

**Dangerous Gifts:
Alternative mental health politics and a new wave of psychiatric resistance
A Dissertation Proposal**

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Synopsis: *This project proposes to examine significant shifts in the politics of psychiatric resistance and mental health advocacy movements that have emerged in the past decade. In particular, it will contrast the politics of earlier generations of the consumer/survivor/ex-patient movements with those expressed by a new wave of activists. This new wave of activists has emerged against the backdrop of an increasingly expansive diagnostic/treatment paradigm, and within the context of a worldview whose genealogy can be traced through the veins of social movements that have emerged over*

the past few decades. This project will closely study a particular radical mental health advocacy organization, The Icarus Project, as well as a series of scenes, from Occupy Wall Street to DSM-5 protests at the American Psychiatric Association conference, that serve to highlight this transformation through encounters between actors that bring this shift into focus. This new wave of resistance also emerged amidst a revolution in communication technologies, and this project will consider how activists are utilizing new generation of communications tools, and the ways in which their politics of resistance resonate deeply with the communicative modalities and cultural practices emerging across the web. Finally, this project will conclude with an analysis of the current state of psychiatry and probable trajectories, as well as provide recommendations for reconciliation and remediation between the establishment and their critics.

I. WHAT IS THE PROJECT?

Introduction

In the first decade of the 21st century mental health activists reinvented psychiatric resistance with a politics that deeply resonated with participatory culture and the affordances of a new generation of communications technologies. This new wave of resistance to the psychiatric establishment and the pharmaceutical industry emerged against the backdrop of unprecedented expansion in psychiatric diagnosis and treatment, and at the intersection of networked identities and authentic virtual communities. Organizations such as The Icarus Project and The Freedom Center developed hybrid models of peer-support and direct action that were accelerated and amplified by new communicative possibilities. These groups 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 of mental health policy is nothing new. Activists have struggled for decades (Crossley, 2006), if not centuries (Foucault, 1988; Whitaker, 2003), to resist the production of mental illness as a disciplinary mechanism of hierarchical societies. In the past few decades, theoretical work in fields such as the philosophies of science and mind, science and technology studies, and cultural studies have posed powerful critiques of science and society, which can be forcefully leveled against prevailing psychiatric practices and paradigms. Cultural theorists such as Brad Lewis and Jonathan Metzl have exposed the entrenched ideological and commercial interests who aggressively promote the hegemonic narratives that flatten minds into brains and reduce feelings to chemical reactions (Lewis, 2006; Metzl, 2010). A new wave of psychiatric resistance, sometimes self-identified as the “mad pride” movement, advances 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 new wave of critique has less to do with any particular dogmatic position around hospitalization, medication, or labels, and is rooted in challenging authority and

knowledge production (DuBrul, 2012). The disability rights movement's radical epistemology, captured in their mantra "Nothing about us without us", succinctly represents this transformative shift (Charlton, 1998). Instead of formulating resistance around human rights discourses while fighting forced drugging and electroshock therapy, these groups embrace liberation politics and stage direct actions that attempt to reinvent 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 transformational shift that characterizes this emerging wave of resistance can be construed as a shift from advocating for a particular ontology, to advocating for a new epistemology. Instead of 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 in the 1970s have argued (and still continue to argue) that there is no such thing as mental illness, while the newly emerging wave of psychiatric resistance can be understood as being more concerned with insuring that all of the relevant stakeholders have seats at the table 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 co-creation of their stories, as the content of their message may vary from subject to subject. Crucially, their insistence on co-constructing their own identities and narratives underlies their platforms, critiques, and actions.

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). 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. While ACT UP demanded more attention from the Pharmaceutical industry, in contrast to mental health activists, who in many cases are demanding less attention, there are interesting parallels in their rhetoric and the underlying structure of their demands.

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." James Carey articulates a strategy that closely mirrors Plato's in preparation for his analysis of the effects of the telegraph. "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.

Creatively Maladjusted

In this project I will not attempt to reproduce the rich scholarship detailing the forms of psychiatric resistance that were prevalent in the second half of the 20th century (Morrison, 2005; Crossley, 2006). Rather, I will summarize the salient characteristics of these historical movements and contrast them with emerging forms of protest imagined and enacted by a new wave of psychiatric resistance born into our networked society. In particular, I will closely 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. 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, permaculture, harm-reduction and queer pride—has informed their adoption of media and communication tools, and given rise to new forms of collective action.

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 (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 Michel Foucault (1988) and Erving Goffman (1961) 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.

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)

Risssmiller and Risssmiller's article generated a flurry of controversy, as the activists they purported to speak for took issue with the article's characterizations and misrepresentations (Oaks, 2006b). In particular, the psychiatric survivors did not appreciate being labeled with the marginalizing 'anti-psychiatry' moniker, and they refuted the overarching narrative of their movement's collapse in the face of psychiatry's so-called reforms. Risssmiller and Risssmiller illustrate a model of the kind of moderate, policy-oriented, mainstream activism that psychiatry was willing to engage:

By avoiding the antipsychiatry movement flaw of being radicalized without being politicized, radical consumerists continued to maintain informal ties with more conservative consumerist organizations such as the National Alliance for the Mentally Ill in the United States and the Mental Health Foundation in England. Mainstream consumerist groups benefited from such unofficial relationships through increased impact in grassroots lobbying and legislative advocacy efforts. (2006:865)

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 expansively introduced new therapeutic compounds (Barber, 2008; Whitaker, 2010), and marketed them directly to doctors and consumers at an unprecedented scale (Lane, 2008). Critics of the industry maintained that Big Pharma's business strategy was best understood as the production 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 traditional forms of protests such as civil disobedience, strategic litigation, and generating coverage in the mainstream media ([PsychRights, call for strategy]). 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).

These forms of scholarship and activism have achieved some notable successes. For example, in 2003 psychiatric-survivors staged a hunger strike, which forced the APA to admit that it could not produce any scientific evidence that mental illness was caused by a neurochemical imbalance (APA, 2003).

Morrison also explains how the c/s/x activists have begun leveraging the Internet to improve their efficiency:

Consumer/survivor/ex-patient activists amplify the personal aspects of resistant identity and talking back by taking their claims and grievances into the larger public arena. The campaigns and ongoing strategies focus on central movement

issues of voice and representation, exposing and challenging expert psychiatric knowledge and practice, promoting and developing alternatives to traditional treatment, and prevention of human rights abuses such as forced treatment.

Keeping abreast of these issues requires constant vigilance and monitoring of information sources. This activity is greatly enhanced by the use of the Internet. Newspapers, medical journals, websites, etc are monitored every day. Many people are involved in these activities with a few central nodes of information flow, supported by dozens of group and individual websites. There is also active participation in topical listservs, members of which can be galvanized into action when needed. (p. 134)

Although Morrison asserts that these media campaigns are effective and consequential, they can also be regarded as quixotic. The explosive growth of psychiatric diagnoses and treatments indicates that Pharma has effectively outflanked and appropriated these frontal assaults through aggressive marketing, direct contributions to patient advocacy groups, and astroturfing campaigns, as we will see in our case study in chapter one. Sophisticated advertising tools such as product placement, Google AdWords, and Facebook campaigns are bolstered by nearly omniscient surveillance, and have enabled entrenched power to become even more entrenched (Andrejevic, 2007). Although optimistic pundits like Clay Shirky are hopeful that the web will level the playing field between the oppressed and the oppressors (2008), Pharma seems to be mastering and leveraging these new approaches to a greater effect than the response of traditional activists. Overall, the tactics of 20th century mental health activists mirror the centralized hierarchical forces they are struggling against. They both ultimately rely on mainstream broadcast media to promote their message, and they have not yet fully embraced the insurgent potential that participatory theory, culture, and technology collectively suggest.

Chapter 1: Psychiatry's Expanding Diagnostic Nets

In the years preceding the emergence of the mad pride movement, the psychiatric establishment and the pharmaceutical industry were not idle. During this period, the rates of psychiatric diagnoses and treatments rose explosively, and psychiatric drugs became multi-billion-dollar blockbusters and household names.

The recent publication of the DSM-5 has generated extensive criticism from a wide range of critics, including the chairperson of the DSM-IV task force, Allen Frances. In his book, *Saving Normal*, Frances condemns Psychiatry's direction, especially the predatory and expansive diagnostic definition (2013). He largely attributes this direction to profit-driven pressure from the pharmaceutical corporations, and provides a rich account of where he thinks DSM-IV went wrong, and how the DSM-5 task force failed to learn from their mistakes.

One important area of controversy in the years leading up to the publication of DSM-5 is the controversy around the diagnosis and treatment of behavioral issues in children. In this chapter I will spotlight the rise of the pediatric bipolar diagnosis, a case

study that exemplifies the ways in which psychiatric judgment has generated controversy among mental health professionals, journalists, and activists alike.

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?

This case study intends 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. Other areas of diagnostic expansion, such as grief, shyness, anxiety, personality disorders, adult bipolar, psychotic risk, and other lifestyle disorders, all vary in the particulars of their expansion, but they 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.

I plan to adapt my paper “Pediatric Bipolar and the Media of Madness” (http://alchemicalmusings.org/files/essays/mediaofmadness/jbossewitch_mediaofmadness_drugsasmedia_chap7_final.pdf) for this chapter.

Chapter 2: You are not alone: Mad Pride and Narrative Advocacy

I introduce The Icarus Project as representative of the emerging trends that characterize what I calling a new wave in psychiatric resistance. It is actually quite difficult to pinpoint a moment or an individual that typifies this shift, as this social movement, like most others, is composed of complex, dynamic, and overlapping networks of actors. The Icarus Project has many antecedents, and is not sharply distinct from other organizations within the alt-mental-health movement. Nonetheless, the message and vision articulated in their publications marks a stark contrast with many of the organizations that came before them. Their influence has already spread across many other mental health organizations, making it difficult to isolate, but a rich description of their philosophy and culture will propel the analysis that follows in Chapter 4.

In 2002 The Icarus Project formed, and ushered in a new wave of psychiatric resistance. In this chapter I will describe the formation and principles of the project, drawing on the website, print publications, the interactive forums, and the documentary film *Crooked Beauty* as lenses for understanding the project’s ideologies, politics, and visions.

I plan to adapt my paper “Narrative Advocacy: Mad Justice and Languages of Compassion” (<http://pocketknowledge.tc.columbia.edu/home.php/viewfile/93485>) for this chapter.

Chapter 3: Who speaks? Who listens? – Patient empowerment from Disability Rights to ACT UP

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, or ACT UP. 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 in the group began conducting scientific research, drafting policies and protocols, and ultimately became leading experts on their own condition. While ACT UP demanded more attention from the Pharmaceutical industry, and mental health activists are demanding less, there are interesting similarities in their rhetoric and the underlying structure of their demands.

ACT UP is certainly not the only social movement to express the epistemic shift I argue for in this dissertation. However, they emerged at a pivotal time in the history of the current generation of social movements, immediately preceding the explosion of the Internet, and densely connected to many important underground subcultures and movements active in the late eighties and nineties. As the torch-bearers of the larger civil rights movement of the 20th century, they helped transmit many of the values of earlier movements to a new generation of activists, modeling and exemplifying the forms that activism could carry into the future.

As with many other chapters of this dissertation, I will need to conduct more research on the history of ACTUP, including more thorough research into existing dissertations on the movement, reviews of their archives at the New York Public Library, and a study of their oral history project.

Chapter 4: Sites of differentiation:

In the following chapters I will closely examine a series of discursive sites that highlight the emerging rhetoric of patient empowerment.

Chapter 4a: Mindful Occupation: Liberty Park Madness

When Occupy Wall Street first erupted in Zuccotti Park, mental health activists began discussing “occupying mental health”, although nobody knew exactly what that would look like. They felt had important knowledge and skills to contribute to the movement, including talking to people about the ways that psychiatry and big pharmaceutical companies contribute to social and economic injustice, to emphasize how important it is take care of the basics and each other in order avoid burnout, and how these themes are related through the language we use to describe each other’s behavior. Would Occupiers alienate and pathologize each other through languages of oppression, or 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 outside the norm. Reports began to surface of protesters being forcibly hospitalized and medicated, and people were desperate for materials that offered alternative perspectives towards handling emotional trauma and navigating crises. Even amongst the most progressive circles of activists, few were equipped with the tools

for dealing with these crises beyond the mainstream DSM — the Diagnostic 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.

In Fall 2011 I conducted months of field-work around mental health issues and Occupy. I participated in the assembly and publication of a collaborative guide for activists, “Mindful Occupation: Rising up without Burning Out”. 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 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.

I also participated in some of the New York City working groups that organized themselves to help maintain the health and well-being of the protesters. The so-called “Safety Cluster” included people committed to mediation, non-violent communication, security and deescalation, as well as people committed to anti-oppression and reducing sexual harassment (the Safer Spaces working group). Additionally, there was a working group calling itself ‘Support’ that had been 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.

Many heated debates emerged around our work on *Mindful Occupation*, as well as my direct participation in the local NYC ‘Support’ working group. It was through these deliberative processes and exchanges that I rediscovered the promise of Occupy’s discursive ‘public space’. These exchanges also brought into relief the contours and boundaries of the ideologies of these different constituencies. A rich ethnography of these exchanges, drawing on my in-person and online conversations, will illustrate the central hypothesis of this project.

Chapter 4b: Occupy APA: The Radical Psychiatry Caucus

On May 5th 2012, alt-mental-health activists descended on Philadelphia to protest the yearly American Psychiatric Association conference. The protest was especially charged since the DSM-5 was scheduled for publication in May 2013 (a year behind schedule, after 12 years of work), and had received great deal of coverage in the mainstream media.

An especially strange and instructive moment at the conference occurred at the yearly meeting of the “APA Radical Caucus”. This year, the radical caucus invited the protesters to attend their meeting, and the confrontations and showdowns that ensued speak to many of the great divides that continue to exist between even the self-proclaimed radical elements of psychiatry and the alt-mental-health movement. The

dynamics of this meeting warrant close study, as they exemplify the rut that both sides of this controversy are stuck in.

In this chapter I hope to closely examine the dynamics of this meeting within the larger context of the weekend's protests and explore where it broke down, and how the politics of the new wave of psychiatric resistance can help us make sense of this standoff and suggest improvements of future encounters.

Chapter 4c: Voices from the Æther: Participatory Madness and Networked Salvation

To what extent has the mad pride movement been shaped by a new generation of media and communications technologies? How has this movement leveraged these technologies as a means to redefine personal identity and avoid stigmatization? How have they used these technologies to resist and subvert corporate messaging and the relentless advance of biopower? The Internet, and especially free and open source software, played an instrumental role in the formation and assembly of these groups. The cultural practices embodied in these tools, alongside the movement's roots in anarchism, punk, DIY, permaculture, and queer pride helped inform the organizational models, governance structures, as well as giving rise to new forms of collective action.

The relationship between changes in social movement organizing and the concomitant improvements in communications technologies is undoubtedly complex. Attempts to establish fixed causal relations between cultural practices and their technological counterparts are often challenging, as these categories ultimately represent different aspects of unified phenomena (Bijker, 2001). Although it is difficult to demonstrate how social movements are shaped by (and shape) revolutions in media and communications technologies, it is valuable to study how movements leverage technologies, both tactically and strategically.

In this chapter I will describe how alt-mental-health movements are communicating and organizing, and explore the relationships between networked platforms, communication strategies, and the emerging politics in this new wave of psychiatric resistance. In many respects, hints of the trend I am describing can be found in many subcultures on the fringe. Alyssa Quart's book *Republic of Outsiders: The Power of Amateurs, Dreamers and Rebels*, describes a similar politics emerging in the transsexual communities, autistic communities, and even in remix culture. Networks enable participation, and lately, many corporations and cultures have demanded it. How do these patterns of behavior correlate with the values and ethics of the alt-mental-health movements? How can the software adopted by these movements help us understand them better? And, how has this software reflected, and reciprocally shaped, the groups' composition and nature?

Conclusion: Psychiatric instruments of institutional oppression

In conclusion, I would like to tie together these disparate themes, and relate them to the recent release of DSM-5, and the subsequent bombshell disavowal of the work by the National Institute of Mental Health. The course that NIMH has set for psychiatry is possibly worse than the one it is currently on, and the missed opportunity to assemble a consortium of relevant stakeholders is sad and disconcerting. I will make some

recommendations for how to formulate a positive and constructive vision of the future of mental health, and the steps that various constituencies can take to help advance this vision.

Finally, I plan to connect this work to a larger conversation about privacy, surveillance, and an analysis of power through the trend of what I call “pathologizing risk.” I will highlight the importance of incorporating an understanding of the role of the psychiatric establishment and the pharmaceutical industry in a comprehensive analysis of power, and attempt to relate what’s going on in psychiatry with other areas of social justice, such as oppression, profiling, incarceration. Psychiatry has long been the instrument of institutional oppression, but the ways in which it is being operationalized need to be analyzed alongside works that examine continuing discrimination and oppression of race, class, gender, and beyond.

II. WHERE IS THE LARGER CONVERSATION?

This project seeks to synthesize and contribute to a number of scholarly conversations, including disability studies, narrative medicine, the history of social movements, and critical information studies. By developing a thick, detailed account of a significant shift in an important social movement, this project engages with a variety of scholarly conversations and themes that go beyond the specific encounters profiled in these research sites.

The questions “What’s normal?,” “Who decides?” and “How do they decide?” are central to disability studies, and more generally, to identity politics as engaged by scholars, advocates, and activists. The discourse around mental health is particularly provocative and productive, especially as diagnostic categories in the US have grown to encompass 1 in 4 adults who experience a mental disorder in a given year (http://www.nami.org/template.cfm?section=about_mental_illness). There is even a nascent field of study called “madness studies” which is beginning to emerge around this discourse. This project will contribute to these conversations by providing rich descriptions and analyses of key organizations as well as significant interactions that will help illuminate and extend our understanding of these actors and their communication strategies.

As this project will demonstrate, the orientation and focus of the new wave of mental health advocacy resonates strongly with the central concerns of Narrative Medicine. The emphasis on the primacy of subjective experience, and the role of individual stories and voices in producing meaning, are core propositions of Narrative Medicine, and this project can make a significant contribution to this field, in the application of these principles to psychiatry and mental health.

The oppression of the mentally ill has a long and dark history, and the corresponding history of advocacy and resistance to this oppression is equally compelling. Mental health activism is intimately intertwined with other forms of activism, as many activists have experienced mental duress and traversed emotional crisis. Mental health activists have a great deal to learn from the history of social movements, and reciprocally, have a great deal to teach. In recent years, the movement has explicitly looked to other successful civil and human rights movements for inspiration and tactics. Academically, these histories can greatly inform each other,

especially when considering the overlapping networks of actors that comprise these groups. Also, the particular ways in which grassroots social movements are assembling around communications technologies is of general interest to social movement scholars and critical information scholars alike.

Finally, with regards to critical information studies, this project will explore some of the ways that organizational structure and values are mirrored and reinforced by the tools of communication and production. Themes of privacy, transparency, and surveillance run through this projects' inquiry into stigma, as well as the difficulties with providing safe spaces for support in a networked environment. Radical openness, transparency, and security are understood in a new register when applied to psychology and emotions, in addition to their traditional application to technologies and systems.

III. WHY CARE?

This project is also of general intellectual interest due to its urgency, its originality, and what we can learn by closely studying emerging formulations of activism and resistance. While The Icarus Project has been around for over ten years, its web-based foundations suggest an ephemerality that begs for solidification. Once we establish the cultural significance of this project, it becomes imperative to answer the question "What did all of these disparate voices just say?", for many other stakeholders, including academics.

My own personal motivations for completing this project also speak to its urgency and generalizability. When I began this program, I was committed and determined to write about transparency, privacy, and surveillance. During the admissions process (Dec '06 – May '07), I became embroiled in a First Amendment action against Eli Lilly (detailed <http://www.re-public.gr/en/?p=144>), and became more conscious of the corruption and largely unchecked power of the pharmaceutical industry, and their peculiar alliance with psychiatry. I had encountered The Icarus Project before (through a j-school story, of all places - <http://web.archive.org/web/20080313154959/http://jscms.jrn.columbia.edu/cns/2005-11-01/itzenson-bipolardisorder/>), but only became more seriously involved after effectively spending five months on the Big Pharma beat during the case against Lilly. After writing about the Lilly case for my Masters thesis, I began exploring ways to incorporate these topics in my research.

I have never really abandoned critical information studies, or my concern with privacy/transparency/surveillance. To some degree, these elements will always form the substrate of my analysis. Over the past few years I have perceived the parallel topics of surveillance and madness as a necker cube, with the foreground and background trading places depending on my perspective. In particular, especially when I started learning more about the Psychotic Risk Syndrome diagnosis, along with what I have been describing as "pathologizing risk", I started to appreciate how this work on madness could make an important contribution to surveillance studies. Many privacy advocates illustrated their concerns with speculative scenarios built around data mining of government and corporate surveillance. Meanwhile, psychiatry was operating in these advocates' blind spot, normalizing a gaze where risk itself was being diagnosed and treated. These preventative interventions reeked of the pre-crime unit popularized in

Minority Report, and reminded me of the NYPD's stop and frisk program and criminal profiling. I also perceived the danger of how much more powerful this paradigm would become once we start feeding it more data, in the form of electronic health records, data mining facebook, etc, etc.

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