Ghosts of Willowbrook: Disability, Mourning, and Feminism

By

Calla Bowles

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Supervisor: Dr. Hyaesin Yoon
Second Reader: Dr. Jasmina Lukic

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Abstract

From 1951 to 1987, the Willowbrook State School in Staten Island, New York served developmentally disabled children and adults. During its relatively brief tenure Willowbrook was wracked with scandals related to endemic mistreatment and neglect of its residents. Residents, or more accurately inmates, endured physical and sexual abuse from other inmates and attendants alike, suffered from lack of appropriate food, clothing, and hygiene, were purposefully infected with hepatitis as part of a scientific study, had vasectomies and hysterectomies performed without their consent or knowledge, and received no education to speak of despite the purported aim of the institution. In short: an inmate at Willowbrook State School could be the subject of almost all forms of ableist violence within the thirty-six years of operation.

In this project I examine the legacy of Willowbrook as a means to approach the larger construction of violence against disabled people. How can Willowbrook be mourned and what are the feminist possibilities of mourning Willowbrook? My research utilizes documentaries and memoirs about Willowbrook—how they construct Willowbrook, Willowbrook’s former residents, and the aftermath of Willowbrook. For this analysis I utilize the hauntological method, looking for contradictions and absences in my source material—I am looking for ghosts. I suggest in this work that the ghost may have a feminist function in considering our responses to violence against disabled people. There must be a method of mourning that takes the fractured structure of life and death for disabled people as its core precept.
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Introduction

0.1 Preface

“Let me present to you a series of events.” This is how Zoe Gross begins “Killing Words,” the forward to the Autistic Self-Advocacy Network’s (ASAN) Anti-Filicide Toolkit, and I cannot myself think of a better opening for this project.¹ Gross first tells the story of George Hodgkins, then Tracy Latimer, then Daniel Corby, then Katie McCarron. George Hodgkins shot point blank. Tracy Latimer gassed in a car. Daniel Corby drowned in the bathtub. Katie McCarron suffocated with a plastic bag. And then, and then, and then. There is an undeniable pattern here, a “method to the madness,” to use an unfortunate expression. All were disabled. All were murdered by a parent, caretaker, or partner. As Ann McGuire writes on her study on violence against autistic people in Canada: “…such acts of violence are occurring with an aching frequency; we are continually and even routinely encountering resonant stories of violence against autistic people as these stories circulate through our news sources, through our culture, and through our lives.”² Though not all of these people were autistic specifically, McGuire’s point stands. Here is how death comes to the disabled community: again and again and again.

“Killing Words” details each of these murders and their media coverage in their immediate aftermaths. All perpetrators were afforded an enormous amount of sympathy, with their crimes even occasionally outright condoned as understandable, as inevitable, as fair and right if perhaps

more pitiable than just. These killers are angels of mercy instead of mere murderers, dispensing the peace of death to those whose lives were not worth living. Their victims, on the other hand, were constructed as both burdens to their killers and society at large. At the end the essay, Gross lays the blame for these crimes directly at the feet of discourse that devalues disabled life—the “killing words” of her title. Gross wonders who might have heard these words—who will hear these words? What parent, partner, or caretaker will internalize them and decide that they should act accordingly? What disabled person will die? Or rather: when and how will the next disabled person die? The future, the present, and the past are equally on Gross’ mind as she writes about mourning disabled people. In order to protect ourselves and those who might come after us, we must always be thinking about those we have already lost.

The ASAN Anti-Filicide Toolkit is a resource provided on the Disability Day of Mourning website. Disability Day of Mourning is an activist archival project combined with an annual day of action (March 1). As indicated in Gross’ essay, the focus of the Disability Day of Mourning is to draw attention and action to the killing of disabled people by those closest to them. Each year on March 1, activists come together to organize candlelight vigils and other public awareness events. For the rest of the year, activists collect the stories of disabled people murdered by their caregivers and loved ones into an online archive. These stories, though international, are limited in scope by the availability of articles written in English. They are organized via location, the age of the victim (infant to elder), type of murder (neglect, murder-suicide, etc.), and relationship of perpetrator. As of writing, entries date back to 1980 and continue on (quite literally) to the present day. The archive does not include crimes on the basis of whether or not they were considered to be as such by the legal system where the crime took place. Every disabled person who was murdered by a caregiver, family member, or partner is included even if the perpetrator
was not arrested or convicted of a crime. This is activist accounting—necessary, pain-staking, and often terrifyingly dull in its repetitious nature.

A haunting is that what troubles repeatedly—the haunt is that what reappears, what repeats itself, and produces anxiety or suffering through its continued flickering presence. This is the nature of the ghost—to be a ghost, and thus to be able to haunt, a thing (or perhaps a person depending on one’s views on materiality and agency) must appear, disappear, and reappear. It cannot only appear once and its appearance cannot be sustained. The ghost repeats itself—it *insists* and *persists*. As Sara Ahmed writes: “Mere persistence can be an act of disobedience.” The ghost insists that there is something important left unsaid, some crime unpunished, something hidden away without respect or reverence. The ghost is created and sustained by enclosed spaces. Not just any place can be haunted—it needs four walls and a roof. Most likely to be haunted: house, prison, institution, school, church. These are spaces where violence is concealed, where silence is enforced, where victims are erased. A ghost may be nameless, faceless, lacking form and feature and yet it is still a powerful force because of how it always, always returns. The ghost is a figure of fear and terror. It is also a figure of rage, of grief, of longing. I believe that the ghost has potential in feminist thought on violence against disabled people. These acts of violence invariably happen in “private,” as problematic as that term may be, in bedrooms, bathrooms, kitchens, and family cars. It can be difficult, as activists and feminists, to get inside these places, to push past bolted doors and blackout curtains and barred windows—figuratively but often literally as well. Feminists are human—we forget, we exhaust

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ourselves, we even die, eventually, too. Ghosts have none of these problems. The ghost is not human. Its disappearances are always temporary—it always, always, always comes back.

0.2 Research Questions and Background

Willowbrook State School was authorized as an institution for the retarded the New York State legislature in 1938, but did not serve that population fully until 1951. As a result of the entrance of the United States into World War II, the federal government took control of the newly constructed buildings for use first as a general hospital and then a veterans’ hospital. In 1947, after a protracted struggle between New York State and the federal government, veterans were slowly released or transferred to other hospitals. After finally accepting developmentally disabled residents, Willowbrook quickly became dangerously overcrowded. In 1963, there were 6,000 residents in a facility with an official capacity of 4,275. A 1967 professional accreditation report compiled by the American Association on Mental Deficiency found that there were 59 nurses to care for the 6,000 residents with 113 further staff vacancies. Though the report concluded that the conditions were unacceptable, it did not recommend that the institution be closed. One of the first public figures to condemn Willowbrook publicly was Robert Kennedy (then a U.S. Senator from New York) who in a fall 1965 statement described Willowbrook as a “…less comfortable and cheerful than the cages in which we put animals in a zoo…[Willowbrook] was a reproach to us all…We cannot tolerate a new snake pit.” This was after a series of well-publicized deaths at Willowbrook in the first half of 1965. Two residents, a

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forty-two year old man and a ten year-old boy, were scalded to death in the showers. A twelve-year old boy was strangled to death by a restraint device. A twenty-six year old man was struck in the neck and killed by another inmate. No charges—of any kind, civil or criminal—were brought as a result of these deaths. Nor is any information about the victims’ names and lives available. Despite the public attention brought on by Kennedy’s visit—and his address to the U.S. Senate on the matter—there were no major changes to Willowbrook as a result. It remained chronically overcrowded and underfunded until its eventual closure in 1987 after a long, bitter battle between administrators and a coalition of parents, progressive providers, and libertarian politicians.

Willowbrook and its history is the background of this project, but it is not my subject per se. I am interested in the “what happened after” of Willowbrook. Where are the survivors? What became of them? This is not a historical or sociological project—I am not prepared for such a thing in any sense of the phrase. Medical records of former inmates are typically not available to anyone but providers and even then documentation can be unreliable. Outside researchers, family, and even the former inmates themselves are not allowed access except under specific circumstances—usually the whim of an individual bureaucrat. Instead of trying to pursue this history, at what needs to be uncovered, I look at what is already here. Specifically, I look at a selection of documentaries and memoirs about Willowbrook and its legacies. They all grapple with its horrors—the brutality and the cruelty enacted onto its inmates. How successfully they do so is variable. My question is in how—or how not—these attempts contribute to a practice of

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9 Rothman and Rothman, The Willowbrook Wars, 23.
mourning. What is done and what can be done in mourning violent pasts when that violence continues on and beyond its original site?

0.3 Literature Review

*War on Autism: On the Cultural Logic of Normative Violence* (2016) by Ann McGuire, previously quoted in the preface, is the most recently published text on mourning and disability. McGuire argues that violence against autistic people is grounded in rhetoric that dehumanizes autistic people in such a way that separates the autism from the person—the murders she details are imagined as killing the autism rather than killing the person. I utilize many of the same resources and theoretical groundings as McGuire. This includes Butler’s work on vulnerability and mournability, as well as activist writing by Lydia X.V. Brown (Autistic Hoya), Mia Mingus (Leaving Evidence), and ASAN. These authors are notable for their work in imagining strategies for responding violence beyond the state and the carceral system, as well as in theoretical work drawing connections between violence against all marginalized groups. Especially important for this project is Mingus’ work on sexual violence and more specifically sexual violence against especially vulnerable groups—children, immigrants, disabled people. She imagines possibilities that are focused both on the victims themselves and on the communities around them. Only punishing the perpetrator(s) is not enough if it means the traumatic legacy and the system that created them goes unaddressed. Mingus, in concert with other community justice organizers (Bay Area Transformative Justice Collective), term this idea “transformative justice.” This work overlaps with perhaps the most invaluable resource for my work here: *Disability Incarcerated: Imprisonment and Disability in the United States and Canada* (2014) edited by Liat Ben-Moshe, Chris Chapman, and Allison C. Carey. This collection of essays covers a wide ground in issues of autonomy, violence, and institutionalization from anti-incarceration disability activists and
scholars. In this vein I also read Angela Davis’ work on prison abolition as she wrote the preface for *Disability Incarcerated*. Davis’ writing was useful for its incisive analysis and forceful argument against incarceration as a method of dealing with social problems—a way, I’ve found, that Willowbrook is repeatedly described. For a greater historical background on the institution and context on previous writing on the subject, I looked to histories of “madness” and the asylum: *The Mad Among Us: A History of the Care of America’s Mentally Ill* (1994) by Gerald Grob, *The Architecture of Madness: Insane Asylums in the United States* (2007) by Carla Yanni, *The Protest Psychosis: How Schizophrenia Became a Black Disease* (2010) by Jonathan Metzl, *Madness in Civilization: A Cultural History of Insanity from the Bible to Freud, from the Madhouse to Modern Medicine* (2014) by Andrew Scull, and *Committed: The Battle Over Involuntary Psychiatric Care* (2016) by Dinah Miller and Annette Hanson. What was most striking about these readings was how none considered “disability” as either an identity term or a social category. None of these authors identified themselves as “disabled” or as having any diagnosis discussed in their work. I do not mean that not having a disability—or being unwilling to identify oneself as disabled—does not preclude one from writing about disability, as with any other marginalized group. However, not acknowledging the issue of one’s standpoint as related to one’s subject is problematic when considering the spectacle of the suffering of disabled people. The assumption that there might be some subjects “deserving” of involuntary internment and treatment remains, either explicitly or implicitly.

What these texts have in common is their approach to eugenics as a system that creates and reinforces conceptions of difference in American culture and politics, particularly in the essentially violent nature of this system. Crucial for my work here as well is how these texts grapple with “silences” in the historical record. Mourning comes into play here frequently. There is the concern with those who are not there—those who might have existed but do not from a combination of sterilization, imprisonment, and medical experimentation. This is especially true for women, as evident by the importance of Carrie Buck, whose “disability” was found not to be in her body or her mind per se, but in her social circumstances. She first had the misfortune to have been born to a poor, transient family and then the misfortune to be “adopted” by a family to serve as a servant rather to be raised as a daughter. Her second misfortune was to have become pregnant as a result of rape. This marked her as a degenerate that in turn marked her as disabled—and thus a subject perfectly formed for eugenic violence. (Black, Cohen, Lombardo). Similarly formulated in these texts is the alchemy of race and gender. The “identification” of disability is traumatic and once again either a response to or a form of sexual violence itself. (Roberts, Washington).
Histories of disability have major overlaps with histories of eugenics but they are not entirely the same. During my research, I referred to the following: *Inventing the Feeble Mind: A History of Mental Disability in the United States* (1995) by James Trent, *Freak Show: Presenting Human Oddities for Amusement and Profit* (1988) by Robert Bogdan, *The Ugly Laws* by Susan Schweik (2009), and *A Disability History of the United States* (2012) by Kim Nielsen. These works were useful in terms of their perspectives on disability and the construction of the public/private divide. When and how has been disability been allowed in public? Histories of disability activism, distinct from histories of disability, gave especially important context on the post-institutionalization era where the majority of disability histories stop: *No Pity: People with Disabilities Forging a New Civil Rights Movement* (1993) by Joseph P. Shapiro and *What We Have Done: An Oral History of the Disability Rights Movement* (2012) by Fred Pelka. Of interest is how these histories often traffic in rhetoric firmly in opposition to Crews' intersectionality. They imagine the disability rights movement as “like” the civil rights movement, the gay rights movement, the women’s movement. There is also the conception of the disability rights movement “following” these movements as if each is a static moment in time with completed goals. Progress here is a straight line.

In terms of “theory” work on disability, I began with writing taking on disability from a biopolitical perspective: *The Biopolitics of Disability: Neoliberalism, Ablenationalism, and Peripheral Embodiment* (2012) by David S. Mitchell and *The Right to Maim: Debility, Capacity, Disability* (2017) by Jasbir Puar. Both of these works emphasize the workings of disability as it relates to state power, specifically in the context of the global “war on terror” as enacted by the United States and other Western countries. Of significant interest for this project is theory work on disability and sex (here meaning the practice rather than the body): *Sex and Disability* (2012)
edited by Robert McRuer and Anna Mollow, Already Doing It: Intellectual Disability and Sexual Agency (2015) by Michael Gill, Loneliness and its Opposite: Sex, Disability, and the Ethics of Engagement (2015) by Don Kulick and Jens Rydstrom. These texts, though informative, focused on “freedom to” rather than “freedom from” sex—why this approach is not appropriate for my work here will become clear in Chapter Two. While violence and pleasure are not necessarily opposed as concepts, I believe this project is not the appropriate context to complicate. As currently required for any work in disability studies, I also read from the crip theory school of thought most notably Crip Theory: Cultural Signs of Queerness and Disability (2006) by Robert McRuer and Feminist, Queer, Crip (2013) by Alison Kafer. My issues with these works are similar to those on sex and disability (as to be expected as McRuer was one of the editors for Sex and Disability). I find “queer” as a term much too expansive and unwieldy for this work, amongst other problems that would require significant space to discuss in full. This is besides my deep discomfort at using slurs (here meaning both queer and crip) for subjects who have not themselves chosen to use them.

0.4 Theoretical Framework

I base my work here on two guiding concepts: the “willful subject” from Sara Ahmed’s Willful Subjects (2014) and the “ungrievable life” from Judith Butler’s Precarious Life: The Powers of Mourning and Violence (2004). I believe these two ideas when considered together, if not combined per se, allow for robust analysis that can nonetheless still be nimble when called upon to be so. My intention in utilizing these concepts is to demonstrate the wide(r) political and philosophical context I am drawing on as I make my argument. This is not only about the United States in the twentieth and twenty-first centuries—reverberations and affinities are tangled across a global landscape.
Ahmed opens her argument with a discussion of a Brothers Grimm fairy tale called “The Willful Child.” The tale ends with the eponymous character’s death, the worthy punishment for willfulness—except the child does not quite die. She (the child is a she rather than a he or a they or even an it) still refuses authority even after she is laid in her grave. A limb is thrust out of the burial dirt. Dead but not gone—irrepressible if not strictly active. The point here is the previously persistence in my preface. Ahmed writes: “Willfulness involves persistence in the face of having been brought down, where simply to ‘keep going’ or to ‘keep coming up’ is to be stubborn and obstinate.”

10 To live as disabled, to live with disability, is a kind of disobedience. Disobeying the injunction that a life lived with an imperfect (a different from perfect) body and/or mind is not a life worth living. I draw my conception of “insistence” from Ahmed’s “persistence” here. This is that will not go away, that which remains after death, and which thus refuses the authority that demands its repression. Importantly, persistence does not apply to any subject. Ahmed refers to difference, specifically difference as that which is not: “Willfulness might be what we do when we are judged as not, as not meeting the criteria for being human, for instance. Not to meet the criteria for being human is often attached to other nots: not being white, not being male, not being straight, not being able-bodied. Not being is coming against being can transform being.”

11 This is where the ghost is useful—it is a “not,” a not alive, a not dead, a not corporeal, a not incorporeal, that somehow still carries great force and influence. Survivors and victims of ableist violence are termed willful—they did not act correctly, they did not follow directions, they were loud, they were unmanageable.

My second guiding concept, “the ungrievable life,” like “the willful subject,” refers to death and being/not-being a subject. Butler conceives of the “ungrievable life” specifically in the
context of the worldwide AIDS crisis and the Israeli apartheid of Palestinians but I believe idea can be applied to disability quite easily without stretching it out of shape so to speak. The “ungrievable life” is a vulnerable one, meaning here both bodily and ideological vulnerability. These are those who are “unreal,” that is those that do not figure as human subjects. However, this “unreality” does not mean that they do not exist per se. Butler writes: “If violence is done against those who are unreal, then, from the perspective of violence, it fails to injure or negate those lives since those lives are already negated. But they have a strange way of being remaining animated and so must be negated again (and again). They cannot be mourned because they were already lost or, rather, never ‘were’ and must be killed, since they seem to live on, stubbornly, in this state of deadness.”

I am thinking here about the epistemological violence that creates, accompanies, and follows physical violence. Disabled people are always thought of as children—dying children, monstrous children, but children all the same. They are always in a state of almost-dead rather than being alive. Death is a foregone conclusion. To murder a disabled person is not to kill a person per se—it may be a tragedy, but it is not a crime. As Butler writes: “Violence against those who are already not quite living, that is, living in a state of suspension between life and death, leaves a mark that is no mark.” My interest in this work is in the “mark that is no mark.” This is that which is there and not there—what remains when it should not.

0.5 Methodology

The structure and focus of my analysis in this project is based on Jacques Derrida’s “hauntology” from Specters of Marx: The State of Debt, the Work of Mourning, and the New

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13 Butler, Precarious Life, 36.
International (1993). Hauntology, a play on the word ontology, is the logic of haunting and the specter (here synonymous with the ghost). A haunting is ambiguous and ever shifting, denying static boundaries and categories of knowledge. I draw my conception of the ghost from Derrida’s formulation here. He writes: “A specter is both visible and invisible, both phenomenal and nonphenomenal: a trace that moves the present with its absence in advance.”\textsuperscript{14} My subject is necessarily marked by absences. There is very little first person testimony available from survivors of Willowbrook and what there is not sufficient—not that there is ever such a thing as a sufficient history of violence against a marginalized group. However an absence is not strictly nothing. An absence is constituted by the presence that surrounds it. Derrida continues with his description of the specter in this vein. “The specter appears to present itself during a visitation. One represents it to oneself, but it is not present, itself, in flesh and blood. This non-presence of the specter demands that one take its times and history into consideration, the singularity of its temporality or of its historicity.”\textsuperscript{15} Absences and non-presence have their own histories that must be accounted for.

While my focus is on my source texts themselves, I also look at paratextual material: video descriptions, comments, reviews, IMDb (Internet Movie Database) entries, Wikipedia pages, and patterns of algorithmic sorting. In a digitally saturated age, or rather an age in which we are all intertwined with the digital whether we like it or not, this context is important, as Derrida suggests: “It [technology] obliges us more than ever to think the virtualization of space and time, the possibility of virtual events whose movement and speed prohibit us more than ever (more and otherwise than ever, for this is not absolutely and thoroughly new) from opposing


\textsuperscript{15} Derrida, \textit{Specters of Marx}, 133.
presence to its representation, ‘real time’ to ‘deferred time,’ effectivity to its simulacrum, the living to the non-living, in short, the living to the living-dead of its ghosts.”16 These texts are not quire “of their time,” not only in the sense that they recount events of the past but also in the sense of how they have traveled to and in the present. All of these source texts are as contradictory in their representation of historical events as they are repetitious. Both the repetition and contradiction are important, as is the im/material layering of the sources themselves—they refer to each other frequently and consistently. With this in mind, I do not structure my analysis through discrete examination of each text individually. Rather I utilize a holistic approach, understanding these texts as an archive—if a fundamentally fractured, incomplete one. Loss and grief is structurally embedded in my source texts, though not as the author(s) necessarily intended. They are haunted by those left behind at Willowbrook, by those who may or may not be openly acknowledged—as human or nonhuman, as dead or alive. As Avery Gordon writes on the hauntological method: “The way of the ghost is haunting, and haunting is a very particular way of knowing what has happened or is happening. Being haunted draws us affectively, sometimes against our will and always a bit magically, into the structure of feeling a reality we come to experience, not a cold knowledge, but as a transformative recognition.”17 In the following analysis, I attempt to follow what is both omnipresent and disappeared, the unmournable—what is missing and what might be found.

16 Derrida, Specters of Marx, 212.
Chapter One: Haunting Willowbrook

1.1 Introduction

Jennifer Schweiger is missing. It’s 1987 and she’s twelve years old. Her home of Staten Island, New York is awash with search-party volunteers and local law enforcement. Her mother wears sunset-pink tinted sunglasses and cries on TV. It takes thirty-five days to find her. Searchers uncover a shallow grave and a small naked body in the shadow of the former Willowbrook State School. A makeshift campsite is discovered feet from Jennifer’s grave. It belongs to a man named Andre Rand. Rand is indicted, charged, convicted, and sentenced to twenty-five years to life with the possibility of parole. Rand is declared a monster by news media with “the Hannibal Lecter of Staten Island” being only one of his many colorful titles. One of these titles goes further than tabloid headlines: Cropsey, boogeyman of New York State.

*Cropsey* (2008, Joshua Zeman and Barbara Bracaccio) is a horror documentary film about the Cropsey legend—or rather, the concept that “…the urban legend of their [Zeman and Bracaccio] childhood has actually come true.”¹⁸ The filmmakers trace the origins of the Cropsey legend, interweaving the urban myth with the case of Andre Rand. Andre Rand is Cropsey and Cropsey is Andre Rand. However, this film not only about Rand or Cropsey (or whoever or whatever they might be together). There are also his victims or rather his suspected victims: four disabled children and one disabled adult. Jennifer Schweiger, Holly Ann Hughes, Tiahease Jackson, Alice Pereira, Hank Gafforio. The setting of the film is prominent, almost taking on the role of a character itself. Though the legend of Cropsey is known throughout New York State, *Cropsey* the film is firmly focused on Staten Island. The Staten Island of *Cropsey* is a liminal

space. The “greenest borough of New York City” is a suburban paradise where city workers can live the American dream of a house, lawn, and two point five children playing on clean asphalt street. As much as it is a symbol for middle-class desires, however, it is also a dumping ground for unwanted things. Besides rows of white houses with lace-curtained windows, there are ruins upon ruins of terrible places—a tuberculosis ward, a work farm, a garbage dump, and Willowbrook State School. The forests are littered with human detritus—rusted chairs and plastic food trays, soiled clothes and bare box springs. They are preoccupied with it even as they cannot quite face it—it does, of course, remain a ruin rather than a memorial or even a cleared lot for new development. Early in the film local activist and founding member of the group “Friends of Jennifer [Schweiger],” Donna Cutugno, leads the filmmakers through the grounds of Willowbrook. She comments: “You still hear it, you still feel it, the children’s presence there or the adults’ presence there and it’s something you never forget.” Willowbrook looms larger than anything or anyone else in Cropsey, including Andre Rand. It symbolizes everything lost, forgotten, buried, and unwanted.

In this chapter I utilize an analysis of Cropsey to examine the unmournability of Willowbrook and its former inhabitants. My analysis focuses on the nexus of violence that creates and reproduces this unmournability. More specifically, I am interested in the problem of the H/human and disability as it relates to this nexus. Cropsey is uniquely suited to a study of this problem and not only because it focuses on the legacy of Willowbrook—as a horror film it grapples with this problem as an inherent feature of its generic form. Horror is fundamentally about the transgressing of boundaries—this does not mean that it is always, or even often, politically radical. The transgressors of these boundaries are the villains in horror—those who are not human, who are not quite human, who embody or perform humanity the wrong way.
Horror villains, even at their most fantastic, are marked as Other in ways that easily correlate to the Others of the “real world.” However this is not to say that villains are only ever the Other in horror films or that audiences are only meant to sympathize with the heroes, who in fact might be something transgressive too or might be transformed into the transgressive as a consequence of the film’s narrative. The horror film does not even necessarily have a hero—most commonly they have victims and perhaps a lone survivor to witness the carnage. As a horror film, *Cropsey* is organized in this way: Andre Rand is the villain and the five disabled missing persons are the victims. However, I argue in this chapter that the transgressor in *Cropsey*, and thus in some way at Willowbrook, is not Andre Rand. Instead it is dead at Willowbrook—the victims—who truly disturb and unsettle. They are ghosts. They cannot be sent away because they do not exist. They cannot die because they are already dead.

### 1.2 Boogeymen

In the opening narration of *Cropsey*, the filmmakers describe the various iterations of Cropsey the urban legend. Cropsey is, depending on who one asks, a madman, a maniac, or an escaped mental patient. He, and he is definitely a he no matter the version, wields an axe, a carving knife, a hook. Parents, older siblings, camp counselors say don’t ride the bus past the mall, don’t go into the greenway, don’t go behind cabin six. As a boogeyman, he fulfills a socio-cultural function of “keeping teenagers from doing what teenagers do.” This means: having illicit, premarital sex, drinking alcohol, taking drugs, behaving generally recklessly. Before *Cropsey* the documentary, Cropsey the legend was the inspiration for two mainstream low-budget horror movies: *The Burning* (1981, Tony Maylam) and *Madman* (1982, Joe Giaconne). These films inspired by the financial success of *Halloween* (1978, John Carpenter) and *Texas Chainsaw Massacre* (1974, Tobe Hooper) follow a similar formula, one that is essentially the
same as the legend of Cropsey as described by Staten Island residents in *Cropsey*. Teenagers, especially conventionally attractive ones, are senselessly terrorized and murdered by a killer with only the loosest of motivations if any discernable ones at all. The killer is physically large and often seemingly supernaturally fast and resilient. His face is also obscured, either by a mask or by major disfigurement. In the context of *Cropsey*, this particular detail is the most important. Identifying Cropsey, and thus Andre Rand, is not quite about the evidence. It is about finding a suspect who looks the part.

When Andre Rand is first arrested under suspicion for the murder of Jennifer Schweiger, he drools. He appears disheveled, unwashed, and seemingly has a lazy eye. Newspaper headlines identify him as “drifter” and “vagrant.” Rand’s attorney notes how those terms lead public opinion unfairly: “Drifter equals guilty.” These terms also have a close historical relationship to disability in the United States, as Susan Schweik discusses in her book *The Ugly Laws*. The laws referred to in the title ostensibly forbid any physical disability or “ugliness” from being displayed in public. In practice, this was not quite how the laws were enforced. “Ugliness” referred only to the dispossessed and the homeless, the very lowest class of people in nineteenth and early twentieth century America. Wealthy, middle-class, or even housed and respectable working class people with visible physical disabilities were by and large unaffected. Several notable cases of people affected by the ugly laws were beggars accused of faking disability for public sympathy.19 Similarly many interviewees express suspicion that Rand is faking his “difference” to appear as though he is not responsible for his actions. Others suggest that people only see “difference” in photographs of Rand because they are led to do so by their own assumptions of what child-killers look like. During the initial years of the investigation, it is never suggested

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publicly that someone in the community—i.e. not homeless—could be responsible. It is simply unimaginable. Consider Ahmed on willfulness and perversion: “Willfulness is the word used to describe the perverse potential of will and to contain that perversity in a figure. In our tendency to associate willfulness with human flaws and sin would become a symptom not only of the desire to punish the perverts but to restrict perversion to the conduct of a few.”

No one in the community could possibly commit the terrible sin of murdering a child—a disabled child at that. It must be the work of a monster on the loose. “On the loose” is the operative identifier, as cartoonish as the expression may be. The mental patient is not necessarily a danger—the escaped mental patient is dangerous for certain.

None of this is to suggest that I believe Rand is a good person wrongly maligned or even merely innocent of the crimes he was accused of. Indeed the filmmakers of Cropsey make a compelling case that Rand is guilty. There is still, however, a major question: why did he do what he did? The villains of horror films typically either have single-minded motivations or none at all, especially those of the previously discussed type evoked in Cropsey. Of the single-minded motivations the most common is revenge, most usually for the crime of causing the villain’s characteristic disfigurement (as is the case in The Burning). Most of the interviewees in Cropsey who believe Rand is guilty subscribe to theories belonging to the second category: senseless, obscene, and essentially unimaginable to your average person. “Essentially” is a key word. Several people interviewed, including two retired New York police detectives who worked the Schweiger case, suggest that Rand was kidnapping children for the use of a satanic cult. They imagine a minor conspiracy in the halls of the abandoned Willowbrook and the tunnels beneath it. The filmmakers consider this theory. They note that it is demonstratively true that Rand was

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20 Ahmed, Willful Subjects, 12.
21 Yes, really.
not the only person living on the Willowbrook grounds. Whether or not they are Rand’s “friends” or part of a cult is difficult, if not impossible, to confirm. The major evidence for a cult are “Satanic symbols” spray-painted on the inner walls of Willowbrook—ironically, this is certainly “something that teenagers do.” At first the filmmakers entertain the idea that Rand was a former inmate at Willowbrook: “Many [inmates] wandered back to Willowbrook after it was closed, out of habit or looking for a familiar place.” This theory is quickly scrapped when it is discovered that Rand was not a resident of Willowbrook—he was an employee.

In the memoir *American Snake Pit* (to be discussed in detail in Chapter Two), Dr. Dan Tomasulo describes the abuse one of his patients suffered at Willowbrook: “It is…very likely that she had to fight off Andre Rand, an orderly assigned to the building. It was later discovered that Rand was a convicted child kidnapper and murderer who had buried one of his victims in a shallow grave on the [Willowbrook] grounds.”\(^\text{22}\) While this is inaccurate in its details—Jennifer Schweiger did not go missing until after Willowbrook was closed—it is still striking commentary. Rand the rapist is always close behind Rand the killer. The question as to whether Rand was acting out traumas from his own past is briefly entertained but firmly shot down by Rand’s sister. “Nothing happened,” she says, “this is all him.” The filmmaker’s conclusions on Rand’s motivations have little hard evidence and yet they are compelling enough that I am inclined to agree with them. Rand killed these people because they were disabled. He believed they could not, were not, would not be loved by their families, that they would always be burdensome, that they had no futures. If his major interactions with disabled people pre-murders were during his time at Willowbrook, it is hardly shocking that these were his conclusions. His

actions may have been no more than the actions of a system played out by the rogue hand of a single man.

1.3 Innocents

Everyone looks for Jennifer Schweiger. How they look for her—and at her—is important. Schweiger’s mother describes her as “a doll, just an absolute doll.” This description seems accurate if one goes only by the photographs provided in the film. She is small and pale with blonde hair in perfectly coiled ringlets. She smiles broadly in every photo whether in a church communion dress or a dance recital outfit. What makes her “a doll” however is not entirely her outward appearance. It comes from her behavior—her disability—as well. Schweiger was diagnosed with Down’s syndrome. Her mother subsequently describes her as “completely loving, completely trusting…it’s in her nature [as a person with Down’s syndrome].” Therein implied: she might not have needed to be coerced, she might have simply walked away. Similar things are implied about the other missing people—they were lured, not taken. Victimhood has its own kind of willfulness—of not taking care of oneself, of not listening when one is warned, of going to dangerous places, of allowing oneself to die. Schweiger, it seems, learned nothing from the boogeyman stories of Cropsey the monster.

Not every victim of Andre Rand was a feverishly searched for and worried over as Jennifer Schweiger. Two of the missing were children of color: Tiahese Jackson and Alice Perriera. Police at first do not pursue Perriera’s disappearance as a serious crime. They assume Perriera’s father took her back to Puerto Rico. Nothing to be done about it—even as Perriera’s aunt protested that Andre Rand worked as a janitor in their apartment building. Jackson’s disappearance is barely mentioned in the film. Only her photograph is shown with the narration that her family had since moved away from Staten Island and could not be contacted for an
These are lives cast as less valuable than Jennifer Schweiger. Innately less innocent as a result of their racial identity, Jackson and Perriera do not receive the same attention. Theirs is a foregone conclusion, their disappearances not shocking or even particularly interesting. Jennifer Schweiger’s disappearance is a crisis—these Jackson and Alice Perriera’s disappearances are a foregone conclusion. A White man kills a Black girl and a Latina girl—this is an old story and not a horror story. Horror, even as formulaic as it may be, operates on certain forms of cultural shock. The transgression is the innocent body, the White female body, violated on screen. Women of color are basically nonexistent in American horror cinema—the popular, and oft rifted upon, wisdom that “the Black guy dies first” is very gender specific. Of interest is how disabilities of Perriera and Jackson are obscured by their race. Though both are identified as disabled, the specificity of their disabilities are not discussed like Schweiger’s disability. This is to say that their vulnerability is quite different than that of Schweiger. I do not mean that they are more vulnerable than Schweiger—to be torn apart on screen and in public imagination is hardly a privilege. Rather I mean that by their specific vulnerability they are less mournable than Schweiger. Their loss cannot be felt when they are never fully visible.

Ahmed writes that the history of the will, and thus of willfulness, is also the history of the child. The will of the child must be broken. The child must be kept from independent movement. The child must be kept still. This is not an easy or peaceful process: “After wretchedness: this is indeed a wretched history…To follow the figure of the willful child is to stay proximate to scenes of violence.”²³ What is the responsibility of, and the responsibility to, the child that wanders away? In writing on the innocents in Cropsey, it was difficult not to think of the Disability Day of Mourning Archive. How many of the five missing might have been murdered

²³ Ahmed, Willful Subjects, 66.
by someone else if not Andre Rand? Indeed one or more of them might have been—only Jennifer Schweiger’s body was ever recovered. For the disabled people, to be clear of one danger is only one hurdle—there is always another scene of violence close behind, looming in front, surrounding you as if by a person who loves you.

1.4 Conclusion

Harriet McBryde Johnson knows she is going to die. She has always known this. She was born knowing it. On TV she sees children like her. They need your help. They are dying. They are going to die young. You can help find a cure. You can help make children like this disappear. During her childhood Johnson grows to disidentify from the tragic disabled children on TV. She sees herself, a more accurate and fulfilling self, elsewhere:

“I don’t see myself as morbid or obsessed, but I think about death a lot. I know it isn’t normal, but my relationship with death becomes a part of me. I can handle it, even if normal people can’t. I decide to be discreet, like Dracula, and live quietly amongst normal people. No need to trouble them with details. No need for them to know about the coffin I keep in the basement… I figure if I let people peek in my basement, they’ll jump to the wrong conclusion. They’ll define me as one of the undead, an unnatural creature, not really alive but feeding on the lifeblood of others.”

Closeness to death can be more than something to fear, to turn away from and deny. During her life, Johnson was a lawyer and a disability justice activist. She came to her vocations through a stubborn, almost relentless approach to her inevitable death. If she was going to die young, she might as well die a kindergartener, die a college student, die a law school graduate. Her attitude is stubborn refusal. Not a refusal to die but a refusal to pretend that she will not die. I refer to Johnson here because of how she eloquently describes the problem of disabled people being both villains and victims. These poses are not a mismatch, not a contradiction in terms.

24 Harriet McBryde Johnson, Too Late to Die Young: Nearly True Tales from a Life (New York: Picador, 2005), 11.
They inform each other, they shape each other. A disabled person’s status as a villain depends on their status as the victim—when they can no longer be cast as the victim, they become the villain. In her acceptance of death, Johnson refuses this logic. She is willful or rather she uses willfulness in the method Ahmed describes thusly: “Willfulness can be a trace left behind, a reopening of what might have closed down, a modification of what seems reachable, and a revitalization of the question of what is it to be for. Reaching for something, reaching for will, is thus an opening of the body to what came before, reaching back in time. Willful action can create the possibility of not being willing by not giving will up or giving up on will.”

Though Johnson did not die like the other disabled children she saw on TV, she does not disavow them. She does not pretend she is more than them, more capable, more valuable. She does not move away—she continues to reach back, down into the grave, into the cellar, for the dead, the not-quite-living, and the living dead.

Chapter Two: Mourning Willowbrook

2.1 Introduction

There were, of course, those who outlived Willowbrook. Child inmates became adult residents. They aged, made relationships, went on with the ways of living—they remembered what they experienced and endured, they remembered Willowbrook. So did others—parents, providers, and journalists. In this section I examine these accounts in concert, attempting to construct another narrative, though not the narrative. I base my work here on four source texts. The first, Willowbrook: The Last Disgrace (1972, Geraldo Rivera), was already featured prominently in Cropsey, my source text from the previous chapter. Here I am most interested in it for its place in shaping the narrative of Willowbrook in my three other sources. Everything follows The Last Disgrace, even as it aired more than a decade before Willowbrook was closed. My second source text, Unforgotten: Twenty Five Years After Willowbrook (1997, Jack and Daniel Fisher), places itself not as a direct response to Willowbrook per se but to the Willowbrook in The Last Disgrace. This is indicated by its reliance of interviews (more accurately, confessionals—their feelings of guilt characterize their testimony more than anything else) of parents and siblings of Willowbrook inmates as well as interviews with Geraldo Rivera and others involved with the production of The Last Disgrace. There are no interviews with former inmates and they are only seen on screen briefly, in the background of shots with their current caregivers or from family photos and home movies—a similar mode to Cropsey, it should be noted. American Snake Pit: Hope, Grit, and Resilience in the Wake of Willowbrook by Dan Tomasulo (2018) is my third source text. Tomasulo is a psychiatrist whose first job in the field, before he had officially completed his doctorate even, was at Walden House, a group home
established to take on inmates from the recently closed Willowbrook. *American Snake Pit* is primarily based on the memoir form, using Tomasulo’s life as the main narrative thread—his failed first marriage, his struggles making a living with his paltry salary at Walden, battles with local authorities, career post-Walden. His aim with the book, however, is not to document the life of a clinician in the early 1980s but instead to show to readers that people with disabilities “are not very different from you or me.”

The last source text, *I Survived Willowbrook: A Story of Fate and Triumph* by Joseph Dorsey (2015), is the odd one out. It is the only text authored by a former inmate of Willowbrook and indeed the only one I have found to have a disabled person involved in its production at all. *I Survived Willowbrook* is “as told” to Dorsey’s younger sister, Dr. Joyce Dorsey, as Dorsey never learned to read and write beyond his own name. Though I read *I Survived Willowbrook* with a skeptical eye, I found no evidence of duplicitous or malicious editing—or so I determined by as much as my instinct and reading from elsewhere could inform me.

This chapter is divided into three sections, each focused on a former inmate of Willowbrook. Though this structuring bears some obvious similarity to the “case study,” I reject this as a form. In theory the case study humanizes a subject for the reader as it lays out the philosophical groundings and intellectual problems at hand. However the case study also carries the weight of its associations with medicine, psychology, and law. Each of these fields in turn has a difficult and often violent history with disabled people—humiliation, dehumanization, genocide, and every sundry cruelty from the mundane to the macabre. Thus, instead of case studies I term these analytic sections “sketches.” My conception of the sketch comes from advice I received as a child from my mother, a feminist artist: when attempting to capture a subject with

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26 Tomasulo, *American Snake Pit*, loc. 204.
a difficult form, draw the shadows first. Negative space may not tell you everything—it can in fact be quite deceptive, Plato’s cave notwithstanding—but it does show what *could* be there. This possibility interests me. The available information—the *evidence*—of the lives of my subjects is shaped as much by silence as by speech, metaphorically speaking. I do not claim to speak for these people. The spirit does not move me—I may be haunted but I am not possessed. I can only write as myself, however flawed and limited a perspective that may be. Nor do I claim to “give them voice,” as several of the authors of my source materials do. This claim, besides being frankly absurd on a purely formal level, is demonstrative of the sentimental mode of writing on disability that I wish to avoid. Sympathy does not preclude harm—to identify disabled people and disabled lives as emblems of virtue, martyrdom, “the triumph of the human spirit,” is to reduce and, worse yet, to remake them into representations of representation. Instead of simply *being* human subjects, they become emblems of Humanity. In this chapter I am to confront this problem and suggest, if not a solution exactly, a method of resistance. I build off of my writing in the previous chapter grappling with the nexus of violence and the h/Human in the in/ability to mourn disabled people to construct this method. The following analytic sketches are my attempts at shaping the “shadows,” the implied and the unsaid, in the stories of these three former Willowbrook inmates into works of mourning.27

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27 I realize that a reader might wonder why I do not simply call these sketches “obituaries,” even beside my stated inspiration for their form and method. My explanation is rather simple: I have no way of knowing if any of my subjects are dead. Only one of my subjects has a last name available and a Google search has not revealed any pertinent information as he shares a name with several other individuals. More so, my point with these sketches is not to chart a life teleologically—birth, schooling, career, marriage, children—because such a life has been denied to these individuals as a result of their internment at Willowbrook. This is beside the fact that such a life narrative is not desirable for all, at all.
2.2 Joseph Dorsey

Joseph Dorsey considers Geraldo Rivera’s entrance into Willowbrook for the filming of *The Last Disgrace* to be a defining moment of his life:

“…One day in 1972, I heard about a man named Geraldo Rivera. I saw him on WABC TV new Channel 7 in New York. They were discussing Willowbrook and all the wrong things I saw there with people who worked there. The guys in Building Five looked at television, so they saw the news report too. We wanted Mr. Rivera to do more than just talk about what was wrong. We wanted him to get us out. We decided to take Mr. Rivera some keys from Building Six.

I met Mr. Rivera one day soon after taking the keys from Building Six to the police. Her talked to…some of the other guys and me. We told him everything we knew about Willowbrook. The news media began to show up every day, especially ABC in New York. This gave us a cause and we knew a change was gonna come and the whole world would know about Willowbrook. I don’t know if Mr. Rivera remembers me, but even so, I feel he changed my life and those of my friends in Building Five and my brother Robert’s life in Building Six.”

Much of Dorsey’s account here contradicts the “official” narrative of Willowbrook, with the “official” accounts here being *Willowbrook: The Last Disgrace, Unforgotten: Twenty-Five Years After Willowbrook*, and the academic-minded history of Willowbrook, *The Willowbrook Wars: Bringing The Mentally Disabled into the Community* (2017) by David J. and Sheila M. Rothman. Dorsey and his friends are active participants in the struggle to expose the atrocities at Willowbrook. Not only do they give their accounts to Rivera, they also give him the keys to witness the “disgrace” himself. None of the official sources mention this. The credit is given entirely to Rivera and a cadre of doctors at Willowbrook. It would be easy to cast doubt on

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29 My intention here is not to denigrate the Rothmans’ work. *The Willowbrook Wars* was very useful to me for contextualizing and gaining a timeline of Willowbrook.
Dorsey’s account rather than on the official sources. A small, no-name press located in rural Georgia rather than an academic or even mass-market press published Dorsey’s book. He does not cite any sources beyond Wikipedia and ABC news. Technically speaking he did even not “write” it, having had it dictated and edited by his sister. Most importantly—he is disabled himself and thus an unreliable witness by his very nature. By my view, however, there is much to support his account’s veracity. As one of the “least retarded” who lived in Building Five, Dorsey was given a relative amount of freedom, if no support or education, and was often put to work fixing minor issues at the institution—including servicing the vending machines. Dorsey recalls: “The money from the vending machines was very useful then. I could get just enough to pay my way and have a good time on my own…Once I learned a few bus routes, you could say I had it going on. I had newly found freedom and fun. This freedom was a real eye-opener for me.”

If Dorsey could leave the institution and go to the other boroughs of New York every day, why couldn’t he have had access to building keys? Neither Dorsey nor any of his friends appear on camera in *The Last Disgrace* and their contribution goes unmentioned both in *The Last Disgrace* and in the follow-up *Unforgotten*. The purpose of these films is not document the lives of those interned at Willowbrook, or even, I argue, to mourn them. They mean to use the Willowbrook internees to stand for something else: innocence, failure, and guilt. The ending narration of *Unforgotten* is revealing: “They [the survivors of Willowbrook] represent the best part of ourselves. The part of us that instinctively knows the importance of shared responsibility and the part of us that needs to learn from those who can truly teach us about the miracle of living.” The internees of Willowbrook are not themselves, but part of “us.” They are denied specific lives,

experiences, and identities. What happened at Willowbrook, and what happened after Willowbrook, could have happened to anyone—but, of course, it didn’t.

As a Black disabled man, Dorsey is well aware about how his race and that of his family has affected his life. He notes that had his family been White and middle class his life and those of his brothers might have turned out very differently. He posits that if his mother had been provided with the proper medical care for a multiple birth, Daniel and Robert might not have been caught in the birth canal without oxygen thus causing their disablement.31 His sister Joyce believes that she was only able to access the records for Daniel and Robert because a white friend accompanied her.32 The Dorseys only enrolled Joseph and his brothers at Willowbrook because of pressure from New York State social workers—they would have much preferred to keep them at home with an aide.33 So too would they have preferred to at least keep Joseph at home, as he required much less specialized care than his brothers but the state authorities determined that, as triplets, it was all of the Dorsey brothers or none of them. Before Willowbrook was closed, his family attempted to remove Joseph from the institution to live at home. They were informed they did not have the authority to do. Dorsey remembers: “Little did we all know that neither Mom nor Dad had any power. I belonged to the state of New York. That was it!”34 Out of all institutions in New York State Willowbrook had the highest proportion of Black and Latino inmates.35 This was likely not only because Willowbrook mainly served the New York City metropolitan area. Willowbrook also served the “most disabled” which due to the fundamentally racist nature of intelligence testing and other environmental factors like lack

31 Dorsey, I Survived Willowbrook, loc. 239.
32 Dorsey, I Survived Willowbrook, loc. 246.
33 Dorsey, I Survived Willowbrook, loc. 261.
34 Dorsey, I Survived Willowbrook, loc. 399.
of prenatal and maternal care, air and water pollution, and poverty meant these were disproportionately people of color.\textsuperscript{36}

What affects Dorsey the most from his time at Willowbrook is not what he himself experienced. Instead, Dorsey is haunted by what befell his brothers Daniel and Robert. Daniel and Robert were both infected with hepatitis as the result of medical testing on the inmates of Building Six. In 1965, Daniel died as a result of hepatitis and starvation at Willowbrook: “His body was taken to Atlanta to be buried with other members of the family. No one told me anything and I didn’t go to Atlanta. I learned about his death one day when I went to his dorm to take him on a walk.”\textsuperscript{37} Robert survived long enough to leave Willowbrook but he too eventually died from complications of hepatitis. His sister Joyce later informed Joseph that Daniel and Robert were chosen to be subjects for the medical testing because of a system called eugenics—the same system that performed a vasectomy on Joseph without the knowledge and consent of either Joseph or his family. Dorsey is disturbed by what happened to all of those experimented on in Building Six, those he refers to as “God’s weakest children.” He says simply: “That was mean and cold, the more I think about it.”\textsuperscript{38} At the end of \textit{I Survived Willowbrook}, Dorsey reflects on current life and how he came to it.

> “Every day I wonder about the people I grew up with. Some of them seemed normal to me. I can imagine that some may be living with their families too. It’s good to live in a free world and to live with normal people. I hope some of them found jobs like I did and made money for themselves. So many people are homeless these days and when I see them, I give them money because they might have left an institution and now they don’t have a family. Some of the guys I grew up with died before I left Willowbrook, like Daniel did. They are in heaven. I just know it.”\textsuperscript{39}

\textsuperscript{36} Ibid.
\textsuperscript{37} Dorsey, \textit{I Survived Willowbrook}, loc. 340.
\textsuperscript{38} Ibid.
\textsuperscript{39} Dorsey, \textit{I Survived Willowbrook}, loc. 549.
Dorsey can imagine his fellow former inmates outside of Willowbrook, including the ones that died there. Though he expresses this through the language of his Christian faith, Dorsey’s imagining is no less political. He is suggesting that they are not only—or not even—representations, but instead individuals with their own lives and deaths. On a superficial level Dorsey’s words here do not appear entirely different than the previously mentioned *Unforgotten* narration, at least in terms of imagery as it also refers to Christian belief, but unlike *Unforgotten* Dorsey phrases his remarks as questions rather than statements. What he “knows” rather than “wonders” is only that there is a *possibility* of escape and happiness. Dorsey’s current life is possible because of the care and compassion of his family and he is aware that is something that not all of the former internees have or had. He mourns them as they are rather than what he imagines them to be.

### 2.3 Sophia Doe

Sophia Doe doesn’t speak. She doesn’t need to. Her body speaks where she cannot (does not). Dr. Dan Tomasulo recalls his first impression of Doe: “She emerged from behind the dresser naked, destroying everything in her path, her body marked with jagged keloid scars and burns, a geography of abuse from those who came before me.”

Tomasulo, *American Snake Pit*, loc. 248. This introductory encounter is violent and terrifying. After Tomasulo entered Doe’s room alone—and apparently unannounced—she took to the offense, picking up an entire dresser and bodily throwing it at Tomasulo. Tomasulo is as awe-struck as he is panicked: “Her wiry body seemed an odd combination of raw power and poor muscle tone…Her body looked as if someone had placed

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iron cables inside pastry dough…Her strength was a marvel to witness.”41 During the struggle Doe punches through a plexiglass window, catching her arm on shards of glass: “I instinctively ran toward her—exactly the wrong thing to do…I saw her fear mixed with rage…I tried to grab her shoulders to prevent her from pulling [at her arm stuck in the glass], but my action made her more agitated and she made repeated, frantic attempts to free herself.”42 Tomasulo is unable to console her or otherwise convey his peaceful intentions. It is not until Taimi, the house assistant, comes in to find them that Doe is able to center herself: “A small, stocky woman straight armed me with her left arm and bear-hugged Sophia, bringing her to the ground…She grabbed a piece of clothing from the floor and wrapped Sophia’s arm, tourniquet style, as she spoke. ‘Sophia, Sophia, Sophia, what did you do? I go to the bathroom for two minutes, and look at this. How did you do this to yourself?’…To my great surprise, Sophia had calmed down and smiled.”43 The woman portrayed here is simultaneously vulnerable and threatening. More so, her vulnerability is the source of her status as threat—she reacts violently because she has experienced violence. Tomasulo, though shaken, finds this reaction a mark of admirable character: “Sophia wasn’t always the victim…She learned to fight off her attackers by tapping into her rage.”44 Tomasulo’s narration and interpretation of this incident are revealing. Doe is hyperembodied—her self is subsumed by bodily reaction to perceived danger.

The perceived danger Doe is reacts not just any threat of violence. In fact, her fear is quite specific—she anticipates sexual violence and she anticipates sexual violence from men. Tomasulo says Doe suffered many separate attacks over a long period of time at Willowbrook,

41 Tomasulo, American Snake Pit, loc. 257.
42 Tomasulo, American Snake Pit, loc. 281.
43 Tomasulo, American Snake Pit, loc. 296.
44 Tomasulo, American Snake Pit, loc. 439.
from other inmates and, Tomasulo adds with shock, “…even orderlies.”45 For much of the book, Tomasulo struggles to understand Doe. To him, her rages seem random and uncontrollable. Why is she doing what she does and how can he find out when she cannot speak? Taimi, the house assistant who intervened during Tomasulo’s disastrous first meeting with Doe, does not share in his confusion:

“Imagine those goons who held her down and raped her. She probably thought she was calling for help and no one came. All she was left with was rage. That’s why she doesn’t trust you. You’re just another male staff person who’s going to fuck her. She’s got no reason to trust you; that’s why she threw the dresser and hurt herself. I bet she learned to fight as much as she could, and then hurt herself enough to get medical attention. It was the only way she knew to stop someone and get control.”46

Doe’s vulnerability and her propensity for violence once again slide into each other. They mutually form and shape each other. However in Taimi’s view Doe’s actions are not unreasonable. In fact, they are perfectly attuned to the conditions in which she lived and the abilities that she had at Willowbrook.

Doe may or may not have been born in Willowbrook. She may or may not have been the result of a relationship between two Willowbrook inmates. This relationship may or may not have been consensual. This is to say—her origins are unclear. The only certainty is that she lived there from infancy to adulthood. When she comes to live in Walden House at age twenty-eight, she has known no other environment than the institution. Tomasulo claims that before Walden House, she had never felt rain.47 48 In Walden House, everything is new. Doe has favorite

45 Tomasulo, American Snake Pit, loc. 437.
47 Tomasulo, American Snake Pit, loc. 2147. Point of interest—this assertion is actually once again an insight from Taimi—“She’s been in the institution her whole life and thought it was shower time. She’s never felt the rain.”
things—orange juice, Looney Tunes, answering the doorbell. She has relationships with other people. Or rather, she has relationships with other people that are not based on a profoundly unequal power differential. Though certain people in her life do exercise some form of authority over her—Tomasulo and to a lesser extent the other staff—these relationships are still based on mutual trust and consent, especially her relationship with Taimi, as already indicated in the previous section. Taimi finds the treatment of Doe, and others like Doe, by medical professionals to be contemptible:

‘“Psychiatrists are assholes.” She paused to check herself. ‘You’re a psychologist, right?’

I raised an eyebrow, but nodded.

‘You tell me, do you know any psychiatrist who would even think about doing anything with these people besides fuck them up with medication? Their only solution is turning people into zombies. Do me a favor, will you? Don’t ask them for an opinion, because you know what? They’ll give it to you and for the most part they don’t have a flaming idea in their head what to do. They’ll give you a diagnosis, something fancy: “schizoid personality type with borderline intellectual functioning, dysthymia with psychotic features,” or my personal favorite, “severely retarded with psychiatric disorder NOS,” and I’m sure you know what that means, not otherwise specified, so they don’t even have a clue what it is. And it doesn’t even matter what the diagnosis, the treatment is the same. Give them enough medication that they

48 Sophia Doe’s story bears a distinctive resemblance to that of Genie, the so-called “feral child” who was the subject of intense interest from both the scientific community and the larger public in the early 1970s. Genie was raised in a household where she was consistently terrorized by her father in ways including but not exclusive to: being held in a completely dark room, being prevented from speaking or making any noise with the punishment being beating with a wooden board, being held in restraints the vast majority of the time. For obvious reasons, this caused major developmental delays. The point that any person would be disabled after such treatment remained unexamined by the team of doctors and psychologists who studied her after she was “discovered.” After the loss of government funding, Genie entered foster care where she endured more abuse from caretakers. She is still alive today. I have not been able to find any feminist or disability justice oriented writing on Genie. There should be.
don’t bother anymore. Give them enough Thorazine to kill a moose and move on to the next brilliant diagnosis.”

Taimi’s anger here is palpable. Earlier in the text, Tomasulo noted that previous to Walden House, the primary “treatment” given to Doe was indeed Thorazine, also known as “chemical restraints.” Taimi is not the only person to condemn Thorazine—she is in good company. Angela Davis writes about her observations on the mis/use of Thorazine during her time in prison: “I was especially struck by the fact that guards did…try to coax me to imbibe the medication indiscriminately prescribed to the women there [in the psych ward]…What surprised me more…was the recognition that the prisoners I encountered in the main population were thoroughly familiar with the psychotropic medication routines and treated them as an entirely routine phenomenon.” Davis identifies this practice as part of the structural logic conflating deviance with disability—deviant women are disabled and disabled women are deviant. Thorazine—and other sedatives of similar type—is a technology of the carceral state. Scholars Erick Fabris and Katie Aubrecht conceive of chemical restraints as part of what they call “chemical incarceration,” writing: “Chemical incarceration…is a term we use to describe the mandatory drugging of people considered mad or mentally ill, but also anyone in an institution who is drugged without informed consent, with or without a diagnosis.”

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49 Tomasulo, American Snake Pit, loc. 1967.
50 Tomasulo, American Snake Pit, loc. 441.
53 Fabris and Aubrecht’s work comes from the schools of thought known as “mad pride” and “mad studies” which require a more thorough examination of its relationship to developmental
Fabris and Aubrecht’s formulation here is important. What matters in considering the ethics of drugging is not the authority of the prescriber but in the agency of the “patient.” Mandatory drugging without consent is a fundamental violation of autonomy. How Aubrecht describes her own experience with mandatory drugging is revealing: “…[chemical incarceration]…for me…meant being restrained in someone else’s body. Pharmaceutical reason confined me to a glass bubble that separated me from my body and my body from the world.” Chemical restraint involves the fracturing of the body from the self, the self from the body, the self from the world in which the body inhabits. It means to suppress the will of the patient/prisoner entirely so, as Taimi says, “they don’t bother anymore.”

Doe has lost much in her life because of her internment at Willowbrook. Rather, she lost a life. Though Tomasulo presents her as a child, Doe is a fully-fledged adult when she arrives at Walden House. In reading the text, I was startled to realize that in fact I am much younger than Doe at only twenty-three. The facts are difficult for me to comprehend—twenty-eight years of brutality, twenty-eight years alone, twenty-eight years without orange juice or Looney Tunes or answering the door. How could a person survive—how did she survive? Doe most likely did not have the (admittedly meager) comfort Dorsey had in the relative freedom to leave Willowbrook with other inmates he could call friends. Nor it seems did she have any family or friends outside of Willowbrook, a result of possibly being born to Willowbrook itself. If Tomasulo was correct and Doe did not experience rain until Walden House, what could she have known of what existed outside of Willowbrook during her internment? The back ward where Doe was held did not have televisions and it can be certain that no one would have bothered to read to her. No past,  

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54 Fabris and Aubrecht, “Chemical Constraint,” 191.
no future, no present—only the walls of the institution. Death there would not have been a true
death for Doe because she never truly lived. At Walden, with Taimi, this is no longer the case.

2.4 Candy Doe

The problem is not that Candy Doe doesn’t speak. The problem is that Candy is silent—
completely silent, preternaturally silent: “She was lost to the world as if she were in a coma, but
someone in a coma didn’t sit up and stare at you.” At age twenty Candy Doe was gang raped,
beaten, and left naked overnight in the woods outside her school. Her throat was badly cut. It left
a nasty scar but otherwise caused no physical damage. Doe spent three months in the hospital
anyway. She would not eat. She would not drink. She would not dress herself or wash herself or
do anything at all: “Although her body survived, her psyche was dead.” When he meets Doe at
her parents’ house, Tomasulo terms her as case of complete catatonia—one step until a coma,
two steps until death. After the hospital Doe had been sent to Willowbrook for an unspecified
amount of time before she was allowed to return home to the custody of her parents. They are
terrified by what has become of their daughter. Tomasulo is sympathetic. He writes: “How do
you live with someone who isn’t really there?”

Doe does not fit in at Walden House, diagnostically speaking. Tomasulo is the first to
admit this: “I knew she would be the outlier in a home of outliers. She would be the most
different from the rest. However, I also knew no one else would be willing to work with her.”
Like Joseph Dorsey, Candy Doe would not have been a candidate for Willowbrook in normal
circumstances. Before the attack she too was classified as “mildly retarded” and had a family

55 Tomasulo, American Snake Pit, locs. 1318-1329.
56 Tomasulo, American Snake Pit, loc. 1311.
57 Tomasulo, American Snake Pit, loc. 1318.
58 Tomasulo, American Snake Pit, loc. 1361.
both willing and able to care for her needs. Tomasulo writes that because her “double” disability, being both her trauma and developmental delay, providers were generally uninterested in working with her. She was considered a lost cause. Tomasulo does eventually have some success with her, as he writes: “My hope was that, somehow, we’d find a way to reach and teach her. But just the opposite happened: it would be her character strength of perseverance and grit that that would astonish me and make me want to learn more…It would be Candy who would teach me how someone could recover after all hope and dignity had been lost.”

As a feminist it is difficult not to be skeptical, to even feel contempt, towards this sentiment. A woman is raped and a man learns a lesson. Tomasulo even receives a professional award as a result of his work with Doe—apparently he is one of the first to codify techniques for treating trauma in developmentally disabled patients. There is also a slender distinction and a sharp point to be made with Tomasulo’s use of language. Candy Doe’s hope and dignity had not been lost. If anything, it had been stolen.

As with Sophia, Tomasulo’s main goal with Doe is to provide a way for her to communicate with others. Communication is not a goal for its own end, however. Doe needs to communicate in order to reveal the identities of her attackers. Presumably, this will solve everything. At the very least, it will absolve her parents of their grief and guilt: “I’ll tell you what the goal is,’ said her father. ‘The goal is for us to have our daughter back and for those lousy bastards to go to jail for the rest of their miserable lives. That’s the goal Dr. Dan, plain and simple…” Doe’s parents, and Tomasulo to a lesser extent, imagine that there is some way for Candy to return. I use that phrasing deliberately. After her rape, Candy is not Candy anymore but something else—not even someone else. Tomasulo describes Doe in the immediate aftermath of

59 Ibid.
60 Tomasulo, *American Snake Pit*, loc. 2164.
the attack: “Her body was like a sack of sand and difficult to move.”61 She remained difficult to move after the hospital, physically and emotionally—she could not be forced to act or react, “beyond human contact” that she was.

Doe does, eventually, choose to speak. Interestingly enough this happens almost immediately after Tomasulo requests that Doe’s psychiatrist cut the tranquilizers from her prescription drug cocktail. Doe has a lot to say: “Candy started talking, almost nonstop, in the session. It wasn’t gibberish, but it seemed to be a nonstop stream of consciousness that was little affected by what I said or did.”62 This is not entirely true as Tomasulo eventually discerns. As with Sophia, Candy has her own ways of expressing and navigating trauma. Though Candy is not as close to any one of the other residents and staff as Sophia is with Taimi, she still builds relationships. Of particular interest are her interactions with Harold, the cook and handyman at Walden House. Harold, by Tomasulo’s description, is Black, physically large, heavily scarred, and recently out on parole from prison on unspecified charges. He is also an excellent cook.

“‘Questions just make things more difficult,” said Harold. ‘Here you go honey.’ Harold repeated what he had done earlier with Candy. He lovingly folded her hand around the fork and gently pushed the prongs into the bit of stuffed pepper. ‘Just go about your business,’ he said casually. ‘She’ll let us know when she’s done.’”63 Harold’s kindness towards Doe is set in contrast to the temporary staff member Tom, who is demanding and impatient. It can be assumed that Tom, by virtue of Tomasulo’s lack of racial identifier, is White. Though this may be an uncharitable reading I am inclined to see Tomasulo’s descriptions of Harold, both with Walden House residents and with its staff, as a rhetorical device of “surprising” a reader with the idea that a

61 Tomasulo, American Snake Pit, 1311.
62 Tomasulo, American Snake Pit, 2178.
63 Tomasulo, American Snake Pit, 1570.
Black man could be caring, gentle, and understanding of difference. Besides the obvious and uncreative racism at play here, this also belies Tomasulo’s lack of knowledge about the processes of deinstitutionalization post-Willowbrook. At the interview, of which Harold is the only remotely qualified applicant, he briefly mentions that he is used to strange behavior from his time in prison. When institutions closed the vast majority of developmentally disabled and mentally ill people did not go to homes like Walden House. Instead they went to prison, which remains true to this day. Eventually it is Harold, in another mundane encounter, to whom Doe reveals what happened to her beyond the facts on her medical chart and police report.

In her book on prison abolition Are Prisons Obsolete? Angela Davis asserts that rape and sexual assault are tools of the carceral state against women in institutions. On the surface Doe’s experience seems apart from this assertion. Her rape (or at least the one that counts as it is never brought up if Doe did also experience sexual assault at Willowbrook) did not occur in an institution and was not perpetrated by actors of the state. However the onus of defining the sexual violence is still with the state and with authority. Doe’s father wants to punish “the bastards” who did this, who took the real Candy away. There is little interest, even by those who love and care for her deeply, in how Doe feels rather than in the exact details of what happened. The logic remains the same. Doe’s self is overshadowed by what she experienced. Punishment of her attackers will not heal Doe’s trauma. Nor will it change the nature of her vulnerability. When Doe reveals previously unknown details of the attack, her account is narrativized by her own specific experience of her trauma. What she feels is lost is different than what her parents or what Tomasulo feel that she has lost. She does not describe losing “herself” or her “innocence”

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64 Angela Davis, Are Prisons Obsolete? (New York: Seven Stories Press, 2003), 65 Angela Davis, Are Prisons Obsolete?, 1056.
and appears uninterested in the terms entirely. Her description(s) of the attack emphasize her frustration and fear:

“‘Candy,’ I said, ‘do you remember what happened that day?’

‘No more ice cream for me!’ she said sharply. ‘I could never eat ice cream again!’

‘Why is that Candy? Why could you never eat ice cream again?’ I asked.

‘Chocolate chip,’ she said. ‘I could never have chocolate chip ice cream again.’

‘Why couldn’t you have chocolate chip ice cream again?’

‘Because!’ Candy said in a loud whisper as she raised her eyebrows.

‘Because why Candy?’ I answered in turn.

‘Because,’ she said, ‘they would cut my neck open with a knife! With a knife! They cut me a little bit to show me. It would hurt a lot if they cut my neck open. I would bleed all over and die.””

Questions, as Harold the cook had previously commented, do make things more difficult—at least they do for Candy Doe. Tomasulo structures this conversation in the text as if it was a revelation. Tomasulo (and, presumably now, the readers of the text) now understand Doe. Chocolate chip ice cream is the representation of her trauma. She cannot have it anymore because of its connection to her rape. Tomasulo presents this as a juvenile attachment. At the end of this conversation she laughs and laughs and laughs uncontrollably, calling the contrast of a slit throat and chocolate chip ice cream “silly.” Tomasulo provides no more information about Doe in the book. It is left to the reader to assume—or imagine—how her life continues. The beginning of Candy Doe is her rape. The end of Candy Doe is her telling about her rape. By this

66 Tomasulo, American Snake Pit, loc. 2199.
narrative the “real” Candy returns when she submits to interrogation. She has to tell them what happened. She has to tell someone. She cannot keep it to herself.

2.5 Conclusion

Where does Joseph Dorsey fit in with Sophia and Candy Doe? By his own description, Joseph Dorsey’s story is a triumphant one and triumph seems an ill description for the lives of Sophia and Candy Doe—even if Tomasulo chooses to interpret their lives as a triumph in his own life narrative. This is the crux of the problem in attempting to reconcile the stories of Dorsey and the Does. American Snake Pit is fundamentally about Tomasulo, not the former inmates of Willowbrook or the current residents of Walden House. Thus, they are not connected by narrative or even necessarily experience—as a result of their different social positions they experienced ableist violence in different ways. What connects Joseph, Sophia, and Candy is their shared relationship to intimacy. Mia Mingus describes how “forced intimacy” defines the lives of disabled people: “Forced intimacy is a cornerstone of how ableism functions in an able bodied supremacist world. Disabled people are expected to ‘strip down’ and ‘show all our cards’ metaphorically in order to get the basic access we need in order to survive. We are the ones who must be vulnerable—whether we want to or not—about ourselves, our bodyminds and our abilities.”67 I see in these stories a drifting away from, a slipping out of, the embrace of the forced intimacy Mingus conceives of here. As they are each forced to ‘strip down’ to their most vulnerable, they simultaneously reshape their selves to still remain, in some way, unknowable. This is the formation of their practice of mourning. It may not be necessarily political but I do believe it is essentially feminist.

An explanation as to why this practice of mourning is feminist requires a look at Butler’s conception of vulnerability: “A vulnerability must be perceived and recognized in order to come into play in an ethical encounter, and there is no guarantee that this will happen. Not only is there always the possibility that a vulnerability will not be recognized and that it will be constituted as the ‘unrecognizable,’ but when a vulnerability is recognized, the recognition has the power to change the meaning and the structure of the vulnerability itself…Vulnerability takes on another meaning at the moment it is recognized, and recognition wields the power to reconstitute vulnerability.”

A—not exactly or necessarily the—vulnerability of Dorsey and the Does is recognized by power in these texts. The plot of American Snake Pit is essentially Tomasulo’s process of recognizing the vulnerability of the various residents at Walden House. He encounters Sophia and Candy’s vulnerability in their experiences with sexual violence and decides what is “recognizable” and “unrecognizable” in their reactions to it. Sophia and Candy are described pre-recognition as being inhuman—Sophia, the animal in her anger, and Candy, the corpse in her silence. They are termed human when Tomasulo is able to recognize how their vulnerability presents and functions. Tomasulo’s recognition is not violent but it is he alone who sets the terms. He requires coherency; what is coherent to him specifically as a non-disabled man. When they are made to be coherent, Tomasulo recognizes them. The encounter of recognition in Dorsey’s text is less obvious. This is because it is a non-recognition. The writers of Willowbrook’s history do not recognize him. Even when he is literally (physically) seen by Geraldo Rivera, he is not recognized as a human subject. This lack of recognition is intertwined with Dorsey’s vulnerability. Dorsey is vulnerable as a disabled person and as a Willowbrook inmate but he is not vulnerable like the residents of Building Six seen on screen in The Last

68 Butler, Precarious Life, 43.
Disgrace. Dorsey is able to leave—he does leave, physically—but he is still connected to Willowbrook by his sense of loss. He mourns his brothers, his lost friends, people he could have known but did not. He is vulnerable because he mourns.
Conclusions

“Let’s face it. We’re undone by each other. And if we’re not, we’re missing something.”
Judith Butler, Precarious Life, pg. 23.

Not everyone sees ghosts. Seeing ghosts requires sensitivity—a certain kind of sensibility. This sensibility is a feminist one. It requires one to meet others (Others) where they are, rather than where one wants them to be, or where one happens to be. One has to let go of one’s own understanding of one’s self and the relationship of one’s self to the world. I have attempted to do this in my writing of this project. It was not easy. This stance—or attempt at a stance—required several confrontations. Identifying myself as disabled is one thing. Attempting to carry that identification through my work is something else entirely. There is the creeping terror of “it could have been me.” This is a terror that is not a terror. This is fear that is not fear. This is grief. I do not—cannot—call it only sadness. I feel sadness when I spill red wine down the front of a white shirt. Sadness is about the loss of an object, grief the loss of a subject. The subject lost in this project was not someone I can understand as an Other. I cannot consign them to objecthood. Rather, I could but to do so would mean to disavow a part of myself—this is not quite accurate. Even at the end of this project, I still wish to pretend that my own disability is not a fundamental part of myself. This is unsatisfying. This is frustrating.

As much as I write and speak of ghosts, I have only one ghost story myself. Three years ago, I found myself alone and living out of my home country for the first time. I was staying in a building dating back to the medieval period in Oxford, England—as an American, it seemed that if I would see a ghost anywhere, it would be there. I awoke in the middle of the night to a woman
sitting on the edge of my bed, weeping. I immediately reached out, thinking it was my girlfriend. It did not immediately register that this woman had long, flowing curly hair where my girlfriend had short-cropped hair. Nor did it register that my girlfriend was currently a thousand miles away. This was a woman in my bed. I assumed I loved her. My hand passed through her shoulder. She disappeared. My attempt at contact was a failure—except that it wasn’t. After this encounter I immediately texted my girlfriend to ask how she was doing. Contact achieved with the living, far away. My experience writing this thesis has been very similar. Fundamentally unachievable, but with the hopes of some echoing effect.

Mia Mingus’ thesis statement for her blog, Leaving Evidence, was the original inspiration for this project before any other development of its specific subject matter or theoretical grounding: “We must leave evidence. Evidence that we were here, that we existed, that we survived and loved and ached. Evidence of the wholeness we never felt and the immense sense of fullness we gave to each other. Evidence of who we were, who we thought we were, who we never should have been. Evidence for each other that there are other ways to live—past survival; past isolation.” I hope, in some small way, I have answered Mingus’ call.
Bibliography


