Crazy tubby girl/mad fat transman: troubling and reclaiming schizophrenia through women of color feminism and madness studies

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Crazy Tubby Girl/Mad Fat Transman: Troubling and Reclaiming Schizophrenia Through Women of Color Feminism and Madness Studies

A Thesis

Presented in

Partial Fulfillment of the

Requirements for the Degree of

Master of Arts

July 2021

BY Tyler Allen Selsor

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Abstract

Through autobioethnography this project demonstrates a complex, yet incomplete picture of schizophrenia as an illness mediated by and through racist ableist (trans)misogynistic queerphobic capitalist heteropatriarchy. It describes the beginnings of schizophrenia as genetically inherited, yet entirely socially mediated process where subjects come to know themselves as pariahs through the processes of criminalization, incarceration and poor healthcare. Furthermore, it questions the project of wellness and contests schizophrenia as a site of wholly illness. It uses the disciplines of Madness Studies and Women of Color Feminism to argue that schizophrenia is a way of being that upsets patriarchy, so it must be valued. Schizophrenia is a terrifying illness, but it also contains a wealth of counter hegemonic knowledge and new ways of thinking more madly that ‘out mad’ the system and provide liminal space for liberatory politics.
Fig. 1. Tyler Selsor, *Live Through This*. 2020

Image Description: Drawn in black and white, a naked fat figure with scars on their legs and bandages on their arms stands on the right side of the page facing away from a flower that grows up and entwines itself with the burner of a gas stove. The figure has thick thighs, a rounded stomach, large breasts and short curly hair. To the right of the figure’s face, written in capital letters, is the phrase “Live Through This.” Flowers rain down into a small pool of liquid on the far bottom left from cartridge razors depicted above.
Preface

Acknowledgements

First and foremost, I want to thank my parents, Laurie and Mike Selsor, and my partner, Matthew Magliola, for quite literally making my graduate career possible through their endless trips to Chicago from Indiana with me when I was too sick to drive, their advocating for me during frequent and frustrating doctor’s visits and their compassion, understanding and patience as I often stumbled through this process.

I want to thank the faculty and staff at DePaul’s Women’s and Gender Studies Department for their mentorship and support. I am fortunate to have many understanding and patient people in my life and the members of the Women’s and Gender Studies Department were certainly nothing but patient and understanding. I would especially like to recognize Dr. Heather Montes Ireland, Dr. Sanjukta Mukherjee, Dr. Anne Mitchell, Dr. Laila Farah and Leo Masalihi. Dr. Montes Ireland, my committee chair, worked tirelessly to get this project done and inspired me in my first quarter to write about mental illness. Dr. Mukherjee guided me through the proposal writing process, which was invaluable for the development of this thesis. Dr. Mitchell mentored me in a teaching internship where I got to test my skills as a lecturer and learn from the best. Dr. Farah gave our cohort a thought provoking and beautiful bittersweet ending to our last class together. And, of course, Leo runs the show, and I would have been lost without his help.

Thanks as well to my committee members Dr. Noam Ostrander and Dr. Allison McCracken for their thoughtful dedication to the project.

I believe I have made some lifelong friends in my cohort. To Jesse, Hayley, Zayne, Matima, Haley and Laura I am deeply thankful for your friendship, and hey, I think it’s fair to say that I love you all. I’m so glad we met, and even though our lives are going different ways, I know we’ll stay in touch.
Finally, I want to thank my longtime friend, colleague, and fellow trans dude Soren for his love and support through all my ups, downs, twists and turns.

I used to think I was alone, maybe that’s just because I was a teenage edge lord, but I really did feel that way. Now I know I’m not. I wanted someone to perfectly understand everything about me at that time, but now I know that the point of a good relationship is not to understand completely, but to listen, empathize and struggle together.

I quite literally wouldn’t be here without all of you.

Love,

TAS

For all the schizophrenics, for the ones we’ve already lost and the ones we’re already losing

And for all of us who “wake up tired in the dark.”¹

Trigger Warnings: self harm, psychosis, houselessness, racism, violence, suicide, childhood sexual abuse, physical abuse, animal abuse, hoarding, squalid environments, trauma, verbal abuse, kidnapping, racism, colonization, misogyny, ableism, sexual assault, addiction, psychiatric hospitalization, violence, suicide, body image, disordered eating, fatphobia, doctors, slavery, incarceration, racism, chemical restraint, death, memory loss, aphasia, disassociation, hearing voices
Introduction: Boulevard of Broken Dreams

Genealogies of Madness and a Sliver of Hope

Trigger Warning: psychosis

“I got a bad disease,

But from my brain is where I bleed.

Insanity it seems,

Has got me by my soul to squeeze.”

“Soul to Squeeze” Red Hot Chili Peppers

“Mama” I said, pointing to the stained-glass window in the cathedral, “I see Mary up there. Do you see her too?”

“No. It must be the light from the window.”

“It’s not the light from the window. She’s right there.” I pointed above the altar.

“I don’t think so,” my mom said uneasily, but she dropped the matter, thinking that it was just a childhood fantasy.

This was my first hallucination. My first experience of schizophrenia as far back as I can remember.

I first found out that I had Schizoaffective Disorder four years after I had been diagnosed with it. I was handing in the paperwork for my accommodations my freshman year at Columbia College Chicago. In my doctor’s handwriting, the line for diagnosis read: Schizoaffective

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2The Red Hot Chili Peppers, Soul to Squeeze, 1993.
Disorder. I had no idea what that was, only that I had been living with it all my life. I could take a pretty good guess because I knew my symptoms: anxiety, depression, mood swings, and psychotic episodes, but I didn’t know what was in store for me and how it worked. I set out to find this information, but there wasn’t a lot out there except the typical Web MD page. I have been at a loss as to what to do for the last four years and have continued to just live with my condition in isolation. It was not until I began to understand the nature of trauma last year, through feminism, that I began to understand myself as a being both encoded by genetics, but also bound by experiences in a society that is structured by particular social and behavioral norms.

The Thesis Itself

In this thesis I will do the work of analyzing the schizophrenia experience through autobioethnography in order to lay bare the ever-present harm that schizophrenics experience as a medical designation defined by diagnosis. However, this work will not only be about harm, but also about the inherent worth and humanity of schizophrenics, and all disabled people for that matter. My lived experience has led to my strong conviction that schizophrenics have a unique bodymind, and unique multi varied perspectives on how we can use coalitional work to combat the hierarchical oppressive structures that we live and breathe in like toxic fumes (sometimes metaphorical, sometimes real) every day.

There will be discussion of sensitive topics such as self harm, suicide, and medical violence, but not for trauma pornography’s sake. These stories are important as they color and change our lives in drastic ways: they need to be told. Even so, this project is first and foremost for all the schizophrenics, as an expose of the reprehensible harm being done to us, but more importantly a letter of solidarity and love to all schizophrenics. To say, you are valid, you are
loved, and you are important. Your lived experience is real and there are people who believe you just as you are. Whether you’re medicated or not, incarcerated, houseless or alienated, you have the right to be welcomed at the activist table.

This is a call to action for all of us to engage with our mad neighbors and community members in mutual aid and coalition. I also ask nondisabled people to grapple with the madness, trauma and harm within themselves. This will not be an essay merely asking nondisabled people not to actively harm us. It will go beyond the argument that schizophrenics are humans too, and instead task coalitional and mutual aid organizations responsibilities to fight for us and with us as equal members. Our salvation will not come from governments or private charities, but we can take care of each other and wage battles in the streets. In the end, disabled or not, those who dissent and fight for equity are always enemies of the state and it’s just a matter of time (if it’s not happening already) when they “point the cannon at you.”

The Method to the Madness

In this thesis I use autobioethnography as a methodological tool to understand my own experience as a schizophrenic and relate my experiences to others. I understand my experience is not the only one and I do not claim to have the authoritative voice on the schizophrenic experience. Through grafting my lived experience onto the larger socio-political landscape I can see more clearly defined my life in stories up against the monoliths of oppression that tell me who I’m supposed to be. Juan Guerra describes autobioethnography as personal writing that also serves as a jumping off point for structural analysis of systems of oppression. It is only through seeing personal struggles in the context of matrices of domination that we may begin to see how

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our struggles are connected to others. Therefore, autobioethnography is not just a methodology but a tool of personal and political liberation that has both healed my bodymind and activated me as an organizer.

As a liberatory, feminist, and queer tool, autobioethnography also draws from autoethnographic methods. In “Silence and Memories of War: An Autoethnographic Exploration of Family Secrecy,” author Peter Rober writes:

Autoethnography is an approach to research that aims to describe and systemically analyze (graphy) personal experience (auto) to understand social and cultural phenomena (ethno) (Ellis, Adams, & Bochner, 2010). It is research that connects personal autobiography to the cultural, social and political (Ellis, 2004). Starting from the postmodernist assumption that it is impossible to do research from a neutral, impersonal, and objective stance (Anderson, 2006), autoethnographic researchers have chosen a new direction in which they move farther away from the positive science model of empirical research, toward a scientific model that is more akin to literature, philosophy, and history (Ellis et al., 2010). These researchers have started to explore new territory with the aim of producing meaningful and inspiring texts, grounded in personal experience and centered on sensitizing readers to the uniqueness of experience, to the diversity of identities, and to whatever cannot be said in the dominant societal discourse (Ellis et al., 2010). Autoethnographic research often starts from the author’s “epiphanies” (Ellis et al., 2010): moments in one’s personal life that are remembered and seem to have a lot of meaning in giving one’s life sense and direction. The researcher then reflects on, analyzes, and writes about these experiences in such a way that the text produced transcends the strictly personal and illuminates the social and cultural context of the experience.4

My life writing sections in this thesis are my ‘epiphanies’ that I share with the reader in order to develop a ‘unique experience’ that ‘cannot be said in the dominant societal discourse.’

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Furthermore, I analyze this life writing in order to connect ‘personal autobiography to the
cultural, social and political’.

This project diverges from Rober’s in the sense that I am also focused inward on a deep
journey into my bodymind as a white lower middle-class fat trans schizophrenic. This is why I
consider my work autobioethnography rather than autoethnography. By interrogating the
differences between who schizophrenics are supposed to be and who they are, what
they’re/we’re affected by and how they live (or often forced to live) the veil of discourse around
schizophrenics as dangerous, violent, untreatable and always psychiatric patients is pierced to
reveal a kaleidoscope of multiple truths.

I am aided by two other pieces of life writing in order to bring a broader lens to the
project. Both memoirs, The Collected Schizophrenias by Esme Weijun Wang and The Center
Cannot Hold by Elyn Saks, are the stories of women in academia who struggle with some form
of schizophrenia but have relatively stable lives and work. Here it is important to examine who
gets left out by this discourse. I examine the intertextuality between these two texts, in relation to
my own, in order to deconstruct representations of schizophrenics in academia.5

I have chosen these two texts because of their cultural relevance as well as the identities
of the writers. Both texts are in the zeitgeist as ‘real’ accounts of women with schizophrenia and
thus stand as testimonials of the ‘true’ experience of schizophrenia. That both writers are women
and one is a person of color is important because they counter the dominant views of
schizophrenics as either talented white men or psychopathic criminals. Furthermore, memoir and

in Marya Hornbacher’s Wasted and Madness,” Disability Studies Quarterly 31, no. 2 (April 23, 2011),
https://doi.org/10.18061/dsq.v31i2.1591.
memory are powerful in creating a cultural memory or particular experience of schizophrenia that I seek to trouble\textsuperscript{6}.

My voice is but one of a cacophony that can be heard echoing through history in institution halls and whispering through the leaves of family trees. I can hear them whispering to me and I speak my story in conversation with theirs. Follow me into our history, our existence and our future.

The Catalyst for the Thesis

**Trigger Warning: severe self harm**

I started my graduate school career in both the Social Work Program and Women’s and Gender Studies Program at DePaul. In the Social Work Program, we quickly started discussing trauma and a flood of emotions came back to me, anger, despair, sadness, and self-loathing. After one particularly upsetting lecture I came home after my two-hour drive from Chicago to Michigan City, Indiana. As I was doing my nightly rituals to get ready for bed, without thinking I grabbed my partner’s razor from a shelf in the bathtub and began gashing up my right forearm. My loud crying awoke my partner who quickly stopped me and helped me clean up and get to bed. This incident set off a two years long battle with self harm that I am only in the early and dicey recovery stages of.

I began Eye Movement Desensitization and Reprocessing (EMDR) therapy which only accelerated and worsened my self harm. EMDR is only supposed to be done after someone has been taught the tools to process their traumatic memories. In other words, you have to prepare for the memories and strong emotions that will come up during EMDR. This takes months or

sometimes years, but my therapist began EMDR with my therapist on our second session together. When I asked her how to deal with the traumatic flashbacks I was experiencing she would simply say, “sights, sounds, smells” which meant little or nothing to me.

I came into the office on our fourth session having cut myself.

“It doesn’t look serious,” she said.

“Why did you cut yourself? What was the thought process that led you to do that?”

The truth was I didn’t know. I didn’t know why I had cut myself. There were no thoughts when I did it. I just did. It was pure unconscious emotion. Emotions that were stuck inside me.

I only went a few more times after that, but the damage was done. It wasn’t just cutting now; I found every way I could to hurt myself. I burned myself on the stove, hit myself with a hammer, and turned the water to scalding when I took a shower. My self hate was out of control. I wanted to destroy myself, to block out and permanently erase the memories of childhood abuse even if that meant erasing myself. It was escalating. And then the demon came.

A personal manifestation of my self hatred, egging me on to self destruction. The “bad man,” told me I was worthless and dirty and not worth living. Sometimes it was an attack, but sometimes I was in cahoots with him. When I really wanted to hurt myself, I would smile back at him and take his direction happily, which only made me sick to my stomach with shame. The demon comes when I am feeling weak or depressed; when there’s a chink in my armor.

In August 2020, after a month of severe self harm, my psychiatrist finally agreed with me that my current antipsychotic, Risperdal, wasn’t working. I changed to a newer medication, Latuda, and it has fortified my armor. I haven’t cut or burned myself in 6 weeks as of October 2020. This recovery is not born of the fact that I don’t want to hurt myself. I wanted to hurt
myself yesterday. At my new apartment in Mishawaka my partner has locked up everything that I could hurt myself with: knives, scissors, and anything sharp enough to prick my skin. The oven, waffle maker and garbage disposal have been locked out and tagged out. I don’t drive because last time I drove I went to Walgreens and bought razor blades, then cut myself in the park by my house.

Throughout this whole time, I was engaging with feminist theory and that was the lifeline, along with my family and partner, that kept me holding on. Feminist theory teaches hope, that although the world is unfair, depressing, unjust and oppressive, there is still hope through writing about our lived experiences, understanding our differences, and building coalition with each other. Thorough an understanding of feminist theory, especially Women of Color Feminism, we can engage in activist spaces in a responsible and empathetic way. We will make mistakes. We will have victories and defeats. We will go one step forward and two steps back, but we will never lose hope because “we are the ones we’ve been waiting for.”

“There’s a Bottomless Pit We’ve Been Climbing from Just to Get on Level Ground”: Madness and Subjectivity

Trigger Warnings: houselessness, racism, violence

I was standing outside the DePaul classroom building in downtown Chicago with a group of social work students. All of us were white and everyone except me was a woman. It was dark. A Black man was walking in our direction, but not toward us. He was in a fantasy in his own head, talking to imaginary people. He started to yell, but not at us. I knew he was sick. He

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was somewhere else right now. One woman got out her pepper spray. He passed us by. Later I
learned that she worked in a psychiatric hospital. Shouldn’t she have known, as I did, that this
man posed no threat to us at all?

Contemporary public knowledge of schizophrenia is based largely on the image of the
assumed to be violent Black houseless man, as the above anecdote illustrates. On the other hand,
white women are more likely to be seen as harmless but strange, especially if they are middle
class and are able to choose to reveal themselves as schizophrenic. Middle and upper class white
men, as long as they are not criminals, are seen as eccentric and maybe even genius especially if
they are intellectuals (i.e. John Nash of *A Beautiful Mind* and Eric McCormack of *Perception*).  
White men only begin to be seen as schizophrenic when they have committed crimes such as
rape and murder or are in the possession of child pornography. More often than not, schizophrenia or mental illness is used as a cover for greater societal problems such as racism or
white supremacy. Sixteen mass shootings were committed by white men who were influenced

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8 *A Beautiful Mind* and *Perception* do a good job of portraying one version of schizophrenia; the version where someone has full bodied visual hallucinations, is struggling with the decision of whether or not to take psychiatric medication and experiences the terror of psychiatric hospitalization. *Perception* particularly shows Pierce using coping mechanisms, such as listening to classical music and keeping a strict routine. It also posits that schizophrenic hallucinations or visions can be a certain type of knowledge that clues us in to situations in our lives. However, the particular focus on neuroscience in *Perception* falls short as it does not take into account lived experience and makes it seem as though all schizophrenics experience the same phenomena, when in actuality schizophrenia is a complex multivariate experience. Not to mention the racist depiction Lewicki, who is quite literally Pierce’s servant. Similarly, *A Beautiful Mind* takes up the white well educated upper class man trope and voyeuristically focuses on strange behaviors with a ‘twist’ to shock the audience midway through (that Charles, the literary studies roommate, is only a figment of Nash’s imagination). Both represent a limited “diet” version of schizophrenia that adheres to the fallacies of deviation from ‘normalecy’ and ‘craziness’ as a tired trope.

9 In the popular true crime podcast *My Favorite Murder* (with 34 million listeners) hosts Georgia Hardstark and Karen Kilgariff discuss the most gruesome rapes and murders in U.S. history. They claim that discussing the crimes helps them to assuage their fears and anxieties. Premeditated murders and rapes are mostly committed by white men, which Kilgariff and Hardstark call “monsters”, “psychotic” and “schizophrenic.” Upholding the worst crimes in history and attributing mental illness to them is harmful, regardless of if the assailants were schizophrenic because it creates only one version of schizophrenia: the violent one. Surely if this were a more nuanced discussion it would be able to discuss mental illness along with the pain and terror that has been inflicted by these men. Unfortunately, Kilgariff and Hardstark have used triggering shock value and the stories of innocent victims and very sick people to skyrocket into fame and fortune.

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by white supremacist movements worldwide last year, leaving 175 dead.\textsuperscript{11} Mass shootings are legitimized as isolated incidents while entrenched hatred goes unchecked.\textsuperscript{12}

As for Black women, Latinx folks, Asian Americans, and Indigenous Americans, there is no national discourse on schizophrenia. It is almost as if these folks aren’t ‘allowed’ to have schizophrenia because they are expected to conform to various subject positions. Black women are pushed to be strong and have no mental health issues. Asian Americans are sold as a model minority. Latinx folks are seen as non-citizens with no right to health care and Indigenous Americans are relegated to the past by an understanding that sees colonialism as a historical and not current issue (Beauboeuf-Lafontant 2009, Eng and Han 2000, Jenkins 2015, Arvin et al. 2013). Theri Pickens writes that we must consider madness and race in a nuanced way in order to open up the truths that people of color are complex and multifaceted human beings that experience madness in particular ways that are different from white middle class heterosexual nondisabled people.

When it comes to socio-economic status, people living in poverty, especially those who are of color are less likely to receive treatment and more likely to have stigmatized racist


\textsuperscript{12} An FBI study from 2015 found that 25% of 63 active shooters were diagnosed with mental illness. This conflicts with other research from, mostly conservative think tanks (an L.A. Times Op-Ed that claims the percentage to be 59% or high cites the author’s own book as proof), because it does not diagnose shooters using posthumous accounts from eyewitnesses and family members. Therefore, it is difficult to say how many active shooters have mental illnesses, but this is still not an excuse for the extremism that many are also motivated by. (https://www.fbi.gov/file-repository/pre-attack-behaviors-of-active-shooters-in-us-2000-2013.pdf/view?mod=article_inline) While mental illness is sometimes a factor in such shootings, it is rarely a predictor, according to a growing body of research…. Researchers have noted that more commonly shared attributes include a strong sense of resentment, desire for notoriety, obsession with other shooters, a history of domestic violence, narcissism and access to firearms,” reports the Washington Post. After the El Paso and Dayton shootings in 2019 president Trump blamed mental illness and not lack of responsible gun control for the shootings and suggested that psychiatric institutions closed in the 1960’s due to squalid conditions and wide spread abuse be reopened. (https://www.washingtonpost.com/health/after-trump-blames-mental-illness-for-mass-shootings-health-agencies-ordered-to-hold-all-posts-on-issue/2019/08/20/c4030e4c-c370-11e9-b5e4-54aa56d5b7ce_story.html)
experiences and receive poor treatment.\textsuperscript{13} This is of course magnified in houseless folks, but it strains others as well. Schizophrenia is a chronic illness which requires lifelong treatment by specialists, not just a family doctor.\textsuperscript{14} One year of treatment alone can cost from $3,000 to $57,000 per year depending on health insurance status\textsuperscript{15}. Getting disability status is difficult and often requires a person to stop working, which leaves them unable to move up the economic ladder. “In the U.S., less than half of all people who apply for disability benefits — about 45 percent — are ultimately accepted...getting a hearing takes an average of nearly 600 days.”\textsuperscript{16} In addition, family members of schizophrenics may need to take time off to care for them. Family Medical Leave (FMLA) is federally mandated, but unpaid and lasts only 12 weeks per year.\textsuperscript{17}

Being queer provides an added stressor when dealing with the medical industrial complex. Besides being outrightly discriminatory and hateful, most health care providers do not have a model for providing sensitive care to lesbian, gay, bisexual, and especially trans folks.\textsuperscript{18} Furthermore, “Transvestic Disorder,” described as dressing in clothes or behaving as the

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opposite gender that causes distress to the person, is still in the DSM-V. Similarly, “Gender Identity Disorder” is the most current adaptation of what appears to be a diagnosis meant to provide access to gender confirmation surgeries, hormones and other treatments for trans and gender non-conforming people, especially trans and gender non-conforming kids.\textsuperscript{19} This is a double-edged sword because on the one hand, it legitimizes trans care and ensures that insurance companies can code these treatments and (hopefully) pay for them. On the other hand, it pathologizes trans people by merely being in the book (the DSM) that describes mental illnesses.

Also of note is the construction of weight around healthfulness. The real metabolic and hormonal issues that antipsychotics cause was blamed on my fatness, rather than on the effects of the drugs. Furthermore, I have been told that my emotional problems stem from a lack of diet and exercise versus the very real effects of schizophrenia. This is part of my own experience in dealing with the medical industrial complex. The medicines I take made me fat in the first place but the question always seems to be why don’t you just lose weight? Lee and Pause write that current neoliberal practices of the medical industry are focused on “what fat people do and do not do”\textsuperscript{20} rather than on structural inequalities that make it difficult for fat people to access care and maintain ‘healthy’ lifestyles.

Although I am a trans man, my gender queerness affords me the privilege of a white woman. My colleague recently told me that when I revealed my illness, she was curious and not afraid or disgusted. I am a model schizophrenic. I’m white. I’m middle class. I got to graduate school. I dress nicely. I am the schizophrenic that is afforded the privilege of talking about


schizophrenia. I believe strongly that it is my job as a resourced person to help to destigmatize this condition without substituting my voice for all voices or the voices of those who are not heard by academia, no less the general public.

Chapter Breakdown

This project then, seeks to destigmatize schizophrenia through the use of Madness Studies (Disability Studies,), Queer Theory, and Women of Color Feminisms. I am primarily interested in pushing the envelope in feminist discourse in order to coalesce a schizophrenic political identity in feminist scholarship that will radiate out into the general public through activist actions. I am also concerned with building up and archiving a schizophrenic knowledge base that will validate the erotic knowing of all schizophrenics.

Chapter One argues that there is an intrinsic link between madness and trauma, not because schizophrenics are inherently traumatized, but because we are extruded through a harmful and traumatizing system. It utilizes Women of Color Feminisms as an epistemological tool in order to heal trauma both as mad individuals and coalitional communities. Further, this chapter takes psychiatric narratives and uses them as a space to explore madly the lived experience of marginalized people.

In Chapter Two I analyze the many permutations that the schizophrenic disabled bodymind goes through as it navigates the corruption of racial capitalism. Through the queer failure of fatness and madness I set up a framework with which to examine how systematic trauma is wrought on the body and what capitalist myths do to disabled people in terms of many forms of incarceration and devalument of the disabled bodymind. I theorize that the bodymind is a permeable, unstable organism calling on Suzanne Bost, Donna Haraway, and Jasbir Puar’s
work to argue that, once again, our wounds and disablements can bring us together through the method of coalitional intersectionality.

In Chapter Three I analyze the unique knowledges that schizophrenics have through Audre Lorde’s erotic and Moraga and Anzaldua’s concept of lived experiences. I argue that schizophrenics can theorize about their own experiences in order to know themselves better, as I have done in this thesis. I utilize Kafer’s ‘crip time’ as a mode of understanding the lived schizophrenic experience. Finally, I argue that to create change schizophrenics must get to know one another and build coalition through difference with other oppressed people.

This project will gather a robust but incomplete picture of schizophrenia as a way of being that confounds the racist ableist capitalist heteropatriarchy that we live in. I cannot capture the vast range of schizophrenic lives, after all, “we never arrive”\textsuperscript{21}. Still, this entry point holds value in that it pushes the boundaries of academic discourse and calls for an increased activism around schizophrenia and other forms of madness.

The Unintelligible, Sedation, and a Chemical Cure:
An Incomplete (and Brief) History of Schizophrenia in the U.S.

The collection of symptoms that make up schizophrenia were first described in the early 1900s as \textit{dementia praecox} by Emil Kraepelin\textsuperscript{22}, a German psychiatrist who had done


\textsuperscript{22}Kraepelin described many of the psychiatric illnesses that would comprise the DSM until the late 20th century when psychiatrists began to realize many of his diagnoses described actual physical illnesses that were common and untreatable at the time such as syphilis, which in it’s late stages has profound psychiatric effects. It is also of extreme importance to note that Kraepelin’s work inspired nazi scientists because Kraepelin used a pessimistic framework to classify and diagnose mental illness. His view was not that mental illness was treatable, but that it should be eradicated through eugenics. This work, in tandem with the eugenics movement in the U.S., inspired the mass forced sterilization and eventual genocide of asylum patients (including the mentally ill, but also intellectually disabled, Down Syndrome, and physically disabled people) in Germany. That we were the first to go is a fact that is
longitudinal studies of people exhibiting schizophrenia symptoms. Kraepelin describes schizophrenia as a cluster of illnesses, something which psychiatrists still maintain today, hence the schizophrenia spectrum. There was no pharmacological treatment of schizophrenia until the antipsychotic Thorazine appeared on the scene in the 1950’s, which only sedated schizophrenics. It did not treat the root causes of the illness and harmed people more than it helped them. Schizophrenia was treated, or rather not treated, by incarcerating individuals in mental institutions.

In the United States, psychiatrists began to co-opt the work of Freud, taking his work and molding it to fit hegemonic principles of the nuclear family and heteronormativity. They became increasingly convinced that schizophrenia was not biological. They blamed the mothers of schizophrenics for their children’s ailments and settled on the dysfunctional family as the cause. Since most schizophrenics were considered to be beyond talk therapy, especially if they suffered from aphasia, there was no help for them and their families. They were doomed to waste away in inpatient facilities.

At the same time, however, a group of psychiatrists in the United States and Europe began experimenting with LSD and mescaline to mimic the experience of schizophrenia in a controlled environment. They thought that if schizophrenia could be mimicked then it was most certainly biological. One such scientist holding this belief theorized that schizophrenia could be often overlooked. (Mab Segrest, Administrations of Lunacy: Racism and the Haunting of American Psychiatry at the Milledgeville Asylum (New York: The New Press, 2020),225.


treated with large doses of B vitamins, claiming that B vitamins would help absorb excess chemicals in the brain that he thought were responsible for schizophrenia.

In contrast to Thorazine, which was developed to merely sedate schizophrenics, Hoffer was trying to pinpoint the cause and wipe it out. Two other naturally produced brain chemicals would be hypothesized as the cause of schizophrenia: serotonin and dopamine. An overproduction of serotonin was posited as a potential cause of schizophrenia, but this solution was too simple. LSD reduced serotonin in the brain, alleviating psychotic symptoms, but other drugs which produced the same effect did not alleviate symptoms at all. Furthermore, mescaline alleviated psychosis but did not reduce the amount of serotonin in the brain. At this point scientists concluded that an overproduction of dopamine was the main factor in producing psychotic symptoms. Antipsychotics like Thorazine and haloperidol were discovered to have dopamine reducing properties which proved for psychiatrists that schizophrenia was indeed partially biological. Still, these drugs acted as a blunt instrument in treating a delicate set of interconnected symptoms and in no way neatly ended the debate of just how much of schizophrenia is biological or how it works in the brain.

In the 1980’s genetics began to rise tentatively and careful of its connections to nazi germany. Franz Kallman studied schizophrenia in twins, finding higher incidences of schizophrenia in identical twins which suggested a genetic component. Biological psychiatrist Seymour Kety began mining the Danish national database which had been used in the 1920’s for eugenist purposes. He looked for schizophrenics that had been adopted and found that even with

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different parents most developed schizophrenia. Kety and his colleagues argued that schizophrenia was genetic, but also that environmental factors were of equal importance.\textsuperscript{26}

This assertion, that schizophrenia was not caused by dysfunctional family systems and especially dysfunctional mothers, was welcomed by the families of schizophrenics and caught on quickly. Parents of schizophrenics developed the National Alliance for the Mentally Ill (NAMI), which has become a major stakeholder in mental health treatment and judicial proceedings. NAMI became a prominent force in lobbying for research on schizophrenia and has been tirelessly involved in debates of involuntary confinement and consent. Many NAMI parents believe that they should have the right to involuntarily commit their children for safety reasons, while activists within the Mad Movement focus on the autonomy of the person and the tendency for hospitalization to be unhelpful and even dangerous to schizophrenics.\textsuperscript{27}

Since the 1980’s not much has been accomplished in the way of unlocking the mysteries of schizophrenia. No single gene or group of genes points to its heredity, in fact there are hundreds of genes that could cause schizophrenia.\textsuperscript{28} In terms of the way schizophrenics are treated by psychiatrists, the dominant model of drug treatment and talk therapy prevails, as it does for most other diagnosable mental illnesses. The major difference in treatment is that hospitals are generally used for long term interment. The average stay in a psychiatric hospital lasts ten days whereupon people are released, regardless of whether they have been helped or if they are ready to leave.\textsuperscript{29} Community health clinics are supposed to pick up the slack here,

\begin{itemize}
\item \textsuperscript{26} Harrington, 170-175.
\item \textsuperscript{27} Harrington, 175-181.
\item \textsuperscript{28} Harrington, 182.
\item \textsuperscript{29} Esme Weijun Wang, \textit{The Collected Schizophrenias} (Minneapolis: GrayWolf Press, 2019): 106.
\end{itemize}
making sure that people get their follow up treatments, but many clinics are underfunded or were simply never built.\textsuperscript{30} For people without a support system the bottom simply falls out. People with support systems are more privileged, but still face the challenges of complex relationships with caregivers and the problem of caregiver burnout.

The conditions that have created the schizophrenic subject as an object of both public and psychiatric fascination are important to define. Histories such as Anne Hamilton’s \textit{Mind Fixers} and Johnathan Metzl’s \textit{Protest Psychosis} describe how schizophrenia turned from a harmless disease of primarily white women to a disease of violently characterized Black men. Metzl describes how psychiatry medicalized and pathologized Black men within the Black power and Civil Rights movements by diagnosing them with paranoid schizophrenia. Basically, any Black man that dared to fight for his rights or decry white supremacy was labeled as a schizophrenic and detained in mental hospitals or prisons.\textsuperscript{31} The idea of the violent Black schizophrenic, although still highly relevant to Black men, has spread through the ether so that schizophrenics of various subject positions are considered to be violent in the public eye.

The social conditions within which schizophrenics live are also important. Obviously these conditions vary by subject position, but it is important to describe the overarching hegemonic structures in which the public thinks about madness. Liegghio describes violence against mad people as “epistemic.” This means that mad people’s knowledge is constantly being erased by the psychiatric industry. This kind of violence takes place in mental hospitals and doctor’s offices, but it also takes place in the homes, workplaces, and educational institutions of


In media the schizophrenic character is sometimes allowed to have other ways of knowing but these must be delivered in barely intelligible ways and the schizophrenic must be isolated from ‘normal’ society (i.e. the Cheshire cat, the witches in Hercules, Yoda from Star Wars).

There is some biological evidence for schizophrenia, however to say that schizophrenia is purely biological would be reductive. From a trauma perspective, schizophrenia is seen as a combination of lived experience and neurobiological factors, yet trauma theorists, in their penchant for individual experience versus collective experience, discount the role of systems of oppression.

The impact of trauma is often discounted in popular representations of people with schizophrenia spectrum disorders. We are portrayed as criminals, psychopaths, and people who are unable to live within a ‘normal’ society, however, the opposite is true. There are many people struggling silently with schizophrenia and its many complications such as job loss, houselessness, and access to vital services such as therapy and medications. A literature review of studies about Schizophrenia in houseless persons by the Department of Psychiatry and Neurosciences at the University of California San Diego found an 11% average prevalence of Schizophrenia among houseless persons in the United States. This is significant because,

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34 I will use the term schizophrenia from here on out as shorthand for all the disorders that lie under the umbrella of schizophrenia spectrum disorders.

among the general population of the United States the prevalence of Schizophrenia is 0.25% to 0.64%. These statistics are startling and meaningful.

Unhoused people often suffer a cycle of houselessness and detention just for being unhoused and trying to survive:

Mental health issues are prevalent among incarcerated populations. Nearly one million adults with a serious mental illness are booked into jails annually, and many of these individuals have histories of homelessness. Severe mental illness is prevalent among the homeless population and is associated with increased risk of criminal justice system involvement. A study of 6,953 jail inmates found that individuals with homelessness in the year prior to incarceration had symptom clusters associated with mania, depression, psychosis, and substance use at 10-22% higher rates than inmates (sic) without prior homelessness.

In addition, Knopf-Amelung and Jenkins found that houselessness and being involuntarily detained for a psychiatric evaluation were high predictors of incarceration. So unhoused people bounce from jails and prisons to the streets to psychiatric institutions, all of which are not environments conducive to human life. Meanwhile, they are systematically ignored by the public. Those of us who have been involuntarily detained in psychiatric institutions exclusively are still at risk for chemical and physical restraint due to our perceived “violent” nature, when the only thing we’ve done is be schizophrenic based on our biology and the experiences life has thrown at us. We are all susceptible to being tied up for 24 hours and


aspirating on our own vomit. We are all unsafe, some of us more than others. So it shouldn’t be a question of whether privileged schizophrenics want to ‘help’ underprivileged schizophrenics (although we should certainly want to work with them for liberation). It should be that we have stakes in this game. Furthermore, non-schizophrenics also have a stake here, for it is not until we are all free of oppression will the world be a better place.

We All Hold the World’s Eternal Truths in Our Hearts Deepest Pit:

Feminist Theory and Madness

As theoretical frameworks I am using Women of Color Feminisms and Madness Studies. A review of the relevant literature shows that there has been more work on schizophrenia in Madness Studies than Women of Color Feminisms, but Women of Color Feminisms have a lot to offer to a project that is about the lived experience of bodies. I use Women of Color Feminisms because they are universally applicable to the human condition. They are also very focused on praxis, which is something that I want to get out of this project. It is not enough to theorize; we must be committed to making social change.

In the “Erotic as Power” Audre Lorde talks about the deep knowledge that all of us have as long as we are willing to resist eurocentric models of domination and oppression. I think that this is also applicable to neurodivergent people because of our ability to know unreality. I am not saying that schizophrenia is a gift. Often these visions and sensations are frightening, but there is a historical connection between schizophrenics and magic, spirit work, and healing practices. What I am proposing is that schizophrenics have a parallel knowledge, but that it is different in that it is fraught with the pitfalls of psychosis and terror.

39 Wang, 196.
Lorde’s specific formulation of the ‘erotic’ calls us to share ourselves in deep connection and joy, which is useful to the schizophrenic because schizophrenia can be so isolating and stigmatizing. Recognizing that we have non-normative ways of knowing and that they are valid and productive leads us away from the trauma caused by epistemic violence. Where there is joy there is also sorrow, and schizophrenia can be sorrowful and scary, but we as schizophrenics are not all sorrow. If we can reach the erotic within ourselves, we will find a “profoundly creative source... self-affirming in the face of a racist, patriarchal, and anti-erotic society.”

As a group, schizophrenics are generally not thought of as a political force, and it is true that just as in the case of groups who are, there is a wide range of schizophrenics with varying subject positions. This project is grounded in Kimberle Crenshaw’s theory of intersectionality which establishes that schizophrenics have intertwined and complex identities that are inseparable from each other. This is key. It is important to engage with intersectionality and privilege because it is only through that difference that coalitions can happen.

In *This Bridge Called My Back* Gloria Anzaldúa and Cherrie Moraga write of “theories in the flesh” which use storytelling to seek a more complex narrative about how subjects have come to be in the U.S. This theory foregrounds my entire thesis because memoir is a crafted distillation of lived experience. The narrators of the books I have chosen and my own writing will attempt to thread together an incomplete narrative about schizophrenia. These lived experiences are important to the work, but it is also important to question and contest who gets left out.

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Material feminist Suzanne Bost theorizes Moraga and Anzaldua’s lives through illness: Moraga’s premature son and Anzaldua’s diabetes. Different from other disabilities, schizophrenia is considered an illness, however, there is some debate, especially in the anti-psychiatry movement about whether or not it constitutes an illness or merely a different way of being.\textsuperscript{42} Wang writes that schizophrenia is an illness to her and she finds comfort in the description of her diagnosis. I also feel this way, although I don’t want to silence the voices of those that see schizophrenia differently.

Bost writes that Moraga and Anzaldua were influenced by the materiality of living with illness and that it is illness that allowed them to go the borders of identity.\textsuperscript{43} This is important to my project because illness is very material. Throwing up from the pills. Uncontrollable shaking. Twitching. These are all symptoms I experience. We must not cut off the head from the body. Schizophrenia is also an illness of the body and thus the body can be a reparative force. It is important to see each other as living bodies, not because we are all the same, but because we begin to understand both our differences and our commonalities as bound up within each other’s liberation.

As far as Madness Studies goes there has been much work on schizophrenia, mostly under the general category of ‘madness’. Madness Studies, as an outgrowth of Disability Studies thinks differently about schizophrenia. In this project I use the seminal text \textit{Mad Matters: A Critical Reader in Canadian Madness Studies}. Written in 2013, this text collects the most important writings sparked by the mad movement and is foundational to the beginning of Madness Studies.


Also central to my work is *American Quarterly* Volume 69, Issue 2, published in June 2017. Out of these texts many monographs have bloomed such as Ann Cvetovich’s *Depression: A Public Feeling*, Sami Schalk’s *Bodyminds Reimagined*. As I write this thesis texts continue to be published, such as *How to Go Mad Without Losing your Mind: Madness and Black Radical Creativity* by La Marr Jurelle Bruce. My lived experience as a schizophrenic and a scholar builds on this body of work as a small part of a cacophony of voices and experiences that bring together the field of Madness Studies.

For the purposes of this project, I have chosen to use the words schizophrenia and schizophrenics because they describe a particular experience that I share in common with Wang and Saks, who have self-selected the label of schizophrenia. I use the term schizophrenics as opposed to people with schizophrenia in order to bring awareness to the fact that although we are not our illnesses, our illnesses are intrinsically bound up with our lives and cannot be teased out easily.

Ann Cvetovich, in her autobiographical study of depression, describes the ways in which depression can be socially constructed through systems of oppression. She cites public depression as a condition of the neoliberal state and of activism against that state. She also writes about how racism and colonialism have caused a kind of depression in all peoples, albeit for different reasons. In short, she theorizes that white people experience some form of depression when they are not able to attain the American dream, while people of color experience depression because of the systems of oppression that leave them outside of the American dream. This is a structural depression that may not even be noticeable to the people it affects, but it weighs down on people like an oppressive cloud.⁴⁴ Though her work is about depression, I

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believe that it relates to schizophrenia as well because the material conditions of the world determine who is able to survive. Schizophrenic experiences are mediated in and through structures of oppression as well as the media we consume. A hallucinatory experience is culturally contextual in how we make sense of it as both schizophrenics and other factors such as loved ones and authorities. Lisa Blackman uses Cvetovich’s work to talk about the Hearing Voices Network, which was developed by people who hear voices some of whom self-identify as schizophrenic. Hearing Voices maintains that auditory hallucination is another way of communicating and that voices are trying to tell us something about ourselves. In other words, this non-normative experience should not be demonized, and it is up to the person whether or not they seek medication for voices. Blackman writes that voice hearing can be a response to trauma, something that is unknowable, but comes out as a particular experience of the body mind.\textsuperscript{45} Blackman brings up trauma as a possible cause of voice hearing and a way to make sense of the phenomenon, which is interesting in my own story as a person with PTSD.

Queer and Disability Studies theorist Alison Kafer theorizes the term ‘crip time,’ building on Jack Halberstam’s concept of queer time. Kafer and Halberstam write that disabled people and queer people are living out of time with racist ableist capitalist heteropatriarchy. We don’t fall along a the heteronormative trajectory that we are supposed to. Living on crip time means that we are subject to the whims of our disabilities.\textsuperscript{46} For schizophrenics, this also means living out of time with reality during delusions, hallucinations, and dissociative episodes which characterize our particular experience.


\textsuperscript{46}Alison Kafer, \textit{Feminist Queer Crip} (Bloomington: Indiana University Press, 2013):27.
Strengthening this analysis, Black feminist disability studies scholar Sami Schalk theorizes about Black speculative fiction in *Bodyminds Reimagined*. She writes about the character Lizzie from *Stigmata* by Alesia Perry. Lizzie has somatic experiences of the memories of her grandmother and enslaved ancestors. This causes her to be out of time with what is considered normative. Her knowledge is denied and she is put in a psychiatric institution for fourteen years. Schalk makes the point that Black women are hystericized and at the same time denied their knowledges through epistemic violence. Lizzie is violently brought back in time and forced to forego her erotic knowledge.\(^{47}\) Kafer and Schalk’s work is another affective turn that is useful in my research as it validates the experiences of schizophrenics without normalizing them.

To do this work, we must break down ‘normal’ as a fallacy that only serves racist capitalist heteropatriarchy.

**Trigger Warnings: self harm, psychosis**

*I look at the clock. It’s 4:08. I should have gotten this done. I should have. I shouldn’t be so tired. I should go to the gym. I should eat better. Oh my god. Oh my god. Am I going to die? Am I going to die from this? From the side effects of this disease?* I look at the clock. It’s 4:12.


*I can’t see him yet, but I know he’s here. Stalking me. This monster. This nightmare. A demon of my own making I know. The ‘scary man.’ But he’s so real. I look at the clock. It’s still 4:12.*

*He apparates. He runs at me, all bone and sinew.*


And I go to the stove in a trance. And I do it again. I do what he says.

I grab an ice pack from the freezer. I look at the clock. It’s 5:25.

The burn throbs. I have lost time. I have lost so much more.

Schizophrenics face not just epistemological violence or violence from self harm, but physical dangers from the state. In the essay “Mad Futures: Affect/Theory/Violence” by Tanja Aho, Liat Ben-Moshe, and Leon J. Hilton describes the death of Charles Kinsey, a black social healthcare worker, at the hands of the police. Kinsey was attempting to bring his client Arnaldo Eliud Rios Soto, a young man of color, back to the group home from where he had escaped when someone called the police. They claimed that Rios Soto had a weapon, which was really a toy truck. The details of what happened when the police arrived are blurry, but Kinsey was murdered while lying on the ground with his hands up.

This violence, although perpetrated on Kinsey, was tangential to Rios Soto. Thus the violence visited upon him was indirect, but still impactful. We don’t know whether Rios Soto is an autistic man and depending on their subject positions mad people can face physical violence and harassment from the state and its actors, that keeps us afraid and stigmatized. Through this case the authors argue that violence is normalized in U.S. culture, which distracts us as a society from the real structural issues facing mad people.48

Trigger Warning: suicide, psychosis

My Uncle Dan was also a schizophrenic. He left an imprint on my life a fossilized leaf pressed in silt.

And he’s gone now. I feel this aching sadness every day for a man, really a boy, I never knew.

A few weeks ago, the nightmares came three nights in a row. I could barely sleep or eat or breath. I dreamed of the ‘scary man’ again. He peered up at me from the edge of my bed. I asked him what he wanted, and he said, “your meat.”

I prayed for comfort from Dan on the third night of my nightmares, and in the morning, he was there, holding my hand.

I will not deny this knowledge because it tethers me to the Earth in my greatest time of need.

I believe in Dan. I believe myself.
Chapter One: I Heard I’m Still Alive: Madness and Trauma

“Is something wrong?” she said.

‘Well of course there is.’

‘You’re still alive.’ she said.

But do I deserve to be?

Is that the question?

And if so, if so, who answers? Who answers?”

- “Alive” Pearl Jam⁴⁹

Trigger Warnings: childhood sexual abuse, suicide, physical abuse, animal abuse, hoarding, psychosis, squalid environments

Shame. It’s the first word I can think of when I think about my childhood. I was born one year after my dad’s brother jumped off the Golden Gate Bridge. It was my task to fill a void that could never be filled. I was born into sadness, terrible aching sadness for a man, really a boy, that I had never known. I was born a part of him, a part of a whole. I was a cutting of another plant that had been too fragile to survive. I was the only flower in a field that had gone dry for my family. My aunt called me “little miracle”, but to me it sounded like “little marigold”, so a little marigold I was, just trying to understand why everyone was so sad and silent. The sadness was in the way my grandmother stooped when she walked and my father’s sleeping from after work until the next day. The silence was in my grandfather’s fourth glass of wine and the deep crimson cuts on my aunt’s arms. My marigold flower withered and choked on the sadness and silence.

“Mama,” I said, as we collected shells under the bridge in the park in my hometown, “Did Dan drown?”

“No, when he hit the water it was probably like hitting concrete.”

“Oh. Do you think it hurt?”

“I don’t know. I know he was in a lot of pain already. He was very sick.”

I looked up at the bridge. How would it feel if I jumped? I was five and I was also very sick, though I did not know it yet.

It’s one of my first memories. We were in the room my cousin shared with his sister at his house. I always knew there was something off about my mom’s sister’s house. The carpet was saturated with cat urine. In the corner a fish tank full of rats who had been allowed to breed until there was no standing room left. They piled on top of each other, hungry and scared. We were in bed together. I heard the door open as his sister poked her head in the room, followed by the sound of her footsteps pounding down the stairs to tell our parents.

Deflowered is the old cliche. We never talked about it. We didn’t talk about the things he made me do or how I began to enjoy them. We didn’t talk about how he would punch and kick me and bruise my arms and legs. I would go to my mom and aunt, sitting and talking in the foul smelling kitchen. Dishes with moldy food were piled up. Once again, the smell of cat piss permeated the air.

My aunt would say, “Well hit him back!”

My mom would say nothing. And I tried to hit him back, but I was too weak.

I was so ashamed. Ashamed for letting it happen to me. Ashamed for being too weak to fight him. Ashamed for being curious about Dan. All of this led to a profound loneliness that I
carried with me throughout my childhood and that’s never left me. I preferred a good book over play and at recess, I walked, balancing on the retaining walls by myself, picking flowers. My petals shriveled and my stalk turned to dust. I went completely underground.

At night, when I closed my eyes, I began to see violent scenes and monsters. I don’t remember exactly when it started. It crept up on me. Sometimes the violence was enacted on me and sometimes it was on the people I loved. I would keep my eyes open until the last moment of uneasy sleep overtook me. That is, when I could sleep. When I couldn’t, which was often, I would walk in the dark to my parent’s door. I stood on the threshold for upwards of twenty minutes sometimes, not wanting to wake them up, knowing I needed them. Eventually I went in.

It went something like this every time:

“Mama I can’t sleep.”

She rolled over sleepily. “Just keep trying.”

I don’t know why I expected something different every time.

I do not mean to paint my parents as monsters because they weren’t. My mom and I had a very close relationship. We were always laughing and playing and making up some new game. They were just clueless. I was the first child, and I’d be the only child for a while. My mom was so wrapped up in her own experiences of abuse that she couldn’t see how she was affecting me. Unfortunately, it would leave lasting scars.

The Loam That Holds Us

This story was excruciating to write and since writing it I can’t bear to look at it closely. I fly past it with my mouse, flicking the wheel until I feel safe - two or three pages past. To
unearth such trauma is painful and tiring, like taking a shovel to the center of the Earth and loading the grass and soil and limestone onto my back.

What this chapter doesn’t do is attempt to take that burden away because, as I argue below, trauma is always with us. It is wrought on the bodymind. But if there is any way to lighten the load, turn soil and grass to ash, chip away at the limestone, temper the magma with lime, we can do it through Women of Color Feminisms and Madness Studies.

Therefore, in this chapter I argue that we must take up trauma as a lived experience and an experience of our body minds. Disabled people aren’t inherently traumatized, but this ableist oppressive can wound us. Living with wounds that won’t heal then (a metaphor for trauma), how can we cope?

I offer that honest relationships in caring communities and coalitional politics can work collectively to free all oppressed peoples and can transform bodyminds. Though they will never erase our traumas, by being in connection with other people we can find ourselves feeling something close to meaning. To be clear, I am not saying that we must make meaning out of our trauma or that trauma happens for a reason. But what does happen, and what has happened deserves to be both honored and at the same time soothed. I believe coalitional politics and mutual aid, fraught though they are with harm (all of life is), are the best way to open the wounds that we all have, so that they may be soothed by the presence of connection.

Finally, in this chapter I offer madness as not a? schizophrenic’s problems to be eradicated, but an intimately personal and soulful way of being that we can decide to lean into in order to survive. Certainly, there are forms of madness that are distressing and life threatening. I have experienced them firsthand. But schizophrenics are not doomed. We only deteriorate because hierarchical oppression lets us. Because capitalism doesn’t value us.
Our mad ways have produced some of the ‘greatest minds’ in history. Those minds were mostly white cis upper middle-class men. Now, think about if every single schizophrenic had the resources to achieve those heights. Our world would be much better for it.

Thinking madly is an asset. It’s a discipline and a force to be reckoned with. It is a galaxy only known to us...that is until we help each other break out of our cages and shed our chains.

Disabled? Traumatized? Or Both?

Trigger Warning: Trauma, verbal abuse, kidnapping, racism, colonization, misogyny, ableism, sexual assault, addiction

Scientists try to attach specific meanings to certain genes that explain schizophrenia, but they do so with a caveat. 50 Epidemiological research is inconclusive as it is difficult to replicate. There are a hundred different studies saying different things, but they all agree that there is something about childhood trauma that brings out schizophrenia.

Would I be a schizophrenic without my trauma? That’s not the question because the answer is mute. Here I am, composed of what has happened and what I have been given to work with. So, I do. Sometimes. And always in fraught and mixed up ways.

Disability Studies and Trauma Studies are entwined in an uneasy relationship. Since Disability Studies focuses on the material and political conditions of the disabled body, it assumes that trauma is not a part of the equation. To speak plainly, just because someone is disabled doesn’t mean that they are wounded and traumatized. Yet, as James Berger points out, trauma occurs in the nondisabled population, so it must occur in the disabled population as well.

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Whether this trauma is due to disablement or something entirely different matters little. At the same time, Trauma studies focuses too narrowly on the individual without acknowledgement of political and material conditions\textsuperscript{51}. This has led to a cleavage in the two disciplines that has yet to be rectified. There is some benefit to having friction here, as friction can produce new thought, but it is also true that Disability studies needs to account for trauma, lest it alienate an entire population who deals with trauma on a daily basis.

Susan Wendell’s concept of the “paradigm citizen” also factors into the discussion of disabled people and trauma as disabled people are always seen as excessive in these ableist and sanist frameworks. The paradigm citizen is the white cisgender young heterosexual middle class man and it is to his standard that everyone else must live up to. Not only is this almost impossible for most nondisabled people who do not fall in this specific framework, it is almost impossible for most disabled people. A select few disabled people with economic, racial, and gender privilege may ‘rise above’ and become a slightly warped version of the paradigm citizen, but for most disabled people this trap keeps us from thriving and for many disabled people, surviving.\textsuperscript{52}

Speaking mainly about physical disability Wendell writes:

Disability is not a biological given; like gender, it is socially constructed from biological reality.

Our culture idealizes the body and demands that we control it. Thus, although most people will be disabled at some point in their lives, the disabled are made "the other," who symbolize failure of control and the threat of pain, limitation, dependency, and death.\textsuperscript{53}


The sanist ableist frameworks that define U.S. society always demand an explanation for our disablement. Trauma, which is a type of disablement, a type of emotional excess outside the normal that produces certain behaviors and perspectives, then proceeds to overflow the limits of U.S. society’s ability to recognize trauma survivors as human beings. I think of the many people in this country, mostly Black and Brown, who have been imprisoned. Prisons are not places where ‘criminals’ go to ‘think about what they’ve done’ and through literal fucking magic become paradigm citizens, nor is it a place where people go to be rehabilitated. Prisons are places that are inhospitable to human life, where people are systematically dehumanized and retraumatized.

In 2012 one in six incarcerated men in prison reported being physically or sexually abused before the age of 18 “and many more witnessed interpersonal violence.” This is where the state puts those who are excessive and unable to control themselves. This is also the case for psychiatric institutions and group homes. Keeping the body under control is seen as a desirable mark of the paradigm citizen. Paradigm citizens are the least likely to be affected by trauma, therefore everyone else must be controlled through the state, the media (especially advertising), and socially constructed ideas about the way that a bodymind is supposed to be and behave.

Making Comparisons

In contrast to my own writing, Elyn Saks discusses trauma in a more implicit way. Saks implies that her experience with the addictions treatment center turned cult Synanon was traumatic by talking about the punishments she received for acting out of turn. She writes that

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54 Nancy Wolff and Jing Shi, “Childhood and Adult Trauma Experiences of Incarcerated Persons and Their Relationship to Adult Behavioral Health Problems and Treatment,” 2012.
patients were degraded verbally until they were so broken that they submitted to the will of the staff. It sounds like a pretty traumatic experience, however, Saks seems to have made peace with it. She talks fondly of the friends she met at Synanon and it is clear at least some of her time there was enjoyable. For Saks there is not an explicit connection to trauma, which to me, illustrates the idea that there is a great variety of experience among schizophrenics.

Wang discusses her PTSD in her chapter “John Doe, Psychosis” in which she describes a terrifying, but also interesting as it pertains to this thesis, mix of PTSD and psychotic symptoms. She writes that she sees the face of her abusive ex-boyfriend in other men. For example, she says, “I used to see John at inopportune moments. This was most likely to happen in an unfamiliar city, where it seemed semilogical that I might run into him. He also appeared when I was close to home, including one night at a bar when I was supposed to be celebrating someone’s birthday.” This group of sentences she writes under the heading *Hallucinations*. I too, have had the experience of ‘seeing’ an abusive ex-boyfriend in other men, but I attributed this just to trauma and not to schizophrenia.

It is also interesting that Wang combines the research about brain death in PTSD with that of brain death in schizophrenia. In contrast to my work these two claims run against my arguments of schizophrenia as a lived experience. For me, not everything is attributed to my schizophrenia and the biological effects of schizophrenia, though I take them seriously; schizophrenia’s effects are not the center of my thesis. Instead, I am choosing to focus on the systems which schizophrenia is mediated by and through that create misery for schizophrenics. My view is we already have schizophrenia and we can’t stop the course of biology or nature, but

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56 Wang, 133.
we can and we must do our best to make everyone’s lives better while we’re here this short time on Earth. Otherwise, there’s no point in being here for me.

This is not to discredit Wang and Sak’s work. They both have a lot to offer, and as far as popular media depictions of schizophrenia they are both useful in helping the general public understand the significance and breadth of our illness. Saks makes especially salient points about the nature of psychiatric violence and Wang brings up the very real and dark truths of brain death, caregiver burnout and violence. Wang faces death head on. She’s not afraid to write about it. All I mean to say is that I’m doing something different; something that will involve not only lived experience, but a challenge to the systemic slow death and out right murder of schizophrenics in the United States.

“Scar Tissue That I Wish You Saw”\textsuperscript{57}: Wounds and Disablement

Suzanne Bost’s “From Race/Sex/etc. to Glucose, Feeding Tube and Mourning” to describe the traumatic wounding that we all go through as we to some degree as we continue on this journey of life. Bost describes Gloria Anzaldua’s diabetes, which is often brushed aside as a condition that people bring upon themselves by eating poorly and not exercising, but is actually a serious chronic condition that can kill a person, as something “that shaped her day to day existence...[and] also shaped her thinking and her politics.”\textsuperscript{58} Schizophrenia shapes my day to day life, my thinking, and my politics as well. Bost talks about the politics of the open wound, something that is not inherent, but acquired by structured oppression.


In Anzaldúa’s case, there is no cure for diabetes. Why not? Because diabetes is a disease of the poor, the slob, the waste of space. Research on curing diabetes is not a priority. Everyone wants to cure cancer because of the false image that only white women get breast cancer and only white children get leukemia. There’s this idea in racist ableist capitalist heteropatriarchy that only some people are worth saving: white middle class cisgender heterosexual people. Those are the people that supposedly deserve it because they have “earned” their status by working hard and conforming to society’s norms. This hyper-individualist self-sufficient narrative goes along with racial capitalism as it obscures the oppressive nature of Western societies.

Therefore, we must organize against racial capitalism, but we also must find a way to care for each other through our open wounds. Mutual aid does this through the sharing of resources, whether that be time, money, or consumables. Bost envisions this ethic of caring through Moraga and Anzaldúa’s life work. She says:

Can the regulatory boundaries drawn around women and ‘high risk’ groups be broken down by focusing on the material complexity of actual bodies? Studying the fluid matter itself, in defiance of the medical and cultural discourses that demonize such matter, problematizes the distinctions and identities upon which such boundaries rest. By replacing the logic of contagion with caregiving and reshaping family as “out” Chicana dykes with open wounds and incurable diseases, Anzaldúa and Moraga bleed beyond the borders of identity...fusing birth and death, love and mourning.59

Therefore, when we remove the racist ableist capitalist heteropatriarchal “logic of contagion” and replace it with an ethic of caring that not only recognizes, but loves us for our “open wounds and incurable diseases” we create a community/coalition that is not only livable, but also creates the space for people to thrive. We have to recognize the wounds in each other and relate to them in a way that nurtures who we are as people. Illness goes beyond the borders

59 Bost, 347-349.
of identity and opens up the soul to new ways of living. Some people experience this more concretely than others, that is true, but if we use our wounds to create community instead of dividing ourselves, we can uphold each other in a coalitional struggle against oppression.

This is not to say that there are people who absolutely can’t be trifled with. White supremacists, nazis, and most conservatives don’t deserve our time of day. This is also not to say that ‘we’, whoever ‘we’ are, have to educate everyone on our struggle. But it is to say, that a group of people can empathize and work together in a good faith effort if they are willing to be vulnerable and ready to listen.

I presented this idea at that conference and the moderator felt the need to comment on the fact that I described disabled people as wounded. If he had actually listened to what I was saying instead of holding on to that one sound bite, things could have turned out differently. He thought he had found a flaw within my work, so he exploited it in order to look like a good ally, but what he was really doing was knocking a disabled person's work without paying attention to my main point.

This is all to say that, yes, we do all have wounds. That is not unique to disabled people and disabled people aren’t wounded inherently because they’re disabled. But we do live in an ableist society that can traumatize people based on a number of factors. Wendell calls this ‘the social construction of disability.’ She writes:

Disability is socially constructed through the failure or unwillingness to create ability among people who do not fit the physical and mental profile of ‘paradigm’ citizens. Failures of support for people with disabilities result in inadequate rehabilitation, unemployment, poverty, inadequate personal and medical care, poor communication services, inadequate training and education, poor protection from physical, sexual, and emotional abuse, minimal opportunities for social learning and interaction and many
other disabling situations that hurt people and exclude them from participation in major of life in their societies.\textsuperscript{60}

Therefore, denying the impact and prevalence of trauma in disabled people’s lives does nothing but create an insidious culture of silence where it is not appropriate to discuss lived experience.

In a March 2012 TED Talk research-storyteller Brene Brown speaks about shame as a state of being that blocks people from being able to fully experience their lives in a vulnerable and authentic way.\textsuperscript{61} Although I don’t agree with Brown’s exclusive focus on white middle class issues and her ignorance of structural oppressions that shame people for their race, income, ability, gender identity, and sexual orientation I do think that examining the role of shame in the lives of trauma survivors is an important conversation (see chapter 2).

Scientific evidence points to higher incidence of psychosis and schizophrenia in people with adverse childhood experiences that have caused trauma. The recent 2019 article in \textit{Frontiers} (an open access peer reviewed server of journals), “Childhood Trauma in Schizophrenia: Current Findings and Research Perspectives” does a meta-analysis of 36 studies with over 81,000 subjects to determine this result. \textsuperscript{62} Based on the integrity of the journal and the size of the study from a perspective of situated knowledges it is safe to assume that this information is valid. Donna Haraway’s concept of situated knowledges demonstrates how feminist scholars can use

science without falling into the fallacy that science is objective truth. She argues that the social constructionist perspective should not blind us to real material conditions.

Instead, she argues for situated knowledges wherein the perspective of the scholar is always partial and lacking. Therefore, trauma is connected to schizophrenia but that doesn’t mean that all schizophrenics have trauma or that everyone with trauma is schizophrenic. Trauma is a slippery fish that weaves in and through every aspect of a person’s life. Sometimes it’s implicit. Imperceptible. Other times it’s big and bold, right in your face staring you down. It makes sense then, that there are different ways of going about discussing trauma, and none of them are wrong.

Women of Color Feminisms deals with multiple traumas: racism, colonization, misogyny, ableism, and more. Theorists not only share their lived experience, they give the nascent scholar tools for healing. For example, Naomi “Little Bear” Morena writes in “Earth Lover, Survivor, Musician,” “This is a time of healing and taking the blame of the rapes and attempted rapes, the child beatings I received, taking all of that pain off my shoulders and giving it back to whom it belongs.” There is a spiritualism about this statement. It’s not quite revenge. It is simply squarely placing the blame on the shoulders of the harm doers. It doesn’t condemn them; it only gives back what is already theirs.

It is so common for survivors of trauma to feel as if what has happened to them is their fault. In an ethnographic study of women who have experienced trauma and alcohol abuse in Nova Scotia author Catrina Brown found that “despite powerful stories of multiple, chronic, and

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severe trauma, women’ narratives of trauma reveal uncertainty, minimization, and self blame.”

Brown writes that dominant narratives of patriarchy are the major contributor to these factors. This is one place where Women of Color Feminisms make their intervention. They disrupt patriarchy by laying bare their lived experience which so many people connect with on different levels. Naomi “Little Bear” Morena’s work shows how the dominant script can be flipped to engender healing and comfort to survivors of trauma.

In “Acts of Healing” Gloria Anzaldua writes, “The paths we’ve traveled on have been rocky and thorny, and no doubt will continue to be so. But instead of the rocks and the thorns, we want to concentrate on the rain and the sunlight and the spider webs glistening on both.” In her beautiful way Anzaldua acknowledges the deep pain of systemic trauma, while at the same time calling her audience towards an ethic of caring that experiences life beyond pain. Anzaldua’s work isn’t some cheesy self help book, it recognizes and honors the struggles of oppressed people fighting to survive against racist sexist ableist capitalist heteropatriarchy. But it’s not just about surviving, it’s about thriving. Not thriving in the sense that one has a six figure salary, eats vegan, and does yoga every day (although we all deserve that if it’s something we want), but thriving in the sense that one can have moments of happiness despite in the “sham, drudgery, and broken dreams” of the world.

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Anzaldua calls the reader to use these moments of happiness, these moments of strength, to build a bridge to others. She writes, “it is the responsibility of some of us who tap the vast source of spiritual/political energies to help heal others, to put down a drawbridge...ayudar las mujeres que todavía viven en la jaula dar nuevos pasos y a romper barreras antiguas. (To help women who still live in cages to take new steps, and to break old barriers.)” Therefore, healing from trauma isn’t just a personal journey reserved for individuals and their therapists. It’s also a communal and political journey that can take many forms.

They’re Coming to Take Me Away:
The Violence of Psychiatric Institutions

**Trigger Warnings:** trauma, psychiatric hospitalization, violence, self harm, suicide, childhood sexual abuse, psychosis,

Madness Studies, on the other hand, is more about the trauma incurred from the violent psychiatric system of institutions. Psychiatric institutions have been places of violence since their inception in the United States in the eighteenth century. Before institutionalization those deemed mad or insane often lived with their families and were generally tolerated by their communities. Private institutions began incarcerating “violent” people during the industrial revolution as more people migrated to the cities and European immigrants entered large hubs such as New York and Chicago.

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68 Anzaldua, xxviii.

In 1887 muckraking journalist Nellie Bly published *Ten Days in a Madhouse* wherein she posed as an “insane” woman in order to dredge up the truth about how mad people were being treated. Bly found instances of physical abuse by the staff, including choking, hair pulling, and beating with brooms and fists. She also reported deplorable conditions. Wards were brutally cold, with staff leaving windows open on purpose. While staff had adequate clothing for the cold, patients were forced to wear thin cotton shifts. The food was often rotten, moldy, or spoiled. Many patients were unable to eat it and thus collapsed from exhaustion. Incarcerated women were forced to take laudanum and became addicted to it. When they became addicted their requests for more were denied causing them to go into drug withdrawal which is potentially deadly.70

Since this text was written conditions have changed in psychiatric wards in the U.S. Beds are still uncomfortable, and the food is still bad. When I was incarcerated, I at least got to wear my own clothes. Still, physical abuse is common in the use of restraints and forced medication. Saks writes that she was restrained for 24 hours in an institution in the U.S. She was told to put herself in restraints or they would be put on by force. Saks writes that although she had threatened to hurt her captors in the emergency room she had done so because they were forcibly restraining her and shooting her up with antipsychotics. Once she got to the inpatient ward, she was still considered dangerous despite the fact that she showed no signs of aggression. Saks points out that there are other ways to deescalate a “violent” person that don’t involve putting them in restraints. Moreover, you would be hard pressed to find a person who doesn’t fight back when they are scared and psychotic and someone is physically forcing them into submission.71

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71 Saks, 149.
In my experience, a Black eight-year-old girl was held in restraints and shot up with something when she refused to follow staff directions. She was scared and ran away from the staff. They caught her and plunged the needle into her arm with all of us watching this horrible incident. She weighed maybe 60 pounds and could have been easily deescalated. There is no question that racism played into this event as she was considered an angry Black girl who had to be put down by force.

Neurotypical people fear mad people and seem to have no empathy for us. They feel easily threatened especially if the mad person is of color. Mad people on inpatient wards are routinely denied their rights and coerced into taking medication that may not be right for them. Their claims about what is happening in their bodies are denied and laughed at. When I was on the ward because I had heard voices telling me to hurt myself in my family I was extremely overmedicated to the point where lifting a finger felt like running a marathon. When I told the doctor this he laughed in my face and did not decrease the dose. I asked when I could go home and again, he laughed and gave no answer.

Wang writes that she was also denied her knowledge by ward staff. Staff would ask her how she was doing and when she truthfully remarked that she was feeling well, they would ask her, “but how are you really doing?” She had to prove over and over that she could be released, but even that wasn’t enough. Mad people are denied their truths through what Maria Liegghio calls “epistemic violence”, meaning their narratives are assumed to be always already false because they are labeled mad. The stereotypes of madness that are shown in popular media and

72 Wang, 98.

exist in the zeitgeist in the U.S. make it so that a mad person is always committing madness. They can never be happy or successful or have any other human presentation. They are automatically denied their right to personal truth and written off as surplus people: the lumpenproletariat.

This culture of violence within psychiatric institutions traumatizes mad people to the point that they do not trust the system, and why would they? If the very place you were seeking help dehumanized and abused you even more, why would you go back? Clementine Morrigan writes about her stay in various psychiatric institutions throughout her teens and twenties. She was sexually abused as a child and that abuse was normalized by her family. She responded by “acting out”: cutting herself and taking large amounts of pills in attempts to kill herself. When hospitalized she was drugged but denied Tylenol because she had tried to kill herself on it. Instead, the male doctor gave her a head massage, which triggered her memories of sexual abuse. Morrigan sees her “acting out” as a way of indicating that the events in her life were not normal and that something was wrong. Her psychological pain was never addressed, and it is only when she found a good therapist that she was able to cease self harming and heal.⁷⁴

Ji-Eun Lee does a thorough analysis of ways in which psychiatric hospitalization can harm and traumatize mad people. In a study of written narratives of psychiatric survivors, they describe the coercion, repression, and intimidation that results in humiliation, distrust, and shame. Psychiatrists not only force compliance through chemical and physical restraints, they also verbally coerce people into believing their version of reality; that mad people are sick and in

need of medication. Survivors reported yielding to the doctor’s wishes because it was the carrot on the stick that got them out. Nothing was resolved on the ward and additional trauma was created.

Not everyone needs medication. I certainly believe I do based on my partial situated knowledge of neurobiology. There is a mess of social construction and science here. A pile of spaghetti. And just like spaghetti it’s hard to get on to a fork. It slides through tines. Sometimes it’s just way too long or way too short. Regardless of my personal situation, what these sources have shown is that there is an over reliance on medication in psychiatric institutions and in U.S. society in general.

In the United States people are expected to consume psychiatric services in a particular way, and only upper middle class white people are allowed to talk about them. At the time that *Mad Matters* was written psychiatry had taken on a campaign to convince the public that crazy people weren’t abhorrent, just sick. The consensus of the book is that this has not worked, but I would argue that it has worked for a certain subset of the population. White middle class able bodied people have normalized consumer therapy. They go once a week to their therapist to talk out the everyday problems of life: relationship issues, work trouble, stress. Seeing a therapist for this population has become just a regular part of health maintenance. You see the therapist so that you can continue to be productive in your working life; it’s a capitalist pursuit. But you can’t be too crazy.

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In this twisted system trauma layers on thick and mad people are supposed to try to squeeze into that white middle-class able-bodied paradigm and become productive members of society, but the game is always stacked against us. We become the lumpenproletariat; those who cannot be organized. Surplus people that capitalism relies on to maintain itself. But what if we responded by becoming madder instead of trying to fit into a mold that we’re too crazy, too trans, too Black, too poor for?

Jennifer Poole and Jennifer Ward describe their experiences with grief as medicalized and sanitized by psychiatric institutions and U.S. culture at large. They cite prolonged grief as coded in the DSM as a symptom of the way that we are not allowed to grieve in unintelligible ways. The linear grief process is flawed. Grief is spaghetti too. And isn’t trauma all about grief?

We should be allowed to grieve our trauma for an extended period of time. We should be allowed to grieve as much as we need even if that means forever. It’s been 25 years since Dan jumped, and my family is still grieving it. Still wondering what it would be like if he were here today. My trauma is grief. I grieve the childhood I lost. I grieve the cousin, who was my friend at the time. I grieve for the rats. I grieve for missed opportunities at love. I grieve my illness. And I’m not going to get over it.

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Thinking madly then, what would it be like to not get over it? To live with these weights, these incurable traumas, but live madly? Channel madness through your veins and let it spark creativity. Cry when you need to. Feel and not feel. Know that you have a right to exist when believing “seven impossible things before breakfast.” “Break open the bone” and tell the raw story of you and how you came to know madness. This is the benefit of madness: it can produce genius, but much of it is struggle. This struggle is not trivial. These are our lives, our bodies on the line; this is what I will discuss in my next chapter.
Chapter Two: A Body Persisting

Trigger Warnings: body image, disordered eating, self harm, fatphobia, violence, psychiatric hospitalization, medical abuse

I don’t shower as often as I should, but when I do I take the time to cover myself in lotion afterwards. This is something my mom has done since I was little, rubbing her legs vigorously and stretching her arms upward behind her back to get the middle in the steamy bathroom. In the exact same pattern I do it now.

I always thought it to be kind of unnecessary. Does the body really need that much moisturizing? Recently I’ve come to a different understanding. Because it’s not about that. It’s about feeling your body, warm and alive in a world that so often forces you not to feel. I can feel the soft hair on my legs, the weight of my stomach and the smallness of my shoulders as I make circles with the lotion.

I hate my body. I’ve hated it for a long time. I hate it because it’s fat, because it’s unruly, because it’s always tired. I hate it because it has limits, because it’s addicted to nicotine, because of what I’ve done to it. I have these scars from burning it, cutting it and beating it.

My body is the collateral damage of my illness. I like to say that. It sounds right to me. The meds made me fat and the scars are proof of what I’ve done to stem the pain. But here I am still rubbing the lotion, patiently, not fast like my mom. It’s true that I still want to escape it, this fucked up body: to be thin and without scars. But it is also true that I want to begin to live with it, but not because of some mighty ideas about loving myself.

The slogan of the diet industry is “if you can’t love your body, change it.” Body positivity declares that we can and should love our bodies no matter what. This seems unattainable and frustrating, especially for someone whose size and queerness are barely
reflected in that movement, partially because it has been corporatized by companies like Unilever, who fittingly make both Dove and Axe products.

My body is pretty gross sometimes, and I don’t mean it’s objectively gross. It does gross things. I have weird gross pimples and I certainly don’t love that. Plus, to be disabled means to a certain degree for me that my body is fallible in a way that a lot of people don’t experience until they are older. It’s more complicated than loving myself or accepting myself. It’s the push and pull of hate, desire, care and the recognition of the beauty of my bodymind that has survived so much hurt, but also given and received so much love.

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I’ve always loved to eat. I’ve always loved to cook. From the time I could stand I would get up on a kitchen chair and peer over the counter as my grandma flattened out salmon patties and mixed up frosting, the whirring of the blender, deafening and exciting. Once a week after school my grandma picked me up and we went to the local deli across the street. It was a culinary wonderland to me filled with everything I could imagine: fried chicken, sandwiches, sushi, and even a Starbucks. I would slurp down my green tea Frappuccino and whatever other delectable snack I’d gotten that day, sharing my elementary school woes and triumphs with grandma. I remember talking frequently about my troubles with my other side of the family.

“He’s such a meanie.”

“Well, your cousin has a lot of problems,” she said. “He’s mean because other people have been mean to him, but it’s still not right. Don’t play with him. Try to just ignore him.”

Maybe the advice was unrealistic. I couldn’t escape the situation I was being put in time after time, but it helped to have someone to listen to me. Someone to empathize with my
struggles. These are some of my favorite memories and sometimes I wish I could go back to that
time where everything was so simple.

In sixth grade, I decided to become a vegetarian. I also decided it wouldn’t be fair to
make my mom cook all my vegetarian meals, so I took on the responsibility of cooking for my
family. Standing in our old kitchen with the window open, the cool air breezing through as my
arms were up to their elbows in hot soapy water I marveled at the beauty of the field behind our
house. I turned on the burner and let the pan heat up before pouring in the olive oil, just like
grandma taught me. I tossed in the chopped onions and let them sweat and then the garlic. The
room exploded in fragrance.

Those memories are spiritual to me. Cooking is spiritual to me. The bodily movements of
cooking – chopping the vegetables, scraping and stirring, pinching the spices between my fingers
and letting them flow down into the pan – the rhythm of cooking was the only rhythm I had. It
was a place where I really knew what to do. I wasn’t clumsy, or too big, or too awkward and
fumble fingered. Time would go away, and I focused on my hands doing something of import.

Of course, cooking is an activity of the body and mind, or more properly the bodymind,
but I think that wrapped up between the letters of the bodymind is the spirit/soul. With all the
talk of “Do we have a soul?” or “Are we just brains simulating the concept of soul?” it seems
like Western Imperialism has another thing they want to pin down and stick in a glass case.
Whatever spirit/soul is/are we know them when we feel them deeply, it doesn’t matter what we
call them or whether they are scientifically quantifiable. This is about what we know, our sense
of Audre Lorde’s erotic. And that is just what I feel when I cook.

Cooking good food is one of the biggest ways I show care for other people. I take pride in
my ability to feed people, and the fact that I make tasty, nourishing and comforting meals.
Cooking was also one of the few ways I could explore the world as a working class kid living in Northwest Indiana. I’m sure my white kid versions of Thai spring rolls, bao (my mom had gotten a bamboo steamer for her wedding) and North African peanut stew weren’t in the slightest bit authentic, but they gave me a way of seeing that there was a world beyond my own, filled with exciting flavors and people who were different from me in many ways, but also enjoyed food and cooking in the way I did.

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How I came to have such a bad relationship with food is a complicated story.

I went to the psychiatric hospital when I was fourteen because I was hearing voices telling me to hurt my family. Now I know that I could have dealt with them, but I was so scared at the time. At the hospital, the doctor put me on nine milligrams of an antipsychotic called Invega. I was so drugged I could barely move. I don’t remember much. I remember watching Gangland like a zombie and also wondering why they let us watch Gangland. I remember the young Black nurse with long hair that offered to walk with me during our recreation hour. That was the only guidance I was afforded. I remember the food. Disgusting, yet eating was the best part of my day.

The night I got out my mom cooked one of my favorite recipes: pinto bean and red pepper quesadillas with cojack cheese. I was so relieved to be able to eat good food again, but that’s when the binging started. I ate and ate and ate. I couldn’t stop eating. I came home from school and ate a full meal every day before dinner. I ate anything that wasn’t nailed down. When there were no snacks, I simply ate sugar.

At the time I was reading a lot about Buddhism, and I came across the concept of the ‘hungry ghost’. In Chinese Buddhist teachings hungry ghosts are beings that walk the Earth in
search of nourishment, but their mouths are constricted and no matter what they consume they
can find no joy. I walked around like a hungry ghost. Filling myself with food, but like the
common American conception of a ghost, it went right through me. I felt transparent. Falling
through chairs, slipping right through my loved ones – like I wasn’t really there. All the while
my flesh grew and grew, but I couldn’t be satisfied because what I really needed was the
affection that my parents couldn’t provide. They were in their own state of melancholy and
worry for myself and my future, fighting their own ghosts.

I decided to throw up after every meal, hoping to get my weight down. I wanted so
desperately to please my family; to say that I was okay. If I was thin, it meant I would be okay.
Lucky for me, I can make myself throw up without sticking anything down my throat, so my
parents just thought I was throwing up because of anxiety. And it was anxiety, anxiety that all
this eating would kill me. That I’d get diabetes and heart disease. That my obesity would prevent
me from doing the things I love.

I weighed 150 when I came to the hospital. In a year I was 180. In another year 230. I
came to rest at my current weight after I gained 30 pounds my freshman year of college.

I am fat. My stomach protrudes over my legs, hanging down like a sack of potatoes. My
thighs are rounded and full. My arms are jiggly. I have a double chin.

I am fat. My belly protrudes over my legs; it rounds out at my thighs, like the full moon.
My belly button is a deep mysterious cave. My thighs are umptious. I put them together in the
shape of a heart. My arms are jiggly like jello when I’m dancing to David Bowie alone in my
kitchen. My calves are like tree trunks, my long hair makes up a layer of soft brown moss that I
haven’t shaved since high school. My cheeks are rounded. My partner loves and envies them.
They say when I wear makeup I look like a model.
I rewrote that paragraph on February 11th, 2021, when I was ‘in a better place.’ The first draft seemed so hollow. Hollow like a hungry ghost. But I am not a hungry ghost anymore, most of the time. So, this begs the question, on February 11th, 2021 do I love my body? No, but I have reckoned with its truth. The truth of my body is that it stays the same no matter what I think of it. It’s always there for me. Heart beating, lungs breathing, synapses firing in all directions, white blood cells guarding me, skin cells shedding and multiplying. The truth of my body is that it’s the only one I have. Bodymind connected, regulating my pulse and weaving my dreams and nightmares.

Unfortunately, many people, institutions and governing bodies do not see my body the way I see it on February 11th, 2021. Every doctor I’ve ever seen has insisted that all my problems stem from my fatness. I was seeing the dermatologist for acne at age 15 when she noticed dark insulin resistance patches on my skin. With her bleach blond hair, tiny frame, and perfect skin she told me I had diabetes based on this symptom and my weight instead of getting a blood test first. This sent me spiraling into a deep depression. What was I going to do with this additional diagnosis? I couldn’t fathom living with more than was already on my plate (no pun intended). Eventually she did give me a blood test, but it came back negative. Years later I was diagnosed with polycystic ovarian syndrome, which can cause the same sort of dark patches. I never went to see the dermatologist again.

Those dark patches are mostly gone, now that I have the right medicine. I still weigh over 250 pounds, but I don’t throw up anymore. After going on a new medicine, the urge to binge subsided. I don’t overeat anymore, but I still can’t lose the weight. It’s tiring, living with this. Living through this. My self-esteem is still pretty low sometimes. I can’t seem to shake the
feeling that when people look at me all they see is fat. Even my loved ones. I feel disgusting sometimes. Sometimes I still eat my feelings.

I avoid the doctor at all costs. Even when I had lost 18 pounds in 2020, she asked for more. Instead of congratulating me she said, “What are you doing to lose more?” implying that I hadn’t lost enough. All she wants is more, more, more. She won’t be satisfied until I lose 100 pounds. Until I am nothing.

Nothing was what I was when I didn’t have a voice. When I let a boy abuse me. When I couldn’t find the courage to leave my hometown. When I didn’t have big plans for my life. I am not nothing. I am something; something real and fleshy and alive in all the glorious and gross ways humans are. So, I will not settle for nothing. I will never be nothing again.

After that disaster, I got a new doctor, to whom I vehemently professed at our first visit that I wasn’t planning on losing ‘the weight’. I came in three months later having lost 20 pounds. Fill in the blanks. Still, I applauded her, as she managed to keep her mouth shut about it until I was getting my coat on to leave.

“You need to lose some more weight.”

I looked at her with a mix of hate, hurt, and the general worn-downness of every fat person who manages to get up the strength, let alone the resources to go to the doctor.

“But you already know that” she replied sheepishly.

My silent screaming response, “No shit!”

Obviously, I’m not going to lose ‘the weight’. In the ups and downs of my illness (mostly downs), it’s too difficult to stay on the straight and narrow all the time. To eat squeaky clean; to exercise every day. To be my best self. I’m not bringing my A game every day, or even once a
week sometimes. But I have to allow myself some compassion. It’s okay. I have to trust not that
it will be okay, but that it’s already okay.

I will live through this, beautifully fat, disabled and queer and sometimes genuinely
satisfied, but more importantly alive in flesh and bone and sinew. A meaty, hairy, gross and
magical body persisting: despite doctors, despite this fatphobic ableist world, despite my
impulses to destroy myself. A hungry ghost no more.

An Analysis but Not a Dissection

My fat body is queer. It is queered through an oppressive capitalist system wherein I was
taught to hate the things I loved the most. The joy I held for cooking was robbed from me and
my relationship with food became distorted and harmful. Although I have regained that joy
through the political practice of seeing fatness as beautiful and worthy, I have trouble seeing it in
myself. Furthermore, there is a certain way of being fat that has become more accepted, but the
‘ugly’ part of fat, the ‘big belly,’ is dissected from the fat body with the use of computer editing
and plastic surgery. (Roxane Gay calls this ‘Lane Bryant fat.’)

As my mother said once, while holding a pair of scissors to her very small belly pooch, “I
just want to cut this out.”

The social conditions of the medical industrial complex that produced my fat body also
sought to destroy it in favor of a thin version of myself that would be better able to produce for
capitalism. The point of the above essay is that I will not be destroyed, but it is tiring to keep this
bodymind whole. To resist the fragmentation that splinters me into ‘just fat’- an unsexed being
who only consumes.
I am a queer failure. I fail to conform to beauty norms, and I’m (happily) failing at heterosexuality. In *The Art of Queer Failure* Jack Halberstam writes, “In fact if success requires so much effort, then maybe failure is easier in the long run and offers different rewards.” And I would argue the same. It’s so much easier not to care too much about what I’m eating. I mean, I know eating out four or five times a week is not healthy for me, but sometimes it’s the best I can do. I ‘try and try again’ to eat a more nutritious diet, but inevitably I find myself in the drive thru sometimes.

We all know that fast food is ‘bad for you’ and it’s ‘what’s killing us’ or whatever, but behind those hollow statements is the specter of personal responsibility that asks us all to do the impossible task of ‘living our best lives’ while it breaks our backs for racial capitalism. There is so much privilege that allows some of us to ‘live our best lives’ and when we poke through the veneer of social media influencers, movie stars and even upper-class families we often find serious mental health issues, addiction and disordered eating.

So Halberstam says queer failure often produces different results. My results are that I am a much happier and less disordered person. This is not to say that I eat whatever I want whenever I want but failing over and over has allowed me to be at peace with my health most of the time. I know I am doing my best. Being a queer failure has also allowed me to actually be a healthier person. It has opened my world to nutritious food that satiates my bodymind, and that I actually want to eat.

I am no longer wedded to the idea that I must count calories or switch carrot sticks for crackers. Because guess what – I fucking hate carrots sticks and I fucking love crackers. I don’t

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agonize over the particulars: You shouldn’t eat butter. Butter is bad. Don’t eat too many nuts. Nuts have fat in them. Don’t put so much hummus on your crackers…don’t don’t don’t don’t.

I believe fatness is a lived experience in a body. Some of us were once thin and some of us have always been fat. The word ‘fat’ is constructed as a term to demean people, especially femmes, queer people, and people of color and with that term comes the loaded attachments of irresponsible, lazy, gross, ugly, etc.

Fatness is constructed through the myth of the deserving poor. You are not deserving if you have already taken in excess which is assumed by your body. Fatness is used to deny basic human rights to people of color, especially femmes of color – as in the myth of the ‘Welfare Queen’. Associated with this falsity of the deserving poor, fat Black women and femmes are assumed irresponsible because they cannot gain ‘control’ over their own bodies. In actuality fatness is in part caused by the scarcity of resources (i.e. food deserts), long slave wage working hours, and lack of safe outdoor space for many urban women of color that are designated as ‘welfare queens’.

But there is nothing inherently wrong with being fat. The idea that weight is the problem has been fueled by the diet industry to coerce fat people into buying products that don’t work. Extreme workouts such as the P90X series encourage fat people to just ‘work it off’. This is an aspect of biopower sustained by the state because normalcy (thinness) is desired for an ‘able bodied’ and productive workforce, even though we know that fat people can be no less able-bodied than their thinner counterparts. At the same time, everyone who lives in the US, especially the working class, is being fed extremely addictive food substances such as high fructose corn syrup and monosodium glutamate. These substances are bad for everyone, but they
may lead to weight gain depending on a person’s genetic makeup, social position, and access to resources.

When people don’t have access to healthy food, outdoor spaces/gyms, time to cook/money to buy pre-made healthy food, time for physical activity, competent medical care, childcare, etc they may gain weight, but that is not the point. There are plenty of ‘skinny’ people living the same lives with similar health effects. With the disintegration of the social safety net more and more people are going to have poor health outcomes and live shorter, more stressful, more harmed lives.

In the disciplinary society of the U.S. blame is placed on the individual because analyzing structural inequality would mean that we would collectively have to face the harm we are doing to fat people and therefore all marginalized people.

In this chapter I am using this story of my lived experience as an entry point to argue that systemic trauma is played out on the bodyminds of marginalized people. Capitalist myths devalue the disabled bodymind and render our lives worthless in the face of systematic oppression. Telling our stories counters this dogmatic vision where everyone is forced into productivity or ground up under the weight of oppression or, more helpful to capitalism, held up as a problem to be erased in the culture war. Again, I am not arguing for our worth here. I am not asking the state to “please not kill us.” I am uplifting the value of schizophrenic and disabled bodyminds and illustrating the cruel raced, gendered, and classed challenges we face as a political class.

In analyzing Sona Renee Taylor’s work on body shaming I offer a way to relieve the self-abuse inflicted on schizophrenics and trauma survivors by the broader culture. We are shamed
for our unique experiences and bodyminds and not allowed to flourish as the valuable, creative and learned people that we are.

I offer a different way of thinking about trauma that is physical, psychological, intergenerational and socially situated in the matrix of domination through the work of Bessel Van der Kolk and Sami Schalk. In a society where the mind is privileged and the body is only correct when it is that of the paradigm citizen or default body we must find a way back to our bodymind through honoring all the ways that trauma affects us.

I provide a short history of prisons and psychiatric institutions in order to analyze how disabled people are funneled into these institutions as a result of body shaming under capitalism. The inequities in quality of life that all disabled people become plain when looking at these systems, and even having significant privilege does not mean that a disabled person is necessarily immune to these ableisms. Furthermore, the way that disabled people are cast through inspiration porn distorts us again into two categories: the deserving and the undeserving, both of which completely misinterpret our actual lived experiences.

I analyze the language of assessment in the medical practice as a splitting of the body mind that causes harm in the form of misdiagnosis, untreated side effects and chemical dependency. To better understand the phenomenon, I use Kimberle Crenshaw’s theory of intersectionality to demonstrate that it is possible to care for each other as whole human beings. I take a node of intersectionality to examine how ‘mad behaviors’ mark schizophrenics as unworthy and subhuman and theorize how people who do not experience this madness react to such displays of grandiosity with confusion, fear, loathing, and finally shame. Alternatively, I analyze what is like to be a more privileged schizophrenic and evaluate the practice of speaking for others in this context.
I end the chapter by building upon the theories of Suzanne Bost, Donna Haraway, and Jasbir Puar, suggesting an alternative way of seeing our bodyminds. Through this burgeoning theory we can see how we are connected in material ways as unstable organisms that are constantly changing, with permeable borders. I use these theories to interpret the process of taking psychiatric medication and to analyze my lived experience of a psychotic episode and how the psychotic episode actually does bring together bodymind, experience, and emotion, though it is not a pleasant experience for me. Illustrating this serves to examine the ways in which even the emotions and facial expressions of the mad and disabled are shamed and trained out of in service of conforming to a heteropatriarchal society.

“Your Body is the Most Beautiful Void”78: Trauma and Sensation

Trauma survivors often have trouble being able to feel their bodies. For example, when asked to focus on a certain body part they are unable. When asked to identify an object that was put in their outstretched hand while they closed their eyes trauma survivors had difficulty doing so. One woman said:

I have... no human sensations... each of my senses, each proper part of myself, is as it were separated from me and can no longer afford me any feeling; this impossibility seems to depend upon a void which I feel in the front of my head, and to be due to the diminution of the sensibility over the whole surface of my body, for it seems to me that I never actually reach the objects which I touch.79

In my experience I often feel pain when asked to do body exercises that ask me to focus on certain parts of my body. I feel like I’m on fire and it takes a great deal of energy to bring my


wandering soul back into my body. It’s not that I believe that the mind and body are separate, I believe this separation occurs when trauma has bifurcated us as a survival strategy. By leaving what tethers us to the Earth we don’t have to feel the deep sorrow of traumatic experiences, especially when those experiences have been wrought out on our very bodies.

In the book *The Body is not an Apology* Sonya Renee Taylor describes how ‘body shaming’ culture in the U.S. has harmed all of us. Taylor is not just talking about fatness, but about any deviation from what she calls the ‘default body,’ (similar to Wendell’s paradigm citizen) which is what we picture when we think of the perfect culturally sanctioned body: probably white and thin with blond hair and blue eyes. The effects of this body shaming are not just rhetorically harmful, they are violently imposed on bodies, causing deep traumas and wounds.

An obvious example of this is the murder of Black people at the hands of the police. To Taylor racism goes back to the body, and I would say more precisely the bodymind. Trauma is wrought on the body through a society structured around oppression. Taylor writes that changing these oppressions starts with ourselves, but I am positive that she doesn’t think that we can change the police’s body shaming racism. Taylor’s work is centered on our own communities and what we can do to uplift each other whether we be neighborhoods, coalitional groups, unions, or families etc.

Individually, marginalized populations are subject to this persistent body shaming, but Taylor extrapolates this to the community. Taylor’s approach is one of changing our thoughts about ourselves and other people through the practice of radical self-love. She writes:

I know radical self-love can seem like a planet outside any galaxy you’ve heard of. I want to assure you: radical self-love is not light years away…it lives in you. It is your very essence... think of body shame like the layers of an onion. For decades in our own lives and for centuries in civilization, we have
been taught to judge and shame ourselves and consequently shame and judge others. Getting to our inherent state of radical self-love means peeling away those ancient toxic messages about our bodies. Taking Taylors advice then, it is possible for we trauma survivors to reclaim our bodies. We do this partly by understanding where these messages come from. In order to ‘peel away the layers’ and get to our radical self-love Taylor insists that we must understand the conditions that have brought us to self-loathing and self-abuse. The deepest sources of body shame on an individual level are abuse and trauma at early ages, most inside the home or family sphere. People who are traumatized at young ages, such as myself, often feel that their bodies are bad or wrong. Taylor says that this can profoundly affect the way we treat ourselves; it certainly has affected me in those ways. Through a process of de-indoctrination, we can begin to work away at that moldy old onion to find the tender root.

Taylor leaves us with a final thought in this section of the book. Quoting adrienne maree brown she remarks, “‘I touch my own skin, and it tells me before there was harm, there was a miracle.’”

“I Keep These Visions to Myself” Surviving Trauma and Lying for Your Life

Trigger Warnings: trauma, psychiatric hospitalization, self harm, violence, slavery, incarceration, racism, chemical restraint, death, memory loss, psychosis, aphasia

The bodily sensations that come with an added schizoaffective diagnosis designate schizoaffective disorder as a condition of the bodymind. I sometimes feel ‘trapped in my mind’.

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81 Taylor, 40.
hypothesize that this is the medicalized language that I have been taught via the myth of Cartesian Dualism. This is compounded with my defense mechanisms to abate the pain of trauma; I put myself all in my head because I cannot bear to feel. Unfortunately, this behavior is rewarded in U.S. society, which privileges the working of the mind over the body. We decry manual labor and service work, while upholding the idea that we all must get our 150 minutes per week of physical exercise.

As a child, my brain was encouraged. I got good grades and read books. I was sent to enrichment camps for ‘smart kids.’ I did exceedingly well on standardized tests, which measure certain types of abilities but not a vast amount of others. I would find myself doing well on the placement test. In the class, however, I struggled to keep up, which was a blow to my self-worth because I believed that all I had was my brain. I continued to go on believing this until junior year of college when my therapist quietly proclaimed, “You’re really in your head aren’t you?”

Not only is there a body attached to my head, there is a system of nerves throughout our bodies that connects the whole of us and governs our everyday lives. According to trauma expert Bessel van der Kolk, our bodies are more of a network of interconnected pathways of nerves that communicate with our brains to produce somatic experience. When I believe that bugs are crawling all over my skin there is a complicated misfiring of nerves happening inside my body that produces an experience not just for my mind but for my body.

In *Bodyminds Reimagined*, Sami Schalk uses Black speculative fiction to theorize about disability. In her chapter on mental disability, specifically a schizophrenia like mental disability, she describes the character Lizzie from the book *Stigmata* by Phyillis Aleisa Perry. Upon receiving her grandmother’s truck Lizzie begins to experience the memories of her grandmother.

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83 Kolk, Bessel van der, 83.
and an ancestor who was enslaved. She not only mentally experiences these flashbacks, but physically does too, sustaining an injury that makes her parents think she was attempting suicide. Her parents send her to a psychiatric hospital, where she is interred for 14 years. She only is able to get out when she starts to conform to the doctor’s expectations of what a neurotypical person is. Despite not having gotten any help with her experiences, she is only able to leave through the facade of wellness.

Schalk’s work illustrates two things: one, that mental disability can be linked to somatic experience and the physical body and two, that mental disability is marked differently on the Black woman’s body. The fact that Lizzie isn’t believed by her parents and the doctors and medical staff is directly related to her Blackness and her gender as well as the intergenerational or ancestral trauma handed down to her by her forebearers, just like the trunk. Schalk writes that “disability in this novel is an allusion to the historical legacies of slavery. Lizzie’s disability is also a real and, at times, incredibly painful experience impacting her bodymind and the trajectory of her life.”

Schalk’s analysis connects to my life writing insofar as it is an accurate portrait of intergeneration trauma from slavery and the physical implications of trauma that in many ways define my life.

My intergenerational trauma is not that of African chattel slavery, but of untreated mental illness, physical, psychological and sexual harm, and the poverty that my ancestors experienced. When we create life, we often pass down our traumas just as much as we pass down our personality traits, most of the time without even knowing it. Even if we make a concerted

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85 Schalk, 61.
effort to stem the tide and protect our children from our own pasts, just as my mom did, we often end up inadvertently doing so anyway.

Although the harm my family has produced and experienced is not a result of structural racism, there is still a class aspect to it. A lack of economic privilege, poor education that did not identify my parents and grandparents for disability education services and a genuinely broken, discriminatory and ignorant healthcare system set my ancestors up for failure as they dealt with both biological mental illnesses and traumas. As a white genderqueer man, I have many privileges that protect me from the direst of circumstances. Even so, healing trauma from any subject position is hard work, physically, mentally and emotionally. This is why Schalk’s analysis is so important. Along with the work of Bessel Van der Kolk, Schalk demonstrates that trauma is more than just a feeling. We can no longer limit our conception of trauma to the battlefield, although it is important to discuss and hold the truths of those who have been affected by war. Trauma is every day; it’s the little things. Lizzie’s disability affects her every day, not just in her physical flashbacks, but in the way she is treated as a ‘mad Black woman’ and how she is constantly robbed of her truth by doctors and even her own family.

My everyday trauma is connected deeply to my mom’s. When I lived at home, I would try to clean our house before my mom got home from work, knowing she desperately needed a clean environment. My mom was raised in a house where it was never clean. Her parents were too depressed and execratively dysfunctional to take out the trash, let alone clean the bathroom. Now that my mom doesn’t do their cleaning, the house is a putrid mess. Whole meals sit out for weeks and grow mold. The entire place is piled so high with broken and unused objects that you can barely walk through it. When I didn’t get our house absolutely perfect, my mom would come home angry.
“It’s disgusting! I can’t believe how filthy it is in here!”

In actuality it was always just one trashcan not emptied, one bathroom towel on the floor, or a few of my sister’s chocolate milk cups sitting by the couch. For my mom though, it put her back in a place of so much pain. Where her sister beat her and screamed insults at her; where her mother did nothing to protect her.

At the same time I was like a rabbit, in a perpetual state of terror, trying to make everything perfect for my mom, so she would be happy. Inevitably, I would always forget one thing and that would set her off. I waited for the tirade every time she came home. My adrenaline pumped and cortisol coursed through my veins when she opened the door. But I thought maybe, just maybe I’d get it right this time – I never did.

This is how the trauma is passed. My mom’s not a neat freak. She’s a brutally traumatized woman, as were her parents who were paralyzed by their own trauma that they could not escape. They chose to shut down. My mom chose to scrub it all away. I’m not sure what I’m choosing, but I think it’s to face it. Not in a bold and dramatic way. It’s just to look at it, let my gaze soften and let myself be taken by the undercurrent. I’m still breathing. I’ve learned how to breathe under water now. I know somewhere there is a river basin with a sparkling sandy beach and I will float up. All of me will float up; my whole bodymind and I will be cleaved in two no more.

Locating the Bodymind in Systemic Oppression

In the reality of systematic oppression, some bodies are treated differently than others and deemed either worthy or unworthy of care. Disabled people, especially disabled people of color, are incarcerated at a higher rate than those without a disability. This produces additional traumas and reproduces already experienced traumas through the subjugation of prisoners by guards,
prison administration, and the state. Specifically, “more than half of all prison and jail inmates were reported to have a mental health problem.”\textsuperscript{86} Cook County Jail in Chicago has been considered by some activists to be the largest mental health facility in the country.\textsuperscript{87}

Prisons in the 1700’s began as a way to hold people until they paid their debts off or while they were awaiting trial, but as mercantilism switched to capitalism institutions grew up to warehouse disabled people, aging people, and ‘criminals’ together. During the Progressive Era reformers pushed for these institutions to create model citizens out of incarcerated people, an idea which still exists today but has had its funding gutted since the drastic cutting of social programs starting in the 1980s. Rehabilitation serves capitalist purposes to make disabled people worker drones that feed the machine. The goal is not to empower them to be leaders and activists, it’s to serve neoliberalism.

Despite the push for reforms, conditions in prisons and institutions have never been adequate. Multiple investigations throughout the years (Kinsey, Rosehan et al., Wang, Saks, Tampa Bay Times, Kobielski, Dix), such as Nellie Bly’s (above), have revealed inhumane conditions such as freezing temperatures, broken plumbing, overcrowding leading to the spread of deadly infections like tuberculosis (and yes COVID-19) and widespread systematic sexual assault and physical and psychological abuse. In the U.S. this comes from the Protestant ‘work ethic’ which produces the notion that there is a worthy and unworthy poor, combined with racialized misogynist ableist capitalism that sees anyone (except white mothers and housewives).


\textsuperscript{87}Samantha Michaels, “Chicago’s Jail Is One of the Country’s Biggest Mental Health Care Providers. Here’s a Look Inside.,” Mother Jones, January 9, 2019,
that cannot or will not work as a surplus population that deserves to be abused and whipped into shape until they are forced to work.

In “Mad Futures: Affect/Theory/Violence” by Tanja Aho, Liat Ben-Moshe, and Leon J. Hilton write:

Police forces were established to protect owners at a time when black people were considered unruly property, when indigenous people and other people of color, women, and people with disabilities were construed as “irrational” others against which liberal personhood was constructed. The ongoingness of racialized police violence extends this history and continues to assign to social death and literal death those deemed irrational, unruly, unstable, and unpredictable. To draw from Alexander Weheliye’s recent work on Hortense Spillers’s hieroglyphics of the flesh, the “enfleshed” are the foundations on which Western Enlightenment’s political, social, and scientific models have been constructed, and continue to bear its burden even as their embodied and cognitive unruliness resists “the legal idiom of personhood as property.”

Therefore, policing and imprisonment are used as a way of controlling surplus populations that were considered not “enfleshed” or wholly human.

In Jonathan Metzl’s *The Protest Psychosis* he tracks the development of schizophrenia from a disease of primarily harmless white women to a disease associated with Black men who were accused of being violent. During the protest movements of the 1960s and 70s, especially with the advent of the Black Panther Party, Black men taken into custody for their participation in the movement were routinely subjected to psychological exams and labeled as paranoid schizophrenics. White psychiatrists diagnosed Black men with paranoia because of their critique of structural racism that involved advocating for their rights and disrupting and bringing down the system. For these psychiatrists, there was no such thing as structural racism and any attempt

to name it and combat it was seen as paranoid that white people were ‘out to get them’ (which they were). Black men labeled as paranoid schizophrenics would then either be incarcerated in mental institutions, with no time limit as to when they would get out, or prisons, in which they languished for crimes they did not commit. \(^{89}\)

Once incarcerated disabled people, especially mentally disabled people, are frequently subjected to chemical restraint in order to restrict their bodily autonomy, contain their psyches, and promote docility when given orders. Fabris and Albrecht write that, “it is not just the fact that drugs are ordered on patients that makes coercive alone, but that they restrain the body and create dependency, using the body against the person, which results in an indefinite form of detention.” \(^{90}\) The official reasoning for using chemical restraint is to calm violent prisoners, but the effects of injectable antipsychotics in such large doses are anything but calming. You feel sluggishly trapped inside your own body, screaming out for help internally but unable to speak. So antipsychotics do not stop panic or alleviate the pain of depression and grief, nor do they work on the side effects of trauma. Furthermore, in many cases they do not stop hallucinations or delusions. Anti-psychotics, especially injectable ones given at a time when a person is under duress, are used as a means of controlling prisoners, as they obviously do nothing for the person being drugged. They are used to quiet prisoners in an environment where the staff that actually work with the prisoners face to face (not psychiatrists) are overworked and underpaid. \(^{91}\)

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\(^{89}\) Metzl, xiv.

\(^{90}\) Fabris and Albrecht, 186.

The overcrowding and underfunding of social programs within prisons and mental institutions, and the capitalist racist misogynist ableist neo-colonialist nature of the prison itself all collide to create a racialized gendered classed intersection on the bodies of the incarcerated. This plays out in different ways as far as subject position, but the disabled body is always already devalued. This is especially apparent during the Coronavirus pandemic. For example, *The New York Times* noted that, “Overall, the death rate among all patients with Covid-19 was 0.6 percent. By contrast, 1.22 percent of those with developmental disorders and Covid-19 died, as did 3.37 percent of those with intellectual disabilities.”

Developmentally disabled people and intellectually disabled people are more likely to die from COVID-19 and there is an overrepresentation of these populations in prisons and jails. Here it is obvious that the state does not value disabled lives, as it has imprisoned intellectually and developmentally disabled people and concurrently denied them access to life-saving treatments. Intellectually and developmentally disabled people are portrayed as unable to work, therefore they’re worth nothing in a capitalist society. This is true of almost all disabled people except for those who can ‘hide it,’ which often comes along with privileges such as whiteness, healthcare and flexible workplaces.

The other side of the coin is the ‘inspiration porn’ phenomenon, which portrays a usually white disabled person as a hero figure for having achieved things that ableds believe disabled

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92For example, prisons in 17 states are now providing ‘free’ tablets through outside telecom companies that charge prisoners for exorbitant amounts of money for everything: video chats, email, music, and money transfer. All the while prisons are eliminating law libraries, physical books and physical letter writing all together. Of course, the DOJ is guaranteed a portion of this tablet revenue. But without other opportunities, besides working to make the prison run for slave wages, tablets are maybe the only source of leisure. ([https://www.prisonpolicy.org/blog/2019/03/07/free-tablets/](https://www.prisonpolicy.org/blog/2019/03/07/free-tablets/))

people usually don’t. This term was coined by disability rights activist Stella Young. In her 2014 Ted Talk she says, “No amount of smiling at a flight of stairs has ever made it turn into a ramp… No amount of standing in the middle of a bookshop and radiating a positive attitude is going to turn all those books into braille.” Ableds like to feel good about ‘supporting’ disabled people through empty gestures, but they also like to compare themselves to us:

“Well at least I don’t have it that bad!”

“Wow! I should be grateful I can walk.”

“You’re so INSPIRING!”

What they really don’t have to confront, is that they are not doing anything materially to help disabled people and create a more equitable society. When they do see disabled people that are not so inspiring, like the Vietnam veteran in his wheelchair asking for money on the corner or the woman on the sitting in the street just asking for a fucking tampon, they shy away.

“He’ll just use that money for drugs!”

“Oh my god she stank up the whole train car!”

“I prefer to donate to organizations.”

Even disabled people do this to each other because the privileged of us fear that we will one day become ‘the person on the street.’ And it’s not farfetched to say so for the better half of us.

Despite the highest privileges, the disabled bodymind is always already worthless, and we have to work twice as hard (sometimes three and four times, etc.) to ‘achieve’ what ableds want us to be. There is a spiderweb we’re ensnared in at the intersections, pushing the bodymind down,

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trying to force us into the cogs of capitalism, and if it can’t do that it simply pushes us to the grave or prevents us from ever being born in the first place.\textsuperscript{95}

\begin{quote}
--“I Am Doll Parts, Doll Eyes, Doll Heart”\textsuperscript{96}:-Stitching Us Back Together Like a Crazy Quilt”

Assessment is the primary language of the medical. Insurance companies have made it so that doctors and other medical staff have to tick off boxes that contain symptoms and illnesses.\textsuperscript{97} But people are not containable in this way, and often the wrong boxes are ticked as a result of the perennial rush to move people through the machine, or the inability for doctors and other medical professionals to think outside the box. I, myself, was misdiagnosed with anxiety and depression for seven years due to this phenomenon.

Assessment of the body is always an invasion of the privacy of the person being assessed. Though sometimes medically necessary, it feels more like an assault due often time to the uncaringness and callousness of the assessor. Medical professionals are taught to see people as a collection of symptoms and organs, thus chopping the body into parts. Mind and body are separate for them; one not able to affect the other. If mind and body cross the general consensus is that it’s ‘all in your head.’ My doctor tried to convince me that my real physical pain was ‘just depression’ and that once I got my depression ‘under control’ it would go away. While that may be true, there is no getting depression ‘under control’ because it’s something that just happens to me without my consent through a combination of biology, environmental factors and multiple

\textsuperscript{95} See Alison Kafer Feminist Queer Crip “Debating Feminist Futures: Slippery Slopes, Cultural Anxieties, and the Case of the Deaf Lesbians” and Rebecca Conkley Disability Visability: First Person Stories from the Twenty First Century Ed. Alice Wong “The Anti-Abortion Bill You Aren’t Hearing About”

\textsuperscript{96} Hole, Doll Parts, 1994.

other elements that science cannot yet explain. Depression can be mitigated through therapy, medication, spiritual practice and many other strategies, but to say that it is a phenomenon that can be controlled is a misnomer because depression is a much more slippery concept than many physical illnesses.

In “The Myth of the Chemical Cure” psychiatrist Joanna Moncrieff argues against the idea that psychiatric medicines work as a lock and key mechanism. In other words unlike say insulin for diabetics psychiatric medications do not work to provide a tangible fix to psychological problems. Selective Serotonin Reuptake Inhibitors (SSRIs) work to wash the brain with serotonin in order to increase serotonin levels, which is identified as a hormone that helps humans feel good. They do not however ‘fit’ into the neuron. Therefore, the body is complicated and requires multiple angles to properly make life easier and better for mad people and it is clear that the current medical system, with all its ableism and sanism, is not doing that job.

As discussed above, psychiatric medications cause harmful side effects that can be life long. For me, the worst side effect of my medication was rapid and heavy weight gain that has caused me physical problems and psychological misery. The medication made me binge, but it also makes it incredibly difficult to lose weight even after I have stopped binging. It’s hard to watch people around me eat the exact same food and not gain weight. Less severe but equally

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100 Maisel.
distressing side effects plague me as well. Diarrhea, tiredness, poor sleep, and constant pain are all conditions I experience daily that impact my life negatively. It’s hard to live your life when you’re always going to the bathroom, or perennially tired, or not sleeping at night, or in pain so bad you can’t concentrate.

The problem of side effects is not given enough respect. Many disabled people experience them, “for example the prevalence of diabetes in people with schizophrenia is around 15% compared to a rate of 2-3% for the general population,” writes the World Health Organization, yet we are expected to be full time ‘productive’ agents of capitalism. Just because we are on medication doesn’t mean we’re ‘fixed’. In my experience, being on medication with its side effects is not worse than being off medication, but for some people it is. Often symptoms break through anyway, so now we’re dealing with both the side effects and the illness itself. The biggest problem is when medications are forced upon or implemented through coercion. Dependency is created without the person’s consent, sending them on a harrowing journey of side effects, improper dosage, and chemical constraint.

Women of Color Feminisms can be effectively employed to understand this situation in a structural manner. Kimberle Crenshaw’s intersectionality, which is a mode of analysis that helps to define the ways in which U.S. society specifically (although it can be used in a transnational context) structures itself through oppression. Intersectionality takes the ways that bodies are marked by identity and processes them through structural oppression. The first part of Crenshaw’s analysis is the ‘matrix of domination.’ She uses the metaphor of a house where the

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102 Fabris and Albrecht, 186.
more oppressed you are lower you reside in the house, with the most oppressed people in the basement. It is more difficult for the most oppressed to climb up to the top of the house where there are better living conditions and more fresh air.  

The second part of intersectionality is that all of our identities exist at a crossroads or intersection of power. But it is more than just a stacking of identity on top of identity. Crenshaw writes that these identities are constantly moving and shifting. The intersection becomes like an actual intersection and, just like a real accident, in the aftermath it is difficult to tell who is at fault. Crenshaw was inspired to create this mode of analysis based on a discrimination case where the plaintiffs were five Black women who brought an employment discrimination case against General Motors. Since there were only laws covering women and separate laws covering Black people (read Black men) the plaintiffs could not be both at the same time. In other words, they had to decide whether they wanted to base their claims based on sex discrimination or racial discrimination. They were simultaneously Black and women which left them incoherent to the law.

In terms of the mad and disabled, it is pertinent to recognize that we all have simultaneous multiple identities, but we must remember the basement metaphor. Based on the way U.S. society is structured around multiple oppressions, it is easier for some of us to get out of the basement than others. Remembering the two parts to this mode of analysis is key, lest we

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risk the co-optation of intersectionality that recenters white women at its core instead of “mapping the margins.”

However, when intersectionality is used as a mode of analysis in the activist or classroom space, it can bring people together under their common causes. There is an understanding that our oppressions are not the same and we don’t understand what it’s like to ‘be’ each other, but we are all struggling under the same system, under varying degrees, that sees us as surplus populations and either wants us dead or doesn’t care if we live or die. Furthermore, every cause needs allies, but allies don’t go shouting about being allies, they just do the work. Intersectionality allows us to do the work in communities without having to rank oppressions.

Intersectionality allows us to see how bodies are marked differently and how some bodies are not marked at all, as in most nondisabled heterosexual cis white men. People of color, visibly disabled people, fat people (especially femmes and people of color), or combinations thereof are all marked as deviating from the white patriarchal norm and therefore are used as fodder for a system that denies them value in physical (as in physical violence), mental and emotional (as in slurs, images projected on our screens and streets) and cultural (as in the devaluing of Black culture) ways.

Mad people are often denied not through their physical bodies, but through their behaviors - an extension of the body, sometimes uncontrollable - which can be seen as a node of intersectionality. Mad behavior stokes the fire of uncomfortabiltiy with outside the norm. In the U.S. people have been ingratiated by media and policy to believe that outward ‘strange’ behavior always means violence, and this is compounded oppressed identities that people (especially non-Black people) have also been taught to fear. The result is a looking away from madness, ignore it

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105 “Mapping the Margins,” 1241.
and maybe it will go away. Walk faster down the street. Mad people become less than human, someone people will not even look at. They are denied personhood through this process, which only makes the world lonelier.

Madness is feared in part because of the way that popular media depicts us. When the unhoused person is screaming at some unseen foe, they don’t see a sick person; they see a dangerous criminal because there is so little understanding of what it’s like to be a schizophrenic in this country.

White ableds are especially afraid of mad people because the ‘mad person on the street’ forces them to reckon with the fact that the U.S. might not be a free and equal society. Furthermore, it forces them to account for themselves as privileged people, who do not have the resources to help others. More likely, it stokes in them a fear of the poor that middle class ableds have been taught to believe as an explanation of their relative wealth. Without that myth, it leaves them with that reckoning of their privilege. It also leaves them helpless because they have been taught that the only thing an individual can do is donate to charities for the poor. Therefore, they don’t understand all the ways that charities are inhospitable means tested environments for mad people, people of color, women, and trans people.

As far as housed mad people, who have the economic privilege to stay off the streets, there is a deep sense of anxiety of letting anyone see what mad looks like. Madness is only revealed to the closest friends and relatives, and sometimes not even to them. I spent a lot of time trying to control my madness and shut it out. When I had an episode, I would isolate. Take myself to my room and let the terror play out. Even now, I have trouble asking for help. Sometimes I lay awake psychotic for hours, while my partner sleeps peacefully beside me. There
is a great pressure to conform to the norm. To reign the body in, even if the mind is in crisis mode.

Unwell: The Curse (And/Or Blessing?) of Madness and Embodiment

“I’m not crazy, I’m just a little unwell.

I know right now you can’t tell.

But stay awhile and then maybe you’ll see a different side of me.

I’m not crazy, I’m just a little impaired.

But soon enough you’re gonna think of me and how I used to be. [my emphasis]”

- “Unwell” Matchbox 20106

Esme Weijun Wang writes of her visit to Chinatown in San Francisco, where she was asked to speak to a group of schizophrenics. In her chapter “High Functioning” she describes her fears of becoming like the people she is talking to who look vacant, dull, and display symptoms of tardive dyskinesia, a side effect from psychiatric medication that causes uncontrollable muscle movements mostly in the face. In her push to fit into the norms of capitalism, she has great anxiety about becoming ‘one of them.’107 Though Wang will probably never be unhoused or unmedicated because of her economic privilege, degeneration is a real fear as we get older.

It’s the specter in the night as Wang and I age. Although some schizophrenics are now living into their 70’s and 80’s, many suffer from accelerated aging, resulting in a “10–25-year reduction in life expectancy (three-fold higher mortality rates) in schizophrenia patients when compared with the general population.”108 The fear that madness will overtake us, rob us of our

106 Matchbox 20, Unwell, 2002.

107 Wang, 46.

language and ravage our corporeal forms with the comorbidities that come with medication keeps me awake at night. Everyone dies in the end, and I have long expected this illness will kill me at some point, but it doesn’t make it any less difficult to know what I’m up against and to live my whole life with the shadow of knowing.

Intersectionality enters into this conversation when you think about the fact that Wang and I, as well as Saks, have the privilege of speech and executive functioning that some schizophrenics don’t. Although oppressed by our different identities, Wang and Saks being women, Wang being a person of color, and me as a genderqueer trans man, we all have economic privilege and healthcare. So, what happens to schizophrenics who are literally unintelligible? What is our responsibility to speak and where do we draw the line to avoid speaking for others?

In feminist theorist Linda Alcoff’s article “The Problem of Speaking for Others” she discusses the post-structuralist perspective, taken on by many feminists, that it is always harmful to speak for others, yet when persons of privilege do not speak up they retreat into a position that also reifies dominance and imperialism simply by avoiding the issues of structural oppressions all together.109 At some points in time, it may be politically expedient to speak for others, but I believe I can’t speak for others without first knowing them. And I don’t know any other schizophrenics; this illness is very isolating. So what I propose is a larger project that will continue throughout my life of getting to know other schizophrenics so that I can speak with them. For now, I am using my privilege to make a politically expedient gesture of speaking about

others - describing their situations in the hopes that they will be heard- even though I acknowledge this to be problematic.

Another useful theory that pertains to schizophrenia as bodymind is assemblage theory. In Donna Haraway’s “A Cyborg Manifesto” she writes that technology has become so interconnected with our lives that we can be considered cyborgs in so far as the barriers of the skin of our bodies are porous and connected to the world around us. Everything is a set of connections and we have to quell the idea that humans are privileged over anything else that we interact with. The meshing together of technology and body is most present when it comes to psychiatric medications; technology that enters the body, becomes a part of it. Medication changes you. It changes your thought patterns and behaviors; it changes your mood. It becomes a part of who you are. It is integrated into your bloodstream and it floods your synapses. So this begs the question, is this new version of you who you really are? The authentic you?

Haraway would say that it doesn’t matter. There is no one authentic truth or one authentic you. The concept of individual is a flawed imperialist myth, based on meritocracy and racist ideas that encourage white people (especially cis men) to pillage and plunder to get what’s ‘theirs’ because of a sense of entitlement that preaches they are special as individuals. In many instances, there is no universal truth because all of our subject positions are vastly different. Much like Suzanne Bost, we can think of ourselves as a set of permeable connections that converge and diverge, attached to everything in our atmosphere. A body is not just a body standing alone, it is interacting with air, water, other bodies, technology, nature, materials.

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Therefore, we can think of the psychotic episode just as Jasbir Puar does; as an event in time based on connections, not an individual who does something.\footnote{Jasbir Puar, “‘I Would Rather Be a Cyborg than a Goddess’ | Transversal Texts,” transversal.at, January 2011, https://transversal.at/transversal/0811/puar/en.}

The dusk is fading to darkness. A trigger somewhere in my bodymind is pulled. Body pain...because of the anxiety? Anxiety because of the body pain? Vivid images suddenly flash into my mind. I feel the sharpness of razors cut my torso. I can see them in my mind. I can feel them on my body.

A somatic experience that can’t be teased out between body and mind. A set of connections from the trigger of the darkness, me interacting with my atmosphere, and the bodymind feeding back on itself. The psychotic episode is emotion, action, and bodymind strung together.

Madness studies also offers up useful ways of thinking about the body, particularly paying attention to affect theory and violence. When used in the context of critical theory, affect theory concerns itself with the liminal space between language and action; in other words, emotion. The violence that has been visited upon mad people takes many forms. It settles in the bodymind, creating the bifurcation of trauma that wedges itself between the body and the mind creating a floating head that rises like a balloon in the wind with no tether. There is no right or wrong emotion to approach trauma and the bodymind. Certain emotions have been normalized as connecting with different states of being, but this is an ableist concept. Sometimes we react with scattered, unprocessed, or no emotion at all.

Aphasia, or lack of emotion in the face, is a condition of schizophrenia that is seen as off putting to nondisabled people. The assumption is if the face doesn’t move in certain ways that
are expected in U.S. society, that the person is angry, bored, or not paying attention. In any case, I shouldn’t have to contort my face, just for the comfort of nondisabled people, much like autistics shouldn’t be forced to make eye contact; but I do it and it is exhausting.

My body is often in service of nondisabled people in the sense of capitalist production and the normalization of my body and behavior. This is even more so wrought on the bodies of those who are imprisoned and forced to work for less than poverty wages. Schizophrenic bodies are taken up in institutions, prisons and psychiatric hospitals, but also schools, churches, and governing bodies, that force normalization through violence and coercion. Bodies are violated both by violence and assessment, and the constant medical gaze.

Depending on their subject position, bodies are treated differently with people of color more likely to be imprisoned and white people more likely to be medicalized through psychiatric institutions. Intersectionality teaches us that though these oppressions are different, we all have a stake in liberating ourselves from this interconnected system of capitalist racist ableist heteropatriarchy. Assemblage theory teaches us to view our bodies as a set of connections that interact with the world through our porous skin. This is especially important in the case of schizophrenia when considering the psychotic episode, not a stagnant phenomenon that happens in the head, but a living triad of bodymind, action and emotion that are strung together through powerful sensory images and somatic experience. Affect theory helps us to consider the normalization of emotions forced on the bodymind in service of capital and how all these concepts are foundationally mediated through structural oppression.

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In the next chapter I will discuss the bodymind further and its relation to accessing what I call ‘schizophrenic knowledges’ or ways of seeing and being that I have experienced to be inextricable from my schizophrenia. I will offer a situated reflection of how the bodymind expresses itself in mad forms in order to celebrate the non-normativity of schizophrenia and attempt to repair the wounds of the bodymind through the implementation of spiritual practice and deep knowing, communal healing, and radical mad activism.
Chapter Three: Schizophrenic Knowledges

Dates

“And I know that you gotta know how to listen to the sound of your own heartbeat in the dead quiet of night sometimes,

And I know that can be so frightening

But I also know that the deepest darkness is always the most enlightening.”

“I Know This” Rachel Kann113

Trigger Warnings: psychosis, suicide, self harm

When I lay there in the dark, tortured by my own imagination, I never think I’ll make it until the sun comes up again. My body becomes a rigid prison for my muscles and sinew as my mind and soul are caged by these horrific thoughts and images. Think of every scary movie you’ve ever seen, but darker, indescribably darker and more terrorizing. I won’t talk about what they are on the page. They’re too disturbing. Just know that they are there and that they haunt me every day.

But sometimes there’s a break in them. A break as clear as day. Last night there was. As I was choking on that darkness, drowning in a pool of sweat, there was this flash of a beautiful place. I was looking out of a cave and onto the beach. The bright white sand gave way to aqua marine water, crystal clear and opulent. I knew in an instant this is where Dan was. He had shown me his spirit world, wherever it is. I knew this because I had a feeling. A feeling of overwhelming calmness and togetherness with him. I could see through his eyes and I felt at peace at once, if only for a moment.

113 Rachel Kann, I Know This, 2004.
And there have been other instances of this. I had a dream he was sitting on an old exercise bike in my childhood basement, the kind from the 70’s with a big metal wheel. The kind you wonder why they even exist, so clunky and impractical. We met for the first time and he said

“I’m so sorry I never met you.”

Then he faded away.

Those words meant so much to me and they still do. I hold in my heart that it is possible to cross beyond this world and into another. The borders of reality are thin for me, so if the worst happens, the best is within reach. It’s just over there in my dreams.

Sometimes, when I feel so alone, I put my hand out and I feel warmth. Maybe it is not real. Maybe all of this is a hallucination, but it is a powerful one. One that keeps me going every day. It is no less valid than any other type of knowledge; it is what guides me.

And I know something else too. Dates are important. Dates are what guides us in so many ways. Birthdays, holidays, anniversaries. Just waiting for the next important date.

Dates are a hauntology of dates passed. An essay due, a deadline half forgotten. Like scribbles on a page erased and then marked over again, dates are scribed over and over again until we have this certain feeling that in the past this date was important somehow, or until we completely forget them.

But there are some dates burned into our memory. The things we can’t forget or the things we don’t want to. When we miss a friend’s birthday or forget to call our grandparents on their anniversary it feels bad. Irresponsible. We’ve let them down.

Important dates haunt our past and set markers in our present and future. These are my dates. My most important ones. The ones I hold in my hands and cherish when I look at the clock
and it spells them out. They are intrinsic to my identity, and they give me hope when I am on the verge of suicide. I know my sister’s (and Dan’s) birthday will come and I will feel that bittersweet spiritual love that I have come to know as comfort, even in my bleakest of times.

May 27th. On this date I write in my journal:

I’ve been 24 for approximately 12 hours and I am so proud. I am so proud that I made it here. That I made it another year. A cause for celebration. I dressed up real pretty today. Full makeup. Black and gold dress with tulle. Sparkle sprayed all over my chest and face. Dark cherry lipstick. I showered too. I made an occasion of it.

My parents came over. We had pizza and cake. Peanut butter cake with chocolate frosting and chocolate ganache in the middle because my favorite combination is peanut butter chocolate. After that we opened presents, and I am happy to say I got what I wanted.

I answered various texts and calls from loved ones. I drove 50 miles to pick up my prescription. It was beautiful outside. Sky like a marble of blue and white. Grass saturated and vivid. And then it rained for a little while hard and strong. Pounding. But we drove through it.

I mostly thought of you and how you’re not here to see it. Yes, you’d probably still be living in California, but you’d call me on the phone or text me. Strange to think you died before text messaging. I know you had an email. Your emails are somewhere out there on some server locked behind an AOL password that only you knew.

You were 23 when you died. I am now a year older than you. I wonder how that last birthday was for you. Did you eat cake? Did you get everything you wanted? I hope you did. I hope it was a good one.
I wonder what your skin felt like that summer day. Hot to the touch or goosepimply in the breeze? What were you wearing? Was your t-shirt soaked with sweat? Did the collar on your short sleeved button up hang loose? Why’d you take off your purple Birkenstocks?

Probably because it’s hard to climb over the railing in sandals.

What was your last meal? Were you hungry? Afraid? Were you ready? Did you notice the sign? The sign that said:

Golden Gate Bridge: Open to Foot Traffic

May 27th, 1937

I take the pieces of my broken heart, this broken family, this broken world into my hands on this day of my birth. I try to hold your heart and know that you’re not gone. I recover old memories that don’t belong to me. I look at photographs. I read your stories. I wish I could read your emails. Better, I wish I could hear your voice.

But I guess what I really want to say to you is that we’ve made it here together. Because I am not complete without you. Because I’ve never been just myself and you’ve always been with me even when sometimes it doesn’t feel like it.

June 24th.

A butterfly landed on me today and I knew it was you because today is the day you jumped 19 years ago. Butterflies don’t just land on people. There was another one with you and I wondered who it was. Matthew was with me and I whispered “look,” my breath catching in my throat. They saw it too. Proof that I wasn’t hallucinating, at least this time I wasn’t. You stayed for a minute, affixed to my left shoulder, and then you joined your friend. Off you went to I don’t know where, but wherever you are I hope it’s nice. I hope it’s beautiful. I hope you are well and happy and fulfilled. I count the days until we meet.
December 12th.

My sister Johanna is 13 years old today. You would have been 47 on this exact same day. Or would Johanna even have been born without you? She is a gift from you, bearing your name as hers: Johanna Danielle. She doesn’t understand the significance, the holiness of this day. Because she is just a child and it is her birthday after all.

I look up to the heavens through the sunroof in my car and think about you. The party is over and everyone is in bed. I scan the radio channels with my right hand, spinning the tuning dial slowly, a lit cigarette in my left hand. I know it will come. I know I’ll hear that old familiar song, and I do. As clear as day you call out to me. Comfort washes over me. A shooting star sparkles overhead through the clear winter sky. You wink at me as you pass me by. Just another star in the universe, but this time my own.

Dates mark my calendar as they mark my soul. My soul cracked, old, rotten, bleeding, warm, shut tight, and full of something - maybe love. I look at these scars, at what I’ve done, just trying to fill the void, to scratch an itch, to feel and I think to myself, “would they still be here if you were around?” And the answer is probably yes, because I’d still have this illness weighing me down like a load stone and you’d have yours too.

But when I’m about to break I find what little I have of you. A keychain, a blank check, a coke bottle that says “Share a Coke with Daniel” that I got on my first day of college. I take your things and place them in my hands, mulling over them. Then I put on those old familiar songs and I light a candle. Lavender and clean linen. I hold out my hand. And I let my soul open. I let myself believe because I know.
“Young Man Full of Big Plans and Thinkin’ About Tomorrow”114

Trigger Warning: racism, genocide, (child)prisons, murder, rape, transmisogyny, xenophobia

When I was young Dan was my world, but as I began to grow my world slowly opened up to other people. Real people. Friends that I believe will be lifelong and of course Matthew, who I hope to grow old with. When the world opens it can be terrifying, but it is the best and most important thing that can happen to a person. It is horrible at first. I learned about racism and injustice and genocide. I learned about the horrors of prisons, the murder and rape of Black and Brown transwomen and children trapped in cages (both in the U.S. and at the U.S./Mexico Border). I felt hopeless. I was drowning.

That was until I met Audre Lorde through her work Zami: a New Spelling of My Name. Lorde captivated me. I read more. Her concept of the erotic pulled me in. Anzaldua and Moraga’s theories of lived experience made me realize that I had something to offer. Through both these theories I argue that schizophrenics can speak their truth even in a world of multiple truths. There is no one story, but every story is important. Through intersectionality we can take these stories and lived experiences and coalesce them in a coalitional manner. We are only blinded by racial capitalism from the power of our erotic and the truth of the lived experience that lies in our bodyminds. Taking care of our bodyminds includes affective practice, but it also includes the work of coalition and relationship building.

But sometimes, I just can’t bring myself to get out of bed, and that’s where Alison Kafer makes a theoretical entry in this chapter. Kafer’s concept of ‘crip time’ allows all disabled people

114 Ray LaMontagne, Beg Steal or Borrow, 2017.
to loosen their grip on the capitalist myth that we all must always be productive. This myth, though it is not supposed to, sneaks its way into our coalitions and activist circles, when we get sick or can’t fulfill a promise we made. And it is especially hard when we let someone or something down that we deeply care about.

I argue that instead that we be frank and open about ‘crip time’ in our activism. It is important to be accountable, but it is equally important to tear down the barriers that prevent disabled people from participating in activism for fear of being ‘unreliable’. Only by widening and deepening our relationships in honest and open ways will be able to survive this neoliberal hellscape.

I end with a line of further inquiry and a promise to myself to get to know other people, though they may not be ‘schizophrenic’ in label, whose lives run parallel to me through their lived experiences of voice hearing, impossible stories and ‘strange’ behavior. Our paths diverge in many ways, and I am often in the privileged position as the helper or the giver, but I do not think that means that we can’t have a relationship that isn’t reciprocal or on their terms. It is not my job to save anyone. That’s not what I’m looking for. I’m looking for someone that when I see my reflection in their eyes I see a part of myself, I see Dan, I see a spark of that mad genius, I see us with infinite possibility despite everything against us.

Time

Trigger Warnings: dissociation, psychosis, trauma, hearing voices

I believe in miracles and I guess I believe in god, but I think things got too out of hand for them and they lost control over this universe and we are left to try to pick up the pieces. Through the deep knowing of our erotic knowledge, we can do some of this work. Audre Lorde
writes that the erotic is a deep well inside ourselves where we can bring forth our intuition. For so long intuition has been devalued as a feminine concept and ‘rational’ thought has been privileged over it. But now that we know that rational thought is always a ‘god trick’, in other words, all thought comes from a certain positionality. So called ‘objective’ thought comes from the position of the ‘enlightened’ cisgendered heterosexual nondisabled middle to upper class white man. This knowing is false insofar as it obfuscates the lived experience of others, and falsely reclaims history in order to objectify and erase the ‘other(s)’.  

Erotic practice for schizophrenics means practicing the notion that we have a deep center of knowing, even when it seems like we are scattered. Psychotic episodes and trauma trick me into thinking I am nothing but a shell for those thoughts and when I don’t know what’s real, I cannot find myself as a stable object in space. I disassociate and become a floating head again. There is a way though, in this world of multiple truths and multiple selves, to know that I am real again, and it starts by connecting to the erotic.

The erotic is much more than personal practice though. It informs the way we live, how we treat other people in our personal relationships, and how we do our activism. Lorde would want us to take the erotic a step further and face our fears of difference. In fact, in “The Master’s Tools Will Never Dismantle the Master’s House” she writes, “I urge each one of us here to reach down into that deep place of knowledge inside herself and touch that terror and loathing of any difference that lives here. See whose face it wears. Then the personal as the political can begin to

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illuminate all our choices.”¹¹⁶ It is only in using our erotic power to face difference that we can build coalition using the method of intersectionality.

In “Entering the Lives of Others: Theory in the Flesh” Gloria Anzaldua and Cherrie Moraga focus on theorizing from their own lived experience as Chicana women living on the borders of the U.S. and Mexico. It is important that our feminist, queer, and liberatory theory comes from lived experience because it is what connects the mind to the body.¹¹⁷ Without the reality of lived experiences we risk over generalizing about the conditions of all oppressed people. Lived experiences are multifaceted concepts that are different for each one of us. Common experience does bring us together, but difference can also bring us together in mutual respect for each other via intersectionality.

Intersectionality is a methodological tool that Crenshaw (see Chapter 2) developed in order to show how systemic oppressions are linked, but also how multiply oppressed people (those in the basement) are less likely to be able to ‘overcome’ their oppression. The basement metaphor is extremely useful as it exemplifies how some people who are not multiply oppressed can get ‘out of the basement’. This is an explanation of tokenism, where we see, for example, one Black CEO, and are coerced by this system of power and domination to think that is enough liberation for oppressed people. It’s not. Of course, it is important that oppressed people rise to positions of power, but this is also individualistic in nature. It is not until multiply oppressed people are free that we all will be free. Furthermore, Women of Color Feminisms relies on the collective, not tokenism, to organize. It is only in coalition with each other can we dismantle the


‘master’s house’. When Audre Lorde says, “the master’s tools will never dismantle the master’s house,”\(^{118}\) she implies that the current system which ranks people based on their bodies\(^{119}\) will not free us. Working within that system of tokenism that is meant to pacify us, while completely necessary in order to improve people’s lives, will not lead to the abolition of state and interpersonal violence. We have to come up with creative tactics, and collectivism foregrounds Women of Color Feminist organizing.

Coupled with the concept of the master’s tools, is Lorde’s erotic, which teaches us that before racialized capitalism and despite what we are told about who we are by this oppressive system we are whole and limitless beings. The erotic is a deep well of knowing that honors the whole person as a powerful, sensual, living, breathing bodymind imbued with spirit and intuition. Tapping into the erotic helps us to recognize our power to collectively change social conditions.

For schizophrenics, our lived experience is so important to knowing ourselves as people and tapping into that erotic power. While there are subconscious thoughts and desires that we may never know, and many aspects of our illness that we may never understand, what this thesis does is theorize based on lived experience. This is because, through speaking from my experience, I can present that experience and apply theory to it. It is when I relate to others that have similar experiences, that I begin to see commonalities through partial situated knowledges.

By theorizing about our own experiences, schizophrenics can not only get to know themselves better, but they can also find those who have similar experiences even though their


\(^{119}\)The term ‘bodies’ here is used in Sonya Renee Taylor’s sense of “body shaming” that includes racism, (trans)misogyny, queerphobia, fatphobia, and ableism, lookism etc.
subject positions may be different. Therefore, while it is true that schizophrenics should not have to educate nondisabled people, it is also true that this project does some of that. What it does not do is shed light on the universal experience of schizophrenia by any means. This is a drop in the bucket of the schizophrenic experience, but it has allowed me to access and process my experience and this is a part of taking hold of my erotic knowledge.

As far as other erotic practices, there are many spiritual, physical and mental activities that can help us to survive in this hostile world. Wang borrows her spiritual practice from many different traditions including astrology, tarot, and Catholicism. She writes, “By learning about the liminal I was not trying to prolong my psychotic experiences but attempting to make sense of them.”\[^{120}\] Cvetkovich, although experiencing depression and not schizophrenia, used the physical movement of swimming to produce some enjoyment while depressed.\[^{121}\] Many strategies such as yoga, meditation, tapping, and creative arts are helpful for a lot of people in order to alleviate their psychic and physical pain.

But not everyone has access to these comforts, and those of us who have privilege need to fight for a better world so that everyone can have access to the things that heal them, whatever they are. Furthermore, not all of these strategies may work for people, especially when they are deeply depressed. I know when I am very depressed all I do is stare at the wall and chain smoke. And that’s something I haven’t figured out as of yet. I haven’t figured out how to live with the incredible pain of my trauma and illness. I’m not sure if I ever will, but I think if I could know that there were people out there like me, if I could meet some of them, then I would feel a whole lot better.

\[^{120}\] Wang, 194.

One of the things I think is most difficult for me, and many other disabled and chronically ill people, is the concept of living on ‘crip time,’ which can feel stifling to the erotic. Allison Kafer describes ‘crip time’ as a concept created by the disability community to describe the slowing down of time that disabled people experience throughout their daily lives. “As one slang dictionary puts it ‘crip time’ means both ‘a flexible standard for punctuality’ and ‘the extra time needed to arrive or accomplish something’. Kafer takes this further and writes that it is actually ableist barriers that create this time suck for disabled people.122

Time may go slower for schizophrenics, as I know that I have limited things I can do during the day or limited ‘spoons’123. Sometimes time can go incredibly fast, as in the short lives of many schizophrenics. Time is just weird in the sense that we may not be conforming to the heteropatriarchal ableist capitalist conception of the timeline of life that middle class white nondisabled people are supposed to pursue. Being in a different time zone (the crip time zone) means having a different life than friends, family, and people in your community and it can be very isolating and shaming. The pressure to conform to normative standards of time is high and makes me feel inadequate all the time, especially as friends and relatives my age get married and start families. My mother in law’s imagined life for my partner and I as middle class and heteronormative do not live up to our realities as queer disabled millennials with hundreds of thousands of dollars in combined student debt.

The psychotic episode, for me, is like another break in time. I experience time differently during these episodes and everything feels like it’s happening all at once or not at all. I am out of

123 For a discussion of spoon theory see “The Spoon Theory” by Christine Miserandino
time and out of sync with the rest of the world when I disassociate. Minutes feel like hours and 
hours feel like minutes. I feel trapped inside myself for a lifetime. Monsters move at incredibly 
fast speeds toward me and I feel like a rabbit, tense and upright in bed, trying not to make a 
noise.

Living on crip time isn’t easy, but what I’ve learned is that you can’t fight it. The harder 
you fight to be a ‘normal’ citizen of capitalism, the harder it will take you down. So I ask myself, 
what would it be like to accept my disability as part of myself? What would it be like to shed the 
guilt of heteropatriarchal capitalism and let myself live on crip time instead of always trying to 
catch up to the norm? What would it be like if we all did that? What would it be like if I told my 
mother in law to fuck off? And if we called for the right of ourselves and others to live happy 
lives without the heavy burden of bills, insurance, and inadequate housing? Because we’re 
already fighting to live; what would it be like to fight together?

One group that has done this work is the Hearing Voices Network. Hearing Voices works 
primarily in England as a collective of people committed to erasing stigma around voice hearing 
and providing coping strategies and safe alternatives to hospitalization. They have in person and 
online groups that are led by voice hearers with personal experience, professionals, or both.124 
Unfortunately, there are no Hearing Voices groups in the U.S. There used to be one in Chicago 
hosted by the University of Chicago, but when I called the three facilitators in Spring 2020 I got 
only dead ends and out of service telephone numbers.

Most group therapies in the U.S. exist around insured healthcare, so there is no group 
primarily organized and run by people with lived experiences of schizophrenia in the U.S.125 A

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place to start, however, is in my work with the activist group Food Not Bombs. We share food every weekend with our community, and many of the people who attend are houseless. Many of the houseless people are voice hearers or tell the wild stories that have the marks of schizophrenia. It is not to say that I am diagnosing the people I share food with. I just believe that we have some similar experiences in terms of hearing voices and believing impossibilities. In a later iteration of this project, I would like to work with this group, possibly on an ethnography, in order to bring community to my project.

The concepts of erotic power and lived experience are fundamental to my understanding of schizophrenia and my philosophy as a feminist. It is only through theorizing our lived experience that we can begin to reach out and touch each other’s lives with intersectionality in mind. Making sense of one’s own experiences is the beginning of something beautiful, that radiates out into everything we do. Our erotic knowledge is the pull inside our bodymind that validates this lived experience and helps us to meet others at their differences.

Affective practices such as spirituality, physical movement, and mental stimulation are important ways that schizophrenics can find relief and refuge from emotional pain, but they are not the complete answer. Affective practice needs to be combined with advocating real material change to this racist ableist capitalist heteropatriarchal system. While I have not yet made connection with other schizophrenics because it is beyond the scope of this project, I have been able to grapple with my own experience and interpret it through Women of Color Feminisms and Madness Studies.

The next step comes in getting to know other schizophrenics. But it is also through difference that we build coalition, so it is true to say that I can still build with other people without them having to be schizophrenics. Schizophrenia is an isolating, lonely, and terrifying
illness, and I’d like to find people who share my experience, but I know that people who don’t can be just as good of comrades. It is my hope that mad people will be able to come together again, just like they did in the U.K. from 1999 to 2012, and scholarship is currently experiencing a renaissance. That is something I want to be a part of, and this paper puts forth a gentle foray into mad scholarship, seeking connection and coalition through difference.

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There'll Be Peace When You are Done: A Reflection on Autobioethnography

Trigger Warnings: trauma, incarceration, psychiatric hospitalization, doctors

In this thesis I painted a picture of the schizophrenic experience that is neither whole nor complete, and leaves room for the experience of others. My autobioethnography has been foundational at helping me to tap into this experience and illustrate how this illness works for me as both a burden, but also a part of myself that is inextricably made up of my bodymind.

Trauma has impacted me greatly and is vital to my experience as a schizophrenic. Disabled people aren’t inherently traumatized, but many experience trauma because of the oppressive system we live in. This needs to be recognized by disability scholars and dealt with so that everyone can feel comfortable having a seat at the table. Women of Color Feminisms offer up non-normative ways of healing traumas that are foundational to feminism. Madness Studies discusses the trauma of the institutions, both psychiatric and prisons, and offers a succinct tear down of those institutions as racist, ableist, homophobic and transphobic, and misogynistic.

The history of the prisons, psychiatric institutions, and the medical industrial complex provides us with an ample critique of what the U.S. was founded on (slavery and racism) and what is wrong with U.S. society to this day. Intersectionality helps us to see each other as human beings with multiple and unique oppressions that are inextricable from each other in order to build coalition through difference. Assemblage theory helps us to see how we connect to other beings in the environment and how those connections affect our everyday lives. Affect theory shows us the powerful hold that capitalism has over regulating our emotions so that we can be worker bees for the machine. Intense combinations of emotion, bodymind, and somatic experience, such as psychotic episodes and dissociative experiences, that are relevant to the
schizophrenic experience tell us that there are many connections between bodymind, trauma, and oppression.

I have found theorizing about my own experience in order to make sense of it has helped me to let go of some of the pressure that was in my bodymind. I know now to respect the gut feelings of my erotic, and to take that erotic power into all the relationships in my life. Affective practice also makes sense as a way to heal, but we must fight for everyone to have access to it and also understand there will be points where it is impossible and there is no answer but to try to survive another day. Living on crip time can be a struggle, but we have to realize that there is no perfect version of us, only a multiplicity of ways that we can interact with the world and make connections with other beings.

The shortcoming of this thesis is that I have not been able to get into contact with other schizophrenics. I am still very isolated in my illness, but I know there will come a time, hopefully soon, that I will be able to do so. Because of the internet, we no longer have to live in isolation, but setting out into the internet to meet people like you is a murky task in uncharted waters. For now, I know that I have relationships with people that may not understand, but still care for me and respect my limitations.

The most important takeaway from this thesis is that schizophrenia is an illness mediated by and through racist ableist heteropatriarchal capitalism. Schizophrenics would have better lives if everyone had access to universal healthcare, housing, food, education, and other essentials. Prisons, police, and psychiatric institutions should be abolished in favor of community supports and an influx of financial support to communities that have been uninvested in and divested from.
But I don’t believe we’re going to get to this place without coalitional support of each other. Building community through difference, with mad people having a seat at the table, is the most important thing we can do to fight all oppressions. It’s already happening with new scholarship coming out in the field, but we need to turn that scholarship into action and connect our networks to places like where I live that have little direction. In writing this thesis I have realized that there may be more mad communities out there in bigger cities like Chicago, but they are hard to find in a place like Mishawaka, Indiana. It is a deeply isolating feeling.

I believe many of the policy principles that follow apply universally in the United States, or at least in the Midwest, but it is also important to know that I am thinking in context about the community that I live in right now and what I believe it needs. I believe strongly in mutual aid and I have become a bit disillusioned with the government in general, but that does not mean we should not shoot for the loftier goals of realizing the dreams of universal healthcare, police and prison abolition and more fair and equitable schools.

**Policy Initiatives**

**Prisons**

Almost one million mentally disabled people are sent to jail every year. Most of these people are Black and Brown. In fact, “in a sample of 109 urban, low-income, predominantly African American patients hospitalized for first-episode psychosis, 57.8% reported a history of incarceration. Among those who reported having ever been incarcerated, 58.1% had more than one past incarceration.”

Prisons, police brutality, and lack of housing create a revolving door where schizophrenics are shuttled from prisons to the streets and back again until their deaths.

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which are often premature and of preventable causes. It is clear that this system is not working for schizophrenics. The problem is that it is working for the ruling class. It is in their interest to make money off the incarceration of severely mentally disabled people, and to keep the social safety net thin or nonexistent in order to continue profiting.

Since the beginning of prisons there are people who have called for the abolition of them. This is not a new idea, but it continues to be one that is resisted by mostly white people of all classes, and middle and upper class folks of all races. The first question that comes to people’s minds and the biggest point of resistance is on this issue of the most violent crimes.

Trigger Warnings: rape and murder

When asked what to do about rapists and murderers if there is no prison activist Mariame Kaba remarked:

This is the question that always gets thrown at anyone who identifies as abolitionist- and my question back is “what are you doing right now about the rapists and murderers?” That’s the first thing: Is what’s happening right now working for you? Are you feeling safer? Has the current approach ended rape and murder? The vast majority of rapists never see a courtroom let alone get convicted and end up in prison. In fact, they end up becoming President. So the system you feel so attached to and that you seem invested in preserving is not delivering what you say you want, which is presumably safety and an end to violence. Worse than that it is causing inordinate additional harm. The logics of policing and prisons are not actually addressing the systemic causes and roots of violence. [my emphasis].

It is easy to throw people in prison, but not only is there no plan for when they come out, there’s no sense of what the violent conditions of prison can do to people, especially people that have already harmed (the classic saying “hurt people, hurt people”) or are already hurt. There is no prison without violence because prison breeds the conditions for people to be violent and

\[128\] Mariame Kaba, (n.d.).
attracts the sort of overseers or guards that enjoy violating people, the same way the police force attracts violent recruits. There are surely some people on prison staff that are kind of heart and there with an altruistic vision, but the system is set up so that even those people become disillusioned that they can’t change things from the inside, or so frustrated that they become harm doers themselves. I think of a childhood friend who decided to enter the police force through the route of becoming a prison guard first. He is a kind and good man. What is he now?

Therefore, we desperately need prison abolition, but it is not enough to just abolish prisons and send people out into the streets. Prison abolitionists believe that we can solve these issues through ending racial capitalism. This would include funding marginalized communities so that all manner of community supports can be set up, safe, accessible and rent controlled housing can be achieved, and basic needs such as local grocery stores that offer a full array of products and are affordable can be introduced, as well as widespread and accessible public transportation. Other needs include changing tax codes and wages to reflect the lived reality of working class people, and in all this communities should be in charge of what they want.

Someone with whom I’ve had a complicated relationship with once said to me, “The money’s always there,” and this was the truest thing she ever said. The money is always there; it’s just in the wrong place. It’s at the top being hoarded by the rich, but we are not powerless to change things. The money is always there for programs and institutions that the state supports to violate the most marginalized in U.S. society. Just like prisons, the police force needs to be abolished as well as the court system. We think that if we put ‘murders’ and ‘criminals’ behind bars that we will be safe, and the problem will go away. But as Kaba writes, why is there still crime? Rape? Murder? Violent assault and domestic violence? And hate crimes? We have done
nothing as a society to stop these things from happening. Police make this worse by bringing the violence of the prison into the streets.

In the Justice Department’s investigation of the Chicago Police Department under Attorney General Eric Holder 68% of police officers in Chicago reported that they felt there needed to be a cultural change in the department. Many officers anonymously reported being afraid to speak out on their colleagues who were breaking the law and brutalizing people, lest there be retribution against them. They too felt trapped in this system. Not to mention that CPD officers have high rates of domestic violence and often get away with it due to their connections with the justice system.¹²⁹

But how do we get to a cultural change in policing? The answer is we can’t. We’ve tried. CPD officers receive sensitivity training, but obviously don’t respect it. It has made no systemic change in their policies or practices. To abolish policing, of course we’ll need a replacement, but we need to make sure we aren’t repeating the same practices of oppression - just with less lethal force. Some departments¹³⁰ are having social workers go out with police to attempt to deescalate situations, especially with mentally ill people or people that are threatening suicide. The issues here is whether these social workers are just as committed to state systems of oppression as police are.

Accountability which has long been used in some way, shape or form by indigenous people, communities of color, and third wave feminists presents another solution to the systems

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of policing and the court system. Accountability is a strategy for healing in which harming parties are held accountable for their actions. It doesn’t look like people holding hands and singing kumbaya. It looks like people getting the services they need such as adequate housing, food, and care while taking accountability for their actions in ways that suit the community.

Feminist scholar Ann Russo describes her theorization of accountability – feminist accountability – as not a “zero tolerance approach” but on that recognizes “the roots of oppression and violence that operate on intimate, interpersonal, institutional, and systemic levels, rather than beginning and ending with the individual.” She continues, “When one of us perpetuates the harm of racism, then, we approach it not as an individual and unchangeable moral flaw… but as an action for which we can take responsibility and make amends, and that we can commit to change.”

For example, if someone was to rob someone else while armed and get caught, instead of sending them to prison we could ask why. Maybe that person doesn’t have an essential basic need. Putting them in prison wouldn’t solve that. It would only make it worse. It would give them a record where they would most likely not be able to find employment, leading them to a worse situation. Still, they would need to be held accountable for their harm. Maybe this looks like the harmed forgiving the harm doer because they understand the situation. Maybe it doesn’t. Maybe it looks like the harm doer performing community service or seeking counseling from a therapist, community member, or religious leader.

In violent situations, something we can do right off the bat is have better gun control. Most gun deaths in the U.S. are suicides, and people who die by gun suicides the most are white

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132 Russo, 20.
The solution is not to stigmatize mentally ill people by keeping a list of them and preventing them from gun ownership because under the current authoritarian regime these lists can be utilized to discriminate against mentally ill people in employment, housing and benefits. A ban on assault weapons, bump stock bans, and raising the age to buy guns are all fairly harmless remedies. According to gun violence experts though, these won’t do as much as banning concealed carry and instituting red flag laws where guns can be seized if a person or persons around them are in immediate danger as well as cool off periods for buying guns. One myth about prison and police abolition is that there would be chaos and anarchy if these systems were to be abolished. That’s not true. We would still have to have systems to keep people safe. A transformative justice accountability collective could require a person to have their guns taken away as a condition of continuing to live in the community. This also doesn’t mean that a transformative justice system wouldn’t keep track of people who have committed harm and that it couldn’t be decided that someone would lose their right to own a gun following an incident of violence.

These solutions are sort of the last resort. If people’s needs are met, no one can guarantee that there won’t be any violence, but there will be less. Why wouldn’t we want to try to live in a world where needs are met even if that means violence isn’t completely eradicated?

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Healthcare

One crucial issue that could alleviate a lot of suffering, especially for schizophrenics, is healthcare. Universal healthcare for all would profoundly affect many of our lives: disabled people, chronically ill people, children, poor people, people of color, and the elderly. Not to mention every single other person in the U.S., would benefit because we all need more health care services as we age and we all will be injured in accidents big or small sometime in our lifetimes.

Still, it is clear that universal healthcare is a long way off, or even impossible given the unempathetic people who supposedly represent our best interests in the government. It is not futile to protest for universal healthcare, but at the same time we have to help each other right now. A good example of this is the medic teams that organized at the 2020 Breonna Taylor and George Floyd protests. Because of the medics ambulances did not have to be called in many cases, which would have put people in danger of being arrested, as police always follow 911 calls. Another example of this is the DIY medical group Four Thieves Vinegar that has created a $30 EpiPen in response to the price increase to $300 per dose in 2016.135

Intersex activist Pidgeon Pagonis ‘zooms’ in to doctor’s appointments with intersex kids and their parents as an advocate and is considering creating an intersex ‘phone a friend’ service.136 Having advocates for people who are often ignored and bulldozed by the medical system (if the person desires them of course) or having a mentor who has gone through something similar, such as experience with the medical system as an intersex person can be an

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invaluable tool in order to hold medical professionals accountable. This advocate can certainly be a friend or family member, but what if we could create a whole group of advocates within our communities so that people who have to brave the medical system alone, for a variety or reasons, would not have to suffer the consequences of lousy dead end healthcare? Because I’ve been there and it is a hopeless place to be, not to mention a bottomless money pit.

Education

Trigger Warning: Bullying, Fatphobia, Suicide, Self harm, Violence, Psychosis, Sexual Abuse

Poor services and accommodations in schools are one of the most frequent reasons that young people drop out, thus severely limiting their lives in this capitalist system. My story is one of a complete lack of attention to my severe emotional distress and anxiety about school from kindergarten to twelfth grade. Not one teacher or member of the school staff protected me from being bullied because I was fat even though my parents brought the issue up numerous times. Eventually my parents just decided that the hell I endured every single day would just be the way it’d have to be. I used to contemplate throwing myself down the stairs every day in order to get out of school, but my body protected itself and I never did it.

In third grade I began choking myself in the back seat of my mom’s car and nonchalantly mentioned that I was trying to kill myself. In fifth grade, just three months after my little sister was born, I overdosed on my mom’s blood pressure medicine and spent a few days in the hospital. It wasn’t necessarily all the bullying. I had an undiagnosed mental illness and a lot of childhood trauma. I’m not sure what it was. I just knew that I felt like dying.

I was put into counseling at school during fourth grade, but she left after a few months and was never replaced. As I entered middle school, I was pushed into high pressure honors
classes that expected more from me than the pace I could give. I did my best, I got A’s, so no one considered me for an Individual Education Plan (IEP), even though I regularly cut myself in class with the ends of my earrings. The bullying continued, not just because of my weight, but because I stood up for other disabled kids, came out as bisexual, and pretty much unabashedly shared my leftist opinions in a right-wing world.

I did all this even though I was constantly in a state of panic, experiencing crippling depression, violent mood swings, and self harm and had only one real friend besides the ones I made up in my head every night. I was addicted to the attention that my imaginary friends gave me, even if it was negative and violent, and I often stayed up until three of four in the morning acting out both my fantasies and my worst fears. I was perennially exhausted, lonely, and out of touch with reality.

High school came and I faced even more trouble. I was hospitalized the first month of school. The imaginary friends wouldn’t go away, and I knew I was too old to have them. I was ashamed and I didn’t know how to cope. I had been in therapy since I was choking myself in the backseat in third grade, but my therapists and psychiatrists continued to focus on my grades instead of my mental health problems.

I don’t remember much about my early therapy, just that it never made me feel any better and that I never really figured anything out about myself except to lie about being suicidal in order to avoid the hospital. I would frequently go months without appointments when my parents decided I seemed better, only to relapse into madness again. I was responsible for making and keeping my own appointments as well as refilling and doling out my own medications, as my parents would also frequently forget to do those things too. It was a lot of responsibility for a young person that never should have been foisted on me, but my parents were
overwhelmed with my mental illness and left me struggling in the water by myself for much of my early years.

After the hospital, freshman year of high school continued with an abusive sexual relationship that triggered my early memories of sexual abuse. I had nightmares every night, and I still have nightmares once or twice a week to this day. I couldn’t sleep in my own room because that’s where the abuse happened, so I stayed on the couch for the next three years until I finally had my own bed again in college.

I shouldn’t have had to wait twelve years for it, but college was my prize. I registered with the students with disabilities office and joined a program called the Conaway Achievement Project (CAP). The office was a small space in the basement of a building with a cozy lounge area and computer lab. My counselors there, although not trained as traditional therapists, helped me much more than any therapist ever had. They were kind, supportive, and genuinely interested in each of their students. They treated us as equals. They loved us. They were always there for us to back us up at any point. They really went to bat for us.

Luckily, I didn’t have much trouble with getting my accommodations met. Professors always respected my accommodations and never questioned my absences or late work as long as I communicated. Unlike my high school teachers, they had compassion for my situation and I felt like I could tell each one what I was going through without judgement. This is exactly what I deserved. This is exactly what every student, every employee, every person, disabled or not deserves. I should have had this throughout my school career, instead of floundering alone in a vast ocean with not a single adult to take care of me. Still, I am grateful for the experience that I had, and for Andrea and Adam, my CAP counselors, who stood by me through every up and down, always happy to see me and always happy to help.
Wang, on the other hand, had a very different college experience. A high achiever, she was accepted into Yale for undergraduate school. However, after two breakdowns, one resulting in hospitalization, she was forced to leave Yale. The college immediately confiscated her student ID and would not let her back on campus. They told her that she had to leave that night. She couldn’t even come back to campus to collect her possessions. Her dad had to do that for her. After petitioning the college to come back, when they told her she’d be able to have a review, she was interviewed by an administrator. Weeks after the interview, after not hearing anything, she contacted someone higher up and they simply never wrote her back.¹³⁷

Throughout the schooling process from K-12 to higher education disabled students rights under the Americans with Disabilities Act (ADA)¹³⁸ are frequently and flagrantly violated with no recourse for the institution’s actions. Only very privileged families are able to sue against institutions such as this, and institutions usually have a team of lawyers dedicated to discrimination cases that are highly trained in the loopholes of the law. The myth that schizophrenics are dangerous and the privileging of the institution over the students that are the ones funding it contributed to Wang’s departure. Yale decided that protecting themselves from liability was more important than engaging in an honest conversation about mental health and they lost one of their best and brightest. Wang transferred to Stanford, an equally prestigious institution. I am not denying that this was a horribly painful situation for Wang, but I do want to say that this is Yale’s loss and these practices do deter some of the most qualified, intelligent, and creative people that they would surely like to boast as part of their alumni.

¹³⁷ Wang, 77.
¹³⁸ See for a breakdown of the ADA as it relates to education: https://www.stimmel-law.com/en/articles/americans-disabilities-act-ada-and-educational-accomodation
In my case, there was a total lack of empathy and care for my emotional problems. I was put on a section 504 plan, but these plans are usually used for physically disabled people to make sure that the physical environment is accessible. The school staff didn’t take my emotional pain and destructive behaviors seriously and were also probably biased against labeling an academically successful kid with an IEP. Another ableist myth that students with IEPs are “underachievers”, are “destined to only to be able to achieve GEDs” and are “just plain stupid”. Obviously, it is the social supports, both at school and through governmental agencies, that make students successful. If you are food insecure, living in unstable housing, or your parents are unable to help you with your homework for any number of reasons (work, disablement, language barriers, etc.), or don’t have healthcare, it is much more difficult to succeed in school.

Because I am mentally disabled and mental illness is not recognized and not taken seriously, I was left without any accommodations or support for my family. We were expected to find our own private services and keep my disability to ourselves. Even so, I have been privileged to have my basic needs met. I have healthcare, and although it was substandard, I was able to afford medications and therapy. Though that therapy was ineffectual, and my medications didn’t work for a long time, with the right doctors I have come to a point where I am able to do the things I love and remain a generally happy person even with the ups and down.

Schools can be better for disabled people. One huge problem is that schools are funded by property taxes, which leaves families without much generational wealth with under-resourced schools, thus propagating the cycle of poverty. Schools instead should be federally funded on the basis of population. All schools should be able to have a variety of social programs without meeting some kind of quota. For example, in middle class neighborhoods there also can be many people who are food insecure. My family was affected by this when my mom was in nursing
school. She went to school to give us a better life, but she couldn’t work while doing so and thus we had trouble keeping enough food in the house, so much so that I usually skipped lunch in high school because I had no lunch money and I wanted to save the food in the house for my little sister. Of course, a school that had 11% of food insecure families would receive less funding for that program than a school that had 50% funding. This seems simple but being food secure is the first and most basic step to ensure disabled people succeed in school.

Police are also increasingly being used as disciplinarians in school for problems that schools could deal with themselves, especially in Black and Brown schools. Racist teachers (whether they know they are racist or not) call in “resource” officers to solve problems that could be handled with transformative justice and whole child approaches. Schools are called to report incidents and truancies to the police and students are criminalized for minor mistakes that all children should be allowed to make without violent recourse. The police are overfunded and the schools are underfunded, so schools resort to the most readily available resource.

This policy is damaging and may have major life consequences for children, forcing them into the school to prison pipeline. Police need to be replaced with an influx of social services and trained staff dedicated to transformative justice and assisting students with IEPs and other disabilities. The onus should not be on teachers to single handedly fill all these roles, although they should also be trained in these things. Schools are one of the best ways for families to learn about social services in their communities, so resources should be in place to connect families with social programs.

Justice for all disabled people requires that the U.S. let go the myth that wealth resides in monetary gain, that rich people are inherently more deserving and hardworking, and that everyone can become rich with hard work. This work is being done as more and more people
spread the idea (especially through social media) that U.S. society is structured by oppression. There is already a large movement of people already demanding these programs, services, and calling to abolish prisons and police. We need to continue to spread these ideas and push politicians through activism. Just a few ideas are protesting in the streets, participating in mutual aid, working with anti-racist, anti-fascist, people of color led organizations (such as Black Lives Matter), or writing letters to incarcerated folks. And there are many, many more ways to activate.

Everything Else...

The more I write, the more I realize that the basis of freedom from these kinds of systems all comes down to a sort of Maslow’s Hierarchy of Needs. It is only when we are safe, well fed, and taken care of that we can begin to truly fight for the long haul. I have also begun to realize that the government is not going to give us these things. The democrats are going to give us our pittance of $1400 and the republicans are going to continue to fight the culture war to merely stop everything (abortion, immigration, taxes, etc.).

We are the ones who must take care of us. This is where mutual aid comes in for me. Mutual aid is the process of circulating resources through your community. For example, if my neighbor needs food for the week, then I’ll lend him a hand. Maybe next week I’m laid up with chronic pain and need someone to clean my house. Disabled people of color have been practicing this model of community care for years now, and it has recently caught on in wider spheres. In Care Work: Dreaming Disability Justice Leah Lakshmi Piepzna-Samarasinha writes that this process is not always easy or perfect. We are all human beings with faults and emotions, and it takes open communication and a willingness to be wrong to build any type of community.  

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139 See Care Work: Dreaming Disability Justice by Leah Lakshmi Piepzna-Samarasinha
Building community like this is also slow. Currently I organize with Food Not Bombs in my hometown. We are an organization that shares vegetarian and vegan food in public every weekend. During COVID it is not easy to share food with people, even while outside. We have to package up the food and most people don’t hang around to eat anymore. It feels more like charity right now than anything, but I know slowly, we’re doing something - just by being there and just by being dependable, friendly, and non-judgmental of the many houseless folks who aren’t often recognized as human.

**Writing in 2020**

As the COVID-19 virus grew in China in February 2020 I wasn’t as worried as I should have been about transmission to the U.S. It seemed like a tragedy that was far away, and although I was aghast at the number of deaths, I just couldn’t see it coming here. Matthew talked to his uncle, who is on the American Board of Emergency medicine, who told him that things were about to get much worse. I expected a quarantine, but I didn’t expect this and I don’t know why. It was very naive of me to think that the current administration would take care of this, but to be honest, I wasn’t thinking about Trump even being a part of the response. I was thinking that the CDC would be the primary force in adjudicating what would be done to contain the virus.

As March came around and we started quarantine, I was beginning to realize the scope and magnitude of this situation. Matthew began working from home and the days blended together as I sat on the couch staring at the wall and smoking while Matthew typed away on the computer. At this point we only had one computer so I would have to do my work after Matthew had finished theirs. In the early evening I completed my assignments and tried hard to get into my work and forget all that was happening. I tried to forget my fears. At night I lay awake
thinking about Matthew or I dying alone in a hospital bed, unable to hear each other’s last words or hold each other’s hands.

Through the summer and the fall it became normal. We moved to a new apartment to be closer to my parents. I didn’t go out much, just to get groceries and medications, and to protest the Breonna Taylor and George Floyd murders, but I forgot to wash my hands a lot. Life seemed to be getting back to normal. Things were opening up in Indiana. It was counterintuitive. The message from the government was that everything was fine, but I knew everything was not fine. At the same time, I was subconsciously taking in this message that everything was fine and I felt crazy, caught between what I knew to be true and the propaganda.

I kept thinking, “I don’t know why I don’t have it yet.” I was waiting for the other shoe to drop. I have a lot of covid symptoms all the time. Diarrhea of course. Migraine headaches. Allergies that cause a cough and a sore throat every morning. Body aches all the time. I was constantly afraid that these symptoms were actually covid. I laid my hand on my forehead at least twice a day. “Okay, I don’t have a fever. It’s okay.” Matthew and I would wake up with a sore throat from the dry air in our apartment and hold each other crying. Do we have it? Are we gonna die?

We felt hopeless. We could not change what was happening. Hundreds of thousands of people were dying and getting sick and there was nothing we could do but shout into the void. I emailed my representatives. Every time the same response: “We stand with Senator McConnell and the President.” Indiana senators Mike Braun and Todd Young are feckless weak sycophants to the president and they don’t care about their constituents.

I feel the same way now, a little better as we have gotten into some activism with Food Not Bombs and an anarchist free store, and since I have been writing to my friend in prison. I
don’t cry in the night as much because this kind of situation numbs a person. Yes, I still get my news. I won’t tune out completely. I am not very hopeful though. With the election of Joe Biden came some sense of relief, but also a sense of dread. It was a very close election, showing that these white supremacists are not going to back down. Almost half this country still believes in Trump despite the horrible things he has done and failed to do.

Joe Biden is not the candidate we deserve nor the candidate we want. His platform of unity is only going to push the country to the right as democrats acquiesce to republicans policies in the name of keeping the peace. That is what we have seen in the last 60 years. And I’m sick and tired of it. We need to be more divided, not more unified. Democrats need to fight tooth and nail for what the people need and want, but they won’t. They have this old-fashioned focus on civility when that has gone out the window with the new right. We all thought maybe we could push Biden to the left, but I’m skeptical of that as he backs down on providing debt relief for student loans and chastises the Black Lives Matter movement.

What this pandemic has taught me is that we are the only ones that will free us. Getting involved in mutual aid has helped me stem the tide of awfulness that permeates our everyday lives, and has now for some time. Before the pandemic things were not good and they have never been okay for most people in this country: people of color, the poor, elderly people, children, disabled people. These are the people that make up more of the U.S. than the middle class or the one percent. And we’re pissed. Pissed as we have ever been, and I give my utmost gratitude to these people who have been fighting for centuries for a better life. These people who have laid the blueprint for us and taught us not to back down. In this ugliness I have found their words and their actions as a model for my own activism and it is a privilege that I have been able to study them.
I still cry a lot, but I think that’s okay. Emotions are okay and not showing emotion doesn’t mean you don’t care. Sometimes I’m so busy dealing with my own psychological and physical problems that I forget the world. I feel terribly guilty about it, but I do think that we all deserve a break. We have to know that while we are down someone else is picking up the slack, and when we get back up again, we will keep fighting.

Though it may be a boulevard of broken dreams there are many of us. No matter where we are, we do not walk alone. It is only through collective action that we will be able to make our lives and everyone else’s lives better. It is only through forming relationships with other activists, though they don’t necessarily have to be friendships, that we can create a world the world that we dream of living in.
Appendix

A Story for Those Who Came This Far

Trigger Warning: suicide

*I Do Not Take to Water Like You Do*

The sunset is beautiful over the Golden Gate Bridge. At least what’s left of it. The sky is just like Van Gogh’s “Starry Night” except aqua marine. The same color as the ocean I am floating in. Staring up through the unfinished bridge. There’s no traffic. How could they drive on a bridge that is incomplete, suspended in space with parts that shift back and forth unexpectedly. I am climbing now. Grabbing onto deep orange beams. They carry me, seemingly moving on their own. I am not afraid of falling as I spring forward out and catch a loose cable. It doesn’t even hurt. No rope burn; no pull as the weight of my body catches itself on the string as thin as a thread. Scaling up onto the precipice of one of those golden arches. Looking out I see a city illuminated by the ever present sun. Skyscrapers, clock towers, power lines in blues and blacks and purples. Hazing, rolling fog when I notice you, balanced on a guard rail ready to slip yourself like an orange and white koi into the aqua marine water.

I am diving for you. Falling through the fog and past the giant beams and towers. Through the road and up and over. Down and back into the water; but you’re gone. And the sun is gone. And the sky is turning black, and I know I’ve missed my chance again. Sighing back in the water and letting myself slip under and into the depths. It’s dark and at least warm as I’m curled round rocks and curled around dead trees. I seem to be breathing beneath the inky black sky. Breathing through water, making “sounds like sobbing”140...because I cannot catch you. Because I do not take to this water ‘like a fish’ - like you do.

140 Cisneros, 58.
When suddenly I see you out of the corner of my eye. My white and orange Koi darting through the black. And then I’m racing, racing to catch, but my legs pedal uselessly and slowly because there’s only so much I can do in this water, not being a fish - like you.

You’re around every corner and though every reef before I can even conceive of getting there. In your wake leaving scales. Tidbits of you. A letter, a poem, a picture, a pair of shoes.

And when I wake up to the sirens of the city or the rush of wind from the bay I find I’m still searching for you. I’m going out to the bay with my photographs. Knowing that you stepped on this sand. Why are you not here? I don’t take to this water like you. I cannot swim through my depression. I cannot navigate this illness. I cannot throw it all away with one final leap into the bay like you. I am not a fish. But I’ve been close. I’ve been over the railing, hanging on by my finger tips and I’ve felt it too. I have felt the awesome power of my life in my hands; knowing that I could end it - that I too could let myself drop. I could become that elusive figure you are to me. Almost passed down as a caption in a history book:
This was your uncle, a great and promising young man, who was also very sick, who ended his life by jumping of the Golden Gate Bridge on June 24th, 1995, who you will come to know because you very much like him. Who you will start to think could save you from your illness. Who you will start to think holds all the answers, if you could just find him and unlock the key.

But no, No. I know you through pictures, and letters, and songs, and clothes and dreams, the most beautiful dreams I’ve ever had. But I will never find you. You’re not living off the grid in Alaska. You’re not hiding out somewhere; passing me on the street and wondering if you know me. For whatever reasons you jumped off a bridge and into an ocean and became a figment of my imagination. A comfort in the night. A caution when I feel like jumping that little sister will be left alone with me as an escaped koi of her own. I do not take to water like you did; I do not know how to swim pedaling around and trying to find my way to somewhere where it doesn’t hurt to exist anymore but still somehow coming out alive. And I have a feeling that you felt the same when you made the decision to jump off a bridge, because you could not alleviate the pain of the weight that was crushing you, so you made the decision to free yourself by completely accepting it, by letting go of the guardrail with your fingertips and down below a family was watching and they shielded their eyes. Could it possibly be? No.

But it was. And now I am trying to put the pieces of you together from the sources I’ve gathered. And breathe under water. And don’t let it consume me. And please for the love of god, keep away from high places and guard rails and bright orange bridges, except when I’m chasing you in my dreams.
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