously as equal stakeholders, they too must learn to listen more closely to the fears and desires of their potential allies.

Agenda setting and consensus building need to be shared across much wider constituencies to fully realize a more ethical coalition. Future meetings of the Radical Caucus ought to expand this coalition even wider, inviting senior citizens, veterans, prisoners and children’s rights activists to represent their voices and concerns. All of these groups are facing an onslaught of psychiatric attention and it is crucial for them to figure out how to effectively communicate and work together to respond to this offensive.



# You Are Not Alone: The Icarus Project and Psychosocial Wellbeing

“ Stories matter. Many stories matter. Stories have been used to dispossess and to malign. But, stories can also be used to empower and to humanize. Stories can break the dignity of a people, but stories can also repair that dignity.

— Chimamanda Ngozi Adichie  
TED Talks, 2009

In the last two chapters we saw examples of mental health activists whose advocacy shifted from challenging the existence of mental illness to demanding a role in the production of psychiatric knowledge and greater control over narrating their own stories. We saw how non-credentialed mental health activists were silenced and marginalized by mental health professionals at Occupy Wall Street and by the psychiatrists who made up the APA’s Radical Caucus. The mainstream mental health establishment demonstrates even less regard for activists’ concerns, rarely acknowledging their existence, never mind respecting their viewpoint. In this chapter we will explore what these activists would say if they more carefully articulated their views and treatment recommendations, and why their own perspectives and vernaculars matter. In particular, we will closely examine an organization at the forefront of the mad movement’s transformation—The Icarus Project.

In the first decade of the 21<sup>st</sup> century, mental health activists reinvented the psychiatric survivor movement through a series of strategic overtures that borrowed from participatory culture and the possibilities opened up by communications technologies. This freshly reconstituted field of resistance to biopsychiatry and the pharmaceutical industry formed at a moment when networked actors sought collective empowerment and forged authentic connections in virtual spaces. These communities formed against the backdrop of an unprecedented expansion in psychiatric diagnosis and treatment, and at the intersection of the emergence of a more participatory internet, dubbed “Web 2.0” (O'Reilly, 2005), and a trend within social movements demanding greater inclusion (Kavada, 2013).

During this period The Icarus Project developed hybrid models of peer-support and direct action that were, at times, accelerated and amplified, and at times overwhelmed and thwarted, by the proliferation of new communicative possibilities. The Icarus Project runs an independent community website with active blogs and forums; it publishes newsletters, articles, books, flyers, stickers, apparel, artwork, music and video; its facilitates mailing lists, social media and community conference calls; and, it organizes and hosts events, peer-support groups, and workshops. The project freely licensed all of their digital and print materials, and originally mobilized around free and open-source software (FOSS), and later, proprietary social media.

The collective leadership has strived to create a participatory architecture supporting their commitments to access, advocacy, transparency, engagement and community building. These attempts were not always successful, and the project continues to grow in fits and starts, even a decade after its creation. The Icarus Project long has

grappled with organizational instability, a bewildering proliferation of platforms and communication channels, internal conflict and unrest, and a deep ambivalence about digital interactions. These tumultuous organizational dynamics mirror the precarious emotional lives of its membership, and the project's perseverance is a testament to its resilience and the deep resonance of its messaging. At various times, the national collective or local chapters have stalled in the face of paralyzing organizational and communicative dysfunction, only to reboot with a fresh influx of members, energy, and, occasionally, funding.

For over a decade The Icarus Project has generated and facilitated publications, conversations and events across a wide array of media platforms. All of this activity warrants close study in order to synthesize an understanding of the project's core beliefs. What did they say? How, if at all, can we weave their disparate strands of discourse into a coherent narrative? The project's history, culture and ideology provide us with important indications for how they believe mental health should be discussed and supported. The language and tactics they have cultivated suggest alternatives that can be adopted on a much larger scale.

The Icarus Project conducts much of its discourse within peer-support groups, either face-to-face or online. These conversations are understood as safe spaces and are largely outside the boundaries of ethical ethnographic research. Accordingly, my analysis of the project focuses primarily on published media, communications infrastructure, and representative public projects and controversies that illustrate the way *Icaristas*, as members affectionately call each other, think and act. These snapshots are as diverse

and fragmented as the project itself, and together provide a holistic perspective of the organization's identity and values.

My selection of these discursive snapshots is based on my direct participation within the organization as well as numerous conversations and interviews since I began working with this project in 2005. In the next chapter I detail my introduction to the project and my personal involvement as an activist and organizer. My involvement included providing technical consulting and maintenance, participating in New York City support groups, strategic consulting for the national collective, and organizing public campaigns and events. My direct participation provides me with a unique vantage point for gathering primary sources, navigating convoluted histories, and critiquing the project, as a participant-observer.

## 5.1 Preamble: Friends Make the Best Medicine

In 2002 Sascha “Scatter” DuBrul published a first-person narrative in the San Francisco Bay Guardian about his “poly-polar” experiences (DuBrul, 2002). He shares his intensely personal history of radical ideas, exhilarating states of mind, and eccentric, often dangerous, behaviors. He boldly came out of the mad closet, disclosing his psychiatric diagnosis, and recounted his history of repeated institutionalizations and over-medication. DuBrul’s narrative about himself contained strong currents of social criticism (and heroism), and he contextualizes his own inner psychological struggles within the external reality of society’s political struggles. Finally, he shares how psychiatry’s labels make him feel, introducing us to the importance of struggles over language and framing:

But I feel so alienated sometimes, even by the language I find coming out of my mouth or that I type out on the computer screen. Words like “disorder,” “disease,” and “dysfunction” just seem so very hollow and crude. I feel like I’m speaking a foreign and clinical language that is useful for navigating my way though the current system but doesn’t translate into my own internal vocabulary, where things are so much more fluid and complex. (DuBrul, 2002)

*Bipolar World* is not a traditional manifesto, but can be read as a form of what I call “narrative advocacy”, a statement that blends intensely personal narratives, framed in the storyteller’s language, with persuasive arguments that engage and resist dominant mainstream narratives. In *Bipolar World*, DuBrul begins to recognize the power inherent in the language used to tell a story, and the implicit control that narrators exert over the language, metaphors, and imagery they invoke. The power he exercises through the deliberate choice of language for describing his history and condition, and his inclusions and exclusions, has been analyzed and explored in the classic discourse around “framing” in sociology and media studies (Goffman, 1974), and is a central problematic for Disability Studies (Davis, 1997) and the burgeoning discipline of Narrative Medicine (Charon, 2002; Lewis, 2011). This choice of language determines how seemingly objective facts are infused with value and meaning, as I considered in the introduction.

In the documentary film *Crooked Beauty* (Rosenthal, 2010a), Jacks Ashley McNamara retells their (Jacks prefers the pronouns ‘they/them’) initial encounter with DuBrul’s story, replying with their own story, and recounting their dream of creating safe spaces for the exchange of stories, both in person and online:

I met Sascha because I had responded to a version of his life story that he had written and got published... about his experiences with madness, quote unquote, and wanting to live an authentic adventurous life and not crash and burn over and over because of the fragile fire in his brain. I ended up sending him my whole life

story and he showed me all these emails he had been getting from people all over the country... he and I decided that there had to be a place for these people to read each other's stories and to know that they existed. And so we thought we would start up a website. It became The Icarus Project and it had way more than just a few stories, it became an interactive forum for people to talk to each other. And, just grew and mushroomed into this whole network of people all over the country. (Rosenthal, 2010b)

The Icarus Project was born, then, in the nexus of two stories and expanded into a galaxy of networked storytellers –sharing, exchanging, generating meaningful wisdom and authentic narratives, spawning a pidgin language of empowerment and resistance in the process. These encounters were rarely simple. Local communities ebbed and flowed, often starting in a burst of exuberant enthusiasm, only to implode and collapse under the stressful demands of organizing, compounded by the emotional weight of peer support.

The Icarus Project has achieved great success, positively impacting tens of thousands of people, and by many accounts, saving numerous lives. Throughout its existence, Icarus has also grappled with the problem maintaining resilience: (a) at the individual level of its membership facing the demons of heightened sensitivity and relapse; (b) at the local group level, as groups struggled for stability, combating burnout and struggling to maintain the capacity to listen and support each other through crisis; (c) online, with continuity often challenged as interlocutors arrived and disappeared without notice, and flamewars regularly erupted; and, (d) at the national level, as the national collective struggled with finances, governance models, internal strife, power dynamics, its relationship with local groups and organizer fatigue.

Distinct patterns of dysfunction have emerged, and although the project's leadership has recognized many, they have proven difficult to break. For example, groups with

the best intentions often discover they do not have the time, training or emotional capacity to support members in crisis. Some peer-support groups have fallen apart shouldering more responsibility than they could handle, and the pressures of supporting members has precipitated emotional chain reactions. Another example of a dysfunctional pattern is the predictable burnout of volunteer group facilitators. Peer-support facilitators typically bear the brunt of organizing responsibility. Groups often start out with multiple facilitators, but facilitators inevitably drop out, leaving an overwhelming responsibility on one person's shoulders. Eventually, the last facilitator succumbs to the pressure, and the group terminates when they quit.

Some of these problems could be addressed with additional resources, such as funding for meeting spaces, facilitator salaries, and support for facilitator trainings, although others suggest inherent flaws in the support models. Throughout this turmoil the project successfully built a cohesive community, one that fulfilled the project's mission statement:

The Icarus Project envisions a new culture and language that resonates with our actual experiences of 'mental illness' rather than trying to fit our lives into a conventional framework. We are a network of people living with and/or affected by experiences that are often diagnosed and labeled as psychiatric conditions. We believe these experiences are mad gifts needing cultivation and care, rather than diseases or disorders. By joining together as individuals and as a community, the intertwined threads of madness, creativity, and collaboration can inspire hope and transformation in an oppressive and damaged world. Participation in The Icarus Project helps us overcome alienation and tap into the true potential that lies between brilliance and madness. (The Icarus Project, 2006b)

One important aspect of the project that distinguished it from prior efforts was an understanding of the significance of fostering solidarity around subjective, first-person

narratives, and the relevance of these stories to resistance and healing. The Project began to explore a liminal space between peer-support and activism. Traditionally, peer-support groups are private and introverted, and activism is public and extroverted. A tension exists between the quieter safe-spaces a peer-support group needs, and the louder provocative spaces that activists often intrude or agitate.

Icaristas developed a strategy to balance the competing demands of peer-support and activism by focusing on the relationships between personal suffering and the conditions of structural violence and injustice in the world. Personal struggles were understood in sociopolitical contexts, and individual dysfunction was traced to the larger social systems of dysfunction that individuals are embedded in. Icaristas emphasized psychosocial explanations for emotional suffering and crisis, especially among those who exhibit “heightened sensitivities”. They resist the prevailing “bio-bio-bio” model of explanation that neglects accounts of poverty, racism, intergenerational trauma and other forms of oppression in understanding the human condition. Simultaneously, these explanations never outright denied the influence of biology or an individual’s personal responsibility for their behavior. The problems were not exclusively “out there” nor were they exclusively the product of what transpired inside someone’s skull. The project attempted to embrace the non-deterministic interaction between nature and nurture, while incorporating a sociopolitical critique that aimed to hold institutions and states accountable alongside individuals.

By emphasizing the direct connections between social injustice and personal trauma, many Icaristas discovered the benefits of treating activism as a “therapeutic substrate”, finding tremendous value in the communal bonds that activism fosters. The phrase

“therapeutic substrate” is meant to capture a psychological mechanism for working through personal issues by operating on similar issues, displaced onto an abstracted or symbolic terrain. I interacted with many Icaristas whose participation in activism around mental health issues provides an outlet for integrating disparate elements in their worlds—a way for their closeted mad identity and their public persona to converge. Mental health activism opens up a space for them to discuss mental health without divulging their own experiences directly. Talking about mental health issues helps reduce the stigma around the topic, and enables activists to broach these topics from a position of relative power, within an activist movement, rather than as a vulnerable individual. Safe communal spaces encourage people to “come out” and tell their personal stories. Beyond the boundaries of the project’s safe spaces, many Icaristas continue to engage publicly with political mental health issues without necessarily disclosing their personal psychiatric history. Their involvement in public discourses resists the monoculture of psychiatric knowledge production, and incorporates a diversity of perspectives that are ordinarily silenced by stigma.

McNamara recalls that, early on, the Icarus Project “had some vague idea that, a key piece of recovering mental health had to do with building community... [and] becoming willing to trust other people on the planet.” (Rosenthal, 2010b) The website, peer-support groups, activist campaigns, media publishing, art and music shows, and events all became ways for people to come together. At their best, they came together in solidarity, forged friendships, and learned that they were not alone. At their worst, participants emotionally overextended themselves, sabotaged relationships, and become unwell. Yet, I never met anyone who wished that they had never encountered Icarus, or felt that their investment

was wasted. In fact, I met many who claimed that encountering Icarus materials, and joining a likeminded community had saved their lives. The intensity of interactions, with either positive or negative valences, left a memorable impact on almost everyone who passed through the project. Even those who grew disillusioned with the project's current form emerged with a newfound commitment to "overcome alienation" and "inspir[e] hope and transformation" in the world. The project's visions and aspirations were always grander than its ability to follow through, but the membership continues to pursue these dreams, and motivate others to follow.

Unlike many in the previous generation of psychiatric survivors, Icarus refused to dogmatically condemn or judge anyone's *informed* treatment choices. Informed consent is a difficult standard to meet, since accurate information is hard to find amidst the sea of Pharma's marketing and spin, and 'consent' is violated in cases of coercion and forced treatment. 'Consent' is also questionable in the context of treating children, prisoners, seniors in nursing homes, and other populations without full agency. However, in the case of free, informed, consenting adults, Icarus chooses to deeply respect an individual's choices regarding medication and self-identification. This acceptance stands in stark contrast to many elements of the anti-psychiatry and psychiatric survivor movements, who outright deny the existence of mental illness, and dismiss psychiatry and psychiatric labels and treatments. In this sense, the psychiatric survivor movement is guilty of committing an offense similar to that of the psychiatric establishment, by dictating to others how they should think and feel. The more extreme contingents of the old guard maintain that anyone who finds solace or support in psychiatric drugs or labels is being deceived, challenging the agency and self-definition that characterizes the new wave of

mad resistance. Some Icaristas I met felt that the denial of mental illness negated their suffering and amounted to an “ableist” claim leveled by those who were high functioning against those who experienced disabilities.

In contrast, The Icarus Project aims to create safe, supportive spaces for people to share their subjective narratives: spaces where people could teach each other how to “navigate the space between brilliance and madness.” These spaces are often challenging for participants and what makes them “safe” are the explicit meeting agreements which we will examine shortly. The project aspires to be inclusive, welcoming those who take or refuse psychotropic medications, as well as proponents of alternative wellness plans. The project makes a crucial distinction between a strong stance for (or against) an individual’s informed choices regarding pharmaceutical treatment, and a critique of the psychiatric establishment and the pharmaceutical industry. This distinction opens the space for them to embrace members who choose to take psychiatric drugs and accept their psychiatric labels, and still unite in their exploration of alternatives, their critique of psychiatry’s abuses, and their opposition to the predatory practices of the industry. Their critique goes beyond the minority of psychiatrists, like those we met in Chapter 4, who are also critical of greedy pharmaceutical companies and widespread over diagnosis and overmedication. Their original mistrust was rooted in anarchist politics that mistrusted capitalism, consumerism, and “The Man”. Beyond the simple account of Pharma’s greedy profit motives, many Icaristas believe the stigma around mental illness feeds the isolation and alienation that, in turn, perpetuates and propels the capitalist system.

As the project evolved, its membership refined their critique, as they became informed by the history of the mad movement, critical theory, and their interactions with

students, academics, and experienced activists. Over time, Icaristas have downplayed some of the language that defined the project in its early years. Some have backed away from identifying themselves as part of the “Mad Pride” movement, as they called into question taking “pride” in negative states and behaviors, such as aggression or self-harm. They have also backed away from their original slogan, “Navigating the space between brilliance and madness”, the title of the project’s original publication. Icaristas have become more sensitive to those who do not characterize their mad journeys as “brilliant”, and who feel alienated by the elitism of a slogan that dismisses “mediocre” madness. The project has also undertaken a major “decolonization” effort, in the hopes of extending its membership to minorities and the poor. Finally, Icarus continues to develop its understanding of accountability for their behavior in altered states, a complex ethical question that troubles and perplexes the membership.

The Icarus Project evolved with a critical self-awareness of its own structures and processes. Deliberate efforts were made by the collective to model the kinds of power relations within the project that the membership desired to see in the world around them. These efforts sometimes fell flat, and the project progressed in punctuated bursts. Tensions between the online community, local chapters (who often did not engage in the online support forums) and the national organizers regularly threatened the project’s coherence. The national organizers devoted so much energy to developing internal process that they were often accused of navel-gazing. They believed that a well-articulated governance model was crucial among “mad folk”, especially important in accommodating extreme moods and heightened sensitivities. However, despite the leadership’s best intentions, decision-making and accountability remained ambiguous

throughout the project's history. They clung to an anarchist-inspired consensus-based decision model, but transparency and lines of communication were often muddled. Some decisions seemed unilateral, while others stalled in indecisive purgatory. The online community, largely composed of membership living in places where there was no local group, often complained that their needs were neglected. The national organizers often neglected the online spaces, and focused on organizing in-person groups and events. Local groups operated autonomously, and were often outside the loop of national's decisions and planning. The constituents were largely self-aware of these shortcomings, and regularly focused on trying to improve communication and trust, however progress was slow due to fuzzy goals, expansive scope and organizational turnover. In spite of these dysfunctions, the project has endured, experimenting with different governance models, and continuing to function and grow.

In 2004, DuBrul and McNamara, fresh with an infusion of private funding, stepped back from their roles as co-founders and joined a larger collective that guided the project. The project's founding principles explicitly embrace consensus-driven, non-hierarchical, transparent decision-making – across the project's governance, autonomous local collectives, and within peer-support groups. These principles also endorse non-violence, respect for diversity, anti-oppression, and access across identities, abilities, and class. DuBrul describes their 2005 mission statement as follows:

These were revolutionary words and acknowledged our relationship to history and our debt to the movements and cultural workers that had come before us. These words put us outside all the other organizations working in our field. They acknowledged to us and everyone else that we were taking a radical stance in the true meaning of radical: from the roots to the extremes. No one else in the field of mental health was talking about non-hierarchy and transparency the way we were.

We were bringing the radical narratives and models into the door of the mainstream.  
(DuBrul, 2012)

When DuBrul talks about radical, ‘from the roots to the extremes’, he means the project’s ideas about mental health are radical, as well as their governance and processes. The organization he dreamt about was radical to the core, from its mission, to its organization and operations. The principles are echoed and embodied in the meeting agreements, which are collectively read at the beginning of all Icarus peer-support meetings. The preamble begins with a variation of the mission statement and then continues:

... This is a space for people to come together and learn from each others' different views and experiences of madness. People who take psychiatric drugs are welcome here, as are people who don't take psychiatric drugs. People who use diagnosis categories to describe themselves are welcome, as are people who define themselves differently. The Icarus Project values self-determination and mutual support... (The Icarus Project, 2006a)

The meeting agreements include basic actionable guidelines to “ensure inclusion, safety, and open dialog”. The agreements specify practices such as: (a) “listening like allies”, where peers are encouraged to adopt an empathetic stance, as opposed to a contrarian or adversarial one. In practice, this guideline is used to gently redirect feedback that is perceived as overly harsh or critical; (b) “stepping up, stepping back”, a guideline encouraging quiet participants to speak up, and loud participants to give others a chance to speak. Good facilitators invoke this guideline to encourage shy or otherwise intimated participants to speak, and to try to contain willful personalities from dominating the conversation. This guideline is also invoked to provide typically marginalized participants, including women and minorities, a chance to set agendas and

kick off discussions; (c) “practicing owl vision”, a guideline intended to empower all of the participants to be mindful of the group’s dynamics, and take collective responsibility for enforcing the guidelines without relying exclusively the facilitator; (d) “challenging prejudice”, the meeting agreements explicitly acknowledge the group’s commitment to eradicating social injustice, and affirm the connection of prejudice to emotional distress; (e) “respecting beliefs outside the mainstream”, this agreement directly challenges the psychiatric medicalization of strange, nonconsensual beliefs. Provided they are non-violent and non-oppressive, participants agree not to judge spiritual, religious, conspiratorial, paranormal and other non-conventional beliefs that do not conform with the mainstream. Upholding this agreement is often fraught, since many non-consensual belief systems (e.g., conspiracy theories) contain seeds of oppression, and this also includes acceptance of alternative approaches to physical and mental health; (f) “using ‘I’ statements”, a central, foundational agreement meant to steer people away from abstractions, generalizations, and so-called ‘violent communication’ (Rosenberg, 2003). ‘Speaking from the I’ helps avoid lecturing, grandstanding, and formulating statements in ways that are likely to antagonize others with different perspectives. Participants in Icarus groups regularly correct each other’s speech by gently reminding them to speak from the ‘I’, just as a *Jeopardy!* contestant is reminded to re-state their answer in the form of a question; (g) “paying attention to repeating patterns”, This agreement is more difficult to attend to, as it implies a continuity between groups that is not always present. Good facilitators have tried to take this into account, and steer conversations to people’s issues who have not received recent attention, and try to avoid recurring personality conflicts. However, confronting repeating patterns is arguably one of the reasons participants are

attending peer-support groups. This agreement acknowledges that it can be difficult to notice repeating patterns, never mind disrupt them; and (h) “respecting confidentiality”, an essential component of a safe space. In practice, this agreement is ambiguous, since peer support meetings sometimes meet in semi-public spaces, have fluctuating attendees, and are often hybrid support and organizing meetings, with the expectation that the organizing notes will be shared publicly. Topics resurface in meetings where new people are present and the original participants are not. Some groups interpret confidentiality to mean protecting people’s identities, while others are adamant that even the stories told in groups should not be shared with outsiders. For these reasons, groups are encouraged to clarify their intent around confidentiality.

The Icarus meeting agreements build on a history of activist meeting agreements, and extend them with a powerful template that should be widely adopted to other settings outside of mental health advocacy. These agreements are direct extensions of the project’s core values that manage to effectively distill highbrow social theory by embodying it in day-to-day practice. In particular, encouraging everyone to “speak from the ‘I’” helps minimize broad generalizations and the imposition of one person’s beliefs onto someone else’s identity. The meeting agreements reiterate the group’s belief in autonomy and self-determination and reinforce the belief that all of us are the ultimate authority on our own well-being.

Even with these sophisticated agreements in place, facilitating an Icarus peer-support is a stressful and exhausting responsibility. Icarus peer-support groups are notorious for forming in a burst of exuberant energy, and dissolving or imploding within a year. In practice, Icarus groups have struggled to enforce the meeting agreements, as one or

two obstinate individuals can threaten a group's stability. Individuals have been asked to take breaks from groups, and on rare occasions people have been banned, however, without clear pre-defined behavioral boundaries, the process of asking someone to leave is fraught with politics and nearly impossible to enforce. The combination of heightened sensitivities and spirited energies, often crossed with wide differences in participant's age and class, creates volatile conditions for intimacy. Icarus groups have never established firm accountability guidelines, and it has historically been difficult to address conflicts that arise in groups. The very act of setting boundaries invites conflict, and the project has shied away from firm definitions, embracing ambiguity and fluidity in multiple contexts.

For example, I once participated in a group where a participant refused to introduce himself along with his preferred gender pronoun. Like many other groups who attempt to create a welcoming atmosphere for queer participants, Icarus checkins typically begin with the participant introducing their name, followed by their preferred gender pronouns (he/him, she/her, they/them, ze/zir). This introduction is intended to make all participants feel welcome and comfortable, since having everyone specify their preferred pronoun avoids drawing attention to those who feel they need to clarify their own. For reasons he never articulated, one participant was unwilling to include his preferred pronoun in his introduction, making the larger group uncomfortable. The facilitator was at a loss for how to handle his defiance, and he continued to attend the meetings until he eventually dropped out, on his own accord, a few weeks later.

Similarly, I have been a part of many support meetings where one participant has dominated the conversation, despite the agreement to "step up, step back". Local groups

have developed various protocols for asking participants to take a break from the group, but conflicts recur. By their nature, support groups often draw participants who are in various emotional states, and a significant challenge of the model is trying to figure out ways to attract and retain participants who are in a relatively stable place, instead of only showing up to a peer support group while experiencing an extreme emotional crisis.

Unsurprisingly, financial resources help stabilize support groups. Many groups struggle to find a meeting location, especially since many are uncomfortable in clinical spaces, such as hospitals. A small funding stream can secure suitable non-profit meetings spaces and light refreshments. Similarly, providing a salary for facilitators also improves the stability of the group. However, the challenges with The Icarus peer-support model likely extend beyond financial constraints. Building an authentic community is challenging work, and there is no formula for fabricating friendships. Some groups found that by organizing social events instead of peer-support groups they forged more genuine bonds. Others have proposed exploring a one-on-one sponsor model, similar to Alcoholics Anonymous, although no Icarus chapter has tried this yet.

Many of the healthy, longer-running Icarus peer-support groups have been composed of a small number of regular participants (3-5), instead of a larger, fluctuating participant pool. A sustained commitment over time and continuity between groups has proven essential for forging intimate bonds and authentic relationships. In recognition of these dynamics, some local groups have experimented with capping the number of participants in their groups. Some have even defined a finite duration of the group (e.g., 6 or 8 months), as opposed to an open-ended engagement. This limited horizon is meant to address the inevitable power dynamics that may ossify within a fixed pool of supporters.

These models are promising, and some Icaristas have talked about developing systems to help interested participants find a compatible Icarus “cell”. On the surface, closed groups sound antithetical to the group’s anarchist tendencies, but an open network of closed groups is more compatible, and could provide essential continuity to the organization over time.

It is unclear if the project’s failure to sustain peer-support groups over the long term represents a flaw in the model, the execution, or a combination of the two. What is clear is that the membership continues to be drawn towards peer-support, clinging to the idea and persevering in the face of repeated failures. In what may sound like a rose-colored interpretation, I believe these adaptations illustrate the project’s fluid resilience, and not merely stubbornness, or simply history repeating itself. When the project reaches an impasse, it morphs and adapts to new circumstances, circumventing breakdown through creative reinventions. Some Icaristas give up and move on to other projects, taking with them the lessons they have learned, and often, lifelong friendships. Others continue to devote themselves to the project, tenaciously iterating, and struggling to improve upon models and processes.

Historically, grassroots organizing has been plagued by cycles of intense activity followed by disruptive burnout. The core constituency of the The Icarus Project tends to amplify these dynamics since many of the participants exhibit behaviors that exacerbate these patterns. The activists attracted to the project at times exhibit aggressive, overbearing and self-centered behaviors, and at other times withdrawn, submissive and self-deprecating ones. These behaviors are common among activists, but magnified among people who struggle with altered states. Grassroots organizing is difficult in any

context, and the challenges around organizing within communities that are struggling with deep trauma, emotional crises and neurological diversity amplifies and exaggerates these challenges. Icarus organizers are prone to inadvertently stumble upon each other's "triggers", as one person's madness (e.g., excessive interruptions or yelling) exacerbates another's sensitivities (e.g., a history of bullying or abuse).

The project's day-to-day conflicts and long-term dysfunction are obstructive to their goal of manifesting solidarity. At the same time, this dysfunction creates a fertile ground for developing new languages, instigated by provocations that engage and intrigue its membership. In her recent dissertation, Erica Fletcher, a doctoral candidate at the Institute for the Medical Humanities at the University of Texas Medical Branch, has argued that the project's resilience, best understood as a function of its romantic aesthetic and heroic narrative, has maintained a strong sense of solidarity in spite of its dysfunction (2015). Fletcher's in depth ethnographic critique profiles the project's reliance on digital communication technologies, such as mailing lists, discussion boards and collaboration tools, that continually disappoint due to misuse, obsolescence, and "bitrot" (digital corrosion). These technological letdowns parallel the members' anticipation of their own personal and psychological collapses, and provide essential insights to the inner workings, and failings, of Icarus throughout its history.

## 5.2 Discursive Snapshots

In the following snapshots I focus on the ways that the project publicly articulates its vision, and how this vision is sometimes realized.

### 5.2.1 Crooked Beauty

In 2010 Ken Paul Rosenthal released a documentary film featuring Jacks Ashley McNamara, the co-founder of The Icarus Project (Rosenthal, 2010). *Crooked Beauty* artfully captures many essential aspects of the project's core message, and has been used regularly in Icarus-led presentations and workshops. Alongside *Navigating the Space*, the original graphic novel that DuBrul and McNamara released in 2003, the film has become one of the project's canonical pieces of media, shared by the membership and forging an “imagined community”, in Benedict Anderson’s sense of the phrase (2006). *Crooked Beauty* has been instrumental in communal workshop and educational settings, where screenings are followed by facilitated conversations, and it also functions well as a standalone work. It deserves a close study since it was deliberately crafted to distill the essence of the projects’ values. A close analysis of the film in context provides us with a powerful lens for understanding the The Icarus Project’s message and the emerging movement it signals.

The 30 minute film opens like a traditional documentary, with a medium close up shot of McNamara, narrating a poem:



*And that late afternoon sadness,  
rolls in like the luminous California fog, crossing over the hills.  
And some part of me is convinced that I might have never really felt joy.  
And yet there is a mythical quality to the garlic mustard,  
the afternoon, the angle of light that fills me with a peculiar, heartbreaking beauty.  
And I wonder, as I often do, if things will ever be simple.  
The train sounds down by the river.  
The cloud passes over the sun.  
And what could be memories feel like déjà vu.  
Like they happened underwater a long time ago. (0:11-0:49)*

This is the only depiction of McNamara's "talking head" throughout the entire piece.

In film studies, *mise-en-scène* refers to "everything that goes into the composition of a shot – framing, movement of the camera and characters, lighting, set design and the visual environment, and sound." (Film Language Glossary, 2005). In a self-published essay about the conceptual and creative process of making *Crooked Beauty*, Rosenthal writes about his struggles with questions of representation and exploitation:

How could I recount [their] troubled history with compassion rather than exploitation typical of films about mental illness?... How would we see Jacks onscreen? The traditional model of the featured character speaking to an off-screen interviewer felt contrived and inauthentic because it deferred to an unseen authority. So I began to think outside of representation and more about embodiment. What if I dispensed with a talking head altogether and found symbols for the face of "madness"? (Rosenthal, 2010b).

Rosenthal constructs a cinematic language that immerses the audience in the moods, themes, and experiences McNamara narrates.

Light and shadows:



Urban and rural:

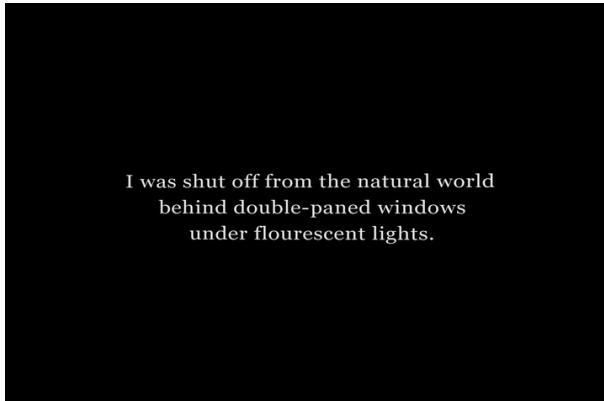


Technological and natural:



Explicitly leveraging film's primal relationship to light, he explores visual metaphors for "difference and conflict" in natural and urban landscapes. This imagery functions as visual counterparts to extreme moods and states of mind. The rhythm and pacing of his

editing is accompanied by evocative sound effects (e.g. sprinklers, trains, rushing water) and a haunting original score. With the exception of the opening poem, the conscious decision to not show McNamara's face and body onscreen during their narration, in addition to silent, inter-titled segments, draws the audience into a first-person experience of the story.

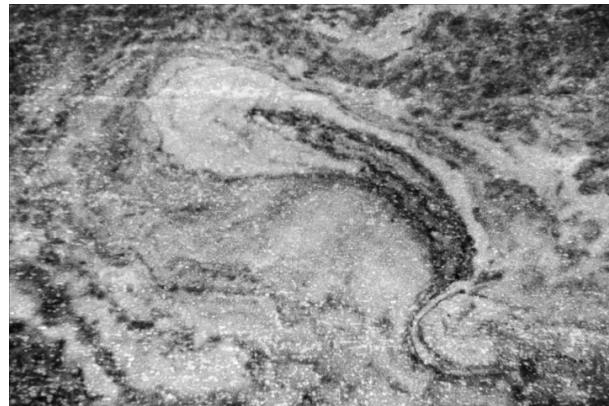


I was shut off from the natural world  
behind double-paned windows  
under florescent lights.

Such techniques are intended to create a space for McNamara's story to become the audiences' story, with McNamara listening to *us*, acting as a shamanic guide through a cinematic vision quest. Listening closely, McNamara doesn't always speak strictly from the 'I'. They often seamlessly transitions into 'We' statements to emphasize their critiques and recommendations. Although there is an implied 'I think' or 'I believe' around all of their propositions, *Crooked Beauty* is a film, not a support group. As a leader in an activist organization with years of experience running workshops and support groups, McNamara is entitled to 'speak for' those whose trust they have earned. Through a piece of public media, they have the opportunity to extrapolate beyond their own experiences, channeling the community they helped build while speaking for them.

To analyze *Crooked Beauty*'s discursive style, I draw heavily on the primordial environment from which it sprung. The film organically absorbs and reflects The Icarus Project's values and aesthetics within its own poetic structure. *Crooked Beauty*'s particular formal structure is a powerful example of how storytelling can operate on multiple narrative levels simultaneously. The balanced interplay between contrasting narrative elements such as text/image, literal/metaphoric, personal/universal, mundane/metaphysical, illumination/shadow is articulated through cinema's fundamental grammar of light of dark.

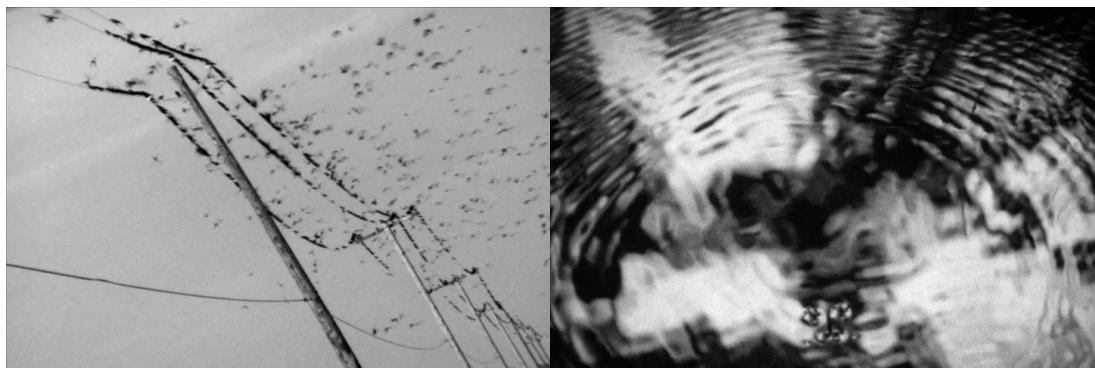
A textual analysis of McNamara's story provides us with many traditional examples of the power of narrative. McNamara eloquently reframes the pathologizing master narratives that dominate the discourse around mental illness and wellness. Narrating the emotional crisis that led to their hospitalization, they explain:



I went to a prestigious, private university. And at the time I was taking a class on the origin of life in the universe, and got totally convinced that if I could teach every high school student in America, that their bodies were made out of molecules that were born in the super novas of stars fifteen billion years ago, then we would all understand that we are all the same and there would be no injustice and no inequality and we would stop treating each other so badly. (Rosenthal, 2010a:5:22-5:44)



And so I'd gone through a period of just total expansion and incredible energy, and so much insight. But insight at a level where I couldn't really connect with other people. Your brain takes off into this level of cosmic and cerebral connections but your heart isn't working quite right. And, you can connect fifty thousand ideas, but you can't listen to your friend talk about her relationship. (5:52-6:28)



And so I went through a period which they would say is mania, all mental energy and connections and divine expanses of space and time and no grounding on the earth. And, then I crashed, really badly. And a lot of it for me was mixed up with drugs and alcohol. (6:30-6:46)



I slipped into such a state of total and utter depression and despair that I didn't know what day it was, I didn't shower, I didn't change my clothes. I didn't really eat. Stopped going to school, stopped doing work, stopped going outside, stopped talking to people. Every time I tried to watch the television I was convinced that the world was ending and I would run out of the room screaming and shake and hide in the corner. And I was snorting Ritalin so I could write my final exam papers and then blacking out on the floor. Finally my girlfriend ended up calling up my parents, "I can't take care of your daughter anymore. (6:55-7:28)

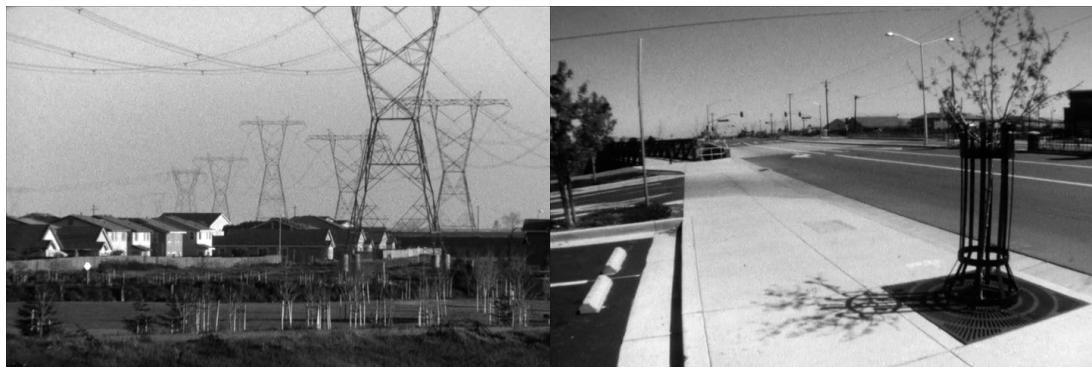


As a poet, McNamara has a deep understanding of how words convey different shades of meaning through inflection, connotation, and association. A cursory comparison with the Diagnostic and Statistical Manual of Mental Disorders captures the contrast between a language of compassion and language of oppression. The DSM-IV-TR's definition of mania includes the following symptoms:

(1) Elevated or expansive mood "characterized by unceasing and unselective enthusiasm for interacting with people", (2) Inflated self-esteem such as giving "advice on matters about which he or she has no special knowledge" or claiming a special relationship with God, (3) Speech that is loud, rapid, difficult to interrupt, and often "full of jokes, puns, plays on words, and amusing irrelevancies", (4) A flight of ideas "i.e., a nearly continuous flow of accelerated speech, with abrupt changes from topic to topic, usually based on understandable relations", (5) Increased involvement in goal directed activity including "excessive planning of, and participation in, multiple activities (e.g., sexual, occupational, political, religious). (6)"God's voice may be heard explaining that the person has a special mission." (DSM-IV-TR, 2000)

It should be evident to any who consider these two descriptions side by side that both McNamara and the DSM both leverage the power of narrative. The DSM's point of view is difficult to discern, indeed the book's producers attempted to assert an objective view from nowhere (Lewis, 2006), until it is juxtaposed against the rich backdrop of McNamara's personal experience. Once we read an alternative description of similar behaviors, the blunt force of the diagnostic frame comes into clearer focus.

This comparison also demonstrates the power of inclusion and exclusion, as McNamara contextualizes their sensitivities against the backdrop of a cultural critique:



... I grew up in a region that was rapidly being developed and where, what used to be horse fields and meadows were being turned into strip malls, and condominiums, and corporate headquarters. Just watching the rape of this land... (3:00-3:13)



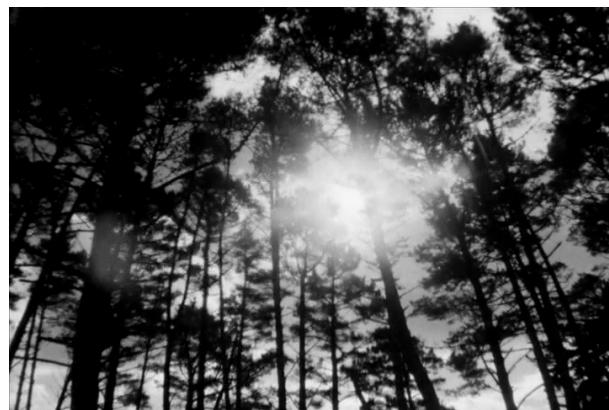
I started to really lose interest in a lot of the trappings of popular culture. All these messages about the kind of person I was supposed to be. The world around me was

way more interesting than a television show. And what everyone talked about on the bus to school was movies and celebrities and I just didn't care. I wanted to talk about like love and loss and life and the meaning of human existence and spirit and unity and freedom, and that's not what 12-year-olds were talking about... (3:28-4:02)



If I was determined to live my life in a city and to work a really intensive, steady job in an office I think I would have to take medication to do that. But I don't think that fact means that I have a disease. I think that it means that it would take a pharmaceutical substance to override my instincts to make me capable of fitting into a system that was not designed for someone with a spirit like mine...

I'm just really sensitive and my moods shift in ways that I don't really keep a rhythm that fits with the clock of capitalist society. (13:45-14:24)

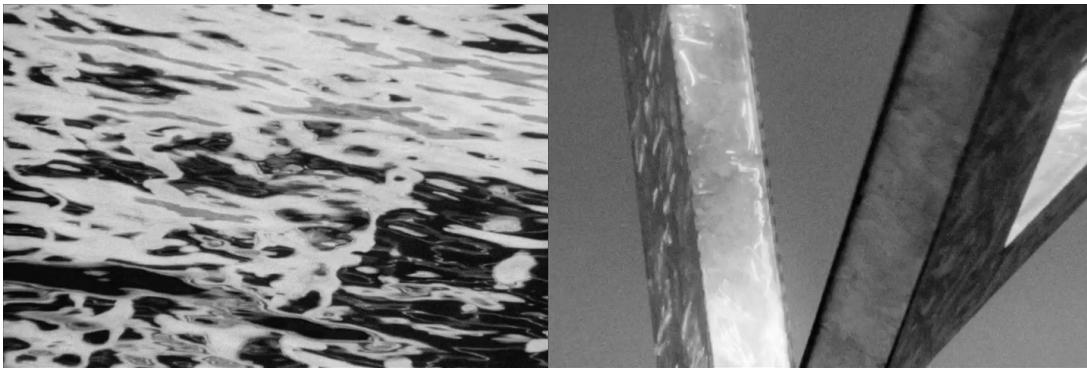


In the course of narrating their story McNamara indicts capitalism, popular culture, the media, gentrification, urbanization, and the assumptions of the modern western

lifestyle. The objectifying response they heard from psychiatry was “I’m a mood disorder with legs”. Your life is insane because you have a biochemical problem. If you take these drugs religiously for the rest of your life, your life won’t be insane.” The ability to recognize the structural violence that McNamara feels oppressed by is entirely absent from psychiatry’s response, again illustrating the power of framing, omission, and commission. We witness in this dialectic the forceful power of oppressive language, and the empowerment that comes from reclaiming languages of oppression. However, reclaiming this language still invokes it, and for many, healing involves supplanting this language with compassionate alternatives. *Crooked Beauty* mobilizes this language of compassion to conjure authentic visions for thinking and speaking about “extreme states of consciousness”.

McNamara claims “there would be a lot, a lot less mental illness, quote unquote, in our society if people were given spaces to work through emotions like anger and grief instead of denying them and suppressing them, if we had a language of compassion.” (Rosenthal, 2010a). Rosenthal provides a cinematic space for McNamara to tell their story, and as we listen to them work through their emotions, both McNamara and Rosenthal attempt to model the language they imagine. Through screenings and workshops the film seeks to recreate this compassionate space, introducing an empowering new language, and then stepping back to give participants the communal space to reflect on their own emotions and experiences.

The alternative vision that McNamara promotes sounds simple and obvious, once articulated, but is tragically far from our current reality:



We need to stop saying, “You are crazy, stop being crazy.” We need to stop putting all the focus and treatment on; How can we make you stop being the person you are? How can we stop telling you, that you are wrong if you experience these things? And how can we instead, help you to learn how to handle your sensitivities, that you might make the transition from having these sensitivities overwhelming you, to having these sensitivities be giving you information you can use? (15:40-16:12)



Beyond the obvious advantages of framing, *Crooked Beauty* also captures the paradoxical power of complexity and contradiction. Life is messy and complicated; to pretend that it isn't denies our humanity and reduces subjectivity to a multiple-choice survey. By embracing the contradictory emotions inevitable in a complex world, the film avoids the common pitfall of romanticizing illness and denying suffering. McNamara describes their initial reactions to their biochemical diagnosis:



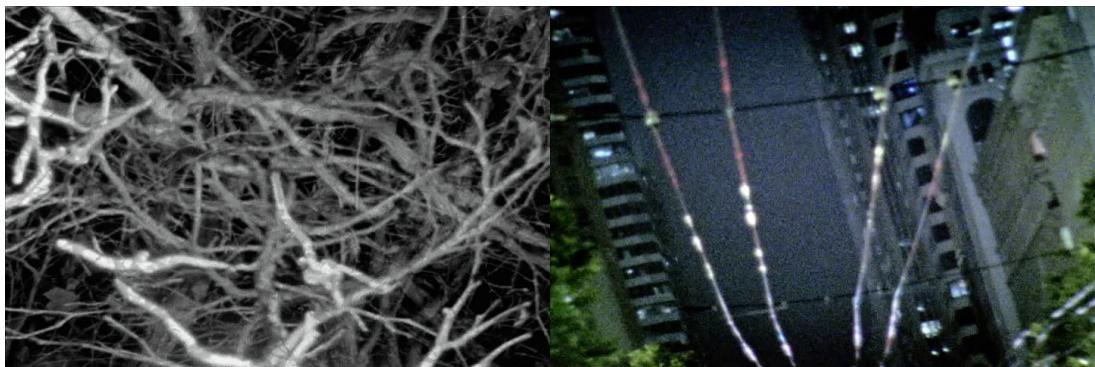
Part of me really wanted an answer that left me off the hook as far as responsibility went. And being told that I had a mental illness was both horrifying and very conveniently left me out of responsibility for my life. And it enabled me to recast everything that had happened to me up to that point as a result of this mental illness. And part of me hated that and part of me was totally relieved. 'Cuz then it was just like, "Oh, that's why it's all been so hard. I've just got this brain disorder." But, I don't think that's actually the whole answer, at all. (9:40-10:16)



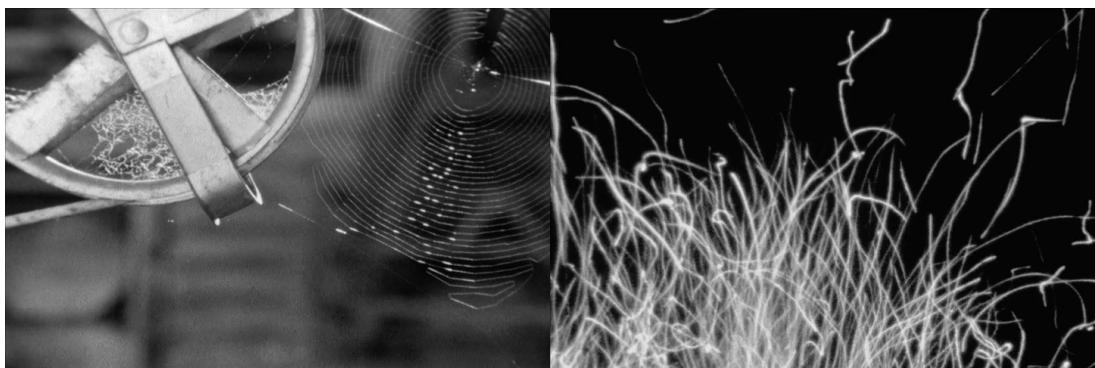
Later, they elaborate on the beautiful and dark sides to all aspects of our reality – material, psychological, social, and metaphysical—and their ambivalence over their ability to acutely perceive and experience these extremes.



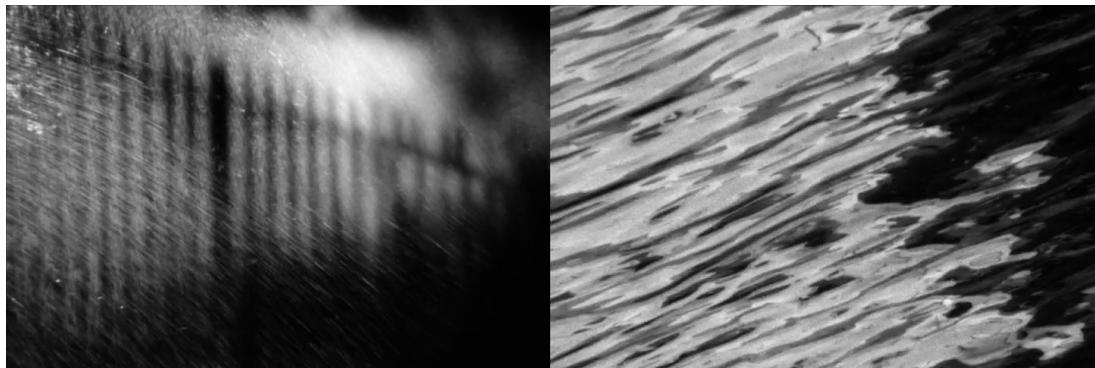
The dead flower over there and the shadow over here and this person over there and the love letter over there and the map over here and the apocalypse over there and Walmart down there and the ocean and the children and... and in my mind they're all connected. And they're not separable... (17:28-17:44)



I don't just see beauty and light and god and grass. I see suffering and bodies rotting in the streets and injustice and a lot of pain and terror and fear also comes in. 'Cause the dark side of humanity is very, very, very real. And we don't want to think about that. There's moments when people have glimpses of what is luminous and transcendent and that's fantastic, but no one stays there. (18:01-18:23)



God knows there have been more times in my life than I could ever count when I have been like please take this fucking thing away from me I don't want it. It is too painful, it is too much pain and suffering. You can have it back. Just let me close down and be like a normal person walking around the world. I don't want access to these frequencies. Can I please just shut the dial off? (18:29-18:52)



“Lilies and urine”; expansion and contraction; transcendence and despair; beauty and darkness. Narratives, and images, are able to represent a continuous spectrum of perspectives that are difficult—if not impossible—to capture through ordinary propositional discourse. McNamara’s narration relates the ambiguity of their situation, raises questions instead of making categorical assertions, and depicts how their perspectives oscillated and transformed over time and space. It is around the representation of ambiguity and contradiction, as well as voice, that the language of cinema helps amplify McNamara’s story and transform it into a cinematic vision quest.

*Crooked Beauty* embodies an emerging style of documentary filmmaking that blends and extends the boundaries of narrative advocacy and cinematic convention. The film is simultaneously an expression of hope and an act of resistance that powerfully captures a snapshot of the hierarchies of power in the domains of mental health and capitalist society at large. It defies many of the traditional sub-genres of documentary film – it

cannot be easily categorized as historical, investigative, issue-oriented, ethnographic, or biopic. *Crooked Beauty* poignantly refutes the prevailing medical gaze towards mental illness through an intensely personal narrative spoken over a backdrop of visually poetic imagery. The film's storytelling embodies a distinct perspective that provokes and challenges mainstream diagnostic paradigms. Its discursive style resonates deeply with the language, aesthetics, and values that have been painstakingly cultivated over the years by communities of radical mental health activists in peer-support groups and workshops across the country. This holographic work is simultaneously an expression of hope and an act of resistance, and can be read as a post-modern manifesto – one that often speaks from the subjective 'I's of personal experiences, and raises questions and contradictions instead of making grandiose assertions and categorical declarations.

The complex tensions created by these interwoven narrative threads contribute to *Crooked Beauty*'s captivating hold. The work is rich with contradiction and complexity, demanding and deserving multiple viewings to fully appreciate it. It is neither exactly McNamara's story, nor is it exactly not. Similarly, it is neither exactly the origin story of The Icarus Project, nor is it exactly not. The settings where the film has been distributed and screened also inform its reception. It has screened at multiple film festivals, often followed by a panel of Icarus members and/or the director to facilitate audience discussion. It has been distributed at Icarus events, and Icarus continues to develop supporting curricular materials. It is even being used in professional training settings to educate mental health practitioners. Its multi-dimensional style suggests a simultaneous reinvention of the documentary and the traditional manifesto.

Unlike mainstream documentaries that often talk *at* the audience, *Crooked Beauty* is designed as a space in which the audience can immerse themselves, and become narrators of their own stories, while employing McNamara's language of compassion. This is a grand ambition for a film as great cinema typically evokes admiration or contemplation, at best, and rarely such a degree of embodiment. Rosenthal's reciprocal technique is quite distinct from the conventions of mainstream storytelling, which are designed to provoke a compulsory identification with the protagonist, but not necessarily a first-person immersion in their experience. The line between identification and immersion is blurry, but Rosenthal's solution for avoiding the objectification or exploitation of his subject is to try to make them disappear, drawing the audience into the leading role. Many viewers experience the emotional roller coaster the film for him/herself, beyond just identifying with Jacks. *Crooked Beauty* employs the characteristically evocative power of poetry to transport the reader into the mindsphere of the writer and directly experience McNamara's frame of mind. Especially when combined with a well facilitated, follow up workshop, *Crooked Beauty* achieves the director's ambitions.

*Crooked Beauty*'s central position as a formative piece of media helping to represent, and in turn define, The Icarus Project is a function and a testament to this accomplishment. The film enacts the change it advocates by modeling a language of compassion and liberation. It exercises this language through the performance of authentic narratives and allegorical storytelling. It also reaches beyond the representation of the narrative, and attempts to embody the narrative through a series of storytelling techniques designed to immerse the viewer in the experience of the narrator. These immersive techniques are designed to take the audience on a phenomenological journey which tracks the narrator's

experience, taking the viewer beyond identification towards a direct experience of the moods, themes, and feelings expressed in the film.

The audience responses to this film have been almost uniformly positive, and it has screened at almost thirty international film festivals, and has won over a dozen awards (Rosenthal, n.d.). Mental health professionals, academics, journalists, c/s/x activists as well as individuals struggling with their mental health have all found the film unique, provocative and powerful. I have participated in multiple workshops that opened with a screening of the film and participated in the conversations that followed. The film, combined with a skilled facilitator, helps create a conceptual clearing where people feel empowered to reclaim their own identities, to reevaluate the shame and stigma they feel about their own experiences, and even to try emancipating themselves from the alienation and isolation of psychiatry's dominant paradigm. A typical workshop engages the audience by asking them to share their own stories in response to the provocation of the film. Next, they separate into small groups and discuss questions such as "What am I like when I'm most alive?" "How do I know when I'm well?", and "What are the signs that you are struggling?." After a period of discussion, the groups reconvene and share the highlights of their conversations with the larger gathering. Often, remarkable patterns emerge that challenge the mainstream understandings of health and wellness. Participants described their newfound recognition for the power that labels and narratives wield in identity formation, and expressed how the film articulated ideas they have felt, but have been unable to put in words. These workshops would lead to the development of the ongoing Mad Maps project, described later in this chapter.

## 5.2.2 Open Source, Open Minds

The project's day-to-day practice was also embodied in The Icarus Project's digital infrastructure, and during periods when the leadership flourished, they deliberately chose tools supporting the project's participatory values and collective governance. From its inception, The Icarus Project was conceptualized as a network, with its web site operating as an inclusive communal hub, not just a broadcast transmitter. Interaction and participation were essential—The Icarus Project goes beyond curating and disseminating media stories, and connecting disjoint groups. The project also aspires to democratize the production of psychiatric knowledge, and conceived of itself as an active listening space where the marginalized and their supporters would participate in sharing and exchanging their experiences, without judgment. At its best, the project has succeeded in living up to this aspiration, although it has always struggled with stability—financial, organizational, and emotional. At other times, the site has functioned as the locus of conflict, or neglected to the point that there were barely enough resources and attention to pay the hosting provider and keep the domain name active.

The site was imagined as a space, not a wall or a billboard, and members actively embraced the discussion boards, and contributed user-generated content in the form of links, blogs, photos, and event postings. The project also collectively produced numerous zines, paraphernalia, artworks, podcasts, videos, and events. Through these prolonged discourses, people shared diverse narratives and invented new frames for talking about mental health. DuBrul and McNamara designed a platform for activists to speak directly to each other, and these personal encounters fostered collective empowerment and

communal engagement. Regular art shows encouraged membership to submit their own artwork, which were in turn, featured and celebrated at local events and on the website galleries. *Friends Make the Best Medicine*, published in 2007, included a template and a call for readers to create their own local support groups, lightly coordinated through the public web forums (2007). Will Hall's *Madness Radio* show regularly featured guests from the community, as well as journalists, activists and academics from across the movement. The first segment of the hour-long show was always devoted to the guests' personal story, told in their own words, with Hall's warm and compassionate interview style.

In 2003 DuBrul and McNamara wrote:

We would like this site to become a place that helps people like us feel less alienated, and allows us, both as individuals and as a community, to tap into the true potential that lies between brilliance and madness. (DuBrul & McNamara, 2003)

At the outset, Icarus aligned itself with radical technology collectives, such as the Riseup.net collective and the May First/People Link. Unlike traditional hosting vendors, these organizations were devoted to social justice and independent media, and support a range of progressive activist organizations. These technical collectives managed the project's servers and mailing lists, providing secure hosting services that were organized like a cooperative instead of a corporation. These organizations strongly advocated for the use of free and open-source software (FOSS) based on their deep understanding of how these tools embodied the values of the causes they supported.

FOSS ecologies have been a breeding ground for experimenting with various models of structure and governance, promoting constructionist learning and civic engagement within communities of practice (Coleman, 2012). Since writing software is an act

of creative expression, it is often the case that the artifacts created by a software community capture the values of that community through the inclusion (and omission) of the software's metaphors and features. The recursive questioning of process and structure is a habitual pattern of programmer's thinking, and it is no surprise to see this analytical gaze turned back on itself. The community's proximity to the architecture of their own communication channels encourages a reflexive attitude towards their own communicative superstructure, a communal disposition that the anthropologist Chris Kelty describes as a "recursive public" (Kelty, 2008).

Throughout the first decade of the 21<sup>st</sup> century, some members of The Icarus Project have recognized their deep ideological compatibility with free culture, and embraced FOSS tools and Creative Commons licensing at almost every turn. Although their original public-facing website was a custom proprietary implementation, the community forum was implemented using phpBB, a popular open source bulletin board system with flexible configuration that supported delegated moderation and pseudo-anonymous registration. The bulletin board software was deployed on an Icarus server, managed by May First, and Icarus had complete control over the software configuration and the data. The project went to great lengths to maintain civility on the discussion boards without instituting harsh, disciplinary tactics, such as banning. Volunteer moderators wrestled with this charge and worked heroically to facilitate discussions and mediate conflict. DuBrul describes the unique culture that developed in the forums:

We were attracting interesting people. We had discussion forums with names like *Alternate Dimensions or Psychotic Delusions* and *Give Me Lithium or Give Me Meth*. There was nowhere else around that was explicitly a place where people who used psych meds and people who did not and people who identified with diagnostic

categories and people who did not could all talk with each other and share stories. Because of the outreach in the anarchist and activist community there was a high percentage of creative people with a radical political analysis. And with the (seeming) anonymity of the Internet, people felt comfortable being honest and sharing intimate stories about their lives. Our website served as a refuge for a diverse group of people who were learning the ways in which new narratives could be woven about their lives. (2012)

Throughout this dissertation we have encountered the new narratives that DuBrul alludes to in this quote. The Icarus Project carved out a “radical middle”, opposed to the extremes of psychiatry’s bio-bio-bio model and anti-psychiatry’s dogmatic opposition to everything psychiatry offers. This radical middle is a precarious position to maintain, and this instability partially accounts for the continually shifting sands of Icarus ideology. The Icaristas’ stories help define and renew this middle ground, regularly challenging stereotypes of psychiatric resistance, and testifying to the power of lived experience as an important source of knowledge. Icarus governance evolved into a hub-and-spoke model, with local autonomous spokes meeting in person, running peer-support groups, organizing events, talks, screenings, and teach-ins. The collective was able to intermittently raise infusions of funding which also supported operational costs, like hosting, office space, and minimal part-time salaries. The national collective relied heavily on tools like free conference calling, mailing lists, and especially wiki software to support transparency in their decision-making and leadership. For the period between 2004-2008, all of the national collective’s meeting agendas, minutes, and finances were shared publically on project’s organizing wiki and available to the membership for review. Support for this organizational model relied heavily on tools developed in the FOSS

community, in this case OpenPlans.org, a suite of open-source organizing tools developed by a non-profit dedicated to using technology to improve the way citizens interact.

Icaristas have expressed a range of attitudes towards electronic communications—sometimes ambivalent, sometimes contradictory, sometimes hostile. There is a deep suspicion of digital communication, and many of the organizers express an aversion to screens and a strong preference for face-to-face communications. Some Icaristas engage the project exclusively online, others exclusively through face-to-face meetings and events, and some through a hybrid of online and in-person. The project has always been self-aware of the pitfalls of electronic communications, especially when negotiating conflict. In 2006 the collective published an “Email conflict Policy for Volunteers, Interns, and Staff” which stipulated:

The Icarus Project supports direct and clear lines of respectful and supportive communication in the event of grievance, conflict, or interpersonal difficulty. Such communication is best done face to face, or, if face to face is not possible, on the telephone.

No attempt should be made to resolve, process, debate or deal with interpersonal conflict issues of any kind over email. This includes discussion forums, instant messaging, chat rooms, blogs, commenting, etc.

Attempts to resolve conflicts or grievances over email have consistently been shown not only to fail, but to make matters worse. Email is an impersonal and misleading medium that while helpful in rapidly transmitting information, promotes miscommunication, misunderstanding, mistrust and confusion when it comes to interpersonal conflict and difficulty. (2006c)

This email policy recognizes the shortcomings of digital communication that Rasmus Neilsen identified in his research on the use of email in political organizing (2009). The policy extends his findings that email communications within a group often lead to

“miscommunication, overcommunication and communication overload”, and recognizes an additional emotional layer of mistrust characteristic of the medium. I have not seen this policy adopted elsewhere, and to my knowledge The Icarus Project originated this language, based on experience and necessity. As with The Icarus Project’s meeting agreements described above, the email conflict policy is widely applicable beyond mental health organizing, and other groups should consider adopting it to help manage internal conflicts.

On numerous occasions a participant or moderator has linked to the email conflict policy and I have seen electronic conflicts averted. On many other occasions I have seen this policy flagrantly neglected or violated, often resulting in the outcomes it warns against. While this policy is difficult to enforce, at the very least it functions as an important reminder of the limitations of online peer-support forums, as experienced by the membership. Icaristas are a diverse group, with different backgrounds, priorities and communication styles. Conflicts erupt on a regular basis, group moderators work hard to mediate, and often burn themselves out in the process. Conflicts usually revolved around breakdowns in trust and miscommunication, and were exacerbated by the community’s mad dispositions. Local groups were often wary of the national organizers, suspicious of information and community plans being withheld. As in any other community setting, gossip abounds, and mundane interpersonal conflicts spill over into community spaces. Few of the conflicts revolved specifically around mad issues, and most seemed typical of any activist community, at times amplified by the participant’s sensitivities.

The intensity of the interactions was often striking, but their substance was fairly mundane. Disagreements over the substantive issues the group was advocating for

were surprisingly civil, and pages of long-form, thoughtful, exchanges were common. Popular topics of discussion include questioning the value of medication, struggling with side-effects of medication, sharing alternative wellness practices, and coping with the stress of family, friends and employment. A fixture of the forums is the daily “Roll Call”, a forum devoted to people greeting each other online every day. The value of this forum was best appreciated when the site experienced an outage in 2015, and the community was shocked and outraged.

It is one thing to recognize the pitfalls of electronic communication, and another thing altogether to transcend them. The realities of communication between and beyond Icaristas have presented extreme challenges. The project’s self-awareness of these patterns feeds their continual efforts to improve these dynamics and break free of the repetition compulsion of these dramatic standoffs and implosions. Digital communications are fragile to start with, and their use within the project has only compounded the challenge. The national collective never developed a template or set of platform recommendations for local groups to follow, nor did they provide the infrastructure for local organizing, beyond the Forums, which were ill suited for sustained organizing and knowledge management. Groups were left to fend for themselves and for years wandered between a bewildering labyrinth of listservs, Yahoo! groups, Google groups, Facebook groups, even though many of these platforms were ill suited for these needs as well.

The national collective also cycled through patterns of communication breakdown. It seemed that just as the group had settled on one communication channel, the listserv was renamed, or the group decided to relocate. Bitrot, or, digital corrosion, was constantly

nipping at the heels of the project, as their MySpace archives, numerous listservs, and content fell victim to deterioration in the course of upgrades and neglect.

In 2006, the public-facing website was rebuilt with Drupal, a FOSS content management system whose slogan is “Community Plumbing” and has a vibrant non-profit ecology. This new environment was intended to realize the original site’s ambition of becoming a platform run by and for the membership. The site was designed to support distributed research across the community, as well as empower Icarus spokes with the tools they needed to organize locally. Although the Drupal site was successfully relaunched, the site’s full capabilities were never realized. The national collective seemed stymied and blocked, and never took full advantage of the platform. These blocks may have been rooted in the challenge of generating fresh content rather than the technological hurdles, but for a variety of reasons the site never flourished. Funding shortages caught up to the project, and the membership was never trained on the site’s new features. Significantly, around this time social networking platforms began competing for the attention of the membership.

At the time of this writing, the site is once again undergoing a major overhaul. In the past few years the project has been losing its control over the dynamics of the discussion as conversations have migrated to social networks like Facebook and Twitter. These proprietary platforms pose a grave threat to the project’s autonomy and values. When activists organize on these platforms commercial interests dictate the contours of the conversational spaces, not the membership’s needs. In particular, many of the dynamics of the original forums, including pseudo-anonymity, communal discretion over membership and content, and long-term control over archival records, will be lost unless

the community returns to platforms that are under its autonomous collective ownership. The form of interactions on the PHPbb forums is dramatically different than those on Facebook. The forums regularly hosted sprawling, long-form debates, while Facebook interactions are staccato and terse. It is incredibly difficult to sift through Facebook archives, and once a conversation falls off the wall, it only exists in the memories of the participants. Forum conversations regularly referenced earlier posts, and some threads endured for months, or even years.

The drive to migrate is multi-fold. Over the past few years the rise in the popularity of Facebook, combined with the importance of mobile accessibility have pressured the project in this direction. A significant majority of the online participants access the site via their mobile devices, and the 2006 site was clunky and cumbersome, especially compared to the slick experiences of a modern social media site. Facebook also leverages powerful network effects, and since people are already spending large swaths of time on the platform it is much more convenient for them to interact there. According to Facebook's 2014 second quarter report, the average American spends 40 minutes per day on the site, a number that is certainly higher among the younger demographic that makes up The Icarus Project (Brustein, 2014). The collective also grappled with the fact that an unofficial Facebook group would likely form if they did not endorse one themselves.

In the winter of 2013 an incident occurred within The Icarus Project's official Facebook group that illustrates the threat posed by this loss of autonomy. In December 2011 Facebook introduced a tool that enables users to report their friend's comments as spam, bullying or suicidal (Donald, 2011). Users could "flag" a comment and submit their

report to Facebook, whereupon Facebook employees review the comment to determine if it complies with Facebook's community standards. One morning in November 2013, a member of the Icarus Facebook group woke up to an email from Facebook administrators encouraging them to call the national suicide hotline, without disclosing who had submitted the report about their comment. The recipient of this email experienced the message as cold and coarse, and immediately returned to the Icarus Facebook group and accused its members of snitching on them. The Icarus members all denied reporting the comment, and wondered if friends from a different Facebook group might have been responsible.

The national suicide hotline has a reputation within the Icarus community for strongly endorsing the biomedical model and erring on the side of caution by forcefully encouraging medication compliance and summoning law enforcement to hospitalize the caller whenever there is any doubt. Icarus peer-support meetings have long practiced non-judgmental, active listening and most of the membership is fiercely opposed to the violence inherent in forceful coercion. Icaristas generally believe that sharing suicidal ideations is healthy and therapeutic, and the fear of being reported will inhibit people's willingness to share. Icarus peer-support groups have a long history of creating relatively safe spaces where people feel confident that sharing their darkest fantasies will not result in calls to authorities, followed by the inevitable involuntary hospitalization and treatment (with rare exceptions, under the most extreme circumstances). Facebook's architecture violated some of the most basic shared values of the group.

After days of heated discussions, the group moderators began to preemptively delete comments that might be construed as suicidal. This adaptation is the response to what

was described as an “absurdly coarse policy” that “fails to recognize diversity and context”. In the summer of 2014, the group began discussing a Facebook exodus and a return to the Icarus managed forums. The situation is complicated since the people who remained on the Forums are wary of welcoming a massive influx of Facebook members, and it is currently unclear what platform will support group discussions moving forward, or if the discussion environments will begin operating independent of the Icarus collective and become self-governing.

This incident of reporting a suicidal post on Facebook was not an isolated occurrence. Rather, it illustrates how embracing proprietary corporate tools can lead to environments that are deeply at odds with the project’s core values. One Icarista I spoke with discussed his fears of honestly sharing his dark feelings on Facebook since he was “friends” with his family, and did not trust Facebook’s privacy settings. There are reliable accounts of Icarus members being hospitalized on the basis of their Facebook posts, and more are sure to surface. These stories may not accurately reflect the causes of hospitalization, but it is still significant that people have begun to fear this aspect of social media’s power. One Icarista I know shared with me that her high frequency updates, and the erratic times of day they were posted, was used by her parents as evidence to her psychiatrist that she had relapsed to an “altered state”, leading to her re-hospitalization. She claimed that the content of her updates was not all that strange, but the timestamps betrayed that she was not sleeping. While it is possible that posts to the Icarus forums could have been used in a similar fashion, the Icarus-controlled forums do not require that people use their real names, and are generally a much safer space for sharing fears and dark fantasies, with an expectation that people will actively listen without judging. Only when

the project directly controls its communications software does the membership have the freedom to decide for themselves how to moderate and surveil their own spaces.

Over the past decade The Icarus Project has gravitated to media that are consistent with their core values of transparency, empowerment and participation. From their in-person participatory workshop formats to the Kickstarter campaigns that have funded their collectively authored zines, the project has systematically attempted to emphasize the importance of incorporating the voices of their membership directly in their messages. Even the forays into platforms like Facebook, which is at odds with these convictions, has highlighted the project's commitments against the backdrop of tensions that emerged around its use. The relationship between a group's core values, organizational structure, and communications infrastructure is always complex, but we can clearly see strong correlations between these three pillars. The project's politics are enacted in the ways it acts and communicates, and the deliberate selection of distributed, participatory media reflects a fundamental commitment to the principle "Nothing about us, without us". These communicative modalities operationalize the ways that "us" can be present and express their voices.

### 5.2.3 The Problems in 'the' Movement

In May 2013, Nev Jones, a doctoral candidate in community psychology, published a blog post on the problems inside the mad movement. (Jones, 2013) This post generated a great deal of debate across the c/s/x movement, and the Icarus Facebook group alone generated hundreds of responses to this post. Threads of this length and intensity are a

regular occurrence within the Icarus forums and Facebook group, and I have selected to analyze this exchange since it does not involve anyone's personal condition and also does an excellent job surfacing some of the core issues the project is currently negotiating. The thread is representative of the tone and style of exchange across a wide range of issues, and my inclusion of this debate provides a sampling of the texture of these conversations.

The post critiqued the larger mad movement's leadership, organizational structure and contradictory politics. Jones begins:

[I do not know of] one national user/survivor organization... with a transparent, robustly democratic organizational structure: at the extremes, some organizations that (explicitly or implicitly) claim to 'represent' a national constituency do not even publicly list the names of their leaders, administrators or board members. There are no elections, and sometimes absolutely no way for 'outsiders' to get involved even as volunteers. Little or no attention is paid to widespread geopolitical disparities, to the de facto silencing of service user voices in huge swathes of the country, or to the trickle-down effects of SAMSHA [the federal Substance Abuse and Mental Health Services Administration] funding (or the lack thereof) [the bulk of SAMSHA's funding is administered through block grants, which are in turn, dispensed by individual States], which remains largely contingent on the presence of "statewide" consumer networks which many states do not have in place (no matter how dense or active the smaller groups within these states).

A handful of SAMSHA Technical Assistance Centers exercise more or less exclusive control over the only "national" US c/s/x conference (*Alternatives*), and other 'events' and gatherings are by and large 'by invitation only,' further consolidating the power of small and select 'insider' networks."

A curious combination of anti-intellectualism and anti-empiricism seems to fuel such 'lines of flight'; apparent, for example, in the simultaneous valorization of 'good' science (viz. "science" that matches particular ideological positions regardless of the methods employed) and disregard for the transdisciplinary cultural and political complexities of all knowledge production and dissemination. If financial 'conflicts of interest' are an issue in the world of Big Pharma, they are no less an issue (albeit on a vastly smaller scale) in the increasingly commodified world of training packages and

patented interventions (e.g. OpenDialogue [an alternative, dialogue-based approach to psychosis interventions, developed in Finland (Intervoice, 2013)]). (Jones, 2013)

Some of the initial, knee-jerk reactions to the post were defensive, and some attacked Jones for her jargon-filled academic language and simplified her position as an anti-anti-psychiatrist and sympathizer with the biomedical model.

Icarista01: I don't see this author's appraisal existing within that "grey zone" of auto-critique and meaningful dialogue that they praise. Their own biases and unquestioned assumptions are clear as day in this piece. For example, in this quote: "truly chronic" problems are either explained away as casualties not of madness but rather overmedication and iatrogenic trauma" they frame the biopsych perspective as absolute fact ("truly") and the antipsych perspective as simply dodging those facts ("explained away"). Throughout the piece they slap a "problematic" label on various things with little explanation or attempt to back it up. This piece lacks substance and just looks to me like the tl;dr [too long, don't read] version of an "amirite, guys?" to the consumer crowd. I have frequently seen (and see reflected in this piece) a sense of entitlement coming from those whose belief system is more closely aligned with the mainstream — a smug belief that their perspective is the gold standard of uncontested fact, that the burden of proof rests on anyone deviating from such, and that no perspective can be "nuanced" or "complex" unless it includes or validates theirs in some way.

As the thread progressed, some others urged a closer reading, especially after people discovered Jones' personal identification as a mad activist and voice hearer with a schizophrenic diagnosis.

Icarista02: I'm going to do my best to say a few things about this in a non-polarizing way, cause these comment threads too often lead to that. First, I basically agree completely with the blog post, however I do not agree with how it is framed in some of the above responses. The post is not pro-Pharma, nor is it coming from a 'consumer' as opposed to a 'radical' perspective. In fact, part of the point of the post is to reject that dichotomy. There are not 2 or 3 perspectives in "c/s/x" or "mad" or "radical mental health activism," there are many. In the case of the blog, I would suggest considering the source-a completely credible radical mental health activist

and researcher with (also credible) lived experience of madness and the system. I would also suggest considering the audience. That is, ‘us.’ People involved in ‘radical’ mental health activism. She is objecting to within movement issues, and they are quite serious concerns, ones related to things that I would hope any ‘radical’ identified person would be open to hearing: silencing dissent, appropriation of mad identities for profit, consolidation of power, representing marginalized others from a place of privilege while discrediting their experience, etc. I would say the Icarus Project, if it’s anything like it used to be, would be right on board with this. After all, Icarus was ‘grey’ back in the day.

Throughout the thread Icarista02 patiently tried to explain Jones’ position against an initially stark rejection. However, even Jones’ invocation of personal stories within the movement was criticized on the grounds that she mobilized these stories for a utilitarian purpose:

Icarista03: I very much enjoy hearing people’s personally stories, whatever shape their stories has. But I like it as long as it is deeply human, as me, human, getting to know another human. I don’t like to listen to listen to personal stories as some sort of utilitarian or intellectual exercise to achieve conclusions that are outside the person, to analyze the person in ways that i think will ultimate benefit/validate or agree with me. I find it very dehumanizing and degrading. I enjoy intellectualism, but certainly not that flavor of it. I also find disagreement to be a beautiful thing, because disagreement births multiple ideas and multiple places where a variety of people can find ‘home’ or ‘help’ or whatever it is they are looking for, so I don’t necessarily think that should be the end goal of conversations or practices.

The debate over the connotations of “chronic” conditions continued:

Icarista01: to respond to your comments to me from earlier: I think you missed my point. “Truly chronic” is a de facto endorsement of biopsychiatry because it implies a permanent biological disorder. You’re doing the same thing Nev [Jones] did, basically stating this as an absolute fact of reality when really you have no way of knowing that — not for yourself, not for your mother, not for anyone.

Icarista02: I truly apologize if my careless use of language caused offense. This format is an inherently dehumanizing way to communicate. this was not my intention.

As to ‘chronicity,’ I think it’s not in touch with the reality of many peoples lives to not acknowledge that these difficulties are inherently a part of the person, biological or otherwise. As to disorder, that is socially defined. We acknowledge eye color is genetic, but not a disorder.

Icarista04: damn this is a debate. really appreciating everyone’s comments. I really disagree with this statement: “Truly chronic” is a de facto endorsement of biopsychiatry because it implies a permanent biological disorder.” I do not think that saying someone’s distress recurs means it is in any way inherently biological, or a disorder. My distress has certainly turned out to be chronic, no matter how many non-pharmaceutical treatment alternatives or lifestyle changes I have made. (And I have tried SO MANY.) It comes back and comes back and comes back, in small micro-storms I can navigate, and in huge episodes that wreck my entire life. I don’t think that means I have a biological disorder, but I do not identify with all the linear recovery stories, the narratives that say it is all caused by psychiatry or all caused by the meds, or with the political rhetoric that minimizes actual experiences of madness. I do not feel like my experience is at all included in the narratives so popular right now on places like Mad in America and Madness Radio that so often focus only on recovery from first break “psychosis” or single episode depression, that therefore debunk research only specifically around anti-psychotics and anti-depressants, etc, but don’t look at things on the bipolar spectrum. It’s so much more complicated when your shit recurs over and over, and when in your experience mood stabilizers help and prevent crises and are not a fucking placebo - but when you go look at media produced by some of the top movement critics - Peter Breggin’s [a staunch anti-psychiatrist] toxic psychiatry website, for example, there’s nothing on mood-stabilizers and anti-convulsants. Clink on those links and they’re empty. Bob Whitaker doesn’t write about them either.

The chorus of support continued to gain volume:

Icarista04: Once I felt like I was duped by psychiatry because I listened to anti-psychiatry. Then I felt like I was duped by anti-psychiatry... Now I don’t listen to any extreme, but the shame never goes away... I’m a survivor of the system and of mental illness too... I had periods where I’ve been jobless, friendless, no support from family, homeless, hungry, tortured and really fucking crazy to the point of putting myself and others in danger... On medication I’m at least stable enough to not be constantly tormented inside... Do the medications have dangers?... Pharma would have me believe those dangers are nothing and anti-pharma would have me believe my head’s going to explode tomorrow. I’m right now making an informed

choice to be on medication... That's based on my past actual states of mind and behavior (and the police arriving at the right time), not just conjecture... From my perspective, both "sides" of this thing are doing it wrong and both have considerable persuasive power in their own way.

But these arguments would never convince the die-hard psychiatric survivors in the group, who continued to stick to their dogma:

Icarista05: "Mental illness does not exist" is not a line, it is not a move in a parlor game to be played by postmodern intellectuals. It reflects an existential position about what it means to be a human being. After a few years of working in the mental death system I realized—I was too stupid to see sooner— that the mental illness attribution was the most powerful way to invalidate people as human beings. Anyone who was once ever a patient (as I was—in therapy) ought to know that.. You've convinced yourself now it's just "a line." Did you forget how important it once was to you to be taken as seriously as everyone else, how discrediting it was to be dismissed as schizophrenic or bipolar or whatever?

Discussions like this are typical within the Icarus community, and diverse and contradictory views are cultivated and developed. This thread never came to a resolution, although the insight around the prevalent "first break" narrative would resurface in later conversations. Contradiction, reflection and critique are the norm as diverse beliefs clash and coalesce. Sometimes people's positions soften and change. Other times they remain steadfast and resolute. What is most notable is that a space has been cleared that is tolerant of differing positions where people are generally respectful to each other, with some exceptions. They are committed to listening to and learning from each other's wisdom, especially when it was gleaned through personal lived experience. These conversations are often highlighted and synthesized in the group's publications, which are published in the form of newsletters, articles and zines.

## 5.3 Addendum: Mad Maps

The Icarus Project is currently focusing on a major new initiative to develop a set of resources designed to help people create their own personal tools for self-care and peer-based support. This effort is a direct continuation of the project's initial vision, and has developed out of workshops, personal practices, and hardened experience.

For many years, members of The Icarus project have been imagining maps and roads and labyrinths that would lead us in our journey and ground us in the moment. These have been called “wellness maps” or “mad maps” – reminder documents we create for ourselves and the people around us about our wellness goals, warning signs, strategies for health and who we trust to look out for our best interests when we’re not at our best. (The Icarus Project, 2013)

The project explicitly recognizes the authority of individuals to recognize and determine their own health and well being. In workshops conducted in 2014-15, participants were invited to describe the conditions and behaviors they associate with their own wellness, as well as their own struggles. These responses are being collected and curated into what can be thought of as the “people’s DSM”. In other words, the behaviors and coping mechanisms as described by the people experiencing, and sometimes struggling with, extreme states of consciousness will be indexed and cataloged into an interactive resource. The intent of this resource is to allow individuals to share and exchange their experiences, in their own words in the hope that their experiences will resonate with others. The emphasis on “grounding us in the moment” parallels the emphasis on “speaking from the I”, as participants are encouraged to focus on the present, and avoid excessive preoccupations with the past or the future. In contrast to the cold and clinical diagnostic language of the DSM, the Mad Maps project is about trying to develop new

ways of talking about mental health and wellness that resonate with the lived experiences of Icaristas.

Mad Maps take a variety of forms, ranging from a few pages of text, to graphical diagrams and drawings. Typically, they are created by people when they are feeling healthy, and are an attempt to describe to themselves and their friends, what they are like when they are well, unwell, and techniques that have worked in the past to improve their condition. In ways, they resemble and extend the legal instrument of Psychiatric Advanced Directives, documents prepared by patients when they are mentally competent, stipulating instructions and preferences for care if they become ill (National Resource Center on Psychiatric Advance Directives, n.d.). Psychiatric Advanced Directives are still relatively new, have not been tested in court, and are mostly restricted to specifying a patient's preferences for hospitals, medications, and electroconvulsive treatment. Mad maps are more encompassing, and often include agreements with specific friends, warning signs that the author and friends agree upon, and strategies for coping with those emerging conditions. People may designate a friend as their delegate, indicate their preference to distance themselves from their family, and recommend various tactics for coping with crisis, such as isolation, respite centers, music, art, etc. At their heart, Mad Maps are a reflective tool that help people to communicate with their friends and future selves, a reminder of what they are like when they are sick, what they are like when they are well, along with strategies for managing and traversing these altered states.

## 5.4 Virtual Phenomenologic Interventions

The preceding thick descriptions of The Icarus Project help locate the project in the context of its forerunners. Experiments like R.D. Laing's Kingsley Hall (Laing, 1971) and Loren Mosher's Soteria houses (Mosher, 1999) were intended to promote healing and liberation through the ethos of peer-support and mutual-aid, although they did not go as far to challenge hierarchy and promote horizontal equality. These experiments, with all of their blemishes and failures, represent alternative treatment regimes for acute emotional crises and can be viewed as antecedents to the Icarus approach towards healing by, and through, participation within a therapeutic community.

In his description of Kingsley Hall, a community center in East London that Laing converted in 1965 to a non-restraining, non-drugging schizophrenic treatment experiment. Laing writes: "Events have included painting, weaving, yoga, poetry readings, Indian temple dancing, exhibitions, films, and lectures on anthropology, psychiatry, the theater, etc.... Many people visited the Hall. Those living there, decided who they wished to see." (1971:60) This vision of Kingsley Hall is sharply challenged by the version depicted in *Zone of the Interior*, a thinly disguised fictional account of Kingsley Hall written by its co-founder, Clancy Sigal (1976). In this account, Sigal paints a much starker picture of disconnects between Kingsley Hall's vision and its operation. Patients were neglected, drugged and abused, and Laing's megalomania was laid bare. After many reports of harassment from the local community, the project was shut down in 1970. Visitors to the hall included celebrities such as Timothy Leary, Allen Ginsberg and

the Beatles, and often involved LSD experiments designed to help participants “break through”.

The Soteria method (from the Greek  $\Sigma\omega\tau\eta\rho\iota\alpha$  for “salvation” or “deliverance”), resembled Laing’s Kingsley House, but was founded in America in 1971, and was not associated with psychedelics. Mosher describes the foundation of the method as follows:

Basically, 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, non-controlling 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,” “standing by attentively,” “trying to put your feet into the other person’s shoes,” or “being an LSD trip guide” (remember, this was the early 1970s in California). The aim is to develop, over time, a shared experience of the meaningfulness of the client’s individual social context—current and historical.

Note, there were no therapeutic “sessions” at Soteria. However, a great deal of “therapy” took place there as staff worked gently to build bridges, over time, between individuals’ emotionally disorganized states to the life events that seemed to have precipitated their psychological disintegration. The context within the house was one of positive expectations that reorganization and reintegration would occur as a result of these seemingly minimalist interventions. (1999:146)

These descriptions bear a strikingly similarity to DuBrul and McNamara’s initial visioning statement:

... While many of us use mood-stabilizing drugs like Lithium to regulate and dampen the extremes of our manias and the hopeless depths of our depressions, others among us have learned how to control the mercurial nature of our moods through diet, exercise, and spiritual focus. Many of us make use of non-Western practices such as Chinese medicine, Yoga, and meditation. Often we find that we can handle ourselves better when we channel our tremendous energy into creation: some of us paint murals and write books, some of us convert diesel cars to run on

vegetable oil and make gardens that are nourished with the waste water from our showers. In our own ways we're all struggling to create full and independent lives for ourselves where the ultimate goal is not just to survive, but to thrive. (2002)

While the outcomes of the Kingsley Hall and Soteria experiments are still hotly disputed, some clear limitations of these earlier models are challenges with sustainability and difficulty scaling. Kingsley Hall hosted a total of 119 people between 1965 and 1970 (Laing, 1971), and each of the Soteria house cohorts numbered in the dozens (Matthews et al., 1979). In 2008, The Icarus Project website hosted five thousand unique visitors a month and maintains an active membership mailing list of over four thousand emails. An open challenge for The Icarus Project is overcoming the problem of sustaining a community over time, a problem with which Soteria houses have historically struggled.

More significant than the quantitative scale of these interventions, digital media facilitates the creation of alternative spaces through the inherent malleability of software (Manovich, 2001). In a virtual environment, the architectural constraints that influence the social dynamics of a community are actualized through software interfaces. As we have seen above, free and libre open-source software systems are especially well suited to the design of environments that cut against the mainstream. A virtual Soteria house would be difficult to maintain within the Facebook platform, alongside pharmaceutical advertisements and within an inherently volatile and insecure privacy setting. In contrast, The Icarus Project has recreated the essence of the Soteria house's phenomenological interventions through a hybrid online/offline networks organized around their shared multimedia publications and exchanges. Crucially, The Icarus Project extends the Soteria model by constructing a context where people who are not contending with an acute crisis

can plan and organize. This model encourages experimentation that blends Soteria's peer-support model with traditional activism and protest.

David Graeber's formulation of direct action is also helpful in theorizing The Icarus Project's contrast with the psychiatric survivor movements that preceded it.

The reason anarchists like direct action is because it means refusing to recognize the legitimacy of structures of power. Or even the necessity of them. Nothing annoys forces of authority more than trying to bow out of the disciplinary game entirely and saying that we could just do things on our own. Direct action is a matter of acting as if you were already free. (Evans and Moses, 2011)

Instead of exclusively protesting egregious abuses of institutional power, The Icarus Project activists, like the Soteria houses before them, assert their freedom by constructing and inhabiting the alternative worlds they envision. They explicitly struggle with the legitimacy of the structures of power that regulate their own organization, almost to a fault. The project's preoccupation with its own governance structure has been criticized as self-indulgent. The project has also been accused of being organizationally unaccountable, since they lack a traditional non-profit structure, with a well defined membership and board. Acting as if they are free may in fact be a euphemism for acting childishly, perhaps an essential aspect of the project's romance, aesthetic and what Fletcher describes as its "uncivilizing" force (Fletcher, 2015).

The Icarus Project thrives when practicing peer-support, offering emotional first-aid, and caring for each other's basic needs. The project offers us a glimpse of alternatives to both mainstream biopsychiatry and 20<sup>th</sup> century psychiatric resistance. The psychiatric survivors' defiant rhetoric paradoxically reinforces the mainstream psychiatric frame by speaking for others and dictating how they should narrate their own experiences. For

*Icaristas*, radical mental health is about interconnectedness, diversity, embodied expertise, options, and politics. Community functions as the antidote to stigma, diffusing the isolation and alienation perpetuated and reinforced by a cold and inhumane system. The idea that community, peer-support, and mutual aid foster healing is barely acknowledged by the mainstream discourse.

## 5.5 Conclusion

The field of mental health is undergoing rapid shifts along with most other fields of society and sectors of the economy. These revolutions are happening concurrently with our transition to a networked society, and it is tempting to claim that the Internet has given rise to one emerging practice or another. However, when considering the influence of communications tools on social movements it is crucial not to fetishize technology. At the same time, it is foolish to ignore it or dismiss its impact.

In this chapter, instead of asking how the Internet has shaped The Icarus Project's communicative practices, I investigated their communications through a range of media. Although DuBrul does not enumerate participatory web culture as one of the original influences on The Icarus Project (2012), the Internet's capabilities are implied by the group's initial manifestation as a web site. The Icarus Project's longstanding slogan, "You Are Not Alone" is an undertaking that can only be realized in a networked society, where the web allows the long-tail of the neurologically diverse to locate each other and organize more easily than ever before in human history. The plummeting costs of production and distribution have enabled a range of independent publications, from

books, to radio shows, to documentaries that, until recently, would be nearly impossible to produce without access to large amounts of capital. This media allows activists to talk back to psychiatry, promotes a diversity of voices, and galvanizes communities around issues and protests.

Perhaps the most promising and elusive potential of these shiny new tools lies in their capacity to help activists manifest their visions, and sidestep protest through the construction of alternative worlds. Once built, these same activists now face the struggle of sustaining these worlds, often requiring far more energy than their initial creation. A history of convulsions, implosions, and disintegrations has plagued The Icarus Project, similar to the way it has plagued Soteria houses before it. Perhaps the ease of creating worlds only serves to amplify the effort required to sustain them. The proliferation of communicative modalities can lead to a cacophony of voices, unless there is an organizing principle, sometimes embodied in strong leadership, to harmonize them.

Most significantly, this investigation traces the contours of a profound transition in psychiatric resistance. The Icarus Project represents a new wave of resistance, one that shifts from the ontological questions of the definition of disease and illness to the epistemological questions of whose stories and voices are considered in the production of psychiatric knowledge. This insistence on full-fledged participation in one's own healing, and more importantly, in healing by and through community, represents a new modality of protest joined to an alternative vision, one that goes beyond the discourse of human rights and individual choice. It is a modality of protest that meshes well with our “decentralized networked-era culture” and offers a path for taking direct action in the context of mental health.

As we have seen, there is no singular set of demands that Icaristas are making on psychiatry. The unifying principle is their demand to participate in the production of psychiatric knowledge—to have a say in their own diagnosis, treatment and most importantly ownership over their own personal narrative. The Icarus Project is a space of experimentation, a clearing outside of the mainstream where people are beginning to redefine mental wellness, and are treating each other the way they want to be treated. In some respects the project is focused on creating alternatives that sidestep direct confrontation with the system. Icaristas are creating the kinds of spaces and protocols they would like to see in the world, prior to attempting to integrate these alternatives with mainstream psychiatry. From this perspective, The Icarus Project is currently concerned with setting its own table, rather than demanding a voice at anyone else's. Once this table is set, and people are nourished, they will be in a much stronger position to engage with the psychiatrists, CEOs, and politicians dining at the other tables of power.



# Mad Horizons

“ We’re all mad here.

— Cheshire Cat

Alice’s Adventures in Wonderland

My personal engagement with The Icarus Project began in Winter 2005 when I encountered a journalism student’s article in the Columbia News Service entitled “A new movement views bipolar disorder as a dangerous gift” (Itzenson, 2005). Itzenson’s article spotlighted The Icarus Project, and characterized the project as pioneering a new movement, more nuanced and ambiguous than its predecessors. Itzenson captures the contradictions of the group:

The Icarus Project embraces a wide range of treatments, and many members openly rely on lithium and other medications. But there is an edge of militancy within the group, particularly among members who denounce the pharmaceutical industry. Some have rejected the advice of doctors and struggle to get by without medication... Members of the Icarus Project say they do not romanticize the image of the tortured genius, nor do they downplay the seriousness of the condition. The group provides members with information on both traditional and alternative treatments, and supports members in making their own choices.

There is a history of mental illness and emotional distress in my family, and I responded to the article by directly emailing Sascha DuBrul, the project’s co-founder and sharing some of my own writing on creativity and madness. Throughout my studies the theme of madness surfaced in contexts such as explaining consciousness, understanding creativity and interpreting ancient and religious texts. DuBrul replied

enthusiastically to an essay I sent him about prophecy, creativity and madness and we began corresponding (Bossewitch, 1995). In December 2005 I attended my first organizing meeting, and was soon consulting with other volunteers on how the project could improve its communications strategy and technical infrastructure. Through these encounters I began to learn more about the wider c/s/x movement, its history, politics and ideology.

During this time I was working as a full-time software developer and attending Teachers College in the Communications and Education program. I was studying critical information studies with an emphasis on privacy, transparency and surveillance. In the Fall of 2006 I became embroiled in an incident that would later form the basis of my Masters thesis, and was also a pivotal turning point in the direction of my academic focus. The scene I entered began in a Federal District courtroom where the pharmaceutical corporation Eli Lilly was defending itself from a class action lawsuit alleging the harmful side-effects of their multi-billion dollar blockbuster drug Zyprexa (*olanzepine*), an atypical anti-psychotic approved for the treatment of schizophrenia. A witness for the plaintiffs decided to leak thousands of incriminating documents that were enjoined, sealed by the judge to expedite discovery. The documents implicated Lilly in knowingly downplaying the side effects of Zyprexa. These internal memos showed that Lilly scientists and executives had known for over a decade that Zyprexa causes diabetes, and not merely obesity as the class action suit alleged. The memos also showed that Lilly had actively marketed Zyprexa “off-label”, and their salespeople had created an internal marketing campaign, code-named “Viva Zyprexa!”, designed to push the powerful drug on children with behavioral disorders and seniors with dementia.

I wrote a more complete account of the actions that followed the leaks of these memos in an article published in re-public magazine, “The ZyprexaKills campaign: Peer production and the frontiers of radical pedagogy.” (Bossewitch, 2007) In summary, essential findings from the memos were published by the New York Times in a series of front-page investigative stories. Subsequently, a group of activists began analyzing the primary sources and were soon defending their First Amendment rights against a legal action instigated by Eli Lilly. Utilizing an array of legal instruments, Lilly’s lawyers attacked the digital sites where activists were analyzing the documents, and attempted to shut down their efforts. The Electronic Frontier Foundation (EFF), a non-profit impact law firm dedicated to defending digital civil rights, agreed to represent the activists against the suppression of their speech under the “prior restraint” provision of the First Amendment.

## 6.1 Jonah Doe

In January 2007 I personally became a client of the EFF and agreed to have them represent me against Lilly and defend my right to speak. The circumstances of this case converged around my intellectual and activist passions. At this point in my life I was an active supporter of the EFF, and active in the “free culture” movement, a direct descendant of the free speech movement and was becoming more engaged in psychiatric resistance. As a part of this action I also chose to exercise my First Amendment right to litigate anonymously, and the EFF protected my identity by referring to me throughout the case as “John Doe”. At the time I was concerned about the attention and coverage

the case might generate, especially since I did not know how the case would unfold. To this day I am relieved that not a single court briefing or newspaper article about the case bears my name, and internet searches for me are not dominated by results detailing my involvement in a provocative First Amendment action around an anti-psychotic. Stigma continues to surround activism and mental health issues, and I felt it was important to exert whatever control I could manage over my public reputation. I am disclosing my identity for the first time now since almost a decade has passed, and this experience was pivotal and transformative. My direct involvement in this case helped set the course for this entire project.

The six weeks I spent as a client of the EFF were among the most harrowing of my life. Since the entire action was a sidebar in the larger class-action suit there were no formal charges filed against me. However, the presiding judge had the power to hold me in criminal contempt of court if he determined I had knowingly conspired to violate his injunction, a ruling that could have resulted in large fines and/or incarceration. Though I knew I was innocent, anything can happen in open court, and each day brought new developments and court briefs that might affect the outcome of my case. I was riveted by the proceedings, and devoured every document as they appeared. My reaction to Lilly's court briefs was often a mixture of frustration, horror, indignation and disbelief. I observed Lilly's lawyers framing and interpreting the facts in ways that distorted reality. They alleged conspiracies where none existed, ascribed nefarious motives without supporting evidence for these insinuations, and repeatedly tried to unmask my anonymous standing. The experience provided me with a crash course

on First Amendment law as well as powerful case study on activist communications strategies and how stories travel through the media ecosystem.

A professional investigative journalist on the mental health beat became a close confidant, and we corresponded daily about developments in the case and the contents of the ZyprexaKills memos. My hunger for news surrounding the case was insatiable and I started researching and following news across the entire pharmaceutical industry. I learned about corruption and malfeasance across the sector, and that Lilly's crimes were typical, not exceptional. I learned about the toxic side-effects of the entire class of anti-psychotics, even the new generation of so-called "atypical" anti-psychotics. Most importantly, I learned what it was like for a journalist to cover a beat, and the essential function that professional journalists serve in making sense of complex narratives. By the time the judge issued his ruling I had gained a fresh understanding for how this domain constituted a legitimate field of academic research, and how urgent, important and neglected this research is.

## 6.2 Corrective Lenses

These experiences led me to view the work of the Icarus Project in a fresh light. The ZyprexaKills campaign opened my eyes to the changing landscape of mental health treatment, and I became more conscious of the corruption and largely unchecked power of the pharmaceutical industry alongside their peculiar alliance with psychiatry. This alliance is one of the factors standing in the way of involving patients in knowledge making, and psychiatrists, journalists, and patients all recognize the industry's profit-

driven motives. I spotlighted the dramatic expansion of psychiatric-pharmaceutical influence earlier in Chapter 2, which focused on the growth of the pediatric bipolar diagnosis. And, as the psychiatric context shifted and evolved, so did the language of resistance.

As mentioned at the beginning of this chapter, my initial exposure to The Icarus Project was via an article entitled “A new movement views bipolar disorder as a dangerous gift.” The Icarus Project membership tended to be young and well-educated, though many were unaware of the history of psychiatric resistance in the 20<sup>th</sup> century before joining the project. With their openness to psychiatric medications and diagnoses, Icaristas believed they were breaking with the past, and viewed their movement as innovative and fresh. They described themselves in these terms, and this narrative was often represented in the mainstream press, in publications such as the *New York Times*, (Glaser, 2008; Heffernan, 2010) *Newsweek*, (Quart, 2009) and *O, The Oprah Magazine*. (Quart, 2013)

When I began this project I also viewed The Icarus Project through this lens, as a distinctly new voice with a fresh message that broke from the ideas of R.D. Laing, Thomas Szasz and Peter Breggin, who all demonized psychiatry, and to varying degrees, denied the existence of mental illness and any value in psychiatric medications. I started this project with the belief that The Icarus Project represented the cutting edge of the movement, and in many important respects I still believe this is the case. My research and analysis has focused on trying to understand how the project is different—What did the cacophonous voices of the membership express over the past decade? In what ways is this message different than previous generations of the c/s/x movement?

Through my interactions with the community over the years I have learned that members of Icarus generally share inclusive attitudes and a tolerance for diversity, but they don't explicitly share consistent justifications for their positions or beliefs. The analysis of the underlying justifications that I advance in this dissertation is under-theorized within the community itself. Positions are often justified based on intuitions and gut feelings and members of the community sometime find it difficult to represent their beliefs and persuade others to take their perspectives seriously. What seems to be missing is a framework that grounds these critiques, a concise articulation of the commonalities among this collection of sprawling perspectives and expressions.

Throughout this dissertation I have emphasized the importance of a plurality of voices in the construction of psycho-social knowledge, and the power of the mantra "nothing about us without us" that is implicit in the language and advocacy of The Icarus Project, although they have not adopted this slogan themselves. Icaristas' behaviors embody participatory ethics, but this emphasis is partially mine, as this rhetorical formulation has not been widely and crisply articulated in the movement's public communications. This formulation is implied, but not uniformly articulated, as the movement is currently in the process of clarifying and refining its own message. The absence of clarity suggests an important direction for the movement, which would be greatly strengthened by a sharper framing and vision. My analysis is grounded on years of conversations and interactions as well as on the soup of sentiments present in the Icarus Project's voluminous communications, especially when contrasted with the movement's historical predecessors.

My interpretive stance is an attempt to make sense of multiple expressions demanding an inclusive role in the production of knowledge and policy. Sometimes the activist's expressions imply this demand sometimes they make it explicitly. A powerful argument motivates their story-telling, what I have called "narrative advocacy", and crystalizing this argument is the next step in this movement's growth. This argument's novelty is evident in the popular misconception that all resistance to psychiatry rejects the existence of mental illness, and throughout this project I encountered surprise and enthusiasm around an alternative perspective. Beyond narrative advocacy, the movement has the opportunity to learn from ACT-UP and begin participating directly in the production of scientific research that bears on their condition. With notable exceptions, such as Kay Jamison (1996), researchers who self-identify as mad have been historically scarce. A new generation of academic social scientists, including Emily Martin (2007), Nev Jones, and Timothy Kelley (2015) are actively contributing to our understanding of madness from the perspective of people who have received psychiatric diagnoses and treatment, and are providing crucial bridges between academia and activism.

The movement's messaging has an opportunity to align itself with the messaging of other oppressed groups by framing their objections around the sins of being excluded from the production of knowledge and policy that directly affects them. Inclusion is shorthand for the kinds of ideas that this participation will incorporate, and the examples that follow below suggest how this participation might alter perspectives, training and support.

## 6.3 Exploratory Salvos

A vivid way to illustrate the generative and explanatory power of this rhetorical frame is by considering a series of recent developments and analyzing them through this lens. These examples are drawn from ongoing conversations on the future of mental health, and represent different vectors of attack that the mainstream psychiatric establishment is facing.

### 6.3.1 MADLOVE: A Designer Asylum

*Is it possible to go mad in a positive way? How would you create a safe place in which to do so? If you designed your own asylum, what would it look like?*

These are the questions motivating “MADLOVE: A Designer Asylum”, an innovative art project-cum-intervention that previewed in Liverpool, England in the Spring of 2015. The project is compelling since it demonstrates an act of resistance that does not demonize psychiatry or condemn asylums outright. Rather, it suggests a middle ground for critiquing the asylum precisely along the lines I argue the movement is advancing—by listening to the voices of the people on the receiving end of the asylum’s services

The installation was featured as a part of an exhibit entitled “Group Therapy: Mental Distress in a Digital Age” and was on display from March 5, 2015 through May 17, 2015. James Leadbitter, aka “The Vacuum Cleaner”, was the 34 year-old lead designer who describes himself as an “art and activism collective of one”. (2015) Leadbitter’s work has appeared at the Tate Modern and Chicago’s Museum of Contemporary Art, and he has struggled with his mental health most of his adult life. He has been institutionalized

in the UK multiple times, including for almost a year when he was 18.(Taylor, 2015) He experienced institutionalization as punishing rather than loving, more like a prison than a hospital. He actively wonders how we can transform our support for people undergoing mental distress and create beautiful, enticing and supportive environments for their recovery.

Leadbitter collaborated with Hannah Hull, the show's producer who is currently a doctoral candidate at Goldsmiths at the Institute for Creative and Cultural Enterprise. Hull also consults on “creative practices for social change” and describes herself as a “situation-specific artist” who creates “social sculpture and political interventions”.(Hull, 2015) The Foundation for Art and Creative Technology (FACT) commissioned the project with support from the British Psychological Association in collaboration with the Wellcome Trust foundation.

The installation that previewed at FACT was preceded by a series of workshops throughout the Fall of 2014. Leadbitter and Hull conducted workshops around the UK that brought together mental health professionals, artists, academics, designers and particularly people with lived experience in the mental health system. Over 300 people participated in these workshops and their contributions were translated into design principles and the final installation. Participants were prompted to imagine happiness, health and wellness across a spectrum of sensory inputs. How does good mental health taste, smell, sound, touch, look? They explored what “objects, sounds, smells, colors, shapes, food, facilities and activities we need to create safety around ‘madness’?”(Taylor, 2015)

Participants dreamed of an asylum where there were no corridors, of walls that could change color, of a Library with books floor to ceiling and DVDs filed under ‘Happy Ending’ and ‘Sad Ending’, where there was a Trampoline Room, a Tree House, a Smash Room, all laid out in a building set near a river close to a forest, where there were no passive-aggressive signs and the emphasis was on meditation, not medication. (O'Donoghue , 2014)

The workshops were well facilitated, and the facilitators avoided most conflict by listening to all participants, and filtering out some suggestions in their artistic translation. Not all of the workshops were published online, and it is unclear if there were disruptions, and if so, how the groups handled them and how prevalent disagreements were in this process. The asylum they designed has also never been field tested, and the group avoided some of the harder questions of what kinds of asylum policies would accompany their architecture. Under what, if any, circumstances would patients be forcibly separated, medicated or isolated? What rules would govern intake and discharge? These policies are as important as architecture in governing a patient's asylum experience.

Some of the participant's visions are reminiscent of a children's playground, but they also presented nuanced views of privacy zones, ranging from private (with the patient in control of their seclusion) to semi-private to a bird's eye view of the ward. There was an emphasis on nature—the smell of the ocean, the sounds of birds and laughter, views of trees and flowers—as well as the surreal. A young man in Birmingham remarked: “All I want is a room with Fabergé eggs and a hammer.”

Leadbitter and Hull contrasted the participants' responses with the stark reality of institutional design. Its utilitarian furniture, drab colors and prison-like aesthetic reinforced distress and misery. Promotional materials for mental hospitals often feature

bucolic settings, but in Leadbitter's experience there was "No green landscape. No rainbow. No butterfly.", as featured on their brochures.

The final art installation was a cross between a Dr. Seuss book and Salvador Dali's house. It features a ceiling strung with upside down umbrellas, a lush teal carpet, an orange-striped "cooling tower", and a pastel pink cabin referred to as "Turkish delight". The cooling tower is lined with pillows and functions as "a humorous twist on the padded cell," where people can retreat to cry or scream without being locked in. There is a stairway to nowhere, lined with a bookshelf full of books, selected by workshop participants. The welcome desk contains bottles filled with various pleasant scents, such as lavender and cinnamon. James Christian, an architect who contributed to the project writes: "Each structure, is an abstract interpretation of the feedback from the workshops, designed to offer varying levels 'of privacy and intimacy ranging from total isolation to complete togetherness.'" (Hohenadel, 2015)

An unnamed, middle-aged workshop participant interviewed following a workshop reflected on his experience:

The lightbulb moment was the idea of taking ownership... Where it fell down a bit, is how do you care for people that don't want to be cared for? How do you look after people who are in [the] mental health [system] but are unwilling to recognize they are in crisis? That was missing. But there was a real collective sense of wanting to create something real and actual. The energizing thing about was that it wasn't wishy-washy or hippie-dippy; it was based on real experience... a collective sense of wanting to create something real and actual. (O'Donoghue, 2014)

Here again we see that people asserting their voice by designing their psychiatric treatment is a fundamental, but surprising shift. A position that seems obvious once articulated is novel due to its rareness. According to this workshop participant, challenging

questions around coercion and safety were avoided, but were present as a perpetual backdrop. While some of the designs imagined by the participants are impractical or unsafe, many could prove beneficial and effective. Following through on the design of a loving and supportive space must involve the input of all of the participants in that space. Crucially, the MADLOVE project does not deny the existence of mental distress, or even the value of safe institutional respites for support and healing. This radical expression emerges vividly from a straightforward application of “nothing about us, without us”.

Leadbitter and Hull fully intend to continue developing this project after the installation closes. They continue to tour, plan to bring their designs to the UK’s National Health Service, and have even talked about opening their own day hospital. They continue to advocate that design is important, and are committed “to creat[ing] unique space[s] where mutual care blossoms, stigma and discrimination are actively challenged, divisions understood, and madness can be experienced in a less painful way.” (Disability Arts Online, 2014).

The MAD LOVE asylum is a clear example of applying the principle of “Nothing about us without us” to mad advocacy. While the project is not as radical as some experiments in non-coercive respite houses, it demonstrates the kinds of value the perspectives of patients can bring to the production of asylums, as well as how patient advocacy is not purely black and white in its criticism of the status quo. The participants in the designer asylum do not reject the need for asylums, but they do object to their current implementation, and the fact that they are excluded from participating in designing these facilities.

### 6.3.2 Understanding Psychosis

In 2014 the British Psychological Society, a professional association representing psychologists and psychology in the UK, published a controversial report entitled “Understanding Psychosis and Schizophrenia”. The report acknowledges the role of trauma, abuse or deprivation in the development of extreme experiences, talks about the advantages and disadvantages in calling these experiences symptoms of mental illness, and emphasizes the role of talking treatments in helping people make sense of their lives. The report also claims that “professionals should not insist that people accept any one particular framework of understanding, for example that their experiences are symptoms of an illness”, and insists that “services need to change radically, and that we need to invest in prevention by taking measures to reduce abuse, deprivation and inequality.” (p. 6)

Contributors to the BPS report included leading experts and researchers in the field and “more than a quarter of the contributors are experts by experience — people who have themselves heard voices, experienced paranoia or received diagnoses such as psychosis or schizophrenia.” (p. 5)

The report was directed at therapists and practitioners, and was initially launched at a daylong conference in London on November 27, 2014. The conference program included academics, activists, contributors as well as the Shadow Minister for Public Health and Mental Health. A much wider audience engaged with this report, and reviews and responses have appeared in the *BBC* (Hill, 2014), *The Guardian* (Freeman & Freeman, 2014), *The New York Times* opinion pages (Luhrmann, 2015), *The Huffington Post* (Frances, 2014b), and the mass-market magazine *Psychology Today* (Davey, 2014;

Maisel, 2014). The authors of the report worked hard to draft a document with a widely inclusive tone that incorporates a variety of perspectives and highlights the uncertainty in prevailing scientific explanations. It is rare for an association of mental health professionals to endorse such a blunt critique of psychiatric knowledge, and to admit alternative treatments and modalities of care. The report discusses the risks and benefits of taking psychiatric drugs, differentiates between acute and long-term pharmaceutical interventions, and questions evidence around specific accounts of the drug's mechanism of action.

The editors cite ambiguous studies of patient outcomes and spotlight individuals who are thriving without medication and positions drugs as one of many viable treatment options, not an absolute. (Slade, Amering & Oades, 2008; Van Os, Linscott, Myint-Germeyns, Delespaul & Krabbendam 2009; Zipursky, Reilly & Murray, 2012) They claim "prescribers need to help people to weigh up the risks and benefits of taking particular drugs or indeed taking medication at all. People need to be able to try things out and arrive at an informed choice. Services should not pressurise people to take medication." (p. 55) Throughout the report, users of mental health services are quoted taking various positions, illustrating the benefits and downsides of different treatment regimes. The service users are treated as experts on their own lived experience, promoted to first class participants in the describing and evaluating their own care. The report questions the justification for various forms of coercion, stating that while compulsory detention may sometimes be justified, a UN task force has called for a ban on forced drugging, electroconvulsive therapy, restraints and seclusion (p. 110). The report also recognizes emotional suffering, and the role of professional treatment. Stories of professional

support appear alongside those of pain and trauma, and they cite patients who have thrived after abandoning traditional psychiatric treatment. Its radical perspective is most evident in the call for providers to accept views other than the illness model, the call for collaboration to replace paternalism, and recognition of the role that social injustice and inequality plays in triggering individual pathologies.

The report became a polarized lightning rod, and it was simultaneously praised by some for its “remarkable” rejection of the centrality of diagnosis and also accused by others of drumming up psychiatric hate-mongering (Luhrmann, 2015; Coyne, 2015). It was challenged on multiple grounds, including the research methods employed, the publication format, and paradigmatic frame. Beyond their rational critique, establishment reviewers sounded infuriated by the report and lashed out with insults and putdowns:

*Understanding Psychosis* should be seen as a cruel hoax perpetrated against more typical severely disturbed mental health service users, their family, and policymakers.  
(Coyne, 2015)

Responding to a positive editorial review of the report written by Stanford anthropologist Tanya Marie Luhrmann, Columbia University’s Chairman of Psychiatry and past president of the American Psychiatric Association, Jeffery Lieberman, attacked the journalistic integrity of *The New York Times* for publishing her review, and questioned the legitimacy of an anthropologist “opining on the scientific validity of [a medical specialty’s] diagnoses”:

The article about mental illness was an incredibly unscholarly, misinformed, confused—at worst, unhelpful, and at best, destructive—commentary that will add to the confusion about the diagnosis of mental illness, enhance the stigma, and may lead some patients to doubt the veracity of the diagnoses that they have been given and the treatments that they are receiving... What would give an anthropologist license to

comment on something that is so disciplined, bound in evidence, and scientifically anchored? (Lieberman, 2015)

Here Lieberman rehashes the battle lines of the Science Wars (Ross, 1996), and wants only psychiatrists to speak about treatment. Lieberman insists that psychiatric research is objective, based on “hard scientifically grounded” evidence, and fails to appreciate the values imposed by the narrative frame. In response to the report’s contention that there is no sharp dividing line between mental illness and normality, Lieberman writes: “Although everyone knows that there is a spectrum of severity of symptoms in the context of an illness, there is no question that, at some point, they cross a threshold that defines symptoms as an illness.” Anthropologists such as Luhrmann have a great deal to say about the construction of this threshold—who determines it, how they determine it, and how has it shifted over time. In effect, there is a question. Lieberman continues: “Viewing it this way is, in a way, challenging the veracity of diagnoses and giving people who have symptoms of a mental disorder, license to doubt that they may have an illness and need treatment.” Here, Cooke and Luhrmann would likely agree. The report does challenge the veracity of diagnosis, drawing on a range of methods and evidence.

An intriguing line of critique is the claim that *psychiatrists’ voices* were stifled its creation, and this omission undermined the legitimacy of the findings:

Key stakeholders were simply excluded – primary care physicians, social workers, psychiatrists, police and corrections personnel who must make decisions about how to deal with disturbed behavior, and –most importantly- the family members of persons with severe disturbance. There was no check on the psychologists simply slanting the document to conform to their own narrow professional self-interests, which we are asked to accept as “expertise.” (Coyne, 2015)

Of note, I didn't see any psychiatrists named as contributors to the report, but I'm happy to be corrected. (Laws, Lanford & Huda, 2014)

The insistence on incorporating stakeholders in the creation of this document is particularly ironic, since psychiatry has perpetrated this exclusion for decades. As the dominant actors, there are ample platforms available for psychiatrists to express themselves, as their voices represent the mainstream status quo and are amplified by the pharmaceutical juggernaut. None of the stakeholders enumerated in this critique are consulted in the composition of the DSM, and similarly, there is "no check" on psychiatrists "simply slanting the document to conform to their own narrow professional self-interests". The report might have garnered more legitimacy with psychiatrist contributors, but it extensively cites psychiatric journals and studies, and many of the psychologists who contributed have appointments at psychiatric institutes. Notably, Coyne ignores the inclusion of people diagnosed with psychiatric conditions and their lived expertise, as he snidely dismisses the expertise of clinical psychologists with scare quotes.

The voice of psychiatry can be heard throughout this report, explicitly through citations, and implicitly, through the hegemonic paradigm this report challenges. Non-human actors, such as the DSM and studies endorsing the medical model, speak on psychiatry's behalf. There is certainly a vocal minority of psychiatrists who might have participated in this report, but their absence does not undermine the report's legitimacy. We need to acknowledge mechanisms for challenging the dominant paradigm even if the powers under assault refuse to participate in this critique.

The *Understanding Psychosis* report also quotes the language of The Icarus Project to illustrate alternative frames used by people use to describe their altered states. "Self-help

organization *The Icarus Project* views both ‘psychotic’ and ‘bipolar’ experiences as ‘a dangerous gift’ and aims to help its members ‘navigate the space between brilliance and madness’” (p. 53). The authors of the report did not directly consult with members of The Icarus Project, but The Icarus Project was elevated to a stakeholder by virtue of its inclusion. The ensuing discourse surrounding the report’s publication reveals the position of the psychiatric establishment. The credibility of the British Psychological Association proved difficult to ignore, and mainstream US psychiatrists were compelled to listen to them, even if, on the whole, their response was demeaning and dismissive. This is more than can be said about the voices people without professional credentials but who possess an informal expertise that derives from self-study and lived experience. Their critiques are rarely heard or responded to, and demanding this recognition needs to become a central platform of the c/s/x movement.

It is intriguing that both the designer asylum project and the *Understanding Psychosis* report came out of the UK, begging the question of cross cultural comparison. The UK has a strong history of Critical Psychiatry, which resembles the APA’s radical caucus, but has greater traction and a larger membership. Perhaps underlying the strength of the Critical Psychiatry network and the greater popularity of these ideas is the UK’s universal health care. Much of the conversation around US mental health policy is caught up in the question of access to services, whether or not those services are beneficial or harmful. In the UK, and other countries with socialized medicine (e.g., Finland, where the OpenDialogue method was pioneered), where access to services is assured, the conversations around mental health policy can focus on the *nature* of services.

### 6.3.3 Advancing Innovative Neurotechnologies

On March 7, 2015 I attended a lecture given by Mark Solms entitled “Neuropsychoanalysis: Dangers and Opportunities” at NYU’s School of Medicine. Over one hundred people attended the lecture, and the lecture hall was literally standing room only. Solms is part of an emerging movement to incorporate psychoanalysis into the study of neuroscience, and his talk was aimed at a general audience and was not focused specifically on pathologies. Solms spent a long time in his presentation discussing theories of mind, and regularly attends conferences on consciousness alongside neuroscientists and analytic philosophers of mind (notably, he mentioned that clinicians, psychiatrists, and psychologists are typically absent from those conferences). He describes himself as a “dual-aspect monist”, explaining his commitment to avoiding mind-body dualism, while maintaining that the language of feelings cannot be simply reduced or translated to the language of neurons, and that both discourses remain valuable and meaningful. His research program aims to advance the psychoanalytic program, with the generous incorporation of neuroscientific findings where helpful, alongside the infusion of neuroscience with psychoanalytic knowledge.

Solms connects Freud’s theories of mind to neurological research, but maintains that the two discourses inform one other, and can’t be simply translated or reduced. He views neuropsychoanalysis as completing Freud’s program, revising and correcting it based on new evidence. The neuropsychoanalysts interpret neuroscience findings as a confirmation of Freud’s central ideas, including unconscious motivation, repression, the pleasure principle, and the id/ego/superego. Solms has argued that the brain’s “seeking

system” may be the basis for Freud’s libido drive, and has used cognitive neuroscience findings on aphasia to interpret narcissistic tendencies (Solms, M., & Turnbull, O. 2002).

Solms is perhaps most famous for engaging in a decade-long debate with Allan Hobson, professor of psychiatry at Harvard Medical School, over the relevance of Freud to neuroscience and especially over the significance of dreams. A detailed summary of the details of their debate is not relevant to this dissertation, but I include a sketch of their debate to provide some texture. Hobson’s research on the neurological mechanisms of dreaming aims to show that dreams are effectively random, and that emotional interpretations of dreams are misguided. Dream interpretation is one of the foundational methods of Freudian analysis, and rendering dreams meaningless is an assault on psychoanalysis itself. Solms deliberately designed a research program with the aim of salvaging dreams, and through a series of clever experiments with brain-lesion patients, demonstrated that dreams are in fact generated by a network of structures in the brain associated with instinctual-motivational circuitry. Solms helped render Freud’s wish-fulfillment theory of dreams respectable again, and in April 2006 Solms and Hobson met for the first time for a formal “Dream Debate” in Tuscon, Arizona at a conference entitled ‘Toward a Science of Consciousness’. The debate was the culmination of a series of standoffs in journal articles, books, and a pair of articles in *Scientific American*. Other researchers have challenged the pairs’ methods and conclusions, and have argued that Hobson and Solms have used their evidence around dreaming to advance their respective beliefs about Freud. (Dumhoff, 2005)

As we saw earlier in Chapter 4, and as Brad Lewis argues in “Where is US Psychiatry Going? From the Biomedical Model to Neuropsychiatry” psychiatry is poised to embrace

neuroscience along with information processing models of cognition and pathology (in press). In the wake of the publication of the DSM-5, the National Institute of Mental Health announced that it would be “re-orienting its research away from the DSM-5” and will be “collecting the genetic, imaging, physiologic, and cognitive data to see how all the data – not just the symptoms – cluster and how these clusters relate to treatment response.” (Insel, 2013) The Obama administration’s BRAIN (Brain Research through Advancing Innovative Neurotechnologies) initiative alongside the European Union’s Human Brain Project are both modeled on the Human Genome Project and seek to map every neuron and brain circuit in the human brain. As with the genome, there is some recognition of the uniqueness and diversity of individual brains, but there are also assumptions being made about uniform features across individuals and demographics. The theory of “neuroplasticity”, the idea that brain structures continue to change as we learn, has gained acceptance among neuroscientists, challenging even further our ability to make generalizations about an individual’s brain. The BRAIN initiative’s website describes the project as follows:

By accelerating the development and application of innovative technologies, researchers will be able to produce a revolutionary new dynamic picture of the brain that, for the first time, shows how individual cells and complex neural circuits interact in both time and space. Long desired by researchers seeking new ways to treat, cure, and even prevent brain disorders, this picture will fill major gaps in our current knowledge and provide unprecedented opportunities for exploring exactly how the brain enables the human body to record, process, utilize, store, and retrieve vast quantities of information, all at the speed of thought. (The Brain Initiative, n.d.)

These efforts and advances threaten to displace the biochemical paradigm that currently dominates psychiatric models. There is an air of inevitability around the

encroachment of neuroscience and brain imaging into our understanding of brains and behaviors. In this context, Solms and the larger neuropsychoanalytic movement represent a leading hope for the incorporation of subjectivity, feelings and meaning into the psychiatric discourse. Yet, neuropsychoanalysis remains a fringe discipline, largely ignored by mainstream neuroscience.

How will the c/s/x movement respond to these new realities and constructs? In a narrow sense, the encroachment of neuroscience on the biochemical model is consistent with decades of critique by those critical of psychiatry, and might be celebrated. But the questions remain: Is the emerging paradigm an improvement? Does it reinforce existing power dynamics?

Undoubtedly, the movement's criticism of psychiatry is becoming stale as the underlying context shifts. However, many of the essential critiques we have distilled remain as relevant as ever. To begin with, Solms and the larger field of neuropsychoanalysis neglect a socio-cultural analysis in their models of pathology. Neuropsychoanalysts continue to locate all pathology within the heads of their patients, and do not broaden their analysis to include interpersonal relations such as oppression, injustice and intergenerational trauma. Beyond this omission, a deeper critique of their approach centers on questions of authority and knowledge production. Although neuropsychoanalysis sounds more encompassing analytically, the scientist and/or psychotherapist make the important, defining judgments. The analysand may provide feedback to their analyst, but does not participate in the creation of the rubrics and models that shape their diagnosis and treatment. If this participation were an essential component of the treatment, at least there would be an opportunity and a mechanism to address the prior omissions of the

socio-cultural factors. Such an approach would introduce many demands on the analyst, and require a flexibility that few schools of analysis exhibit. There are certainly gifted and caring analysts who adopt a more inclusive approach by virtue of their personality and values, treating each and every one of their patients as unique individuals. However, there is also overwhelming pressure to treat patients using assembly-line protocols, aimed to maximize efficiency and treat as many patients as quickly as possible, leaving little room for variation and context.

Speculating on the impact of the neuropsychoanalytic frame is not simply a polemical exercise since psychiatric paradigms are shifting. The language and values that the Icarus Project has developed are still widely applicable to these emerging contexts, although clearer articulations of their beliefs and demands are important to distill. Overly simplistic rejections of the “biomedical model” risk exposing the group to charges of “anti-science”, and being lumped in the same camp as the anti-vaccine movement or climate-change deniers. The richness of the language that the Icarus Project has developed expresses much more than the rejection of the biomedical model, and their critique may very well endure well beyond the lifespan of the biomedical model itself. By returning to the foundational assertion of self-determination, informed consent, and their right to participate in the co-construction of the knowledge of their own diagnosis and treatment the problems with neuropsychoanalysis are readily apparent.

Many of the same issues The Icarus Project confronts under the existing psychiatric regime will continue to exist under whatever paradigm succeeds next. Informed consent, requiring access to accurate information, is becoming increasingly difficult to obtain in the face of a sea of information and misinformation. Pharma’s marketing campaigns

continue to grow in sophistication. When it comes to consent, technologies of surveillance continue advance coercive techniques through the enforcement of drug adherence and behavioral monitoring. Congress is poised to pass federal legislation extending involuntary outpatient treatment programs, modeled on New York State's Kendra's Law (1999) and California's Laura's Law (2002). Beyond the clear-cut cases of state mandated compliance, prisoners, seniors in nursing homes, and children are all constituents whose agency is limited and whose consent is questionable. And, as cultural pressure mounts to correct deviant behavior and perform according to prescribed standards, it is becoming more difficult to opt-out of treatment. Consent has become elusive, well beyond the obvious violations of state mandated forced treatment.

## 6.4 Mad Futures

Recognition at the tables of power is only a precondition for the kinds of changes in treatment, attitude and policy that the movement would like to see emerge. What might the regime of mental health look like if the activists prevailed? What would victory look like and what issues might displace the current priorities? What are the stakes of these showdowns and how do they intersect with broader trends in advocacy for social justice, freedom and equality?

The BPA's report on *Understanding Psychosis* does an excellent job painting a picture of what a treatment paradigm would look like if it incorporated a deep respect for the expertise of lived experience. This perspective is characterized by loving and compassionate support instead of punitive punishment, collaboration over patronization, and

self-determination and informed consent over bullying and coercion. It is also clear that time and again stories of interpersonal and intergenerational trauma dominate the personal narratives of people struggling with their mental health and these histories need to be appreciated and acknowledged, not minimized and neglected. While various schools of psychoanalysis and forms of therapy try to deal with interpersonal and intergenerational trauma, these frames of treatment have been almost entirely displaced by dispensing pills. Tanya Luhrmann's ethnography of American psychiatry, *Of Two Minds*, identified the twin poles of the biomedical model and the psychodynamic model that dominated psychiatric training and clinical practice in the 1990s. This tension is almost unrecognizable today, as the biomedical model has come to completely dominate psychiatric practice in America (Martin, 2007).

The problems with psychiatry do not begin and end with bedside manner, but a culture of arrogance and bullying exacerbates the doctor/patient relationship and undermines trust. People receiving treatment want to feel listened to. They want their experiences validated and they want to be treated like a person not a label. The language of their interactions should reflect these concerns and respect their agency, not assault them with a barrage of aggressions, micro- and macro-. Sayantani DasGupta's call in the *Lancet* for "narrative humility" traces the problems in doctor's attitudes to an educational curriculum that certifies cultural mastery at the completion of a weekend workshop (2008).

An Icarista's anecdote illustrates this dynamic: After ten years on a particular anti-depressant she wanted to try switching to another since they were dissatisfied with the drug she was taking. After a few weeks on the new drug she asked her doctor to help

wean her off the new drug and wanted to return to the original one she had been taking. She believed that the new drug was causing panic attacks and extreme anxiety, and she experienced less anxiety when she reduced her own dosage. Her psychiatrist stubbornly refused to acknowledge that the new medication might cause anxiety and would not write her a prescription for their original medication. The Icarista asked the psychiatrist if he had ever taken the drug (he had not), and was hurt that her experience was belittled and dismissed. She had not asked to come off of her medication entirely, merely explore alternative medical treatments, but nonetheless she was rendered effectively invisible and powerless. Providers need to listen better and work together with their patients to create an environment of mutual respect and trust, conducive to long-term healing.

C/s/x activists are also some of the most vocal advocates for examining the connections between systems of inequality and injustice and their correlations with mental illness. We live in a world where violent, self-destructive, and even suicidal policies are regarded as sane, and it's the captains of government and capital who ought to be restrained. War criminals, environment destroyers, and compulsive usurers walk free while those who speak truth to their power are often diagnosed and aggressively treated. Our consensual reality is crazy sick, and desperately needs an imagination infusion.

These broader issues of injustice are inextricably linked to mental health, as numerous studies have linked poverty, racism, discrimination to mental health. (Link & Phelan, 1995; Cohen & Timimi 2008; Metzl & Hansen 2014) This is unsurprising as mental illness is also strongly correlated to stress and trauma and these systems of oppression generate an excess of both. Marginalized populations like minorities, prisoners, children in foster care, and the poor are also more likely to receive certain diagnoses and treatments.

(Metzl, 2010; Levine, 2015) In these circumstances psychiatry become visible as an instrument for oppression and control, far exceeding its mandate to alleviate emotional suffering.

Popular social justice leaders rarely incorporate the pharm-psychiatric complex into their analysis of power, even though it is an important cog in wheel of the systems they critique. It's accurate to say that the school-to-prison pipeline is greased with psychiatric diagnoses and treatments, as a diagnosis of Oppositional Defiance Disorder (ODD) is often the first step on the road to juvenile detention. Through stigma and shame, the system also perpetuates feelings of isolation and alienation that, in turn, help reinforce the growth of a range of '-isms' (capitalism, consumerism, neoliberalism, etc).

Our current trajectory suggests dystopic futures, especially in light of the trend towards predictive diagnosis and treatment. As we saw in Chapter 2, prodromal diagnosis, also known as psychotic risk syndrome, threaten to expand psychiatry's reach exponentially. As Frances, the editor of the DSM-IV argued, the diagnoses of present conditions are already overly expansive. Diagnosing and treating people who are *at risk* for developing these conditions will expand the diagnostic net to threatening proportions. Preventative treatment and algorithmic diagnoses pose a grave threat to civil liberties, analogous to the criminal profiling, the notorious "stop-and-frisk" practices of the NYPD (New York Civil Liberties Union, 2014) and the "signature kills" of the Obama administrations drone program (Shane, 2015). The counterfactual logic of this paradigm is slippery and dangerous—if you manifest symptoms, you are psychotic; if you have not manifested them, yet, you are prodromal. The treatment of prodromal patients who

fail to develop symptoms is seen as a success, even though there is no reliable way to ascertain how they would have progressed without treatment.

The threat of prodromal diagnoses looms even larger under the emerging neurobiological-information processing paradigm than it did under the DSM paradigm. NIMH's move away from the DSM is motivated by the unreliability of the diagnostic categories, and endorses an evidence base built around symptoms, described by neuroimaging, neurobiology and genetics. The new paradigm doubles down on scientific objectivity, formulating pathologies in terms of symptoms with objective laboratory measures. Instead of seizing the opportunity to reformulate psychiatric knowledge through the assembly and composition of a wider range of stakeholders, psychiatry is on track to define mental wellness and illness exclusively in terms that can be measured in a laboratory. This materialist reduction completely disregards the socio-cultural context, as well as the experiential perspectives and expertise that are not represented by seemingly objective measurements. The value judgments that continue to underlie the acceptance of different ranges of human experience are masked by the appeal to measurable evidence.

This focus on measurable symptoms, many of which are correlated with crisis but alone are not enough for a diagnosis, is even more amenable to algorithmic monitoring and predictive profiling. A recent study currently underway in Australia illustrates this trend. The study, called "Facebook use in affective disorders" is a collaboration between researchers from the Monash Alfred Psychiatry Centre and computer scientists from the School of Intelligent Systems at RMIT University. (The FAD Study, 2014) A central question motivating the study is to find out if the onset of manic episodes can be predicted by changes in Facebook use. After encountering anecdotal accounts of

dramatic changes in Facebook usage around episodes, the researchers designed this study. They are not analyzing the contents of participants' postings. They are recording the date and time of user activity where activity is defined as a comment, a like, a post, an upload or a message. Participants also self-report their moods to researchers daily, and also indicate historical date ranges for previous manic episodes to establish baselines of activity. The results of this study have not yet been published, and the study does not recommend actionable interventions based on these findings.

During my field work with The Icarus Project I encountered many situations where social media was used to monitor and judge people's mental states. In some instances, social media played a wide a role in diagnoses and forced treatment. One friend of mine described how his mother had printed out his status updates and brought them to his doctor to argue he should be institutionalized. The conspiratorial status updates were unthreatening, but were out of character and were construed as bizarre. He was involuntarily committed, and his social media updates combined with his Mother's concern were surely a factor in his psychiatrist's judgment. Other stories I have heard were related to people expressing sadness and despair, scaring their friends and loved ones. In another specific instance a friend shared disappointing news on Facebook, and although she did not threaten herself, another friend called the suicide hotline after jumping to the conclusion she was suicidal. Instead of reaching out to support her directly, her friend intervened based on a status update. Unleashing predictive algorithms on these behavioral data sets threatens to expand the diagnostic gaze even wider and exposes many populations to widespread abuse through new forms of control.

## 6.5 #alternatives

The most important undertaking for the movement right now is the creation of positive alternatives. Without these alternatives, even well intentioned authorities have little recourse when faced with personal crisis. Establishing projects and programs that embody the values and priorities of the movement will help advance the agenda through demonstration and performative critique.

Numerous leaders in the mental health reform movement have called for a focus on the creation of these alternatives. One of the movement's most important peer-organized national conferences is simply called "Alternatives." This conference has run yearly since 1985 and explores support and treatment models beyond the mainstream. (Zinman, 2009) Alternatives is sponsored by the Substance Abuse and Mental Health Services Administration (SAMHSA), a federal agency founded in 1992 to advance the behavioral health of the nation.

The Icarus Project, a long time participant in the Alternatives conference, represents an attempt to seed these kinds of alternatives, and their membership and media continue to play a central role in fertilizing other organizations and initiatives. New therapeutic paradigms such as the Open Dialogue Approach, a crisis intervention technique pioneered in Finland, show great promise for transforming these interventions, as well as ongoing therapy (Olson, Seikkula, & Ziedonis, 2014). The Open Dialogue approach is a holistic technique that locates pathology in the network of social relationships, rather than any one person's head. The therapeutic technique has its roots in schools of family therapy and multidisciplinary crisis intervention teams and invites the person's social network

into dialog seeking to create psychological meaning out of symptoms and experiences. Open Dialogue emphasizes flexibility and focuses on promoting dialog. In contrast to many forms of family therapy it encourages “being with” rather than “doing to” and for therapists to “actively listen” rather than interview. The outcomes reported in Finland are extremely positive and the ideas have been spreading quickly in the US and beyond. (Intervoice, 2013)

New approaches for avoiding hospitalization are also emerging and gaining some tenuous traction. In 2012, SAMHSA funded an innovative project in New York City designed to help reduce incidents of forced hospitalization. The Parachute project runs a series of respite houses that provide services for people in crisis. Prospective guests can apply for up to 14 days of free accommodations once a mental health professional provides a letter that they are not a threat to themselves or others. With locations in four out of five of New York City boroughs, the Parachute facilities are run by peers, practice harm reduction approaches to substance abuse, do not forcibly medicate, restrain or seclude, and residents can come and go as they please. Parachute also supports a support line and a mobile intervention team that arrives at the site of a crisis and is trained to diffuse it using an open dialogue approach. During its initial three year pilot, Parachute’s outreach was limited, targeting social workers and mental health advocacy groups. The project publishes brochures, runs a website, and manages a 24-hour support line, and awareness of the program mostly travels through word of mouth. The three year pilot has just received approval to begin accepting Medicaid, which will allow it to continue operating beyond the period of its seed grant. It is unclear if the respite model can scale beyond a few dozen beds, but early indicators suggest that the program has been very

successful at helping the participants who have been lucky enough to be aware of it avoid hospitalization, at a greatly reduced cost.

SAMHSA has faced harsh criticism for creating inclusive spaces for dialogue and for their sponsorship of peer-run community programs and patient advocacy groups. In the wake of the Sandy Hook shootings in 2013, SAMHSA came under attack and was called to testify at a series of hearings before the House Oversight and Investigations subcommittee of the Energy and Commerce Committee to justify their funding priorities. (Earley, 2013; Examining SAMHSA's role in delivering services to the severely mentally ill, 2013) The chairman of the committee, Congressman Tim Murphy (R, PA), is also a clinical psychologist who also serves in the Naval reserves and works with service members suffering from PTSD. In his opening statements at the May 22, 2013 hearing, Murphy remarked: "the committee has seen substantial evidence that too many of these grants are directed to advancing services rooted in unproven social theory and feel-good fads, rather than science... we expect SAMHSA's work to be firmly rooted in evidence-based practices, enduring high-level scientific peer review at the hands of licensed mental health professionals." (Examining SAMHSA's role in delivering services to the severely mentally ill, 2013) He critiqued the organization for sponsoring the Alternatives conference by referencing a mind/body fitness session with questionable scientific merit, and for providing grant funding to groups that are hostile to the sciences of psychiatry and psychology, question diagnostic labels, and provide advice about coming off of psychiatric medication. During the hearing SAMHSA was challenged for having only four full-time psychiatrists on their staff of 534, and for lacking a policy mandating that their grant reviewers were lacking scientific credentials versus "just experience".

SAMHSA would likely benefit from more clinical and research psychiatrists on staff, to increase their credibility as well as integrate more perspectives from across the divide. This current breakdown serves to reinforce the divisions between different constituencies of mental health professionals.

Neither the congressional subcommittee or SAMHSA explicitly discussed what kinds of evidence would constitute support for continued funding of alternative approaches, although divergent assumptions about what constitutes valid evidence was an implicit tension underlying this hearing. This tension extended beyond alternative approaches to healing, and encompassed the very methods for evaluating these approaches, and the means for resolving conflicts when people disagreed on their effectiveness. Murphy's perspective assumes medical experts collecting quantifiable variables is the best way to objectively measure efficacy. Other committee members, and some of SAMHSA's constituents believe that efficacy cannot be objectively measured, and that the qualitative stories of people receiving these interventions need to be considered alongside quantitative methods. This divide is visible in many other areas of policy and research, and it is important to recognize this standoff as an instance of a wider disagreement over what evidence counts, not just a disagreement over how to best support the mentally ill.

The SAMHSA administrator Pamela Hyde responded defensively to the committee's allegations. She explained that SAMHSA awards grants to projects, not organizations, and the projects funded aligned with SAMHSA's mission even if the grantee's overall mission did not. She claimed SAMHSA did not review each session at the conference and was unaware of their contents. She also pointed out that psychiatrists command higher salaries than SAMHSA can afford, and that the kinds of services SAMHSA sponsors are

within the expertise of social workers. Instead of overtly defending the support and inclusion of alternative voices and treatment initiatives, Hyde's responses were timid and evasive. She relied on Congresswoman Diana DeGetten's (D, CO) questions to remind the committee that SAMHSA was mandated by congress to support patient advocacy groups, and that congress set SAMHSA's priorities and mandated the percentage of their budget to apply to substance abuse versus serious mental illness. Hyde avoided taking a strong stand for SAMHSA's inclusive policies, perhaps in reaction to the committee's hostility, as they seemed intent on challenging her agency's mandate.

This hearing clearly demonstrates the stakes of credibility. The legitimacy of lived experience is repeatedly questioned, denying the very possibility for gathering evidence to support voices from outside mainstream psychiatry. In her opening statement, ranking Congresswoman DeGetten remarked on a glaring omission in the hearing's testimony:

Now, I just want to raise one concern about these hearings. This is the third proceeding on mental health, and for the third time we don't have a witness appearing to provide the perspective of people who are living with mental illness. We discussed this the other day. We keep talking about issues that affect their daily lives. We keep having providers and family members and others coming in to talk about people with mental illness but we haven't had people who have mental illness directly talk to us, and I think there are people who would be willing to come forward and talk about their concerns and their issues, which of these SAMHSA programs work for them, which of them don't work for them. What about the privacy provisions and what about the everything, the funding and everything? So I am hoping in our next hearing we could have a panel of people who have mental illness to talk about from their perspective what works and doesn't work. (2013)

To the best of my knowledge, witnesses living with mental illness were never called to testify.

The outcome of these hearings was the drafting of the Helping Families In Mental Health Crisis Act, also known as the Murphy bill. H.R.3717 was introduced in December 2013, but was never enacted. Murphy plans to reintroduce the bill in 2015. The bill includes provisions to gut SAMHSA's funding and power by redirecting funds to the NIMH and through the creation of a new office in the Department of Health and Human Services. The bill also legalizes "assisted outpatient treatment" (AOT), which is a euphemism for forced treatment in outpatient settings. The AOT measures helped mobilize many patient and civil rights advocacy groups to speak out against the bill.

At its heart, the bill was crafted under the erroneous assumption that mental illness causes violence. Studies have repeatedly shown that the occurrence of violence amongst the mentally ill matches the rates of violence in the general population, and that the mentally ill are more likely to be the victims of crimes than the perpetrators (Metzl, & MacLeish, 2015). Increased mental illness screenings and forced preventative care will not lead to a reduction in violent crimes. What the investigations behind this bill also betray is the central contention of this dissertation—mental health activists need to demand a legitimate voice in their support and treatment. Their voices are systematically marginalized and dismissed despite the practical value of their techniques and approaches.

Many of the ideas and proposals have been articulated and piloted. What remains is their adoption. Alternative voices with relevant expertise have been speaking up for decades. We just need to start listening to them.

## 6.6 Conclusion

In 1998 the American Legacy Foundation (ALF) was established as a part of the settlement agreement between the states and the tobacco industry. ALF is the largest non-profit public health organization in the US and is dedicated to tobacco control. The organization funds campaigns and educational initiatives to help reduce smoking and counters the marketing engine of the tobacco industry. The tobacco industry betrayed everyone's trust with decades of toxic cover ups and lies, and this record-setting, landmark settlement included the establishment of an independent non-profit that would counter their marketing and advertising through education and outreach. In effect, ALF speaks for the smokers and their families, and has launched incredibly successful campaigns, such as Truth.org, around awareness and cessation.

The mad movement would benefit greatly from a similar organization, and the parallels between Big Tobacco and Big Pharma are striking. The pharmaceutical industry has betrayed the Hippocratic oath to do no harm, and has also perpetrated decades of toxic cover ups and lies. The scandals and lawsuits around anti-psychotics and anti-depressants may yield settlements that rivals the settlement with the tobacco industry, and when that day arrives the movement should be ready with an implementation plan for the kinds of campaigns and educational programming it would sponsor. There is a desperate need for education and marketing around psychiatric diagnosis and treatment that is not sponsored by the pharmaceutical companies, according to alternative frames and narratives.

The central problematic we grappled with in this dissertation is how mad folk can assert their voices when their own identity renders them irrational, categorically excluded from all discourse. At the heart of these issues, it remains peculiar and unjust that a very small group of mostly white, middle-aged men with degrees in medicine (Lewis, 2006) are deciding the criteria for a normal range of human experience. We witnessed the systemic marginalizing and silencing of people with lived psychiatric experience among some of the most progressive groups of professionals at Occupy Wall Street and the APA's radical caucus. Without question, the attention and respect paid to the non-credentialed only gets worse outside these circles.

We also explored the history and culture of the Icarus Project, synthesizing an answer to the question—what did they just say? After a dozen years of organizing, the membership of The Icarus Project said many things, some directly, some implied. One powerful theme that emerges from their advocacy is simple, yet immensely powerful. The organizing principle most visible in this examination is the repeated assertion of the demand – “Nothing about us, without us”. This finding is at once, both subtle and stark. While this principle may seem innocuous, a deep realization of this goal would go a long way towards correcting some of the most egregious over-extensions of psychiatric oppression and control.

Seats at the tables of power are only the precondition for change. Good ideas need to be proposed, heard and acted on. Throughout this project we also heard, loud and clear, the values and principles that mad folks prioritize and the kinds of language and treatments they prefer. Language and labels matter. Stories and identities matter. Cultural competency matters. Basic humility and sensitivity matter. Force and coercion

are blatantly unjust, but in many encounters with psychiatry trust is violated long before these lines are crossed. Patronizing attitudes, self-assured certainty and unchecked arrogance run rampant in clinical settings, percolating through the system and running through research agendas and advertising campaigns alike.

These attitudes run deep in our epistemic culture, and cut to the heart many practical standoffs around what's knowable and how we go about knowing. Congressman Murphy's insistence on "evidence-based" research is code for a certain kind of research—namely quantitative data, backed by objective scientific methods. Ethnographies are struggling for recognition and validity across a range of disciplines, including psychology, public policy and political science, and represent one way that the voices can be represented, albeit through the medium of a researcher. These fields continue to be dominated by quantitative methods, which may provide important knowledge, but must be tempered and balanced with qualitative methods for a fuller comprehension of any social phenomena. A strong embrace of "Nothing about us, without us" includes adjustments to our current standards of knowledge production. Ethnographies of psychiatry such as Luhrmann's *Of Two Minds* (2001) and patient experience such as Martin's *Bipolar Expeditions: Mania and Depression in American Culture* are two examples of anthropological contributions to the field. The designer asylum art project represents yet another model of direct participation in the creation of solutions and meaning. The burgeoning "quantified self" movement may represent yet another avenue for developing a deeper understanding of what helps, liberating quantification from the exclusive hands of the experts, with interesting implications. Similar to journaling, but with the potential to collect and correlate many more data streams, some individuals are taking

the responsibility to systematically catalog patterns in nutrition, sleep, exercise, stress and medication interactions. I have heard presentations where some patients report curing their own Irritable Bowel Syndrome, managing their blood sugar, and using these techniques as an instrument to promote behavioral change. There are numerous mood tracking applications that may soon be brought to bear on some of these questions of efficacy, incorporating both quantitative and qualitative data, from the perspective of the individual stakeholder. At some point, even the FDA may be forced to consider these data sources alongside formal research studies.

Many viable alternatives to mainstream approaches are being floated and piloted across the country. These alternatives need to be studied using a variety of methods, and nurtured and successful experiments need to be given the resources to scale and flourish.

Evaluating the efficacy of these alternatives is a challenge, and a range of methods and stakeholders need to be incorporated to make sense of what works for whom. As with other areas of alternative medicine, such as acupuncture, chiropractice, herbalism there is no single solution that works for everyone, yet many of these approaches work very well for some people. It is very difficult to develop an accurate picture of what helps, especially when the approaches defy prevailing paradigms, and do not support existing profit models. Combatting these biases will require open minds and a dedicated effort to listen to people who are suffering—patients, their families, c/s/x activists, and the full range of service providers they encounter. Synthesizing these perspectives is a formidable challenge that multiple choice surveys and economic indicators cannot capture alone. Whether someone prefers to treat their psychosis or to cultivate approaches for controlling

their dangerous gifts, they need to be given the respect they deserve, as human beings and as fully empowered partners in their own treatment and care.

In the coming decade, the mad movement will face serious threats as it pursues the elusive dream of liberation. The movement's context is shifting dramatically, and their messages will need to be retargeted and refreshed. By staking their claim on their right to speak and be heard, they will create the platform to surface and shape their concerns. Escaping from the prison of tautological silencing is imperative for all future campaigns. Framing the struggle in terms of the meta-issue of participation and empowerment enables coalitions of activists to stand in solidarity with their mad comrades. Remember, whatever happens next, you are not alone.



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# Colophon

Thanks for making it all the way to the end ;-)

*Almost done!*

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mad love,  
Jonah Bossewitch

