The Spectre of Institutionalization: Disability, Law, Performance, and Policy at the Pennhurst State School & Hospital and Pennhurst Asylum

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DEDICATIONS

To all those who have died—my family and friends—before I could finish this work.

To the people of Pennhurst—past, present, and future.

To the next first-generation dis/abled college student.

ABSTRACT

Keywords

Bioethics, biomedicine, community living, disability, education, ethnography, historiography, horror, law, museology, performance, policy

Abstract

This dissertation combines archival and ethnographic research to investigate the Pennhurst State School & Hospital (PSSH), a custodial institution for dis/abled people turned haunted attraction, primarily staffed by dis/abled performers.¹ I ask how Pennhurst became a performance venue which commodifies violence for entertainment, while paradoxically fostering community for the very people the former institution sought to eliminate. In doing so, this dissertation uncovers how institutionalization constructs and enforces legal, medical, political, and social notions of disability, producing identities which simultaneously dehumanize and sustain dis/abled people. I theorize institutionalization as an ongoing social process and show how one dis/abled community uses performance to reinterpret and reclaim it.

Chapters examine the commitment process to the PSSH through the lens of disability, law, and performance (<u>Act I</u>), and compare official "accounts" of care at the PSSH with the experiences of those forced to exist at the institution (<u>Act II</u>). The first

¹ Click <u>here</u> to forward to my definition of these terms.

half of the dissertation ends by examining the lawsuits that closed the PSSH, and Pennhurst's influence on current disability policies (<u>Intermezzo</u>). The second half of the dissertation offers an ethnographic analysis of the contemporary Pennhurst Asylum haunted attraction (PA). The PA's immersive performances of horror elide fact with fantasy and conceal ongoing violence against dis/abled people (<u>Act III</u>). The dissertation ends by showing how (in <u>Act IV</u>) the community of dis/abled and nondisabled people who work for PA perform vernacular dis/ability heritage work through their collective inhabitation of and care for this former institution. In doing so, they reclaim the space once intended for their segregation from society to create a space for dis/abled people made by dis/abled people.

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OVERTURE

Performing Disability: A Vignette

It is raining, and water drips through a dilapidated roof as a group of soggy visitors tromp

into the Mayflower Building—a former boys' ward on the grounds of the former

Pennhurst State School & Hospital (PSSH) in Spring City, Pennsylvania in May 2021.²

Shaking themselves dry, and affixing their rain-soaked face masks, the group of

predominately White, middle-aged female patrons breathes in the musty, stale air of the

long, corridor-style ward for the first time. Serving as a last-minute replacement for the

regularly-scheduled docent-Donna Samluk, a former PSSH "Mental Retardation Aide

I"—I introduce myself and the space to the group with my usual spiel.³

Welcome to the Pennhurst Museum—the country's only operating museum of dis/ability history and culture located within a former custodial institution for dis/abled people.⁴ My name is Nathan Stenberg. I am a first-generation dis/abled college graduate and PhD Candidate at the University of Minnesota and I am your guide today.

Before we begin our tour, I want to give y'all the background on how the Pennhurst Museum (Museum) came into existence. After the PSSH closed in 1987, private owners purchased the property in 2008. They renamed it the Pennhurst Asylum (PA) and opened a haunted attraction and paranormal

² Pennhurst, like other state institutions in Pennsylvania, has assumed several names throughout its history. It was initially established as the Eastern Pennsylvania State Institution for the Feeble-minded and Epileptic. Around the 1920s, concurrent with the hospital's expansion, the name was changed to the Pennhurst State School & Hospital. In the 1970s, it underwent another name change to become the Pennhurst Center. The origin of the term "Pennhurst," as well as when or why the institution started referring to itself with this name, has never been explicated in official documents. ³ Donna Samluk gave her permission to be identified on a full-name basis.

⁴ Donna Sannuk gave her permission to be identified on a full-hame bas

⁴ Click <u>here</u> for my definition of these terms.

investigation site here in 2010. The Museum, as we encounter it now, opened in 2016, and dis/abled people, former PSSH employees, and nondisabled people staff this Museum together.

Leading the group into the first exhibit of the Museum, a middle-aged White woman stares intently at a photograph of a former PSSH inmate—Anna—affixed to an admission file on display in a case. With her brow furrowed and her hand affixed to her chin, the patron remarks, "Wow. She doesn't even look disabled…" My KN95 surgical mask covers my shock.

What does it mean to look disabled? How does a nondisabled person learn what dis/abled people look like? Where, how, and by whom does this look get established? I am dis/abled, but do I look disabled? Does my gait give me away? What about my "handicap moments," those times where I fall over flat on the ground or take "too long" to process? Why do I need to look disabled to a nondisabled person to be dis/abled? God, do they think I look like I belong here? ... I did tell them if I was born in the area, they woulda placed me over in Quaker Ward. Is she scanning my body like she scanned the photo of Anna for the signs that would justify my commitment? ... I feel like I am going to vomit.

As the patron continues to look over the patient file on display, she glances at the court decree committing Anna, as an inmate, to the institution. Puzzled, the patron asks me, "Was she an inmate, patient, or a resident?"

"An inmate."

"Why do you call them inmates?"

"I call them inmates because that's what the Pennsylvania legislation refers to *us* as. I also call the former PSSH inmates, *inmates* because I spent much of my childhood

growing up in a hospital—Shriners Hospital for Crippled Children, in Minneapolis, Minnesota. As a person living with cerebral palsy, which is considered a developmental disability, doctors told my parents I would never walk or talk or have a "normal" life. I've undergone numerous surgical operations, spent considerable time in various hospitals, all before I turned 18. But, unlike the former PSSH inmates, I could refuse my treatment. I was a *patient*."

"Wow! Your story is so inspiring."

Sigh. Inspire? You say I inspire you, but you do not want to **be** me. You just want me to make you feel better about your life. But am I inspirational or do I really disgust you? Either way, why must my life always be an object for judgement? Can I not just be?

The patron's gaze reaches the young girl's death certificate. "Only 25… Hmm. Cause of death: 'idiocy.' What's that? How does someone die of *idiocy*?"

"It was a diagnostic label. Doctors typically gave this label to people deemed as "custodial"—or crib—cases, the inmates that doctors thought would never leave the institution because they would never cure them of their idiocy. Though doctors often made these diagnoses in haste, and they remain highly unreliable. Anna *actually* died of tuberculosis, but coroners would often put a person's disability label—idiocy, imbecile, moron, mongoloid, retard—first and their actual cause of death second."

"So, was she *actually* disabled then?"

God. This question, again?? If I had a nickel for every time someone asked the same thing about me.

Plastering my best "customer service smile" on my face, I respond, "Well, in the eyes of the institution—she was—and that's all that mattered. The process of

commitment was never about diagnosis or, even to some extent treatment, but about convenience—the institution's convenience to society to dispose of inconvenient people."

I could have, and perhaps should have said, that what she was really asking me in that moment was to engage in the institutional impulse define a human by and as their supposed disability, and in doing so, legitimate the abridgement of our rights, lives, and humanity. While nondisabled people often ask this everyday inquiry out of a perceived sense of ethical concern for dis/abled people, it nonetheless seeks to enforce a sharp line of demarcation between what critical disability studies scholar Rosemary Garland Thomson calls "normates" and dis/abled people.⁵ This distinction guards the former's sovereignty over the latter.

As of 2023, twenty-seven percent of America's population identifies as dis/abled,⁶ while thirty-four states in the United States still segregate dis/abled people, commonly deemed developmentally disabled by educational and medical professionals, in institutions.⁷ The Commonwealth of Pennsylvania alone operates two institutions.⁸ The

⁶ Centers for Disease Control and Prevention (CDC), "Disability Impacts All of Us," September 16, 2020, <u>https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html</u>.

⁷ Sheryl A. Larson, "Are Large Institutions for People with Intellectual or Developmental Disabilities a Thing of the Past?" (Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, June 2022), https://publications.ici.umn.edu/community-living/prb/29-2/main.

⁵ Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York, NY: Columbia University Press, 1997), 6.

⁸ Combining both developmental centers and psychiatric facilities, they operate nine. Commonwealth of Pennsylvania, "State Centers," Department of Human Services, n.d.,

https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/State-Centers.aspx; Commonwealth of

deinstitutionalization movement of the 1970s shifted philosophies of care away from mass custodial institutions to more individualized home- and community-based settings (HCBS). And yet, the issues which plagued custodial institutions—such as abuse,⁹ high mortality rates,¹⁰ negligent levels of government oversight and compliance,¹¹ professional discrimination against dis/abled people,¹² rampant underfunding by state and federal legislators,¹³ and severe understaffing—also haunts HCBS.¹⁴

Despite the plethora of operational and decommissioned custodial institutions around the world, Pennhurst stands out as a unique site for scholars interested in institutionalization. Pennhurst is notable not only for its influence on the legal and political conceptions of disability but also for its role in shaping the wider public understanding of institutionalization through its reincarnation as a commercially-run haunted attraction.¹⁵ My investigation into Pennhurst leads me to argue that

Pennsylvania, "State Hospitals," Department of Human Services, n.d.,

https://www.dhs.pa.gov/Services/Assistance/Pages/State-Hospitals.aspx.

⁹ Danny Hakim, "At State-Run Homes, Abuse and Impunity," *The New York Times*, March 12, 2011, <u>https://www.nytimes.com/2011/03/13/nyregion/13homes.html</u>.

¹⁰ Emily Lauer and Phillip McCallion, "Mortality of People with Intellectual and Developmental Disabilities from Select US State Disability Service Systems and Medical Claims Data," *Journal of Applied Research in Intellectual Disabilities* 28 (2015): 394–405; H. Stephen Kaye and Joseph Caldwell, "Excess Deaths of Medicaid Home and Community-Based Services Recipients During COVID-19," *Health Affairs* 42, no. 1 (2023): 115–20, https://doi.org/10.1377/hlthaff.2022.00457.

¹¹ U.S. Department of Health and Human Services, Administration for Community Living, and Office for Civil Rights, "Joint Report: Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight," January 2018, <u>https://oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdf</u>.

¹² Gina Kolata, "These Doctors Admit They Don't Want Patients with Disabilities," *The New York Times*, October 19, 2022, <u>https://www.nytimes.com/2022/10/19/health/doctors-patients-disabilities.html</u>; Lisa I Iezzoni et al., "Physicians' Perceptions of People with Disability and Their Health Care," *Health Affairs* 40, no. 2 (2021): 297–306, <u>https://doi.org/10.1377/hlthaff.2020.01452</u>.

 ¹³ United States Congress, Senate, Special Committee on Aging, "An Economy That Cares: The Importance of Home-Based Services, 117th Cong. 2nd sess., March 23, 2022, 1-415, <u>https://congressional-proquest-com.ezp3.lib.umn.edu/congressional/docview/t29.d30.hrg-2022-ags-225859?accountid=14586</u>.
 ¹⁴ Amanda R. Kreider and Rachel M. Werner, "The Home Care Workforce Has Not Kept Pace With Growth In Home and Community-Based Services," *Health Affairs* 42, no. 5 (2023), <u>https://doi.org/10.1377/hlthaff.2022.01351</u>.

¹⁵ In this dissertation, I have consciously adopted specific terms for distinct aspects of my subject matter. I use "PSSH" when referencing the historical institution, "PA" for addressing the present-day haunted

institutionalization comprises two intertwined aspects: First, despite widespread belief among scholars, disability advocates, and the general public that custodial institutions died out completely following the deinstitutionalization movements of the 1970s, they remain alive and well. Second, institutionalization is an ongoing structural and performative process—a discrete and repetitive social performance in which is reliant on and enacted through embodiment. This process—one wherein nondisabled people view dis/abled bodyminds and expect dis/abled people to manifest certain signifiers of disability—continually propagates dehumanizing and violent ideologies, logics, and practices towards dis/abled people today.¹⁶

Examining Pennhurst—a custodial institution for people historically deemed feebleminded or contemporarily deemed developmentally disabled—reveals the broader process of institutionalization, both as a physical space and a performative process. The performative process of institutionalization extends to physical locations such as psychiatric institutions, intermediate care facilities (ICFs), hospitals, nursing homes, prisons, large, public and privately owned group homes, and segregated special education classrooms. While not custodial institutions, bureaucratic systems such as the Social Security Administration, the Department of Education, and the federal government's "Schedule A" prioritized hiring for dis/abled people also depend on performative processes embedded within historical and contemporary institutionalization. In essence, institutionalization's influence on these agencies necessitates that dis/abled people

attraction, and "Pennhurst" to refer to the combined continuity of these two disparate elements of the same site.

¹⁶ I explain the term bodymind later in the Overture. Click <u>here</u> for my definition.

perform as disabled to gain access to specific services, protections, and/or benefits, inevitably reinforcing institutional perceptions of disability.

My analysis of institutionalization as a performative structural process finds its grounding in the work of Indigenous studies scholar Patrick Wolfe. Wolfe contends that settler colonialism is not a static, singular event but operates as an ongoing means to eliminate Indigenous people.¹⁷ While Wolfe does not incorporate disability or performance studies in his analysis and views the historical and ongoing seizure of Indigenous land and resources as the core motive for elimination, his theory bears striking parallels to the experiences and ongoing institutionalization of, disabled people. Building on Wolfe's work, I argue that institutionalization functions as a "complex social formation," which persists through time to the present, even after institutions themselves close.¹⁸ This complex social formation has both positive aspects (e.g., rights, protections, access to medical services) and negative aspects (e.g., relying on bureaucratic systems to gain such benefits, systematic discrimination, and ongoing poverty entrapment). In this study, I apply Wolfe's conceptualization of settler colonialization as a complex social formation to the historical and present trends in care policy and community-making for dis/abled people. I not only frame institutionalization as a structural process but also reveal how the experiences of dis/abled people intersect with structural forms of discrimination and violence experienced by other marginalized communities.

¹⁷ Patrick Wolfe, "Settler Colonialism and the Elimination of the Native," Journal of Genocide Research 8, no. 4 (December 2006): 387-409.

Institutionalization describes not just the physical spaces used for incarceration and the individualized, material acts of transferring embodied knowledge within an institution's daily practice. Institutionalization *also* creates a broader social understanding about what should, does, and is feared to happen within institutional spaces. Thus, this dissertation shows how institutionalization occurs both inside and outside of actual institutions, while shaping nondisabled social imagination to conceive of disablement as something which is feared and inhuman.

Furthermore, this dissertation exposes how institutional performativity ritualized and repeated acts of performance—creates environments where the line between perceived care and received violence blurs. Performances of everyday life in institutions, such as confining full-grown adults to cribs and restraining children to toilets, transfer embodied knowledge about what it means to live with dis/abilities. This type of embodied knowledge gets restaged for entertainment in the PA haunted attraction. These performances demonstrate how institutional environments normalize abuse in a way that constructs a dis/abled body as impervious to pain, injury, and harm. In doing so, the haunted attraction highlights how such actions performed in institutional settings are not only legally sanctioned but also justified as forms of care. The PA also exposes society's tacit acceptance of such violent acts, as evidenced by their willingness to pay for such experiences. Thus, what ostensibly seems like a mere night of fright uncovers a recurrent cycle of embodied knowledge transfer which informs nondisabled people that institutional violence against dis/abled people is acceptable.

This dissertation exposes how multiple historical and contemporary mechanisms sanction the violence of institutionalization and fuel the fear of disability within the

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collective consciousness of nondisabled society. While scholars, advocates, and the public often condemn the PA haunted attraction for dehumanizing dis/abled people, they often fail to question the current mechanisms that legitimize institutionalization and its violence. Laws, regulations, and policies have not only facilitated the establishment of institutionalized care but also serve as a dual-faceted mechanism that defines the parameters of disability. On one hand, advocates have used law and policy as a tool to end *some* of the violence of institutionalization and the discrimination of dis/abled people. On the other, acts of violence and dehumanization which remain overlooked by existing laws and policies, normalize and sanction daily occurrences of institutional performativity in care settings for dis/abled people.

After the law closed the PSSH, spectacular performance—specifically: horror became the mechanism which furthered knowledge-making about both institutions and disability in the nondisabled societal imaginary. Thus, the institution, as represented by the PA attraction, becomes a space of sanctioned violence against a subject society deemed hopeless and nonhuman. All the while, the genre of horror, and its presentation in the PA haunted attraction, becomes the afterlife of the law.¹⁹ What makes Pennhurst particularly unique, however, is that the PA community—the group of mostly dis/abled people that staff the attraction and/ or the Museum—locates itself at this point of mediation, in such a way as that allows them to partially control, or at least inhabit, this process of transmission.

¹⁹ Saidiya Hartman, *Lose Your Mother: A Journey along the Atlantic Slave Route* (New York, NY: Farrar, Straus, and Giroux, 2007).

This dissertation explains how a public institution, designed for the "care and maintenance" of dis/abled people, can devolve into a holding pen for human beings outcast from society. It also takes as analytically significant what, initially, seems like a cruel irony: that private owners have reinvented the property as a haunted attraction that profits from the very themes of dehumanization and violence that caused the court to close the institution in the first place. Taken together, I suggest the historical narrative of the PSSH, and the performances of PA haunted attraction, illuminate why the structural issues of institutionalization persist despite the continued move away from institutional care settings. Examining the historical and contemporary existence of this former custodial institution in the same lens can help activists, scholars, educational, legal, and medical professionals, and policymakers better understand how institutionalization continues to shape the day-to-day lives of dis/abled people. Exploring these questions, alongside the role of performance in legal, medical, political, and social constructions of disability, gives a clearer understanding of how institutionalization informs the individual and shared bodily memory of dis/abled people, shapes nondisabled social imaginary of what it is to live with dis/abilities, and influences legal precedent and legislation regarding rights for dis/abled people in America.

Situating Pennhurst

The Commonwealth of Pennsylvania opened the Eastern State Institution for the Feebleminded & Epileptic (later PSSH and, finally, the Pennhurst Center) in 1908. Located in rural-suburban Spring City, Pennsylvania, this custodial institution housed children and people deemed disabled until the institution was closed seventy-nine years later. On May 30, 1974, plaintiffs filed a class-action lawsuit in the United States District Court for the Eastern District of Pennsylvania against the PSSH—*Halderman v. Pennhurst.*²⁰ On December 23, 1977, United States District Court Judge Raymond Broderick issued a Findings of Fact and Conclusions of Law concluding that the institution violated the inmates' constitutional right to be free from harm and that their segregation from society was both separate and unequal. The court declined to impose monetary damages because it found that the PSSH employees—the individual defendants—made their actions in good faith, and the Commonwealth's inability to provide sufficient funding stunted the success of those actions. The court did, however, issue an injunctive relief order closing the institution and appointing a special master to oversee the placement of PSSH inmates in the community. Following a protracted legal battle which included two separate appeals to Supreme Court of the United States by the Commonwealth of Pennsylvania, the two parties reached a settlement, and the institution finally closed by consent decree on October 27, 1987.

The Commonwealth, despite a legal obligation to maintain and not sell the property, sold the grounds of the former institution to private land developers in 2008. The owners subsequently remade the dilapidated property into a for-profit haunted attraction and renamed it the Pennhurst Asylum. The attraction features paid actors, most of whom identify as dis/abled, and/or BIPOC or LGBTQ, who "haunt" attraction customers. The actors and designers produce the attraction's aesthetic of horror by leaning into themes of criminal insanity and medical violence. In addition, the PA hosts

²⁰ "Case: Halderman v. Pennhurst," Civil Rights Litigation Clearinghouse, July 9, 2023, <u>https://clearinghouse.net/case/490/</u>.

regular paranormal investigations and events on campus, in which patrons search for signs of and encounters with the spirits of former PSSH inmates.

Since opening the attraction in 2010, public debate continues over the morality and ethics of the PA. The original management and ownership of the PA—Pennhurst Associates—unabashedly did little to protect the property, commemorate Pennhurst's legacy, or foster access for the people working there. But, in 2016, management and ownership of the PA changed, and Pennhurst Limited Liability Company (LLC) instituted significant changes to the attraction. Since 2016, all the management team identifies as dis/abled and/or as parents of children with dis/abilities. Further, almost all the PA employees believe Pennhurst is a safe space that offers them a community they could not find in "normal," nondisabled society. In contrast to the performances of the haunted attraction that continue the themes established by the previous owners, the PA community actively attempts to preserve the legacy of the PSSH. They salvage artifacts from dilapidated buildings planned for demolition and maintain the Pennhurst Museum, resulting in the only operating museum of disability history and culture housed in an institution in the United States.

Because of Pennhurst's unique legacy, it serves as a three-fold site of investigation. First, the historical evolution of institutional legislation in the Commonwealth of Pennsylvania spotlights the onset of institutionalization. It also reveals the role of performance not only in forming disability policy but also in determining both the intended recipients of this care and the nature of that care. Among other issues, standards of care and use of force pose a particular concern for dis/abled people in the United States. Given the continued institutionalization of dis/abled people, particularly

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dis/abled children in nursing homes,²¹ the increasing incidents of police violence against dis/abled people,²² the devaluation of and budget cuts to welfare supports such as Medicare,²³ growing calls for the return of mass institutionalization by politicians,²⁴ the return of involuntary commitment in major cities,²⁵ the ableist and ageist weaponization of dis/ability diagnoses to call political candidates and elected officials unfit for office,²⁶ along with other issues such as guardianship laws²⁷ and sub-minimum wage labor,²⁸

²¹ Richard Luscombe, "Judge Orders Florida to Stop Putting Children in Nursing Homes," *The Guardian*, July 20, 2023, <u>https://www.theguardian.com/us-news/2023/jul/20/florida-children-nursing-homes-judge-ruling</u>.

²² Vilissa Thompson, "Understanding the Policing of Black, Disabled Bodies," *Center for American Progress*, February 10, 2021, <u>https://www.americanprogress.org/article/understanding-policing-black-disabled-bodies/</u>.

²³ Maya Goldman and Victoria Knight, "The Health Care Dangers of a Debt Default," *Axios*, May 5, 2023, <u>https://www.axios.com/2023/05/05/debt-ceiling-breach-health-care-meltdown</u>.

²⁴ Donald Trump, "Remarks by President Trump on the Mass Shootings in Texas and Ohio," Remarks, August 5, 2019, <u>https://trumpwhitehouse.archives.gov/briefings-statements/remarks-president-trump-massshootings-texas-ohio/?utm_source=link;</u> Maya Kaufman, "Democratic Mayors Lead Course Correction on Psychiatric Commitments," *Politico*, March 1, 2023,

https://www.politico.com/news/2023/03/01/democratic-mayors-lead-course-correction-on-psychiatriccommitments-00084387; Kierra Frazier and Adam Wren, "Trump and Pence Compete for Ovations at the NRA after a Rash of Mass Shootings," *Politico*, April 14, 2023,

https://www.politico.com/news/2023/04/14/pence-calls-for-quick-execution-of-mass-shooters-at-nra-summit-00092136.

²⁵ Office of the Mayor of New York, "Mayor Adams Announces Plan to Provide Care for Individuals Suffering from Untreated Severe Mental Illness Across NYC," *Nyc.Gov*, November 29, 2022, <u>https://www.nyc.gov/office-of-the-mayor/news/870-22/mayor-adams-plan-provide-care-individuals-suffering-untreated-severe-mental#/0</u>.

²⁶ Tal Kopan and Joe Garofoli, "Colleagues Worry Dianne Feinstein Is Now Mentally Unfit to Serve, Citing Recent Interactions," *San Francisco Chronicle*, April 14, 2022,

https://www.sfchronicle.com/politics/article/dianne-feinstein-senate-17079487.php; Jerry Goldfeder, "If Dianne Feinstein Were President," *Just Security*, April 19, 2023, <u>https://www.justsecurity.org/86048/if-diane-feinstein-were-president/</u>; Michael Schaffer, "Autism Advocates Are Dreading a Campaign Season of Insinuations about Ron Desantis," *Politico*, June 2, 2023,

https://www.politico.com/news/magazine/2023/06/02/autism-advocates-desantis-gop-primary-00099769#:~:text=Column%20%7C%20Capital%20City-

[,]Autism%20Advocates%20Are%20Dreading%20a%20Campaign%20Season%20of%20Insinuations%20About,worry%20they%2711%20go%20mainst.

²⁷ Center for Disability Rights, Inc., "Adult Guardianship," October 2018, <u>https://cdrnys.org/wp-content/uploads/2018/11/guardianship.pdf</u>.

²⁸ "Subminimum Wage," U.S. Department of Labor, Wage and Hour Division, n.d.,

https://www.dol.gov/agencies/whd/special-employment; Kate Anderson, "Subminimum Wage: What Is It, Why It's Unjust, and Why It Needs to End," *World Institute on Disability* (blog), September 28, 2022, https://wid.org/subminimum-wage-what-it-is-why-its-unjust-and-why-it-needs-to-end/.

society and lawmakers alike abridge dis/abled people's rights out of fear and convenience.

Second, an exploration of the contemporary PA haunted attraction provides an understanding of how performance shapes and perpetuates societal perceptions of disability, as characterized in the institutionalization process. I call this perception the spectre of disability—in that disability is that which haunts "normal," non-disabled society.²⁹ This fear of the spectre of disability simultaneously promotes, sanctions, and erases the ongoing forms of violence committed against dis/abled people in institutions like the PSSH today through the fictionalizing, spectacularizing, and rehearsing of violence through the aesthetic of the horror genre.

Third, the community consisting of both dis/abled and nondisabled people at the PA haunted attraction, models accessibility and care towards each other and the site itself. They do this by actively ensuring that community members' access needs are met, and meticulously collecting and preserving artifacts left on the campus. In doing so, they provoke a reimagining of current notions of advocacy, commemoration, and community-based living that comes from dis/abled people, designed for dis/abled people.

Taken together, the PSSH and the PA, make the specter of institutionalization apparent. The spectre of institutionalization is the way in which institutionalization—as a pervasive social process—haunts both nondisabled society and dis/abled communities. The spectre of disability haunts nondisabled society as the loss of bodymind control and the threat of abjection from society should they deviate from nondisabled "normality."

²⁹ In this dissertation, I intentionally employ the British spelling, "spectre," as opposed to the American variant, "specter." This choice specifically underscores a sense of divergence, paralleling the deviation from normality often associated with disability.

But the spectre of institutionalization haunts dis/abled communities—those with and without historic ties to custodial institutions—as a collective memory and ongoing experience that continually re-appears in the present, even when institutionalization is supposedly dead. The spectre of institutionalization is at the same time a revenant—a being which returns after death—and a translucent integument—a non-apparent protective shell—which conditions everything from the debates surrounding issues of care versus harm for dis/abled people to the forms of creativity, expression, and community-making among the performers at the PA haunted attraction.

The elision of institutionalization history and spaces of care does not remain unique to Pennhurst. One such example, relevant both to my life and research, comes from the afterlife of the Shriners Hospital for Crippled Children in Minneapolis. In September 2019, the University of Minnesota purchased the original 10-acre hospital campus on 2025 East River Parkway as part of the University's hospital expansion. The now "Shriners Hospital for Children" sold the property to the University for an unannounced sum and moved their Twin Cities' campus to Woodbury, Minnesota. The old campus, which I spent most of my childhood in, is only two miles away from the University's Theatre Arts Department's Rarig Center. The spatial relationship to, and later absorption of, my childhood place of treatment by the University illustrates how, under the spectre of institutionalization, institutional settings such as hospitals elide educative, care, and punitive functions. To those that lived and worked at Shriners, the hospital represents a multitude of experiences and a range of values, but to the greater public and the University of Minnesota, it is now a site remembered merely for education and medical progress. What happens then to the narratives of Shriners past? The

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University—like various private owners and government agencies that now own the parceled-out portions of Pennhurst—seem completely uninterested in preserving, let alone, commemorating the history and the people, of the spaces they have control over. Thus, the spectre of institutionalization elides institutionalization history, dis/abled people, trauma, and the various actors involved in the process.

Surveying the Literature

As the first sustained ethnography of a former institution turned tourist attraction, this dissertation shines new light on the fields of bioethics and biomedicine, critical disability studies, law, medical history, and public policy. It does so by redefining institutionalization as a performative structural process and repositioning the discussion to focus on embodiment. With the distinction between qualitative and quantitative fields of study becoming further entrenched within academic, political, and professional environments, institutionalization and dis/ability often remain siloed into disciplinary approaches such as the humanities, social sciences, and science, technology, mathematics, and medicine (STEMM). Those interested in addressing dis/ability often assume quantitative, social science, and/or professional fields such as education, law, medicine, psychology, psychiatry, public policy, social work, and sociology offer the most useful interventions. All the while, qualitative fields such as critical disability studies, performance studies, and other humanistic disciplines become perceived as providing more theoretical explorations on dis/ability. While quantitative research provides insights regarding the prevalence, phenomena, and identification of dis/ability, qualitative research intervenes by providing insights on the lived experience of dis/abled

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people. Crucially, qualitative research identifies what quantitative research often misses: the material bodymind costs of time and energy that come with interacting with systems involved in what legal scholar Elizabeth F. Emens calls, "Disability Admin."³⁰ Isolating institutionalization and dis/ability by field of study and methodological approach remains not only counterproductive, but oblivious to the history and process of institutionalization. Various networks and disciplinary approaches have historically influenced institutions or have been birthed out of institutions—such as music therapy and Montessori school pedagogy. Instead, this dissertation brings these supposedly disparate fields of study together to generate productive dialogue and address the ongoing issues of institutionalization by examining both its historical evolution, and how a community of dis/abled people redefines that history.

Performance studies, and its focus on embodiment, serves as the nexus to bring these various fields together in conversation. Instead of extrapolating bodymind experiences into data sets, this research focuses primarily on the ways embodied enactments transfer knowledge to other bodyminds by moving through spaces, taking part in communal activities, and reinterpreting normative narratives through embodied acts and the patterns those actions present. In particular, this study concerns itself with how the process of institutionalization transfers knowledge to dis/abled bodyminds about care, memory, value, and personhood. Simultaneously, this process also transfers

³⁰ Elizabeth F. Emens, "Disability Admin: The Invisible Costs of Being Disabled," *Minnesota Law Review* 105, no. 2329 (2021): 2329–77. Emens defines "Admin life" as "...a particular form of labor that especially burdens people with disabilities. ... Life admin is all of the office-type work that it takes to run a life and a household--from everyday tasks like scheduling doctors' appointments and paying bills, to annual or periodic projects like planning a wedding or funeral. This is the kind of work that managers and secretaries do in an office for pay but that we all do in our own lives for free." She analyses how nondisabled people tend to severely underestimate the amount of admin life dis/abled people have to perform, identifying three crucial areas: "Medical Admin," "Benefits Admin," and "Discrimination Admin."

knowledge to the nondisabled public that violent practices against dis/abled people masquerading as care are acceptable, while the institution becomes a site of abjection and horror. This dissertation reveals how the PA community models the care that remains absent in our contemporary HCBS frameworks simply because our contemporary models often left dis/abled people—particularly multi-marginalized disabled people and people with significant care needs—out of their planning, implementation, and evaluation.

Performance & Disability

This project's primary intervention addresses the fields of critical disability studies and performance studies. While performance studies scholars have analyzed how dis/abled identities are represented in conventional genres of performance, such as plays and performance art,³¹ they largely offer only two arguments: that dominant culture discriminates, objectifies, and commodifies dis/abled bodies, or that dis/abled people use performance to resist dominant nondisabled culture. This dissertation brings new insight to this topic by applying two separate components of performance to institutionalization: performativity and embodied knowledge transfer.

One of the overarching themes of this work is to reveal how performativity identity construction via iterative citational practices³²—enables the law, institutional

³¹ For example, Petra Kuppers, *Disability and Contemporary Performance: Bodies on Edge* (New York, NY: Routledge, 2004); *Community Performance: An Introduction* (New York, NY: Routledge, 2007); Phillip Auslander and Carrie Sandahl, eds., *Bodies in Commotion: Disability & Performance* (Ann Arbor, MI: University of Michigan Press, 2005); Patrick McKelvey, "A Disabled Actor Prepares: Stanislavsky, Disability, and Work at the National Theatre Workshop of the Handicapped," *Theatre Journal* 71, no. 1 (2019): 69–89.

³² For more on performativity, see J. L. Austin, *How to Do Things with Words* (Cambridge, MA: Harvard University Press, 1962); Jacques Derrida, "Signature Event Context," in *The Margins of Philosophy* (Chicago, IL: The University of Chicago Press, 1982), 307–30; Judith Butler, "Performative Acts and Gender Constitution: An Essay in Phenomenology and Feminist Theory," in *Performing Feminisms:*

procedures, and medical discourse to materialize disabled bodyminds and norms. The first two Acts of this dissertation build off the work of performance studies scholar Joshua Chambers-Letson—who analyzes how performance couples with the law to make racialized subjects³³—by exposing how performance structures the legal, medical, and procedural phenomena of institutionalization. For example, court commitments were often used to involuntarily commit children and adults to the PSSH. In the courtroom, lawyers and doctors used speech acts to materially produce the people on trial—who were often physically absent from their own trial—as an institutionalized disabled subject. Once committed, institutional inmates become subjected to performances of institutionalized care: repeated and dehumanizing practices of what became perceived as care in the institution but received as violence to the inmate. These performances, such as restraining inmates in seclusion rooms and forcing inmates to care for other inmates, ultimately served the needs of the institution, not the needs of the people it housed.

Performance also transfers knowledge—remains and traces of kinesthetic memory³⁴—that gives historiographic insight into Pennhurst and its people. This dissertation intervenes in the dialogue regarding embodiment by analyzing the contemporary PA community's relationship with the PSSH. My research uncovers a complex social site in which dis/abled people—some of whom survived

Feminist Critical Theory and Theatre, ed. Sue-Ellen Case (Baltimore, MD: John Hopkins University Press, 1990), 270–82.

³³ Joshua Takano Chambers-Letson, A Race So Different: Performance and Law in Asian America (New York, NY: New York University Press, 2013).

³⁴ For more on embodied knowledge transfer, see Diana Taylor, *The Archive and the Repertoire: Performing Cultural Memory in the Americas* (Durham, NC: Duke University Press, 2003); Joseph Roach, *Cities of the Dead: Circum-Atlantic Performance* (New York, NY: Columbia University Press, 1996); Harvey Young, *Embodying the Black Experience: Stillness, Critical Memory, and the Black Body* (Ann Arbor, MI: University of Michigan Press, 2010).

institutionalization—create their own community through creative expression *as part of* a corporate attraction that exploits legal, medical, and societal conceptions of disability. The dis/abled artists' performances expose societal fears around disability and show how that fear morphs into discrimination and violence. And yet, these performances also empower artists to weaponize their dis/abilities and create an accessible community on their own terms.

When examined together, performativity and embodied knowledge transfer also unsettle bioethics and biomedicine critiques of disability and institutionalization and call for a reconceptualization of the field. While scholars have critiqued bioethics and biomedicine through a dis/ability lens,³⁵ they have yet to address the performativity of institutionalization's instrumental role in creating normative conceptions of personhood. Further, this dissertation places the affective bodymind experience of dis/abled people back into the frame through centering its analysis on how institutional settings transfer embodied knowledge of what it means to be dis/abled. The PA community's embodied acts of performance and commemoration not only makes material the need for bioethicists to account for dis/abled people, it also provides material examples of how dis/abled people redefine bioethics' conceptions of autonomy, community, justice, memory, non-maleficence and, simply, the right to live with value.

³⁵ Rosemarie Garland-Thomson, "Disability Bioethics: From Theory to Practice," *Kennedy Institute of Ethics Journal* 27, no. 2 (2017): 323–39; Alicia Oullette, *Bioethics and Disability: Toward a Disability-Conscious Bioethics* (Cambridge, UK: Cambridge University Press, 2011); Jackie L. Scully, *Disability Bioethics: Moral Bodies, Moral Difference* (Lanham, MA: Rowman & Littlefield Publishers, 2008); Anita Silvers, "Defective Agents:' Equality, Difference and the Tyranny of the Normal.," *Journal of Social Philosophy* 25, no. S1 (1994): 154–75; Shelley L. Tremain, "The Biopolitics of Bioethics and Disability," *Journal of Bioethical Inquiry* 5, no. 23 (2008): 101–6.

Advancing the dialogue on law and disability, this research delves into the historical evolution of institutionalization and the legal category of disability. Most of the legal literature addressing dis/ability focuses on the disability rights movement,³⁶ the Americans with Disabilities Act (ADA) and the three major United States Supreme Court decisions regarding that legislation,³⁷ the history of eugenics,³⁸ and/or incorporating critical disability studies and other humanistic disciplines into conversation with law.³⁹ A

³⁶ Samuel R. Bagenstos, *Law and the Contradictions of the Disability Rights Movement* (New Haven, CT: Yale University Press, 2009); Katharina Heyer, "A Disability Lens on Sociological Research: Reading Rights of Inclusion from a Disability Studies Perspective," *Law & Social Inquiry* 32 (2007): 261–93; Katharina Heyer, *Rights Enabled: The Disability Revolution from the US, to Germany and Japan, to the United Nations* (Ann Arbor, MI: University of Michigan Press, 2015); Michael Ashley Stein, "Disability Human Rights," *California Law Review* 95 (2007): 75–121; Jacqueline Vaughn, *Disabled Rights: American Disability Policy and the Fight for Equality* (Washington, D.C.: Georgetown University Press, 2003); Michael E. Waterstone, "The Costs of Easy Victory," *William & Mary Law Review* 57 (2015): 587–635.

³⁷ Samuel R. Bagenstos, "The Perversity of Limited Civil Rights Remedies: The Case of 'Abusive' ADA Litigation," *UCLA Law Review* 54, no. 1 (2006): 1–36; Elizabeth F. Emens, "Disabling Attitudes: US Disability Law and the ADAA Amendments," in *Disability Reader*, ed. Lennard J. Davis, 4th ed. (New York, NY: Routledge, 2013), 42–57; Elizabeth F. Emens and Michael Ashley Stein, eds., *Disability & Equality Law* (London, UK: Routledge, 2013); Leslie Francis and Anita Silvers, eds., *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions* (New York, NY: Routledge, 2000); Linda H. Krieger, *Backlash Against the ADA: Reinterpreting Disability Rights* (Ann Arbor, MI: University of Michigan Press, 2003); Stephanie K. Wheeler, "The Construction of Access: The Eugenic Precedent of the Americans with Disabilities Act," *Continuum*, Normality and Disability: Intersections Among Norms, Law, and Culture, 31, no. 3 (2017): 377–87.

³⁸ Adam Cohen, Imbeciles: The Supreme Court, American Eugenics, and the Sterilization of Carrie Buck (New York, NY: Penguin Press, 2016); Paul A. Lombardo, Three Generations, No Imbeciles: Eugenics, the Supreme Court, and Buck v. Bell (Baltimore, MD: John Hopkins University Press, 2008); Susan Schweik, "Begging the Ouestion: Disability, Mendicancy, Speech and the Law," *Narrative* 15, no. 1 (2007): 58–70; The Ugly Laws: Disability in Public. (New York, NY: New York University Press, 2009); Elizabeth Stephens and Peter Cryle, "Eugenics and the Normal Body: The Role of Visual Images and Intelligence Testing in Framing the Treatment of People with Disabilities in the Early Twentieth Century," Continuum, Normality and Disability: Intersections Among Norms, Law, and Culture, 31, no. 3 (2017): 365-76. ³⁹ Bradley A. Areheart, "Disability Trouble," Yale Law & Policy Review 29, no. 2 (2011): 347-88; Rabia Belt and Doron Dorfman, "Disability, Law, and the Humanities: The Rise of Disability Legal Studies," in The Oxford Handbook of Law and Humanities, ed. Simon Stern, Maksymilian Del Mar, and Bernadette Meyler (London, UK: Oxford University Press, 2019); Jasmine E. Harris, "The Frailty of Disability Rights," University of Pennsylvania Law Review Online 29 (2020): 58-61; Jasmine E. Harris, "Taking Disability Public," University of Pennsylvania Law Review 169, no. 6 (June 2021): 1681-1750; Arlene S. Kanter, "The Law: What's Disability Got to Do with It or an Introduction to Disability Legal Studies," Columbia Human Rights Law Review 42, no. 2 (2011): 403-80; Sagit Mor, "Between Charity, Welfare, and

more recent slate of legal disability scholarship has addressed the Supreme Court of the United States' handling of dis/ability-related cases,⁴⁰ the material time and labor involved in navigating bureaucratic systems related to living with a dis/ability,⁴¹ criminal conduct and use of force,⁴² disability as a suspect classification,⁴³ and the sexual agency of institutionalized people.⁴⁴ This research expands on this literature by examining the role of performance and law in the institutionalization process and the effect of de/institutionalization's afterlife on contemporary legal conceptions of disability. Law is not just the mechanism that creates, regulates, and polices custodial institutions; law— when combined with performance—produces disability as a condition eligible for institutionalized disabled subject's rights become void. This project uncovers how the law both produces disabled subjects in order to protect them—through a positive rights framework which positions dis/abled people as a minority class—while also defining them as disabled and, thus, simultaneously outside of the law's protection.

Through an extensive examination of Pennhurst's legal history, this investigation illuminates how, in law, cases purportedly about dis/ability rights—specifically those stemming from issues of violence and discrimination in care settings—get decided on the

Warfare: A Disability Legal Studies Analysis of Privilege and Neglect in Israeli Disability Policy," *Yale Journal of Law & the Humanities* 18 (2006): 63–136.

⁴⁰ Jasmine E. Harris, Karen M. Tani, and Shira Wakschlag, "The Disability Docket," *American University Law Review* 72, no. 1667 (2023): 1667–1730.

⁴¹ Emens, "Disability Admin."

 ⁴² Jamelia N. Morgan, "Rethinking Disorderly Conduct," *California Law Review* 109, no. 5 (2021): 1637–1702; Jamelia N. Morgan, "Disability's Fourth Amendment," *Columbia Law Review* 122, no. 2 (2022): 489-[x].

⁴³ William D. Araiza, "Was Cleburne an Accident?," *University of Pennsylvania Journal of Constitutional Law* 19, no. 3 (2017): 621–70; Doron Dorfman, "Disability as Metaphor in American Law," *University of Pennsylvania Law Review* 170, no. 7 (2022): 1757–1812.

⁴⁴ Jasmine E. Harris, "Sexual Consent and Disability," *New York University Law Review* 93, no. 480 (2018): 480–557.

basis of other legal questions entirely. Instead of considering and ruling on performances of institutionalized care—everyday acts of violence such as restraint, discrimination, and abuse—courts often rule on issues adjacent to, but not related with, the embodied experience of dis/abled people. While legal scholars have addressed how dis/ability erasure reifies ableist ideologies by upholding the nondisabled bodymind as the boundary for deciding doctrinal issues⁴⁵ and critiqued the Supreme Court for using dis/ability cases as a vehicle to gut civil rights protections broadly,⁴⁶ their scholarship does not address institutionalization or embodiment.

This dissertation intervenes in disability law by revealing why institutionalization and its violence persists. Most legal literature addresses dis/ability and institutionalization from a reactive posture (i.e., "A problem has occurred. How can we alter our approach to rectify it?"). By examining a site that has transitioned from custodial institution to haunted attraction, this research provides a proactive intervention by shedding light on a space typically thought outside of the law. In doing so, this dissertation demonstrates how the paradigm of institutionalization endures, replicating and embedding harmful ideologies within nondisabled social imagination. This becomes especially important when contemplating courts' reliance on "common sense" conclusions regarding dis/ability in the absence of statutes or precedent. Within a legal system haunted by the spectre of institutionalization, dis/ability motivates and animates legal questions

⁴⁵ Morgan, "Disability's Fourth Amendment," 560. Morgan argues: "Erasure sets the boundaries between what is relevant and what is not within doctrinal analyses and underprotects disabled people in its failure to recognize and address how both disability and social responses to, and meanings of, disability can and should structure courts' doctrinal analysis. Disability erasure produces and reinforces vulnerabilities to police violence for disabled people."

⁴⁶ Harris, Tani, and Wakschlag, "The Disability Docket," 1670.

concerning autonomy, capacity, guardianship, responsibility, and the limits of relational care. Yet the narrow, evidently biased "common sense" conclusions reached by courts often diverge from the experiences of dis/abled people. This discrepancy is evident in the landmark disability discrimination case *Alexander v. Choate* (1985).⁴⁷

In *Choate*, the Supreme Court unanimously ruled that the State of Tennessee's decision to reduce the number of days of in-patient care it covered through its federally funded, state-provided insurance program—Medicaid—did not count as discrimination under Section 504 of the Rehabilitation Act of 1975.⁴⁸ Justice Thurgood Marshall, writing for the Court, invoked common sense to argue, "Because the handicapped typically are not similarly situated to the nonhandicapped..." deciding in favor of Choate (the dis/abled plaintiff) would create a standard in which would require States—as recipients of federal funds—to review all planned changes to their Medicare programs to ensure it was not discriminatory against dis/abled people.⁴⁹ Therefore, Justice Marshall concluded—without referencing the statutory language of Section 504 or referencing previous case law-that the Court must favor the State because, "The formalization and policing of this process could lead to a wholly unwieldy administrative and adjudicative burden."⁵⁰ Justice Marshall's common sense conclusion in *Choate* underscores two poignant and recurrent themes in this dissertation and disability law. First, it demonstrates how nondisabled people's perceptions of dis/ability-even if well-intentioned-often involve unconscious ableist biases and fail to fully understand the bodymind experiences

⁴⁷ Alexander, Governor of Tennessee, et al. v. Choate et al., 469 U.S.. 287 (1985).

⁴⁸ Alexander v. Choate, 469 U.S. 287 (1985).

⁴⁹ Alexander v. Choate, 469 U.S. 287 (1985), 298.

⁵⁰ Alexander v. Choate, 298.

of dis/abled people. Second, it reveals how administrative convenience has time and time again outweighed the needs and equitable treatment of dis/abled people. Notably, this study, especially through the investigation of the PA community in <u>Act IV</u>, not only underscores why courts need an informed understanding of dis/ability—dis/abled common sense—but also provides a model for incorporating such understanding.

Institutionalization

Medical historians define institutionalization as a static, medical concept in which a dis/abled person receives custodial, in-patient care for an indefinite amount of time relating to their medically diagnosed disabilities. Institutionalization literature can be broadly conceived in three strands. The first strand represents a swath of scholarship that conceives institutionalization as a humanitarian effort; benevolent, medically legitimate places of care that eventually grew too large and unsustainable.⁵¹ The second strand— often referred to as social control theory—raises significant skepticism towards the altruistic intentions of institutions. This scholarship argues that instead of providing care, institutions rid growing bourgeois populations in burgeoning industrialized urban centers

⁵¹ Norman Dain, Concepts of Insanity in the United States, 1789-1865 (New Brunswick, NJ: Rutgers University Press, 1964); Albert Deutsch, The Mentally III in America: A History of Their Care and Treatment from Colonial Times (Garden City, NY: Doubleday, Doran & Company, 1937); Jan E. Goldstein, Console and Classify: The French Psychiatric Profession in the Nineteenth Century (New York, NY: Cambridge University Press, 1987); Gerald N. Grob, The State and the Mentally III: A History of Worcester State Hospital in Massachusetts, 1830-1920 (Chapel Hill, NC: The University of North Carolina Press, 1966); Gerald N. Grob, Mental Institutions in America: Social Policy to 1875 (New York, NY: Free Press, 1972); Gerald N. Grob, Mental Illness and American Society, 1875-1940 (Princeton, NJ: Princeton University Press, 1983); Gerald N. Grob, From Asylum to Community: Mental Health Policy in Modern America (Princeton, NJ: Princeton University Press, 1994); Gerald N. Grob, The Mad Among Us: A History of the Care of America's Mentally III (New York, NY: Free Press, 1994); Peter L. Tyor and Leland V. Bell, Caring for the Retarded in America: A History (Westport, CT: Greenwood Press, 1984); R. C. Scheerenberger, A History of Mental Retardation (Baltimore, MD: Paul H. Brookes Publishing Company, 1983).

of social undesirables.⁵² The third strand of institutionalization literature rejects the sweeping generalizations made by the social-control perspective about the function of the institution. These scholars offer what they believe as a corrective history to the earlier studies by using individual institutions as case studies and examining administrative records, case files, census data, patient-doctor-family correspondence, and patient-produced cultural artifacts. They also pay particular attention to the role of race and gender in the various influences of institutionalization and the production of

institutionalized subjects.53

Recent scholarship from Katrina N. Jirik⁵⁴ and Chelsea D. Chamberlain⁵⁵

provides far more nuance, examining institutionalization from the perspectives of

⁵² William Bronston, Public Hostage, Public Ransom: Ending Institutional America (Conneaut Lake, PA: Page Publishing, 2021); Robert Castel, "Moral Treatment: Mental Therapy and Social Control in the Nineteenth Century," in Social Control and the State: Historical and Comparative Essays, ed. Andrew T. Scull and Stanley Cohen, trans. Peter Miller (Oxford, UK: Oxford University Press, 1983), 248–66; Michel Foucault, The Birth of the Clinic (London, UK: Routledge, 2003); Michel Foucault, Madness and Civilization: A History of Insanity in the Age of Reason (New York, NY: Random House, 1977); Gerald V. O'Brien, Framing the Moron: The Social Construction of Feeble-Mindedness in the American Eugenic Era (New York, NY: Manchester University Press, 2013); David J. Rothman, The Discovery of the Asylum: Social Order and Disorder in the New Republic (New York, NY: Aldine De Gruyter, 2002); Scully, Disability Bioetihcs; James W. Trent, Inventing the Feeble Mind: A History of Intellectual Disability in the United States, 2nd ed. (New York, NY: Oxford University Press, 2017).

⁵³ Ellen Dwyer, Homes for the Mad: Life inside Two Nineteenth-Century Asylums (New Brunswick, NJ: Rutgers University Press, 1987); Phillip M. Ferguson, Abandoned to Their Fate: Social Policy and Practice Toward Severely Retarded People in America, 1820-1920 (Philadelphia, PA: Temple University Press, 1994); Peter McCandless, Moonlight, Magnolias, and Madness: Insanity in South Carolina from the Colonial Period to the Progressive Era (Chapel Hill, NC: The University of North Carolina Press, 1996); Constance M. McGovern, "The Myths of Social Control and Custodial Oppression: Patterns of Psychiatric Medicine in Late Nineteenth-Century Institutions," Journal of Social History 20 (Fall 1986): 3–23; Anne E. Parsons, From Asylum to Prison: Deinstitutionalization and the Rise of Mass Incarceration after 1945 (Chapel Hill, NC: The University of North Carolina Press, 2018); Benjamin Reiss, Theaters of Madness: Insane Asylums and Nineteenth-Century American Culture (Chicago, IL: The University of Chicago Press, 2008); Nancy Tomes, A Generous Confidence: Thomas Story Kirkbride and the Art of Asylum-Keeping, 1840-1883 (New York, NY: Cambridge University Press, 1994).

⁵⁴ Katrina N. Jirik, "American Institutions for the Feeble-Minded, 1876-1916" (PhD Dissertation, Minneapolis, MN, University of Minnesota, 2019).

⁵⁵ Chelsea D Chamberlain, "Challenging Custodialism: Families and Eugenic Institutionalization at the Pennsylvania Training School for Feeble-Minded Children at Elwyn," *Journal of Social History*, March 19,

legislators, parents, social workers, and others, and highlight the tensions of

institutionalization debates from the perspective of different actors in the process.

Additionally, disability scholars address issues of institutionalization from a lens of

critical disability studies and disability history centering institutionalization outside of the

predominantly medically based discourse.⁵⁶ To date, the PSSH and PA has received only

modest scholarly attention.57

This dissertation adds to institutionalization literature in two critical and

interrelated ways. First, this research supplements existing literature on

^{2021, 1–26, &}lt;u>https://doi.org/10.1093/jsh/shab009;</u> Chelsea D. Chamberlain, "Receiving, Sorting, and Disposing of Children: Institutions, Education, and Feeblemindedness in Progressive America" (PhD Dissertation, Philadelphia, PA, University of Pennsylvania, 2022).

⁵⁶ Susan Burch, *Committed: Remembering Native Kinship in and beyond Institutions* (Chapel Hill, NC: The University of North Carolina Press, 2021); Liat Ben-Moshe, Chris Chapman, and Allison C. Carey, eds., *Disability Incarcerated: Imprisonment and Disability in the United States and Canada* (New York, NY: Palgrave Macmillan, 2014); Liat Ben-Moshe, "The Institution Yet to Come': Analyzing Incarceration Through a Disability Lens'," in *The Disability Studies Reader*, ed. Lennard J. Davis, 5th ed. (New York, NY: Routledge, 2017), 116–30; Liat Ben-Moshe, *Decarcerating Disability: Deinstitutionalization and Prison Abolition* (Minneapolis, MN: University of Minnesota Press, 2020); Allison C. Carey, *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America* (Philadelphia, PA: Temple University Press, 2009); Michael Rembis, *Defining Deviance: Sex, Science, and Delinquent Girls, 1890-1960*, 2nd ed. (Champaign, IL: University of Illinois Press, 2013); Schweik, *The Ugly Laws*.

⁵⁷ Since I started this project in 2017, Pennhurst has gained more scholastic notoriety. I am grateful for the scholastic generosity of those researching Pennhurst. Emily Smith Beitiks wrote a short article in the Hastings Center Report that critiqued the imagery of the PA and the ethical questions raised by the attraction; see, Emily Smith Beitiks, "The Ghosts of Institutionalization at Pennhurst's Haunted Asylum," The Hastings Center Report 42, no. 1 (2012): 22-24. Kelly George and Sarah Sutton wrote their theses examining the role of journalism, memory, and public history in the creation of the PA; see, Kelly George, "The Birth of a Haunted 'Asylum': Public Memory and Community Storytelling" (Dissertation, Philadelphia, PA, Temple University, 2014); Sarah Sutton, "Pennhurst: An Exploration of Exhibition and Collection Care Inside a Haunted Asylum" (Masters Thesis, Philadelphia, PA, Temple University, 2017).. Legal historian Karen M. Tani published a law article on the PSSH's legacy in law and disability history; see, Karen M. Tani, "The Pennhurst Doctrines and the Lost Disability History of the 'New Federalism," California Law Review 110, no. 4 (August 2022): 1157-1219. James W. Conroy and Dennis B. Downey coedited a collection about the PSSH in 2020; see Dennis B. Downey and James W. Conroy, eds., Pennhurst and the Struggle for Disability Rights (University Park, PA: The Pennsylvania State University Press, 2020). Downey also edited a special edition of Pennsylvania History: A Journal of Mid-Atlantic Studies in Summer 2022 (Vol. 89.3) which focused largely on the PSSH. Finally, the National Council on History published a series on the PSSH for their History@Work Blog in Summer 2022. While this scholarship provides useful information regarding the contours of institutionalization history, it does not address institutionalization as an ongoing performative practice.

institutionalization by completing a historiographical analysis of custodial institutionalization in the twentieth century. This project fills a significant gap in the literature by illuminating how institutions went from largely benevolent spaces of care and education in the latter nineteenth century, to extralegal human warehouses by the mid-twentieth century. Second, this study recenters institutionalization literature on dis/abled people and the embodied actions of everyday life in and outside institutions. The first half of this dissertation uses embodiment to map the creation of the concept of disability in relationship to institutionalization, and how in institutional settings violence came to constitute care. In the latter half of this dissertation, I use ethnographic research to identify patterns in how contemporary dis/abled people process the kinesthetic memory of institutionalization and the ways in which the spectre of institutionalization continues to haunt our community.

Methods

The PSSH, like other custodial institutions, did not operate in isolation. Intimate family relationships between parents and children, regional and national professional networks, and shifting cultural ideas about disability, productivity, and social reform influenced the PSSH. This dissertation thus uses a combination of archival and ethnographic research to capture the nuance and breadth of these various cultural, economic, legal, medical, political, and societal axes involved in the performative process of institutionalization. Further, this dual methodology reveals resonances between historical and contemporary understandings of disability and ongoing trends in institutionalization.

Archival Methods

To understand how these legal, medical, political, and societal axes incorporated performance to create the category of disability through institutionalization processes and materials, this project begins by using archival research. The first two Acts rely on a range of published and unpublished sources to explore how individual and societal influences regarding institutionalization spread throughout Pennsylvania, the broader mid-Atlantic, and the nation.

This dissertation examines bi-annual reports made by institutions, legislatures, newspapers, patient files, parental handbooks, and other materials published by the Commonwealth of Pennsylvania and institutional advocates. My analysis focuses on how these materials used eugenic rhetoric to remove the personhood from inmates, leading to their abuse in institutions. In examining these materials, this dissertation applies the method of performative language analysis—or analysis of language that performs socializing action within a perceived set of governing norms—to reveal how persistent medical and personal ideas about disability, heredity, and curability created and reinforced legal and medical assumptions about dis/ability in the social imagination of the American public.

To understand the role of performance in committing someone to the institution, I examine commitment trial transcripts and patient files of former inmates who died at the PSSH under the age of 21. I identify patterns of medical and legal claims and moral determinations made through the forms of treatment and the restraints used on the former inmates of the PSSH. This data allows me to focus my analysis on the connections

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between the malpractice and violence documented in the archival materials and the performance practices of the PA attraction.

Ethnographic Methods

This dissertation draws on critical performance ethnography, a participatory and reflexive approach that seeks to understand cultural phenomena by studying social relationships, the body, and its movements and relies on data from over 2,000 hours of fieldwork at the PA from 2018 to 2023. In my fieldwork, I assumed several roles within the attraction (director's assistant, event staff, patron, actor) to understand how the attraction constructed its performance aesthetic not only from a directorial standpoint but also from the more ambiguous perspective of the performers as they moved, felt, and communicated in the attraction.

To gain an understanding of how the PA community operates and transfers embodied knowledge about dis/ability and Pennhurst's legacy, I attended managerial, event staff, and artistic staff meetings. In addition, I collected scene and character breakdowns and participated in actor trainings, paranormal investigations, and historical tours, interacting closely with patrons. These perspectives reveal not only how the PA operates but how those who work at and attend the attraction grapple with the complex history of the site. Further, this methodology elucidates the tensions in which the PA community must navigate simply to survive under the spectre of institutionalization.

Inside the attraction, I used ethnographic methods to pay close attention to the dynamics of developing and executing interactive dramatic scenarios between the patrons and the dis/abled haunters. By detailing the choices made during scenes, transcribing

employees' improvised performances, and the patrons' reactions to those performances, patterns arose showcasing how haunters used their dis/abilities to elicit fear. This fieldwork illuminated how the dis/abled actors used performance to address their lived experiences of institutionalization, medical violence, and trauma alongside how the (mostly) nondisabled patrons reacted to such performances. Finally, by amassing interviews with the actors and artistic staff of the PA, my analysis illuminates how the PA community uses performance to mobilize and question institutional discourses of disability, while also creating an accessible space where they can share their lived experiences of dis/ability and find community.

Defining Terms & Positionality

Dis/ability, Disability & Nondisability

In past versions of this text and other writings, I used the phrase "people with disabilities," honoring the "Speaking for Ourselves" Movement many PSSH survivors participate(d) in. While important to recognize ourselves as people first, I believe this phrase unwittingly freezes disability into a transhistorical, medical concept placing it as a natural, biological category, or characteristic that only certain individuals embody or possess, instead of a historically contingent network of force relations in which everyone occupies a position.⁵⁸ Therefore, I employ the identity-first language "disabled people." Further, I make distinctions between "disability" and "dis/ability." I use disability to refer

⁵⁸ Shelley L. Tremain, *Foucault and Feminist Philosophy of Disability* (Ann Arbor, MI: University of Michigan Press, 2017), 21.

to more normative, largely medically derived concepts, groupings, understandings, and discourses of disability that arose in the context of institutionalization. I adapt the term dis/ability from critical disability studies scholar, Dan Goodley, who uses the slash to connote the "ways in which disablism and ableism (and disability and ability) can only ever be understood simultaneously in relation to one another.⁵⁹ I employ Goodley's term because it creates a distinction between the institutionalized notion of disability and the fluid, nuanced, and complex embodied experience of living with a dis/ability. Using a slash to make this distinction does create inherent access issues, such as being overtly theoretical and, also, being less accessible for people who use screen readers. But I make this choice deliberately to push against the streamlined, static notions of disability and accommodations as derived by in my object of study.

Bodymind

Critical disability studies scholars have critiqued the fields of education, medicine, and philosophy for creating a dualistic schism between one's body and mind, and thus use the term bodymind to refer to the interrelationship between the two as sometimes independent but nonetheless linked.⁶⁰ Throughout this study, I use the term bodymind to signify both the intertwined relationship of body and mind but also the embodied, affective experience of living with a dis/ability. In this way, bodyminds affectively

⁵⁹ Dan Goodley, *Dis/Ability Studies: Theorizing Disablism and Ableism* (New York, NY: Routledge, 2014), xi-xiii.

⁶⁰ For more on bodyminds, and disability scholars' push from dividing the body and mind, see Margaret Price, "The Bodymind Problem and the Possibilities of Pain," *Hypatia* 30, no. 1 (2015): 268–84; Sami Schalk, *Bodyminds Reimagined: (Dis)Ability, Race, and Gender in Black Women's Speculative Fiction* (Durham, NC: Duke University Press, 2018), particularly Act 3 on bodymind futures.

experience dis/abling conditions—referred to as "impairments" in medical and critical realist perspectives of disability⁶¹— but they also hold memory and make knowledge about dis/ability and dis/abled people. Further, employing the term bodymind pushes back against how education, law, medicine, and policy hierarchized mental and physical dis/abilities in ways in which allows for categorization and the segregation of our own bodyminds for the ease and benefit of the nondisabled gaze.

Since institutionalization has defined generations of dis/abled people's experience—how bodyminds create, hold on to, and pass on knowledge and memory our bodyminds remain intrinsically linked to the institution. Most healthcare policies and government-funded welfare supports for dis/abled people continue to rely on medically defined models of disability. All the while, many dis/ability advocates and scholars assert that dis/ability emanates from societal, economic, and cultural barriers—more commonly referred to as the social model of disability—but leave dis/abled people's material bodymind behind. In contrast, I argue that to arrive at such a definition of dis/ability, one must overlook institutionalization. To remove embodied experience from constructions of dis/ability completely negates the performative process of institutionalization and its afterlife, the specter of institutionalization.

⁶¹ For a critical realist's perspective on the usage of "impairment" see, Tom Shakespeare, *Disability Rights and Wrongs Revisited*, 1st ed. (New York, NY: Routledge, 2006); for a rights/social model perspective on "conditions," see "The Words We Use: CommunicationFIRST's Style Guide," July 11, 2023, <u>https://communicationfirst.org/the-words-we-use/</u>.

Developing Disability: Feeblemindedness, Mental Retardation & Developmental Disability

While diagnostic labels and categories separate more than they unify the dis/ability community, the historical evolution of disability-related terminologies and labels play a significant role in both institutionalization and the legacy of Pennhurst. Grasping these ever-developing terminologies remain critical to the work of this dissertation because it provides essential context to the near-constant expansion and constriction of historical and contemporary definitions of disability. These changes continue to affect the types of care dis/abled people receive and the funding disability policy initiatives, such as institutionalization and HCBS, receive. Ultimately, these terminologies affect the choices dis/abled people must make throughout their daily lives. In short, to fully understand why dis/abled people chose to work at and find community in a former institution turned haunted attraction, one must first understand the evolution and impact of this language.

As medical historian Beth Linker discusses in her seminal article, "On the Borderlands of Medical and Disability History," the category of disability, as both medical professionals and society now use it, did not exist until relatively recently.⁶² Prior to the 1800s, American society and medical doctors understood feeblemindedness and insanity as essentially the same and few options for care existed—other than locked bedrooms and county almshouses—for individuals and families in need.⁶³ By the early

⁶² Beth Linker, "On the Borderland of Medical and Disability History: A Survey of the Fields," *Bulletin of the History of Medicine* 87, no. 4 (2013): 499–535.

⁶³ R. C. Scheerenberger, *A History of Mental Retardation* (Baltimore, MD: Paul H. Brookes Publishing Company, 1983), 25-50.

1800s, the term feeblemindedness, as well as the field of study devoted to its etiology and treatment, struggled to find its footing in the medical community.⁶⁴ It was not until the late 1800s, into the early 1900s, that doctors solidified the concept of feeblemindedness.

The evolution of diagnostic categorization has and continues to play an important role in care, education, and advocacy for the dis/ability community. Starting in the nineteenth century, researchers and practitioners made firm distinctions which separated the categories of feeblemindedness and insanity. Despite this, people in direct contact with and influence over people deemed disabled often only made hard distinctions between those deemed insane or crippled (people deemed physically disabled to the point of being incapable of productive labor). Everyone else—those either in need of specialized care or deemed inconvenient—received the label of feebleminded.

As disability historian Katrina N. Jirik notes, from the late eighteenth century to the first decades of the twentieth century, doctors and educators assigned the term feeblemindedness equated to anyone deemed "socially inadequate."⁶⁵ This broad category included both physical disabilities and developmental disabilities, as well as orphans, immigrants, people of color, drunkards, among others that institutional authorities labeled as not "insane."⁶⁶ Jirik clarifies that, by the mid-1800s, doctors largely understood feeblemindedness as occurring either at birth or in early childhood, and early institutions for people deemed feebleminded served mostly children.⁶⁷ On one hand,

⁶⁴ Katrina N. Jirik, "American Institutions for the Feeble-Minded, 1876-1916" (PhD Dissertation, Minneapolis, MN, University of Minnesota, 2019), 103-04.

⁶⁵ Katrina N. Jirik, "American Institutions for the Feeble-Minded, 1876-1916" (PhD Dissertation, Minneapolis, MN, University of Minnesota, 2019), 1.

⁶⁶ Jirik, "American Institutions for the Feeble-Minded," 19.

⁶⁷ Jirik.

institutions during this period held that people deemed feebleminded could receive education from institutional training to re-enter society and become productive members of society. On the other hand, doctors believed insanity occurred in adults brought on by the growing anxieties of the urban life and moral intemperance, and thus it required a different approach for treatment.⁶⁸ In the first decade of opening, for example, local almshouse directors would occasionally commit a person to the PSSH they considered feebleminded. Once at the institution, if the medical examiners deemed the inmate typically violent adults—as insane, they would transfer the inmate to a state psychiatric institution, such as the State Lunatic Hospital in nearby Norristown, Pennsylvania. Institutional authorities did this because they could not properly treat—or, realistically, restrain—them at the PSSH.⁶⁹

The vague and overarching definition of feeblemindedness played not only a key role in the commitment trials of the PSSH inmates examined in <u>Act I</u> and the blurring of care into violence analyzed in <u>Act II</u> but also remains central to the contemporary performative process of institutionalization. As Jirik highlights, feeblemindedness "was strongly based on middle-class mores. It was nebulous enough to have a wide-ranging application to populations who were often poor or were composed of immigrants."⁷⁰ The definition of feeblemindedness, and its association with custodial institutions, shifted and narrowed in scope as the language of the field changed. In the first three decades of the twentieth century, the terminology of "mental deficiency" and "mental defective" gained

⁶⁸ Grob, Mental Illness and American Society, 36-37.

⁶⁹ Norristown remains operational as of 2023.

⁷⁰ Jirik, "American Institutions for the Feeble-Minded," 1.

popularity as the usage of feeblemindedness waned. In the mid-twentieth century, the label "mental retardation" became the commonly used terminology.

Contemporarily, academics, disability advocates, lawyers, lobbyists, politicians, and educational and medical professionals often use "intellectual and/or developmental disabilities (I/DD)", though some, particularly educators and medical professionals, continue to use the terminology of "retardation." In my writings, however, I use "dis/ability" as a general term. In instances where specificity, or code-switching (when a person changes their behavior, appearance, and/or language to successfully navigate an environment), is required, I consciously use "developmental disability," or "mental dis/ability." I avoid using "I/DD" because, in my view, it represents a medical diagnosis that casts individuals—particularly those with so-called "intellectual disabilities"—as living with a (often apparent and performative) deficit. Further, I argue that those living with "I/DD" engage with and communicate within an entirely distinct epistemological framework compared to neurotypical and/or nondisabled people.

While this updated label removes the harsh connotations of previous labels, the specificity of the term I/DD brings both advantages and disadvantages. On one hand, the federal government's definition of "developmental disability" as found in the Centers for Disease Control (CDC) remains relatively broad. It includes people with "an impairment in physical, learning, language, or behavior areas," that "begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime."⁷¹ This broad, medically derived notion of developmental disabilities serves a

⁷¹ Centers for Disease Control and Prevention (CDC), "Facts About Developmental Disabilities," Developmental Disabilities, April 27, 2022, <u>https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html</u>.

useful purpose because it allows more room for people to gain access to valuable services provided with such a diagnosis. On the other hand, reliance on the I/DD label severely limits scholarly and societal understandings of the scope, reach, and impact of custodial institutions. Further, such distinctions often create an arbitrary separation between disability advocacy groups, resulting in unnecessary infighting largely caused by scarcity of funding and recognition. The academic and public reception of the PA community serves as an example of this.

The members of the PA community identify with a large swath of dis/abling bodymind experiences that resemble the vaguer label of feeblemindedness, such as learning, mental, and psychiatric dis/abilities more commonly referred to as "mental health issues," rather than the more specific I/DD label. As critical disability studies scholar Margaret Price argues, this language creates an implicit preference for "the healthy disabled" or people without "fluctuating" dis/abilities.⁷² I/DD advocates remain critical of the PA community and often question what the percentage of the PA community population identifies as living with I/DD. In this way, I/DD advocates' (generally nondisabled parents and/or siblings) concern for specific diagnostic labels halters progress for the dis/ability community. By using specialized diagnostic labels most of which were not created by dis/abled people for use by dis/abled people advocates screen who can claim to belong within the dis/ability community. Unfortunately, this gatekeeping and infighting is not unique to the I/DD community.

⁷² Margaret Price, *Mad at School: Rhetorics of Mental Disability and Academic Life* (Ann Arbor, MI: University of Michigan Press, 2011), 13.

One of the greatest challenges facing the dis/ability community—broadly defined—is how various diagnoses, categorizations, and bodymind experiences divide and conquer our community, pitting dis/abled people against dis/abled people, often solely because of the scarcity of resources made available to us by lawmakers and society.⁷³ Despite academics, advocates, and policymakers often overlooking the PA community, it serves a potent model for how dis/abled people and nondisabled people can come together, to create an accessible space in which they feel they belong and have their needs met.

Inmate vs. Resident & Institution vs. Facility

Most scholars and advocates—regardless of discipline—refer to custodial institutions as residential facilities, and the people housed within them as residents. In contrast, I refer to institutions as institutions, and the people housed there as inmates. I do this for several reasons. First, as Jirik's groundbreaking research illustrates, early institutions for people deemed feebleminded and epileptic during the late nineteenth century often released their pupils—these people were residents because institution. In contrast, institutions of the twentieth century, such as the PSSH, assumed those committed to the institution would likely *not* leave. Second, the lawmakers, institutional legislation, educational and medical authorities, and the public all referred to the people existing at the PSSH, and other

⁷³ As one dis/ability advocate once told me, "We eat our own young."

institutions, as inmates. Third, the act of referring to dis/abled people committed to institutions—especially those committed involuntarily—as residents acts as nondisabled fragility by creating distance between the realities of custodial care and neutral language. Likewise, despite going through multiple name changes during its existence—eventually becoming the "Pennhurst Center" in the 1970s—the PSSH was an institution. Calling it anything else not only sanitizes the dehumanizing environment of the institution, but it also relieves federal and state lawmakers, educational and medical professionals, Universities, families, and the general public of their culpability in the historic and ongoing systematic violence against dis/abled people caused by institutionalization.

Positionality

Disclosing one's dis/ability involves serious risk both in educational and employment settings, and disability rights laws have often valued privacy over disclosure.⁷⁴ Disclosure can cause dis/abled people to experience both explicit and implicit ableism, despite being protected from discrimination by Section 504 of the Rehabilitation Act of 1973 and the ADA.⁷⁵ Further, people living with more apparent dis/abilities often have no choice to disclose, while others with less apparent dis/abilities can decide whether to disclose their dis/ability.

As a White, first-generation dis/abled college graduate from a low-income, divorced family in rural Minnesota, born with readily apparent developmental and

⁷⁴ For more on disclosing antidiscrimination laws, privacy, and the importance of disclosing one's disability see Harris, "Taking Disability Public."

⁷⁵ Sarah von Schrader, Valerie Malzer, and Susanne Bruyere, "Perspectives on Disability Disclosure: The Importance of Employer Practices and Workplace Climate," *Employee Responsibilities and Rights Journal* 26, no. 4 (2014): 251.

physical dis/abilities, who now largely passes as nondisabled and neurotypical, I argue it is essential for scholars working within dis/ability-related fields and topics to disclose their dis/ability. I choose to disclose my dis/ability—including portions of my patient files—in this dissertation because I want other dis/abled people and future generations of dis/abled scholars to know that people with dis/abilities do work on dis/ability.

Finally, a high percentage of nondisabled people work within critical disability studies, disability advocacy, and dis/ability adjacent professional fields such as education, law, medicine, policy, and social work. Given this, it remains important that dis/abled people know who advocates for us, studies us, publishes research about us, and makes decisions for us, and what experiences they bring to those discussions. While being a parent or sibling of a dis/abled person, for example, is an indispensable experience, it does not substitute for the experience of living with a dis/abled bodymind. This is *not* to say that only dis/abled people can do dis/ability work; everyone brings unique talents, skill sets, and experiences, and we must work together to generate lasting change within our community. Nonetheless, we must reflect seriously on who has historically retained positions of privilege and power in the dis/ability community. Only then can we create accessible, equitable, and inclusive platforms for dis/abled people—particularly dis/abled people with intersecting areas of marginalization—to make change within the dis/ability community and elsewhere.⁷⁶

⁷⁶ For Critical Disability Studies approaches to disclosing dis/ability identity see, Simi Linton, *Claiming Disability Knowledge and Identity* (New York, NY: New York University Press, 1998); Adrienne Asch, "Critical Race Theory, Feminism, and Disability: Reflections on Social Justice and Personal Identity," *Ohio State Law Journal* 62, no. 1 (2001): 391–423; Rosemarie Garland-Thomson, "Integrating Disability, Transforming Feminist Theory," *NWSA Journal* 14, no. 3 (2002): 1–32; Tobin Siebers, *Disability Theory* (Ann Arbor, MI: University of Michigan Press, 2008); Lennard J. Davis, "The End of Identity Politics: On Disability as an Unstable Category," in *The Disability Studies Reader*, 4th ed. (New York, NY: Routledge, 2013), 263–77; Ellen Samuels, *Fantasies of Identification: Disability, Gender, Race* (New York, NY: New

A Note on Diagnostic Terminology

Throughout this study, I avoid categorizing dis/abled people. I do this for three reasons: first; I do not wish to create a hierarchy of dis/abling experiences. Second, categorization perpetuates medically derived notions of disability, which prioritizes medical professionals' authority to claim and verify a person's experiences of dis/ability and make it into a disability. This model situates disability as a person's biological problem(s) which an expert must thus locate, isolate, and cure. Third, the categorization of dis/abling experiences has historically isolated and separated dis/abled communities from one another rather than as a tool to bring us together. By not making categorical distinctions, I show despite differences in individual experiences, dis/abled people gain strength in unity.

The language used throughout this dissertation, drawn from my primary source material—especially in the first two Acts—is disgusting and dehumanizing. It is, however, the language that was used by my historical subjects, and is occasionally still used by educators, doctors, researchers, and policymakers today. In my lifetime, educators, doctors, and members of the public have referred to me with labels like retard, spastic, hyperactive, developmentally disabled, and cripple. These labels—like the surgical scars on my body—remained tattooed on my bodymind and my sense of self. I do my best to return the humanity and value of those whom I refer to with these terms and labels. But for the sake of historical accuracy, I feel it essential to employ the language of the period, since institutional authorities made such distinctions when

York University Press, 2014); Sami Schalk and Jina B. Kim, "Integrating Race, Transforming Feminist Disability Studies," *Signs: Journal of Women in Culture and Society* 46, no. 1 (2020): 31–55.

categorizing inmates. The work of this dissertation, however, is precisely to examine how academics, government officials, and professionals produced and promulgated these terms in the realms of education, law, medicine, and public policy, and normalized them through the public-facing presence of institutions such as the PSSH.

Overview of the Work

A Note on Trauma, Pain & the Structure of this Work

I began my research on the PSSH while completing coursework at the University of Minnesota's Law School on bioethics and biomedicine during my first semester of doctoral studies in Fall 2017. At the time, I served as my dis/abled father's Power of Attorney (POA), while he received hospice care in the nursing home that my grandmother, mother, and aunt had all worked for previously.⁷⁷ Each night after class, I would make the one-hour trek (one way), using what I had just learned in law school to advocate for my dying father. In class, I would often raise issues stemming from my experience of spending most of my childhood in Shriners, and the newfound experiences of serving as a dis/abled POA. My classmates, mostly third-year law students hoping to pursue careers as hospital ethics counsels and policy advisors for biotechnology companies, did not recognize the inaccessibility of our classroom. Nor did they give thorough attention to the historic structural barriers facing dis/abled people in an age

⁷⁷ My mother died only eleven months prior to my father, on December 27, 2016. My grandmother, who had worked at that nursing home for over thirty years, died in the room on the other side of the wall of the room my father died in on March 29, 2020.

which biotechnological advancements continue to increase the prevalence of velvet eugenics. Garland-Thomson argues that velvet eugenics, like hard eugenics, aims to rid people deemed unfit and inferior from society, but becomes "Enforced by laissez-faire commercialism, rather than by the state." While "velvet eugenics seems like common sense, … it hides its violence and inequality behind claims of patient autonomy and under a veil of voluntary consent."⁷⁸

During my early years as a graduate student, I did not know how my own medically induced traumas served as an evidentiary base to the research problems I hoped to address. Instead of intertwining the affective, embodied experiences of living through extensive childhood hospitalization and my ongoing battles with the bureaucratic behemoth otherwise known as the Social Security Administration, I pushed those experiences aside as irrelevant. I focused on finding empirical answers to what I thought were empirical questions, and my writing reflected that. What I found—thanks to the generous readers of my early writing—was that my experiences are, in fact, evidence of the performativity of institutionalization. Indeed, I was intellectually mining Pennhurst's archive for the origins of the very things I was experiencing time and time again. One example of this comes from the shared experiences of me and my father with the Social Security Administration.

⁷⁸ Sandy Sufian and Rosemarie Garland-Thomson, "The Dark Side of CRISPER: Its Potential Ability to 'Fix' People at the Genetic Level Is a Threat to Those Who Are Judged by Society to Be Biologically Inferior," *Scientific American*, February 16, 2021, <u>https://www.scientificamerican.com/article/the-darkside-of-crispr/</u>. For more on the notion of velvet eugenics—ways in which eugenics continue through more implicit than explicit discrimination practices, see Garland-Thomson, "Disability Bioethics"; Sarah Zhang, "The Last Children of Down Syndrome," *The Atlantic*, December 2020,

Laid off from his warehouse job located in a Minneapolis suburb during the recession of the mid-2000s, my father struggled to find health insurance to afford his medical care. While he sought employment in the surrounding area of the rural town I grew up in, no one would hire him on account of his apparent disability. Unable to find work, he reached out to the county social worker who placed him on Social Security Disability Insurance (SSDI). To qualify for the insurance, Social Security required my father to place his retirement savings into a "Special Needs Trust," designed to help people on SSDI comply with the severe asset limits. (Under current regulations, a person cannot make more than \$2,000 a month or have over \$10,000 in assets to maintain their eligibility.) Once on SSDI, the social worker placed him in a sheltered workshop—a direct vestige of the institutional peonage discussed in <u>Act II</u>—in which he earned 35ϕ an hour to sort recycling items and adhere buttons to garments. During this time, my father struggled to pay his monthly mortgage and had to rely on food-stamps to afford groceries. After my father died of cancer in 2017, the Social Security Administration put a lien on the assets in his trust and his estate. Ultimately, his estate was pillaged by the government to repay his debt to Social Security. In a country in which generational wealth transfer remains the primary means of securing financial stability, such experiences illustrate how dis/abled people and their families have yet to leave the institution. While nondisabled society may allow for us to live in their community, the spectre of institutionalization keeps us from flourishing.

To better incorporate my experiences in this work, I envision this dissertation as an opera. My rationale is structural, personal, and compositional. Structurally, I hope this work will function as an invitation to doctoral programs to reassess what a dissertation—

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as the pinnacle achievement of a PhD—is, and who it excludes, particularly those deemed intellectually and/or developmentally disabled. Considering that only nineteen percent of college undergraduate students, eleven percent of graduate students, and four percent of faculty in the United States identify as living with a dis/ability, this problem needs to be addressed.⁷⁹ Examining and critically engaging the implicit and explicit ableism within doctoral programs is one place to start.⁸⁰

Personally, I chose opera—rather than another large-scale musical form such as a symphony or ballet, for example—because of the affective bodymind experience it invokes within me. Singing is the only thing that allows me to feel the entirety of my bodymind. Trained in opera, I left the profession because of disability discrimination, which made singing too painful to continue. Upon entering my doctoral program, I found safety in examining dis/ability from a disembodied theoretical distance. Even so, I have long turned to music to better understand and process the affective and embodied stories of Pennhurst and its people. The operatic frame allows my writing to keep both the theoretical nuance and technical prowess required by a dissertation, while also making space for creative freedom and recounting affective bodymind experience. I hope that this intricate blend of theory and personal narrative might act as a model—though not perfect—for future dis/abled scholars, specifically first-generation and multiply-

⁷⁹ National Center for Education Statistics, "Students with Disabilities," Fast Facts, n.d., <u>https://nces.ed.gov/fastfacts/display.asp?id=60</u>; Lilah Burke, "A Difficult Pathway: Faculty Members with Disabilities Say Stigma Prevents Some from Being Open about Their Conditions, and the Path to the Academy Still Has Its Barriers," *Inside Higher Ed*, May 11, 2021,

https://www.insidehighered.com/news/2021/05/12/faculty-disabilities-say-academe-can-present-barriers. ⁸⁰ Jay Timothy Dolmage, *Academic Ableism: Disability & Higher Education* (Ann Arbor, MI: University of Michigan Press, 2017).

marginalized dis/abled researchers.⁸¹ They too can, and should, integrate their profound bodymind experiences into their scholarly work.

Compositionally, the operatic form allows me to interweave theoretical concepts with embodied experience with the finesse and poignancy that a conventional dissertation format would not. This dissertation mirrors the relationship between a composer and librettist. As the dissertation's writer-the composer-I take the stories that the past and present people of Pennhurst have provided—the libretto—and set them to a textual soundscape to evoke the fluidity, interconnectedness, and tensions they hold. The stories provided by Pennhurst lend themselves to a rich pallet of tones and colors with layers of nuance and dramatic flair much like an operatic score. Pennhurst's stories yield rich opportunities (in musical terms) for melody, harmony, dissonance, counterpoint, theme and variation, and changes in both volume and speed, all the while never fully resolving. The operatic form—with overtures, recitatives, acts, an intermezzo, and a finale provides the format to best tell Pennhurst's story. I conceive what would traditionally be called chapters as "Acts." These larger bodies of work function as a singular piece in which expound on a particular theme relating to institutionalization. Likewise, I use smaller, auto-ethnographic vignettes, or "Recitatives," to provide an access measure to my readers: a break from the Acts' densely technical and theoretical excavations into institutionalization. These Recitatives also tie the past with the present, revealing how the

⁸¹ For more on multiply-marginalized dis/abled people see, Dikko Yusuf, "Why Multiply Marginalized People with Disabilities Should Be Prioritized Before, During, and After Disasters and Emergencies," World Institute on Disability, n.d., <u>https://wid.org/why-multiply-marginalized-people-with-disabilities-should-be-prioritized-before-during-and-after-disasters-and-emergencies/#:~:text=Multiply%20marginalized%20people%20with%20disabilities%20are%20those%20 who%2C%20in%20addition,sexualities%2.</u>

performativity of institutionalization informs the kinesthetic memory and every-day lives of both myself and other dis/abled people. While the ways in which we—dis/abled people—continue to encounter and wrestle with those histories and interactions remain an individual experience, they, nonetheless, possess a collective essence.

Finally, I have formatted this dissertation using universal design principles hoping to make it as universally accessible to all people, and abilities, as possible. Readers will note high contrast headings and internal bookmarks allowing readers to navigate this large document more easily. In addition, readers will note the use of captions and alt-text describing the figures within the dissertation. While most Universities—including the University of Minnesota—and publishers do not require writers to engage in such practices, I hope this dissertation will serve as a model for why such access measures not only matter but are necessary.

Overview of Acts

To illuminate how the performative process of institutionalization informs the bodily memory of dis/abled people, shapes nondisabled social perceptions of what it is to live with dis/abilities, and disability law and policy, each Act examines a separate form of the performative institutionalization process occurring throughout Pennhurst's legacy.

Act I: Producing the Prescription: Law, Medicine, Performance, and the Institutionalized Disabled Subject in the Courtroom

<u>Act I</u> lays the groundwork for my understanding of the relationship between disability, law, and performance. The Act delves into the evolution of institutional philosophy, legislation, and the commitment process of people deemed "feebleminded" in Pennsylvania from the 1890s to the 1920s. The process created a legal standard which required a dis/abled person to perform as disabled while simultaneously stripping away their personhood and making them into institutionalized disabled subjects.

This Act examines what I call rhetorical legal performatives: speech acts that bring about doing, and performances of disabled appearance: acts of showing materially apparent signs of disability, drawn from the commitment trial transcripts of disabled children institutionalized at the PSSH. This Act investigates: how did institutionalization laws emerge and reflect the shifting beliefs held by superintendents, politicians, social reformers, and others regarding the purpose of the institution, both in Pennsylvania and the nation? Second, since institutionalization legislation was often the first legal framework that addressed dis/abled people explicitly as a distinct legal class of people, what does it mean to appear as disabled in the "eyes of the law?"⁸² And, third, what role did performance, particularly rhetorical legal performatives used in the courtroom and doctor's office, play in making dis/abled bodyminds materially appear as disabled to the Court? I reveal how this performative process placed dis/abled people within an exceptional legal, medical, and ontological status. I argue that this status allowed both institutional authorities and society to imaginatively conjure and linguistically choreograph the disabled subject, and render it fit for institutionalization and legal exception.

⁸² My use of this phrase, which favors the ability of sight, is intentional. Frequently, in discussions about law and performance, certain abilities or sensory experiences are prioritized over others—particularly the abilities to read, write, and speak in neurotypical ways.

Act II: Enforcing the Prescription: Performances of Habilitation & Institutionalized Care at the Pennhurst State School & Hospital

Act II investigates what happened to disabled subjects after their commitment by another register of the performative process of institutionalization: how systematic abuse and violence came to constitute care, not harm. This investigation is caried out by comparing official narratives created by the Commonwealth with the experiences of PSSH inmates and survivors, as documented in patient files. In these files, I pay particular attention to patterns regarding the language used to describe the inmates and patterns of the care (or lack thereof) they received in the institution. My analysis of this materials reveals the PSSH, along with other institutions, developed amidst an unresolved conflict between eugenic logic and rehabilitative goals. This pivotal contradiction fostered an environment in which the transmutation of perceived care into received violence was possible.

This Act uncovers how institutional environments—such as the PSSH—not only reaffirmed performances of disabled performances, but also created and enforced performances of habilitation and institutionalized care. Performances of habilitation required (and continue to require) nondisabled norms by forcing institutionalized disabled subjects into performing socializing acts such as labor, ways of dressing, and behaving in public settings. Performances of institutionalized care —everyday practices of coercion, neglect, restraint, and abuse—turned perceived care into received violence. While this Act examines phenomena that occurred during the twentieth century, it ends by making apparent how these performances of habilitation and institutionalized care continue in care settings today.

Intermezzo: The Litigation that Closed an Institution & Birthed an Asylum

The Intermezzo, true to its musical form, acts as a short piece inserted between the first two Acts and the final two Acts of this work. The Intermezzo examines the litigation involved in closing the PSSH while probing the institution's significance to legal history. It surveys the tensions that arose among varying stakeholders and examines debates surrounding Pennhurst's history, preservation, and legacy. The Intermezzo reveals that, despite being on its face about disability rights and dis/abled people, Pennhurst's litigation, its closure, and the debates that followed made dis/abled people—and their bodyminds—disappear.

Act III: The Pennhurst Asylum & the Spectre of Disability: (Re)Performing and Reclaiming the Repertoire of Pain

Act III offers an ethnographic analysis of the PA's performances, exposing how the attraction's immersive performances elide fact with fantasy and erase ongoing violence against dis/abled people. The PA attraction serves as a bracketed performance space by creating a bounded, safe, aestheticized experience of an institution. This space exposes deep societal fears around the performative characteristics of what I call the "specter of disability," or performances that reinforce perceptions of disability as the ghost of ability lost. This bracketed performance space erases ongoing acts of violence committed against dis/abled people in institutions, all the while transferring embodied knowledge about disability, care, and violence. While this violence evades the review of the Court, the PA attraction, through its location in this former institution, captures this violence, making it possible for review. Finally, the PA not only reveals nondisabled society's willingness to commodify institutional violence, but it also creates a space and a mode of

performance—haunting—where dis/abled people unsettle nondisabled ontological assumptions of disability that returns political agency back to the spirits of PSSH inmates.

Act IV: Remembering and Redefining a House of Horrors: Advocacy, Crip Historiography, and Community Living at the Pennhurst Asylum Act IV explores how the community of dis/abled and nondisabled people who work for the PA conduct vernacular and performed historiography through their collective inhabitation of and care for this former institution turned attraction venue and grass-roots museum. Engaging performance as an embodied practice of enacting memory, I explore formations of community and knowledge-making at the PA. This Act documents how the dis/abled people who work at PA actively preserve the history of institutionalization while reclaiming the space once intended for their segregation from society to create a space for dis/abled people made by dis/abled people. But they create this community not by undoing the ongoing violence of the specter of institutionalization, but by living in, through, and alongside it.

RECITATIVE

Welcome to the Machine

I am sitting on my couch, in my apartment's living room, in Washington, DC. It's February 2022. My laptop rests on my coffee table. I insert a flash drive into the computer. My body tenses, my heart starts to race, while my hand tremors as my fingers move across the trackpad.

I am safe. I am safe. I am sa—FUCK! I can't do this!

Breathe. You can do this. You need to do this.

I can't. I need to get out of here—I'm going to run out of here!

And go where?

Right. I'm in my own apartment.

Dumbass.

Breathe. You are safe. Take a deep breath and let it be.

The cursor hovers over the flash-drive's only file: "Stenberg, Patient Files."

Тар. Тар.

The trackpad makes two audible clicks as I open the files. Adobe Acrobat

launches and slowly digests the immense PDF.

Almost 400 pages?? Jesus. Where do I begin?

I scroll to the end of the PDF and notice the date: 2009.

Okay, this looks like it's the discharge stuff. What about the admission and intake files? They've gotta be near the top. That's what you're looking for. If there's a connection here between me and the people at Pennhurst, it's gotta be there.

I scroll back to the beginning of the files.

My breathing starts to get shallower the longer I spend looking over the files. I pause, on occasion, to see what the documents are. Progress reports; preoperative examinations, postoperative examinations—these are the worst. I stare at the body diagrams and see how the surgeons' pencil in the work they completed on my body, cutting into it, molding it, rearranging it like putty. I can't look at them for long. (I still haven't returned to them.) Finally, I found what I am looking for.

In a pre-admission *examination*, a pediatrician writes in 1995 (when I am three years old): "[Nathan] is, however, rather hyperactive and impulsive. He is prone to noncompliance, and his mother is rather indulgent with him. He will be a challenge therapeutically..."⁸³

I slam my laptop shut.

I feel like I am being choked. I cannot breathe. I cannot move. My vision starts to blur, and I lose sense of where I am.

I can't do this.

Go outside. Clear your head and get some fresh air. You are safe. Why am I alive?

Just breathe.

But that's all I am, all I will ever be—a problem.

⁸³ Stenberg, Patient Files.

Society must be protected from pollution and tragedy on one hand, and on the other the innocent imbecile must be saved from punishment for heedless or reckless transgression for which he is absolutely irresponsible. The interests of both therefore demand permanent sequestration. But where, and how? A way must be prepared for the crisis which even another decade may for upon us. ... We, with our broad territory, are able to meet the same issue in a more humane way; but with us also a national need can be met only by a national provision. The government is caring for the deaf-mute, the Indian, and the negro; then why shall it not care for this race which is at once more helpless and more aggressive, which is incapable of self-preservation and fast becoming a standing peril to the nation?

Martin W. Barr, Superintendent of the Pennsylvania Training School for Feebleminded Children, Paris, July 1898.⁸⁴

ACT I

Producing the Prescription: Law, Medicine, Performance, and the Institutionalized Disabled Subject in the Courtroom

Introduction

To better understand institutionalization as an ongoing structural and performative process, or a pervasive repetitive social performance, this first Act examines the evolution of institutional philosophy, legislation, and the commitment process of people

⁸⁴ Martin W. Barr, "Defective Children: Their Needs and Their Rights," *International Journal of Ethics* 8, no. 4 (July 1898): 487.

deemed "feebleminded" in Pennsylvania from the 1890s to the 1920s. This Act uses a performance studies methodology to navigate within legal and medical history by illustrating how institutionalization legislation, diagnostic methods for identifying people deemed feebleminded, and the expert witness testimony at commitment trials dehumanized dis/abled people. Act I analyzes the commitment procedures of children to the Pennhurst State School & Hospital (PSSH) during this period. In doing so, I reveal how legal language materially produced the bodyminds of children, who were absent from their own trials, as disabled and worthy of institutionalization.

I begin this study by posing three questions: First, how did institutionalization laws emerge and reflect the shifting beliefs held by superintendents, politicians, social reformers, and others regarding the purpose of the institution, both in Pennsylvania and the nation? Second, since institutionalization legislation was often the first legal framework that addressed disabled people explicitly as a distinct legal class of people, what does it mean to appear as disabled in the "eyes of the law?" And third, what role did performance, particularly rhetorical legal performatives used in the courtroom and doctor's office, play in making dis/abled bodyminds—the interdependent relationship between body and mind—materially appear as disabled to the Court?

The legislation for institutional commitment in Pennsylvania vested legal and medical authorities with the power to use rhetorical legal performatives to materialize the bodyminds of children and rhetorically choreograph them as disabled while simultaneously making their personhood disappear. This process resulted in turning children deemed feebleminded into institutionalized disabled subjects. I understand rhetorical legal performatives as utterances, words, and actions made in the courtroom

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and physician's office, as well as statutes, policies, and judicial opinions that *do* something because of the force of the law as a system of regulatory norms. Crucially, legal and medical authorities used these rhetorical legal performatives in conjunction with public displays of what they claimed were apparent signs of a subject's disability. During commitment trials, the child became the object of these demonstrations. I term these public displays of perceived disability as performances of disabled appearance. These performances of disabled appearance can be traced back to the trials discussed below and the performances of institutionalized care and habilitation examined in <u>Act II</u>. In short, performances of disabled appearance created an expectation that a dis/abling bodymind experience *must* be readily apparent—as a disability—to a nondisabled spectator to be considered legitimate under the law.

Because performances of disabled appearance involved experts claiming authority to speak to, and thereby show, a person's supposed disability, these trials set a precedent where dis/abled people could not (and still cannot) represent and have claim over their own bodymind experiences. Further, these trials removed dis/abled people's ability to express, for themselves, the medical and social ramifications of those experiences. Though the trial was intended to determine a person's eligibility to receive custodial care at an institution, the courts did not give children committed to the PSSH the option to express whether they wanted (or needed) that care. Instead, a constituency of mostly nondisabled people—institutional authorities, lawyers, and parents—spoke for the children. They used their words to materially manifest the supposed disabling conditions expresed by the children necessary to meet a standard of proof.

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Using rhetorical legal performatives to generate performances of disabled appearance cuts to the core of not only historical legal, medical, and societal conceptions of disability, but also contemporary disability policies and social services in the United States. The definitions of disability arrived at in the commitment trials of PSSH inmates foreshadow the definitions of disability as found in our contemporary disability policy. The commitment trials helped set a precedent where actual dis/abled bodymind experiences must conform to nondisabled expectations of disability. If the actual dis/abled experiences do not conform to expectations, then the standard of proof for disability-related services and protections is not met. For example, the Americans with Disabilities Act (ADA),⁸⁵ and Social Security Disability Insurance (SSDI)⁸⁶ both require a person to meet a standard of proof that depends on a successful performance of disabled appearance in order to have legal eligibility for these services. In turn, the often fluid and unpredictable bodymind experiences—ranging from debilitating pain fare-ups and bodily exhaustion to significant yet temporally brief mental dis/abilities—most dis/abled people live with on a day-to-day basis become the very thing that disqualifies them from receiving needed benefits and/or protections because they may not always be readily apparent. Since dis/abled people experience a range of both apparent and nonapparent dis/abling conditions, these experiences often do not qualify as performances of disabled appearance within the wider society and thus disqualify people from the services that

 ⁸⁵ "Americans with Disabilities Act of 1990, As Amended," 42 U.S.C. § 12101 et seq. (1990), <u>https://www.ada.gov/law-and-regs/ada/</u>. The ADA protects dis/abled Americans against discrimination, but primarily through the vehicle of workplace accommodations.
 ⁸⁶ Social Security Administration, "How Do We Define Disability?," Red Book, n.d.,

<u>https://www.ssa.gov/redbook/eng/definedisability.htm?tl=0%2C1</u>. SSDI provides health insurance for dis/abled workers with limited incomes.

they are legally entitled to receive. Finally, these performances of institutionalized disabled subjectivity also established a repertoire of embodied signs that legitimized the continuation of violence and dehumanization against dis/abled people.

Disability as Law's Other

Legal and medical historians readily agree that most institutional authorities, up until the late nineteenth century, intended institutions to provide custodial, in-patient care and education for people deemed disabled, or feebleminded, for a specific, finite period of time.⁸⁷ Private institutions catered to clientele who could afford to receive services, while state institutions served mostly low- and middle-class families.⁸⁸ As the constellation of education, law, policy, medicine, and society converged with the eugenics movement at the turn of the twentieth century, however, disability became perceived as nondisabled society's Other.⁸⁹ In turn, the institutional philosophy of use shifted from providing boarding-school-like education to categorizing, capturing, and segregating disabled

⁸⁷ Albert Deutsch, *The Mentally III in America: A History of Their Care and Treatment from Colonial Times* (Garden City, NY: Doubleday, Doran & Company, 1937); R. C. Scheerenberger, *A History of Mental Retardation* (Baltimore, MD: Paul H. Brookes Publishing Company, 1983); Peter L. Tyor and Leland V. Bell, *Caring for the Retarded in America: A History* (Westport, CT: Greenwood Press, 1984); Michael Rembis, *Defining Deviance: Sex, Science, and Delinquent Girls, 1890-1960*, 2nd ed. (Champaign, IL: University of Illinois Press, 2013); Katrina N. Jirik, "American Institutions for the Feeble-Minded, 1876-1916" (PhD Dissertation, Minneapolis, MN, University of Minnesota, 2019); Chelsea D. Chamberlain, "Receiving, Sorting, and Disposing of Children: Institutions, Education, and Feeblemindedness in Progressive America" (PhD Dissertation, Philadelphia, PA, University of Pennsylvania, 2022). State governments established, funded, and operated most institutions for people deemed feebleminded in the United States. Philanthropists, educators, and medical doctors also established privately funded institutions such as the Pennsylvania Training School for the Feeble-Minded Children (Elwyn)—the first in the Commonwealth and second in the nation.

⁸⁸ Though, throughout its history, Elwyn received supplemental funding from the Commonwealth of Pennsylvania.

⁸⁹ Sharon L. Snyder and David T. Mitchell, *Cultural Locations of Disability* (Chicago, IL: The University of Chicago Press, 2006).

people away from society for indefinite periods of time in the name of "care."⁹⁰ The aforementioned constellation, along with burgeoning institutional legislation, set the stage for this shift to happen, while law and performance combined in the courtroom to materialize this change.

The otherization of disability that resulted in institutionalization philosophy shifting from education to segregation in the twentieth century manifested in two ways. First, because eugenic philosophy significantly influenced the confluence of social, medical, and political movements during the early 1900s, disability became the antithesis of an idealized, "normal" bodymind. The transition from Lamarckian genetics—which focused on acquired characteristics-to Mendel's hard heredity principles rediscovered in 1900 emphasized that, regardless of the amount of education or training a child labeled as feeble-minded received, change was deemed unattainable. As a result, eugenicists argued that all forms of training and education were a wasteful expenditure of state funds and that custodialization was the only suitable approach. The concept of "normal" has a complex and contentious history; it would not be entirely accurate to attribute the majority of responsibility for the promulgation of this nebulous concept to eugenics.⁹¹ As disability historian Douglas Baynton points out, "The natural and the normal both are ways of establishing the universal, unquestionable good and right. Both are also ways of establishing social hierarchies that justify the denial of legitimacy and certain rights to

⁹⁰ Trent, Inventing the Feeble Mind.

⁹¹ For more on the concept of normal, refer to this non-exhaustive list: Douglas C. Baynton, *Defectives in the Land: Disability and Immigration in the Age of Eugenics* (Chicago, IL: The University of Chicago Press, 2016); Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (New York, NY: Verso, 1995); "Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century," in *Beyond Bioethics: Toward a New Biopolitics*, ed. Osagie K. Obasogie and Marcy Darnovsky (Oakland, CA: University of California Press, 2018), 63–72; Georges Canguilhem, *The Normal and the Pathological* (New York, NY: Zone Books, 1989).

individuals or groups."⁹² In this way, knowing how to identify someone as legitimately disabled—nondisabled society's Other—became a hotly debated topic within both law and medicine. The authority for identifying disability often rested in the hands of the physician but also fell to other people in positions of power—particularly professionals—such as social workers, almshouse directors, educators, and others.⁹³

Second, as institutionalization's philosophy of use shifted in the early 1900s, it coincided with a period in which women and other minority groups fought against legal exclusion. In short, if you were not a nondisabled white man, you were considered a nonlegal subject and disabled under the law.⁹⁴ In this way, law sanctioned inequality by using the category of disability to justify the discrimination of both people contemporarily deemed disabled *and* other minority groups on the basis of class, gender, race, and ethnicity.⁹⁵ For example, being a woman was considered a "legal disability" under common law's principle of coverture and justified not giving women individual rights or personhood outside of marriage. But marginalized groups also used the category of disability as an argument against the inequality they experienced. As Baynton explains, "Such arguments took the form of vigorous denials that the groups in question actually had these disabilities [such as being a woman or having non-white skin]; they were not disabled, the argument went, and therefore were not proper subjects for

⁹² Douglas C. Baynton, "Disability and the Justification of Inequality in American History," in *The New Disability History: American Perspectives*, ed. Paul K. Longmore and Lauri Umansky (New York, NY: New York University Press, 2001), 35.

⁹³ For more on the push and pull between medical and legal jurisprudence, and the concept of legal personhood, particularly regarding insanity and the legal category *of non compos mentis*, refer to Blumenthal, *Law and the Modern Mind*, especially chapter 2, 59-86.

 ⁹⁴ Legal historian Barbara Welke calls this the "borders of belonging," *Law and the Borders of Belonging in the Long Nineteenth Century United States* (London, UK: Cambridge University Press, 2010), 1-5.
 ⁹⁵ Baynton, "Disability and the Justification of Inequality," 33.

discrimination."⁹⁶ In this way, marginalized groups used disability as a category they could pass in and out of, depending on whether it provided purchase for their arguments against inequality and towards their fight for recognition as having a legitimate claim to citizenship under the law. This positioned disability as a literal and figurative metaphor for the law's Other. The phrase "disabled under the law" situated the category of disability as being void of citizenship and personhood. But it also removed any mention of the rights and personhood of people who experienced dis/abling bodymind conditions. Therefore, by employing disability as a vehicle for legal rights without including dis/abled people in the discussion, further otherized dis/abled people and left the category of disability as outside of legal protections.

The eugenic frenzy for categorizing people as normal or abnormal, combined with the absence of dis/ability as a positive legal concept left dis/abled people in America dangerously vulnerable to discrimination during the early decades of the twentieth century. As state legislatures began to enact lunacy laws for the identification and commitment of people deemed "insane" and commitment laws for people deemed feebleminded, these statutes provided often vaguely worded definitions of disability.⁹⁷ In turn, the statutory language often gave medical professionals, lawyers, educators, etc. the power to declare someone disabled, thus combining law with performance to materially produce disability.⁹⁸

⁹⁶ Baynton, "Disability and the Justification of Inequality," 34.

⁹⁷ I am using the contemporary language of "disability," but the terminology of the period's legislation would have largely consisted of "insanity" (psychiatric disabilities), "feeblemindedness" ("socially inadequate," incorrectly associated as *only* I/DD by many contemporary scholars), "epilepsy" and "cripples" (physically disabilities), etc.

⁹⁸ Who had the power or expertise to determine a person's disability status remained hotly contested within the courtroom and varied by states. Unfortunately, the literature on commitment trials for people deemed feebleminded during the early twentieth century is not as robust as it is for people deemed insane, but for

Disability, Legal Ritual & the Unmaking of Persons: Moving Towards Performance

My research is not the first to examine how law, as a governing body of norms enforcement, makes and unmakes people. While a growing amount of legal scholarship investigates the role of law in subject-making, disability remains the law's other, and dis/abled people remain largely left out of the conversation.⁹⁹ For example, legal scholar Collin Dayan examines how the law makes and unmakes subjects while also, presumably unknowingly, revealing the law's nondisabled assumptions about disability.¹⁰⁰ Dayan focuses on how legal rituals make "persons, variously figured, gain or lose definition, become victims of prejudice or inheritors of privilege. And once outside the valuable discriminations of personhood, their claims become inconsequential."¹⁰¹ Dayan refers to how legal rituals remove personhood from certain people and place them into a category in which she considers "negative personhood," or "slaves, animals, criminals, and detainees who are *disabled* by the law."¹⁰² According to Dayan,

[these] *disabilities* are made indelible through time in fictions of law, law words that wield the power to transform. [These] residues of terror are never really dead and gone but, through the terms of law, survive and always find new bodies to inhabit, new persons to target. ... Disfigured as persons, they are then judged outside the law's protection or most susceptible to its violence.¹⁰³

more on the play between lawyers and doctors in determining disability in the courtroom, refer to Blumenthal, *Law and the Modern Mind*.

⁹⁹ There is a growing amount of disability legal studies literature, for example see, Mor, "Charity, Welfare, and Warfare"; Kanter, "The Law"; Sagit Mor, "The Meaning of Injury: A Disability Perspective," in *Injury and Injustice: The Cultural Politics of Harm and Redress*, ed. Anne Bloom, David M. Engel, and Michael McCann (Cambridge, UK: Cambridge University Press, 2018), 27–49; Belt and Dorfman, "Disability, Law, and the Humanities."

¹⁰⁰ Collin Dayan, "Legal Slaves and Civil Bodies," *Nepantla* 2, no. 1 (2001): 3–39; *The Law Is a White Dog: How Legal Rituals Make and Unmake Persons* (Princeton, NJ: Princeton University Press, 2011). ¹⁰¹ Dayan, *The Law Is a White Dog*, 10.

¹⁰² Davan, 11 (emphasis my own).

¹⁰³ Dayan, 13 (emphasis my own).

Dayan's conceptualization of how legal rituals make and unmake a subject's personhood is messy. On one hand, she completely elides the larger conversation of dis/ability and how it intersects with all the other marginalized groups she claims the law "disables." While Dayan's use of "disability" and her elision of dis/abled people in this study does not seem nefarious, it does illustrate how the law (and, in turn, lawyers and legal scholars) understands disability as a static, permanent, and negative category. More broadly, the disappearance of dis/ability in studies about oppressive systems—intentional or unintentional—remains commonplace and particularly glaring as conversations regarding intersectionality and diversity, equity, and inclusivity within both academia, government, and society continue to grow in popularity.

Disability, as a legal framework, has historically not incorporated dis/abled people, nor the unique experiences resulting from living with a non-normative bodymind.¹⁰⁴ Instead, the legal disability framework focuses on what is deficient, impeded, and/or missing. It is crucial to make apparent the frame which the law understands disability in order to examine the commitment trials of PSSH inmates, but also in scrutinizing contemporary cases regarding deinstitutionalization and accommodations in the United States.

On the other hand, Dayan's argument for how legal ritual not only dehumanizes people but also *naturalizes* and *perpetuates* that dehumanization remains useful for the examination of institutionalization and performativity. In this way, performativity—role,

¹⁰⁴ My language of disability "frames" comes from a law review symposium organized by Karen M. Tani and Jasmine E. Harris and hosted by the University of Pennsylvania Law School on February 18-19, 2022. To view a YouTube playlist of those proceedings, access the following link: <u>https://www.youtube.com/playlist?list=PLJBnPepsYGDRPn3sHK5Cc7EfyMpg8yzp-</u>.

repetition, citation, and iteration-provides law with an ability to naturalize and perpetuate dehumanization.¹⁰⁵ Dayan also points to the law's engagement of speech acts in legal rituals to give words "the power to transform."¹⁰⁶ In the process of making institutionalized disabled subjects, legislation provided medical-juridical authorities with the authority to *speak* to whether a person was disabled or not. As performance studies scholar Joshua Chambers-Letson describes, "the law is also performative, which is to say that the law is structured by series of speech acts that produce a *doing* in the world. But this *doing* ties the performativity of the law to performance insofar as legal performativity is given form when the law manifests itself in and on the body through expressive acts."¹⁰⁷ For example, what occurred in the courtroom created a process in which nondisabled people used words and legal rituals to transform dis/abled people into institutionalized subjects while simultaneously removing their personhood. This process further highlights the relationship between law and performance, and how rhetorical legal performatives constitute and reconstitute institutionalized disabled subjects through rehearsal and repetition.

Legal Performatives

One key element of the PSSH commitment trials is that the person on trial was often physically absent from the courtroom. Strikingly, however, much of previous performance studies scholarship on the topic of performance and legal subjectivity

¹⁰⁵ Butler, "Performative Acts and Gender Constitution."

¹⁰⁶ Dayan, *The Law Is a White Dog*, 13.

¹⁰⁷ Joshua Takano Chambers-Letson, A Race So Different: Performance and Law in Asian America (New York, NY: New York University Press, 2013), 6 (emphasis original).

requires a materially present body. For example, Chambers-Letson analyzes how law creates a system of racializing norms that becomes enforced through the performances of Asian American bodies as they go about embodied acts of daily life.¹⁰⁸ Chambers-Letson explains that "legal performatives...produce knowledge about racial difference" and "compel and inspire Asian Americans to perform in response to and for the law..."¹⁰⁹ In turn, the law and the racialized standards it enforces, compels "this body to perform in a fashion that fosters the maintenance of dominant norms."¹¹⁰ While, as Act II highlights in its examination of performances of habilitation, the use of performance to maintain dominant norms is especially pertinent in the institution, what remains essential to this study is how law enforces and conforms bodies to norms. Nevertheless, Chambers-Letson's conclusions rely on analyzing how the law governs bodies as they materially exist in space, while participating in some form of embodied action. In contrast, my research exposes how law and performance not only "compel[ed] and inspire[ed] [disabled] Americans to perform in response to and for the law," but also materially created a subject without the person even being present.¹¹¹ They then effectively eliminated that subject through social death—or when society does not consider a group of people as fully human—resulting from segregation in the institution.¹¹² The power of rhetorical legal performatives to conjure absent performances of disabled appearance is essential to understanding the ramifications of the PSSH commitment trials. These trials

¹⁰⁸ Chambers-Letson.

¹⁰⁹ Chambers-Letson, A Race So Different, 213.

¹¹⁰ Chambers-Letson, A Race So Different, 214.

¹¹¹ Chambers-Letson, 213.

¹¹² For more on social death, see Orlando Patterson, *Slavery and Social Death: A Comparative Study* (Cambridge, MA: Harvard University Press, 1982); Joshua M. Price, *Prison and Social Death: Critical Issues in Crime and Society* (New Brunswick, NJ: Rutgers University Press, 2015).

set a precedent where nondisabled people used rhetorical legal performatives to effectively "make up"¹¹³ dis/abled people and their supposed disabling conditions, while simultaneously removing their personhood.

Making Up Disabled Children

This dissertation begins by examining the trials for two reasons: first, because they relate to the commitment process at the PSSH, second, because of the subjects on trial: children. The significance of children on trial in relationship to disability illuminates how disability—as an educational, legal, medical, and societal category—became constructed as immutable and defined the institutionalized disabled subject's life-course as frozen and/or truncated. Further, precisely because they were children on trial, the later citations, and iterations of performances of disabled appearance situated dis/abled people in positions of inferiority. One of the clearest examples of how this continues today is in how nondisabled advocates will say a dis/abled person "is 35 years old but acts like a 5-year-old." Former PSSH employees often refer to their former charges regardless of age as the "children" they cared for.

Under American family law, children are not legal subjects, but still, they possess legal subjectivity.¹¹⁴ Even so, parents have almost total authority to deem what is "best" for their child.¹¹⁵ Further, a nondisabled child's legal disqualification ends after they turn a certain age. The narratives of the children committed to the PSSH, and other

¹¹³ Ian Hacking, "Making Up People," in *Reconstructing Individualism*, ed. Thomas Heller, Morton Sosna, and Wellberry, David E. (Stanford, CA: Stanford University Press, 1986), 161–71.

¹¹⁴ Robert W. Gordon, "Critical Legal Histories," Stanford Law Review 36 (1984): 57–125.

¹¹⁵ Martin Guggenheim, *What's Wrong with Children's Rights* (Cambridge, MA: Harvard University Press, 2005), 44.

institutions, however, remain unique. They occupied two distinct yet compounding categories of legal disqualification: their biological age *and* their status as institutionalized disabled subjects. By declaring these children disabled subjects, the court curtailed their eligibility for citizenship, and eliminated their humanity and personhood by excluding them from "normal," non-disabled society. In this way, the ruling from these trials dilated juridical time and prolonged institutionalized disabled subjects' legal disqualification often until death.

I now turn to the evolution of institutional philosophy by examining the institutional legislation in Pennsylvania to illustrate how this legal performative process of institutional subject-making occurred. By examining the progression of institutional thought alongside the creation of institutionalization laws, this section shows how this legislation set the stage for institutional authorities to use rhetorical legal performatives to create institutionalized disabled subjects through compelling performances of disabled appearance.

Situating Institutionalization & Creating the Disabled Subject in Pennsylvania Legislation

Offering a historical analysis of the legislation that established the Commonwealth's first institution for the feebleminded in 1893 highlights the evolving philosophy of custodial institutionalization in the Commonwealth of Pennsylvania and the nation. An examination of eugenics' role in the shifting institutional philosophy as exhibited in three pieces of Pennsylvania legislation: the Establishing Act of 1903, the Act of 1913, and the Mental Health Act of 1923 shows the progression of the concept of feeblemindedness and how the institutional philosophy in the United States shifted from education to segregation. Additionally, this legislation also laid the foundation for rhetorical legal performatives to carry declarative power. These pieces of legislation described the necessary circumstances in which performances of disabled appearance met the satisfactory burden of proof that resulted in making someone an institutionalized disabled subject.¹¹⁶

Performing Pupil: The Establishing Act of 1893 & a Historical Overview of the Education of the Feebleminded in Early American Institutions

On June 3, 1893, the General Assembly established the State Institution for the Feeble-Minded of Western Pennsylvania in Polk, Pennsylvania (eventually the Polk State School & Hospital, and today, still operating as the Polk Center).¹¹⁷ The Commonwealth designated this new institution "for the accommodation of the feebleminded *children* of Western Pennsylvania."¹¹⁸

Prior to the 1870s, people deemed feebleminded often worked on family farms where relatives could supervise a dis/abled child or adult.¹¹⁹ But as industrialization

¹¹⁶ Austin, *How to Do Things with Words*, 8.

¹¹⁷ Pa. Law, *The Establishing Act of 1893*, Pub. L. No. 256.

¹¹⁸ *The Establishing Act of 1893*, §1, 289, emphasis added. By the time the *Establishing Act of 1893* passed into law, the community of doctors and academics devoted to the care for, and study of, feeblemindedness had established themselves within the larger medical and scientific community and institutional authorities made a clear argument for the role institutions served in aiding society. ¹¹⁹ Jirik, "American Institutions," 2.

resulted in more Americans leaving the farm for urban centers, the demands on families with dis/abled children or adults in the household changed. The demands of hourly-wage employment meant that families could not remain home to care for their dis/abled relatives. With few community resources available for the care for and education of people deemed feebleminded, custodial institutions served as the primary option for specialized care for dis/abled people. While mutual aid societies and charities existed by the end of the nineteenth century, they did not offer specialized care for people with multiple care needs, and little to no community services were available for families. As disability historian Katrina N. Jirik describes "Institutions for the feeble-minded, as sites that provided care, were clearly a response to the perceived societal desire to 'do something' about feeble-mindedness...What that something was, though, changed over time."¹²⁰ In the years before the American Civil War, custodial institutions educated school-aged children and returned them to their families to work on the farm. Following the War, and largely necessitated by severe funding cuts from state legislatures,¹²¹ institutional philosophy shifted away from providing vocational education to pupils for their eventual release to teaching inmates skills to maintain the institution and conducting research on inmates to understand the etiology of feeblemindedness.

Interestingly, the 1893 Act does not provide criteria for what it meant to be classified as "feebleminded." Instead, this legislation illustrates a pattern found in both the 1903 and 1913 legislation, where feeblemindedness was not defined by lawmakers, but left up to the expertise of medical professionals. By 1893, institutional advocates

¹²⁰ Jirik, 3-4.

¹²¹ Jirik, 140-50.

understood feeblemindedness to exist in three broad diagnostic categories: "superior grades," "imbeciles," and "idiots."¹²² Superintendents at this time largely assumed they would release only those deemed superior grade back into society, while imbeciles and idiots would spend their lives in the institution—imbeciles being trained to provide care for the "lower-grade" idiots.¹²³ This act of forcing persons into certain named categories of disability functioned as a performative act of power that forced a predetermined ontological and legal status upon that person. The linguistic performative act of naming a subject as disabled, coupled with the authority given by the legislation, afforded institutional representatives, as authorities of the state, the power to transform human beings into institutionalized subjects. Even so, most institutional advocates prior to the twentieth century believed feebleminded persons (especially children) could still receive meaningful care and education that would result in their return to society.

This focus on educational programming resulted in the creation of separate curricula for each diagnostic category. The Establishing Act of 1893 (Polk) reflected these pedagogical separations, stating, "this institution ... shall provide separate classification of the numerous groups embraced under the terms, idiot and imbecile or feeble-minded. Cases afflicted with either epilepsy or paralysis shall have due proportion of space and care in the custodial department."¹²⁴ Furthermore, the 1893 Act separated the spaces for learning and the spaces for existing, by dividing the institution into "the

¹²² Jirik, 86.

¹²³ Chamberlain, "Receiving, Sorting, and Disposing of Children."

¹²⁴ Pa. Law, *The Establishing Act of 1893*. It bears highlighting that in §15, the legislation makes provision for a select number of feebleminded adults. Additionally, while I do not have documentation that Elwyn Superintendents Isaac Kerlin or Martin Barr directly influenced legislative language or intent for Polk and Pennhurst, I believe they likely did. Researchers interested in this connection would benefit by examining the Elwyn's Annual Reports or the proceedings from the State Association for Superintendents during this period.

educational department" and the "custodial department."¹²⁵ At Polk, and other institutions such as the PSSH, the educational department comprised a school, gymnasium, farm, and laundry. This department taught institutionalized pupils vocational skills designed to make them productive both inside and outside the institution. These skills included things such as shoemaking, printing, broom and furniture making, sewing, and homemaking, among others. At Polk, the custodial department consisted of sixteen custodial cottages that provided sparse living spaces for the pupils to receive rudimentary care. The spatial design and layout for institutions derived largely from the curricula developed to provide vocational training for people deemed feebleminded.¹²⁶

The combination of the spatial design of institutions, alongside the development of early institutional educational programming, illustrated one of the primary functions of institutions: to instill inmates with the governing norms of "normal," nondisabled society through acts of social performance. Early institutional authorities, such as Edward Sequin,¹²⁷ designed curricula for training children deemed feebleminded, focusing on basic primary education and agrarian and industrial vocational skills.¹²⁸ Jirik describes this programing explaining:

...superintendents considered educational services, somewhat broadly defined, as the primary function for institutions. ... Each category was to have a different program plan based on the work of Seguin. The focus on

¹²⁵ Pa. Law, *The Establishing Act of 1893*.

¹²⁶ Additionally, Thomas Kirkbride, the former Superintendent of the Pennsylvania Hospital, developed an architectural design for institutions that became standard practice for both asylums and institutions, known as the "Kirkbride Plan." This design emphasized the placement of institutions in rural areas located just outside of urban centers with plenty of windows and specific architectural layouts to aid habilitation. For more see, Tomes, *A Generous Confidence*; Carla Yanni, *The Architecture of Madness: Insane Asylums in the United States* (Minneapolis, MN: University of Minnesota Press, 2007).

¹²⁷ Edward Seguin, *Idiocy: And Its Treatment by the Physiological Method* (New York, NY: William Wood & Co, 1866).

¹²⁸ In a rather ironic twist, this curriculum once intended for "idiotic" institutional subjects now exists today in the form of Montessori pedagogy.

the superior grades was to develop personal care and vocational skills so they could be discharged back to their families in five or ten years as functional members of society. Imbeciles were candidates for lifetime care as their skill attainment would not rise to the level where they could function without adult supervision. Thus, they should be taught skills of use to the institution. The final group, the idiots, would not benefit from education or industrial training. As they required lifetime care, their programming should consist of amusements, exercise, and the development of good habits. However, most of those admitted to the institution were those seen benefiting from the programming, not imbeciles or idiots.¹²⁹

In this way, both institutional curricula and spaces functioned to reinforce expectations of what rehabilitated disabled subjects *could* do through performance. Performance studies scholar Shannon Jackson argues in her work on theatre and American social reform that "the role of spaces (such as the configurations of rooms and furniture) informed bodily adjustments and reinforced bodily disciplines."¹³⁰ In this way, institutional educational programming reinforced the bodily disciplines of the pupils, and the type of spaces, like the family farm or the custodial institution, that those bodies could function within.¹³¹ Early institutions served to discipline their pupils in nondisabled norms through discrete social performances of education and labor. In addition to nondisabled educational and labor norms, class played a predominant role throughout the history of institutionalization, as state-operated institutions also provided significant support to families who could not afford to properly care for their dis/abled family members.

The Establishing Act of 1893 highlights another aspect in the evolution of institutional care: families' need for care supports and increased state welfare programming. The General Assembly granted the State Board of Public Charities and the

¹²⁹ Jirik, "American Institutions," 86-87.

¹³⁰ Shannon Jackson, "Civic Play-Housekeeping: Gender, Theatre, and American Reform," *Theatre Journal* 48, no. 3 (1996): 356.

¹³¹ Jackson, 340.

Board of Trustees of Polk the power to determine what the price of admission was, and to what extent families had to pay.¹³² In turn, courts investigated and certified the parent(s)', or *guardian ad litem*'s, ability to pay for the services rendered by the institution. The burgeoning social welfare mechanism of institutionalization became especially important as America moved to an urban wage economy and families could not afford to forfeit their hourly job to stay home and care for their dis/abled children.¹³³

The role of families also proved significant in who received preferential admission to institutions. The 1893 legislation placed preference for what types of families or caring situations received preferential treatment for institutionalization. This hierarchy for admission preference highlighted both the institutional authorities' and lawmakers' desire to educate institutional pupils. The logic being that with an intact family unit to return to, the habilitated pupil would have the most potential to contribute to society and live a meaningful life. Prospective institution pupils with both parents living together would receive top priority for admission. Admission preference would then move to children with only one parent living at home. These two categories required permission from the child's parents. Preference would then move to those with a guardian, followed by an orphanage superintendent. Prospective admits from "any other institution or asylum where children are cared for" were least preferred among lawmakers.¹³⁴ These last three categories did not require parental consent to become

 ¹³² Pa. Law, *The Establishing Act of 1893*, §16, 292; Pa. Law, *The Establishing Act of 1903*, §15, 447.
 ¹³³ For more on class, early social welfare programming, progressivism, eugenics, economics, and race, see Thomas Leonard, *Illiberal Reformers: Race, Eugenics, and American Economics in the Progressive Era* (Princeton, NJ: Princeton University Press, 2016). While Leonard does not explicitly address disability in his analysis, his analysis proves useful for understanding the power socio-economic status played in early eugenic programming in the United States.

¹³⁴ Pa. Law, *The Establishing Act of 1893*, §11, 291.

institutionalized.¹³⁵ The reality of early social supports, however, did not match the intention. Orphanages and county almshouses faced significant overcrowding, and as Americans became more aware of state-funded institutional care, the waiting lists for admission continued to grow.

By 1900, without adequate social support, state-funded institutions provided the only option offering specialized care for American families who could not afford to care for their dis/abled children at home. Unlike private institutions, such as the Pennsylvania Training School for Feeble-Minded Children (currently operating under the name Elwyn, Inc.), in Elwyn, Pennsylvania, which required most applicants to pay for their services, state institutions allowed families to pay what they could. Charity organizations such as the National Conference of Charities and Corrections launched campaigns promoting the awareness of care services provided by state-funded institutions to prevent pauperism. The thinking being that if the disabled child was institutionalized, the parent(s) could work instead of relying on charity in order to supervise their child. While not a direct objective of state institutions for people deemed feebleminded, charity reformers saw institutions as a more suitable option to curb pauperism than overcrowded almshouses or jails because of the education the child could receive. Disability and labor historian Sarah F. Rose notes how this awareness came with an unexpected result, "Charity reforms intended to prevent dependency on public aid... had inadvertently led asylums to preferentially admit people who could not easily be returned home."¹³⁶ As awareness grew, so did the influx of admission applications, especially from middle- and working-

¹³⁵ Establishing Act of 1893, 291.

¹³⁶ Sarah F. Rose, *No Right to Be Idle: The Invention of Disability, 1840s-1930s* (Chapel Hill, NC: The University of North Carolina Press, 2017), 88-89.

class families, who had limited ability to provide care to their dis/abled family members. Institutional philosophies slowly shifted as a growing emphasis on admitting custodial cases further stressed the rapidly filling institutions for the feebleminded.

By the early decades of the twentieth century, the combination of growing awareness of state institutions, immigration, compulsory education laws, and the industrialization of American society resulted in a massive influx of institutional populations. As the nation switched from an agrarian-labor market to an urban, wagebased market, jobs moved from farms to cities. In turn, superior grade pupils released from institutions skilled in agrarian labor held less opportunity to find work in an urbanized society and, therefore, needed lifelong custodial care. Rose explains that, "Since most superintendents, lawmakers, and charity officials did not fully grasp why it became so difficult to return those formerly termed 'pupils' to their families, asylum directors ... saw few alternatives other than expanding their institutions to serve — and in many cases, employ — a permanent custodial population of *inmates*."¹³⁷ This switch from pupil to inmate, and specifically what institutionalized subjects *did* in the institution, reveals how the combination of performance, law, and institutional life defined feeblemindedness as something ontologically and teleologically negative.

¹³⁷ Rose, No Right to Be Idle, 51.

From Pupil to Inmate: The Establishing Act of 1903, Eugenics, & the Stigmata of Disability

Eugenics and Institutional Philosophy in Pennsylvania in the Early 1900s

The devolution of pupil to inmate in Pennsylvania's institutional philosophy became apparent through the rhetoric of institutional advocates in the Commonwealth during this period. This linguistic shift not only repositioned dis/abled people from learners to carceral subjects, but it also fortified disability as nondisabled society's Other. As historian Dennis B. Downey explains, many physicians "promoted an ideology of care in turn-of-the century Philadelphia that brought physicians, social workers, psychologists, public hygiene proponents, and politicians into a municipal alliance to combat impediments to social progress."¹³⁸ With an 1890 federal census identifying Pennsylvania as having the largest population of people deemed feebleminded,¹³⁹ feeblemindedness became the target of what Philadelphia physician Charles Frazier, deemed "The Menace of the Feebleminded."¹⁴⁰ Furthermore, institutional experts, such as Elwyn superintendent Martin W. Barr, implored his fellow superintendents, in a 1902 article in the field's *Journal of Psycho-Asthenics*, to stop educating inmates in the hope of releasing them and, instead, to focus on lifelong institutionalization,

I believe a consensus that abandons the hope long cherished of a return of the imbecile to the world. ... Indeed, I think we need to write it very large, in characters that he who runs may read, to convince the world that by

¹³⁸ Dennis B. Downey, "The Idea of Pennhurst: Eugenics and the Abandonment of Hope," in *Pennhurst and the Struggle for Disability Rights* (University Park, PA: The Pennsylvania State University Press, 2020), 19.

¹³⁹ Downey, 18.

¹⁴⁰ Charles H. Frazier, "The Menace of the Feeble-Minded in Pennsylvania" (Philadelphia Public Charities Association, 1908).

permanent separation only is the imbecile to be safe-guarded from certain deterioration and society from depredation, contamination, and increase of a pernicious element.¹⁴¹

As chief physician in the second-oldest institution in the country, Barr's words brought significant influence, pushing others in the field to consider the importance of permanent custodial institutionalization. Barr's words laid the groundwork for the constellation of education, law, medicine, policy, and society to discursively create and enforce governing norms regarding feeblemindedness (and later disability). In this way, Barr's words functioned to set disability within what critical disability studies scholar Shelley L. Tremain calls, a "historically and culturally specific apparatus of power relations that effectively brings disability (and its naturalized antecedent, impairment) into being a problem."¹⁴² Barr's problem-based language perceived disability as not only nondisabled society's Other, but also a clear and present danger to the country that required immediate intervention and echoed eugenic concerns regarding other marginalized groups of people such as slaves,¹⁴³ immigrants,¹⁴⁴ and indigenous tribes.¹⁴⁵

The growing concern for the rising population of people deemed feebleminded in Pennsylvania (and the nation), coupled with Mendelism—an agriculture-science of hard hereditary that eugenicists used to argue feeblemindedness passed through family

¹⁴¹ Martin W. Barr, "The Imperative Call of Our Present to Our Future," *Journal of Psycho-Asthenics* 7 (September 1902): 5-6.

¹⁴² Shelley L. Tremain, *Foucault and Feminist Philosophy of Disability* (Ann Arbor, MI: University of Michigan Press, 2017), 48.

¹⁴³ Steven Noll, *Feeble-Minded in Our Midst: Institutions for the Mentally Retarded in the South, 1900-1940* (Chapel Hill, NC: The University of North Carolina Press, 1995).

 ¹⁴⁴ Baynton, *Defectives in the Land*; Jay Timothy Dolmage, *Disabled Upon Arrival: Eugenics, Immigration and the Construction of Race and Disability* (Columbus, OH: The Ohio State University Press, 2018).
 ¹⁴⁵ Susan Burch, "Dislocated Histories': The Canton Asylum for Insane Indians," *Women, Gender, and Families of Color* 2, no. 2 (2014): 141–62; *Committed: Remembering Native Kinship in and beyond Institutions* (Chapel Hill, NC: The University of North Carolina Press, 2021).

bloodlines as a recessive trait—led physicians and politicians to abandon "the hope long cherished" of rehabilitating institutional inmates back to society.¹⁴⁶ Instead, they publicly advocated for drastic measures to control the feebleminded menace. By preventing the reproduction of defective classes of humans through sterilization or marriage prohibition laws, this "municipal alliance" of law, medicine, and society could create a world without human defect. Barr's comments illustrate only one component of the growing eugenic campaign to stop educating people deemed feebleminded and remove them from society through institutionalization in Pennsylvania.

To curb the growing population of people deemed feebleminded, eugenic advocates in Pennsylvania also pushed for forced sterilization in the Commonwealth. For example, Elwyn performed the first documented sterilization of a person deemed feebleminded and performed the procedure at least 279 more times by 1900.¹⁴⁷ Elwyn's first superintendent, Isaac Kerlin, claimed to commit the first castration of a dis/abled person in 1889.¹⁴⁸ In an effort to legalize this practice in Pennsylvania's state-funded institutions, the General Assembly passed a bill in 1905, which allowed a "skilled surgeon" to "perform such operation for the prevention of procreation…" at any state institution in the Commonwealth. Governor Samuel Pennypacker, however, vetoed the bill nine days later.¹⁴⁹

¹⁴⁶ Superintendents and institutional authorities used this idea to push for sterilization, since they believed it was impossible to identify who carried the recessive "feeblemindedness" gene.
¹⁴⁷ Deumon, "Idea of Demphysical" 27

¹⁴⁷ Downey, "Idea of Pennhurst," 27.

 ¹⁴⁸ Julius Paul, "...Three Generations of Imbeciles Are Enough...": State Eugenic Sterilization Laws in American Thought and Practice (Washington, D.C.: Walter Reed Army Institute of Research, 1965), 604.
 ¹⁴⁹ Pa. Law, Act of March 21, 1905, cited in Harry Hamilton Laughlin, Eugenical Sterilization in the United States (Chicago, IL: Psychopathic Laboratory of the Municipal Court of Chicago, 1922), 35.

Seemingly aware of the slippery slope of eugenic philosophy, but not opposed to

the social welfare institutions provided to a "helpless class in the community",

Pennypacker warned lawmakers in his veto:

What is the nature of the operation is not described, but it is such an operation as they [institutional surgeons] shall decide to be 'safest and most effective.' It is plain that the safe and the most effective means for the prevention of procreation would be to cut the heads off the inmates, and such authority is given by the [proposed] bill to this staff of scientific experts. It is not probable that they would resort to this means for prevention of procreation, but it is probable that they would endeavor to destroy some part of the human organism. ... This bill, whatever good might possibly result from it, if its provisions should become law, violates the principles of ethics. These feeble-minded and imbecile children have been entrusted to the institutions by their parents or guardians, for the purpose of training and instruction. It is proposed to experiment upon them, not for their instruction. but in order to help society in the future. It is to be done without their consent, which they cannot give, and without the consent of their parents or guardians, who are responsible for their welfare. ... This bill assumes that they cannot be so instructed and trained. Moreover, the course it is proposed to pursue would have a tendency to prevent such training and instruction. ... A grave objection is that the bill would encourage experimentation upon living animals, and would be the beginning of experimentation upon living beings, leading logically to results which can readily be forecasted. ... To permit such an operation would be to inflict cruelty upon a helpless class in the community, which the State has undertaken to protect.¹⁵⁰

Strikingly, unlike many institutional advocates of the time, Pennypacker understood institutional philosophy of use as providing inmates with "training and instruction." Further, Pennypacker emphasized the importance of protecting the inmates' ability to consent to treatment, and in turn, their humanity. As <u>Act II</u>'s examination of performances of institutionalized care and unethical experimentation on institutional inmates, neither lawmakers nor institutional authorities heeded Pennypacker's warning. The growing influence of eugenic philosophy championed by institutional advocates such

¹⁵⁰ Samuel W. Pennypacker and Commonwealth of Pennsylvania, "Vetoes: By the Governor, of Bills Passed By the Legislature, Session of 1905" (WM Stanley Ray, 1905), 25.

as Barr and Frasier became more apparent in the institutional legislation of the early twentieth century. This growing disregard for the humanity of institutional inmates and their ability to consent to treatment, along with the move from instruction to custodialization, marked the delineation between institutions of the early nineteenth century, and the monoliths of social death that came in the twentieth century.

The Establishing Act of 1903

Within only six years of opening, Polk already suffered from overcrowding and reported a waiting list for admission.¹⁵¹ To help relieve the burden, the General Assembly established the Eastern Pennsylvania State Institution for the Feeble-Minded and Epileptic, later the PSSH, in 1903.¹⁵² While the 1897 and 1903 legislation appear, at first glance, identical, slight deviations in the legislative language point to the changing philosophies regarding the purpose of institutions in the Commonwealth, and the nation, at the beginning of the twentieth century.

Unlike the legislation that established Polk, lawmakers expanded the target institutional population in the 1903 Act that established the PSSH to admit children *and* adults. Lawmakers also struck the section detailing admission preference based on parental status. While the legislation did not provide a rationale for why it struck this section, one can infer that the General Assembly desired to streamline the admission process so that the institution could receive more people, particularly adults.¹⁵³ The

¹⁵¹ The Journal House of Representatives of Pennsylvania's General Assembly does not mention the number of people awaiting admission at Polk.

¹⁵² Pa. Law, *The Establishing Act of 1903*, Pub. L. No. 424, § 10 (1903).

¹⁵³ I have searched for legislative proceedings, notes, and other documents to discover what discussion, if any, lawmakers had regarding the decision to strike this language, but have found none.

legislation stated that the PSSH would devote itself to "the care and maintenance of epileptics and idiotic and feeble-minded *persons* of Eastern Pennsylvania."¹⁵⁴ And yet, the primary word this 1903 Act used to describe the human beings placed in this new institution was "inmate." From its origin, the PSSH was a place of incarceration. There was no mention of the institutionalized persons' rights or recognition of their humanity, only that they were to be occupants of this singular place for an indefinite amount of time.

In addition to using carceral language to refer to the subjects committed to the PSSH, the Establishing Act of 1903 intentionally used broad terminologies to classify disability. The legislation states:

That this institution shall be entirely and specially devoted to the reception, detention, care and training of epileptics and idiotic and feebleminded persons, of either sex, and shall be so planned, in the beginning and construction, as shall provide separate classification of the numerous groups embraced under the terms "epileptics" and "idiotic" and "imbecile," or "feebleminded." Cases afflicted with epilepsy or paralysis shall have a due proportion of space and care in the custodial department.¹⁵⁵

No longer just for reforming children through vocational training and basic education, legislators and institutional advocates intended the PSSH to detain and maintain all people designated as "feebleminded." This language also provided room for the institutional authorities to exponentially expand the category of feeblemindedness employing performances of disabled appearance. As critical disability studies scholar, Tobin Siebers points out, "Oppression is driven not by individual, unconscious syndromes but by social ideologies that are embodied, and precisely because ideologies

¹⁵⁴ Pa. Law, *Act of May 15, 1903.* I shortened the language for space reasons. Both statutes feature identical language in those sections. Emphasis added.

¹⁵⁵ Pa. Law, Act of May 15, 1903.

are embodied, their effects are readable, and must be read, in the construction and history of societies."¹⁵⁶ In other words, as eugenicists pushed that feeblemindedness was "readable" to society through performances of disabled appearance in the doctor's office and rhetorical legal performatives in the courtroom, the medico-juridical parameters for what met the standard of feeblemindedness expanded, and so did the oppressive social ideologies against dis/abled people. As critical disability studies scholars Sharon L. Snyder and David T. Mitchell argue, eugenics "promoted a slanderous ideological violence against all categories of disabled people based on stigmatized physical, sensory, and cognitive characteristics."¹⁵⁷ Eugenicists defined characteristics using performances of disabled appearance, looking at bodies and judging everything from apparent dis/abilities to minute performances such as drooling, or nonapparent performances such as forgetfulness, as "signs" of feeblemindedness.¹⁵⁸

Spectating the Stigmata of Degeneracy and Performances of Disability

By the twentieth century, eugenicists morphed and expanded the already ubiquitous category of feeblemindedness to focus on more outward, apparent performances of disabled appearances. Speaking to the United States Congress on March 13, 1903, to establish a "laboratory for study of criminal, pauper, and defective classes," Arthur MacDonald, a specialist for the Bureau of Education, coined the phrase "Stigmata of Degeneracy." This new concept linked what MacDonald believed were appearance-based

¹⁵⁶ Siebers, *Disability Theory*.

¹⁵⁷ Sharon L. Synder and David T. Mitchell, *Cultural Locations of Disability* (Chicago, IL: The University of Chicago Press, 2006), 80.

¹⁵⁸ For more on how eugenicists determined qualities of feeblemindedness, see Dolmage, *Disabled Upon Arrival*; Rembis, *Defining Deviance*.

qualities of disability, with a predisposition for deviancy, or the "permanent inclination to immorality and maliciousness."¹⁵⁹ MacDonald understood bodily appearance, such as facial and bodily asymmetry, as clear signs of feeblemindedness. Language like the Stigmata of Degeneracy points to how nondisabled doctors and educators assumed that supposedly outward performances of disabled appearance distinguished feebleminded people from everyone else.

MacDonald's concept of the feebleminded person with the stigmata of degeneracy is the antithesis of what critical disability studies scholar Rosemarie Garland-Thomson calls the "normate," or "the social figure through which people can represent themselves as definitive human beings."¹⁶⁰ In creating the stigmata of degeneracy, MacDonald employed a performance-based tool to assert the nondisabled bodymind in a position of power over the dis/abled bodymind through bodily appearance. In doing so, feeblemindedness became identifiable and, thereby, knowable through aesthetic performances of a bodymind. Many superintendents, physicians, and researchers like MacDonald, employed this performed appearance of disability to "prove" a person's diagnosis and prognosis.

 ¹⁵⁹ Arthur MacDonald, "Moral Stigmata of Degeneration," *The Monist* 18, no. 1 (January 1908): 111–23.
 ¹⁶⁰ Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York, NY: Columbia University Press, 1997), 8.

PLATE XXVIII

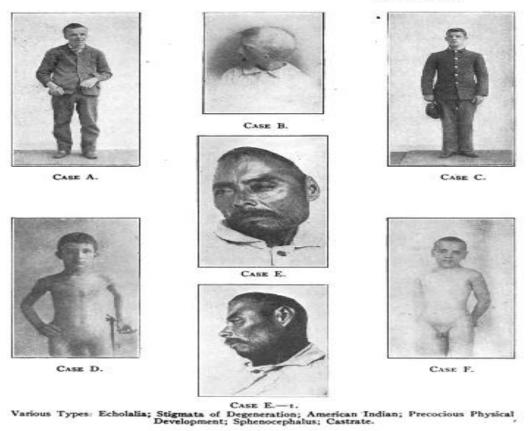
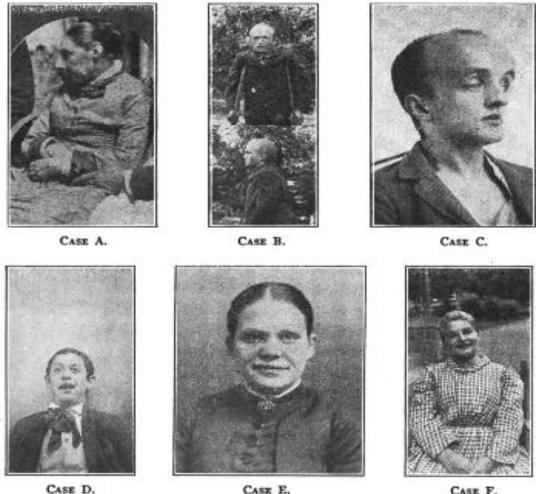


Figure 1: A photocopy of "Plate Twenty-Eight" from Martin Barr's Types of Mental Defectives (1920).

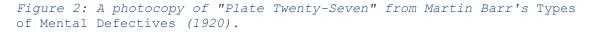
Elwyn Superintendent Martin W. Barr was one of the most prolific users of the performed appearance of disability, and the stigmata of degeneracy. Barr photographed many Elwyn inmates, most of them children, naked at admission and other points during their institutionalization, to document the various types of "mental defectives."¹⁶¹ These two plates (Figures 1 & 2) come from a book Barr published in 1920, in which he discussed the "illustrative cases" of the stigmata of degeneracy.

¹⁶¹ For more on the photographing of institutional inmates, see Katherine D. B. Rawling, "The Annexed Photos Were Taken Today': Photographing Patients in the Late-Nineteenth-Century Asylum," *Social History of Medicine* 34, no. 1 (2019): 256–84.

PLATE XXVII



CASE D. CASE E. CASE F. Various Types: Microcephaly; Hydrocephalus; St'gmata of Degeneration; Adenoma Sebaceum; Pilosis.



By calling them "illustrative cases," Barr intended these photographs to educate other medical professionals on what to "look for" when identifying people who fell under the category of feeblemindedness. These photographs functioned as citations while the bodies themselves acted as representations of the stigmata of degeneracy. Like Jean Martin Charcot, a French neurologist who used photography to study the apparent signs of "hysteria," Barr used photography to capture these bodies and their supposed performances of disability. In doing so, Barr became what performance and disability studies scholar Petra Kuppers describes as "director and manager of bodies whose symptoms were made to speak loudly and clearly of invisible conditions."¹⁶² Each plate—consisting of six different subjects—featured both headshots and full-body shots of inmates. While Barr provided short elaborations on each "case," those elaborations mentioned nothing of the inmate's humanity, personality, or whether they consented to being photographed. This lack of contextual information regarding who the person was or what they were like suggests Barr did not regard them as fully human. Instead, they were mere objects of study.

Further, Barr captured sparse, minimalistic scenes through the photographs. Blank walls served as the backgrounds for most of the photographs, suggesting Barr took the photos in the examination office, while a few of the photographs appear as if Barr took them on the institution's grounds. Finally, each featured different inmates—children and adults, men and women, White and Indigenous bodies, genitally intact and castrated—in different positions. The lack of a universal "pose" suggests that the subjects received little to no explanation of the purpose of the photographs. The sparse backgrounds and lack of purposeful direction in the photographs as citational imply Barr assumed that the "stigmata of degeneracy" was obviously apparent to a trained medical observer. As Chamberlain explains, the expansion of what constituted feeblemindedness allowed, "superintendents to assert their authority as diagnosticians who possessed specialized

¹⁶² Petra Kuppers, "Bodies, Hysteria, Pain Staging the Invisible," in *Bodies in Commotion: Disability and Performance*, ed. Carrie Sandahl and Phillip Auslander (Ann Arbor, MI: University of Michigan Press, 2005), 149-50.

knowledge that lay people and non-specialist physicians lacked."¹⁶³ By using photography, Barr combined the backdrop of a medical environment with the medium of the camera to surveil bodies deemed disabled. In doing so, Barr created a precedent in which assumed disabling conditions appeared naturally without provocation. Medical doctors could assess a person's disabilities not through rigorous assessments of bodyminds in motion or action, but through visually observing and categorizing the material body and mind. This diagnostic not only relied on the ability of sight (thus preferencing normatively appearing bodyminds) to classify disabling conditions, but it also made the dis/abled person a passive object of observation. This further revoked a dis/abled person's agency in expressing how they identified as dis/abled, and/or how their perceived dis/abling conditions effected their day-to-day lives.

Growing Emphasis on Eugenics & Testing

With eugenic philosophy on the rise by the 1910s, institutional authorities developed and advocated for more "scientific" forms of categorization and diagnostics; thus, resulting in a wider target population for institutions. For example, Henry Goddard of the Vineland Training School in Vineland, NJ, adapted Alfred Binet and Theodore Simon's IQ Test. Goddard studied what he called "morons," or feebleminded people who could pass as nondisabled.¹⁶⁴ Eugenic rhetoric loathed and warned of the "passable" quality of feeblemindedness, especially for those categorized as morons. In turn, as disability studies scholar Allison C. Carey argues, eugenicists:

¹⁶³ Chamberlain, "Receiving, Sorting, and Disposing of Children: Institutions, Education, and Feeblemindedness in Progressive America," 48.

¹⁶⁴ Henry H. Goddard, *The Kallikak Family: A Study in the Heredity of Feeblemindedness* (New York, NY: Macmillan Company, 1921).

constructed categories of 'feebleminded' and 'fit' that were sharply demarcated, with rigid expectations regarding the behavior and abilities of people with disabilities, static views of disability that denied its dynamic nature, and intense inequality, all of which heightened the relevance of passing. To then prevent passing, they relied heavily on extensive systems of identification and segregation. ... Feeblemindedness served as a conceptually advantageous focal point for the politics of the eugenics movement rooted in genetics and biology; it indicated biological, social, and moral inferiority; and it justified medical treatment or control and legal and social restrictions.¹⁶⁵

This emphasis on categorization, the relevance of passing, and the justification of medical treatment and legal restrictions by eugenic-minded institutional authorities further moved institutions away from educating to providing custodial care. This shift resulted in discourse about disability shifting from one of human capacity—through education a disabled person could prove useful to nondisabled society—to discourse about ontology—a disabled person was a different category of humanity who needed to be eliminated from society. This shift further fortified dis/abled people as nondisabled society's Other.

This history of eugenics, the stigmata of degeneracy, and performances of disabled appearance provide important context regarding the motivations for creating the PSSH and the change of legislative language in the Establishing Act of 1903. This history also proves useful in examining the legislation that followed.

¹⁶⁵ Allison C. Carey, "The Sociopolitical Contexts of Passing and Intellectual Disability.," in *Disability and Passing: Blurring the Lines of Identity*, ed. Jeffrey A. Brune and Daniel J. Wilson (Philadelphia, PA: Temple University Press, 2013), 142–66.

PA Act of June 12, 1913, No. 328

In 1911, the Committee on the Segregation, Care and Treatment of Feeble-Minded and Epileptic Persons in the Commonwealth of Pennsylvania recommended that the General Assembly pass legislation streamlining the process of commitment. The Committee urged lawmakers to define "insanity and feeblemindedness as forms of mental unsoundness", place "all indigent mental defectives under the care of the State..." and require courts to commit said defectives to an institution.¹⁶⁶ The General Assembly passed the Act of 1913 on June 12 which required a court commitment for people deemed feebleminded.¹⁶⁷

Before 1913, institutional legislation in the Commonwealth of Pennsylvania gave parents or the *guardian ad litem* the power to admit a child to the institution without court intervention. As stated by Pennsylvania's Deputy Attorney General, William M. Hargest, in a letter to the PSSH's superintendent in 1919, "the Act of 1913 changed the scheme for admission of inmates and provided that they should be admitted upon the commitment thereto by the Courts of Quarter Sessions of certain counties upon the petition" of parents, guardian, next of kin, or county/local officials. This amended legislation placed the authority to commit disabled subjects to the institution with the court, not just through the application from the parents and guardians.

¹⁶⁶ Joseph S. Neff, "The Report on the Commission to the Honorable General Assembly of the Commonwealth of Pennsylvania" (Harrisburg, PA: Commission on the Segregation, Care, and Treatment of Feeble-Minded and Epileptic Persons in the Commonwealth of Pennsylvania, 1915), 55. The Committee also advocated for the General Assembly to enact legislation restricting dis/abled people from marrying and stipulated the custodial institutionalization of individuals grappling with various forms of drug and alcohol addiction. Additionally, the Committee drafted and appended proposed amendments to the Act of 1893 (pertaining to Polk) and the Act of 1903 (pertaining to Pennhurst), thereby broadening the institutions' purview and further explicating the commitment process.

¹⁶⁷ Pa. Law, Act of June 12, 1913, Pub. L. No. 328 (1913).

Giving the courts authority to commit people to institutions generated a two-fold dynamic. First, this legislation solidified the intertwined relationship between education, law, medicine, performance, and policy. As a rhetorical legal performative, the legislation provided medical doctors the power to make judgments, which rested on observations made regarding the person's outward appearance and their compliance with nondisabled societal behaviors. These judgments were performative in that they did not simply describe something about the person in question; they resulted in the institutionalization of the person deemed feebleminded and, thereby, irrevocably altered their life course. At the same time, they hardened the criteria exhibited by the supposed feebleminded person and compelled apparent, and thereby, citable norms that materialized disabled subjects. The legal statement of "you are hereby committed thereto as inmate of the Pennhurst State School & Hospital" became a statement of ontological fact about the person. Unlike the previous legislation which only mentioned children being eligible for institutionalization, this legislation helped to create a wider population of those deemed worthy of commitment, by expanding it to both children and adults. Fueled by eugenics, institutional authorities and lawmakers expanded the criteria for who was eligible for institutionalization over the following decade.

Eugenics, The Feebleminded Menace, and the Mental Health Act of 1923

While the Act of 1913 mandated court commitment for people deemed feebleminded, it kept the commitment process for insanity and feeblemindedness distinct. In 1923, during the height of the eugenics movement, the General Assembly enacted the Mental Health

Act, the first legislation in the Commonwealth that detailed both the commitment of persons labeled as insane and those labeled as feebleminded.¹⁶⁸ The Mental Health Act of 1923 conferred on the courts the authority to commit children and other people deemed feebleminded or insane involuntarily to institutions such as the PSSH. This legislation stated the parameters that allow institutional representatives to employ rhetorical legal performatives to make an individual into an institutionalized disabled subject, explaining that:

 \dots If it shall be made to appear to the said court or judge that the said person is mentally defective and a proper subject for commitment \dots and that best interests of the said person or the safety and welfare of the public require such commitment, the court shall make an order committing such mentally defective person to the school named in the petition, and direct his removal thereto by a proper officer or person...¹⁶⁹

This legislation accomplished three things: first, it required that evidence (a completed application form and the testimony of a practicing physician) presented to the court adequately meet a standard of proof. Second, in the pursuit of that standard, it compelled the lawyers, doctors, and judges to produce (or linguistically conjure) a performance of disabled appearance from the person in question. In doing so, this legislation extinguished the agency of the dis/abled person, while it also simultaneously required someone other than the dis/abled person to produce their disabled subjectivity ("shall be made to appear"). Third, this legislation allowed the legal counsel, the parent, *guardian ad litem*, and/or the medical expert the freedom to use speech acts to cite the qualities that made that person *appear* disabled, thus making their disability material. Medical and

¹⁶⁸ Pa. Law, *Mental Health Act* (1923), 1007.

¹⁶⁹ Mental Health Act, 1007. Emphasis added.

juridical authorities, therefore, used rhetorical legal performatives to argue that a person's everyday performance established them as a "proper subject for commitment."

Once categorized as feebleminded, the legislation allowed the courts to place disabled subjects into a state of legal exception. Legal exception references a moment, during a crisis, in which a sovereign suspends juridical order—or in the case of the United States, the Constitution—and thus a person's constitutional rights, to preserve order. The state of exception also relegates certain populations to a state of bare life, or partial personhood.¹⁷⁰ This exceptional status disqualified the institutionalized disabled subject from receiving legal protections. As one advisor remarked to the General Assembly in 1911, feebleminded people should be considered "unfit for citizenship, [a] menace to the peace, and ... regarded and treated as anti-social beings [that] may be permanently segregated in institutions..."¹⁷¹ The law did not consider the permanent institutionalization of a disabled subject a state-sanctioned death sentence but a utilitarian requirement for the "... best interests of the person [and] the safety and welfare of the public."¹⁷² This legislation, coupled with the previous Acts that established Pennsylvania's state institutions Polk and the PSSH, set the parameters for rhetorical legal performatives to define the bounds of nondisabled citizenship and society. It also allowed institutional authorities to create the institutionalized disabled subject and place

¹⁷⁰ Carl Schmitt parses out the State of Exception in *Political Theology: Four Chapters on the Concept of Sovereignty* (Chicago, IL: The University of Chicago Press, 2005). Walter Benjamin addresses the concept in, "Theses on the Philosophy of History," in *Illuminations: Essays and Reflections*, ed. Hannah Arendt, trans. Harry Zohn (New York, NY: Harcourt, 1998), 253–64. Finally, Giorgio Agamben takes the term up in his monographs, *Homo Sacer: Sovereign Power and Bare Life* (Stanford, CA: Stanford University Press, 1998); *State of Exception* (Chicago, IL: The University of Chicago Press, 2005), and argues that the state of exception is *the* defining feature of the State, not something that only pertains in a state of emergency. ¹⁷¹ Neff, "Report on the Commission."

¹⁷² Mental Health Act, 1007.

them into a state of legal exception, thus disqualifying their legal and ontological personhood. The juridical-medico procedural process of institutionalization placed the disabled subject outside of law and society and, therefore, the interests of nondisabled society came first over the interests of the institutionalized disabled subject.

The statutory language in the Mental Health Act gave institutional authorities the authority to deem whomever they felt met the standards of feeblemindedness through rhetorical legal performatives. Careful inspection of the legislation uncovers no definition for feeblemindedness, or any form of disability. As noted in the American Bar Foundation's (ABF) 1961 report on the rights of people deemed, at the time, mentally disabled, "[state] statutes are so broadly worded that they fail to identify with sufficient clarity or precision the type and degree of mental illness for which involuntary hospitalization, with the accompanying deprivation of many personal and civil rights, is justified. The statutory language in this area is almost universally obscure."¹⁷³ As with other states, the Commonwealth delegated its authority to make such determinations to institutional agents. The legislation gave extraordinary power to institutional authorities to deem almost anyone as worthy of institutionalization through rhetorical legal performatives and performances of disabled appearance. As Chamber-Letson reminds us, "Because a legal declaration announces itself as the articulation of an established legal fact at the same time that it makes the law, the legal production of subjects is neither purely constative nor purely performative but both."¹⁷⁴ By declaring a person "disabled"

¹⁷³ Frank T. Lindman and Donald M. McIntyre, Jr., (eds), *The Mentally Disabled and the Law: The Report of the American Bar Foundation on the Rights of the Mentally Ill* (Chicago, IL: The University of Chicago Press, 1961), 20.

¹⁷⁴ Chambers-Letson, A Race So Different, 15.

and ordering their institutionalization, the court both performatively produced and confirmed that person's subjectivity and exceptional legal status. Thus, this disability status made that person ineligible for citizenship and equal protections under the law.

Lamento: Another Number, Another "Hopeless" Case

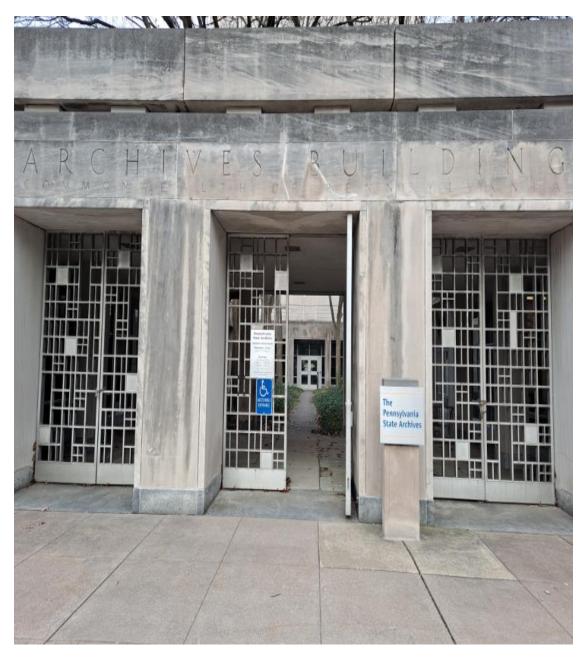


Figure 3: The front entrance to the Pennsylvania State Archives in Harrisburg, Pennsylvania. Photograph credit: Tyler Stump.

Sweat beads on my forehead and my KN95 surgical mask feels moist from the humidity as I walk through the strange garden walkway—the "courtyard"—that leads to the front entrance of the Pennsylvania State Archives in Harrisburg, in the middle of August 2021.

Embarking on my third trip to the archives, I know exactly what I'm looking for, but my body does not desire to stare into the abyss. My stomach clenches and my muscles tighten as I get closer to the door.

I feel like I'm walking through a decontamination tunnel. Is this some kind of purification ritual? Gotta cleanse the cripple before he is worthy of entering the temple's inner sanctum of knowledge. I wonder if they know people called me "retarded?" I hope my letter of access from the State Archivist is still on file.

I go to open the door, but the door is locked.

I knock on the door to alert the archivist at the front desk to let me in.

I approach the front podium to sign in and introduce myself.

"Hi, my name is Nathan Stenberg. I am the Erickson Law & History Fellow and a

PhD Candidate at the University of Minnesota researching the Pennhurst Center."¹⁷⁵

"Yes, we've been expecting you. Please sign in here, Mr. Stenberg."

"Please call me Nathan."

¹⁷⁵ I leave this portion of dialogue from our conversation in deliberately. As a disabled person, particularly a first-generation disabled college graduate with a developmental disability, I find that credentialling myself is often the only way to get people to take me seriously in professional and academic settings (though it does not always work). As James Fetter writes, "I have published a peer-reviewed article in an academic journal, graduated in the top ten percent of my law school class, and have clerked on the Fourth Circuit. I recite these accomplishments not to brag or dazzle the reader but to perform the kind of credentialing that has been constantly demanded of me in my search for employment, and that is still never enough." James Fetter, "The Sisyphean Struggle for Secure Employment," *Journal of Legal Education* 71, no. 1 (2021): 14. For these reasons, I am also adamant about using honorifics for individuals. For more on minorities and the use of honorifics see Ella F. Washington's LinkedIn post: https://www.linkedin.com/feed/update/urn%3Ali%3Aactivity%3A7067469369563344896%29

"Right this way, Mr. Stenberg."

I take my usual seat—the "station" right next to the window, #9.

I like to see the sky, but I still feel *trapped*. My muscles stiffen as my fingers struggle to grab the pencil.

Damn cerebral palsy; now is not the time.

I scratch down the call number on the slip. "Department of Human Services (Previously Public Welfare), Office of Mental Retardation: RG-023—AMRT—Pennhurst Center,

Patient Files, 1908-1961. 36 cartons."

Cartons. That's what they call the vessels that hold the names of Pennsylvania's forgotten.

As I await the arrival of my "cartons," the archivist at the reference desk remarks: "Pennhurst, eh? You're only the second researcher to look at those materials."¹⁷⁶

My first cartload of patient files arrives. I heave the "carton" to my "station." The table makes an audible groan under the weight of disremembered souls. I take the lid from the "carton," unearthing hundreds of files stacked away. I breathe in as my fingers hover just above the files. The air rises from the files like spirits springing to life.

Cold. Like the morgue. That same sterile, lifeless cold. At least they preserve these, right? But is it, better? Perhaps it stings more knowing that the atrocities of the state that lie before me go unnoticed by all that pass through this place. Why would our government need to worry about culpability if they can simply hide their violence in plain sight? No one will notice anyway.

¹⁷⁶ At the time of writing, there have been three other researchers who have requested to view this material.

I hear Pablo Casals' string-quartet-like motet of Lamentations 1:12 ringing through my mind's ear.

O vos omnes, qui transitis per viam, attendite, et videte: si est dolor sicut dolor meus! Attendite universi populi, et videte, dolorem meum, Dolorem meum.

(Oh, all you who pass by stop, and bear witness. Does it mean nothing to you—my pain, my sorrow!? Everyone, pay attention to what I have suffered!)¹⁷⁷

I pull out a patient file at random. #1290. A 12-year-old Black girl in an unadorned dress stares back at me from two photos—front and profile. She looks scared and sad. I feel the same.

I open the file in search of something specific: trial transcripts. A folded clump of onion-skin papers bulges out from the other documents in the file. I found what I was looking for. In the moment, I feel a slight twinge of excitement at finding another transcript. But as I read the proceedings, my heart sinks. My eyes scan over words and phrases like, "hopeless," "constant care," better off "for her and the community [if she gets committed]."

As with every life sent away to the PSSH I encountered in these files before, I rush to the end to find the discharge notice (one of the reliably consistent documents included in these often-scattershot files)—did they die, or did they get released?

¹⁷⁷ Pablo Casals, *O Vos Omnes*, vocal score (Fort Lauderdale, FL: Tetra/Continuo Music Group, 1965) Translation of my own.

Sitting in the back of the file, I find my answer in the form of a death certificate. "Age: 17." "Primary Cause: Enteritis. Secondary Cause: Epilepsy."

Her last name is America.

Conjuring the Other: Law & Performance in Creating the Institutionalized Disabled Subject in the Courtroom

Understanding how rhetorical legal performatives created institutionalized subjects in the courtroom requires focusing on the context of the PSSH's commitment trials and the role of legal status. The contextual information regarding the history of court commitments for people deemed feebleminded in both Pennsylvania and the nation is scant and suggests the process varied by state and often required little more than a medical doctor's approval. As noted in the ABF's 1961 report, even into the mid-twentieth century, the commitment "of patients to these hospitals [in the United States] was effected with surprising ease and informality. The request of a friend or relative—or perhaps an enemy—to a member of the hospital staff for an order of admission would often suffice. The staff member might then hastily scribble a few words on a scrap of paper, sign his name, and the procedure would be completed."¹⁷⁸ In Pennsylvania, for example, a person could be committed to an institution with little more than a signature of someone willing to attest to the subject's supposed performance of disabled appearance. This remained the

¹⁷⁸ Lindman and McIntyre, Jr. (eds), *The Mentally Disabled and the Law*, 15-16.

case until the General Assembly passed the Act of 1913, which required a commitment trial primarily to assess a family's ability to pay for the services rendered by the institution.

Of the fifty-five patient files examined for this dissertation, pulled at random from the dates between 1910-1950 (from the approximately 5,723 files in the State Archives' possession),¹⁷⁹ eleven had commitment trial transcripts, and only nine other patient files had court orders regarding their commitment included in their files. Because administrators culled most of the patient files for space-saving reasons, it remains difficult to ascertain whether the other inmates had a trial or not. And, if they did have a trial, whether administrators removed the commitment trial transcripts from the files or the authorities failed to document the trial.¹⁸⁰ While difficult to know the frequency of these trials, they do underscore the importance of the courtroom as a space where medico-juridical authorities used rhetorical legal performatives to make and declare ontological determinations about disability and people deemed disabled.

What remains evident, however, is that the rhetorical legal performatives premised on the imagined embodied performances of disabled appearance—the courts used to institutionalize dis/abled people made that person a disabled subject. This section now turns to the commitment trial transcripts of children committed to the PSSH to investigate how these rhetorical legal performative practices took place.

¹⁷⁹ The Archives' holdings are not complete, and this is a rough estimate. The Archives' patient files records only go to 1961 and the later years have significantly fewer patient files.

¹⁸⁰ Sociologist Harold Garfinkel examines clinicians' and researchers' tendencies for leaving information out of patient files in, "Good Organisational Reasons for Bad Clinical Records," in *Studies in Ethnomethodology* (Englewood Cliffs, NJ: Prentice-Hall, 1974), 189–208.

Rosalie America

The court committed Rosalie America, age 12, to the PSSH on November 29, 1915.¹⁸¹ Rosalie's commitment trial illustrates three relevant aspects: first, the often-underdiscussed medical realities faced by dis/abled people and their families, and the intended purpose of the institution to give care (despite almost always taking away care). Second, since Rosalie was not present for her own trial, these trials reveal how rhetorical legal performatives functioned to bring about a performance of disabled appearance *in absentia*. In turn, this performance of disabled appearance provided evidence sufficient to commit Rosalie. Third, this trial highlights how eugenic philosophies of race, class, and gender intersected with disability and institutionalization.¹⁸²

¹⁸¹ The Pennsylvania State Archives privacy policy states: "names are included only if the individual is known to have been deceased for at least seventy-five years or longer (i.e., died in 1947 or earlier) or if names are documented in prior publication such as court cases, autobiographies, or published news articles." In accordance with this policy, I have chosen to *not* anonymize the names of the inmates I discuss in this section as way of remembering that these are real people who experienced systematic, state-sponsored violence under the guise of care. While the ethics of privacy and naming remain largely debated, my inspiration for naming past inmates of the PSSH comes from the "Say Their Name" slogan started by Black social activists drawing awareness to police violence. For more see, Henry H. Wu et al., "Say Their Names: Resurgence in the Collective Attention Toward Black Victims of Fatal Police Violence Following the Death of George Floyd," *PLoS ONE* 18, no. 1 (2023): 1–26. For more on the question of the ethics of privacy see, Susan C. Lawrence, *Privacy and the Past: Research, Law, Archives, Ethics* (New Brunswick, NJ: Rutgers University Press, 2016); Susan Burch and Penny Richards, "Documents, Ethics, and the Disability Historian," in *The Oxford Handbook of Disability History*, ed. Kim E. Nielson and Michael Rembis (London, UK: Oxford University Press, 2018), 1–17.

¹⁸² For more on the intersections of race and disability see, Nirmala Erevelles and Andrea Minear, "Unspeakable Offenses: Untangling Race and Disability in Discourses of Intersectionality," *Journal of Literary and Cultural Disability Studies* 4 (2010): 127–45; Nirmala Erevelles, "Crippin' Jim Crow: Disability, Dis-Location, and the School-to-Prison Pipeline," in *Disability Incarcerated: Imprisonment and Disability in the United States and Canada*, ed. Liat Ben-Moshe, Chris Chapman, and Allison C. Carey (New York, NY: Palgrave Macmillan, 2014), 81–100; Anna Mollow, "Unvictimizable: Toward a Fat Black Disability Studies," *African American Review* 50 (2017): 105–21; Schalk, *Bodyminds Reimagined*; Jessica Horvath Williams, "Unlike the Average Mental Disability as Narrative Form and Social Critique in Morrison's the Bluest Eye," *Studies in American Fiction* 45, no. 1 (2018): 91–117; Angela Frederick and Dara Shifrer, "Race and Disability: From Analogy to Intersectionality," *Sociology of Race and Ethnicity* 5, no. 2 (2019): 200–214.

Rosalie's mother had died at an unspecified age, and her father, James, worked as

a house cleaner. Given the demands of his job, James could not provide in-home care for

Rosalie, who reportedly lived with epilepsy.¹⁸³ While her father worked, a neighbor, Mrs.

Georgianna Harris, watched Rosalie. Because of his low wage, James could not

compensate Georgianna for her services. James applied to admit Rosalie to the PSSH on

November 22, 1915.

James explained his rationale for petitioning for Rosalie's commitment in the

questioning:

Q: [From James' counsel] What is the nature of her mental weakness?

A: What is that.

Q: First, how old is she?

A: Thirteen next birthday.

Q: What is the nature of her mind?

A: She has epileptic fits, that is what the doctor pronounced them. And I asked him if there was any cure, and he said he thought not.

Q: Does she attend school?

A: No.

Q: Is she able to receive instruction in school?

A: She probably might be if she had a little medical attention, I suppose, but not in the condition she is in now.

Q: How often does she have these attacks?

A: Well, generally about one a month?

Q: How many in one day? The greatest number in one day?

A: Well, she has had eight in a day.

•••

Q: Have you any one else to support besides Rosalie?

A: A little boy.

Q: Is your wife living?

A: No she is dead.

Q: Who does the child live with when you are at work?

A: Living with Mrs. Harris.

¹⁸³ As a dis/abled person in the position of an expert analyzing these commitment trials and patient files, I am wary of adhering diagnostic labels on the people I study. Although I reference the medical labels assigned to the PSSH inmates within their files, I question both methodologies employed for diagnosis and the intentions behind these labels. The power to define one's dis/ability, and how it affects their bodymind, should rest with the individual. While medical diagnoses serve a valuable function, they should not be the sole or definitive means of describing dis/abling experiences and conditions.

Q: Does *it* require some one to be with *it* to take care of it? A: Yes.

Q: She is not able to take care of her self?

. . .

A: No sir. Her mind is all right, she can talk with you as long as she don't have these spells.

Q: Do you think it would be to her best interests to have her committed to this institution at Spring City [Pennhurst]? A: Yes I do.

BY THE COURT: Q: Why? A: So that she will have good attention and medical attention.¹⁸⁴

I quote this passage at length to show how, for many families such as Rosalie's, institutions held the promise of providing care for their children that families could not provide at home. This line of questioning exhibits how James did not have the financial means to support his daughter, nor the ability to care for Rosalie at home. And yet, in doing so, this testimony also shows how the lawyer assumed Rosalie's incapacity.

The lawyer started his line of questioning regarding Rosalie by positioning her as inferior. The lawyer does this by asking, "What is the nature of her mental weakness?", and even referred to Rosalie as "it," in his questions. Strikingly, this passage reveals a dichotomy between how the lawyer and Rosalie's father envisioned the purpose of Rosalie's commitment to the institution. The lawyer pressed James about the severity of Rosalie's dis/abling condition. While the lawyer undoubtedly chose this tack to demonstrate how Rosalie would benefit from institutionalized care, this questioning also reduced Rosalie a to medical problem. In his testimony, James consistently mentioned his

¹⁸⁴ Rosalie America, Patient Files, December 21, 1915, Patient Nos. 1200-1313, 1915-1916, Carton 7, RG23, Department of Human Services, Office of Mental Retardation, Pennhurst Center, 1908-1961, Pennsylvania State Archives, Harrisburg, PA (hereafter PSA). Emphasis added.

belief that institutional care—medical and educational—could help Rosalie grow as a person in ways she could not at home. Despite this, the lawyer repeatedly referred to Rosalie in relation to supposed problems presented by her bodymind.

As with most commitment trials I examined, the doctor appeared at the end of the

proceedings. In this way, the doctor performed the role of "authority figure" in the

courtroom. Vested with the credential of being a practicing physician within the

Commonwealth for five years, the doctor attested to signs of Rosalie's performed

defectiveness. The judge questioned Dr. Willis Read Roberts, the physician that had

examined Rosalie.

Q: Did you examine Rosalie America?

A: I did on November 2nd. I called at the house and Rosalie was apparently alone. There was no one there at the time and I talked with her. She was rather hard to make understand the questions that I asked her but she finally did. She speaks with poor enunciation and with an impediment. She is undersized for her age and yet over developed physically. ...

Q: Do you think she is feeble minded, an epileptic?

A: Yes it is a true case of epilepsy.

Q: Is there any other evidence of mental weakness?

A: Yes her speech is an evidence of mental weakness. And then she is undersized, yet she is rather mature too, but this is a sexual kind of development.

Q: Do you think it would be to her best interests to have her sent to this institution?

A: I think she would be much better there, where she could be taught to read and write and probably do some manual work, and take care of herself physically.

Q: Does she need constant care?

A: Yes I would say that she needs constant attention.

Q: Is she a proper subject to be committed to this institution?

A: She is.

Q: And she would be better off there, as would the community?

A: Yes.

[End of Transcript.]¹⁸⁵

¹⁸⁵ America, Patient Files.

This passage illustrates how the doctor relied on the performance of disabled appearance to diagnosis Rosalie's supposed "mental weakness." Furthermore, the doctor's testimony elucidates how, under the medical gaze, Rosalie's bodymind became readable. As Kuppers explains, "a body performs its materiality and meaning to a doctor, a specialist, who is empowered to read hidden histories and signs."¹⁸⁶ In this way, Rosalie's supposed "poor enunciation" along with speech impediments and an "undersized" body became evidence of performances of disabled appearance rather than mere bodymind difference. Of note, the doctor read Rosalie's physical development through a eugenic, gendered, racist lens of hypersexuality that produced another performance of disabled appearance.

Despite her "undersized" stature, the doctor paradoxically reported that Rosalie was "rather mature" in a "sexual kind of development." The doctor's racialized hypersexualization of Rosalie framed her bodymind as a threat to the community and marked her as feebleminded in the same way that the doctor interpreted Rosalie's speech as signs of "mental defectiveness." Strikingly, as I discuss in <u>Act III</u>, similar forms of hypersexualization in connection to embodied enactments of disability appear again in the performances of the dis/abled haunters at the Pennhurst Asylum.

After establishing Rosalie's performance of disabled appearance in his encounter with her, the doctor used rhetorical legal performatives to ritualistically manifest Rosalie's performance of disabled appearance in absentia. The lawyer, by asking each witness about Rosalie's presumed disabled performance, created a ritual where Rosalie was disabled because words described her as such. As performance studies scholar

¹⁸⁶ Petra Kuppers, *Disability and Contemporary Performance: Bodies on Edge* (New York, NY: Routledge, 2004), 39.

Dwight Conquergood notes in his analysis of the execution rituals involved in capital punishment, "rituals carry their weight and earn their cultural keep by restoring, replenishing, repairing, and re-making belief, transforming vague ideas, mixed feelings, and shaky commitments into dramatic clarity and alignment."¹⁸⁷ That Rosalie was not present for her own trial did not matter because the commitment trial and process of institutionalization served to place dis/abled people in legal exception, or to be a non-person in the eyes of the law. Therefore, the trial functioned as a sacrament of social death disguised (and likely intended as) an attempt to provide care.

This passage illustrates how the credential of medical doctor allowed the doctor's expert testimony to go uncontested: it was presented without cross-examination. Without guidance from the legislation, the judge relied on his own common sense understandings of disability and the professional expertise of the medical doctor to make appropriate judgments regarding whether or not a person *was* feebleminded. Chambers-Letson addresses this phenomenon regarding race and law stating that when performance and law collapse together, racial knowledge "takes hold of (inhabits, choreographs, and shapes) the raced body and makes it into a racialized subject."¹⁸⁸ Performances of disabled appearance in absentia made possible through rhetorical legal performatives functioned effectively in the same way as Chambers-Letson's racializing performatives, but with disability and the dis/abled body. And yet, crucially, unlike the subjects in Chambers-Letsons' analysis, there often were no dis/abled bodies present in the courtroom when these performatives occurred. This illuminates how performances of

¹⁸⁷ Dwight Conquergood, "Lethal Theatre: Performance, Punishment, and the Death Penalty," *Theatre Journal* 54, no. 3 (2002): 342-43.

¹⁸⁸ Chambers-Letson, 5.

disabled appearance in absentia and rhetorical legal performatives took on a ritualistic quality in the commitment trials.

Rhetorical legal performatives have a dual functionality in bringing about performances of disabled appearance in absentia. Rhetorical legal performatives are both rhetorical in that they use spoken elements in service of argumentation, but also, they are rhetorical in the sense that they produce a desired outcome already foreclosed rather than merely eliciting new information.

This latter function of the rhetorical legal performative highlights the ritual involved in the courtroom. Rosalie's fate was all but sealed before the trial began since the physician had approved Rosalie's commitment to the PSSH. However, since the Act of 1913 required a court commitment, the trial was a mere formality, but that formality also functioned as a ritual that made Rosalie legible as disabled and worthy of institutionalization. Committing Rosalie to the institution became the court's only option to provide her with care, while serving the better interests of—or, in words of legal historian Michael Grossberg, "protecting"—the community.¹⁸⁹ While the lawyer's examination made the argument for providing Rosalie with the care she needed to live and flourish clear, this transcript begs us to question how society defined, and continues to define community, the bounds and norms of that community, and the types of citizens that made and continue to make up that community. In <u>Act IV</u>, I examine how the PA community serves as a potent model for challenging these normative notions of disability community.

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¹⁸⁹ Michael Grossberg, "From Feeble-Minded to Mentally Retarded: Child Protection and the Changing Place of Disabled Children in the Mid-Twentieth Century United States," *Paedagogica Historica* 47, no. 6 (2011): 729–47.

In the context of this trial, when the judge asked the doctor, "And she would be better off there, as would the community?" this created a performative boundary for what community was and who should belong within it. In this understanding, the "community" was identified as non-disabled. As political science scholars Nancy J. Hirschmann and Beth Linker explain, "disability' does not describe the body per se, but the body in a hostile social environment. … Citizenship thus usually entails an attachment to a specific locality; we are citizens *of* something, generally a nation, but alternatively (or at the same time) of states, cities, towns, or even organizations."¹⁹⁰ In this instance, the Court understood Rosalie as something alien to the community of Philadelphia, and the Commonwealth.

Anna McMullen

The court committed Anna McMullen, age 11, to the PSSH in 1922. Anna's narrative provides a morose yet instructive study for understanding how rhetorical legal performatives created the institutionalized disabled subject. Crucially, Anna's trial illustrates how authorities not only made a dis/abled person appear *in absentia* through performance, but also simultaneously foretold their disappearance from society and presumed demise on the basis of their specific diagnosis.

The petitioner in the case, Elizabeth McMullen—Anna's mother—asked the court to remove her daughter from the family's household. Anna was not present for her own trial because she was ill, and her mother left her at home. Elizabeth McMullen states,

¹⁹⁰ Nancy J. Hirschmann and Beth Linker, eds., *Civil Disabilities: Citizenship, Membership, and Belonging* (Philadelphia, PA: University of Pennsylvania Press, 2015), 5-6.

"[Anna] was very sick, and last night she had some of those epileptic fits."¹⁹¹ This comment points to the realities of why families sought institutional care. Families often needed the care offered by institutions, and institutional growth did not simply occur due to eugenic malice as many social control scholars tend to argue.¹⁹² But the rhetorical legal performatives used by medical and juridical authorities to describe her diagnosis, convinced the court that Anna would die prematurely and thereby merit institutionalization. Further, authorities argued that, if the court did not institutionalize Anna, her disability—reported as epilepsy—could make her into a murderer.¹⁹³ Analyzing law's racializing power, Chamber-Letson explains, "legal discourse forgets its own performative power, transforming a court's performative utterance into a codified reality."¹⁹⁴ Chambers-Letson's analysis serves as an important parallel to understand what occurred in the courtroom at the time of commitment. Like Rosalie, through the words used to describe Anna, the judge, lawyer, doctor, and mother performed Anna's existence as a disabled subject into being.

Anna's construction as an institutionalized disabled subject and a threat to society on the basis of her diagnosis began with the first line of questioning by her own legal representation. After Anna's mother, Elizabeth, verified the family's home address and her current occupation as a "houseworker," the lawyer questioned her about her daughter.

- A: No, sir, she is not well.
- Q: What has she been *suffering* from?
- A: Epileptic fits.

Q: What is her physical condition, is she a well child or —

¹⁹¹ Anna McMullen, Patient Files, October 28, 1922, Patient Nos. 2461-2607, 1922-1924, Carton 12, RG23, PSA.

¹⁹² See, for example, Trent, Inventing the Feeble Mind; O'Brien, Framing the Moron.

¹⁹³ Deutsch, *The Mentally Ill in America*, 3.

¹⁹⁴ Chambers-Letson, Chambers-Letson, A Race So Different, 15.

- Q: How long has she been suffering from them?
- A: Since she was three years old.
- Q: Do you feel that she ought to be sent away to some institution?
- A: Yes, sir.¹⁹⁵

. . .

This line of questioning illuminates the rhetorical, performative quality of the legal counsel's examination. Most of these questions were closed, and all presumed their own answers. The lawyer's questions created an aesthetic expectation of wellness (which clearly denotes both normalcy and manageability), highlighting the double-sided rhetorical nature of these rhetorical legal performatives. After Elizabeth replied her daughter was "not well," the lawyer asked what Anna was "suffering from." This specific speech act created a subject that was ontologically negative and in pain, while presuming that Anna's physical condition was a prerequisite for feeblemindedness. Without even being present in the courtroom, Anna performed "defectiveness."

The medical doctor's testimony regarding Anna's examination before the trial further solidified Anna's status as defective. The medical expert did not challenge the prevailing opinions of normalcy inherent to the court's questioning. Anna's lawyer asked the medical expert:

Q: Have you examined Miss Anna McMullen, who is about eleven years old, daughter of Mrs. Elizabeth McMullen, lately?
A: Yes.
Q: Have you found her an epileptic and feeble minded patient?
A: Yes.
Q: Do you think it would be proper that she be sent away to an institution such as ... Pennhurst?
A: I do. I think she ought to have been there long ago.¹⁹⁶

¹⁹⁵ Anna McMullen, Patient Files, Emphasis added.

¹⁹⁶ McMullen, Patient Files.

Unlike the doctor in Rosalie's trial, the physician who examined Anna provided no evidence whatsoever as to why the Court should institutionalize her. This short exchange between Anna's lawyer and the physician demonstrates the degree of power in determining what constituted a performance of disabled appearance the Court gave to licensed physicians.

The judge presiding over Anna's case continued this line of questioning, and asked the medical expert:

Q: And epilepsy is considered, as a rule, incurable, I take it?
A: I think so.
Q: It's one of those ailments that the doctors speak of as progressive, or something of that kind? It's more likely to terminate in death than anything else?
A: More apt to.¹⁹⁷

The lawyer, judges, and expert witness confirmed and perpetuated Anna's performed defectiveness and presumed a teleological state of decline. This testimony performed what J. L. Austin calls a perlocutionary act, or "what we bring about or achieve *by* saying something, such as convincing, persuading..."¹⁹⁸ In this way, the medical expert brought about Anna's disability, therefore, established the standard of proof *by* saying that she was disabled. There was no counterargument to whether Anna was anything other than feebleminded or epileptic; she was "incurable" because the medical and juridical authorities said she was. By virtue of being a medical doctor, within the performative space of the courtroom, the doctor's testimony was not merely words, those words *did* and *enacted* something—Anna's institutionalized subjectivity. Without cross-

¹⁹⁷ McMullen, Patient Files.

¹⁹⁸ Austin, How to Do Things with Words, 108.

examination, this testimony became understood in a non-adversarial way, which allowed the testimony to become ontological and teleological truth about Anna.

Declared incurable, Anna was no longer fit for society, and unable to speak for her own best interests. Permanent institutionalization was the only remedy for this abnormal disabled subject. The order to institutionalize Anna removed her from the assumed linear progression of human existence and placed her in a state of exception where she was always already presumed ontologically dead. As the authorities in the courtroom performed Anna's disabled existence in absentia—and made her "appear"—in the courtroom, this ritual also *disappeared* Anna from society. Anna's example demonstrates how, while the driving force behind her institutionalization was labeled as "care," there was no afterthought regarding what an institutionalized disabled subject gave up in return for that "care."

Irvin Etzel

The commitment of Irvin Etzel illustrates how these commitment trials constructed and reinforced boundaries between the qualities of "normal" nondisabled citizens and the qualities of institutionalized disabled subjects. After the Commonwealth committed Irvin's parents to the Danville State Hospital for the Insane, it sent Irvin and his brother Joseph to the Coal Township Almshouse. Soon after, the Almshouse petitioned the Court to commit the brothers to the PSSH. The Court committed 14-year-old Irvin Etzel, along with his brother Joseph, to the PSSH in 1920. Irvin's case elucidates how malleable the definition of "feeblemindedness" was, and the minimal standards necessary for justifying custodial institutionalization.

The trial began by examining the medical expert. The lawyer asked the doctor about Irvin's diagnosis:

Q: What do you find as to his mental condition?

A: I should say deficient.

Q: Would you call him feeble-minded?

A: Well, he certainly isn't mentally what he should be for a boy of his age.¹⁹⁹

While the medical doctor who examined Irvin compared him to other boys his age, the

doctor provided no specific framework or examination protocols that guided him in

formulating his judgment. As with Rosalie's and Anna's trial, the line of examination

presumed the outcome of its own argument. Because the state legislation conferred

authority to the medical official to identify defectives, the doctor's words became

evidence enough to commit Irvin. The doctor's testimony-as a rhetorical legal

performative-made Irvin appear to the court as deficient.²⁰⁰

Continuing the examination, the lawyer asked the warden of the Almshouse about

Irvin's behavior. This testimony further illustrates how rhetorical legal performatives

rendered Irvin as deficient.

Q: What do you say as to his conduct?

A: Well sometimes it is middle and other times he acts kind of peculiar.

Q: Do you consider he is fully developed – a normal child for his age?

A: No, sir.

Q: Does he show any peculiarities?

A: Some times.

Q: Can you name some?

A: Well sometimes he talks when no one pays attention to him and then you talk to him and he forgets it right away.²⁰¹

¹⁹⁹ Irvin Etzel Patient Files, August 11, 1920, Patient Nos. 2129-2237, 1920, Carton 9, RG23, PSA.

²⁰⁰ Chambers-Letson, A Race So Different, 5.

²⁰¹ Etzel, Patient Files.

The warden's wife echoed the "peculiarity" of Irvin's behavior in her testimony as she explained to the lawyer:

A: He isn't developed as a child of his age should be.
Q: Does he show any peculiarities in his conduct?
A: He is forgetful and it is very hard to make him understand what you want.
Q: Mrs. Knarr is Irvin Etsel a well behaved child?
A: He isn't a bad behaved child – he is like all children.²⁰²

Irvin's forgetfulness, not his behavior, set him apart from other "normal" children. This testimony reveals the low bar required by a court to meet the standard of proof necessary for commitment. While authorities only needed to attest to a person's deviation from certain norms, they never actually interrogated or established what those norms were or how they came to be.²⁰³ Instead, the actors in the courtroom produced those norms through their assertation of Irvin's deviance from them—such as being "forgetful", "peculiar", and not developed. Therefore, Irvin's lack of desire, or possible inability to comply with assumed societal norms—not a readily identifiable medical diagnosis—placed him outside the bounds of normal society and made him an eligible subject for institutionalization.

Ralph Kriebel

Ralph's recommitment trial sheds light on the purpose of the commitment trial, and how that differed for legal and medical authorities. It also illustrates what kinds of standards of disability needed to be performed in order for the court to commit someone.

²⁰² Etzel, Patient Files.

²⁰³ For more on the convergence of ableism, racism, sexism, and law in creating and perpetuating a hierarchy of normative bodymind expression in nondisabled society, see Morgan, "Rethinking Disorderly Conduct."

Anomalous from the other trials I found, this trial to technically recommit Ralph Kriebel was a formality required by the Act of 1913, which the General Assembly passed after his commitment to the institution. The Director of the Poor for Montgomery County in Upper Providence, Pennsylvania, sent 12-year-old Ralph Kriebel to the PSSH, on November 7, 1910. Almost a decade later, the Board of Trustees of the PSSH petitioned the Court to commit Ralph again, on March 15, 1920. The Board sent Dr. William J. Stewart, the PSSH's superintendent, to represent the institution. Stewart explained the purpose of the trial in his testimony stating, "We have had some correspondence with the Attorney General, about certain cases, and he has advised that from time to time we have them re-committed under the new Act [of 1913]."²⁰⁴ While both of his parents attended the trial, Ralph remained at the PSSH, and absent from the courtroom.

Both judges present for the trial—Aaron S. Swartz and John Faber Miller expressed confusion regarding the trial and Ralph's absence from his own trial. Superintendent Stewart argued he "did not deem it necessary" for Ralph to attend court.²⁰⁵ The counsel representing the PSSH began his examination by questioning Dr. Stewart regarding Ralph's status as an institutionalized disabled subject:

BY JUDGE SWARTZ: Q: He was not placed there [PSSH] through any Court proceeding? A: No, sir.

BY MR. HOLLAND: Q: Simply admitted on the application of his parents? A: Yes. Q: He is feeble minded? A: Yes.

²⁰⁴ Ralph Kriebel, Patient Files, December 21, 1915, Patient Nos. 430-596, 1910-1911, Carton 4, RG23, PSA.

²⁰⁵ Kriebel, Patient Files.

Q: What is the result of his condition, as to his actions? Would it be safe for society for him to be at large?

A: In our opinion it would not.

Q: And would or would not it be in his best interests to be confined in such an institution?

A: It would.

Q: Is he capable of taking care of his own affairs, in your estimation?

A: No, he is not of that mentality.

Q: Just describe to the Court what his mental condition is, in detail, your diagnosis of the case?

A: His is a boy that will be twenty one years of age this coming month, with the mentality of a child of eight. Physically he is in good condition, unable to take care of himself, and measure up to the ordinary requirements of himself, and measure up to the ordinary requirements of the average man, or to the necessary requirements.²⁰⁶

In this first passage, the PSSH's counsel, Mr. Holland, relied on two common tactics used

in the commitment trials I have examined: first, he emphasized the importance of the

doctor's credential to "know best." As discussed previously, the medical gaze allowed the

doctor to know what others could not, a person's inherent medical faults.²⁰⁷ Ralph was

not present in the courtroom, and therefore could not speak for himself. But the

combination of his credential as a medical doctor and superintendent of the PSSH

allowed Dr. Stewart to speak definitively regarding Ralph's ability to conduct himself in

non-disabled society.

Judge Miller furthered this line of examination, asking Dr. Stewart:

Q: Has he shown improvement, or betterment, in his mental condition, since he went to pennhurst? [sic]

A: I could not say; I have known him for six years, and his condition has been stationary since I have known him.

Q: What is he able to do, up to this time?

A: He is able to do a certain amount of manual work under competent supervision.

Q: Has he been capable of being instructed in skilled work of any kind? A: No, and he never will.

²⁰⁶ Kriebel, Patient Files.

²⁰⁷ Kuppers, Disability and Contemporary Performance.

Q: He is likely to remain there for some time? A: Yes.²⁰⁸

The second of these two passages highlight the medical gaze of institutional authorities. Ralph *was* feebleminded because the superintendent of the PSSH declared he was. Once deemed an institutionalized disabled subject, the dis/abled person became incapable of progressing to the point of discharge by the institution. Furthermore, the superintendent did not reference any diagnostic tests or measurement criteria for how he determined Ralph did not "improve" at the PSSH. The repeated lack of evidence required to declare someone worthy of institutionalization created a citational pattern that further revoked the power of claiming dis/ability from the person themselves. Effectively, only "experts" had the authority to claim whether someone was disabled, thus making the actual bodymind experience of the person in question irrelevant. Finally, this testimony above also illustrates how, despite Dr. Stewart's testimony being non-objective, the court still interpreted it as objective truth on the basis of Stewart's medical credential and stature as the PSSH Superintendent.

The lawyer representing the PSSH, J. Burnett Holland, further played on the eugenic fears of disability and deviance pulsing through legal and medical circles of the

1920s. He asked Dr. Stewart:

Q: In the opinion of the profession, Doctor Stewart, when a man of this type, or boys of this type, of the grade of intellect that this man is, are turned loose into society, which are their usual actions; how do they conduct themselves? A: That depends on the case.

Q: I mean do they not work, or do they become, whether they are harmless or not harmless, do they become vagrants, or do they work, or do they give society any trouble in the opinion of the profession?

A: The majority of them.

Q: What is the nature of their conduct, if they are turned loose into society?

²⁰⁸ Kriebel, Patient Files.

A: The majority of them become ne'r do wells, and Ralph has such propensities that he is dangerous at times. He has a violent temper, and is uncontrollable in action at times, and he is at times liable to do harm. Q: In your opinion it is to his best interests and the best interests of society, that he should remain in this institution? A: Yes.²⁰⁹

Here the focus shifted back to whether Ralph could function within *nondisabled* society. Themes of vagrancy, violence, and dependency pervaded Dr. Stewart's testimony, and yet Stewart did not cite any specific instances of such acts committed by Ralph while at the PSSH or before his admission to the institution. This language positioned Ralph as appearing disabled to the court, despite a lack of any evidence other than expert testimony. As legal scholar Bradley A. Areheart points out, diagnosis and prognosis rely on social and political inputs that lead doctors to articulate such labels.²¹⁰ In his capacity as representative of the PSSH and an expert witness, Stewart was required to proclaim a diagnosis and prognosis served the institution's interests. And yet, the Court remained unconvinced.

A short exchange between the PSSH's lawyer, Mr. Holland, Judge Miller, and Judge Swartz illustrates the legal paradox of commitment legislation and a momentary concern for Ralph's absence from the courtroom:

BY JUDGE MILLER: Under your present arrangement does his father contribute anything to his support?

[Dr. Stewart responds] A: That I don't know, nothing about that.

MR. HOLLAND: We have the father here.

JUDGE SWARTZ: Should a decree be made committing this boy, nearly twenty one years of age, without giving him a chance to be heard, he having

²⁰⁹ Kriebel, Patient Files.

²¹⁰ Bradley A. Areheart, "Disability Trouble," Yale Law & Policy Review 29, no. 2 (2011): 363.

been for sometime in this institution now? Had he any notice of this hearing?

MR. HOLAND: He had no notice, no. The parents had notice, and I told the parents the exact nature of the proceeding, and I told them if they wanted to, they might have the opportunity, if they saw fit, to oppose it, if they thought he ought to be out, and if they desired to oppose it.

JUDGE SWARTZ: It may be that he has some right to choose his own guardian, or some right to say who shall have supervision of his body, or estate. I do not know. The matter can be looked into. It is a peculiar case, because the boy is there, and I have no doubt was properly admitted, because there was no law at the time he was admitted, making it necessary to do it by a Court proceeding, and the institution was established to receive children of this kind, and I imagine that if there was no Act of Assembly prescribing just how it was to be done, that the authorities at the institution could determine that themselves. At least, so it seems to me."²¹¹

Judge Swartz's concerns underscore how medical and legal definitions of what we now call disability remained in flux during this period. Furthermore, the judges' open discussion regarding the legality of Ralph's commitment to the PSSH illustrates how early institutional processes relied on the medical expert's opinion, along with other actors such as the director of the poor and teachers, to determine whether a child was a proper subject for institutionalization. Swartz's commentary illustrates the power of the medical credential in the commitment process. Without specific legislative language guiding the commitment process, prior to 1913, Ralph's commitment was legitimate solely because a doctor said he was eligible. As such, the Court relied on the citationality of rhetorical legal performatives and performances of disabled appearance. Remarkably, Judge Swartz questioned the procedure of committing people in absentia. But because doctors deemed Ralph worthy of institutionalization prior to the Act of 1913, the Court had no other option than to readily agree with the institution's decision yet again.

²¹¹ Kriebel, Patient Files.

Following this discussion, the judges, lawyer, and superintendent conferred about

the PSSH's waiting list of approximately 150 children and whether habeas corpus-

constitutional protection against unlawful and indefinite incarceration-applied to

institutionalized subjects. This discussion provides context about the population demands

on the institution by 1920, the institution's desire to retain its inmates, and the legal

ambiguity regarding the legal process of commitment.

MR. HOLLAND: I would like to bring out this fact, for it might bear upon the situation.

BY MR. HOLLAND:Q: Is this institution full, filled to its present capacity?[By Dr. Stewart] A: It is.Q: Are there any applications still in existence, for admissions, that cannot be filled on account of lack of capacity?A: We have applications; our capacity will be increased, though, by the fifth of June.Q: How many applications have you?

JUDGE SWARTZ: A waiting list of applicants?

THE WITNESS: Yes.

- Q: How many?
- A: Possible 150.

Q: One hundred and fifty applications that cannot be filled, of people who admittedly should be in an institution, and cannot be admitted on account of your being filled to capacity?

A: Yes; some of these probably will not materialize by the first of June.

MR. HOLLAND: I will see what can be done, if Your Honors want to have the boy brought into Court; we will have to continue it to another date, if necessary, and give him notice, and have him brought into Court.

JUDGE SWARTZ: I do not say that it is necessary. I have not been convinced of the necessity, as yet, for this proceeding; the Attorney General has looked into it, and I suppose he has made up his mind that this ought to be done, but the witness says the boy has been there for ten years.

MR. HOLLAND: Almost ten years.

JUDGE SWARTZ: So far as there was any law at that time, they apparently did not disregard any law in sending the child there, and he has been in their care, and I do not see but that he is in their care just as much now, as if an order was made, and they have the same supervision over him now as they would have after an order is made. I have not looked into it, but I suppose the authorities have.

MR. HOLLAND: The question is, suppose he wanted to make an application to this Court for discharge; wanted to get out; he might take a writ of habeas corpus.

JUDGE MILLER: I am not very familiar with the matter of practice. Does this Act of 1913 contain a provision that the institution itself acting, through its management, can apply to the Court for an order?

MR. HOLLAND: It may.

• • •

JUDGE MILLER: It seems to me that the question here is whether a person of the age of this boy, and of his condition, with the waiting list that they have there, ought not to make way for some more exigent case.

MR. HOLLAND: Just as your Honors think. The institution has no interest. I have here the application upon which he was committed. (Same handed to the Court) He was committed upon the certificate of a physician in Conshohocken, Dr. Beaver.

BY JUDGE MILLER:

Q: If Ralph came home do you think he could earn his own living, and take care of himself? From what you have observed of him, on his vacations, and at Spring City, when you visited him up there?

[By Ralph's father, Reynard] A: Well, I think he could, yes, sir.²¹²

While there is no information regarding population levels at the time of the trial, the

PSSH had an inmate population of over 1,200 with only 300 attendants only two years

²¹² Kriebel, Patient Files.

later.²¹³ The first part of this testimony illustrates the changing philosophy of institutions from rehabilitate and release to lifelong custodial capture. The commentary by the judges demonstrates the power of the medical professional and the citationality of rhetorical legal performatives as precedent for institutional commitment. Once again Judge Swartz raised the prospect of rescinding Ralph's sentence of social death but retracted his appeal. Resting on the precedent that "the authorities" committed Ralph in full compliance of the law, Judge Swartz assumed the good faith and intention of the previous ruling. Thereby, neither of the judges questioned the merits of the previous commitment based solely on the judgment of the Superintendent's examination. Despite the opinion of Ralph's father, who wanted Ralph returned home, the judges sided with the medical professionals to keep him at the institution. Strikingly, despite a clear need to make room for inmates with more immediate care needs and his parents' desire to bring him home, the court upheld Ralph's commitment. As discussed in the following Act, Act II, this demonstrates the need for inmate labor by the institution and role performances of habilitation by inmates deemed "high-grade."

After this exchange, the Court called Ralph's father, Reynard, to the stand. In this segment, Ralph's father detailed the scene that triggered his son's commitment to the institution. This testimony points to the low standard of proof required to make someone appear disabled and the arbitrary justification for commitment:

BY MR. HOLLAND:Q: It was on your application to this institution that your son was committed ten years ago, was it not?A: Well, it was done through Mr. Longaker.Q: Who was he?A: He was the Director of the Poor.

²¹³ Chester County Republican, SFHS, Newspaper Clipping, July 8, 1922, 9.

Q: What did he do?

A: Well, he seen the rest of the directors, and he made inquiry of the institution, and he came to me, and he says, "Give me the boy" he says, "and we will see that he goes to a place that will take care of him."

Q: And he put him in there for you?

A: Yes.

•••

Q: What was the condition of the boy, so far as you observed that caused you to desire to put him in an institution?

A: Well, during the vacation, school vacation, I left him go on the milk wagon, and thought, of course, he was going in good company, helping to serve milk. ... One day he was coming from school, and the boys told him to chase the girls.

BY JUDGE SWARTZ:

Q: To do what?

A: To chase girls. Well, he had great sport, running after them, running after anybody, to see them run. He enjoyed that. I never knew him to do any harm to anybody, but... There was a complaint made to the school board, and he was expelled from the school... I went to Barren Hill to see the school board, and they told me the best thing was to put him in an institution.

•••

BY JUDGE MILLER:

Q: And the only real wrong that he was charged with having done was when he was between ten and eleven years of age, chasing this girl to the railroad station? In the daytime, or night?

A: Day time; coming home from school.

Q: She was a school child too, was she?

A: Yes.²¹⁴

In this passage, Ralph's father recounted how the rather innocent offense of "chasing

girls," not Ralph's supposed feeblemindedness, led to his commitment. Despite this

revelation, the fervent discussion over the legality of Ralph's initial commitment, and the

PSSH's overcrowded condition, the Court decreed that "the said Ralph Kriebel, a feeble-

²¹⁴ Kriebel, Patient Files.

minded person, be committed to..." the institution on March 15, 1920.²¹⁵ The Court recommitted Ralph despite being presented evidence that suggested the Court should have discharged him. This outcome reveals yet another example of how commitment trials functioned as performances of disabled performances in absentia and the power of rhetorical legal performatives. Dr. Stewart's testimony involved no criteria or measurements that suggested why Ralph should remain in the institution. Dr. Stewart simply said Ralph was feebleminded, and the Court sided with the superintendent because of his credential.

Despite this rather hopeless decree, Ralph eventually found freedom from the PSSH thanks to his parents advocating on his behalf.²¹⁶ Given the scattershot nature of what documents remain in Ralph's patient file, it is difficult to ascertain the exact date when Ralph's parents began the discharge process. However, correspondence from PSSH Superintendent, Dr. Earl William Fuller on May 29, 1924, indicates that Ralph left the institution on parole. Ralph's mother, Jane, continued to petition for Ralph's ongoing parole until she eventually petitioned the Court to discharge him from the PSSH. Almost a year later, on May 13, 1925, Judge John Miller (the same from the 1920 re-commitment trial) discharged Ralph from the PSSH.

The testimony given about these children functioned as a rhetorical, performative practice by simultaneously describing the characteristics of defectiveness that they possessed while implying the characteristics of normalcy they did not. By nominating themselves to speak on behalf of the best interests of these children, legal and medical

²¹⁵ Kriebel, Patient Files.

²¹⁶ I examine parental advocacy further in the <u>Intermezzo</u> and in <u>Act IV</u>.

authorities used rhetorical performatives to *produce* the disabled subject as inhuman and excluded from normal society, while claiming to do so out of kindness for the child. Though these trial procedures—on their face—espoused presumed to consider the best interests of dis/abled people, a circular argument was created. This argument effectively predestined a disabled individual to become an institutionalized disabled subject prior to even setting foot in the courtroom. Therefore, their appearance in court was degraded to a mere procedural formality, instead of being recognized as a personal right.

Conclusion

This Act examined Pennsylvania's institutionalization legislation and the commitment trials of former PSSH inmates. By using performances of disabled appearance, sometimes in absentia, and rhetorical legal performatives, medico-juridical authorities imaginatively conjured and linguistically choreographed the disabled subject to render it fit for institutionalization and legal exception. These trials used performance to place dis/abled people into legal exception, remove them from society, and take away their personhood in the name of care. The performative processes the court used to institutionalize a dis/abled person *made* that person a disabled subject in the context of court. These commitment trials and admission materials did more than label children as feebleminded. They removed children, described, and assumed as disabled, from the established trajectory of citizenship and life.

Act II places its focus on what happens after the person becomes an institutionalized disabled subject, and how institutional authorities at the PSSH used performance to (re)confirm their institutional disabled subjectivity. Further, Act II

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highlights the role the PSSH played in affirming the precedent of the institutionalized disabled legal subject set in the courtroom and the performativity of disability by examining the dichotomy between the public relations materials published by the PSSH and the narratives found in the patient files of its inmates.

RECITATIVE

Parallel (Bars)

I sit alone, waiting, in the lobby of Hanger Orthopedic Clinic in what feels like upstate Washington, DC, on March 11, 2022. My left foot taps in nervous anticipation.

It's always the same—the anticipation of when the door will open, and someone will call my name, builds as each minute passes. Like some backward cleansing ritual before entering the inner sanctum of the temple, they must call me and recognize me as worthy to enter.

The door opens. A tall, dashing, young Black man wearing navy blue scrubs opens the door and calls my name as he looks down at his clipboard.

Assuming the usual clinical procedure, I presume the man is a nurse performing an intake assessment. The man leads me through the door from the outer court of the waiting room to the inner court behind the door.

I stare down a long hallway lined with doors on each side. Portraits of dis/abled people with phrases like "I'mPOSSIBLE" hang from the walls in between the doors.

God. It feels like I'm walking through a hall of taxidermized crips.

I feel my stomach tense up under the sterile buzz of the linear fluorescent lights. My mind suddenly flashes back to Shriners Hospital. I am laying on a gurney facing up toward the ceiling. A heavy, warm blanket prohibits me from moving a muscle, as the gurney's wheels clack on their way to the operating room. Nurses, dressed in surgical gowns and personal protective equipment, look more like aliens than people. I flashback to the waiting room. I barely pass the threshold of the lobby door before my body lurches to a halt.

Still behind me, the young man in scrubs asks me to keep moving and enter the "second door on the right." I follow his orders, almost instinctually.

My body moves forward. Feeling watched, I lose my balance and jaggedly enter

the third door on the right.

"No, the other room. The one with the light on," the man in scrubs says.

Dumbass. "Right. My mistake "

I enter the correct room, as the man in scrubs still looms behind me. Looking at an examination table and a chair, my body stops moving.

"You can sit down."

"Oh, right. Yes. Where?"

"In the chair is fine."

I sit.

"So, you're here to get fitted for a Richie Brace and some foot insoles, correct?" "Yes."

"So, tell me about yourself and why you're here today."

"Ah, well, I live with cerebral palsy, and it's been about thirteen years since I was sent to see a specialist. I've been experiencing some pain in my feet and right calf, so I decided to see a podiatrist. The podiatrist referred me here to get a brace and some insoles." "Great! I'm here to assist you and I'll get you fitted for both the brace and the insoles. So, tell me, have you used AFOs [ankle foot orthosis] in the past?"

"Yes. I've used a variety of CFOs [custom foot orthosis] and AFOs since birth, but I stopped using them at eighteen after I was discharged from Shriners."

"Why did you stop using them?"

...*Really*...?

"Honestly, I hated them. I never wanted them; they were clunky, burdensome, and got me bullied in school. I have no desire to use them ever again."

"Oh. I see. Well, before I fit you for your leg brace, I would like to take you to the next room and have you walk through the parallel bars."

"I'm sorry, but I'm not here for a gait check. I'm here for foot orthotics."

Beat.

"Wait, can you please tell me who you are?"

"I didn't introduce myself. My name is John [which I've changed], I am originally from Ghana, but now a medical student at Boston University in residency here. I want to perform the gait analysis because that's what my research is in, and I am curious to see your gait."

"Pleasure to meet you, John. I am also a doctoral candidate at the University of Minnesota."

"What do you study?"

"How perceived care becomes received violence in healthcare settings."

"Interesting. Would you please come with me to the next room?"

John stands from his desk and turns for the door. Once again, my body instinctually follows his command. But this moment feels both familiar and foreign.

You know what's going on here. You can say "no." You're in need of care, not a research methodology.

John leads me back towards the lobby door, and we enter a large room with a set of parallel bars. My heart pounds, my muscles tighten, and my vision starts to blur. I lose sense of where I am or what I'm doing. The thought of advocating for myself—and my care needs—retreats from my mind as I submit to the omniscient medical professional. Almost robotically, I position myself at the end of the bars, and my arms reach out to brace my body weight as if I was re-learning to walk again from a wheelchair.

"You can walk through the parallel bars now."

I comply.

"Great! Would you mind doing one more pass for me?"

I comply.

"Thank you, Nathan. That was informative. You can follow me back to the other room now and we'll start fitting you for your AFO."

I'm not here for an AFO...

A DICTIONARY OF HEREDITARY DEFECTS The comparison of idiots and normal children must always be a comparison between two separate species.

It's shocking, really, how many ways a being can go wrong before they're even born into the world.

Cretinism: you are caught between human and animal. heavy and flat-faced. You have hoofs for hands, a cow's wide tongue.

Epilepsy: you are destroying yourself from the inside out.

Feeblemindedness: I could shout into the cavern of your mouth and hear my own words echo back off the high walls of your head, over all the blank space of your brain. This is the most useful noise that you will ever make.

> Idiocy: you cannot even reproduce my echo. You are living, yet already your body has started to decay. It knows you are not for this world. You go limp or spastic, turn to stone or slime.

At home, I drown the smallest kitten in the litter. I hold its head under water for a minute, feel its heart stop with my thumb. It's done.

You are not for this world. It would be cruel to let you replicate yourself and make another creature fated to crawl around, feeble and stunted, yowling for absent milk.

Molly McCully Brown²¹⁷

²¹⁷ Molly McCully Brown, "A Dictionary of Hereditary Defects," in *The Virginia State Colony for Epileptics and Feebleminded: Poems* (New York, NY: Persea Books, 2017), 56–57.

ACT II

Enforcing the Prescription: Performances of Habilitation & Institutionalized Care at the Pennhurst State School & Hospital

Introduction

Act I examined Pennsylvania's institutionalization legislation and commitment trials of former PSSH inmates. It revealed how those trials used performances of disabled appearance and rhetorical legal performatives to disqualify the institutionalized disabled subject from receiving legal protections, thus removing them from society, and taking away their personhood in the name of care. Act II investigates what happened after an institutionalized disabled subject got committed to the PSSH during the period between 1920-1968 when the institution reached the height of its population. As disability historian Katrina N. Jirik warns, the transition during the twentieth century, "from educational and vocational programming, even with increased emphasis on custodial functions… to the inhumane conditions of the 1960s and 1970s needs much more investigation."²¹⁸ This Act assesses that transition by investigating trends of care and violence at the PSSH.

²¹⁸ Katrina N. Jirik, "American Institutions for the Feeble-Minded, 1876-1916" (PhD Dissertation, Minneapolis, MN, University of Minnesota, 2019), 264-265.

The PSSH, like other institutions, evolved astride a contradiction between eugenic logic and habilitative goals that persisted and shifted, but was never fully resolved. This fundamental contradiction gave way to environments in which the transmutation of perceived care into received violence became possible. In short, systematic abuse and violence—grounded in eugenic and ableist philosophies—came to constitute care, not discrimination. This Act adds a critical dimension to the work of disability scholars²¹⁹ and sociologists who have analyzed institutions solely as places of incarceration,²²⁰ and of legal and medical historians, who have often described institutions as benevolent places of care that suffered from a lack of funding and overcrowding.²²¹

To understand how perceived care becomes received violence in institutional settings, this Act begins by comparing the official "accounts" of life at the PSSH as produced by the Commonwealth with the experiences of PSSH inmates and survivors. By analyzing narratives mined from patient files, details regarding the types of care provided at the PSSH emerge. In these files I pay particular attention towards patterns regarding the language used to describe the inmates as well as patterns of the care (or lack thereof) inmates received in the institution. While the Pennsylvania State Archives has volumes of patient files in their collection, these files often retain only sparse records for individual

²¹⁹ Ben-Moshe, *Decarcerating Disability*; Chamberlain, "Challenging Custodialism"; Chamberlain, "Receiving, Sorting, and Disposing of Children"; Christine Ferguson, *Determined Spirits: Eugenics, Heredity, and Racial Regeneration in Anglo-American Spiritualist Writing, 1848-1930* (Edinburgh, Scotland: Edinburgh University Press, 2012); Jirik, "American Institutions"; Rembis, *Defining Deviance*; Schweik, *The Ugly Laws.*

 ²²⁰ Bronston, *Public Hostage*; David Goode et al., *A History and Sociology of the Willowbrook State School* (Washington, D.C.: American Association on Intellectual and Developmental Disabilities, 2013); Joseph E. Jacoby, "The Endurance of Failing Correctional Institutions: A Worst Case Study," *The Prison Journal* 82, no. 2 (2002): 168–88; O'Brien, *Framing the Moron*; Rothman, *Discovery of the Asylum*; Rothman; David J. Rothman and Sheila M. Rothman, *The Willowbrook Wars: Bringing the Mentally Disabled into the Community* (New Brunswick, NJ: Aldine Transaction, 2005); Trent, *Inventing the Feeble Mind*.
 ²²¹ Deutsch, *The Mentally Ill in America*; Scheerenberger, *A History of Mental Retardation*; Tyor and Bell, *Caring for the Retarded in America*.

inmates. Most of the files kept in the inmates' records contain documents that provide only large-picture overviews of their institutional commitment. Records such as daily observations, notes on restraint and medication usage, educational progress, and letters to and from family members all remain absent from the files. These archival silences mark the spaces where institutional violence took place, but to the institution they remain bureaucratically, medically, legally, and historiographically unimportant.

To gain a fuller picture of institutional life, and public perception of the institution, this Act analyzes articles from local and regional newspapers including the Philadelphia-based *Philadelphia Inquirer* and local newspapers such as the Pottstown-based *Mercury*.²²² To obtain a perspective regarding life in the institution as an institutionalized subject, this Act also analyzes an autobiography of PSSH survivor and self-advocate, Roland Johnson.²²³ In doing so, I pay particular attention to the ways Johnson details the institutional environment's effects on both his bodymind and those around him. Finally, this Act examines the information packets and public relations materials provided to inmates' parents and families to investigate how the institution presented itself to both families and the broader public. The analysis of these materials exposes the role of (re)presentational and rhetorical performance in making the sublimation of institutional violence against dis/abled people possible.

²²² I graciously received a PDF file of digitalized newspaper clippings about the PSSH from the Spring-Ford Historical Society in Royersford, PA. While I quote the full name of the newspaper when readily apparent, I will occasionally cite the newspaper using the shorthand used in the PDF file. In those citations, I also provide the date and corresponding PDF page number.

²²³ While I critique the label of "self-advocate" in both the <u>Intermezzo</u>, <u>Act III</u>, and <u>Act IV</u>, Johnson and other institutional survivors identified with this phrase. Therefore, I use it out of respect for them.

These materials present the PSSH, and those confined to exist there, as a "world apart." As sociologist, James Trent Jr. argues, the placement of institutions, such as the PSSH, in rural settings, "symbolized the rejection of urban society with its potential for vice, degeneracy, and abnormal behavior."²²⁴ In addition to its geographical separation from society, authorities materially designed the PSSH, and other institutions at this time, as a space of inhabitation, a self-sufficient place of permanent existence for the inmates. In turn, the everyday performances of life in the institution produced what I call, performances of habilitation: socializing people deemed disabled through an embodied pedagogy aimed at installing nondisabled norms. These performances include a wide array of activities from learning labor valued in nondisabled society to embodying dominant gender and class norms by dressing and moving in particular ways.

The placement of the PSSH in rural Spring City also created a spatial divide that allowed it to become a place of legal exception. Legal exception references a moment, during a crisis, in which a sovereign suspends juridical order—or in the case of the United States, the Constitution—and thus a person's constitutional rights, to preserve order. The state of exception also relegates certain populations to a state of bare life, or partial personhood. ²²⁵ This exceptional status disqualified the institutionalized disabled subject from receiving legal protections. Institutional authorities and the public, due to lingering eugenic philosophies of disability as inhuman bare life, deemed many inmates of the PSSH "hopeless."

²²⁴ Trent, Inventing the Feeble Mind, 98.

²²⁵ Schmitt, *Political Theology*; Benjamin, "Theses"; Agamben, *Homo Sacer*; Agamben, *State of Exception*. Agamben argues that the state of exception is *the* defining feature of the state, not something that only pertains in a state of emergency.

As one reporter for the *Philadelphia Inquirer* remarked in 1925, "This [the treatment of inmates], to the average person, would excite their sympathy, but the only way to know how to handle inmates of such low mentality is to be among them."²²⁶ The journalist rationalizes harmful practices by positioning the inmates of the institution as a literal sub-class of humanity. In turn, these violent practices became acceptable because the recipients did not meet the level of "normal," nondisabled humanity. In presenting the PSSH as an idyllic refuge of care and comfort for disabled people while not displaying the overcrowding and abuse experienced by the inmates, these materials created a repertoire of care-*qua*-violence and performed the transmutation of perceived care into received violence. As a repertoire, these materials not only reaffirmed the performances of disabled appearance declared in the courtroom but also reinforced the continued dehumanization of dis/abled people.

In contrast to the public documentation presented by the institution and local newspaper reporting, the internal records found in inmates' patient files expose patterns of neglect, negligence, apathy, and abuse that reveal the logic of dehumanization held by the institution. Confined within a place of exception, institutionalized disabled subjects became subject to what Giorgio Agamben calls "bare life", or "life exposed to death" through state violence.²²⁷ In this way, institutional authorities used the same rhetorical performatives found in the courtroom to review and confirm disabled subjects' deficiency and inhumanity in the institution. When examining an institutionalized subject—often

²²⁶ *Philadelphia Inquirer*, "Patients at Spring City," 1925, Spring-Ford Historical Society, SFHS, 13-14. ²²⁷ Giorgio Agamben, *Homo Sacer: Sovereign Power and Bare Life* (Stanford, CA: Stanford University Press, 1998), 88. Judith Butler also takes up Agamben's bare life in *Precarious Life: The Powers of Mourning and Violence* (New York, NY: Verso, 2004).

shortly before or after death—authorities read documented actions of neglect and abuse as evidence of the subject's deficiency, not of their own malpractice. To declare and reconfirm a person as an institutionalized disabled subject, therefore, did not require evidence or reasoning. Rather, a dis/abled person becomes an institutionalized disabled subject by virtue of an institutional employee's enunciation. The continued use of these omnipotent rhetorical performatives within the institutional environment gave PSSH authorities latitude to sanction violence that masqueraded as care (and often resulted in death) while absolving themselves of any culpability.

Spatially separated, materially constructed to render compliance from their subjects, and allowing their officials to act with impunity, institutions bred violence.²²⁸ But within a space in which perceived care became received harm, violence became difficult to define. Writing on the intersections of disability, law, performance, and public health, Kate Rossiter and Jen Rinaldi define institutional violence as: "*all* practices of humiliation, degradation, neglect, and abuse afflicted upon institutional residents, regardless of intention or circumstance."²²⁹ Rossiter and Rinaldi further explain, "institutional care is, by its very design, a kind of violence, and the omnipresence of care*qua*-violence is rooted in the dehumanization of institutionalized residents, and marks institutions as spaces where violence is normalized. This provides cultural space and permission for seemingly more egregious types of violence to occur."²³⁰ Taken together,

²²⁸ Sociologist Erving Goffman writes about spaces in which a large number of persons are separated from the larger society and controlled in everyday life by a smaller number of persons, always leads to violence—independent of the logic used to rationalize the situation. For more see, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (Chicago, IL: Aldine, 1962).

²²⁹ Kate Rossiter and Jen Rinaldi, *Institutional Violence and Disability: Punishing Conditions* (New York, NY: Routledge, 2019), 3.

²³⁰ Rossiter and Rinaldi, Institutional Violence and Disability, 39.

the relationship between how the PSSH represented the care it purported to give, combined with the PSSH's repeated practices of care-*qua*-violence, and the resulting dehumanization of dis/abled bodies gives way to what I call performances of institutionalized care.

The PSSH helps us understand how care becomes violence in custodial environments—historically and contemporarily—because educational, legal, medical, and policy experts still understand care as the regulated bodymind compliance with the space, time, and practices of the institution. Performances of institutionalized care serve the needs of the institution, not the needs of the dis/abled people it houses. But these performances also extend from custodial institutions to contemporary care settings such as hospitals, nursing homes, as well as bureaucratic systems for obtaining care like the Social Security Administration and private insurance companies. While the quality of care has vastly improved from mass custodial institutions, the eugenic undertones of medical paternalism and infantilization, pathologization, and the preference for nondisabled, professional experts intervening on dis/abled people—rather than creating care plans with us—comes directly from performances of institutionalized care.

The question of how to care for those with significant care needs through government-funded services—that does not result in performances of institutionalized care—remains difficult to answer.²³¹ Most medical history, biomedicine, and bioethics literature, medical professionals, and (some, but not all) parents of dis/abled children argue custodial environments offer the only form of care suitable for children and adults

²³¹ I use the term "significant" with caution, as it often carries negative, medically driven connotations of inferiority. Nonetheless, this is still the primary language used in policy and advocacy settings, such as it is in the Rehabilitation Act of 1975.

living with significant care needs. The research that follows in this Act does not deny that dis/abled people living with multiple and/or significant dis/abilities face certain medical realities which necessitate specialized care and near-constant attention. However, custodial institutionalization—often marketed as the only option for people living with significant care needs—creates environments where care inherently becomes harmful. We must find ways to give care to dis/abled people that do not strip us of our rights and humanity. As I argue in <u>Act IV</u>, the Pennhurst Asylum community offers a model for what dis/ability community by dis/abled people can look like.

Performance studies, and its emphasis on embodied knowledge transfer, proves invaluable to understanding how care becomes violence in institutions. Performance's ritual and repetitive quality is central to understanding this "care-*qua*-violence" process. For example, the repetition of violent acts in the institution not only forces an institutionalized disabled subject's bodymind compliance but also naturalizes the violence for the perpetrators. In turn, these repeated acts of violence produce what disability scholar Tobin Siebers, calls "disqualification."²³² Accordingly to Siebers, disqualification naturalizes "inferiority as the justification for unequal treatment, violence, and oppression."²³³ As a result of disqualification "Medicine and charity, not social justice, are the answers to the problems of the disabled body, because the disabled *body* is thought to be the real cause of the problems. Disability is a personal misfortune or tragedy that puts people at risk of a nonquality existence – or so most falsely believe."²³⁴ The commonly used institutional term, "hopeless cases," not only suggested the PSSH

²³² Tobin Siebers, *Disability Aesthetics* (Ann Arbor, MI: University of Michigan Press, 2010), 24-25.

²³³ Siebers, *Disability Aesthetics*, 24-25.

²³⁴ Siebers. Emphasis my own.

inmates possessed a "nonquality existence", but it also gave capacity to those in power to expose disabled subjects to violence in the name of care. These performances of institutionalized care thus created performed repertoires of violence that transferred knowledge about disability to the institutionalized disabled subject and the perpetrator.

Therefore, performances of institutionalized care, such as confining full-grown adults to cribs and restraining children to toilets, transferred embodied knowledge about disability as being disqualified for a flourishing life. As I shall argue in <u>Act III</u>, this repertoire of embodied knowledge gets restaged for entertainment as well as torqued for reclamation by the dis/abled haunters in the Pennhurst Asylum attraction. The contemporary performances in the haunted attraction, as well as their historical counterparts, demonstrate how institutional environments ritualize abuse in a way that constructs a disabled subject's bodymind as impervious to pain, injury, and harm, legally, medically, and socially sanctioning such abuse.



Figure 4: An undated aerial photograph of the Pennhurst State School & Hospital (c. 1940s).

Up on Crab Hill: The Development of Space and Devolution of Care at the Pennhurst State School & Hospital

The devolution of care at the PSSH began with the spatial and material development of the institution itself. Examining this development reveals how, despite the emphasis on education through performances of habilitation—embodied, social performances of nondisabled assimilation—the spatial design of the institution allowed for care to become violence from its inception.

The PSSH opened its doors in September 1908.²³⁵ The Commonwealth built the institution on a plot of land referred to as "Crab Hill," just outside of Spring City, Pennsylvania, approximately a one-hour train ride outside of Philadelphia. Hailed as "the best known skill in modern science" to educate and care for people deemed feebleminded, the PSSH, like many institutions created in the early twentieth century, grew exponentially in a short period of time.²³⁶ The institution used a "colony plan," which included a school, in addition to an industrial, custodial, and farm department. The first buildings constructed by the Commonwealth became part of the "boys' colony" or what was later known as the lower campus. By 1908, six buildings had been built: a dining room and kitchen, a power plant, the school, two wards, and a teachers' residence; in addition to several farm fields and barns.²³⁷

The colony plan gained significant popularity because it accommodated a wide range of inmates with varying bodymind abilities from diverse socio-economic backgrounds.²³⁸ The colony plan also accommodated rapid expansion of the property, as required by growing institutional rosters. Both in name and design, the colony plan functioned to create a space separate from, but still under the control of nondisabled society. This design implied that the institution's role centered on performances of habilitation—vocational training and rudimentary training. While seemingly innocuous, the placement of the institution away from nondisabled society, situated along the

²³⁵ *Philadelphia Inquirer*, "Furniture Comes for State Hospital: Dr. Weeks Hopes to Open at Spring City Early Next Week–Many Men Want Work," September17, 1908, (SFHS), 3.

²³⁶ *Philadelphia Inquirer*, January 11, 1908, (SFHS), 3.

²³⁷ Inquirer, "Looks Like a College," January 11, 1908, (SFHS), 3.

²³⁸ Chelsea D. Chamberlain, "Receiving, Sorting, and Disposing of Children: Institutions, Education, and Feeblemindedness in Progressive America" (PhD Dissertation, Philadelphia, PA, University of Pennsylvania, 2022), 107-108.

Schuylkill River (as represented in Figure 4), implies that the institution intended these performances of habilitation and institutionalized care to remain hidden from scrutiny. Though institutional authorities designed these spaces under the label of education and habilitation, the spaces reinforced social performances of nondisabled existence to the institutionalized disabled subjects committed at the PSSH.

A "Safe and Pleasant Home"²³⁹ or House of Hell: Differing Messages of "Care and Treatment"

This section addresses the PSSH's rapid population growth and the growing eugenic fervor in the first two decades of the twentieth century to better understand the slippage between care and violence. Many institutions, like the PSSH, remained adamant in their public-facing communications that they provided care and education to inmates. And yet, many institution superintendents remained privately, and publicly, concerned about the need to combat disability as a social problem. This dualistic rhetoric, in turn, created competing social imaginaries of both institutions and disabled subjects—and eugenic intent and habilitative hopes—that continue today. As I examine in <u>Act III</u>, this dualistic social imagination of institutionalization and disability lives on through the horror genre's relentless reliance of tropes taken from this rhetoric. But, by first examining the historical evolution of care, the picture of how violence masqueraded as care at the PSSH

²³⁹ PSSH Informational Booklet (1940s), 7.

Writing shortly before the PSSH opened in 1908, a journalist from the *Philadelphia Inquirer* stated, "There is nothing present to the eye which suggests an institution. Built in Colonial style, and with wide avenues and approaches which will be eventually graded and terraced, the buildings resemble a huge boarding school or college."²⁴⁰ This suggests to the reader that the institution's spatial design under the colony plan provided a progressive model for care. Unlike the drearily designed institutions of popular imagination,²⁴¹ the PSSH's design offered the most cutting-edge care and education to its inmates. True to its design, this new and innovative institution quickly reached capacity.

Overcrowding contributed significantly to the transmutation of care into violence at institutions during the twentieth century. Intended, in part, to alleviate overcrowding at its sister-institution Polk, the PSSH suffered from substantial overcrowding almost from inception. Less than a year of its opening, in July 1909, the PSSH already had 257 inmates.²⁴² By July 1913, the institution's population had doubled, with 543 inmates on its rolls; half of its allotted 1,000-inmate capacity.²⁴³ By January 1915, the PSSH had already reached a population of over 700.

This startling population growth, combined with the colony-style layout of the institution, points to several themes within the debates around institutional care during this time. First, as mentioned in <u>Act I</u>, no other form of specialized care for dis/abled

²⁴⁰ Inquirer, "Looks Like a College," January 11, 1908, (SFHS), 3.

²⁴¹ Scholars from philosophy, architecture, literature studies, and horror studies have all examined the stereotypical design of institutions of the nineteenth century. For more, see Diane E. Goldstein, Sylvia Ann Grider, and Jeannie Banks Thomas, *Haunting Experiences: Ghosts in Contemporary Folklore* (Logan, UT: Utah State University Press, 2007); Yanni, *Architecture of Madness*; Foucault, *Madness and Civilization*.
²⁴² Inquirer, "Patients at Spring City," Newspaper clipping, July 28, 1909, (SFHS), 3.

²⁴³ Inquirer, July 31, 1913, (SFHS), 5.

people existed at this time, and institutions served a vital role for families in need. As society became more aware of institutions such as the PSSH, their admissions grew. Second, prevailing institutional philosophy in the early twentieth century still claimed to educate dis/abled people and their families. The *Philadelphia Inquirer's* reporting presents the PSSH as almost utopic—a quasi-boarding school for people deemed feebleminded. The *Inquirer's* presentation of the PSSH to the greater public reified the notion of institutions as a place of education and habilitation. But slippage existed among this idyllic image of the PSSH presented to the public, the realities experienced by the institution's inmates, and the eugenic philosophies of the time.

Eugenic rhetoric grew vitriolic in its targeting of dis/abled people at the turn of the twentieth century. Fear-mongering calls to institutionalize people for indiscriminate reasons became more commonplace. Further, an increasing number of institutional advocates called for "total institutionalization"—the universal and permanent institutionalization of people deemed feebleminded—as well as marriage bans and forced sterilization. For example, a *Philadelphia Inquirer* reporter quoted a warning given to the Pennsylvania Charities and Corrections in 1910 by eugenicist, Dr. Henry H. Goddard:

'We are allowing imbeciles to marry, we are allowing imbeciles to beget and bear children out of wedlock, with the result that our almshouses, our jails, our institutions for our feeble-minded are filled with people who never ought to have been born, who might have been kept from being born if we wisely understood the problem and acted in accordance therewith.' With these words, Dr. Henry H. Goddard, of the New Jersey Training School for Feeble-Minded Children [formerly West Chester University, West Chester, PA], brought home to the delegates the seriousness of the problem of the feeble-minded.²⁴⁴

²⁴⁴ *Inquirer*, November 17.1910, (SFHS), 5. To clarify from the newspaper clipping, Goddard taught on the faculty of West Chester University, in West Chester, Pennsylvania, until 1904. Ironically, he left West Chester University due to a conflict with his department over his teaching load. He went to Vineland so he could have more dedicated time to conduct research. Goddard's quote also raises questions regarding tort

This quote demonstrates how institutional advocates perceived disability and feeblemindedness as not only a medical but also a societal problem, both in Pennsylvania and the United States. Goddard did not argue for separating dis/abled people from society on the basis of care, education, and habilitation. Instead, Goddard proclaimed nondisabled society must segregate and isolate dis/abled people because of the threat of infection and danger posed by disability. In turn, this created a bifurcated purpose of care in the institution. The growing emphasis on the "problem of the feeble-minded," led authorities at the PSSH and other institutions to harness the eugenic ideas that the institution could rid society of a real and present danger. While institutional authorities advocated in public that institutions could curb feeblemindedness, in private, they admitted much less certainty on account of the recessive nature of the trait.

The colony plan—and its spatial design to train high-grade inmates in performances of habilitation—played a significant role in eugenicists' plan of ridding society of the feebleminded. The performances of habilitation taught at the institution allowed for the use of high-grade inmates to care for the low-grade custodial cases. Despite significant underfunding from legislatures, institutions could still expand and accommodate the growing numbers of inmates (which resulted from both expanded testing and a significant push from parents to admit their children). All the while, families and society still firmly believed institutions would provide professional care to their family members with significant care needs and habilitation to their family members

law, wrongful life cases, and dis/ability. For more on topic, see Karen M. Tani, "When a Wrong Creates a Disadvantaged Life," Paper Presentation at the University of Pennsylvania Carey Law School (Philadelphia, PA, July 12, 2023).

deemed feebleminded through vocational and educational training, or performances of habilitation.²⁴⁵

Despite the altruistic rhetoric found in the reporting about the PSSH, the placement of the institution away from public view and the limited visitation periods, combined with the growing eugenic rhetoric around dis/abled people, laid the seeds for fostering an environment for neglect, cruelty, and abuse. As in many institutions, a combination of bureaucratic apathy, underfunding by legislatures, financial mismanagement, and a sheer disregard for the lives of dis/abled people fertilized the roots of systemic issues and allowed for the growth of harmful practices.²⁴⁶ For example, within a year of its opening, the PSSH's first superintendent Dr. H. M. Weeks was charged with allegations of "mismanagement, cruelty and neglect" as well as being a "drunkard".²⁴⁷ (The PSSH's Board of Trustees eventually dismissed these charges.²⁴⁸) By February 1911, the Judiciary General Committee of the Pennsylvania State Senate held public meetings regarding the conduct of the PSSH's Board of Trustees.²⁴⁹ In July 1922, Governor Pinchot announced that he appointed an entirely new Board of Trustees at the institution.²⁵⁰ While none of the former board members discussed specific allegations, Board members claimed the conditions at the PSSH were so deplorable they have "been

²⁴⁵ For more on this slippage between eugenics, institutional superintendents, and families see, Chamberlain, "Receiving, Sorting, and Disposing of Children"; "Challenging Custodialism: Families and Eugenic Institutionalization at the Pennsylvania Training School for Feeble-Minded Children at Elwyn," *Journal of Social History*, March 19, 2021, 1–26.

²⁴⁶ For a wrenching examination of the bureaucratic mechanisms of the institution from the perspective of a ward physician at the Willowbrook State School in Staten Island, New York during the 1970s, see Bronston, *Public Hostage*.

²⁴⁷ Inquirer, September 14,1909 (mis-dated in the PDF as 1908), (SFHS), 3.

²⁴⁸ *Inquirer*, October 4, 1909, (SFHS), 4.

²⁴⁹ Inquirer, February 13, 1911, (SFHS), 6.

²⁵⁰ CR, July 28, 1922, (SFHS) 9.

itching for some time to get a chance to make a full and complete investigation.²⁵¹ The newspaper article also cited that the PSSH had an inmate population of 1,200 (200 over capacity) and only 300 attendants. The second decade of the twentieth century marked the transition from vocational and educational training to warehousing at the PSSH.²⁵²

Welcome to the Pennhurst State School & Hospital: Experiencing the Intake Process in the Mid-Twentieth Century

Pennhurst State School & Hospital in Historiographical Context

This section investigates how the PSSH navigated the slippage between education, care, and violence enumerated in the previous section. It begins by offering context around how lingering eugenic philosophies, bureaucratic mismanagement, and parental apathy led to a hazardous institutional environment during this period.²⁵³ This section then investigates how the institution marketed itself through both discourse and photographic representation, by examining handbooks designed for parents of PSSH inmates by the

²⁵² Overcrowding, legislative underfunding, and lack of oversight were not exclusive to the PSSH and occurred at almost every institution in the Commonwealth. To get a better sense of the PSSH in relation to larger institutional system in the Commonwealth during the mid-twentieth century see, Howard K. Petry, "A Complete Study of the Mental Hospitals of the Commonwealth of Pennsylvania" (Harrisburg, PA: Department of Welfare, Commonwealth of Pennsylvania, July 1944),

https://archive.org/details/reportofcommitte00penn_0/page/n9/mode/2up?view=theater.

²⁵¹ CR, July 28, 1922, (SFHS), 9.

²⁵³ States and institutions also influenced parents during this period. For example, many states mandated the termination of parental rights upon institutionalization. Additionally, institutions, such as the PSSH, placed severe limitations on visitations during this period.

institution. By paying particular attention to what the institution chose to disclose or not disclose in the documents, highlights the attitudes of institutional authorities. To conclude, this section uses narratives mined from local and regional newspaper reporting to glean public perceptions of the PSSH during this period.²⁵⁴

The 1940s and 50s were tumultuous decades for the PSSH. Despite touting a flawless, altruistic image, PSSH leadership remained convinced of its eugenic mission to rid society of people deemed feebleminded. These eugenic philosophies and fears drove the significant abuses experienced by inmates. State and local newspaper reporting from this period is rife with commentary from state and institutional authorities pontificating these philosophies. For example, PSSH Superintendent, Dr. James W. Dean advocated for expanding the institution to free up nondisabled citizens for the war effort by telling reporters for the Pottsville, PA-based, *Daily Republican* in 1944,

I do not need to remind you of the enormity of the problem of mental deficiency in Pennsylvania. Our homes, our schools, our churches, our welfare agencies, and particularly our criminal courts, are quite as conscious of it as is the Department of Welfare. As a matter of record, however, it might be well to state here that estimates reveal that there are some 190,000 mentally defective individuals in the Commonwealth of Pennsylvania; 10% of these normally should require institutionalization, while actually slightly less than 5% are institutionalized in the Commonwealth in both public and private institutions. In other words, 95% of the mental defective population roams at large. Estimates reveal that they out-reproduce the normal families by approximately 50%.

While this problem, is serious enough in peace time, it is all the more important in time of war. Mental deficiency has a distinct relation to the war effort, both from a domestic as well as a community standpoint. From a domestic standpoint, many a relative or parent in a home could be freed for

²⁵⁴ While the PSSH may have made multiple versions of these handbooks, only two have surfaced in my archival research. The handbook primarily analyzed in this section is undated but was published sometime during 1943-1945. I have determined this through cross-referencing the employees and superintendent mentioned in the handbook. Additionally, the handbook mentions the "war effort." PSSH published the other handbook in 1954.

military service or defense produce were these dependents institutionalized. From a community standpoint, the situation is all the more serious. At the present time the entire nation, as you know, is most alarmed over the unusual rise in juvenile delinquency. The percentage of mental deficiency in juvenile delinquency is high; and I am convinced that the roll call of our prisons and reformatories could be materially reduced in the immediate future were these mentally defective youngsters institutionalized early enough, before they became seasoned delinquents.

Also, as a matter of record, I should point out that the situation attending mental deficiency differs markedly from that attending the insane. Many of the insane, as you know, are curable, while no mental defective is ever curable, although by long training his self-sufficiency may be improved to a degree compatible with his return to society. The waiting list of an asylum may vary and may often decrease, but the waiting list of an institution for mental defectives can be made to decrease only by deaths or admission. I mention this self-obvious fact because it has a definite bearing upon the extent to which this institution should immediately expand.²⁵⁵

Written almost two decades after the "height" of the eugenic movement, Dean's quote mirrored calls by earlier institutional superintendents and eugenicists such as Goddard in 1910. Dean links disability—particularly childhood disability—with delinquency, crime, poverty, a lack of labor productivity, and an over-abundance of sexual reproductivity. Unlike insanity, which held hope of a cure, Dean argued mental deficiency remained a permanent defect and required swift action to contain. Thus, society would need to fund further institutionalization to control the continuing problem of the mental defective (or as authorities increasingly referred to dis/abled people during this period, the dependent, delinquent, and defective).

Dean also cited an out-of-control population of disabled defectives roaming free, like a heard of wild animals, contributing to crime, and robbing the nation of productive bodyminds—nondisabled citizens. As such, this quote positioned disability as that which

²⁵⁵ Daily Republican, January 1, 1944, 43.

nondisabled society must fear and control. The only hope for nondisabled society's survival through this moment of compounding crises was to identify, categorize, and capture dis/abled people in institutions. In turn, nondisabled people could return to fulfilling their duties as citizens and assist in the war effort. Institutions like the PSSH, Dean argued, needed further funding from legislatures to curb this growing issue and accommodate more inmates. In 1947, Dean doubled down on his public calls to rid society of disability. Speaking with a reporter from the *Inquirer*, Dean expressed his hope that "the institution may assist in removing the foul blot of feeble-minded from human life..."²⁵⁶

Superficial examination of this period suggests an almost conspiratorial air of nefarious intentions on behalf of institutional authorities. Despite almost constant construction of new buildings until the 1940s, the PSSH reached its peak population and warehoused 3,869 inmates in spaces designed to hold only 2,800 in 1957.²⁵⁷ In 1958, the PSSH reported only having four physicians, an regiment of approximately 300 staff, and a waiting list of 900 people.²⁵⁸ Superintendent Dr. Leopold Potkonski lamented to reporters in 1958, the institution "is very much undermanned, both by physicians and attendants."²⁵⁹ This continued pressure on the institution by the Commonwealth's General Assembly to do more with less impacted both the employees and the inmates.

²⁵⁶ Philadelphia Inquirer, July 26, 1947, 46

²⁵⁷ Daily Republican, February 7, 1957, (SFHS), 70.

²⁵⁸ Daily Republican, February 7, 1957, (SFHS), 70. The exact number of PSSH staff is difficult to ascertain. I cite this staff number from J. Gregory Pirmann, "Living In a World Apart," in *Pennhurst and the Struggle for Disability Rights*, ed. Dennis B. Downey and James W. Conroy (University Park, PA: The Pennsylvania State University Press, 2020), 50.

²⁵⁹ Daily Republican, February 7, 1957, (SFHS), 70.

especially those with significant care needs. In turn, aides often turned to using performances of institutionalized care—various forms of physical and chemical restraints—to control inmates and ensure their compliance within the institutional space.²⁶⁰

These performances of institutional care led to numerous investigations by state and federal agencies during this period. The PSSH received near-constant scrutiny pertaining to overcrowding, malpractice, bureaucratic mismanagement, and suspicious deaths. In 1949, the State Police investigated the death of an inmate under questionable circumstances and found evidence that, on at least one occasion, someone other than the attending physician altered inmates' death certificates.²⁶¹ Former PSSH employees also went on record describing "cruel and unusual punishment" of inmates. For example, an aide working in a female ward detailed to reporters a commonly used practice at the PSSH called a "cold dip."

The patient is placed in a strait jacket and her head and shoulders are repeatedly held in a tub of cold water until she becomes unconscious. The patient... was then revived by being slapped and shaken, and the process repeated. Afterward the girl was placed in solitary confinement.²⁶²

Cold dips functioned as yet another act of heinous violence enacted and repeated in the name of care as a behavioral modification technique. Employees often inflicted this form of violence in response to inmates that would not or could not conform to the institutional environment. This repeated embodied practice then transferred knowledge to both inmate

²⁶⁰ James W. Conroy and Dennis B. Downey, "The Veil of Secrecy: A Legacy of Exploitation and Abuse," in *Pennhurst and the Struggle for Disability Rights* (University Park, PA: The Pennsylvania State University Press, 2020), 64.

²⁶¹ *Philadelphia Inquirer*, June 3, 1949, (SFHS), 48.

²⁶² Chester Republican, June 10, 1949, (SFHS), 52. This notorious practice remains used in institutions.

and perpetrator. To the inmate, it communicated that anything other than performances of habilitation and compliance to institutional norms would result in pain and torture. It communicated that their human needs—emotions, comfort, safety, and wellness—ultimately did not matter.

To the perpetrator, this act communicated that the inmates were less than human—worthy receptacles of harm—and, as such, their actions would go unpunished. While actions such as the "cold dip" may suggest that all institutional staff were cruel, sadistic and, at the very least, uncaring, this was (and often remains) not true. Often, the dehumanizing environment of the institution—long hours, low-wages, insurmountable demands—also dehumanized staff, especially those providing direct care. This theme continues in HCBS programming today.²⁶³ Violence often was (and remains) systematic; not gratuitous or personal. Violence presented itself as a method to make the institution *work* by bringing dis/abled bodyminds into compliance with its functioning.

As the ultimate authority on what types of care inmates received, and what types of disciplinary measures institutional employees received for violating regulations, Superintendent Dean's lack of regard for human life directly influenced all levels of power within the institution. For example, the aide that detailed the cold dip told reporters, "This treatment was given by the attendants, but had the sanction of the 'higher-ups'... The immediate assistant to the supervisor of the female patients administered the 'cold dip' [the aide] witnessed."²⁶⁴ Further, another former PSSH aide

²⁶³ Hakim, "At State-Run Homes, Abuse and Impunity"; Kendall Taggart et al., "Profit, Pain, and Private Equity: The Private Equity Giant KKR Bought Hundreds of Homes for People with Disabilities. Some Vulnerable Residents Suffered Abuse and Neglect," *BuzzFeed News*, April 25, 2022, https://www.buzzfeednews.com/article/kendalltaggart/kkr-brightspring-disability-private-equity-abuse.

²⁶⁴ Chester Republican, June 10, 1949, (SFHS), 52.

told reporters that "The extent of official connivance in the mistreatment of prisoners... was evidenced by the fact that only special attendants were singled out to enter Buildings U-2, the punishment block at the PSSH, and that each of these men was issued a special key for the doors to the building."²⁶⁵ Taken together, these reports by PSSH aides represent a pattern of institutional authorities ignoring and even engaging in the abuse, neglect, and harm of inmates. The beliefs held by institutional leadership, such as Superintendent Dean, that the inmates were bare life, trickled down to the lowest rungs of the institution's employee hierarchy. Evident throughout the entirety of the PSSH's history, the disregard for human life and the positioning of disability as inferiority created environments in which such abuses could run rampant.

Throughout this period the PSSH also opened its doors to researchers, such as Dr. Joseph Stokes, Jr., of the University of Pennsylvania, to complete various forms of research on inmates. This research further highlights how institutional authorities viewed dis/abled inmates not as people, but as viable subjects for their (often unethical and devastatingly harmful) research. While I have not yet ascertained the exact extent of "research" that Stokes and others conducted at the PSSH, institutional materials cite studies completed to combat infectious disease. The 1940s handbook, for example, explains that studies were "carried out under the direction of the professor of pediatrics of the University of Pennsylvania."²⁶⁶ My archival research has revealed exchanges of correspondence between Superintendent Dean and Dr. Stokes in December 1945 and January 1946. In these correspondences, the doctors discuss "medical research projects

²⁶⁵ Chester Republican, June 10, 1949, (SFHS), 52.

²⁶⁶ Pennhurst State School & Hospital, Parental Handbook, circa 1943-45.

[Stokes] has undertaken here in connection with immunization against influenza and other infectious diseases."²⁶⁷ Stokes replied,

I believe the fact that Pennhurst was included in the inclosed [sic] reprints should be used with the greatest caution, since this fact might be readily misunderstood if broadly publicized. We have omitted the names of the institutions. If you use openly the name of the institution in mentioning the work, emphasis should be placed upon the fact that no study was ever conducted which would not redound to the benefit of the inmates.²⁶⁸

I cite this correspondence to illustrate the slippage between care and violence in the minds of institutional authorities. Stokes' language suggests that he, and presumably Dean, believed that these trials proved not only necessary but advantageous to society and the inmates. They did not discuss the ramifications of those trials on the dis/abled people they experimented on. Further, the PSSH was not the only institution during this period to conduct these research studies.²⁶⁹ Many university researchers held comfortable relationships with institutional authorities, who offered their inmates up as test subjects. For example, researchers conducted polio vaccine tests at Polk State School & Hospital in Pennsylvania and hepatitis studies at Willowbrook State School in Staten Island, New York. These experiments at the PSSH and other institutions, illustrate not only a violation of the Nuremberg Code—the fundamental document to the field of bioethics and

²⁶⁸ Letter to James W. Dean by Joseph Stokes, Jr. January 14, 1946, Joseph Stokes, Jr. Papers, Series III, Hospitals, Universities; American Philosophical Society, Philadelphia, PA.

²⁶⁷ Letter to Dr. Hilding Bengs, Assistant Director, Bureau of Mental Health, Department of Welfare, Harrisburg, PA by Dr. James W. Dean, December 29, 1945, Joseph Stokes, Jr. Papers, Series III, Hospitals, Universities; American Philosophical Society, Philadelphia, PA.

²⁶⁹ Institutions have conducted unethical research on inmates since their inception, and this was not an issue confined to solely to the twentieth century. For more, see Jirik, "American Institutions," Chapter 3.

biomedicine, which mandates the researcher receive the subject's consent—but a sheer disregard for dis/abled people as human beings.²⁷⁰

Despite these overwhelmingly negative reports of life in the institution, public and parental perceptions of the PSSH during this period remained mixed. In letters sent to Governor James Duff, some parents expressed outrage after reading claims made by journalists regarding the PSSH's treatment of their children. Yet others wrote to Duff celebrating the institution and stated their willingness to "testify to the courtesy and kindness and wonderful care which [their children have] received at Pennhurst..."²⁷¹ These mixed reviews on the behalf of parents also highlight a historical and contemporary discrepancy between parents of and families with dis/abled children. On one hand, some families want the best for their dis/abled family members and advocate for the best scenarios possible for them. On the other, some families want their loved ones cared for, but accept certain realities of custodial care which sacrifices the autonomy and freedom of their dis/abled family member. In return, the nondisabled member can relieve themselves of the "burden" of carrying for their dis/abled family member.²⁷²

²⁷⁰ Even though the Nuremberg Code was not drafted until 1947, Stokes' language suggests he anticipated public scrutiny and disapproval, at least indicating that Stokes understood *carte blanche* access to institutionalized research subjects was increasingly under scrutiny.

²⁷¹ Letter to Duff from Maria C. Rainear (1949), MG190, James H. Duff Papers, 1943-1951, PSA.

²⁷² American society's ongoing reliance on large, segregated group homes, intermediate care facilities, and custodial institution—as well as nursing homes, which are modern equivalents of almshouses—underscores the continued presence of the latter.

"The General Nature of Pennhurst": The Pennhurst State School & Hospital as Experienced through Parental Handbooks

A World Apart

The positioning of the PSSH, and its inmates, as an idyllic "world apart" led to the devolution of care into violence and the horrors that occurred there by labeling dis/abled people as inferior and sequestering them from society. In turn, permanent custodial institutionalization was not deemed as social death, but as a haven. Newspapers were not the only source to position the institution as a refuge for society's most vulnerable. PSSH authorities carefully crafted its image to create an illusion of the institution as a refuge, especially in the parental handbooks.

Both handbooks consist primarily of photographs with headings and limited bodytext writing. The language used describes various aspects of the institution, and its purpose, while the photographs depict what the PSSH called "everyday life" in the institution. The primary difference between the two handbooks is the photographs. The language, including a "Note to Parents" written by two different superintendents, remained strikingly similar. Each handbook depicted the PSSH, and the process of committing a family member to the institution, as a seamless and painless affair. The handbooks provided to the families of inmates highlighted this curated image of an idyllic home for dis/abled people, all while it reified the inferiority of disability. Both handbooks open with a "Letter to the Parents" written by the Superintendent.

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One of the most obvious and poignant themes taken from the "Letter to Parents" is how the PSSH viewed itself as a separate place from the outside world. Writing in the 1940s, Superintendent Dean comforts parents:

if you have left your child at the Pennhurst State School in our care, or are planning to do so, let me urge you to disabuse your mind of needless worry or feeling of parental guilt. The Commonwealth of Pennsylvania has provided very remarkable facilities of all kinds for the welfare, treatment, and education of your unfortunate boy or girl. If the outlook for the child is hopeless for training, you will be given expert advice to this effect and we shall do all that is medically possible to make him happy and comfortable. And, if the outlook is hopeful, let me say that when you leave your child in our hospital, rather than feel you have sealed his doom, be assured you have probably opened a gate to many opportunities for him.²⁷³

Dean's words created two-fold expectations for parents. First, under the medical gaze, their dis/abled child lived an "unfortunate" life, and only the medical doctor and the institution could help them. Dean positions the PSSH as a utopic refuge—a lifeline for institutionalized disabled subjects and their families. While still separate from society, the PSSH offered a disabled family member an abundant chance for opportunity for those deemed "hopeful," and palliative care for those deemed "hopeless." Critiquing the meaning of labels assigned to dis/abled people, disability activist Simi Linton argues, "Society, in agreeing to assign medical meaning to disability, colludes to keep the issue within the purview of the medical establishment, to keep it a personal matter and 'treat' the condition and the person with the condition rather than 'treating' the social processes and policies that constrict disabled people's lives."²⁷⁴ In this way, Dean's words reified the medical establishment's authority over dis/abled people and their families. Only the

²⁷³ Pennhurst State School & Hospital, Parental Handbook, circa 1943-45, 2.

²⁷⁴ Simi Linton, "Reassigning Meaning," in *Beginning with Disability: A Primer*, ed. Lennard J. Davis et al. (New York, NY: Routledge, 2018), 22.

institution and its professionals could understand and care for children deemed feebleminded.

Second, while the PSSH provided more specialized care for its inmates than an average family could at home, it held institutionalized disabled subjects as categorically different from the rest of nondisabled society. This understanding of disability as different—as disqualified for humanity—allowed for continued abuses to occur. Dean's language enforced the same negative ontological assumptions of the institutionalized disabled subject found in the commitment trials examined in the first Act. Dean describes the institution as offering "remarkable facilities of all kinds for the welfare, treatment, and education for your unfortunate boy or girl." This language explicitly illustrates how while Dean (and the Commonwealth) views the PSSH as fulfilling a necessary social function by providing care and treatment, institutional authorities ultimately perceive the inmates committed to the institution as inherently inferior to the rest of nondisabled society. Thus, the "opportunity" Dean spoke of came through the institution removing the problematic disabled subject from society and offering them an opportunity for vocational training in service of the institution.

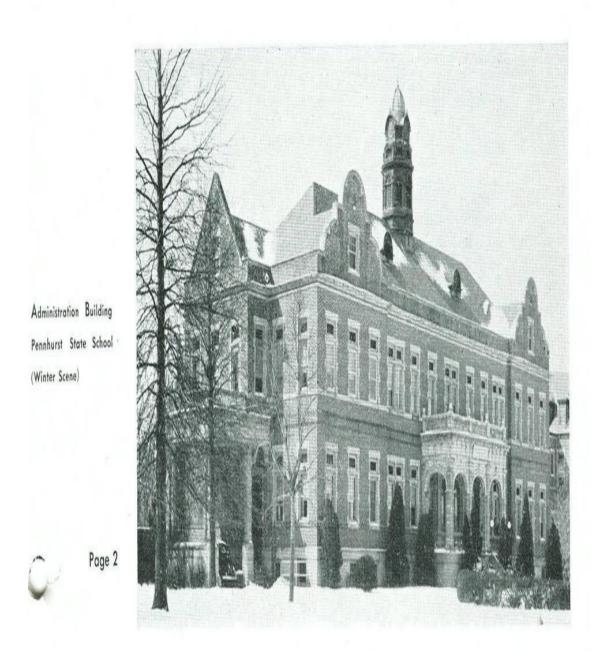


Figure 5: Photocopy of a page from the Pennhurst Parental Handbook (c. 1940s).

To further position the PSSH as an idyllic refuge the creators of the handbook placed numerous photographs in the document. The photographs used throughout the handbook presented the PSSH as spatially distinct from nondisabled society. Figure 5 directly followed Dean's note quoted above and is captioned as: "Administration Building Pennhurst State School (Winter Scene)." The photographs depicted various scenes from the exterior of wards to inmates working in the fields and factories on campus, as well as ample scenes of leisure activities like male inmates playing baseball or female inmates swinging around a maypole. Taken together, the photographs paint the PSSH as something reminiscent of a summer camp or boarding school. Strikingly absent are interior photographs of the wards, especially the first-floor institutional wards where authorities placed the low-grade and crib-case inmates, within the booklet. In this way, the handbook animates a past and present that exists behind a screen of institutional occlusion. The handbook and the scenes depicted in its photographs present a façade of altruistic care and serenity. In turn, the presentation of the PSSH in this handbook, at its best, obfuscates the realities of neglect and harm experienced by its inmates. At its worst, this presentation convinces parents and families that institutionalized care is the best option for their family members.

Education

Institutions of the twentieth century operated under a contradictory philosophy of use. On the one hand, overt and subconscious ableism and eugenics guided institutional policy. On the other, institutions, like the PSSH, remained adamant that they educated inmates. The PSSH, for example, used their public facing documents to duplicitously position themselves as a benevolent provider of care and education. While inmates would never reach the full potential of a nondisabled bodymind, the institution—or so it claimed offered a home for those "unfortunate" enough to experience disability.

By positioning the institution as an idyllic refuge, these documents contributed to the horrors of the institution, through what James W. Conroy and Dennis B. Downey call, "The Veil of Secrecy."²⁷⁵ This veil of secrecy—the public-facing idyllic image—made the everyday occurrences of abuse and neglect nonapparent. Yet these parental handouts advocated for the education of high-grade inmates while simultaneously admitting to being unable to care for low-grade inmates. In the 1940s handout, PSSH authorities state:

Pennhurst State School is at the same time a hospital and a school, having the dual purpose of providing adequate custody for all patients and of providing all necessary facilities for diagnosis, treatment, education, and training. It is our aim to provide a safe and pleasant home and at the same time try to simulate conditions of the outside world as much as possible, especially for those children whom we hope eventually to restore to society with some measure of self-sufficiency. The entire institution is, in fact, quite comparable to a small city with an adjacent farm.

Approximately one-third of our patients are paralyzed, helpless, and hopeless for training. For these unfortunates we can render only custodial bed care. In many instances these children could better have been cared for at home and their presence here simply deprives an opportunity for a more hopeful patient on our waiting list. While we therefore discourage the admission of such hopeless cases, every medical and nursing attention necessary is rendered them.²⁷⁶

Referring to nondisabled society as "the outside world," the PSSH marks itself as a place specializing in social performances of habilitation. The institution thus teaches inmates through simulating "conditions" of nondisabled society with the hopes of returning the inmate to the community. But this education extends only to the high-grade inmates.

In the second paragraph, the institution marks a clear divide in its purpose and the types of institutionalized disabled subjects who receive an education. The PSSH stated it will *only* provide education to high-grade inmates that still presented the hope of being "restore[d] to society with some measure of self-sufficiency." The institution further laments to families regarding the abundance of "helpless, and hopeless...

²⁷⁵ Conroy and Downey, "Veil of Secrecy," 58.

²⁷⁶ Pennhurst State School & Hospital, Parental Handbook, circa 1943-45, 7.

unfortunates...". Because no other options existed for families in need, a coy admission of guilt—the institution admitted it could "render only custodial bed care" for low-grade inmates (putting an inmate in a crib or gurney until they die)—served to remove the institution from liability of apathy and violence. In this way, the PSSH openly conceded to the inevitable neglect and death for a certain population of inmates. Further, this concession created two repertoires of disability.

First, it created a preference—under the nondisabled gaze—for so-called highgrade disabled subjects over low-grade subjects. This preference suggested that dis/abled people with less apparent dis/abling conditions or care-needs literally held more hope or promise for a useful, but still institutionalized life. The counterpoint to this, however, becomes that high-grade inmates got positioned as an *almost-but-not-fully nondisabled person.* In turn, they became caricatures of ability-lost, or what I theorize in <u>Act III</u> of this dissertation, as the spectre of disability: disability as that which haunts and terrorizes nondisabled society. All the while, the institution actively abjected the inmates with more apparent dis/abling conditions and/or significant care-needs into a space of bare life by designating them as low-grades.

This abjection created a dynamic of ableist skepticism towards dis/abled people in how legal, medical, and policy authorities determined a person's eligibility—e.g., impairment—to receive benefits based on disability status. All the while simultaneously preferencing an institutionalized disabled subject's ability to work as a corollary to societal approval.²⁷⁷ Both the skepticism and preference for production depend on

²⁷⁷ For a critical analysis of the contemporary connection between disability, illness, health, and labor production see, Beatrice Adler-Bolton and Artie Vierkant, *Health Communism* (Brooklyn, NY: Verso, 2022).

performances of disabled appearance. This bifurcation further deepened the divide between those deemed high-grade and low-grade.

On one hand, the institution positioned high-grade inmates as simultaneously dangerous (due to their ability to pass as nondisabled) yet educatable, definitively disabled yet possibly an imposter.²⁷⁸ On the other, the low-grade inmate's apparent performance of disability marked them as necessary cases for institutionalization, uneducable, and a general drain on society. In this way, institutionalization set a precedent that does not allow dis/abled people to authenticate our own bodymind experiences. Only experts—often nondisabled and trained in professional disciplines— can determine the difference, however, and only after a thorough examination.

What these documents do not capture, however, is what the experience of the admission process of the inmates of the PSSH was like for the inmates themselves. The experience of being committed to the institution, ruptured the veneer of the PSSH as a place of care and tranquility set aside in the rural hills of Chester County, Pennsylvania.

²⁷⁸ This later notion becomes intertwined with the more contemporary concept of the "welfare queen" and becomes significant to politicians concerned with the overuse of social welfare. For more on faking disability see, Doron Dorfman, "Fear of the Disability Con: Perceptions of Fraud and Special Rights Discourse," *Law & Society Review* 53, no. 4 (2019): 1051–91.

The Intake Process: "Tender, Kindly Care" or Embodied Terror?

"Tender, Kindly Care": Intake from the Pennhurst State School & Hospital's Perspective

This next section moves from examining how the PSSH curated its outward appearance for families to investigating the intake process by comparing perspectives of the experience. This section begins by giving context to the intake process and examining the official account offered by the PSSH authorities from the parental handbooks. Next, I contrast that with the perspective of the late PSSH survivor and self-advocate, Roland Johnson. This inquiry reveals how, from the outset, the institution generates terror, harm, and trauma disguised as care.

While some specifics of the admission process for PSSH inmates varied throughout the decades—such as the physical locations of where certain activities occurred—the basic exercises involved in this ritualistic practice remained relatively similar. Once committed to the PSSH, parents, guardians, or law enforcement brought the inmate to the institution. Upon arrival, a small team of authorities examined the inmate.

A parental handbook from 1954 details the process stating:

A new admitted patient spends the first two weeks in the Hospital under constant supervision of a nurse. During this time, observations of the patient's health, behavior, abilities, habits are made and noted. A series of examinations follow, that comprise of physical, neurological, psychiatric, psychological, laboratory, dental, and x-ray tests.

The child is vaccinated and inoculated at spacings throughout the first two months. A chart is started that follows the patient wherever it [sic] is assigned, recording any change in weight or condition relative to its health and welfare. The initial orientation occurs in the hospital. The association with other children is studied. Simple but satisfying answers are given to

their many questions. The nurse and her associates who are trained to provide emotional security for the child create an atmosphere wherein the patient receives tender, kindly care which substitutes for the absence of parental love so essential to effect a successful adjustment to institutional life.

•••

[After placement in a ward,] The Head Nurse's daily visits usually determine if a child is properly placed. The conduct, ability to socialize with others is noted. The prevalent mood is observed. Oftentimes transfer to another ward or cottage will greatly aid adjustment.²⁷⁹

This passage is quoted at length to illustrate how the institution perceived the intake process for the new inmates. It suggests to families that institutional authorities could provide care and emotional support to their loved ones, while positioning the two-week period of observation as necessary and useful for the inmate's "successful adjustment to institutional life." This quote further illustrates how the institution viewed itself as the predominant source of care for people deemed feebleminded and the individualized, biological problems their disabilities manifested.

While this process reads as consisting of a routine regiment of medical procedures for ensuring the inmates' adjustment to the institution, it also functioned to communicate embodied knowledge to the inmate. First, the intake experience—from the PSSH's perspective—placed the care and love given to a child by their parents on an equal footing with that given by the institution. And yet, the materials went so far as to refer to children as "it" in their description. This subtle change in language—whether intentional or not—again highlights how the institutional environment dehumanized dis/abled people. Second, the setting of the hospital communicated knowledge regarding separation

²⁷⁹ Pennhurst State School & Hospital, Parental Handbook (1954), 9, emphasis added.

and segregation to the inmate. Located on the western end of the campus—spatially separated from the wards—the physical separation of the hospital complex from the rest of the institution's wards signaled complete abandonment of the inmates. Third, the hospital setting allowed authorities to constantly review and monitor the inmate, which ensured total control over the inmate and guaranteed the inmates' compliance to institutional norms. Finally, this spatial separation also allowed for more abuses to occur. The literal distance between the hospital complex and the administration building (let alone the wards), allowed for employees in the hospital to act often without review by their superiors. This spatial design further allowed for a lack mandatory reporting of abuses since the inmate would go directly to the institution's hospital.

"I'm Here for Life": Embodied Terror & The Intake Process for the Inmate

Despite the institution positioning the intake process as providing a level of care equivalent to that which the inmate received at home, the process caused inmates significant harm and trauma. In stark contrast to the official account of the intake, is the experience as recounted by a Black PSSH survivor and self-advocate, Roland Johnson. Born in 1945, Johnson grew up in a working-class family in North Philadelphia. Johnson's parents committed him to the PSSH at age twelve, due to disruptive behavior. After thirteen years in the institution, the PSSH paroled Johnson, and he eventually received community-placement in various group homes.

The quotes below come from Johnson's autobiography, *Lost in a Desert World* (*As Told to Karl Williams*), published in 1994. Karl Williams, a White neurotypical artist and disability advocate recorded Johnson giving his oral history and transcribed the tapes

into a monograph. The idea came to Johnson after Williams recorded several oral histories with other self-advocates for a book project sponsored by the self-advocacy organization, *Speaking For Ourselves*. Williams recorded Johnson at Johnson's home in Collegeville, Pennsylvania, over several sessions. According to Williams, he started the interview by asking Johnson about his family. From there, "he'd say something that would lead me to ask him about something else completely different", Williams described over an email.²⁸⁰ Detailing the process of interviewing Johnson, Williams said, "I don't believe there are any places on the tapes where he spoke about a topic in what you could call a paragraph – I was always asking him questions to find out more & then I put his sentences together to make the paragraphs in the book."²⁸¹

Unlike the necessary but tender and kindly care described by PSSH authorities, Johnson described what intake process was like from an inmate's perspective. In his autobiography, Johnson detailed the process of his intake to the institution in 1958, saying:

I saw Pennhurst for the first time. Where you come down on the main road you see this big thing up at Pennhurst, the water tower, coming into Pennhurst. Things looked different to me—because it wasn't like a house that I lived in. I'm out here in this gray institution with three thousand people that live in it. ... They admit me on the hospital ward. ... I didn't know the first thing about the place; didn't know where I was going or what I was doing there. ... Well, I was on the hospital ward. They interview your mother — my mother — and they axed my mother some questions. I wasn't there; I was getting undressed to be on the ward. I didn't know what she was saying; I don't know what took place.

But once I was there [in the hospital ward] things got very overwhelmed to me. I stayed there for a week and ten days. They did some tests, psychological evaleration and stuff like that. The doctor kept axing questions. It was so much overwhelming that there's this great big ward

²⁸⁰ Karl Williams, "Question about Roland's Autobiography," October 12, 2022.
²⁸¹ Williams.

with all these people; I'm used to my mother and father, my sisters. Never was used to all these other people around. It was just something. I was just crying, with tears. I cried that, "My mommy's gone; my daddy's gone. I will never see my sisters again or my brother or anybody. I'm here for life.²⁸²

Johnson's retelling of the intake process at the PSSH illustrates a different narrative from that of the institution. Nowhere in either parental handbook did the superintendents describe the process of separating an inmate from their parent or guardian, the questions asked of an incoming inmate, or the ways in which that experience could traumatize a person, especially a young child.

Johnson's narrative elucidates several components of how the intake process caused harm to incoming inmates. First, as mentioned earlier, the separation of the child from their parents or guardians in the hospital ward generated a sense of confusion, loss, and abandonment. Second, forced to remove their clothes, the inmates literally and metaphorically became bare life. In the moment between removing their clothing from the "outside world" and donning their institutional clothing, the inmate became stripped bare, made vulnerable, and ultimately, docile to the institutional regime. Finally, the bombardment of examinations—coupled with the physical separation of the hospital ward—created a repertoire of surveillance and observation for the disabled subject. The examinations did not provide the "tender, kindly care" the institution advertised to families.²⁸³ Instead, the intake process measured and regulated the institutionalized

²⁸² Roland Johnson, *Lost in a Desert World: An Autobiography (as Told to Karl Williams)* (Philadelphia, PA: Speaking for Ourselves, 1994), 26.

²⁸³ The available archival documents provide little to no information on the exact "examinations" performed on inmates upon admission. However, context has been gained through information gleaned from Johnson's autobiography and oral histories with former PSSH employees and survivors.

disabled subject's every movement. Thus, provoking an unfathomable degree of terror and trauma for the inmates.

Performances of Habilitation & Institutionalized Care: Existence at the Pennhurst State School & Hospital for High- and Low-Grade Inmates

This section examines the practices of everyday in the institution more closely, to understand how restraint, neglect, and abuse came to represent performances of institutionalized care. First, this section provides overview sketches of both high- and low-grade inmates to understand how the institution not only categorized its inmates but how that category impacted the types of care inmates received.²⁸⁴ Then, the investigation becomes more granular by offering case studies from individual inmates' experiences. In doing so, these cases highlight specific patterns of performances of habilitation and institutionalized care found at the PSSH.

²⁸⁴ While "low- and high-grade" was the official terminology, staff in direct care roles, and sometimes even inmates, often developed their own systems of classification. Furthermore, institutional authorities often applied only perfunctory labels when examining inmates, just to adhere to the management standards stipulated by the State for funding purposes. For an account of this within New York State and the Willowbrook State Hospital, refer to Bronston, *Public Hostage*.

Existence as a High-Grade, "Working" Inmate

Peonage as a performance of habilitation defined high-grade inmates' existence in most institutions until the 1970s.²⁸⁵ At the PSSH, peonage was a performance of habilitation commonplace for high-grade inmates, because the PSSH, like other institutions, crafted its notions of habilitation through labor. A discursive analysis of the mission statement from the PSSH's bi-annual report to the Commonwealth's General Assembly in 1926 reveals how the institutional philosophy of use and performances of habilitation, coupled with the design of the PSSH as a world apart, led to the outcome of warehousing and abuse that plagued the institution throughout its existence.

The Institution's Mission: Performances of Habilitation

Performances of habilitation served as the primary tool for monitoring and enforcing compliance within an institutional space. In a bi-annual report to the Commonwealth from 1926, the PSSH states its "aim" as:

To train each and every one of the patients so that they may be more useful to themselves and those in charge of them; to eliminate asocial and other undesirable habits and replace these habits with habits of industry and habits that are socially acceptable; to bring out and develop in the individual patients all abilities that will help to make the patient as near self-supporting as possible and return to the community all those patients whom we believe

²⁸⁵ In Souder v. Brennan, No. 367 F. Supp. 808 (D.D.C. 1973), the U.S. District Court for the District of Columbia ruled that the Fair Labor Standards Act covered inmates at non-federal institutions as "employees." In turn, they became eligible for minimum wage and overtime compensation. This effectively ended institutional peonage because state institutions could not afford to pay their inmates. To counter the resulting labor shortage, institutions began recruiting volunteers. For example, at the PSSH, a program called "foster grandparents" was initiated. This was a group of elders volunteered to provide basic care around the institution and mentor inmates. The Commonwealth of Pennsylvania also outlawed peonage in the state in 1973, see "Institutional Peonage Abolishment Act," Pub. L. No. 731 (1973), https://www.legis.state.pa.us/CFDOCS/Legis/PN/Public/btCheck.cfm?txtType=PDF&sessYr=1973&sessIn d=0&billBody=S&billTyp=B&billNbr=0731&pn=0791.

to be socially and industrially fit and for whom homes can be found that will give the patient such supervision, direction, and care as the patient's mental condition demands. A field Agent [sic] supervises these parole cases and aids them to re-adjust themselves to normal living conditions, thereby allowing the Institution to better serve its district by having under its supervision a larger number of cases than could be accommodated in the Institution and caring for this larger number of cases at a lower cost than would be possible should they all be permanently retained in the Institution.²⁸⁶

This language highlights how the institution, as a space, both generated and governed performances of habilitation that taught nondisabled social norms through labor practices. The institution sought to "train" high-grade inmates to become "more useful to themselves and those in charge of them".²⁸⁷ At the PSSH, and other institutions, high-grade inmates often provided unpaid care and labor for the institution. Doing so allowed institutions to commit more inmates while operating under the heinously low budgets often provided by state legislatures.

This institution did not, therefore, implement this training strictly for the betterment of the inmate. By the institution's definition, the inmates benefited from the institution's vocational training by (supposedly) making inmates into gainfully employable subjects. The state benefited from this arrangement also. The Commonwealth saved money by the institution's ability to train high-grade inmates and use the inmates' performances of habilitation to care for other inmates, grow the institution's food, make clothes and shoes, do laundry, among anything else that institutional authorities could rationalize as vocational skill training. All the while, the institution benefited because it

²⁸⁶ "Report of the Pennhurst State School, 1924-1926" (Spring City, PA: Pennhurst State School, June 1, 1926), 7.

²⁸⁷ "Report of the Pennhurst State School, 1924-1926," 7.

could continue to admit more inmates without necessarily having to hire more employees.

The first sentence from the block quote also highlights an unstated assumption that the institution could not eliminate all "asocial and other undesirable habits."²⁸⁸ Ward reports in patient files as well as newspaper reports often noted that institutional authorities often ignored, neglected, and abused those institutionalized subjects unwilling or unable to perform "socially acceptable" behaviors in compliance to the institutional environment.²⁸⁹ As noted earlier, the colony design intended to accommodate as many abilities as possible. Disability historian Chelsea Chamberlain observes, "Because this system valued and relied on high-grade residents as productive laborers, it de-prioritized and often neglected more severely impaired residents. Their inability to be economically productive, the extra help they might need to participate in institutional entertainment and travel, the tendency of families to accept more readily that a severely-impaired child was incurable... meant that institutional life generally centered on those diagnosed as imbeciles or higher."²⁹⁰ In turn, institutional authorities perceived those diagnosed below imbecile—idiots and low-grades—as subhuman. Or, as Brown writes in the epigraph, "You're living, yet already your body has started to decay. It knows you are not for this world."291 Institutionalized subjects deemed low-grade received a *de facto* death sentence. Often confined to endless rows of cribs on the first floor of the wards, the institution forced these inmates into performing nonexistence.

²⁸⁸ "Report of the Pennhurst State School, 1924-1926."

²⁸⁹ "Report of the Pennhurst State School, 1924-1926."

²⁹⁰ Chamberlain, "Receiving, Sorting, and Disposing of Children," 107-08.

²⁹¹ Brown, "Poems."

The block quote from the Bi-Annual report also illustrates how institutional authorities assumed institutionalized disabled subjects as socially inadequate. The institution sought out and "eliminate[d] asocial and other undesirable habits and replace[d] these habits with habits of industry and habits that are socially acceptable."292 This language—present in a briefing to state lawmakers as to the purpose of and progress made by the institution—condones whatever measures the institution deems necessary to "eliminate" and "replace" those antisocial habits of disability and replace them with socially acceptable nondisabled habits.²⁹³ Institutional performances of habilitation taught inmates social adequacy through vocational and educational training. The skills the inmates acquired in the classroom and the workplace served as repetitious performances to teach a bodymind what it meant to live as a socially acceptable citizen in nondisabled community. Then, for those fortunate enough to enter the parole program and gain provisional release, the "field Agents" would supervise their "performances" outside the institution to ensure they maintained what performance studies scholar Richard Schechner refers to as "twice-behaved behavior," or "behavior that people train for and rehearse."²⁹⁴ If inmates did not follow their performances of habilitation in the outside world, they would jeopardize their parole, and risk being forced to return to the institution.

²⁹² "Report of the Pennhurst State School, 1924-1926," 7.

²⁹³ "Report of the Pennhurst State School, 1924-1926."

²⁹⁴ Richard Schechner, *Performance Studies: An Introduction*, 3rd ed. (New York, NY: Routledge, 2013),28.

Parole

The parole program at the PSSH was not unique. Paroling inmates and making them suitable for life in the community by training them in employable labor skills and (nondisabled) socially acceptable behavior, was a trademark of the "colony" or "cottage" plan of institutions conceived by Dr. Charles Bernstein, superintendent of the Rome State



ON ADMISSION

AFTER PAROLE

ON ADMISSION

AFTER PAROLE

Parole

The ultimate object of the education of the trainable patient is that they may become in some measure self-sufficient and self-supporting individuals, dependent neither on their parents or the tax-payers of the Commonwealth. Those who show proficiency in their endeavors at the institution are first paroled. If they succeed on parole, they are then discharged entirely from the rolls of the school.

RULES GOVERNING PAROLE

There are two types of paroles. 1. Parole to the parents. 2. Working parole. The latter means that your boy or girl may be provided an opportunity for employment outside the institution in the custody of responsible individuals, where he may earn money, which will be deposited to his account at the institution, and drawn upon as needed.

The photographs on this page are a comparative study of 4 patients of Pennhurst State School. Each panel pictures a bay or girl upon admission to the institution, and to its right, a present day photograph in a parole working situation.

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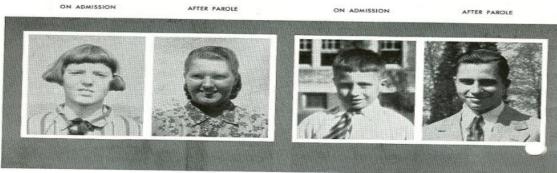


Figure 6: A photocopy of the "Parole" page of the Pennhurst Parental Handbook (c. 1940s).

School in the 1880s.²⁹⁵ The "parole" page in the 1940s handbook description of the program mirrors that found in the mission statement of the 1924-26 bi-annual report. The handout tells parents institutional parole provided "education" to the "trainable patient", so that they became "self-sufficient and self-supporting individuals, dependent neither on their parents or the tax-payers of the Commonwealth." This quote again illustrates the premise of parole as a mechanism for enforcing and rewarding performances of habilitation as embodied actions that trained inmates in becoming productive citizens modeling nondisabled practices of living in the community.

The "Parole" page of the 1940s handbook is especially telling when considering the role of performed disabled appearance and performances of habilitation. Overall, the "Parole" page relies on a performative tactic commonly used in preceding decades at the height of the eugenic era: drawing clear boundaries between "fit" members of society and the feebleminded. This performative boundary reiterates the notion of sharp, categorical aesthetic differences between two completely different *kinds* of people: nondisabled humans and the nonhuman, disabled menaces in the cultural imaginations of the American public.²⁹⁶

The above figure (Figure 6) depicts four children, each with their own "on admission" and "after parole" headshots on the page. The "on admission" photographs capture the children's performances of disabled appearance; performing proof of their legal and ontological inferiority, disabled, and dependent status. Like immigration officials using "signs of the face" to identify feebleminded immigrants, or Martin Barr's

²⁹⁶ Licia Carlson, "Docile Bodies, Docile Minds: Foucauldian Reflections on Mental Retardation," in

Foucault and the Government of Disability (Ann Arbor, MI: University of Michigan Press, 2008), 133-88.

²⁹⁵ Chamberlain, "Receiving, Sorting, and Disposing of Children," 217.

photographs of the "Stigmata of Degeneracy" in <u>Act I</u>, these photographs remind and reinforce performed notions of what disability looks like to the nondisabled public's imagination. The photographs stage the female children to look disheveled and grimacing. This aesthetic performance reinforced the popular performative rhetoric that "feebleminded" females or, "fallen women," posed the most significant threat to democracy. Their photographs become of significant importance to institutional authorities in identifying disability from appearance. As high-grade defectives—morons or imbeciles—these women posed a significant danger to nondisabled society because of their non-apparent performances of disabled appearance. In other words, because these young women did not *readily appear* disabled, they could pass as nondisabled. Thus, without institutional intervention, they could go about living in nondisabled society and reproduce, creating more degenerates.²⁹⁷

In contrast, the boys smile during their "on admission" photographs. The boys' performances in the photographs reinforce the danger of the "morons" non-apparent performances of disabled appearance that allowed them to go undetected in society and, thus, allow them to trick nondisabled women into having illicit relationships with them and producing more defective children.²⁹⁸

The "After Parole" headshots feature the children performing as aesthetically idealized, almost-but-not-quite-nondisabled, productive members of society. Their

²⁹⁷ Several scholars address this including, Baynton, *Defectives in the Land*; Mark Largent, *Breeding Contempt: The History of Coerced Sterilization in the United States* (New Brunswick, NJ: Rutgers University Press, 2008); Chamberlain, "Receiving, Sorting, and Disposing of Children"; Leonard, *Illiberal Reformers*; Lombardo, *Three Generations, No Imbeciles*; Rose, *No Right to Be Idle*; Trent, *Inventing the Feeble Mind*. Jirik explores the leadership roles of females within early institutions in her dissertation, Jirik, "American Institutions."

²⁹⁸ For more on feeblemindedness and passing see, Trent, *Inventing the Feeble Mind*; Carey, "The Sociopolitical Contexts of Passing and Intellectual Disability."

gleaming smiles, clean hair, and new outfits perform a quintessential "Americana" look. In essence, the institution relieved these inmates of their performances of disabled appearance. However, despite the "reformed" children's picturesque performance of American citizenship, the pamphlet kindly reminded the parents that their child-turnedinstitutionalized-disabled-subject is *still* subject to the institution. When the PSSH paroled the child, they placed the child in the custody of "responsible individuals" while the institution kept the child's wages in an institutional account so that the child could draw upon "as needed."

Despite occasionally releasing inmates, the PSSH never completely freed an inmate of their institutionalized disabled subjecthood. In 1935, PSSH Superintendent Walter R. Krause, told reporters of the *Daily Republican* how the institution never completely discharged inmates from the rolls of the institution. "We release them, of course, but only as paroled patients. Their names are taken off the register only when they die.", Krause said.²⁹⁹ Insidiously, newspaper articles throughout the PSSH's existence reveal a stream of Department of Welfare, State Police, and journalistic investigations around the long hours and severe underpayment for paroled inmates. One such article detailed how "Officials and attendants have used and 'loaned out' patients at the Pennhurst State School as virtual slave labor in their own homes and those of their friends."³⁰⁰ These patterns again highlight how, once institutionalized, disabled subjects always served the needs of the institution first. Cases involving officials and attendants "loaning out" inmates to local farmers also point to how the conception of the institution

²⁹⁹ Daily Republican, January 22, 1935, (SFHS), 20.

³⁰⁰ Philadelphia Inquirer, June 3, 1949, (SFHS), 48.

as a world apart helped breed neglect because the institution did not return inmates home to their families or local communities. Instead, the lending of inmates to farmers in the local area further solidified their status as property of the institution. These practices also kept inmates within geographical proximity of the institution and incapable of fully returning to the nondisabled world.³⁰¹ Further, the practice of only discharging inmates upon death reveals the ontological and teleological assumptions made on behalf of institutional authorities. Once a court or physician deemed a dis/abled person an institutionalized disabled subject, they always remained an institutionalized disabled subject.

Existence in a High-Grade Ward

The PSSH had a sprawling campus that encompassed gender-segregated living areas (the lower, "boys' colony," and the upper, "girls' colony), and farm and recreational fields that totaled nearly 1,000 acres of land by the late 1950s.³⁰² The two gender-segregated living areas consisted of cottages, or wards, that were only separated by perceived

³⁰¹ These labor practices also echo carceral practices of imprisoned labor; how that enslavement shifted into carceral punishment and "loaning out" of imprisoned bodies in the nineteenth and twentieth centuries. For more see, David J. Rothman, *The Discovery of the Asylum: Social Order and Disorder in the New Republic* (New York, NY: Aldine De Gruyter, 2002); Lan Cao, "Made in the USA: Race, Trade, and Prison Labor," *New York University Review of Law & Social Change* 43, no. 1 (2019): 1–58; Julie Stone Peters, "Penitentiary Performances: Spectators, Affecting Scenes, and Terrible Apparitions in the Nineteenth-Century Model Prison," in *Law and Performance*, ed. Austin Sarat, Lawrence Douglas, and Martha M. Umphrey (Amherst, MA: University of Massachusetts Press, 2018), 18–67. For more on labor practices in the institution, see Ruthie-Marie Beckwith, *Disability Servitude: From Peonage to Poverty* (New York, NY: Palgrave Macmillan, 2016); Rose, *No Right to Be Idle*.

³⁰² While pervasive racism and classism remained within institutions, affecting both inmates and staff, segregation typically only occurred on the basis of gender. Institutions like the PSSH housed a diverse population of inmates in terms of cultural, economic, ethnic, and racial backgrounds. Interestingly, one element of "humanity" often eroded through the experience of institutionalization was white privilege. This fact adds further complexity to discussions of race and privilege in the dis/ability community, especially given that those who identify as hospital and/or institutional survivors are often the least represented. While disability studies and advocacy communities are predominantly White, the intersection of disability and race is far from a straightforward dyadic issue.

"functioning" level. This resulted in a wide range of demographics within these spaces.

Johnson describes how PSSH authorities placed him on D-4 (the fourth floor of the D

building, later named "Devon") in his autobiography stating:

It was very high function ward. All different patients, light, colored, all mixed. No women - women's used to be up on the hill. And the boys'd be on the boys' side, down the hill. It was about a hundred people on the ward. ... All the beds on one side; there was a bedroom on that side, bedroom on that side, windows in the middle – attendants' windows - the staff offices in between the bedrooms. ... In the day room they had a TV; that's all that was there - just TV and bench. No toys. Only toys in school. It sounded like vibrations: crazy people was going out of their heads, out of their wits. It just sound like people that need to belong there. It sound to me, in my personal feeling, that people was just doing things that should not have happened. So that's what it sound like; it sounded like – fear; that something not right. It was just scary – a frightened, scary place.³⁰³

Johnson's description highlights several facets of institutional life on the ward. First, this passage underscores how the institution did not segregate by race—only by gender. Second, it illuminates the significant role categorization played in determining an inmate's level of care and expected levels of compliance within institutional environments. Finally, this depiction of ward life illustrates not only the sheer volume of people that were forced to exist in such conditions, but the detrimental effects of those conditions on the people and their bodyminds.

Nondisabled society and institutional authorities believed these methods were a perfectly humane way of "treating" institutionalized subjects. Johnson's account reveals the extent to which these "modern methods" devolved into violence. In his recollection of the ward environment, Johnson shows how these spaces and the performances of

³⁰³ Johnson, *Lost in a Desert World*, 22-23. Johnson's account illustrates both general and specific aspects of the inmates' experiences. For example, as evidenced in <u>Act I</u>, not all inmates came from homes. Some came from other places, such as foster care, almshouses, and other institutions.

institutionalized care traumatized, terrorized, and dehumanized those subjected to these conditions.

Strikingly, Johnson's account emphasized three reoccurring themes regarding institutionalization within this dissertation. First, these environments served as feedback loops of hell by creating the conditions to perpetuate their desired outcomes. When Johnson declares "It sounded like vibrations: crazy people was going out of their heads, out of their wits. It just sounded like people that needed to belong there," he highlights this feedback loop. Inmates stimmed and displayed other behaviors not in spite of the institution, but because of it—to do their best to cope with the terrible conditions. In turn, institutional authorities and nondisabled society understood those behaviors as evidence and rationale for their continued institutionalization.

Second, Johnson highlights the profound inhumanity of institutionalization itself by retaking a position of critical agency denied to him by the institution. "It sound to me, in my personal feeling, that people was just doing things that should not have happened," Johnson says. While this quote undoubtedly refers to the sexual and racist violence Johnson experienced at the hands of other inmates, this statement also reflects back on the institution as a whole. Markedly, Johnson also understands the institution administrators, staff, and inmates—as a pathological system that produces inhumanity. Unlike the handbooks and newspaper reporting which positions the PSSH as a refuge for people deemed feebleminded, Johnson's experience exposes the inhumanity of institutionalized care.

Third, Johnson's account highlights the dichotomy between nondisabled society's fear of the spectre of disability and dis/abled people's terror of the institution. While I

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discuss the fear of the spectre of disability—or disability as that which haunts and terrorizes nondisabled society—in <u>Act III</u>, Johnson's words "It was just a scary — a frightened, scary place" illustrates the fundamental dichotomy between the institution for the nondisabled spectator and the dis/abled person experiencing institutionalization. On the one hand, nondisabled people viewed the institution as a necessary and humane form of care. But eugenic fear of disability, as a drain on society, drove societal and professional perceptions of disability. On the other hand, as Johnson detailed both in the intake process and in his account of life on the ward, the experience of institutionalization literally terrified dis/abled people.

"Low-Grade" Existence: Case Studies of Performances of Institutional Care

This section examines how the use of restraints and neglect became common institutional performances of care. To do so, this section begins by highlighting patterns of dehumanization experienced by inmates deemed "low-grade." These patterns of dehumanization reveal how institutional authorities viewed evidence of abuse, restraint, and neglect as resulting from an inmate's deficiency rather than as medical malpractice.

John–Death by Restraint³⁰⁴

John's case illustrates a common experience for many at the PSSH: existence under constant chemical and mechanical restraint.³⁰⁵ As Downey and Conroy detail in their account of the PSSH, "Pennhurst used improper physical restraints—locked and windowless closets, cages, shackles, solitary confinement, powerful medications—and other forms of sensory deprivation to control residents and assess their responses."³⁰⁶ In addition, the newspaper coverage of the institution, analysis of both patient files and *Halderman v. Pennhurst* (1977) detail countless reports of physical and chemical restraint used on inmates.³⁰⁷ The patterns of restraint at the PSSH, as explored in John's narrative, reveal an insidious, subconscious compulsion by actors within the institution, to maintain control over and compliance of a disabled subject by any means necessary.

John, a young White child, grew up in a rural community approximately 10 miles northeast of the institution. John's father worked as a well driller. His mother was a supervisor at the Bell Telephone Company before she left to work as a stay-at-home mother. John was an only child. His parents brought him to the University of Pennsylvania's Psychological Laboratory and Clinic to have him examined by a psychologist, who diagnosed John as "a mentally defective child of low grade" and recommended "that the parents make an application at once for this child's admission to

³⁰⁴ The Pennsylvania State Archives privacy policy states: "names are included only if the individual is known to have been deceased for at least seventy-five years or longer (i.e., died in 1947 or earlier) or if names are documented in prior publication such as court cases, autobiographies, or published news articles." In accordance with this policy, I have chosen to anonymize the names of the inmates under discussion in section.

³⁰⁵ Although John was categorized as low-grade, PSSH staff restrained all inmates they felt required it. Far from being just a historical artifact of large, custodial institutions, mechanical and chemical restraints continue to be used today, often justified as means to protect the disabled subject.
³⁰⁶ Conroy and Downey, "Veil of Secrecy," 64.

³⁰⁷ Halderman v. Pennhurst State School & Hospital, E.D. Pa., 446 F. Supp. 1295 (1977).

the Pennhurst State School."³⁰⁸ Writing to a court authority to recommend institutionalization, the psychologist warned John was "potentially a social menace because of his total lack of self-control [sic], such that if he is not guarded constantly may cause some damage in the community or even physical harm to another child."³⁰⁹ Authorities committed John to the PSSH in October 1957, at age 9.

When institutional authorities admitted John to the hospital complex for the intake process, hospital staff reported his behavior as "generally quite negative, resistive, destructive, and difficult to handle."³¹⁰ Staff responded by restraining the nine-year-old boy in a "camisole," or a straitjacket, for an unspecified amount of time. In addition to the mechanical restraint, PSSH's Clinical Director Dr. Harry Podall also injected John with "50 milligrams" of concentrated Thorazine. Thorazine, a medication frequently used to ease the effects of epileptic seizures, was also used as a chemical restraint in institutional settings. (John had never experienced symptoms of epilepsy or seizures prior to his admission to the institution.)

John died only seven days into his commitment at the PSSH. He never left the hospital or even received his initial psychological examination. His death certificate, signed by Podell, stated John's primary cause of death was "staticus epilepticus"—a prolonged seizure of at least five minutes or multiple seizures within a five-minute period—with an "interval between onset and death" of only "2 hours." Podall listed his secondary cause of death as "mentally deficiency" with an onset of "9 years."

³⁰⁸ John, Patient Files, Patient Nos. 9016-9458, 1957-1961, Carton 36, RG23, PSA.

³⁰⁹ John, Patient Files.

³¹⁰ John, Patient Files.

Analyzing the horrific seven days John spent at the PSSH, only to die at the hands of medical professionals through the specific medical intervention of chemical restraint illustrates how care transmuted into violence in institutional settings. Instead of providing John with individualized and specialized care that treated him like a human with value, emotions, and specific care needs, PSSH staff relied on the convenience of a performance of institutionalized care—chemical restraint—to ensure John's compliance. Furthermore, the institution's emphasis on restraint, both chemical and physical, created a bias that John was less than human. Authorities did not see his "negative," "resistive," and "destructive" behavior as the trauma response of a nine-year-old boy who was just separated from his parents. Instead, John's behavior stems from being a "low-grade," something more animal than human.

This wanton disregard for human life does not stop with John and his fellow inmates, however, it also extended to his parents. Describing the events that led up to and occurred after John's death in a letter to PSSH Superintendent Leopold Potkonski, Podall wrote:

As I was coming into the hospital section to admit the ten new admissions, the nurse called me on the phone saying that this patient [John] was having a seizure. As I walked in, between 1:25 p.m. and 1:30 p.m., the patient showed evidence of being cyanotic [in which the skin takes on a blue tint due to a lack of oxygen in the blood]. He had a series of very severe seizures and about 1:30 p.m. he was given 3 cc. of paraldehyde in each buttocks and oxygen inhalation was also administered. I immediately placed this patient on the critical ill list and within a few minutes I called his mother and told her that I had placed Robert on the critically ill list because of having a severe seizure. I told [John's mother] that she could come to see him as soon as she possibly could.

Although I continued to examine the new admissions, I left word that I should be notified as soon as [John's mother] arrived at the School in order that I might talk to her. Meanwhile, the patient failed to respond to

stimulation with oxygen and he ceased breathing at 2:20 p.m. I pronounced him dead and went back to examine the new admissions. A few minutes later [John's mother] arrived and I cleared my office and they brought her into my office. She sat down and I told her who I was and I also told her about the death of [John] a few minutes ago. [John's mother] became very much emotionally upset and began to moan and it was necessary for me to give her some sedation. ...

It was out of the question for me or anyone else to talk to [John's Mother] at the time when I told her that [John] had died. I tried to do the best I could to tell her what occurred but she became somewhat hysterical and very much emotionally upset and I could not do anything with her."³¹¹

Podall does not describe the type of sedation he gave John's mother, or for how long the sedative's effects remained in her body. From Podall's letter, it appears that John's mother arrived at the institution at approximately 2:30 p.m. and Podall sedated her shortly after. Podall does not list another timestamp until John's father arrived a "little after 4:00 p.m.," at which point, the effects of the sedative apparently wore off.

Once again Podall's complete disregard for human life exhibits how he viewed John's bare life, but it also extended to a person he has no authority over: a parent. The fact that this was John's mother, and not his father, however, was important. The language used to describe John's mother, such as "somewhat hysterical and very much emotionally upset" was (and remains) steeped in sexism and ableism. Critical theorists,³¹² medical historians,³¹³ and disability and performance studies³¹⁴ scholars alike have critiqued the concept of hysteria as a diagnosis of quickly dismissing (or institutionalizing) unruly women. Additionally, while no longer overtly publicized in

³¹¹ John, Patient Files, Letter from Harry C. Podall, M.D., Clinical Director to Leopold A. Potkonski, M.D., Superintendent.

³¹² Michel Foucault, *History of Sexuality, Vol. 1.* (New York, NY: Pantheon, 1978), 103-105.

³¹³ Goldstein, Console and Classify.

³¹⁴ Kuppers, "Bodies."

medical circles at this time, eugenic philosophy, which relied on ideas of heredity and placed the brunt of the "problem of the feeblemind" on the mother, continued (and continues) to create an implicit bias for physicians and society alike. These historical influences likely also influenced Podall's actions of sedating John's mother at the PSSH, but also highlight the unique slippage of the parent, especially the mother, as guardian, threat, and influencer. Finally, it illustrates the primary imperative of the institution was to control bodymind expression and behavior to ensure the smooth functioning of the institution, and that the use of chemical and mechanical restraint to achieve this was routine and unquestioned.

Tom–Death by Neglect

. . .

Neglect constituted another common example of institutionalized performances of care. The PSSH admitted Tom, a young White child, to the institution in September 1957, at only seven years old. Tom and his three other siblings were raised by their father, a painter, after their mother died two years prior, at 29 years of age. Tom and his siblings grew up in Rapho Township, approximately 55 miles northwest of the PSSH.

Prior to Tom's admission to the institution, a social service "agent" from the institution came to Tom's home to investigate whether he was a suitable candidate for admission. The report details the following:

Problem: [Tom] has cerebral palsy and has been subject to epileptic seizures since four months of age. He is mentally retarded. He needs complete care for the rest of his life.

Patient: **[Tom] is a child who merely exists**, spending his waking hours in a high playpen and occasionally walking around a very limited area in a

room under constant supervision. Several physicians have advised immediate institutionalization.

. . .

Amusements: Only throwing about toys. Little interest in anything. Conclusion: This case was considered urgent and was admitted to Pennhurst State School 9-20-57.³¹⁵

The format of this standardized social service report breaks down a human life into components of seemingly measurable and describable symptom clusters. The first heading on the Social Services report, which is followed by the biographical information of the inmate described, is "problem." Written in red, this encourages the reader to presume this person is nothing but problematic. Providing no other contextual information about the person, their background, or interests, the document dehumanizes the person into an institutionalized disabled subject from the moment an "agent" observed an inmate and recorded those observations in an inmate's chart.

Later in describing the "patient", the "agent" states that Tom "merely exists." As with the commitment trials of PSSH inmates, the rationale and evidence for such ontological statements of fact go unsupported. Through the power and authority vested in the "agent" by the Commonwealth of Pennsylvania and by the credential of being a social worker, such observations become crystalized as fact through linguistic performatives. These statements of fact then impact the level of care (or not) an inmate received in the institution.

Further, when the agent declared that Tom "merely exists," the agent's description serves as an example, *par excellence*, of performances of institutionalized

³¹⁵ Tom, Patient Files, Patient Nos. 8611-9005, 1956-1957, Carton 35, RG23, PSA, (emphasis is my own, however the red text is original to document which I reflected in my transcription).

care as bare life. Tom's state, for this institutional authority, did not rise to the level of a full life. Thus, Tom's existence merited extinction without cost. The rest of this section details exactly how the institution extinguished this child's "mere existence," while rendering his human life (his emotions, needs, personhood, etc.) nonexistent.

While most of Tom's patient file materials are missing, his "Clinical Progress Notes" provide a window into the care he received and how the institution systematically extinguished his existence. Following his admission to the PSSH in September, Dr. Podall moved Tom to the first floor of "T" (Tinicum) Building on October 1st, 1957. By the 29th, Tom had already developed pneumonitis, and staff sent him to the hospital. After being returned to T-1, PSSH medical staff moved Tom to various wards almost monthly. The constant movement, combined with the exposure to contagious disease and viral infections in this overpopulated congregate care setting, exhibits one form of bare life. PSSH authorities gave no regard as to how Tom acclimated to new environments, nor did they provide settings that would allow him to flourish as a human. Tom eventually found temporary relief from constant relocation after authorities placed him on the first floor of Quaker in August 1958.

Quaker, or what the PSSH employees nicknamed the "bad boys and girls" ward of the PSSH housed inmates with reported "behavior issues" and/or significant care needs. Institutional authorities' decision to place Tom in Quaker highlights yet another example of extinguishing his existence. One of the smallest and oldest wards on campus, Quaker had (and continues to have) a reputation as a place of great hostility, neglect, and emotional density. This created a feedback loop with devastating and torturous consequences. Most of the inmates' reported "behavioral issues" resulted from the

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experience of institutionalized existence—sensory deprivation or overload, lack of privacy, lack of individualized care, etc. PSSH authorities responded to these supposed "behavioral issues" by placing unruly inmates into Quaker with custodial cases like Tom. This only caused further problems. Instead of relieving inmates from the stressors of institutional existence that the environment caused in the first place, authorities placed people already experiencing sensory overload into a smaller confined space. In turn, this caused the inmates to lash out more.³¹⁶

The reports made by medical examiners during the time Tom existed in Quaker highlight the logic of dehumanization and the use of evidence in performances of institutionalized care to mark subjects as expendable. Approximately seven months into his existence in Quaker, in March 1959, an institutional authority examined Tom. The reporting medical examiner (who is not listed) states: "The above patient weighs 55 pounds. ... He doesn't talk or walk or comprehend. Is fed. He soils and wets." The examiner concludes that physical ability begets cognitive or developmental ability. Further, the evidence of neglect—putting a child in an unsuitable environment, lack of regular attention, and specialized care—functioned as evidence of Tom's expendability and sub-humanity. Therefore, since institutional authorities assumed Tom lacked perception, they forced him to live in an existence of sheer terror without any consolation.

Tom's narrative illustrates yet another component of performances of institutionalized care: a lack of routine attention which leads to death. Institutional

³¹⁶ Johnson, Lost in a Desert World: An Autobiography (as Told to Karl Williams), 24-30.

authorities went seven months without reviewing Tom. On November 4, 1959, nurses make the following observations in Tom's clinical notes:

Patient had a three day episode of fever from 10-29-59 to 10-31-59. Recovered from this illness, and was apparently well until 11-3-59, when it was noted he looked tired and ill. Admitted to hospital on 11-3-59 for observation. On the morning of 11-4-59, suddenly he became gravely ill, spiked a temperature of 101.2, lapsed into unconsciousness, and died at 11:00 a.m. E.S.T. 11-4-59 despite emergency treatment. ... Cause of death: Acute cardiac failure - etiology undetermined, congestion and edema of brain.³¹⁷

Despite only receiving care from his single father and siblings for seven years while living at home, it took less than three years of institutionalization for Tom's quality of life to deteriorate. The constant movement, combined with a lack of regular medical attention and care, all contributed to Tom's tragic death. Patterns of apathy and neglect continuously present themselves in cases like Tom's. In the best light, these patterns highlight how overwhelmed institutional staff became in attempting to give care to the sheer volume of inmates under their watch. And yet, these patterns devastatingly reveal how institutional environments, combined with internal ableist biases, gave way to neglect and abuse that almost always resulted in the degradation of human life.

Conclusion

This Act examined the dichotomy of performances of institutionalized care and habilitation and, specifically, how what institutional authorities perceived as care became received as violence by inmates of the PSSH. The analysis of the official documentation of life at the PSSH, as published by the Commonwealth and regional and local

³¹⁷ Tom, Patient Files, (the red text is original to document which I reflected in my transcription).

newspapers, presented the institution as a benign "world apart." According to these materials, the PSSH was simply an idyllic rural refuge of altruistic care spatially separated from the nondisabled world.

The public-facing documents created by the institution highlighted the performances of habilitation enforced by the institution and embodied by inmates deemed high-grade. These performances of habilitation required (and continue to require) nondisabled norms by forcing institutionalized disabled subjects into performing socializing acts such as labor, ways of dressing, and acting in public settings, etc. These materials also created a repertoire that reaffirmed the performances of disabled appearance declared in the courtroom while simultaneously shrouding the realities of violence involved in day-to-day existence in the institution. However, analyzing the patterns found in patient files, these records exposed the institution's logic of dehumanization. These performances of institutionalized care—everyday practices of neglect, restraint, and abuse—turned perceived care into received violence.

While this Act examined phenomena that occurred during the twentieth century, these performances of habilitation and institutionalized care continue in institutions today. In July 2021, a federal judge ruled institutional authorities could legally perform shock "treatment" on the dis/abled (children) inmates of the Judge Rotenberg Center in Canton, Massachusetts. Unlike Electroconvulsive Therapy (EVT), which doctors use more commonly (and controversially) in the treatment of people deemed psychiatrically disabled, the Center's use of shock "treatment" consists of adhering wireless electric shock restraints to inmates' bodies to assure compliance within the institutional environment. One such behavioral incident resulted in the Rotenberg staff restraining and

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shocking an inmate thirty-one times until he became catatonic.³¹⁸ These performances of institutionalized care-repeated acts of violence in the name of care (or restraint)materially produce a repertoire of material and performative violence which transfers knowledge about disability to the dis/abled person, that we are nonhuman and incapable of feeling pain.

In February 2023, local journalists used the Freedom of Information Act to force the Illinois Department of Human Services to release records documenting conditions in a state institution. These records detailed how institutional authorities overlooked abuse and employees actively harmed their charges.³¹⁹ For example, records reported how staff had broken one inmate's arm and bragged about "intimidating and bullying other employees to keep them from reporting abuse and bragged that they retaliated against those that who spoke up."³²⁰ Further, the reporters found evidence of collusion between state investigators and suspects in the case. In July 2023, the same reporters published another article detailing reports of over two-hundred state police investigations into institutional employee misconduct over the past decade, which included allegations of physical abuse, criminal battery, sexual assault, custodial sexual misconduct, criminal negligence, and criminal deaths.³²¹ Of those two-hundred cases, only twenty-two led to

³¹⁹ Beth Hundsdorfer and Molly Parker, "New Report Says Nurses at Illinois Facility Forced Patients to Dig Through Their Own Feces," ProPublica, February 10, 2023, https://www.propublica.org/article/illinois-choate-mental-health-new-

abuse?utm source=sailthru&utm medium=email&utm campaign=majorinvestigations&utm content=rive

³¹⁸ Robin Young and Serena McMahon, "Disability Advocates Fight Ruling Allowing Electric Shock Treatment Back in Mass. Residential School," Wbur, August 12, 2021, https://www.wbur.org/hereandnow/2021/08/12/shock-treatment-school-disability.

 $[\]overline{^{320}}$ Hundsdorfer and Parker.

³²¹ Molly Parker and Beth Hundsdorfer, "Problems with Abuse, Neglect, and Cover-Ups at Choate Extend to Other Developmental Centers in Illinois," ProPublica, July 11, 2023, https://www.propublica.org/article/abuse-neglect-cover-ups-choate-extends-through-illinois.

convictions. These records mirror those analyzed above from the PSSH and illustrate how not only performances of habilitation and institutionalized care continue, but how legal, medical, and political authorities sanction this violence against dis/abled people.

In June 2023, the United States Supreme Court issued their opinion on Health and Hospital Corporation of Marion County (HHC) v. Talevski (2023).³²² The family of Gorgi Talevski, a man living with dementia, placed him in a nursing home operated by HHC. HHC repeatedly moved Talevski between various custodial environments and chemically restrained him with "six powerful psychotropic medications."³²³ When the family reported concern over Talevski's declining condition with HHC, the nursing home authorities claimed it was related to the progression of his dementia. Eventually, the usage of chemical restraint became clear to the family, and they sued HHC under Section 1983 of the Federal Nursing Home Amendments Act of 1987.³²⁴ At its core, the case centers on the use of chemical restraint and performances of institutionalized care. But the issue before the Court was not about care, treatment, or restraint. Instead, the issue the Court ruled on related to private enforcement of the Spending Clause—whether third parties can initiate lawsuits against public institutions. In citing *Pennhurst v. Halderman* (1981), which I discuss in the Intermezzo, the Court ruled that because HHC received state funding, and was not operated entirely through private funds, Talevski's family could sue HHC.³²⁵ While HHC v. Talevski provided a victory to the disability community, it illustrates yet another legacy of the performances of institutionalized care

³²² Health and Hospital Corporation of Marion County (HHC) v. Talevski, 599 U. S. (2023).

³²³ *HHC v. Talevski*, 3.

³²⁴ HHC v. Talevski, 3.

³²⁵ Pennhurst State School and Hospital v. Halderman (Pennhurst I), 451 U.S. 1 (1981).

that occurred at the PSSH: legal action regarding disability is seldom about the bodymind experiences of dis/abled people; rather it's about the mechanisms and structures that provide care and the money that pays for that care.

Finally, many institutions, institutional staff, and institutional training programs continue to report engaging in or teaching similar performances of institutionalized care as discussed in this Act. Most contemporary literature on this topic argues that contingent restraint (immediate chemical or physical restraint of an inmate after a behavioral incident) works well within a comprehensive treatment program.³²⁶ This treatment program is violent in that it serves the needs of the institution, not the care needs of the dis/abled person subject to the programming. To better understand how performances of institutionalized care receive legal sanction, the <u>Intermezzo</u> discusses the legal history of Pennhurst's litigation and the eventual sale of the property to private owners.

³²⁶ For more on the contemporary use of restraint in institutions see, David Ferleger, "Human Services Restraint: Its Past and Future," *Intellectual and Developmental Disabilities* 46, no. 2 (2008): 154–65; David M. Tilli and Scott Spreat, "Restraint Safety in a Residential Setting for Persons with Intellectual Disabilities," *Behavorial Interventions* 24, no. 2 (2009): 127–36; Timothy R. Vollmer et al., "The Association for Behavior Analysis International Position Statement on Restraint and Seclusion," *The Behavior Analyst* 34, no. 1 (Spring 2011): 103–10; Scott Spreat and Tine Hansen-Turton, "Formative Evaluation of the Implementation of Ukeru Restraint Reduction Strategy.," *International Journal of Education and Social Science Research* 4, no. 4 (August 2021): 12–27.

RECITATIVE

We, the Dis/embodied Storytellers of the United States

A gust of brisk second-winter air pushes me through the turnstile of the Renaissance Hotel in Washington, D.C. on March 30, 2022. I am attending the National Disability Policy Seminar—an annual federal policy conference co-sponsored by several national intellectual and/or developmental (I/DD) disability organizations. The workshops and panels presented on that day outline the numerous public policy initiatives of the I/DD community. They also relay the looming potential threats to the civil rights of dis/abled people living in America in preparation for the upcoming "Hill visits." ("Hill visits" is a term frequently used during national advocacy conferences to refer to times when attendees meet with their respective Representatives and Senators.)

Throughout these panels, one refrain remains a constant: as "self-advocates," our primary tool for effecting change is to craft our varied experiences of trauma—most of which are borne living under the spectre of institutionalization—into polished, inspiring narratives. After invading the offices of our elected officials, we should then bombard them—or, more commonly, their twenty-something, underpaid but overzealous staffers—with those stories. The goal of this storytelling, of course, is to evoke such a level of empathy that the politicians—or at least their staffers—become actively involved in championing the various policy needs of our communities.

In the day's final session, a panel consisting of lobbyists and congressional and federal agency staffers—none of whom openly identified as living with a dis/ability briefs us on proposed legislation intended to eliminate Social Security's asset limits. Like the previous panels, they echo the familiar refrain to the audience: it is our stories, and the emotional reactions they elicit, that have the power to motivate change.

Feeling rather disheartened and worn out from the barrage of people telling me, and other dis/abled folks, we must leverage our corporeal traumas as the primary tool for reform, I jot down a question in my notes to pose during the upcoming Q & A.

As the Q & A session draws to an end, I rise from my chair, amble over to the microphone in the middle of the ballroom, and ask: "Throughout today's sessions, multiple people who don't openly identify as disabled have told me, a disabled person, the urgent need for us to share our stories. This, they suggest, enables government staffers, such as yourselves, to empathize with us and advocate for our needs. How do we create a paradigm where disabled people become more than just storytellers? A paradigm where accessible mechanisms exist for disabled people to pursue and occupy government and political positions, so that *we* are the ones effecting the changes our communities want. More specifically, how can you, the nondisabled people in positions of power, create that access and assist disabled people in navigating into these roles so that our survival isn't solely dependent on storytelling?" My questions bring about an unexpected round of applause from the audience and unsurprising silence from the panelists.

As I sit back down in my chair, take a deep breath, and take stock of my bodymind. My pulse races, my vision starts to blur.

Is a story about my traumas worth it, if my bodymind disappears in the process?

And the only way to break that barrier is to tell people that you are in control. You are in control over your own life and in your own ways. And tell people - be honest and be sincere - and say that: "I am in control over my life; not you tell us what to do and how to control your money and how to control who's in control." And that's what I go around the country saying: "Who is in control?"

- Roland Johnson, Third International People First Conference, Toronto, Canada, June 1993.³²⁷

INTERMEZZO

The Litigation that Closed an Institution & Birthed an Asylum

This Intermezzo surveys the tensions between various stakeholders and debates surrounding Pennhurst's history, preservation, and legacy. It details the nuances of the litigation that closed the PSSH, and the Commonwealth's pattern of deliberate evasion in safeguarding Pennhurst's historical significance to Pennsylvania and the United States. By doing so, this Intermezzo illustrates not only Pennhurst's significance to disability legal studies, but also how the PA haunted attraction came into existence. The legal actions taken to remedy the issue of institutionalization during this period laid the foundation for disability to become a cypher for the law and for Pennhurst to become—at the same time—a magnet and foil for the dis/ability community. While the rhetorical

³²⁷ Johnson, Lost in a Desert World: An Autobiography (as Told to Karl Williams), 79.

legal performatives of <u>Act I</u> materialized physically absent people as disabled subjects in courtroom, the history and ongoing impact of Pennhurst, its litigation, and the disability advocacy movements surrounding the PSSH's closure caused embodied dis/ability experience and history to disappear.

After analyzing the litigation that led to the closure of the PSSH, this Intermezzo explores a less-examined aspect of the debate surrounding Pennhurst's legacy: the accountability of the Commonwealth of Pennsylvania for the events post-PSSH's closure. The Commonwealth not only allowed the institution's appalling conditions to persist, but it also failed in its duty to preserve that history so that we *actually* end institutionalization and never go back. Although disability advocates and the public volley their criticism at the haunted attraction and its employees, as <u>Act IV</u> reveals, the dis/ability heritage work of the PA community is, in part, motivated by the Commonwealth's failure to act. As long as the focus of criticism remains on the PA, rather than the Commonwealth, both disability advocacy groups and the public unknowingly perpetuate the institution as a space of legal exception, allowing the Commonwealth to evade responsibility for what transpired at Pennhurst. But, as <u>Act III</u> exposes, the Commonwealth's strategy of erasing the PSSH's history through deliberate forgetfulness does not prevent the spirits of Pennhurst Past and the dis/abled people of Pennhurst Present, from re-appearing and reclaiming that history through the act of haunting.

Why the Pennhurst Litigation Matters

The PSSH's litigation history proves useful to understand how, instead of considering and ruling on performances of institutionalized care—everyday acts of violence such as restraint, discrimination, and abuse—courts often rule on issues adjacent to, but not related with, the embodied experiences of dis/abled people.

Legal, medical, and disability scholars have thoroughly documented the court cases that shrouded the PSSH in controversy and, ultimately, led to its closure in 1987.³²⁸ Scholars note the PSSH's significance to the deinstitutionalization movement, and granting dis/abled people the rights to live in a community and receive an equal education. In addition to a legal and disability lens, performance studies scholars must

attend to these cases, particularly Halderman v. Pennhurst (1977) and Romeo v.

Youngberg (1982) since the central legal issues and the courts' interpretations deal with

core tenets of the discipline such as embodiment, memory, and knowledge making.³²⁹

Since the 1970s, plaintiffs in institutions for people deemed feebleminded,

mentally retarded, and/or developmentally disabled have filed over forty-five class-action

³²⁸ For these reasons, I will provide an abridged history of these cases. On *PARC*, see, Judith Gran, "From PARC to Pennhurst: The Legal Argument for Equality," in Pennhurst & The Struggle for Disability Rights, ed. Dennis B. Downey and James W. Conroy (University Park, PA: The Pennsylvania State University Press, 2020), 104-23; On Halderman, see, Tani, "Pennhurst Doctrines"; Liat Ben-Moshe, Decarcerating Disability: Deinstitutionalization and Prison Abolition (Minneapolis, MN: University of Minnesota Press, 2020), 55. Romeo lacks an in-depth historiographical analysis that accounts for the significance of the "professional judgement" clause which circumvents an inmates' right to be free from bodily restraint. For more on Romeo, broadly, see David Ferleger and Patrice Maguire Scott, "Rights and Dignity: Congress, the Supreme Court, and People with Disabilities after Pennhurst," Western New England Law Review 5, no. 3 (Winter 1983): 327-62; Ferleger, "Civil Rights Disability Practice: Expediting Institutional Mistreatment Litigation," Mental and Physical Disability Law Reporter 12, no. 3 (1988): 309-18; Ferleger, "Human Services Restraint: Its Past and Future," Intellectual and Developmental Disabilities 46, no. 2 (2008): 154-65; Ferleger, "Disabilities and the Law: The Evolution of Independence," Federal Lawyer 57, no. 8 (2010): 26–50. For more on deinstitutionalization during the 1970s, see Judith Gran, "Deinstitutionalization Litigation: Experiences and Outcomes," IMPACT 9, no. 1 (1995-1996): 8-9; Samuel R. Bagenstos, "The Past and Future of Deinstitutionalization Litigation," Cardozo Law Review 34, no. 1 (2012): 1-52; Elizabeth F. Emmens, "Disabling Attitudes: US Disability Law and the ADAA Amendments," in The Disability Studies Reader, ed. Lennard J. Davis, 4th ed. (New York, NY: Routledge, 2013), 42-57; Ben-Moshe, Decarcerating Disability.

³²⁹ As of the writing of this dissertation, I am the only performance studies scholar to analyze the Pennhurst State School & Hospital, and the significance of court cases associated with the PSSH.

lawsuits.³³⁰ Lawsuits such as *Halderman* and *Romeo* relied on several different legal provisions, which included statutory and constitutional claims at both the state and federal level. Some cases included issues over "negative" rights (i.e., liberty interests) while other cases took issue with "positive" rights (i.e., the right to state resources or services).

In general, these cases alleged that dis/abled people in institutions experienced violations of their individual rights, as set forth in either statutes or the Constitution. Notably, however, these suits resulted in, at best, partial justice for institutional survivors. The Supreme Court's increasingly expansive interpretation of the Eleventh Amendment, combined with various official immunity doctrines, made it difficult for survivors to secure monetary compensation for the harms they experienced.³³¹ Damages and reparations remain important to the outcome of these cases because they would have served as incentive for the Commonwealth—and as precedent to other States—to cease and desist providing poor institutional care. Historically, institutional authorities forced dis/abled people into peonage—unpaid, forced labor—to keep institutions operating until the 1970s.³³² Today, most dis/abled people living in America continue to experience poverty entrapment due to the Social Security Administration's income, asset, and marriage restrictions and/or sub-minimum wage labor.³³³ Given that generational wealth

³³⁰ Gran, "Deinstitutionalization Litigation: Experiences and Outcomes"; Ben-Moshe, *Decarcerating Disability*; "Examining Class Action Lawsuits Against Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)" (Washington, D.C., 2018).

³³¹ The doctrinal barriers here are complex and beyond the scope of this dissertation. While the Eleventh Amendment was an important barrier, it was not the only one. Other barriers included the doctrine of qualified immunity, which is distinct from the Eleventh Amendment.

³³² Beckwith, *Disability Servitude*.

³³³ Kathleen Romig, Luis Nuñez, and Arloc Sherman, "The Case for Updating SSI Asset Limits: Raising or Eliminating Limits Would Reduce Administrative Burdens Without Dramatically Increasing Enrollment" (Center on Budget and Policy Priorities, June 26, 2023), <u>https://www.cbpp.org/sites/default/files/6-26-</u>

transfer remains the primary vehicle for gaining financial security in the United States, damages and reparations would assist dis/abled people in America in becoming financially independent despite historic and ongoing structural financial barriers.

This rights-based model of the deinstitutionalization and disability rights movements, and the lawsuits that it generated, undoubtedly provided our community with some rights. But it has also ensnared us by forcing us to constantly defend what few rights we have by relying primarily on federal class-action lawsuits. Further, because most class-action lawsuits end in settlements and not by court verdict, our legal system often possesses only limited understandings of what harms institutional inmates experienced and, therefore, what the appropriate remedies might be. While settlements are not binding like court verdicts, they can occur at any stage of litigation, and can result in substantive rulings such as motions to dismiss or a summary judgement. Relying on class-action lawsuits for this purpose also affected popular and judicial understandings of what constitutes disability-based discrimination in a way that unduly narrowed understandings of what it means to discriminate on the basis of disability.³³⁴ In turn, this creates what critical disability studies scholar Shelley L. Tremain calls "a recapitulation of ableist subjectivity."335 The rights-model of disability models citizenship for dis/abled people after normative constructions of nondisabled citizenry: "white, heterosexual, able-

<u>23socsec.pdf;</u> Shaun Heasley, "Subminimum Wage Employment Continues to Slide," DisabilityScoop, July 18, 2023, <u>https://www.disabilityscoop.com/2023/07/18/subminimum-wage-employment-continues-to-slide/30461/</u>.

³³⁴ Emens, "Disabling Attitudes," 2013.

³³⁵ Shelley L. Tremain, *Foucault and Feminist Philosophy of Disability* (Ann Arbor, MI: University of Michigan Press, 2017), 110.

bodied, politically conservative, and middle class.³³⁶ Further, nondisabled parental and family advocates historically led and continue to occupy significant positions of power which focused on class-action lawsuits (including the lawyers which represented the PSSH plaintiffs in these suits).³³⁷ This generated a power dynamic that favors nondisabled, traditional rights-based advocacy.³³⁸

Current dis/ability scholars and activists are shifting the paradigm by applying a disability justice framework to evaluate the effectiveness of our current models for advocacy and policymaking within the dis/ability community.³³⁹ They explore whether these models benefit dis/abled people or, conversely, whether they reinforce the normative structures already deeply embedded in our government and society. These structures perpetuate the devaluation of dis/abled labor, overlook our unrecognized contributions to fields such as education, medicine, science, and technology (often at the cost of dis/abled lives), and perpetuate violence that has too often been a part of our bodymind experiences. Deinstitutionalization litigation, specifically, prompts questions about why successful cases did not receive damages and why lawyers and parent groups never considered reparations for those harmed.³⁴⁰ While these issues are outside the

³³⁷ For more on ableism within the legal profession and the difficulties dis/abled people encounter in applying to and succeeding in law school, as well as taking the Bar Exam and navigating the legal profession, see the special collection edited by Lilith A. Siegel and Karen M. Tani, "Disabled Perspectives on Legal Education: Reckoning and Reform," *Journal of Legal Education* 69, no. 4 (2021).

³³⁹ For more on disability justice frameworks, see Sins Invalid, *Skin, Tooth, and Bone: The Basis of Movement Is Our People*, 2nd ed., 2019; "What Is Disability Justice?," June 16, 2020, <u>https://www.sinsinvalid.org/news-1/2020/6/16/what-is-disability-justice</u>.

³³⁶ Tremain, 111. For more on conceptualizations of citizenship in the United States see, Barbara Welke, *Law and the Borders of Belonging in the Long Nineteenth Century United States* (London, UK: Cambridge University Press, 2010).

³³⁸ Allison C. Carey, "Citizenship and the Family: Parents of Children with Disabilities, the Pursuit of Rights, and Paternalism," in *Civil Disabilities: Citizenship, Membership, and Belonging* (Philadelphia, PA: University of Pennsylvania Press, 2015), 165–85.

³⁴⁰ In a slightly tangential example, cultural historian Todd Carmody examines how formerly enslaved people navigated the Civil War Veterans Pensions System. This system, at one point, required

scope of this dissertation, they are intrinsically woven into the context of my broader claims. The complex and relatively unexplored relationships between public and private interests, the convoluted litigation history, and the current and historical context of Pennhurst can and should serve as a starting point for future investigations. In short, Pennhurst serves as a potent site to explore virtually all of the significant cultural, economic, educational, legal, medical, philosophical, and political questions that presently confront the dis/ability community.

The Litigation that Shut Pennhurst Down, 1963-1987

This section explores the litigation history that culminated in the closure of the PSSH. The facts and doctrinal issues in these cases, although complex, are essential for comprehending the consequences of the deinstitutionalization litigation. These lawsuits did more than just close an institution; they conferred unprecedented rights to dis/abled individuals, such as the right to live in the community and the right to equal education. However, they crucially left legal questions about what defines care, restraint, and discrimination open for interpretation by the courts. Given the near-absence of constitutional and statutory language or prior legal precedent to reference, these cases are intricately connected to how courts use nondisabled common sense in deciding issues related to dis/ability and practices of institutionalized care, assuming they even choose to address these issues.

performances of apparent disability to assert claims for reparations. For more see, *Work Requirements: Race, Disability, and the Print Culture of Social Welfare* (Durham, NC: Duke University Press, 2022).

A Prelude to Litigation, 1963-1968

The dualistic "world-apart" narrative of the PSSH discussed in <u>Act II</u> continued until the institution closed in 1987. While the institution continued to posit itself as a care provider for inmates, the inhumanity of the institutional environment only became more apparent throughout the latter decades of the PSSH's existence. Journalistic accounts—written and televised—during this period became the primary vehicle for both supporters and detractors of the institution to express their views. As such, these accounts offer rich insight regarding the oscillating viewpoints held by the public and institutional authorities about the atrocities of institutionalization, their influence as drivers of local economies, and a deeply ingrained belief of disability as society's *other* other.

The newspaper coverage of the PSSH during this period presents a consistent narrative pattern: local reporters positioned the PSSH as doing its best in spite of a severely limited budget, while regional newspapers chastised the institution for its degrading environment. For example, on May 4, 1963, the PSSH authorities hosted an "open house" and invited citizens and lawmakers alike into the institution. While open to the public, significant portions of the institution remained cordoned off to visitors with events being hosted on the recreational fields, farm, and front (typically cleaner) wards of the institution. Reporters from the local, Pottsville, Pennsylvania-based *Daily Republican* proclaimed:

There was a time, and not too long ago, when commitment to a mental hospital was like a sentence to life imprisonment. Today there is hope of a useful life to many of the patients under treatment; indeed, such interesting progress has been made in mental therapy that a sudden break-through may lie ahead. Pennhurst, which most of us know by sight at least, is one of the best and most up-to-date State institutions in the country: It is both school and hospital. Although it is almost entirely supported by State funds, its patients get the kind of care and training best suited to their ability, and miracles are achieved on its limited budget. Visitors may see this personally on Saturday, May 4.³⁴¹

All the while, reporters from the *Philadelphia Inquirer* wrote how the institution was

"...a nightmare, a hellhole. A place where life exists on a subhuman level and swarms of

flies mix with naked bodies, the senseless babbling of multiple-handicapped men and

women and an ever-present stench."³⁴² Describing life in the wards, the reporter wrote:

Document to man's inhumanity [walk] to into a ward and from 82 closely packed cribs twisted and helpless patients stare out at you, some manacled to their prison-like cages. And there are two, maybe three attendants to look after their needs.

In another ward for the severely retarded, grown men lie sprawled naked on a floor. The floor is wet from where a mop picked up a pool of human waste. Thousands of flies dangle in death from the sticky yellow strips of paper extended from the high ceiling. Hyperactive retardates circle and jump and weave about a crowded dayroom. Some are as young as eight, others in their 40s.

•••

In ward C-67, 100 women stampede like cattle as a visitor approaches the doorway. Arms reach out, prodding, touching. A woman in her 50s cries, "Mama, mama." It's in wards like these that the less retarded who have been "naughty" are shipped for two days' discipline.³⁴³

While I explore the importance of differing local and regional newspaper coverage on the

PSSH in the subsequent section, what remains pertinent here is how both reports

portrayed PSSH inmates as fundamentally distinct from the nondisabled society. In the

Daily Republican's perception, the PSSH made institutionalized disabled subjects

"useful." This language highlights how nondisabled society perceived dis/abled people as

³⁴¹ *Daily Republican*, May 1, 1963, (SFHS) 78.

³⁴² Philadelphia Inquirer, July 7, 1968, (SFSS), 83.

³⁴³ *Philadelphia Inquirer*, July 7, 1968, (SFSS), 83.

inherently flawed. The institution, and the performances of habilitation it compelled the inmates to undertake, served to assimilate into nondisabled society. While the *Inquirer's* reporting vividly outlined the harsh conditions of the PSSH, it invariably degraded the inmates, casting them as bestial, infantile, and utterly helpless. It is essential to note, however, that the reporter did not attribute these characteristics to the detrimental impact of the institution's environment or the performances of institutionalized care that the inmates experienced. Instead, the journalist implies a deterministic perspective that these attributes were innate and biological facts inherent to disability. Despite disparate perspectives on the institution's conditions, both local and regional newspapers concurred: the staff knew how to resolve the institution's problems, but the Commonwealth failed to provide the needed funding.³⁴⁴ Strikingly, none of these outlets argued for closing the PSSH, merely its reform.

In April 1966, the PSSH received a \$100,000 grant (approximately \$900,000 in 2023) from the National Institutes of Mental Health to conduct a "psycho-sensory rehabilitation" program.³⁴⁵ This program also gave the PSSH funds to produce a promotional film to accompany the project. Narrated by Hollywood actor Henry Fonda,³⁴⁶ *Somebody Touched Me* (1967) detailed how the project symbolized "an

³⁴⁴ *Philadelphia Inquirer*, July 7, 1968, (SFSS), 83. The reporter notes, "The public must remember that in an enlightened society, we must pay for facilities to take care of those who are less fortunate and are unable to take care of themselves."

³⁴⁵ Philadelphia Inquirer, April 30, 1966, (SFHS), 80.

³⁴⁶ Although I have not discovered specific evidence dictating why Fonda was chosen as the narrator for the film, I suspect it has to do with his "everyman" persona, which was cultivated in his early movies. Interestingly, Fonda studied journalism at the University of Minnesota but left after his sophomore year. Despite Fonda's role in *Somebody Touched Me* not being noted in his filmographies, it is not uncommon for celebrities to participate in smaller voice-over projects which may not be listed in their comprehensive works.

institution's awareness of those who are forsaken because of mental retardation."³⁴⁷ According to Fonda, the project, like the institution, made a positive intervention in the lives of these "unfortunates". "These boys, about to enter the psycho-sensory rehabilitation project might have been destined to vegetate or rock away their existence, but now there's hope for them", Fonda reassured the audience.³⁴⁸ What remained starkly absent from *Somebody Touched Me* was the footage from the overcrowded wards and rampant use of restraint that the *Philadelphia Inquirer* reporter described above. Without depicting performances of institutionalized care, *Somebody Touched Me* propagated illusions of altruism while hiding the realities of the institution—overcrowding, underfunding, and heinous living conditions—and positioning dis/abled people as not fully human.

These institution-friendly promotions, however, did not go unanswered by critics. After visiting the institution in June 1966, Pennsylvania Superior Court Judge J. Sydney Hoffman called the PSSH "a big hell hole" in a speech to Goodwill Industries in Philadelphia.³⁴⁹ Hoffman blamed the General Assembly for underfunding the institution and consigning inmates to a "life of degradation."³⁵⁰ In July 1968, on NBC10-Philadelphia, Bill Baldini released the television exposé *Suffer the Little Children*.³⁵¹ This exposé represented a stark contrast to the altruistic image of the PSSH displayed in *Somebody Touched Me*. Instead of an institution providing cutting-edge habilitation, the

³⁴⁷ Released in 1967 and narrated by Henry Fonda. A digital version of the film is available on YouTube, <u>https://www.youtube.com/watch?v=YChCh2wHGQ8</u>.

³⁴⁸ Somebody Touched Me, 01:57-02:07.

³⁴⁹ Daily Republican, June 10, 1966, (SFHS), 80.

³⁵⁰ Daily Republican, June 10, 1966, (SFHS), 80.

³⁵¹ The exposé is also available on YouTube, <u>https://www.youtube.com/watch?v=ZIepqvHii-M</u>.

exposé revealed the horrifying conditions at the institution. As legal historian Karen M. Tani notes, by the early 1960s, a growing influence of "wealthier and more-resourced" parent-advocates of institutionalized disabled children and adults had "formed networks for support and advocacy."³⁵² Many of these organizations led efforts in the media with the hope of shaming state legislators into action. One of the prominent groups included the Pennsylvania chapter of the Association of Retarded Children (PARC). By the spring of 1969, PARC decided the media coverage from Baldini's exposé would not be enough to bring substantial reform, and they sought legal action against the institution and sued the PSSH.³⁵³

"We No Sooner Take a Step Forward and We're Pushed Back":³⁵⁴ Litigation Looms Over Pennhurst, 1969-1971

This section delves into the conflict between local and regional journalists, highlighting how these accounts depicted the PSSH as either a vital care provider for "unfortunates" or a forcing them to live a "nightmare." It examines this dichotomy, not solely viewing the PSSH as a care*giving* institution but also as a pivotal economic engine for the local Spring City community. These debates focused on the validity of the PSSH's care for its inmates, the embodied experiences of dis/abled individuals disappeared.

 ³⁵² Karen M. Tani, "The Pennhurst Doctrines and the Lost Disability History of the 'New Federalism,"
 California Law Review 110, no. 4 (August 2022): 1167.
 ³⁵³ Tani.

³⁵⁴ Dr. C. Duane Youngberg, PSSH Superintendent, quoted in *Philadelphia Inquirer*, July 18, 1973, (SFHS), 108.

The five-year period between PARC's initial decision to seek legal action against the PSSH and when David Ferleger sued on behalf of Terry Lee Halderman in 1974 was turbulent outside and inside the institution. Outside the institution, a battle between the *Philadelphia Inquirer* and the local newspapers—particularly the *Daily Republican* in Pottsville—raged. During this period, the *Inquirer*—almost monthly—eviscerated the PSSH and the appalling conditions at the institution.³⁵⁵ All the while, the *Daily Republican* claimed the institution was "under severe attack by metropolitan newspapers," and defended the institution by publishing reports about the institution's petting zoo or employee profiles.³⁵⁶

While almost comical, given the degree of separation between issues taken up by the two newspapers, this disparate coverage highlights an important reality of institutionalization as an economic lifeline for local economies. Since institutions are often located in rural areas, they become the major employer in the area. Further, institutions often purchase resources—supplies, food, clothing, etc., from local businesses. In turn, local and state governments, as well as the public, defend institutions because they provide income to local workers, as with the PSSH.

Residents and journalists alike often turned away from the harsh realities of violence and abuse present in institutions because of the revenue generated by the bureaucratic behemoths. "The employees who do continue to work at Pennhurst, do such a completely unbelievable job of caring and loving... that I have never walked away from there without a prayer of thanks and a firm knowledge that whether they think of it or not,

³⁵⁵ Philadelphia Inquirer, June 24, 1970, (SFHS), 100.

³⁵⁶ Daily Republican, "Not All Bad," July 27, 1969 (SFHS), 87.

they are among the purest Christians I have ever known" wrote one mother of a PSSH inmate.³⁵⁷ She concluded by inviting anyone with doubts to visit the institution, stating, "If any taxpayer is in doubt of where Pennhurst money should go, let him see for himself."³⁵⁸ While the letter to the editor provides little biographical context about the mother, an obituary for their daughter—who died in 2012 at a group home operated by the private institution and care-service-provider Elwyn, Inc.³⁵⁹—notes that her parents were "early officers of the Chester County ARC"³⁶⁰ This quote illustrates the rationalization of institutionalization for many parents, especially those coming from middle- and higher-middle-class families. Often families felt they had no other choice than to institutionalize their dis/abled family members and wished to feel they made the right choice despite the reports of horrendous conditions at the institution. This quote also reveals the subconscious ableism often held by family members and members of the public. The mother positions the labor performed by the PSSH employees as that which no one else can or wants to do. Further, by positioning this labor within a religious and moral framework, the mother's words suggest that the PSSH employees fulfill their Christian duty by taking care of the less than human inmates of the institution.

The newspaper coverage of supportive family members who felt their visitations with their loved one signaled the merits of institutionalization did not capture what I call performances of public institutionalized care. These performances of public

 ³⁵⁷ Louise H. Bickley, "Needs at Pennhurst," *Philadelphia Inquirer*, July 16, 1968, (SFHS), 86.
 ³⁵⁸ Bickley, *Inquirer*, 86.

³⁵⁹ Formerly the Pennsylvania Training School for Feeble-Minded Children, the first institution in the Commonwealth, and the second in the United States.

³⁶⁰ Daily Local News, "Barbara Bickley Obituary," Legacy.com, April 4, 2012, <u>https://www.legacy.com/us/obituaries/dailylocal/name/barbara-bickley-obituary?id=20611188</u>.

institutionalized care—such as the open house documented above—differed profoundly from the performances of institutionalized care experienced by inmates within the confines of the institution. For example, at the PSSH institutional authorities seldomly allowed parents or other visitors back to the wards in which they forced the inmates to exist. Staff would clean the inmate up prior to meeting with a visitor and put them in fresh clothes that often differed from their institution-provided clothing, such as clothes the inmate received from their family. They would then transport the inmate to Limerick (L)—a ward next to the Administration building—where the visitor could then meet with the inmate. Strikingly, the first floor of L is the only building at the institution with carpet in it. In doing so, the PSSH staff materially created the boundaries between the interior, "world-apart" of the institution and the exterior, nondisabled world. The staff's performative labor—ritualistically cleaning the inmate, costuming them in "normal" clothes, and staging them within a bracketed institutional space—literally trafficked the inmate across the boundary from less-than-human institutionalized disabled subject to human, habilitated disabled subject. Sadly, these performances of public care remain a common practice in contemporary institutions and continue to act as a façade to hide the violence of institutionalization.

Inside the institution, turbulence turned to chaos during this period. In the wake of the 1968 Baldini journalistic exposé, the Commonwealth announced it would transfer long-time and well-loved PSSH Superintendent Leopold Potkonski to another state institution in July 1969.³⁶¹ Just over a week later, over thirty PSSH employees made the

³⁶¹ Philadelphia Inquirer, June 30, 1969, (SFHS), 94.

three-hour trek to Harrisburg to protest the decision,³⁶² but to no avail. From July 1969 until October 1971, the Superintendent's position changed hands four separate times. The institution remained plagued by overcrowding, underfunding, and a lack of staffing. In July 1971, Commissioner of Mental Retardation Edward Goldman admitted to the *Philadelphia Inquirer*, "We dumped everyone there and then didn't provide the staff. What we hope to do now is cut the population at Pennhurst while, at the same time reducing the waiting lists and guarantee that no one is being dumped."³⁶³

By 1973, the institution had cut its population down to 1,600 from 2,800 in 1968, mostly by moving inmates to "annexes"—other institutions and group home facilities in the surrounding area. Still, the barbaric conditions persisted. "Come and see our warehouse... Actually, none of the other buildings are what you'd call homelike either... ...pack the people in was the idea when they were built... Only another couple of months and we'll be out of here," PSSH Superintendent C. Duane Youngberg told reporters with the *Philadelphia Inquirer* while giving them a tour of the institution in 1973.³⁶⁴ Youngberg's prediction turned out to be half right. While the lawsuit that would bring the death blow to the institution came barely a year later, it would take over a decade for the institution to close.

³⁶² Philadelphia Inquirer, July 9, 1969, (SFHS), 95.

³⁶³ Philadelphia Inquirer, July 15, 1971, (SFHS), 103. The reporter erroneously referred to Goldman's title as "mental retardation consultant." Goldman, now the Pennhurst Memorial & Preservation Alliance's Treasurer, clarified this error in an email, stating, "Geez, they got my title wrong. I never had a title of Mental Retardation Consultant. My title was Commissioner of Mental Retardation (now called Deputy Secretary). A rose by another name…" Edward Goldman, email message to author, February 23, 2022.
³⁶⁴ Philadelphia Inquirer, July 18, 1973, (SFHS), 108. Despite being the named defendant in a controversial lawsuit and serving as the superintendent of Pennhurst from 1972 to 1980, Youngberg exhibited progressive views on disability. Born in Duluth, Minnesota, and raised in Washington State, he earned his Doctorate in Education from the University of Oregon. He was an early advocate for community-based living practices and de/institutionalization. However, Youngberg maintained a somewhat sardonic view of his leadership role at the institution, seemingly feeling constrained by state legislators and government bureaucracy.

PARC & Pennhurst: The Perils of Class-Action Lawsuits as a Tool for Deinstitutionalization

This section details the perils of using class-action lawsuits as the primary tool for closing institutions through examining the two class-action suits filed against the PSSH. While these lawsuits helped to close the institution, they also left significant legal questions regarding autonomy, capacity, guardianship, responsibility, and the limits of relational care open for the common sense of nondisabled courts to rule on. *PARC & Halderman* illustrates how factors like the make-up of courts, sources of financial support, political influence, and others all contribute to not only the success or failure of class-action suits, but also how the embodied experiences of institutionalized disabled subjects get left behind.

Pennhurst as Separate and Not Equal Education: PARC v. Commonwealth (1971)

The initial lawsuit lodged against the PSSH did not pursue its termination but rather sought its reformation. An examination of *PARC* provides valuable insights on the function of class-action litigation in effecting the closure of institutions. On one hand, the quandary PARC, a parent advocacy organization, faced when deciding whether to demand closure or reform for the institution reveals the intricate costs and benefits analysis often employed by families to rationalize institutionalization. Many quickly dismiss the concerns of parents favoring institutionalization with responses like, "I would never do that to my child." However, historically and contemporarily, options remain

limited for families with loved ones who require significant care. This constraining choice is rooted in an acute absence of community services, particularly specialized medical care suited to individual needs. ³⁶⁵ On the other hand, it unveils the unguaranteed outcome of utilizing class-action lawsuits to facilitate progress within the dis/ability community.

PARC appointed Philadelphia-based lawyer Thomas Gilhool as its counsel in 1969. Shortly thereafter, Gilhool crafted a class-action lawsuit charging the Commonwealth of Pennsylvania *vis-à-vis* the PSSH with violating the Equal Protection Clause under the Fourteenth Amendment.³⁶⁶ Using *Brown v. Board of Education* (1954), Gilhool structured his argument not on the basis of the PSSH inmates' right to treatment (or lack thereof), but on how the Commonwealth's public education system kept dis/abled children from equal education opportunities by institutionalizing them. While, if successful, this lawsuit would not close the institution, it would provide school-aged dis/abled children at both Pennhurst and other institutions the right to a public education.

The Commonwealth received the lawsuit surprisingly well and the two parties crafted a consent agreement after only one day of testimony in August 1971.³⁶⁷ This lawsuit provided a major victory for dis/abled children in America, providing the fundamental framework for the Education of Handicapped Children Act of 1975 (later renamed IDEA), which guaranteed a right to equal education in public schools. But the

³⁶⁵ Additionally, prior to the implementation of the *Individuals with Disabilities Education Act* (IDEA) in 1975, there was a significant shortage of services within educational environments. Despite contemporary legislation providing parents and families with more choices, access to specialized services in both medical and educational settings continues to present a challenge. ³⁶⁶ Gran, "PARC to Pennhurst."

³⁶⁷ Tani, "Pennhurst Doctrines," 1176-77.

lawsuit did little to rectify the abhorrent conditions at the institution. Further, it also cost the Commonwealth of Pennsylvania nearly four times as much in special education funding.³⁶⁸ As Tani notes, "The education case had also spawned a new special education bureaucracy and produced a seemingly endless stream of follow-on litigation in federal court as parents advocated for the rights of their children. The message was clear: disability rights could be very costly and policymaking-via-litigation carried significant risks for state actors."³⁶⁹ These risks included both the rising costs of litigation but also the bureaucratic nightmare of closing the Commonwealth's institutions.

Halderman v. Pennhurst (1977)

The risks of the class-action suit as a tool for deinstitutionalization, and the associated costs of removing the dis/abled bodymind from these cases, became exceedingly apparent in the *Halderman* litigation. Although *Halderman* was instrumental in the eventual closure of the PSSH, the testimonies concerning performances of institutionalized care and the experiences of the dis/abled bodyminds that were presented in the trial court decision disappeared during subsequent appeals to the Supreme Court. To the dis/ability community, *Halderman* remains a milestone victory. But, in the broader legal realm, the so-called "Pennhurst doctrines" are significant not because of their focus on disability and performances of institutionalized care, but because of their implication on states?

³⁶⁸ Tani, 1177.

³⁶⁹ Tani, 1177.

³⁷⁰ Tani, 1160.

dis/abled people within the dehumanizing environment of the institution have faded away.

In 1974, David Ferleger, a Philadelphia-based lawyer, sued the PSSH on behalf of Terri Lee Halderman and other PSSH inmates in federal court. The complaint, filed with the Eastern District of Pennsylvania, accused both the institution and the Pennsylvania Department of Public Welfare, along with various employees, of neglect and abuse.³⁷¹ As Tani notes, "Halderman's records alone suggested over forty injury-causing incidents between March 1966 and November 1973, which resulted from performances of institutionalized care committed by PSSH staff. On one occasion, when Halderman fractured her jaw, PSSH employees were so inattentive that, after finally noticing something amiss, they mistook a dangling piece of jaw for a loose tooth and pulled it out."³⁷² The acts reported in the complaint reflect the various performances of institutionalized care discussed throughout this dissertation—excessive physical and chemical restraint, deliberate acts of violence, and the complete dehumanization of dis/abled people.³⁷³

In 1976, Ferleger and Gilhool filed an amended complaint.³⁷⁴ This new complaint sought both damages for the harm experienced by the inmates and the release and community placement of the inmates.³⁷⁵ In 1977, Federal District Court Judge Raymond Broderick issued a sobering opinion chastening the institution and the performances of

³⁷¹ Tani, 1164.

³⁷² Tani, 1164.

³⁷³ Halderman v. Pennhurst, E.D. Pa., 446 (1977).

³⁷⁴ Interestingly, PARC and Gilhool did not initially involve themselves in the *Halderman* lawsuit, but they rapidly integrated themselves into the proceedings. As Tani notes, PARC delayed lodging another suit until after the Pennsylvania Mental Health and Mental Retardation Act of 1966 had been passed by the General Assembly. See Tani, "Pennhurst Doctrines," note 133 at 1179.

³⁷⁵ Gran, "PARC to Pennhurst," 117.

institutionalized care documented there. In one specific example of excessive restraint, Judge Broderick noted that "a female resident who, during the month of June, 1976, was in a physical restraint for 651 hours 5 minutes; for the month of August, 1976, was in physical restraints for 720 hours; during September, 1976, was in physical restraints for 674 hours 20 minutes; and during the month of October, 1976, was in physical restraints for 647 hours 5 minutes."³⁷⁶

Unlike *PARC*, the Commonwealth was not readily willing to accept defeat and the associated financial costs of another victory by disability advocates. Since the plaintiffs won at trial, the defendants—the Commonwealth—faced a choice to either accept the trial court's judgement or appeal. If it chose to appeal, it risked the appellate court affirming the lower court's judgement. But the appeal could also force both parties to enter settlement negotiations. In these negotiations, both parties could come to a mutual agreement, but that agreement could also jeopardize the lower court's ruling and lessen the benefits received by the plaintiffs. As Tani observes, "By then, the State was no longer in a settling mood."³⁷⁷ Thus, the Commonwealth decided to seek a reversal by a higher court rather than try to come to an agreement with the plaintiffs. And so began a bitter legal battle between the Commonwealth of Pennsylvania and the class of PSSH inmates suing the institution.³⁷⁸ It would involve multiple appeals to the Third Circuit and, when these did not favor the Commonwealth, repeated requests that the Supreme Court overturn the lower courts' judgments.

³⁷⁶ Halderman v. Pennhurst, 1307.

³⁷⁷ Tani, "Pennhurst Doctrines," 1177.

³⁷⁸ Members of the Pennhurst Class also included individuals awaiting commitment to the PSSH.

Halderman ultimately went before the United States Supreme Court twice, once in 1981³⁷⁹ and again in 1984,³⁸⁰ but neither appeal addressed the embodied harm caused to dis/abled inmates by institutional authorities. Instead, each appeal dealt with some issue regarding federal and state relations. In the *writ of certiorari*—the request that the Supreme Court order the lower court send up the record of the case for review—for the first appeal, Pennhurst I, the petitioners questioned whether the plaintiffs could sue the defendants for violating the terms of the Developmental Disabilities Act of 1975 (DD Act)—a grant-in-aid statute. They also questioned whether the lower courts had correctly interpreted the DD Act when they read it to include some sort of right to habilitation. The Court's ultimate holding was not obvious from the original questions presented to the Court. Instead, the Court created language around what would become the "clear statement rule," and opined about what rules states had to comply with, based off of the unmistakably clear intention of the legislation, if they used grant funding received from the federal government.

The second appeal—Pennhurst II—addressed state sovereignty and questioned whether the Eleventh Amendment permitted a federal court to entertain a claim based on state law. While a relatively routine practice in cases where the state law claim shared the same nexus of facts with a federal law claim, Pennsylvania hoped the Supreme Court would reconsider. Once again, the Court reversed and remanded the case back to the lower court.³⁸¹ Choosing not to appeal a third time, the legal team representing the PSSH inmates feared the Court's conservative majority might overturn protections secured in

³⁷⁹ Pennhurst State School and Hospital v. Halderman (Pennhurst I), 451 U.S. 1 (1981).

³⁸⁰ Pennhurst State School and Hospital v. Halderman (Pennhurst II), 465 U.S. 89 (1984).

³⁸¹ Pennhurst II.

previous cases.³⁸² In short, without statutory safeguards from legislation such as the Americans with Disabilities Act, the erosion of any remaining constitutional protections would leave the dis/ability community practically defenseless. Following the Court's decision, settlement negotiations between the parties commenced and, on April 5, 1985, Judge Broderick approved the agreement.³⁸³ This settlement superseded Judge Broderick's prior order and, by agreement, Pennsylvania agreed to close the institution.

While *Halderman* ultimately led to the institution's closure, its protracted appeal process meant that the case's core issue—that the institutionalization of dis/abled people violated their constitutional rights under the First, Eighth, Ninth and Fourteenth Amendments to the U.S. Constitution—vanished. As a result, the litany of abuses and the detrimental and material effects of existing in an institutional environment were obscured. While not a class-action lawsuit, the final case in the PSSH's long litigative history—*Romeo v. Youngberg*—sought relief from the performances of institutionalized care documented, but was ultimately left behind by the Court, in Pennhurst I and II.

Romeo v. Youngberg & The Question of Restraint

Decided by the Supreme Court in 1982, between Pennhurst I and Pennhurst II, *Romeo v*. *Youngberg* was a case filed by an individual defendant rather than as a class-action lawsuit and did not seek the closure of the institution. Although legally tangential to *Halderman, Romeo* proved important in understanding how the Court defined care in

³⁸² James W. Conroy, email to author, July 22, 2023.

³⁸³ Tani, "Pennhurst Doctrines," 1197.

institutional settings and who they felt had the authority to decide about what types of care an inmate received. Further, this case becomes especially important when reviewing contemporary litigation, and how the Court continues to rule on issues on their face related, but actually adjacent to restraint and dis/abled embodiment, such as *HHC v*. *Talevski* (2023) discussed in <u>Act II</u>.

Filed on behalf of Nicholas Romeo's mother, *Romeo* took up the issues of restraint, the deprivation of liberty, and the role of professional judgment in determining what constitutes care.³⁸⁴ Nicholas Romeo, 33-years-old at the time of the lawsuit, received numerous injuries during his commitment to the PSSH. From July 1974 to January 1982, Romeo "suffered injuries on at least sixty-three occasions."³⁸⁵ In 1976, Romeo suffered a broken arm and authorities transferred him to the Infirmary—part of the hospital complex. While recovering in the Infirmary with a broken arm, a doctor physically restrained him each day, claiming to do so for Romeo's own protection.³⁸⁶

The Court ruled that the constitution provided Romeo, and other inmates, the right to be free from bodily restraint under the Fourteenth Amendment. But it also ruled that professional judgment circumvented that right. If an educational, legal, or medical professional can make a case for restraint, that professional can revoke the inmate's rights and restrain them.³⁸⁷ This continues to be an issue in institutions, intermediate care facilities, nursing homes, hospitals, group homes, classrooms, etc. because minor

³⁸⁴ Youngberg v. Romeo, 457 U.S. 307 (1982).

³⁸⁵ Youngberg v. Romeo, 310.

³⁸⁶ Youngberg v. Romeo, 311.

³⁸⁷ For more discussion on *Romeo*, and the Supreme Court's decisions on restraint, see Ferleger, "Human Services Restraint."

infractions such as a behavior outburst can cause the prolonged restraint of a child or adult.

Romeo highlights a crucial and compounding component regarding deinstitutionalization litigation: as the narratives of *PARC* and *Halderman* made clear, litigation does not come without significant risks. In *Romeo*, the Supreme Court agreed to review the case simply because it was the first time the Court could consider "the substantive rights of involuntarily committed mentally retarded persons under the Fourteenth Amendment to the Constitution."³⁸⁸ While the Court made it clear that institutionalized people have a constitutional right to care and treatment, along with liberty rights and protections under the Due Process clause of the Constitution, it also held that the interests of a person and the institution may at times be in conflict.³⁸⁹ In these moments of conflict, the Court gave partial favor to "…the judgement exercised by a qualified professional."³⁹⁰ In a footnote, the Court defined a "'professional decisionmaker'" as:

...a person competent, whether by education, training or experience, to make the particular decision at issue. Long-term treatment decisions normally should be made by persons with degrees in medicine or nursing, or with appropriate training in areas such as psychology, physical therapy, or the care and training of the retarded. Of course, day-to-day decisions regarding care – including decisions that must be made without delay – necessarily will be made in many instances by employees without formal training but who are subject to the supervision of qualified persons.³⁹¹

This deference to a professional, as defined by the Court's footnote, confirms the

superiority of the juridical-medical authority first introduced in the commitment trials of

³⁸⁸ Youngberg v. Romeo, 315.

³⁸⁹ Youngberg v. Romeo, 315-320.

³⁹⁰ Youngberg v. Romeo, 323.

³⁹¹ Youngberg v. Romeo, note 30, 323-24.

PSSH inmates in <u>Act I</u>. This language underscores how nondisabled society prioritizes medical professionals' expert knowledge of disability over dis/abled people's embodied experience. As Act II demonstrated, within institutional care settings, what "professional decisionmakers" perceived as care became received as violence for dis/abled people. The potential power imbalance between medical professionals and dis/abled people often cultivates a dynamic that does not center on holistic care nor putting dis/abled people first. What might seem like the best approach from a clinical perspective often does not capture the breadth of embodied dis/abled experience, nor account for the actual needs and desires of the dis/abled person the professional is assisting. By prioritizing the judgement of medical professionals in matters of care and treatment, the Court removes dis/abled people's agency and the vital context of lived experience. While the relationships dis/abled people develop with medical professionals remain indispensable to living a flourishing life, they should not hold the power to make life-defining choices for us. Though the Court, in *Romeo*, made it clear that dis/abled people—especially institutionalized disabled subjects—have the right to care and treatment, *Romeo* also laid the legal precedent that medical professionals have the near-final say over our lives.

While the Pennhurst litigation led to the closure of the institution, it simultaneously set a precedent in which the embodied experiences of dis/abled individuals were overlooked, favoring instead the judgment of medical professionals when discerning what constitutes care for dis/abled people. The erasure of dis/abled people and the horrors of institutionalization did not cease with the litigation. After the closure of the PSSH, the Commonwealth utterly abdicated its responsibility to preserve the memory of the former institution.

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"PENNHURST... A Monument to Indifference!": Post-Closure & Development of the Property³⁹²

The PSSH finally closed its doors on December 9, 1987. This section details what happened to the institution leading up to its closure in 1987 through when Pennhurst Associates purchased the property in 2008.³⁹³ This convoluted history illuminates two critical aspects of Pennhurst's legacy and its perception within both the disability advocacy community and the wider societal imagination.

First, the legacy obscures the interplay between law and performance in the context of institutionalization. Specifically, it conceals how the Commonwealth, using the institutional legislation discussed in <u>Act I</u>, conferred upon medical professionals the authority to use legal rhetorical performatives to conjure dis/abled people into institutionalized disabled subjects. Furthermore, it masks the manner in which the Commonwealth allowed institutions to become spaces of legal exception; a theme explored in <u>Act II</u>.

Secondly, it highlights an often-overlooked facet of the debate surrounding Pennhurst's legacy: the state's culpability in not just allowing the heinous conditions of the institution, but in its proverbial dereliction of duty to preserve that history to ensure it never happens again. While the PA often receives the brunt of the blame for its commodification of atrocity, the PA community's commemoration work discussed in <u>Act</u>

³⁹² Philadelphia Inquirer, October 30, 1968, (SFHS), 90.

³⁹³ Much of details in this section come from the work by the Pennhurst Memorial & Preservation Alliance and compiled in a timeline on their website. See "Pennhurst Timeline," Pennhurst Memorial & Preservation Alliance, n.d., <u>http://www.preservepennhurst.org/default.aspx?pg=93</u>.

IV stems from the Commonwealth's inaction. Thus, by failing to hold the Commonwealth accountable, both disability advocates and the public inadvertently allow it to dodge responsibility for—or even recognition of—the abominable atrocity that is institutionalization.

Prior to Closure, the 1980s

Three years prior to its closure, the Pennsylvania Historical and Museum Commission (PHMC)—the government agency responsible for overseeing the Commonwealth's historic heritage sites—deemed the PSSH eligible for the National Register of Historic Places in 1984. This required the Commonwealth to maintain and not sell the property without the consent of the PHMC. Despite this, the Commonwealth disregarded that obligation. The state further expressed a clear desire to rid itself of the burden of the PSSH even before the institution closed.

The Commonwealth allowed the Veterans Association (VA) to build a new hospital and long-term care facility on the grounds of the upper portion—"female colony"—of the PSSH campus in 1986. In 1988, the Commonwealth gave the VA an additional 147 acres of land. That same year, the Commonwealth also sold 122 acres of undeveloped farmland to private owners, who eventually developed the land into the Spring Hollow Golf Course and Country Club. In yet another example of the elision of dis/ability history and the disappearance of dis/abled bodyminds, the owners of the country club do not acknowledge anywhere on the physical property, nor on the Spring

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Hollow's website, that countless PSSH inmates died on those grounds performing unpaid labor, maintaining the crops and livestock used for the institution.³⁹⁴

"Finally, there is fish.": Indecision & Dreams of Aquatic Grandeur, 1991-1999³⁹⁵

In 1991, four years after the PSSH closed and one year after the United States Congress passed the Americans with Disabilities Act, the Pennsylvania Department of General Services (PADGS) proposed to sell the PSSH to the highest bidder. PADGS reached this decision without consulting former PSSH inmates, the broader disability community, or the PMHC. Like in the creation of the PSSH, the Commonwealth made no attempts to ensure dis/abled people were involved in its afterlife.

In 1992, the East Vincent Township hosted a meeting to discuss development options for the property. One of the most popular ideas involved turning the former institution into a state-of-the-art aqua farm, which would produce "over a million tons of fish per year."³⁹⁶ Shortly thereafter, the East Vincent Township Board of Directors (Township) expressed their interest to the PADGS in acquiring the property for park use. The Township committed to establishing a park on the property in 1992. In 1993, a land use feasibility study determined the former institution's property was best suited for park and recreational use. The Township incorporated the Pennhurst Feasibility Study's recommendations, and in 1994, called for Pennhurst's former ball fields and riverfront

³⁹⁴ Philadelphia Inquirer, "So Many Have Their Sights on the Pennhurst Site," February 11, 1992, (SFHS), 109. <u>https://springhollowgolf.com/</u>

³⁹⁵ Philadelphia Inquirer, "So Many Have Their Sights on the Pennhurst Site," (SFHS), 109.

³⁹⁶ Philadelphia Inquirer, "So Many Have Their Sights on the Pennhurst Site," (SFHS), 109.

area to be used as a park. The following year, the representatives from local municipalities formed the Pennhurst Regional Development Authority (PARDA). In addition, the Commonwealth of Pennsylvania listed Pennhurst on the Heritage Corridor Management Action Plan Resources Map as a recreation space resource for the new Schuylkill River Heritage Corridor. In 1996, the PARDA produced a Master Site Plan, which called for the Township to receive a 36-acre park encompassing the institution's former ballfields and riverfront, while using 62 acres of land to create a long-term care facility. However, in 1997, the PADGS decided, again, to sell Pennhurst to the highest bidder (while not including dis/abled people in the discussion to reach this decision).

"History Over \$": Selling Pennhurst, 2000-2010³⁹⁷

In 2000, Republican Governor Tom Ridge's administration awarded Richard Chakejian the property for a reported sum of \$1 (US). Chakejian's original bid included plans for reusing the PSSH's buildings, but those plans underwent multiple revisions. Eventually, Chakejian opted to demolish the buildings in favor of developing the property commercially.³⁹⁸ In 2003, Democratic Governor Ed Rendell terminated the agreement with Chakejian, citing his failing to uphold the original terms. Chakejian retaliated by suing PADGS for \$800,000, citing the effort and time he spent seeking approvals for

³⁹⁷ Since the purchasing of the property in 2008, urban explorers and protesters gratified the phrase "History Over \$" in various buildings throughout the PSSH, as well as on Pennhurst Associates equipment such as LED signs.

³⁹⁸ Nathaniel Guest, "Preserving Pennhurst: A Consideration of the Re-Use of the Epicenter of the American Disability Rights Movement" (Masters Thesis, Ithica, NY, Cornell University, 2012), 47.

property development.³⁹⁹ In the same year, United States Congressperson Jim Gerlach (R-PA) proposed a bill to establish a federal veterans cemetery on the grounds of the PSSH. However, the VA rejected this proposal in 2006.

In 2005, the Commonwealth adopted the "Keystone Principles for Growth, Investment & Resource Conservation" plan. The plan called for a "coordinated interagency approach to fostering sustainable economic development and conservation of resources through the state's investments in Pennsylvania's diverse communities."⁴⁰⁰ This plan reiterated the Commonwealth's responsibility to preserve and maintain properties like the PSSH. It also stated that the Commonwealth must consult with the PMHC prior to committing to any action on properties considered historic.⁴⁰¹

The Commonwealth breached their commitment to preserve the PSSH once again in 2006 when they reached a settlement with Chakejian and associate, Tim Smith, concerning the 2003 lawsuit.⁴⁰² The agreement stipulated that Chakejian and Smith would pay the Commonwealth \$2 million (US) to acquire the 60-acre PSSH "boys" colony" property, and they would remain immune from any challenges or suits.⁴⁰³ The Township green-lit the transfer of the deed to Pennhurst Associates—Chakejian's and Smith's company—in 2008, following the completion of the sale to the Commonwealth.⁴⁰⁴ (The Commonwealth never notified the PMHC about this transaction.⁴⁰⁵) Only days after Pennhurst Associates acquired the property, former

³⁹⁹ Guest, 48.

 ⁴⁰⁰ "Commonwealth of Pennsylvania Keystone Principles for Growth, Investment & Resource
 Conservation" (Commonwealth of Pennsylvania, May 31, 2005), <u>http://www.phmc.state.pa.us/bhp/pkp.pdf</u>.
 ⁴⁰¹ "Keystone Principles."

⁴⁰² Guest, "Preserving Pennhurst," 48.

⁴⁰³ Guest.

⁴⁰⁴ Guest, 49.

⁴⁰⁵ Guest.

Pennhurst administrator J. Gregory Pirmann and attorney/preservationist Nathaniel Guest established the Pennhurst Memorial & Preservation Alliance (PMPA), a non-profit organization, to advocate for the "sensitive re-use of the site."⁴⁰⁶

The Commonwealth's complete failure in maintaining the PSSH property, coupled with its disregard for the recommendations by the PMHC and its obligation not to sell the property, frequently fades from the discussion surrounding Pennhurst's legacy. Given the analysis of Pennhurst's litigation history outlined in the previous sections, the Commonwealth's blatant disregard for its laws and advice of its agencies is hardly surprising. PMPA co-founder Nathaniel Guest noted that, "By 2008, it is estimated \$300 million (US) of theft and vandalism had befallen the campus."⁴⁰⁷ The Commonwealth's attempts to absolve itself from any responsibility for the site and events that occurred there, poignantly exposes more than just the loss of property. It also lays bare the continued erasure of the dis/ability community. The same indifference that resulted in the horrific conditions at the PSSH also led to the decay of this monument of apathy, the annihilation of dis/ability history, and the complete dismissal of the memories of the people once confined to this institution.

Pennhurst Associates & the Birth of the Pennhurst Asylum

When Pennhurst Associates purchased the property, it intended to demolish the buildings and develop the land into a high-end residential property. After a land feasibility study

⁴⁰⁶ PMPA, "Pennhurst Timeline."

⁴⁰⁷ Guest, "Preserving Pennhurst," 46.

determined building a residential property would cause a loss in revenue, Pennhurst Associates sought commercial options. All the while, the Pennhurst Associates experienced a high number of trespassers and break-ins committed by "Urban Explorers" (UE), who sought to explore the former institution for its lore as an abandoned institution.⁴⁰⁸ Remarking on the growing notoriety of Pennhurst through UE groups, Heath Hofmeister and Chris Peecho Cadwalader explained how "Through the UE websites the vast grounds and buildings of Pennhurst were effectively 'rediscovered' by a public that knew little of the history or past of the campus."⁴⁰⁹ It was that "rediscovering" of Pennhurst, coupled with the growing interest in UE, that fueled Pennhurst Associates to capitalize on this trend by turning Pennhurst into a tourist attraction.

To the shock and resentment of the local disability community and organizations such as the PMPA, Pennhurst Associates opened the "Pennhurst Asylum" in 2010. As I discuss in my examination of the original museum in <u>Act IV</u>, when the Asylum attraction first opened, the managers did little to tease out social lore from historical fact. The attraction's management did not consider the PSSH's legacy for the deinstitutionalization movement, the rights of dis/abled people, or the site as a place of significant trauma. Instead, they focused on providing the best possible "shock value" to customers.

While <u>Acts I</u> & <u>II</u> dealt with the PSSH, <u>Acts III</u> & <u>IV</u> examine the Pennhurst Asylum haunted attraction created by Pennhurst Associates—now owned by Pennhurst Limited Liability Company (LLC)—and the community of dis/abled haunters who work

⁴⁰⁸ Despite the implementation of robust security measures, including round-the-clock surveillance and the employment of a full-time security crew, regular trespassing on the property persists.

⁴⁰⁹ Heath Hofmeister and Chris Peecho Cadwalader, "Touring the Ecology of the Abandoned," in *Pennhurst and the Struggle for Disability Rights*, ed. Dennis B. Downey and Conroy, James W. (University Park, PA: The Pennsylvania State University Press, 2020), 347.

there. Act III investigates the Pennhurst Asylum haunted attraction. I examine the performances found in the attraction to understand how the elision of dis/ability history and the societal sanctioning of violence against dis/abled people takes place. Crucially, the PA also creates a space and a mode of performance—haunting—that allows dis/abled people to unsettle nondisabled ontological assumptions of disability. Haunting compels the spirits of the former PSSH inmates back to life, thereby reinstating their agency revoked in the commitment process, and providing camaraderie for the PA community. Act IV delves into the preservation work undertaken by the dis/abled haunters working for Pennhurst LLC, and their collaboration with the PMPA that began in 2021. Finally, Act IV elaborates on how this community of dis/abled and nondisabled people explore Pennhurst's history together, asking questions, sharing stories, and thinking in-between the gaps of dominant models of disability.

RECITATIVE

"Nothing's Sacred Except the Cupola"

It's August 8, 2018. I'm driving northwest from New Jersey to Pennsylvania on the PA Turnpike in a blue "economy-sized" rental car that feels like a go-cart. As I near Exit 326, the "Valley Forge" exit, I dial my contact from the Pennhurst Memorial & Preservation Alliance (PMPA). The voice of J. Gregory Pirmann booms through my rental's speakers. Pirmann, a gruff and cantankerously well-spoken, retired Pennhurst Administrator turned co-founder of the PMPA, sounds skeptical of me. Pirmann had worked at the PSSH for eighteen years, starting as a case manager and working his way up the bureaucratic ladder to Special Assistant to the Superintendent.

Pirmann told me he had graduated with an English degree from Vassar University and took the Commonwealth's social services exam. He told me how he fell in love with the people of Pennhurst. A sense of pride emanated from him as he told me about his work at the PSSH.

As I made my way West down Bridge Street, coming to cross the town line between Royersford into Spring City, I asked Pirmann if he had any thoughts on the haunted attraction.

"You're getting close to Pennhurst, so I'll be brief. That haunted house is an abomination."

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Point received...

"Heed my warning, young man: stay out of the buildings and watch your step. There's asbestos in the walls and open manholes all over. There's more than one way to die on that property."

As I hang up with Pirmann, I follow my GPS's directions to turn onto North Church Street. The quaint homes of Spring City start to disappear, and the road slowly becomes more dilapidated. Getting closer to campus, my car becomes surrounded by lush vegetation and towering trees—I am totally lost and disorientated. Seemingly out of nowhere, I see two stone, dragon-tooth towers with the words "Pennhurst State School" on them emerge from the thick canopy of green. My gut clenches as my palms start to sweat.

This is literally like out of a horror film. What am I doing?!?

As I round the corner to the intersection of North Church Street and Commonwealth Drive, a cement blockade stands in my way. Confused, terrified, and clearly misplaced, I call my contact from Pennhurst LLC, Neil.

"Hi, Neil. This is Nathan Stenberg, the researcher from the University of Minnesota. I'm here for my tour, but I'm lost. There's a blockage in the road—"

"Oh, the GPS took you the wrong way. You need to come up on Commonwealth Drive. Give me five minutes, I'll come escort you." Neil seems unsurprised.

A few minutes later an early-2000s Ford Police Interceptor comes barreling toward me.

"Follow me!", Neil exclaims.

As I follow Neil down Commonwealth Drive, the cupola of the Administration comes into view. I feel a violent pang go through my body, telling me I am encroaching on dangerous ground. Parking in front of the Administration building, I am greeted by four bloodied and bludgeoned mannequins hanging by meat hooks and industrial chains from a magnolia tree.



Figure 7: "Suspension Therapy," as referenced in the body of the Recitative. Photograph by the author.

Sitting in my rental, staring at the spectacle, I am unable to move. I feel anger,

twinged with disbelief and utter terror.

Whose nightmare is this anyway?

I exit the car and make my way over to the tree.

"We call that 'Suspension Therapy.' The set crew is redesigning the whole haunt now that there's new management. We're not quite sure what to do with them now, so we hung them from the tree.", Neil explains.

What the literal fuck.

"It's certainly something..." I don't hide my shock and disgust well.

"Well, we have a saying around here: 'Nothing's sacred except the cupola.'

"What's with the cupola?"

"Back in the day, each ward had its own cupola to vent the air, but when they installed steam heating they got rid of 'em—except the one on Administration. When they shut the place down, some guys came in with a pickup truck and ripped the original oxidized copper sidings off the cupola. They filmed it and put it up on social media... It looked terrible with just the exposed frame, so when we got here, we patched it up and put a revolving spotlight up there to make it look like a guard tower. It's become a bit of a symbol for the community."⁴¹⁰

Beat.

"So, would you like me to show you around the campus now?", Neil asks.

As we walk, he laughs and tells me about how he was born in the PSSH hospital complex because all the other hospitals in the area were full at the time. When we reach the complex, he takes on a more reflective tone and mentions that his grandfather worked

⁴¹⁰ In 2023, Pennhurst LLC's set designers restored the cupola to its original appearance using newly crafted siding, designed to replicate the green, oxidized copper that was stolen by vandals.

as a dentist at the institution. Neil told me his grandfather often complained to the State about the conditions in the institution.

"My grandfather talked about having to train 'high-grade' patients to work as dental assistants because they didn't have enough staff, and how he was forced to perform procedures on patients without Novocain."

As we return to the Administration building, I drum up the courage to ask Neil why he works at the Pennhurst Asylum and, given his connection to the institution, how he felt about the haunted attraction.

"You know, I am disabled myself. I am blind in one eye. A lot of us identify as disabled or have family that worked here or lived here. Honestly, this is one of the most beautiful places I've ever been. I'll often park over in the courtyard and camp in the bed of my truck overnight. The sunrises here are amazing, there's all these animals running around, and I just feel at home here. I also love haunting. I've been a haunter for 30 years. But, then again, I look at the attraction and I do wonder if what I am doing is right. It's a day-by-day thing. Somedays, I think I have the best job in the world. Other days, I think I'm the worst person in the world." See the animal in his cage that you built Are you sure what side you're on? Better not look him too closely in the eye. Are you sure what side of the glass you are on? See the safety of the life you built. Everything right where it belongs.

And if you look at your reflection Is it all you want it to be? What if you could look right through the cracks? Would you find yourself— Find yourself afraid to see?

Michael Trent Reznor⁴¹¹

ACT III

The Pennhurst Asylum & the Spectre of Disability: (Re)Performing and Reclaiming the Repertoire of Pain

Introduction: Making Institutional Violence Apparent for Review

The Pennhurst State School & Hospital (PSSH) closed in 1987, but as Act II revealed, the

violence of institutionalization did not end with the deinstitutionalization movement in

⁴¹¹ Written by Michael Trent Reznor, performed by Nine Inch Nails, "Right Where It Belongs," *With Teeth* (Interscope Records, 2005).

the 1970s, instead, it has continued into the present. In 2008, the Commonwealth sold the property to private owners who formed Pennhurst Associates. In 2010, Pennhurst Associates opened the Pennhurst Asylum haunted attraction (PA). The PA is a haunted attraction staffed by mostly dis/abled people, housed on the grounds of the former PSSH.

This Act takes up the issue of how performances of disabled appearance, habilitation, and institutionalized care—and the violence inherent to them—get restaged in the PA. The performances found in the PA transfers embodied knowledge about disability, care, and violence, and reveals nondisabled society's horror of becoming disabled—what I later theorize as the <u>spectre of disability</u>. The PA demonstrates nondisabled society's willingness to commodify institutional violence through how the attraction employs representational performances of disabled appearance and institutional care to fashion its aesthetic of horror. These performances create a repertoire of pain which informs the patrons of the PA that the restaged performances of institutionalized care—acts of violence as care—are both acceptable and entertaining through what performance studies scholar Diana Taylor calls, a "nonarchival system of [embodied] knowledge transfer."⁴¹² But the PA also creates a space and mode of performance haunting—where dis/abled people unsettle nondisabled ontological assumptions of disability while also compelling the spirits of former PSSH inmates into existence.

⁴¹² Taylor, Archive and the Repertoire, xvii.

The Performativity of Institutionalization

In the monumental case Olmstead v. LC (1999), the Supreme Court of the United States (SCOTUS) held that medically unnecessary institutionalization qualified as legal discrimination under the Americans with Disabilities Act (ADA). Writing the opinion, the late Supreme Court Justice Ruth Bader Ginsburg noted in a footnote, that institutional violence is "capable of repetition, yet evading review."⁴¹³ The Court commonly uses this phrase, which comes from common law doctrine, because it allows the Court to hear a case that may be, on its face, moot. Federal courts are inherently limited in their jurisdiction to "Cases" and "Controversies" under Article III of the Constitution. Mootness allows a court to get rid of a case after the initial filing of a complaint because intervening events have defused the live case or controversy. In *Olmstead*, for example, the institutionalization of the plaintiffs-the live legal controversy-had already occurred and become moot. But because the plaintiffs could be institutionalized again, and the controversy would finish before the Court could decide on the issue. Thus, the issue of institutionalization would be "capable of repetition yet evading review" because it is moot.⁴¹⁴ Justice Ginsburg's comment strikes at the heart of critical theorist Judith Butler's theory of performativity, while also noting how legal action regarding institutionalization, disability, and violence often repeat while evading review of the courts.

⁴¹³ Olmstead v. L. C., U.S. 581 (June 22, 1999).

⁴¹⁴ In short, if a plaintiff challenges a state law as discriminatory, but the state changes the law while the plaintiff's case is pending to make it nondiscriminatory, then the plaintiff's case is arguably moot.

Butler argues that gender seems biologically secure but relies on the constant repetition of embodied expressions of citational behavior in order achieve this sense of facticity or materiality.⁴¹⁵ Though Butler's arguments focus specifically on gender, performativity relates to dis/ability in and through the assumptions made by legal and medical experts in how they understand disability. For example, nondisabled people expect dis/abled people they label as intellectually and/or developmentally disabled, (I/DD) such as myself, to engage in particular performances of disabled appearances and everyday life.

In my own life, people—often nondisabled disability advocates—have questioned my choice for identifying as developmentally disabled because I am a doctoral candidate.⁴¹⁶ I do not fit the performances of disabled appearance often associated with developmental disability—such as (readily apparent) difficulties in speaking, writing, eating, and moving. But these advocates have not witnessed various teachers, doctors, and publics label me according to my diagnosis. They have not seen me wrestling with bureaucratic, educational, legal, medical, and social structures due to these labels. Nor have these advocates experienced the material ways my condition impacts my day-to-day life. As I elaborate in my analysis of "pulling the card," I have effectively learned to code-switch—switching one's language and embodiment when in different cultural environments—and navigate a nondisabled society. Yet, there are visceral moments when the bodymind realities of my developmental disability become apparent. Even so, from

⁴¹⁵ Butler, "Performative Acts and Gender Constitution"; Judith Butler, *Gender Trouble: Feminism and the Subversion of Identity* (London, UK: Routledge, 1990).

⁴¹⁶ I use the language developmentally disabled here, rather than developmentally dis/abled because I am almost always code-switching in these moments.

the perspective of these nondisabled advocates, I am only developmentally disabled when I portray performances of disabled appearances. This mirrors the way society assumes gender, which, like disability, is perceived as a biological reality located within an individual yet remains entirely dependent on performative citational tropes.

Performances of disabled appearance, habilitation, and institutionalized care also become performative. They become performative through the repetition of an act or belief, such as the capture, categorization, and violence against dis/abled people in institutions and the ways dis/abled people must navigate juridical-medical systems to receive protections and care. The repetition of that act or belief then becomes naturalized and normalized in both the daily work of institutions and the depiction and representation of that work in popular culture and public life.

Repetition and naturalization are core components of the performative process of institutionalization. The repetition of rhetorical legal performatives removed the personhood from children deemed disabled thus making them eligible to become institutionalized disabled subjects. The repetition of performances of institutionalized care—such as abusive acts of restraint in the name of care used in the institution—further dehumanized dis/abled people and cemented their status as institutionalized disabled subjects. Further, performances of habilitation continue to require dis/abled people to perform as disabled to remain eligible for care services. The historical and ongoing repetition of performances of institutionalized care and habilitation are core to how this dehumanization, subjectification, and otherization became naturalized in American society. The afterlife of these performances continues to haunt dis/abled people today through what I call in this Act the spectre of institutionalization. Even though the spectre

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of institutionalization and the spectre of disability, which I discuss later in this Act, can and do occur simultaneously, the two concepts remain distinct. For example, the emotionally and physically violent process of institutionalizing inmates to the PSSH not only dehumanized dis/abled people, but also laid the foundation for legal, medical, and societal imaginary to perceive disability as horror, worthy of being banished from society.

The Spectre of Institutionalization & The Repertoire of Pain at the Pennhurst Asylum

The PA makes state-sanctioned, institutionalized violence against dis/abled people socially acceptable by staging it as entertainment. The PA naturalizes and normalizes the violence of institutionalization by staging disability as horror and characterizing institutions as necessary holding pens for society's banished others. Like Justice Ginsburg's note about institutional violence being capable of repetition but evading review, the PA continues the work of historical and contemporary institutions, such as the PSSH, of justifying the legal, medical, and social abjection of disability. As the attraction restages acts of violence and restraint commonly found (and repeated) in actual institutions, the PA makes institutional violence repeat, year after year. While people often critique the PA for being morally and/or ethically questionable for replicating *past* events, they often overlook the parallel between the fantasized representations of institutional violence as horror and the near-constant reports of violence in actual institutional care-settings today.

Because most of the people who perform at the attraction identify as dis/abled, the PA also raises deep questions about what it means to live in, through, and alongside, what I refer to as the spectre of institutionalization. I theorize the spectre of institutionalization as the continued capture, categorization, and dehumanization of dis/abled people in ways—implicitly or explicitly—connected to brick and mortar institutions. And that the spectre of institutionalization haunts dis/abled people with the fear that at, any point, dominant, nondisabled society could force us to return to the institution in the name of *care.* Thus, this Act argues: first, that the performances found in the PA—the citations of representational tropes of disability as horror found in the set design and marketing, the repetitions of (fictionalized) violent acts, and the deliberate creations of dis/abled performers in the act of haunting—illuminates how disability elicits fear as nondisabled society's *other*. Second, that the performances found in the PA, and the violent reactions by the mostly nondisabled patrons, help better understand how institutional violence and the dehumanization of dis/abled people continue to receive sanctioning from society. Finally, the dis/abled performers at the PA unsettle and make societally assumed narratives of institutionalization appear for review.

The investigation of the role of performance—the citations of horror tropes, the repetitions of performances of institutionalized care, and embodied enactments of haunting—reveals how the PA transfers embodied knowledge about disability, care, and violence. The attraction not only makes the historical and ongoing state-sanctioned violence that continues to elude the review of the Court apparent—as evident from Justice Ginsburg's comment in *Olmstead*—but also illuminates nondisabled society's horror of becoming disabled. In doing so, the PA also makes apparent nondisabled

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society's willingness to commodify violence against dis/abled people in institutions through the PA's scenes and performances of disability as horror. In turn, the repeated and performed repertoire of violence as care reinforces to society that such acts are not only acceptable but entertaining, thus rehearsing and fortifying nondisabled society's abjection of disability.

"FIRE IN THE HOLE!!!": The Making of a Haunted House

The Haunted House Industry

To better understand the PA, one must first get a sense of the larger haunted attraction

industry. Haunted houses have a long history within literature, dating back to the

Romans. But the haunted house gained significant notoriety through Gothic novels of the

nineteenth century.⁴¹⁷ Haunted houses as a physical, theatrical attraction did not gain

popularity in the United States, however, until Walt Disney opened Disneyland's

Haunted Mansion in 1969.418

The contemporary haunted attraction industry continues to blossom. As of 2013, the industry marked profits upwards of \$300 million (US).⁴¹⁹ Replete with a professional

⁴¹⁷ Sylvia Ann Grider, "Haunted Houses," in *Haunting Experiences: Ghosts in Contemporary Folklore*, by Jeannie Banks Thomas, Diane E. Goldstein, and Sylvia Ann Grider (Logan, UT: Utah State University Press, 2007), 143–70.

⁴¹⁸ Chris Heller, "A Brief History of the Haunted House: How Walt Disney Inspired the World's Scariest Halloween Tradition," Smithsonian Magazine, October 31, 2017,

https://www.smithsonianmag.com/history/history-haunted-house-180957008/.

⁴¹⁹ Martha C. White, "It's Aliiiive! Haunted-House Industry Scares Up Big Money," NBC News, October 6, 2013, <u>https://www.nbcnews.com/business/its-aliiiive-haunted-house-industry-scares-big-money-8C11334306</u>.

association—the Haunted Attraction Association⁴²⁰—and an annual trade show— TransWorld's Halloween & Attractions Show⁴²¹—the haunted attraction industry has developed into a robust business. And yet, all haunted attractions are not created equally.

The industry does not offer a uniform standard regarding what a haunted attraction looks, sounds, or scares like. As of 2023, Pennsylvania has over 20 haunted attractions. These haunted attractions range from more family-friendly "haunted hayrides"—where patrons sit on a trailer as a tractor tows them around the property—to the multi-million-dollar, site-specific Pennhurst Asylum.⁴²² Researching the correlation between the fear generated by a haunted attraction and levels of patrons' satisfaction, horror scholars Mathias Clasen, et al., found haunted attractions particularly fertile ground for investigating responses to fear.⁴²³ They concluded haunted attractions proved useful because:

They are live-action experiences where visitors buy entrance to a set, often a building, which is designed to induce feelings of fear, anxiety, and disquiet. Scare actors populate the set and use a variety of scare tactics, from make-up that suggests bodily damage or distortion to threatening behavior. By situating the visitor in an empirical environment replete with cues of danger, haunted attractions may be closer to horror video games and virtual reality than to observational media such as movies. Like horror video games, most haunted attractions use a combination of scripted narrative sequences and interactive elements, but with the difference that a visitor is physically present in the threatening world, while aggressive survival responses are prohibited (i.e., there is no way of fighting back without being evicted from the attraction).⁴²⁴

⁴²⁰ "About the HAA," The Haunted Attraction Association, n.d., <u>https://hauntedattractionassociation.com/about/</u>.

 ⁴²¹ "TransWorld's Halloween & Attractions Show," n.d., <u>https://www.haashow.com</u>.
 ⁴²² "Haunted Houses & Halloween Attractions in Pennsylvania," Pennsylvania Haunted Houses, n.d., <u>https://www.pahauntedhouses.com</u>.

⁴²³ Mathias Clasen, Marc Anderson, and Uffe Schjoedt, "Adrenaline Junkies and White-Knucklers: A Quantitative Study of Fear Management in Haunted House Visitors," *Poetics* 73 (2019): 61–71.

⁴²⁴ Clasen, Anderson, and Schjoedt, 63.

Clasen, et al., reference how haunted attractions use conventional theatrical roles, such as scare actors and patron-observers, to generate an environment rife with fear. Some haunted attractions create scripts for characters to follow while other haunted attractions, like the PA, have actors improvise their characters. Additionally, haunted attractions employ theatrical costumes, as well as set and sound design.

At the PA, for example, if a haunter does not feel confident with more conventional, theatrical acting, management will place that haunter in the Morgue or Tunnels attractions, which feature more set pieces and special effects for the haunter to operate rather than interact face-to-face with patrons. And yet, Clasen, et al., do not acknowledge haunted attractions' relationship to immersive and participatory theatrical performance. Instead, they focus on haunted attractions' connection to video games and cinema.⁴²⁵ Finally, of particular importance, Clasen, et al., cite how scare actors in haunted attractions often employ "bodily damage or distortion" to generate fear, but they do not directly link those signifiers back to disability.

⁴²⁵ The literature on both haunted houses and horror studies remains fixated on mediums such as literature, film, and video games. For further exploration of this connection see, Madelon Hoedt, "Keeping a Distance: The Joy of Haunted Attractions," *The Irish Journal of Gothic and Horror Studies* 7 (December 20, 2009): 34–46; Mathias Clasen, *Why Horror Seduces* (Oxford, UK: Oxford University Press, 2017). The literature from performance and theatre studies scholars that discuss haunted houses tend to focus on "hell houses" of far-right, evangelical Christians. See, for example, Ann Pellegrini, "Signaling through the Flames': Hell House Performance and Structures of Religious Feeling," *American Quarterly* 59, no. 3 (2007): 911–35.

The Pennhurst Asylum

Dramaturgy of the Pennhurst Asylum

Opened in 2010, the PA's management and the attraction itself have undergone significant change over the last 13 years. From 2010 to 2016, Pennhurst Associates— manager, Randy Bates and owners Richard Chakejian and Tim Smith—parceled the PA into three separate attractions.⁴²⁶ The main "Asylum" attraction spanned the first two floors of the former Administration building, while the basement of the Administration Building became the "morgue." The third attraction, then named the "Dungeon of Lost Souls," ran a span of tunnels from Limerick (a former boys' ward) to the other side of the campus near "Industry" (a former vocational skills building that often doubled as a boys' ward). The actors and designers produced the attraction's aesthetic of horror by employing themes of medical violence and disability and blending a fantastical plot line with historical events.

According to the "Legend" page on the PA website circa 2010,⁴²⁷ the plot of the attraction during this period centered around a fictionalized brain surgeon, Dr. Chakejian. Dr. Chakejian conducted medical experiments on prisoners from an undisclosed prison in Austria, until the Austrian government closed the research site down. Shortly thereafter, Dr. Chakejian began a worldwide search for another location where he could restart his research. Settling on Pennhurst, Dr. Chakejian purchased the property from the Commonwealth, restored it, and resumed his experiments. He conducted experiments

 ⁴²⁶ PA employees refer to Pennhurst Associates' management as "old management."
 ⁴²⁷ "Pennhurst Asylum: 16 Aug 2010-09 May 2021," Internet Archive: Wayback Machine, n.d., https://web.archive.org/web/2011015233956/http://www.pennhurstasylum.com/mobile.html.

such as "psycho surgery... body suspension, light deprivation, and intense drug therapy."⁴²⁸ Incorporating an actual fire that broke out on the second floor of the Administration building, PA designers claimed that Dr. Chakejian, along with several of his staff and test subjects, were killed in that fire, while others escaped or were left for dead. The institution once again entered a state of disrepair. But, the page warns, "Its [sic] said that the ghosts of Dr. Chakejian, his staff and inmates are still there too, continuing their experiments and as the number of missing people in the area would attest, the good Doctor is always looking for new test subjects."⁴²⁹

While the PA has employed dis/abled haunters since its opening in 2010, Pennhurst Associates' management allowed nondisabled haunters to openly caricature dis/abilities they did not experience and put dis/abled haunters in scenes that replicated their past medically induced traumas. Furthermore, they used objects found on site, such as wheelchairs, crutches, and other medical paraphernalia as key props for the attraction. Patrons moved through the space voyeuristically observing that violence. It was also not uncommon for patrons to touch or harm haunters under the management of Pennhurst Associates.

The Pennhurst Associates' design of the PA, their treatment of dis/abled haunters, and reliance on disability as a horror reified the trope of disability as nondisabled society's "other." The PA under the management of Pennhurst Associates perpetuated disability as what performance scholar Petra Kuppers calls, "outside 'normal' society and

^{428 &}quot;Pennhurst Asylum: 16 Aug 2010-09 May 2021."

^{429 &}quot;Pennhurst Asylum: 16 Aug 2010-09, May 2021."

bodies."⁴³⁰ The voyeuristic, passive gaze of the patron, combined with the medically themed violence in the attraction under Pennhurst Associates' management, perpetuated disinformation regarding not only the types of violence and care inmates of the PSSH were exposed to, but also what happened to them once the institution closed. For example, one of the most significant misconceptions regarding deinstitutionalization was that when institutions for people deemed developmentally disabled closed, the inmates were left on the street with no were to go. While that did occur in the deinstitutionalization of people deemed psychiatrically disabled, people freed from developmental institutions almost always found placements in group homes.

Setting a fictional custodial institution within an actual institution also models a specific form of immersive performance that transfers knowledge about disability to patrons in a way other sites would not. Performance studies scholar Scott Magelssen calls this type of performance "simming," or "a deliberate, embodied practice involving its participants in a simulated three-dimensional physical environment."⁴³¹ Magelssen examines the role of these environments and the effect they have on patrons, and how "participants learn by making choices within a bounded scenario and learn from the consequences of those choices."⁴³² The PA attraction, as a quasi-immersive and participatory performance, cannot fully duplicate the environment of the PSSH. While the attraction does not give patrons full autonomy of choice—like an escape room or other simming environments where patrons make active choices that dictate their

⁴³⁰ Petra Kuppers, *Disability and Contemporary Performance: Bodies on Edge* (New York, NY: Routledge, 2004), 4.

⁴³¹ Scott Magelssen, *Simming: Participatory Performance and the Making of Meaning* (Ann Arbor, MI: University of Michigan Press, 2014), 5.

⁴³² Magelssen, 6.

experience—the patrons still have free will to act while in the haunt. By citing horror tropes of institutional life as conjured by nondisabled imaginary, as well as other institutions, along with fantasying elements commonly found in actual institutions, the PA captures a slightly out-of-focus snapshot of an institutional environment.

In 2016, Pennhurst Associates defaulted and a new ownership team, Pennhurst LLC, purchased the property from them. As discussed in more detail in <u>Act IV</u>, Pennhurst LLC fired the Pennhurst Associates' management team and hired new management to replace them. Since the management transition, the new PA management attends the annual TransWorld trade show in February to research current trends within the industry and determine if and how the attraction's design will change for the upcoming season.

Under Pennhurst LLC's management, the Asylum attraction—still housed in the former PSSH Administration building—remains the PA's main event. After entering the building, the patrons make their way through twenty-one different scenes that span the first and second floors of the Administration building. These scenes employ both fantasized horror tropes directly quoted from or inspired by popular culture—such as a "Scooby Doo" room and the "Dolls" room. Some scenes derive horror from citing and staging practices that take place in custodial institutions (including the PSSH), such as "isolation," "shock therapy," and "the operating theater." Filled with anywhere from two to four haunters, these actors portray inmates of the fictionalized PA.

In the attraction's plot, the inmates have killed the nondisabled institutional staff that ran this psychiatric institution set at an indiscriminate time between the 1920s and the 1940s. The inmates then place staff uniforms, such as doctors' white coats and

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nurses' uniforms, over their own institution-provided clothes to impersonate the institutional staff. The patrons that enter the Asylum then become the new "inmates," and the former inmates subject the patrons to the same horrors that the institutional staff subjected them to.⁴³³

The Morgue attraction (that services the fictional Asylum), located in the basement of the Administration building, features sixteen scenes similar in style to the Asylum attraction. Distinct thematically from the Asylum and Morgue attractions, the Tunnels feature sixteen scenes that are described as a failed medical experiment that occurred in the 1960s. Strikingly, this blend of time periods and themes not only draws on the nondisabled public's terror of disablement but also a broader repressed consciousness of our shared vulnerability to medical violence.

Despite the changes made under Pennhurst LLC's management, the PA still employs "madness," and specifically "criminal insanity," as the primary source of horror for the attraction. This remains a complicated and nuanced topic of discussion for numerous reasons. First, under both Pennhurst Associates' and Pennhurst LLC's management, the backdrop of the haunted attraction is an "asylum," an institution for people deemed psychiatrically disabled, but the attraction is in an institution for people deemed feebleminded. As disability and memory studies scholar Kelly George notes, this plot choice "reinforces the common stereotypes of both groups: that 'the mentally ill' are violent and 'the intellectually disabled' are hypervulnerable and innocent."⁴³⁴ It also

⁴³³ The PA did not originate this plot. For example, Herman Miller wrote a novella depicting inmates overtaking a slave ship in *Benito Cereno*. For more, see Benjamin Reiss, "Madness and Mastery in Melville's 'Benito Cereno," *Criticism* 38, no. 1 (Winter 1996): 115–50.
⁴³⁴ George, "The Birth of a Haunted 'Asylum," 106.

further blurs an already hazy social imagination of what institutions are and who gets committed to them. Second, it conflates madness as the source of horror rather than disability. As a culturally constructed transient event, madness is scary precisely because it can overtake anyone at any time, thus upsetting our sense of living in a predictable world. Disability is culturally constructed as frightening in a different way because it represents the *other's other*. As I discuss later in my examination of the horror genre, disability ontologically disturbs the foundation of the self and, thus, must be thrust outside society and into institutions. Third, the current director of the PA, along with several other employees, identify as survivors of psychiatric institutionalization. While both nondisabled and dis/abled people can hold ableist and sanist—the systematic discrimination of dis/abled people—beliefs, the make-up of the PA community and the themes of the haunted attraction make any sweeping generalizations regarding outright discrimination of a specific group of people difficult to support.

Performance Modes & The Actor/Patron Relationship in the Pennhurst Asylum

Under Pennhurst LLC's management, the haunted house blends conventional performer and spectator performance, along with quasi-participatory and immersive performance, and multi-sensory special effects performance. Outside the attraction, line performers wander the grounds providing entertainment from a variety of artistic backgrounds such as carnival, fire performance, and flow arts. All three attractions feature the use of heavy fog machines, automated air and water guns, and animatronics. Additionally, the haunters touch patrons as they pass through the attractions and are only limited from the use of profane language and caricaturing dis/abled experiences they themselves do not live with. The patrons—officially—cannot touch the set, props, or actors, but they often verbally harass and, at times, physically assault the haunters. If a patron commits any form of violence, management instructs haunters to immediately stop their performance, and call security to remove the patron from the attraction. Though, in the chaotic environment of the haunt, verbally or physically violent patrons often go without reprimand. The patrons' forceful, and often violent, reactions reveal just how disability elicits fear in the nondisabled imaginary.

Haunter Demographics & Motivations for Working at the Pennhurst Asylum

The haunters of the PA occupy a complicated space. While I discuss the PA community in more detail in <u>Act IV</u>, I provide a brief overview of the haunters' demographics and motivations for working at the attraction in this section. They function as a performance troupe, an interpretive community, as well as a relational and supportive community. The PA employees report living with a wide range of dis/abling experiences that span both mental and physical dis/abilities. Many of the haunters also identify as BIPOC or LGBTQ, and span a wide range of ages, with multiple generations of family members working at the attraction. Several haunters at the PA also have children and/or other family members with dis/abilities. Finally, employees flock to the PA from across the tristate area. While most haunters come from Chester and the surrounding counties, others travel from neighboring states such as New Jersey, New York, and Delaware.

Making money with a sense of purpose and community motivates most of the PA haunters to work at the attraction. Most of the PA employees report coming from lower-and lower-middle class backgrounds and almost all the dis/abled haunters report living

with severely limited incomes and social support networks. Many haunters who work at the PA—dis/abled or nondisabled—rely on the attraction for providing both steady income and a safe community, which they cannot find through existing welfare supports. For example, Nick, a disabled haunter who identifies as autistic, told me how he came to the PA to learn how to create his own haunted house.⁴³⁵

Nick grew up on a farm in the area, and his parents homeschooled him because they felt shame regarding his diagnosis. Because of the isolation and ostracization, he became "almost feral."⁴³⁶ It was not until he came to Pennhurst that he felt accepted and human. "Some members of my family treated me as sub-human. But when I got to Pennhurst, I realized I had found a community of people that not only accepted me, but that claimed me as family."⁴³⁷ With or without experiencing dis/ability, the contemporary PA community resembles the very definition of the "feebleminded and epileptic" population the PSSH was intended to incarcerate: people who identify or, rather had others identify them, as socially inadequate. While no PSSH survivors work at the attraction, a handful continue to come back to visit the campus for history tours, use the site to take photographs, or simply visit with the PA employees who they have befriended. Surprisingly, the PA does not advertise itself as a dis/ability-friendly employer, nor does its marketing choices reflect the diverse background of its employees and their connection to the PSSH.

 ⁴³⁵ This haunter agreed to share his story for this dissertation but requested to remain anonymous. For these reasons, I have changed his name and certain identifying characteristics.
 ⁴³⁶ Interview with Nick, October 2022.

⁴³⁷ Interview with Nick, October 2022.

Patron Demographics & Motivations for Attending the Pennhurst Asylum

Since starting my research in 2018, my focus remains on the dis/abled haunters and the Pennhurst site itself. While I observed patrons throughout my fieldwork, I did not conduct patron-specific ethnography or interviews. As such, this section begins with detailing information about patrons made from observations of how they interacted with the space and the attraction's dramaturgy as well as from the comments made about the patrons by the haunters I interviewed. Finally, this section details information regarding patrons' motivations for attending the attraction through an analysis of their reviews on the PA's Google page, various review websites dedicated to haunted attractions, and social media platforms such as Facebook.

At the peak of the season, typically the weekend before Halloween, over 10,000 patrons will pass through the PA in an evening, totaling over 50,000 people in a sixteenday period. While the PA draws an international crowd, most of its patrons come from the northeastern coastal region. The demographics of the patrons span an equally wide range of gender, sexual orientation, ability levels, socio-economic status, ethnicities, and ages. Their motivations for attending the attraction are, however, relatively similar. Most patrons attend to experience the "unapologetic fear" of the haunted attraction.⁴³⁸ Some patrons come in party buses to celebrate their bachelor or bachelorette parties, while others come in pick-up trucks with beds full of alcohol and illicit substances seeking an excuse to tailgate before a night of fright. As one dis/abled haunter described,

Um, the haunt crowds are typically younger people, people who want to get out and do something fun for Halloween. People who—are kind of more

⁴³⁸ Joe Rovinsky, "The Fear Is Real at Pennhurst Asylum (2020 Season Review)," Dread Central, October 2020, <u>https://www.dreadcentral.com/reviews/349133/the-fear-is-real-at-pennhurst-asylum-2020-season-review/</u>.

trashy—these people are—more often to start fights or be disrespectful to actors or the props... or the property itself. Like we've had people shit on the catwalks [the walkways that connect the buildings of the former boys' colony] and stuff, it's like people have no respect for the place at all. They're just there to have a good time and leave.⁴³⁹

Once they arrive, patrons make their way from the parking lot down to the ticket booth. Patrons have a choice of purchasing a standard ticket for \$50, or a VIP pass for \$85, which allows VIPs to skip to the front of the line for each attraction. Either ticket provides admission to each of the three attractions.

"The Fear is Real" or Is It?:⁴⁴⁰ The Pennhurst Asylum's Historical & Narrative Slippage

The ethics of, and public reception to the PA remains hotly debated. In turn, the specifics of both the PSSH's past and the make-up of the PA community often become conflated. Most Americans have never heard of the PSSH. Those who have, largely know Pennhurst as the Pennhurst Asylum, the "Scariest Haunt in America"⁴⁴¹ and the famed "mental asylum" in season four of the Netflix hit television series *Stranger Things*. These references rely on citational tropes of both madness and disability as horror within popular culture and mass media. Others, primarily disability advocates, know the PA as a "mockery of the nightmarish experience" of people deemed developmentally disabled by

⁴³⁹ Interview with Autumn Werner, March 22, 2021.

⁴⁴⁰ "Pennhurst Asylum," n.d., <u>https://pennhurstasylum.com</u>.

⁴⁴¹ The Rod Ryan Show, "Here Are The Scariest Haunted Houses In The U.S.," 94.5 FM, The Buzz, September 13, 2022, <u>https://thebuzz.iheart.com/content/2022-09-13-here-are-the-scariest-haunted-houses-in-the-us/</u>.

this former institution.⁴⁴² These competing narratives have resulted in a feverish debate between the I/DD advocacy community and the fans of the attraction. The debate largely centers on whether the haunted house is ethical or moral and/or on the issues concerning the preservation of the former institution. Furthermore, almost none of the rhetoric used in this debate discusses the reality that most of the employees at the PA identify as living with a dis/ability, some of whom have experienced institutionalization.⁴⁴³ Additionally, many of the PA haunters have either family members that worked at the former PSSH or that authorities committed to the institution. Most unfortunately, this debate furthers the goals of institutionalization to isolate, segregate, and dehumanize dis/abled people by placing emphasis on the morality or ethics of the haunted attraction while completely obfuscating the dis/abled people that work at the PA. As I discuss in <u>Act IV</u>, this undermines their efforts to preserve the PSSH's history.

Billed as both the "Real" and the "Legendary" Pennhurst Asylum on the attraction's website,⁴⁴⁴ the PA's management claims to make a distinction between the

⁴⁴² Rachel Miroddi and Allison Beck, "Opinion: Pennhurst Asylum Is Exploitation, Not Entertainment," *The Philadelphia Inquirer*, October 9, 2019, <u>https://www.inquirer.com/opinion/commentary/pennhurst-asylum-haunted-house-tours-2019-20191009.html</u>; Emily Smith Beitiks, "The Ghosts of Institutionalization at Pennhurst's Haunted Asylum," *The Hastings Center Report* 42, no. 1 (2012): 22–24, https://doi.org/10.1002/hast.10; "The Final Indignity and the Drawing of Hope," in *Pennhurst and the Struggle for Disability Rights* (University Park, PA: The Pennsylvania State University Press, 2020), 206–21.

⁴⁴³ In October 2022, a reporter from the *Philadelphia Inquirer* approached the Pennhurst Memorial & Preservation Alliance asking for a comment on the attraction. Leveraging my Board membership and the contacts from my volunteer work with the Pennhurst Asylum community, I connected the reporter with individuals from the PA and the wider disability advocacy community. This resulted in interviews with over thirty people and the production of a long-form article which, due to the editorial process, was considerably shortened. The trimmed piece was positively received by the disability advocacy community at large. However, it did not earn similar praise from the PA community. The latter group felt the article failed to fully represent those who now regard Pennhurst as their home. See Abraham Gutman, "Pennhurst Asylum Haunted House Draws Criticism Every Halloween. A Group of Disabled Actors Running the Show Say There Is More to the Story.," *The Philadelphia Inquirer*, October 25, 2022,

https://www.inquirer.com/news/pennhurst-asylum-critics-disability-halloween-20221025.html. 444 "Pennhurst Asylum."

"fact" of the PSSH and the "fantasy" of the PA.⁴⁴⁵ And yet, the attraction—through inattentive marketing choices—does not make this clear to the patrons at any point. Nor does the PA explicitly state to the patrons what the plot of the attraction is before they enter the administration building. Moreover, the attraction plainly invokes Pennhurst's "history" to market their product to their audience, which largely relies on tropes of madness, disability, and horror in nondisabled society's imagination. This tactic remains common within paranormal tourism.⁴⁴⁶ The PA's marketing suggests to its viewers that, because of the PSSH's history, the attraction is more likely to be "haunted" than the average haunted attraction. But the PA leaves out any explanation of what that history involved.

The PA actively encourages patrons to visit the Pennhurst Museum and attend a day-time history tour to gain a fuller sense of the PSSH's legacy.⁴⁴⁷ But, because patrons continue to vandalize the space, management opts to keep the Museum closed when the attraction is open. A patron must buy separate tickets and return to the property at separate times in order to attend the Museum and the haunted attraction, which creates an access barrier.

Without attending the Museum, the PA patrons possess little factual grounding to know what the PSSH *was* and what the PA *is not*. The consensus of the reviews left on the PA's Google page illustrates this lack of understanding of the PSSH's history. One patron wrote in a Google review, "Went there for a fall date night. Had a blast. Loved the

⁴⁴⁵ Interview with Jim Werner, April 29, 2021.

⁴⁴⁶ Diane E. Goldstein, "Commodification of Belief," in *Haunting Experiences: Ghosts in Contemporary Folklore*, by Jan E. Goldstein, Sylvia Ann Grider, and Jeannie Banks Thomas (Logan, UT: Utah State University Press, 2007), 171–205.

⁴⁴⁷ Both are discussed in <u>Act IV</u>.

entire feel of the place. Walking through the grounds was ingenious adding to the creepy feel. A great use for an abandoned asylum.⁴⁴⁸ This patron's commentary reveals how Pennhurst elicits fear, but the question of how this former institution makes one feel scared changes based on the person's relationship to the space. This patron's fear did not originate from knowing institutions were and *remain* a present danger to dis/abled people. Instead, this review leaves out dis/abled people, and the traumas experienced by those committed to the PSSH. The review removes the palpability of Pennhurst's danger as a looming threat of institutionalization yet to come. In this way, the patron's review indexes how the PA creates a bracketed performance space where people can effectively pass through the horror of institutionalization safely in the name of entertainment and not incarceration.

The quotes from the patron also reveal how little most people know about the PSSH. Without providing any background to what Pennhurst was before it became the PA, this patron assumes that the PSSH was an asylum—an institution for people deemed psychiatrically disabled. It was not; it was an institution for people deemed feebleminded and/or epileptic. This distinction remains important because scholarship on and popular entertainment depiction of custodial institutionalization continue to conflate the two experiences. Furthermore, the patron's commentary illustrates a preference for the property being turned into an attraction (a common trope represented in the horror genre) instead of the site being used as a place of documentation of institutionalization. This commentary, and the PA's marketing, marks a slippage in the public's imagination and fears

⁴⁴⁸ Eric P., Google Review of the Pennhurst Asylum, <u>https://g.co/kgs/huYLD4</u>.

about madness and disability and positions institutions and asylums as separated, "other" spaces, with a complete disregard for the traumas experienced by institutional inmates.

The PA's lack of transparency and clarity of what the PSSH *was* and what the PA *is* in its marketing creates more than slippage in the public's imagination of Pennhurst. It also feeds into the bitter binary debate discussed earlier. This debate consists largely of unfounded claims and half-truths—on both sides—debated on social media between two camps. On one side of the debate are the patrons and the fans of the PA who see nothing wrong with the attraction. On the other side, the communities of dis/abled people, parental/familial advocates, academics, and the concerned public who believe the PA is nothing more than the "commercialization of atrocity."⁴⁴⁹

Blurred Lines: Societal Imagination of Institutionalization & The Repertoire of Violence in the Scene Design of the Pennhurst Asylum

Without making it abundantly clear to the patrons that they are the intended recipient of the fictionalized violence of the PA, many scenes within the attraction perpetuate the performative repertoire of institutional violence. In doing so, the attraction blurs the facts of how restraint and violence *was* experienced by the former inmates of the PSSH, and what the fantasy of the PA *is*.

⁴⁴⁹ Dennis B. Downey, "Asylums Used as Halloween Venues Capitalize on Anguish," *Lancaster LNP*, October 31, 2018, <u>https://lancasteronline.com/opinion/columnists/asylums-used-as-halloween-venues-capitalize-on-anguish-opinion/article 3218b53e-dd27-11e8-af20-23f7011da05e.html</u>.

Of the twenty-one scenes in the Asylum attraction, thirteen of them make direct reference to spaces commonly found in an institution and/or asylum. These scenes include: "reception," "the exam room," "apothecary," "hydrotherapy," "padded maze," "padded cell," "dorms," "operating theatre," "autopsy," "shock therapy," "surgery suite," and "isolation." Performance studies scholar, Rebecca Schneider argues that "the past is never actually complete, or completely finished, but incomplete: cast into the future as a



matter for ritual negotiation and as yet undecided interpretive acts of reworking."450 In

Figure 8: An animatronic depicting a femme staff member restrained by inmates of the fictional inmates of the Pennhurst Asylum. Photograph by author.

this way, the repetition of the patrons passively moving through these scenes rework the past (and present) violence of institutionalization as entertainment. Patrons sanction these acts of violence, as a form of enjoyable entertainment, because they are not the subjects of this violence. While, as the PA's marketing claims, "the fear" may be "real", the threat is not.⁴⁵¹

An animatronic found in "dorm 2" (Figure 8) illustrates how these scenes represent past (and present) forms of institutional violence while leaving the meaning of that history to the interpretation of unknowing patrons. A femme-appearing animatronic is restrained to an upright bed leaning against a wall. The animatronic is also restrained with a gray, metallic muzzle. The animatronic has red hair and is wearing white medical scrubs and white crocs. It is designed to represent one of the former institutional authorities at the Pennhurst Asylum that was captured and restrained by the inmates after they took control of the fictitious institution. Patrons activate it passing by a motion sensor. The animatronic then produces a demonic voice (on a looped soundtrack) that threatens the patrons while combatively convulsing.

Without clearly stating the attraction's plot, this animatronic becomes especially traumatic for institutional survivors familiar with this form of violence. Because this realistic pseudo-reenactment mirrors forms of restraint documented both at the PSSH and other institutions, this scene could trigger unwanted memories of trauma. As Schneider

⁴⁵⁰ Rebecca Schneider, *Performing Remains: Art and War in Times of Theatrical Reenactment* (New York, NY: Routledge, 2011), 33.

⁴⁵¹ "Pennhurst Asylum."

warns "the question for both



Figure 9: Autumn holds a wire muzzle she found in Quaker Hall-ward-at Pennhurst. Photo credit: Autumn Werner.

theatricality and for reenactment is how do we confidently arbitrate the differences, especially when the frame is less than strictly delineated?"⁴⁵² Without strictly delineating the frame of reference for the patrons, the historical acts of violence and restraint that occurred at the PSSH become elided with the fictitious representations made in the haunted attraction. A muzzle found by Autumn Werner—the overseer of the Pennhurst Museum and a dis/abled haunter—in the "bad girls" ward of the PSSH (Figure 9) mirrors the fictionalized muzzle in Figure 8; the correspondence poignantly illustrates how these acts of violence become elided. Without making clear to the patrons who the animatronic is or why the inmates restrained it, this scene reifies the kinesthetic memory of muzzles and restraints as a tool of domination and dehumanization for dis/abled people, and a form of control and entertainment for the patrons. In this way, this scene serves as an example *par excellence* of the performativity of the repertoire of violence and how the harm it causes continues to go unnoticed and *enjoyed* by nondisabled society.

This scene cites institutional violence—the *re-re-making* of restraint—but the patron, the intended subject of that violence, has no reference to know that they are the intended target because the PA does not explicitly state the plot of the attraction. Further, most patrons have little to no historical context to know that this exact act of violence has occurred in this space before. Despite the best intentions of the designers, this scene does not inform patrons that the dis/abled haunters are in control of this dis/abled space, nor does the scene transfer knowledge to the patrons of the trauma and atrocity that occurred

⁴⁵² Rebecca Schneider, *Performing Remains: Art and War in Times of Theatrical Reenactment* (New York, NY: Routledge, 2011), 41.

in this institution's past. Instead, this scene simply becomes a spectacle of consumable entertainment that perpetuates the repertoire of violence. This repertoire reifies socially accepted knowledge that dis/abled people are impervious to pain and that restraint remains an acceptable form of care.

Theorizing the Pennhurst Asylum: Horror & Haunting; Memory & Monsters; Performance & The Spectre of Disability

Horror

The PA, like its historical predecessor, the PSSH, has a complicated and nuanced history. The role of horror in the PSSH's contemporary existence, however, plays a substantial part in understanding how the PA not only makes the sublimation of care into violence apparent but also how disability strikes fear in the nondisabled imaginary.

The horror genre, and the questions it raises around what it means to be human, allows us to understand how nondisabled anxiety of becoming disabled plays a leading role in both the horror aesthetic of the PA, but also the continued dehumanization of dis/abled people. Horror studies scholar Stephen Prince proclaims,

The anxiety at the heart of the genre is, indeed, the nature of human being. Within the terrain of horror, the state of being human is fundamentally uncertain. It is far from clear, far from being strongly and enduringly defined. People in the genre are forever shading over into nonhuman categories. They become animals, things, ghosts, and other kinds of undead. Having assumed such forms, they return to threaten ordinary characters and upset our sense of how life is to be properly categorized and of where the boundaries that define existence are to be reliably located. The experience of horror resides in this confrontation with uncertainty, with the "unnatural," with a violation of the ontological categories on which being and culture reside.⁴⁵³

The performative process of institutionalization, and its looming spectre, is as much about creating expectations and boundaries around what it means to *be* nondisabled and disabled (or human, and non-human), as it is about categorizing and capturing people deemed disabled. Just as anxiety is the "heart" of horror, the anxiety of society becoming disabled by feebleminded people drove eugenic fears. These fears resulted in the categorization, capture, and warehousing of dis/abled people in institutions during the twentieth century.

Performances of institutionalized care transfer embodied knowledge to dis/abled people. But this embodied knowledge also reinforces *certainty* to the nondisabled perpetrators that they are human, and that dis/abled people, who are recipients of that care-turned-violence, are nonhuman. Thus, institutionalization remains driven by the same anxiety of creating a society where "the state of being human is fundamentally" *certain*.

Institutions—both former and current—represent a line of separation between "normal human," nondisabled society, and its *other*. Further, while numerous state institutions in the United States have closed, the hard boundaries created by the eugenics movement of the early twentieth century have shifted into a velvet eugenics—where medical, legal, and societal discrimination against marginalized populations is less outward and obvious.⁴⁵⁴ This makes understanding where the line between what is

⁴⁵³ Stephen Prince, ed., *The Horror Film* (New Brunswick, NJ: Rutgers University Press, 2004), 2.

⁴⁵⁴ Garland-Thomson, "Disability Bioethics"; Zhang, "The Last Children of Down Syndrome."

perceived as care and what is received as violence harder to define. Thus, the dis/abled haunters in the PA often craft their performances to make the distinction between human and non-human clear.

The dis/abled performers at the PA often use language such as "non-human" or "monster" to describe their characters. Unlike the common theme within the horror genre where the monster, specter, or undead come into society to "threaten ordinary characters," the PA serves as a place where the largely nondisabled public journeys to have a "confrontation with uncertainty, with the 'unnatural,' with a violation of the ontological categories on which [nondisabled] being and culture reside." Therefore, for the mostly nondisabled patron population that attends the PA, the lure of the haunted attraction comes from experiencing that unsettlement in the safe, bracketed performance environment of the PA where the "fear is real" but its cause is clearly a fabrication.⁴⁵⁵ And yet despite the fictional premise of the attraction, the performances of dis/abled haunters disrupt the easily identified boundaries between nondisablement and disablement—human and nonhuman—and expose deeply held ontological fears regarding a presumed loss of bodymind functioning.

Scholars have thoroughly discussed the history of nondisabled people observing the disabled subject from the stage for disgust, horror, and pity, as well as how dis/abled people use those performances as an act of protest in front of the nondisabled gaze. For example, disability scholars and performance studies scholars such as Rachel Adams,⁴⁵⁶

⁴⁵⁵ "Pennhurst Asylum."

⁴⁵⁶ Rachel Adams, *Sideshow U.S.A.: Freaks and the American Cultural Imagination* (Chicago, IL: The University of Chicago Press, 2001); Rachel Adams, "Disability and the Circus," in *The American Circus*, ed. Susan Weber, Kenneth L. Ames, and Matthew Wittmann (New Haven, CT: Yale University Press, 2012), 2–20.

Robert Bogden,⁴⁵⁷ Petra Kuppers,⁴⁵⁸ Rosemarie Garland Thomson,⁴⁵⁹ Angela Smith,⁴⁶⁰ and Susan Schweik⁴⁶¹ have critiqued the history of the concept of the "freak" and the "freakshow." Like the PA, these scholars describe how freakshows serve as a place where people with perceived bodymind and societal differences can find a home. Freaks not only make a profit off selling those differences to the public, but they also generate their own culture and a sense of belonging. And yet, the PA and freakshows differ in several minute but critical ways. For example, freakshows rely on the freedom of the road, and the ability to travel from place to place to generate their income and sense of autonomy. The dis/abled performers at the PA, however, willingly choose to return to the former institution, where many of them would have been (or already have been) committed and their freedoms revoked. Additionally, the performances of the dis/abled performers at the PA also differ in the process of encounter for the nondisabled audience. Like freakshows, the PA's attractions have a bracketed timeframe of encounter-from entering to leaving the space. But, unlike the freakshow where an audience member passively observes and objectifies the "freak" from the safety of an auditorium, the Asylum's attractions blur that boundary by leaning into the unpredictability of a nondisabled person encountering a dis/abled person in a dis/abled space, or what the dis/abled performers call haunting.

⁴⁵⁷ Robert Bogdan, *Freak Show: Presenting Human Oddities for Amusement and Profit* (Chicago, IL: The University of Chicago Press, 1988).

⁴⁵⁸ Kuppers, Disability and Contemporary Performance.

⁴⁵⁹ Rosemarie Garland-Thomson, ed., *Freakery: Cultural Spectacles of the Extraordinary Body* (New York, NY: New York University Press, 1996); Garland-Thomson, *Extraordinary Bodies*.

⁴⁶⁰ Angela Smith, *Hideous Progeny: Disability, Eugenics, and Classic Horror Cinema* (New York, NY: Columbia University Press, 2012); "Walk This Way: Frankenstein's Monster, Disability, Performance, and Zombie Ambulation," *Literature and Medicine* 36, no. 2 (2018): 412–38.

⁴⁶¹ Schweik, *The Ugly Laws*.

Haunting

Haunting as an Embodied Act of Performance

While the term "haunting" is frequently used by performers in other haunted houses, the haunting that occurs at Pennhurst is unique to the specificity of the location and the dis/abled performers who engage in haunting. It is a form of spectral and monstrous co-performance. This specific instance of a haunting becomes a performance of an encounter where a nondisabled, normative bodymind encounters a dis/abled, non-normative bodymind in a space originally meant for people deemed as disabled and "othered" by nondisabled society.

This encounter serves as a moment of nondisabled bodymind unsettlement, which disrupts the temporal process of the nondisabled gaze in a former institutional space. Haunting creates a rift in the performative script of performances of disabled appearance. In doing so, haunting unmoors the settled ontological assumptions about disability and the institutionalized disabled subject. When a dis/abled haunter scares a patron, they make their dis/abled bodymind apparent, thus going off script from disabled subjectivity and becoming uncontrollable in the gaze of the nondisabled patron. Violent encounters between patron and dis/abled haunter—such as patrons physically or verbally assaulting haunters—occur often in the haunt. This violence stems from the patron's attempt to reestablish control and bring the dis/abled haunter back on the script of disability.

Haunting, as a mode of performance, blurs the distinctions made in classic representational performances such as freak shows. As such, the person haunting is not simply being observed as a passive object or spectacle of dis/abled performance by the

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subject-patron in a nondisabled space. In the moment of the haunting, rather, the dis/abled performer acquires a sense of reclamation, control, and action. In response to this change of control and break from the script of performances of disabled appearance, the patrons often exhibit a loss of their own perceived bodymind control (i.e., sudden postural changes, incontinence, or triggering "fight or flight" responses). Hauntings, therefore, threaten the ordinary bounds of nondisabled existence and perceived nondisabled assumptions of the perfected, controllable bodymind. They violate the ontological assumptions about the institutionalized disabled subject by removing the passivity of the disabled performer and nondisabled observer relationship. Thereby, the act of haunting shatters settled perceptions of difference between disablement and nondisablement held by patrons. And yet, this bodymind unsettlement is not the only apparition summoned in the moment of the haunt.

Haunting as an Act of Compelling the Spirits of Former Pennhurst State School & Hospital Inmates into Being

Reported both in ethnographic fieldnotes and in oral history interviews, numerous haunters and employees that work at the PA believe they occupy the space with the energies or spirits of the inmates that died at the PSSH. Autumn Werner, a dis/abled haunter, describes this relationship with these entities, saying:

Perhaps it's not ghosts, or spirits, or anything intelligible, like a person that's walking around haunting and whatever. But it definitely seems like 'they' refers to, rather, the people who lived here. And I think there is still a lot of energy. There's a lot of bits and pieces of them that are still here. There's gotta be so many memories and pieces of trauma and energy that are imprinted on this space, and I think, somewhere in that timeline, they—they repeat...⁴⁶²

⁴⁶² Interview with Autumn Werner, June 10, 2022

In this way, haunting connects the space itself, the performers, and people once forced to exist there, together, through the kinesthetic memory of trauma as an embodied repertoire of dis/abled experience.

Performance studies scholars such as Harvey Young,⁴⁶³ Joseph Roach,⁴⁶⁴ Rebecca Schneider,⁴⁶⁵ and Diana Taylor⁴⁶⁶ have theorized how performance and kinesthetic memory collide to transmit knowledge and how often the understanding and/or meaning of that knowledge becomes defined by its possessor or observer. For example, Roach argues kinesthetic memory represents the merging of imagination and memory as a "way of thinking through movements—at once remembered and reinvented" through embodied communal practices.⁴⁶⁷ This embodied memory "exists interdependently but by no means coextensively with other phenomena of social memory: written records, spoken narratives, architectural monuments, and built environments."⁴⁶⁸ Roach argues that more traditional repositories of history, such as archives, produce static narratives resistant to change but that kinesthetic memory resists these static, transhistorical interpretations of history through the embodied "transmission of gestures, habits, and skills."⁴⁶⁹ Roach, therefore, understands kinesthetic memory as that which transfers and transforms cultural knowledge from one generation to the next through performance.

The act of haunting in this institution turned haunted attraction binds dis/abled people together in a communal way otherwise impossible due to how diagnostic labels

⁴⁶³ Young, Embodying the Black Experience: Stillness, Critical Memory, and the Black Body.

⁴⁶⁴ Roach, Cities of the Dead.

⁴⁶⁵ Schneider, Performing Remains.

⁴⁶⁶ Taylor, Archive and the Repertoire.

⁴⁶⁷ Roach, *Cities of the Dead*, 26.

⁴⁶⁸ Roach, 26.

⁴⁶⁹ Roach.

have siloed the dis/ability community. Unlike communities where experiences of marginalization, such as racialization, transfer from one family to the next, the experience is similar, yet different, for the dis/ability community. Often dis/abling experiences do not transfer from generation to generation, and if one nuclear family has multiple dis/abled people in it, they may experience separate dis/abling conditions. In the act of haunting, these highly individualized memories skip significant gaps of time and disparate dis/abled bodymind experiences and become bound together through living under the ongoing spectre of institutionalization while also existing within the space of this former institution.

What makes the hauntings that occur at the PA unique is both the people performing them and the site in which they occur in. First, the shared embodied experience of living under the spectre of institutionalization sets the parameters for a haunting to occur but does not cause its existence. Second, the shared space of this institution allows for the dis/abled haunter to produce the haunting. When these two elements combine, hauntings allow for experiences of kinesthetic memory to "jump time,"⁴⁷⁰ and transcend the generational and bodymind gaps found within dis/ability experiences. In other words, if a dis/abled haunter haunted a corn maze, this act would not produce the same haunting as experienced in the PA because it lacks the site specificity of a known institutional space.

Like kinesthetic memory, performance studies' notion of the embodied repertoire challenges static understandings of history through embodied practice and knowledge

⁴⁷⁰ Schneider, *Performing Remains*; Schneider also touches on a similar yet different idea in her article, "That the Past May Yet Have Another Future: Gesture in the Times of Hands Up," *Theatre Journal* 70 (2018): 285–306.

transfer. Taylor argues the repertoire is a "nonarchival system" of knowledge transference that requires presence, or "people [to] participate in the production and reproduction of knowledge by 'being there,' being a part of the transmission."⁴⁷¹ But, Taylor cautions that, like the traditional archive, the repertoire is mediated.

The process of selection, memorization or internalization, and transmission takes place within (and in turn helps constitute) a specific system of representation. Multiple forms of embodied acts are always present, though in a constant state of againness. They reconstitute themselves, transmitting communal memories, histories, and values from one group/generation to the next. Embodied and performed acts generate, record, and transmit knowledge.⁴⁷²

Though some dis/abled haunters do not share the same dis/abling experiences of the PSSH inmates and survivors, their connection to former PSSH inmates comes from the kinesthetic memory of existing under the spectre of institutionalization. This kinesthetic memory and bodymind experience bring the past into the present and allows the dis/abled haunter to connect with shared but distinct experiences and histories. In turn, dis/abled haunters, especially those with family members who died at the PSSH, feel their performances reclaim the memory of dead inmates and family members. Thus, the patron being haunted is also haunted by the ghostly return of the unresolved—the spirits of Pennhurst past—waiting for recognition, repentance, reparation, and resolution.

⁴⁷¹ Diana Taylor, *The Archive and the Repertoire: Performing Cultural Memory in the Americas* (Durham, NC: Duke University Press, 2003), 21.

Made Apparent, Make Appear & the Spectre of Disability

In the moment of haunting, and subsequent bodymind unsettlement, the spectre of disability makes itself apparent. Haunting reveals the spectre of disability as the threat and subsequent anxiety of the spontaneous and unpredictable loss of bodymind ability that haunts nondisabled imaginary. This threat encapsulates the loss of humanness itself. In other words, there *is* no **other** *other* than disabled, nonhuman existence. The spectre of disability *becomes* apparent in the performances of the PA because of the relationship between the spiritual and phenomenological qualities of the space, the hauntings by dis/abled performers, and the historical and ongoing process of institutionalization.

But what does it mean to appear, or to become apparent? The Merriam-Webster dictionary defines *appear* as "to show up," "to present oneself," to present oneself before a person or body having authority," "to have an outward look."⁴⁷³ It defines the adjective *apparent* in several ways. In their "kids" definition, Merriam-Webster defines *apparent* as: "open to view;" the medical definition as "manifest to the senses or mind as real or true on the basis of evidence that may or may not be valid upon deeper investigation," and a legal definition of: "capable of being easily seen, perceived, or discovered."⁴⁷⁴

The PA engages these definitions of *appearance* and *apparent* in three distinct, and yet, simultaneous ways. First, hauntings, and in particular the reactions of nondisabled patrons, make the "us and them" distinctions made through the process of

⁴⁷³ "Appear," in *Merriam-Webster.com Dictionary*, n.d., <u>https://www.merriam-webster.com/dictionary/appear</u>.

⁴⁷⁴ "Apparent," in *Merriam-Webster.com Dictionary*, n.d., <u>https://www.merriam-webster.com/dictionary/apparent</u>.

institutionalization apparent. In this moment, appearance means to illuminate: to make available for critical review. Second, hauntings make apparent the continued acceptance of institutionalized violence against dis/abled people by nondisabled society. Thus, making an apparition, a revenant, where the experiences of institutionalization reappear. Third, because of the connection the dis/abled haunters share with the energies and spirits of former PSSH inmates, haunting also makes those forgotten (and that return), appear in ways that the patrons may not readily perceive, but is apparent to the dis/abled haunters. Therefore, in the context of the embodied act of haunting, to appear is also a political act. Hauntings critique the structures of institutionalization, while the dis/abled haunters struggle against those structures as subversive actors.⁴⁷⁵ Being apparent is not about making something discernible to the senses as real or true that is not already made manifest. To the contrary, to haunt is to bring about the ghostly return of the spectres of disability and institutionalization. The act of haunting conjures the spectral return of the unresolved experiences of the PSSH inmates and makes the ongoing experiences of institutionalized dis/abled people and institutionalization's impact on dis/abled people outside of physical institutions today apparent for review.

In this way, *appearance* becomes a demand for recognition, revision, and revenge. The language used in the institutionalization legislation—"*If it shall be made to appear*" that a person is "a proper subject for commitment... [then] the court shall make an order committing" them to an institution⁴⁷⁶—set the stage for institutional authorities to revoke dis/abled people's claim to public recognition of their humanity and to have

⁴⁷⁵ Judith Butler, *Notes Toward a Performative Theory of Assembly* (Cambridge, MA: Harvard University Press, 2015), 50-51.

⁴⁷⁶ Pa. Law, *Mental Health Act* (1923), 1007, emphasis added.

liveable lives in the community. The subsequent commitment trials demanded performances of disabled appearance in which nondisabled spectators materialized the bodies of children as disabled through the law, as a tool for enforcing regulatory norms, thus entering them into the regime of the institution. Rhetorical legal performatives used during these trials produced their bodyminds in a specific way, crucially, through an act of making children deemed disabled into public objects that manifested material signs of disability in the courtroom. What the dis/abled haunters in the PA do torques this process. Being *made* to appear in the act of haunting is both an act of agency and compulsion. First, on a superficial level, the act of haunting makes the spectre of disability appear by scaring the patron. Second, the haunting compels the spectres of PSSH inmates into material being, which appear willfully and not, as subjects, figures of revision, revenge and, at times, vengeance of, and for, this initial dehumanizing performative.

A Hauntologie

The theoretical groundwork for the analysis of the PA's use of citational tropes of disability of horror and dis/abled haunters embodied act of "haunting," is, philosophically, the concept of the spectre rooted in Jacques Derrida's formulation of *hauntologie*. *Hauntologie* gets later developed by both performance studies scholars such as Diana Taylor⁴⁷⁷ and Rebecca Schneider,⁴⁷⁸ as well as critical theorists Margrit

⁴⁷⁷ Taylor, Archive and the Repertoire.

⁴⁷⁸ Schneider, *Performing Remains*.

Shildrick⁴⁷⁹ and Avery Gordon.⁴⁸⁰ While Derrida's *hauntologie* is undoubtedly concerned about how Marxism still haunts our contemporary philosophical thinking, his construction of the spectre remains useful for this project.

Derrida understands the spectre to be a "paradoxical incorporation, the becoming body, a certain phenomenal and carnal form of the spirit. It becomes some 'thing' that remains difficult to name: neither soul nor body, and both one and the other. ... [This "thing"] is something disappeared, departed in the apparition itself as a reapparition of the departed..."⁴⁸¹

The spectre of disability parallels Derrida's spectre in multiple ways. First, the dis/abled bodymind is a becoming bodymind—fluid and spontaneous. The dis/abling bodymind experiences, like the spectre, can also be transient. Second, dis/ability, when not stabilized as disability confounds medical, legal, political, and societal understandings of "normal," nondisabled existence, particularly when dis/abled people resist cure as the primary means by which to live by. Or, as Derrida describes the spectre, the nondisabled gaze perceives dis/ability as a "paradoxical incorporation." Dis/ability involves both body and mind—sometimes separate, sometimes together. Thirdly, despite this paradoxical incorporation, dis/ability represents what nondisabled imaginary conceptualizes could be and/or is already lost, while also simultaneously representing something that returns to remind the person of what has been lost. The spectre is

⁴⁷⁹ Margrit Shildrick, "Queering the Social Imaginaries of the Dead," *Australian Feminist Studies* 35, no. 104 (2020): 170–85; "Hauntological Dimensions of Heart Transplantation: The Onto-Epistemologies of Deceased Donation," *Med Humanit* 47 (2021): 388–96.

⁴⁸⁰ Avery F. Gordon, *Ghostly Matters: Haunting and the Sociological Imagination* (Minneapolis, MN: University of Minnesota Press, 2008); "Some Thoughts on Haunting and Futurity," *Borderlands* 10, no. 2 (2011): 1–21.

⁴⁸¹ Jacques Derrida, *Spectres of Marx: The State of Debt, the Work of Mourning and the New International* (New York, NY: Routledge, 2006), 4-5.

"something disappeared in the apparition itself as reapparition of the departed..."⁴⁸² Like representations of amputated nondisabled bodies in popular entertainment,⁴⁸³ the spectre of disability is always already lurking to remind us of what could be, or has already been, lost.

While Derrida understands the spectre to manifest temporally, scholars such as Margit Shildrick understand the spectre to manifest materially. Importantly, though, Shildrick understands the spectre "not as an external manifestation, but as an internal companion."⁴⁸⁴ And yet, the spectre of disability manifests, or at times disrupts, internally, externally, and temporally. But the spectre manifests and disrupts in different ways depending on a person's bodymind experience. For example, the dis/abled haunter makes the spectre of disability externally apparent in the way the material dis/abled bodymind is perceived by the nondisabled patron. Likewise, the spectre of disability manifests internally in the connections the haunters feel with the spirits or energies of the former PSSH inmates. This spectre of disability—the revenant of the PSSH inmates provides both comfort for the haunters and a sense of reclamation. For the nondisabled patrons, however, the spectre of disability manifests internally and externally through an encounter with the dis/abled other. As Shildrick describes in what she calls hauntological ethics, "In *Spectres of Marx*, Derrida developed one of his most resonant themes: that we

⁴⁸² Jacques Derrida, *Spectres of Marx: The State of Debt, the Work of Mourning and the New International* (New York, NY: Routledge, 2006), 4-5.

⁴⁸³ For more on affect, amputation, disability, and horror, Angela M. Smith, "Dis-Affection: Disability Effects and Disabled Moves at the Movies," in *The Matter of Disability: Materiality, Biopolitics, Crip Affect*, ed. David T. Mitchell, Susan Antebi, and Sharon L. Synder (Ann Arbor, MI: University of Michigan Press, 2019), 118–40.

⁴⁸⁴ Margrit Shildrick, "Queering the Social Imaginaries of the Dead," *Australian Feminist Studies* 35, no. 104 (2020): 178.

are haunted by traces of otherness that disturb the temporal and ontological heart of being."⁴⁸⁵

Hauntings as Pain & Pleasure: Performing of the Spectre of Disability at the Pennhurst Asylum

Before moving further, I would be remiss without recognizing and honoring the dis/abled haunters I have interviewed, haunted with, and have come to consider family. My research findings would not be possible without them. As I examine in <u>Act IV</u>, the PA community is often left out of both academic and public discourse regarding the PSSH and the PA. Despite this, the dis/abled haunters that call Pennhurst home often hold the most nuanced and poignant viewpoints of both Pennhurst and the ongoing spectres of disability and institutionalization I have encountered.

Autumn & The Journey to Becoming the Spectre of Disability

This section introduces Autumn Werner, a dis/abled haunter and conservator of Pennhurst, who has immensely influenced both my academic research and my life as a dis/abled person.⁴⁸⁶ Autumn's narrative is essential to understanding how the spectre of institutionalization—the past and present humiliation, sexual assault, and dehumanization

⁴⁸⁵ Margrit Shildrick, "Queering the Social Imaginaries of the Dead," *Australian Feminist Studies* 35, no. 104 (2020): 178-79..

⁴⁸⁶ Autumn Werner gave her permission to be identified on a full-name basis.

she faces—haunts her own performances, while she uses the spectre of disability to redirect and reclaim her experience.

Autumn, a first-generation dis/abled college student and caregiver for two younger dis/abled sisters, grew up in a low-income family near the PSSH campus. Her father, Jim Werner (the operations manager), started working at the PA in 2010.⁴⁸⁷ Jim often brought Autumn and her three sisters to Pennhurst, and they became familiar with the campus at a young age. Autumn started working at the haunt in her teens as a makeup artist. She is an ingenious and talented artist and disability theorist. As an ethnographer, I am thinking alongside her, and inspired by her intelligence, intuition, and critical analysis of the PSSH, the PA, and the ongoing spectre of institutionalization.

Autumn describes her relationship with dis/ability, and the conditions of the Ehlers-Danlos Syndrome (EDS) and Postural Orthostatic Tachycardia Syndrome (POTS) she experiences, as "messy."⁴⁸⁸ Because her EDS allows her to dislocate her joints and bones, thus contorting her body, she considers her dis/abilities as "special skills."⁴⁸⁹ And despite causing her immense physical pain daily, especially while contorting, Autumn believes she is "lucky" that her embodiment allows her to have the skills to be employed in such a role.⁴⁹⁰ One of the most striking aspects of Autumn's performances as a contortionist are the dialectical tension between perceptions of beauty and inhumanity.

I understand Autumn's contortionism as an example of her material dis/abled embodiment and experience: an embodiment and bodymind experience which is beautiful

⁴⁸⁷ Jim Werner gave his permission to be identified on a full-name basis.

⁴⁸⁸ Interview with Autumn Werner, March 22, 2021.

⁴⁸⁹ Autumn, March 2021.

⁴⁹⁰ Autumn, March 2021.

and elegant; a body not governed by nondisabled societal norms. But when Autumn contorts, she is also a bodymind in pain. Despite this pain, Autumn moves through the space of the PA poetically with unrivaled finesse and prowess. In contrast, the patrons' recoil in fear and anger toward witnessing Autumn's dis/abled embodiment, or that which is deemed "inhuman." This section argues that Autumn's dis/abled embodiment—as witnessed through her hauntings—acts as a literal and metaphorical example of dis/ability as the spectre which haunts "normal," nondisabled society.

To illustrate this, this section analyzes a scene of Autumn in a long, fog-filled hallway as she "haunts" unsuspecting patrons. Autumn's unique positionality—as someone whose nonapparent dis/ability allows her to pass as nondisabled—combined with her intimate knowledge of the space, makes her an exemplary case study for analyzing the spectre of disability. Autumn's EDS allows her to engage in a wide range of embodiments that appear as both nondisabled and as performances of disabled appearance. In my analysis, I pay particular attention to the dichotomy between how patrons reacted to Autumn when she passed as nondisabled versus how they reacted to her when she invoked performances of disabled appearance. In addition to Autumn's embodiment, her familiarity with the space also makes her a prime study for the spectre of disability.

Because of its immense scale and complex layout, the former PSSH provides a space ripe for conjuring and encountering the spectre of disability. A person easily becomes lost and disorientated in the labyrinth of buildings, tunnels, and walkways. Autumn grew up coming to Pennhurst, and she regularly conducts expeditions to recover artifacts from the collapsing buildings around campus. Therefore, she has an

encyclopedic knowledge of the space. This familiarity provides Autumn with the ability to move through, haunt, and pass in and out of the patrons' views in seemingly spectral ways.

Many of the veteran haunters know the space well—using tunnels, crawlspaces, and other liminal passageways to circumvent patrons. But most haunters must remain within their assigned scenes during the haunt. Managers caution against "scenebleeding," or when a haunter in a specific costume enters a scene that does not correspond with the set design. But given Autumn's leadership role, she moves freely about the attraction and uses these liminal spaces not only to navigate the haunt but also make her performance more effective. Autumn's character becomes spectral—in a material, temporal, and spatial sense—by disappearing from the view of a patron, only to reappear at a completely different location of the attraction in a fashion that makes time feel out of joint. To the patron, Autumn's character becomes a literal ghost unpredictable, disorientating, and unwanted.

Haunting, Pain & the Cost of Waiting

Autumn's performances pose ethical questions regarding pain, dis/ability, and haunting: what embodied costs—physical and emotional—are dis/abled haunters willing to pay to make their art? And, for those haunters like Autumn, who must experience pain to haunt, what does that pain reveal about the spectrality of disability under the nondisabled gaze?

Sociologist Elaine Scarry asks in her seminal monograph, *The Body in Pain*, "How is it that one person can be in the presence of another person in pain and not know it—not know it to the point where he himself inflicts it and goes on inflicting it?"⁴⁹¹ Scarry's question correlates directly to Pennhurst, past and present. With the PSSH, nondisabled care*takers* continually inflicted pain on the inmates, knowingly, and unknowingly. For example, institutional dentists pulled the teeth of inmates without Novocain because they believed the inmates did not feel pain.⁴⁹² In these moments, pain for the PSSH inmates became internalized as something they felt but did not receive permission to express. Therefore, the PSSH care*takers* made the inmates' pain disappear, further dehumanizing the inmates and revoking their sense of agency over their bodyminds, just as medical-juridical authorities made the inmates' personhood disappear through the commitment process.

The literal and material pain experienced by some dis/abled haunters in haunting is yet another form of kinesthetic memory present in dis/ability. I use the examples of both Autumn's and my own experience of haunting to analyze how dis/abled conceptualizations and material experiences of pain differ from those understood by the nondisabled care*takers* of this former institution. These vignettes show that pain is *not* a binary, such as either a bodymind feels pain or does not. Rather, for the dis/abled haunters of the PA, pain is a meaningful dimension of their experience and agency. Instead, as Autumn describes, "I find with haunting that the pain is worth it because of all the cool reactions and featured spots [she receives within the haunt's marketing

⁴⁹¹ Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (New York, NY: Oxford University Press, 1987), 12.

⁴⁹² Unfortunately, accounts from institutional survivors illustrate this was a relatively common practice in custodial institutions and not just at the PSSH. James W. Conroy, "The Pennhurst Longitudinal Study and Public Policy: How We Learned That People Were Better Off," in *Pennhurst and the Struggle for Disability Rights*, ed. Dennis B. Downey and James W. Conroy (University Park, PA: The Pennsylvania State University Press, 2020), 152-53.

materials]. ... The pain is intermixed with happiness and that's better than the regular day-to-day of just pain."⁴⁹³ In this way, haunting provides the dis/abled haunters who experience pain while haunting a sense that their pain has value and meaning. But haunting also serves to reclaim and acknowledge the pain historically revoked by nondisabled care*takers*. The pain experienced in and through haunting serves to make the pain of PSSH inmates reappear—to give the inmates yet another form of agency over their forced institutionalized disabled subjectivity. The dis/abled haunters reconstitute the pain of the past through their pain in the present. And, in doing so, returns to dis/abled people, the power to claim what the pain resulting from dis/abling conditions means.

In making these claims, I do not wish to minimize the experiences of institutional survivors, especially PSSH inmates and survivors. While similarities undoubtedly exist between the dis/abled haunters' experiences, especially those who identify as institutional survivors, the experiences remain separate. Further, I do not intend to idealize, or glorify the choice of some dis/abled haunters to put their bodyminds at risk of harm in order to haunt. The ongoing spectre of institutionalization forces dis/abled people to make choices under duress. Many dis/abled haunters at the PA choose between putting their bodyminds at physical, psychological, and spiritual harm by performing in the haunt, or succumbing to the ongoing spectre of institutionalization. The spectre, as the contemporary afterlife of institutionalization, includes not only continued custodial institutionalization. But, as the biographical sketches of the members of the PA community I examine in <u>Act IV</u> demonstrate, the spectre also results in dis/abled people receiving subpar employment and finding forced community under the bureaucratic system of contemporary dis/ability

⁴⁹³ Text conversation with Autumn Werner, December 8, 2022.

welfare mechanisms such as group homes, sheltered workshops, and sub-minimum wage jobs.

"Why does it move like that?!" Haunting and the Moment of Bodymind Unsettlement

The following vignette comes from an extensive ethnographic study I completed during the 2020 haunt season. I made the observations from this vignette on Sunday, October 25, 2020. While the actors in the attraction knew that I was a researcher, I did not announce my presence to the patrons in the group I observed. I dressed in street clothes and followed them around, from the start of the attraction, as if I were a fellow patron attending the haunt. Throughout the evening, Autumn would whisk me into various spaces and positions—crouching behind a prop or peeking through a hidden doorway—to keep me out of the patrons' view. Unbeknownst to me at the time of the observations, Autumn did this deliberately to direct the scene, because she wanted me to observe the act of haunting without the risk of the patrons becoming distracted by my presence.⁴⁹⁴

<u>A Vignette: Following a Group of Patrons as They Encounter the</u> <u>Spectre of Disability</u>

I follow behind a group of patrons as they make their way into the Asylum attraction. As we enter the first scene—"reception"—the patrons walk by a nurse's desk filled with a row of televisions intended to show a security camera feed that has gone static. "Nurse

⁴⁹⁴ Conversation with Autumn Werner, December 25, 2022.

Betty," who is armed with an electric cattle prod, tells the patrons to keep their distance, their masks on, and to prepare for their intake into the Asylum as they walk by the desk. Slinking from the shadows, Autumn emerges. Her long, flaxen hair falls over her worn and tattered Depression-era dress of the same color. Unaware of Autumn's presence, the patrons continue their way through the attraction. Autumn turns to me and tells me she is roaming through the attraction as a "break actor" to relieve actors and waves for me to follow.⁴⁹⁵

Leaving the reception area, we enter the "exam room," occupied by two "doctors" investigating a sheet-covered dummy on a rusty hospital gurney. Customers clamor together, hunching over one another, as the "doctors" taunt the patrons. Still unaware of our presence, the customers forge forward into the next scene. As the customers exit, Autumn crosses over to the two actors in the scene. She greets the actors with a gentle wave and asks if they need water or a bathroom break. Since the actors do not need assistance, Autumn continues her journey, dissolving into the shadows of the dark, fog-filled Asylum.

As we make our way to the second-floor hallway, Autumn pauses and directs me where to move so that I am out of the way of the incoming patrons. Autumn positions herself in the middle of the long hallway void of any furniture or set dressing. Her already androgynous silhouette is further obstructed by the billowing fog that the dim flickers of a yellow incandescent lightbulb attempt to pierce.

⁴⁹⁵ Throughout the attraction, "break actors" roam around, providing water and much-needed restroom and rest breaks to other actors. Autumn's role, however, stands out due to its uniqueness. She takes on a range of responsibilities, extending from acting to human resources management.

Autumn takes up a pose on the floor; her one leg outstretched and the other contorted underneath her. Her heavy, black leather boots offer the only contrasting color, as her flaxen hair and flowy dress camouflage her in the billowing fog. She positions her torso, so she is laying horizontally. Autumn's body becomes parallel to the floor with one hand along her body, and the other hand outstretched with her wrist contorted so it appears broken. From a distance Autumn looks like a clump of old hospital laundry, but as one gets closer the details of her dis/abled embodiment come into focus. Autumn positioned me along the back wall, against the other side of the doorway where the patrons enter the hallway, to await their arrival.

A long line of patrons moves cautiously through the door leading into the space. The moment is paradoxically serene and tranquil. Surrounded by screams and sounds of terror on all sides, this hallway becomes an oasis; a space where the patron can, if only for a second, relax. The patrons pause briefly to observe their surroundings. There are no air cannons, blood squirters, animatronics, or electric cattle prods to disorientate, just a single mass on the floor. The patrons slowly relax their posture, uncoiling from their huddled and hunched positions. Now aware of Autumn's presence they take a moment to investigate, to observe. Growing curious, if not perhaps impatient, the patrons slowly move towards Autumn.

Coming closer, the patrons recognize the figure is not just a distorted mannequin or an abandoned pile of costumes but a living, breathing being. Autumn slowly and meticulously moves through space coming to life. The patrons begin to shuffle closer together hugging the wall as they approach her. Nearing Autumn, they make comments like, "Why does *it* move like that?! Don't let *it* touch you!" With impeccable timing and

pronounced precision, Autumn springs from her static position with her legs in a squatting position while she raises her torso off the ground. She simultaneously contorts her spine while bringing herself into a vertical position, seemingly breaking her neck.

As Autumn's neck makes a loud, audible *snap* the patrons scream out in terror. Autumn jolts forward, lunging toward the patrons. Then, after a few short steps, Autumn drops to the wooden floor sliding across the hallway on her knees, behind the patrons, as they flee from the space. As the last screaming patron makes their exit, bolting from the hallway, Autumn pauses for a moment. Still on her knees, Autumn allows her body to go limp. She revels, for a moment, in the thrill and exhaustion of the haunt. Her body shifts and sways as she reassembles herself into a pseudo-nondisabled standing posture, finding her not-quite-neutral neutral, and ambles over to me. Beaming from ear to ear and quietly giggling as she removes her stage-blood-stained KN95 mask, Autumn gleefully exclaims, "This was *my* first scene."⁴⁹⁶

Before the Hallway: Haunting to Refute the Performative Process of Institutionalization and to Reclaim a Former Institutional Space

Autumn's performances in and outside of the hallway highlight how both the spectre of institutionalization and the spectre of disability function. The evolution of Autumn's character design becomes significant in understanding how haunting unsettles nondisabled notions of disability as perpetuated by the spectre of institutionalization. Autumn's character design also reveals how that spectre influences the haunters'

⁴⁹⁶ Every haunter I have spoken with at the PA tells me about *their* first room or scene. I did not understand this connection until I haunted in the attraction. One develops a strangely intimate connection with the first room you haunt in... it *becomes* your room.

performance choices. I theorize institutionalization as an ongoing embodied and phenomenological process that lives on through the kinesthetic memory of dis/abled people. Institutionalization becomes about dis/abled bodyminds waiting while being made available for review, at any time, by the nondisabled gaze. All of this occurs within a space that exiles us from nondisabled society, but that also serves as a community where our bodymind experience *is* the norm. Thus, haunting, as a mode of performance, evokes the spectre of disability in how it serves to disrupt the nondisabled gaze's subjectification and objectification of dis/abled bodyminds. Instead of being available for review at any given moment for objectification, haunting allows dis/abled people to reclaim agency over how, when, and why we become available for review.

While Autumn's current performances illustrate how the spectre of disability disrupts the nondisabled gaze in a way that reclaims a dis/abled person's agency, past versions of her character revoked her agency by reifying institutional norms of viewing disabled subjects. Autumn reported that in previous iterations of her costume she would wear tights, skirts, or corsets, which made her humanity and, specifically her femininity, more apparent. Combined with her contortionism, these costumes often left Autumn vulnerable to patrons (predominantly, but not always, men) who would hypersexualize and sexually assault her.⁴⁹⁷ On one hand, patrons read the costume pieces that accentuated Autumn's femininity, such as corsets and tights, as signifiers of sexuality and promiscuity. On the other, patrons read Autumn's dis/abled embodiment, her hyper-flexibility, as both a signifier of inhumanity, and a fetishized object of hypersexuality.

⁴⁹⁷ Unfortunately, many workers, especially women, both at the PA and across the haunt industry, report predatory behavior and/or sexual assault from patrons of all gender identities.

Thus, Autumn's dis/abled embodiment, combined with certain costume pieces, positioned her in the nondisabled gaze as not only a disabled subject, but as a fetishized hypersexualized object-subject that suggested sexual use.⁴⁹⁸ As Autumn describes, the patrons' objectification motivated her to "make my character as *inhuman* as possible. ... I can't be attractive—I can't be human—in any way."499 The pattern of hypersexualizing dis/abled women traces back to institutional advocates' rhetoric regarding women deemed moral imbeciles and morons throughout the nineteenth and twentieth centuries. For example, in a history of the PSSH compiled from Superintendent reports, Dr. Robert S. Smilovitz, cites an unnamed PSSH superintendent who writes: "The helpless idiots and feeble-minded women and girls of child-bearing age are notably those for whom there is increasing demand for custodial care. There is no question that the irresponsible feebleminded person, especially the feeble-minded woman or girl of child-bearing age, at large is a menace from whom the community has a right to demand protection."⁵⁰⁰ The evolution of Autumn's character leading up to the 2020-haunt season highlights how haunting vis-à-vis the spectre of disability disrupts institutional norms of reviewing dis/abled subjects.

In response to the reception of her previous characters, Autumn now "weaponizes" her dis/ability to create as much uncertainty regarding her ontological status as possible—a core component to haunting and the spectre of disability. Autumn

⁴⁹⁸ Robert Smilovitz, "A History of Pennhurst, 1908-1926: Compiled from Superintendent Reports," typescript, cir. 1979, digital reproduction of original manuscript, ARC of Pennsylvania Historical Collection, Lemoyne, PA, 27.

⁵⁰⁰ Smilovitz, "A History of Pennhurst," 27. For a legal perspective on the sexual agency of institutionalized subjects see, Harris, "Sexual Consent and Disability"; on rape in institutions and wrongful life suits, see Tani, "When a Wrong Creates a Disadvantaged Life."

⁴⁹⁹ Fieldnotes, Saturday, October 3, 2020.

uses several performance and costume techniques to weaponize herself. For example, Autumn does not use words to communicate. Instead, she sparingly sounds a series of guttural growls when interacting with patrons. And, unlike most other haunters, Autumn does not employ explicit medically themed movements or costume pieces (despite fully engaging her dis/abled embodiment which results in the physical dislocation of her joints). Instead of adding external layers on to her character for protection, such as extravagant make-up or a bulky costume, Autumn relies on her dis/abled embodiment to haunt patrons. This choice functions as an act of embodied reclamation. The choice to weaponize her dis/abled bodymind not only reasserts her sense of agency and autonomy but does so in a way that manipulates how the nondisabled patrons view her. This performance choice highlights how the more unrecognizable a disabled subject becomes under the norms of institutionalization the more uncontrollable it becomes under the nondisabled gaze. The further a dis/abled person deviates from the script of performances of disabled appearance, the more nondisabled people lose control over us. We no longer become neatly defined and made docile by diagnostic categories, symptomatology clusters, and euphemistic labels like "special needs" or "differently-abled." Instead, we loosen the fetters of our historic and ongoing legal, medical, and social otherization and dehumanization. Thus, we elude the human/inhuman categorization altogether.

This sense of agency and power dis/abled haunters, such as Autumn, feel in reclaiming control over both their bodyminds and this former institutional space also explains the haunters' sense of ownership over their scenes. Autumn's gleeful and giggling claim over a successful haunt in *her* first scene illustrates two powerful aspects of how haunting reclaims dis/abled people's agency over institutionalization. First,

hauntings reclaim ownership over dis/abled bodyminds through performance. In the moment of the haunt, a nondisabled bodymind's temporal process of reviewing a disabled subject gets disrupted. Therefore, dis/abled haunters retake ownership of their bodyminds. Second, by reclaiming their bodyminds through this embodied action they also reclaim this institutional space because it becomes part of their embodied history and kinesthetic memory of the spectre of institutionalization. As Autumn acclaims, "This [Pennhurst] is the first place I've been oppressed really, but it's also the first place I've ever found power in it. Like yeah, I get called a cripple while I'm crawling, but who's the one who just pissed their pants?"⁵⁰¹ In a space marked by historic and ongoing violence against dis/abled people, dis/abled haunters not only reclaim and redefine their collective histories, subjectivities, and bodyminds through haunting, but also reclaim and redefine the space itself.

<u>"This was my first scene": Analyzing the Patrons' Responses to</u> <u>Autumn's Haunt</u>

In the liminal space of the hallway, Autumn's embodied performance is the only performance to which the patrons can react, and it is narratively unmoored. The singularity of this performance helps to understand how the patrons' view dis/abled embodiment. Autumn's contortionism—her dis/abled embodiment and performance of disabled appearance—is a rupture from the familiar themes found in the haunted house.

Most of the attraction consists of scenes in which two to four actors portray inmates of the PA, while performing roles related to their scenes. While haunters

⁵⁰¹ Interview with Autumn Werner, June 10, 2022.

improvise their performances, most follow a similar thematic template of macabre medical violence. Autumn's performances, however, do not use the same tactics. As Taylor explains, "embodied performances," such as Autumn's dis/abled contortionism, "make visible an entire spectrum of attitudes and values" about how the nondisabled gaze perceives dis/abled embodiment. These character choices transfer knowledge through performance in how they function to, in Autumn's words, "make my character as *inhuman* as possible."⁵⁰² Because Autumn's performances are void of any apparent medical themes, reading Autumn's embodiment alongside the patrons' reactions to her bodymind makes the spectrality of disability even more poignant. The patrons' responses suggest that under the nondisabled gaze, Autumn's embodiment is unpredictable, unnatural, and uncontrollable.

Autumn's hallway scene highlights how haunting, as an encounter with the spectre of disability, unsettles the nondisabled bodymind, thus dislocating the temporal process of the nondisabled gaze in a former institution. When they enter the scene, Autumn appears, initially, as an object to the patrons. In turn, Autumn's humanity is not readily clear to the patrons. The objectification of Autumn manifests itself through how the patrons relax from their huddled and hunched posture. They slowly move from an embodied state of panic (moving through the space at a quicker tempo with tense, huddled postures) to an embodied state of curiosity (moving through the space at a slower pace, with more relaxed and open postures). The patrons spend several seconds—a long time in the fast-paced environment of the haunt—staring at Autumn. This illustrates the

⁵⁰² Fieldnotes, Saturday, October 3, 2020.

patrons' attempt to understand just what this object in front of them *is*—in both the literal and ontological sense.

By slowing down the moment of the patrons' attempt to understand what Autumn is, one can more closely analyze the nondisabled gaze's process of reviewing dis/abled bodyminds and constructing disabled subjects. Recalling the commitment trials of the PSSH inmates from <u>Act I</u>, institutional authorities in the courtroom relied on performances of disabled appearance to review children deemed disabled. Then, through that review process, turn them into institutionalized disabled subjects by committing them to the PSSH. To create a successful performance of disabled appearance required a specific temporal process: a sequence that categorized, captured, constructed, and controlled disabled subjects as objects (i.e., diagnosis, prognosis, court decree, and institutionalization). The patrons' response to Autumn in the hallways mirrors this process. As the patrons come closer to Autumn, they slowly identify her as animate, but not fully human. This begins the temporal process of reviewing Autumn's disablement. As Autumn begins to move, invoking her dis/abled embodiment, patrons' clamor and cower while assessing Autumn. In assessing her, the patrons understand Autumn as a disabled subject, thus remaining in control of the space. But as Autumn continues to engage her dis/abled embodiment as the patrons come closer, the patrons' physical and verbal revolt marks the moment when this process ruptures and they become ontologically unsettled.

The patrons' embodied response and ableist rhetoric in this moment of rupture serves a two-fold purpose: first, it functions as an attempt by the patrons to regain control over Autumn, and thereby the temporal process of review and subjectification. As

Autumn begins to weaponize her dis/ability, she becomes increasingly uncertain to the nondisabled gaze and further uncontrollable. The patrons' use of ableist rhetoric also functions as an attempt to position her as disabled and, thus, a familiar object-subject in which they remain in control. If the patrons can "diagnose" Autumn—label her as disabled—she becomes knowable and docile. Second, to the gaze of the nondisabled patrons, Autumn's movements mark her as inhuman; an "other." This distinction is important. "Otherness," as Tobin Siebers argues, "establishes differences between human beings not as acceptable or valuable variations but as dangerous deviations" of which "disability serves as the master trope of human disqualification."⁵⁰³ Outside the bounds of the attraction, the same scene may cause the complete dehumanization of Autumn because the nondisabled gaze would deem her embodiment as "dangerous deviations."

Autumn, thereby, becomes relegated to review, categorization, and control by the nondisabled gaze, under which she remains powerless. But in the PA, Autumn's embodiment becomes a "valuable variation." In the gaze of the patrons', Autumn's performance serves as an unrelenting and uncontrollable display of dis/ability and unsettles the nondisabled bodymind through a display of ownership, dominance, and reclamation. Not only does Autumn's haunt serve to "upset [nondisabled imaginary's] sense of how life is to be properly categorized," but her performance also affronts the reliably located "boundaries that define [nondisabled] existence".⁵⁰⁴

Autumn's performance, combined with the patrons' responses, illustrates how haunting and the spectre of disability threatens the ordinary bounds of nondisabled

⁵⁰³ Tobin Siebers, *Disability Aesthetics* (Ann Arbor, MI: University of Michigan Press, 2010), 24.

⁵⁰⁴ Stephen Prince, ed., *The Horror Film* (New Brunswick, NJ: Rutgers University Press, 2004), 2.

existence and perceived nondisabled assumptions of the controllable body through the uncertainty of dis/ability. Despite the best efforts of the patrons to diminish Autumn's ontology and establish dominance over her as a disabled subject, haunting allowed Autumn to keep her personhood intact. Autumn's embodied performance of haunting acts as the literal and metaphorical spectre of disability. In the moment of the haunt, the confrontation between Autumn and the patrons makes the spectre of disability appear thus making nondisabled imaginary's material and ontological horror of disability apparent.

Encountering the Spectre of Disability in the Boys' Dorm: An Autoethnography

This vignette offers an analysis of the embodied act of haunting as performance not just from the perspective of an ethnographic spectator and performance theorist, but from my first-hand experience of performing in the attraction. This vignette adds a critical dimension to my theorization of haunting as an act of political agency by demonstrating how haunting allows the temporally and experientially disparate embodied memory of dis/abled haunters to bleed together with the embodied memory of PSSH inmates.

My first haunting experience at the PA took place on Sunday, October 18, 2020. Asked if I wanted to attempt haunting, I gave a resounding "Yes!" The general manager assigned me to the "boys' dormitory" scene. Entering uncharted territory, both as a haunter and an auto-ethnographer, I kept my eyes and ears open to everything I experienced in that moment. Before I went upstairs to my scene, I jotted down the following questions in my fieldnotes: How do I *scare* someone? How do I move? How do I sound? What character do I create? What does it mean to move through these spaces? Am I *really* doing this?

Dressed in beige, blood, and dirt-stained thermal underwear and a bloodied, unadorned cloth mask made to replicate those from the 1918 flu that devastated the PSSH, I made my way to the second floor of the Administration building.⁵⁰⁵ Entering the scene, I moved to a bunk bed and sat down. I felt an immense weight come over my body. Alone in the room, but not...*alone*...I could feel a presence with me. Though entirely fabricated to resemble a boys' dorm, neither the green, twin-sized hospital mattresses that sat atop sparse metal bunk frames nor the space in which they filled felt fully fictitious.⁵⁰⁶ As a dis/abled person, the space, and the action of laying on a bed, waiting for the arrival of someone to view me—to view my bodymind—seemed a familiar performance to me. As I sat down on my "bunk" I saw myself, in my mind's eye, sitting down on every hospital gurney I have called *home*.

As I heard the wave of actors yelling "FIRE IN THE HOLE!!!" crash towards me, a sense of dread took over. "How am I going to scare anyone?" I thought to myself. No one gave me specific instructions on how to scare the patrons or the kind of character to create. The only instructions I received was not to swear at the customers, not to impersonate children, and not to disrespect the histories of the institution or the former inmates.

⁵⁰⁵ This decision was made deliberately by the general manager and the costume designer. It not only illustrates the ingenuity of those who design the haunt but also highlights the heritage reenactment that takes place within the attraction, unbeknownst to the patrons.

⁵⁰⁶ While the bed frames and mattresses did not originate from the PSSH, the attraction purchases these props as surplus from institutions and prisons.

With little to base my character from, my brain rummaged through past experiences attempting to find something—anything—that might scare someone. I recalled the experience of being a first-generation college student from rural Minnesota now studying vocal performance at a university in upstate New York. Memories of moving through the music department's building—Cox Hall, the first building on campus which was built in the 1800s—in the wee hours of morning flooded my senses.

I recalled being alone navigating the catacombs of practice rooms, when seemingly out of nowhere, the bleating of the notorious "Cox Hall Screamer" would pierce the silence. Despite later learning that the infamous Cox Hall Screamer was not some phantom tenor who haunted the practice rooms late at night but a real person (in need of some ginger and Throat Coat), the rumors of who, and what, that voice represented served as fodder for tales to terrify incoming music majors with. So, from this memory came my inspiration for my first haunt character: Félix.

My initial efforts to scare patrons as, Félix, an operatic tenor who went from performing the titular role of *Werther* at the *Teatro alla Scala* to an inmate at the Pennhurst Asylum, brought laughable results. While the memories of a shrieking spectral tenor still terrified me, I quickly realized patrons did not feel the same trepidation.

As I reconsidered my character choice, I battled with myself. The solution seemed *too* obvious as my act flopped. I knew I could simply pull the "handicap card:" caricaturing my dis/abled bodymind to evoke a performance of disabled appearance that I could—somewhat—control. All my life, I had done that. I pulled the card to avoid being bullied or beaten by nondisabled people (or lessen the extent of their physical and/or emotional abuse). I pulled the card to invoke pity or laughter. I even used it to gain roles

in performances because no one could do what I could do (or, more accurately, was willing to put their bodyminds at as much risk to do those things). For example, I offered my bodymind up as a prop for physical comedy, often letting actors push me over on stage or improvising self-deprecating lines *ad libitum*, in the hope of landing comedic character roles.

As a person living with cerebral palsy (CP), pulling the card also allows me a proactive means to control, even in the slightest way, how a nondisabled person perceives my bodymind in navigating personal, professional, and social interactions. For example, as a dis/abled person who became ambulatory in adulthood, I often get questioned—if not accosted—when requesting and using access measures such as accessible seating in performance venues. To lessen the instances of being interrogated over whether I "really need" such measures, or to avoid giving my full medical history, I often exaggerate the physical manifestations of my CP. This includes letting my body deviate from what Carrie Sandahl calls "the tyranny of neutral," emphasizing my limp and letting my gait become more slouched.⁵⁰⁷ In embellishing the bodily manifestations of my dis/ability—drawing on performances of disabled appearance—I signal to the nondisabled gaze that I am *indeed* dis/abled because I look disabled.

But I also pull the card to remove myself from the emotional labor of explaining certain bodymind ramifications of my CP to nondisabled people in depth. My CP manifests itself in a multitude of ways that often make nondisabled people outwardly uncomfortable. I often spontaneously drool and experience muscle spasms when

⁵⁰⁷ Carrie Sandahl, "The Tyranny of Neutral," in *Bodies in Commotion: Disability & Performance*, ed. Carrie Sandahl and Phillip Auslander (Ann Arbor, MI: University of Michigan Press, 2005), 255–67.

someone enters a room unannounced, or a loud noise occurs. (To which, almost inevitably, someone responds, "Sorry, I didn't mean to scare you." … They didn't scare me.) I also live with motor functioning and coordination difficulties, bladder control issues, struggle with written and expressive communication, and often misinterpret social cues. While I spent most of my life attempting to make these manifestations less apparent, I found that pulling the card lessened the abjection I received from my nondisabled peers. By pulling the card I did not have to *wait* for a nondisabled person to perceive me, and report back to me, the multitude of ways I was their *other*. In the least, pulling the card provided a buffer; it allowed me to name I was their *other* in a way that felt—somehow, but not really—less dehumanizing.

"Would this be the same thing?", I thought to myself. "Am I just capitulating to ABs again? ⁵⁰⁸ What if my Félix character just needs more fine tuning?" Initially, I felt great reluctance to pull the card, but with every group of bored patrons that passed through my scene of a fictional asylum in a real institution, my bodymind knew the answer. *I needed to give them what they wanted*. They came to an institution, after all, the place which forced people like me, (and those around me and those that preceded me) to perform disabled, making us legible yet erasable to the outside world.

As I laid back in my bunk, I recalled the experience of living in the Shriners Hospital for Crippled Children in Minneapolis, Minnesota. I modeled my new character's movement after my own while recovering from the multitude of surgeries I have undergone over the years. While in recovery, before I started the process of re-learning how to walk, I could only move through space using the trapeze bar above the hospital

⁵⁰⁸ Dis/abled slang for an "able-bodied," or nondisabled person.

gurney to hoist my upper body into various positions and transfer my body from bed to cart, or bed to wheelchair. Living with CP, it is often easier for me to move through spaces in this horizontal fashion because of the unpredictability of how my legs respond. So, in the haunted attraction, I navigated the section of three bunk beds connected in a "L"-shape without the use of my legs, as I did back at Shriners. This movement felt instinctual or already learned to me, even though I had spent most of my adult life trying to mask movements that made me easily identifiable as disabled during my first eighteen years of life (when not pulling the card).

Strikingly, but unsurprisingly, this movement sparked a significant outpouring of response from the patrons. "You okay, buddy? Looks like you need some new legs" one patron jeered at me. Other patrons screamed or cursed at me as I allowed my legs to flail about as I moved across the bunk beds in their direction. One patron even suggested I should be "put down," positioning me as an animal and insinuating a desire to kill me. Despite the vitriolic ableist comments I received, the experience of scaring the patrons entertained me. This *is* how I move—this *is* my dis/abled embodiment. Yet, under the constructed gaze of the patrons, my embodiment was disgusting and scary. In the long lulls in between patrons, I experienced yet another immense moment of emotion.

During an excruciatingly long wait for the next group of patrons to enter, I stared up at the metal underside of the bunk above me. The spectre of my constructed, yet still material and corporeal, disablement reappeared after years of laboring to make it disappear. By moving as I did in the hospital bed and rubbing against the metal bed frame, I tore off the new skin that formed over the places where the doctors' scalpels cut into my body all those years ago. Incisions from surgeries past reopened and bled through

my thermal underwear already stained with stage blood. The fabricated and the factual literally bled together.

Laying on a bare mattress, in a former office, of the former Administration building of the former PSSH, I found myself back in a bed at Shriners—*waiting*. Waiting for my family, for a friend, for a doctor, for a nurse, for a physical therapist, for an occupational therapist... for anyone... willing to *connect* with me.

My past- (and present) self was waiting for someone to console my fear of being left alone in this terrifying environment, not knowing what was going on, what was happening to my body, or why I could not leave. I was waiting for more than someone to just acknowledge me as a bedside chart of "behavioral issues," "current medications," "bowel movements," and "pain levels…" In that moment, I felt intimately connected with those who lived and died at the PSSH. Though I have never experienced the horrors of being institutionalized, I felt in that moment, as if my past touched with the inmates of Pennhurst Past in the present… *waiting*.

In this moment, my mind's eye saw myself laying on the bare mattress, as shimmers of surgeries and the bloody remnants of my post-operation bodymind flashed over me in reverse-chronological order. When the images reached the memories of my earliest surgery—a dorsal rhizotomy (intended to reduce muscle spasticity in the lower extremities by cutting nerve fibers in the spine) at the age of three—I saw nurses and doctors from my past, spliced together with images of PSSH employees and inmates. I saw the hustle of the former Administration building as administrators walked through the space. Then, in the next instance, I saw myself laying in a crib located in some nondescript ward with hundreds of other children. *Waiting*.

The loud shriek of an oncoming group of patrons pierced this vision. As I regained sensation over my body, I felt a sense of warmth and comfort come over me—almost like I was being hugged. This phenomenological, affective experience literally took hold of me—of my bodymind—and served as confirmation that I was not *alone* but comforted by those that had gone on before me. In this moment, the "memories and pieces of trauma and energy that are imprinted on this space" and those imprinted on my bodymind repeated, meshed, and found communion with one another.⁵⁰⁹

As the group of patrons finally arrived, I, paradoxically, felt empowered and supported by this unknowable but simultaneously corporeal presence. I knew that no matter how the patrons jeered at me, or even if they attempted to assault me, I was in a space defined by dis/abled people just as much as it was defined by nondisabled care*takers*. As the night went on, I came to understand—to *feel*—the joy Autumn and other dis/abled haunters described through haunting. I—we—did not pull the card to haunt these patrons, *we fucking reclaimed that card*. Towards the end of the night, several haunters came up to the dorm scene, to haunt with me. "We finally got the OK from the General Manager," they said. "We heard you were killing it up here and waited all night to haunt with *you*."

Analyzing the Boys' Dorm Scene

My observations from haunting in the boys' dorm index several aspects of my argument. First, my initial mis-haunt: my failure to scare the patrons without employing my dis/ability reveals how disability elicits fear in the gaze of nondisabled patrons. Second,

⁵⁰⁹ Autumn Werner, June 2022.

by examining the patrons' rhetoric towards me and other dis/abled haunters, it emphasizes how, as nondisabled society's other, nondisabled people view dis/abled people as nonhuman and therefore worthy recipients of violence. Third, the abuse of dis/abled people by nondisabled perpetrators has defined Pennhurst. Through haunting, dis/abled haunters redefine and reclaim this institutional space. They also redefine and reclaim the historical and contemporary traumas perpetrated in the name of institutionalization and invoked through performances of disabled appearance. Finally, haunting also reveals how we *wait*—painfully—for recognition, repentance, reparation, and resolve of the spectre of institutionalization.

This vignette illustrates how not just any performance will scare patrons at the PA. Despite my best efforts to scare patrons with my distressed opera singer character, Félix, it simply did not work. After I got out of costume, I wrote in my field notes: "Scaring people is hard as fuck. I have immense respect for the haunters."⁵¹⁰ While the space itself does considerable work to prime the patrons for a "spooky" experience, knowing what vocal techniques, movements, etc. will *scare* a patron takes considerable time and practice to rehearse and master. In the subsequent actor training I observed in later fieldwork in the 2021 and 2022 pre-season trainings, veteran haunters encourage rookie haunters to avoid stereotypical performances. These performances include things like saying "boo" or "help me" and making predictable movements in front of patrons such as maintaining regular postures or movement speeds. In short, veterans advise rookie haunters to make their sounds and movements as inhuman and sporadic as

⁵¹⁰ Stenberg, Fieldnotes, Sunday, October 18, 2020.

possible. As I discovered in my haunting experience, this advice is not only accurate but also implies a successful haunt requires employing a performance of disabled appearance.

As a dis/abled haunter generates the gulf between perceived disability and experienced dis/ability thus disturbing the ontological moorings of the nondisabled gaze, these haunting performances elicit violent attempts by the patrons to stabilize that relation. In the words of one dis/abled haunter, "Pennhurst is about who they [the patrons] become when they're scared, and why they're even scared in the first place."⁵¹¹ The encounters I experienced after transitioning into a performance of disabled appearance illustrate the deeply unconscious biases of nondisabled society towards dis/abled people. While my performance became "scarier" when I made my dis/ability more apparent, it also resulted in patrons directing vitriol ableist rhetoric towards me. This language illustrates how dis/abled people not only elicit fear in the nondisabled gaze but how dis/abled people also become worthy recipients of violence. This drive to react with vicious anger and harm becomes further heightened in institutional settings such as those replicated by the PA.

Finally, by being and haunting in this former institution, the performances of dis/abled haunters do more than just scare people. The dis/abled haunters at the PA reveal that disability, as constructed through performances of disabled appearance and institutionalization, is not a material fact about a person. Instead, disability is a haunting effect that unsettles the very ontological foundations nondisabled society has taken for granted. And, in doing so, these performances redefine collective memories and histories

⁵¹¹ Conversation with Emily Wonder, September 12, 2022. Emily gave her permission to be identified on a full-name basis.

of the PSSH and its people. At the same time, these performances also provide dis/abled haunters with a sense of pride in identifying as dis/abled people. As one transgender and dis/abled haunter describes, "I have been shown again and again that people like me are considered to be monsters... and there is something incredibly powerful about just accepting that and becoming the monster."⁵¹²

While the effectiveness of the PA as a haunted attraction indelibly relies on reifying performances of disabled appearance and the repertoire of pain, to haunt does not mean just to "pull the card" or become "the monster." Rather, to haunt is a performance in wait. Unlike spaces like the institution or hospital, dis/abled haunters do not wait for nondisabled people to perceive, recognize, notice, or treat us. While in the haunt, we are in wait to review the patron, crafting a performance that manipulates the nondisabled gaze's process of review. We premise these performances on intimate embodied and historical knowledge of how the nondisabled gaze's process of perception, recognition, and treatment happens within spaces like the PSSH. In this way, haunting pushes conceptualizations of agency in dis/abled performance (i.e., that as a dis/abled person, I am an agent because I am performing) because haunting becomes both a performance of dis/abled agency and compulsion. In the act of haunting, the spirits of PSSH inmates reappear willfully and not, as a subject of revision and revenge, not just scaring nondisabled patrons, but forcing them to reckon with the unresolved horrors of subjecting dis/abled people to the institution.

Haunting, then, becomes the combination of individual reclamation, political agency, and kinesthetic memory transfer. Hauntings forge a community for those who

⁵¹² Conversation with Joey Vanderloop, August 2022.

work at the PA, while also remembering PSSH inmates and reinventing Pennhurst's legacy. Therefore, when the haunters chant "We *are* Pennhurst!!!" before taking their places in the haunt each night, something happens that goes beyond a rallying cry. These words become a rhetorical performative that *makes* an exclamation of transformative power and (re)inheritance using the same tools that once sent our community's ancestors to their slow, social death in this very institution.

Conclusion

This Act examined the role of performance at the PA in transferring embodied knowledge about disability, care, and violence. The PA not only makes the historical and ongoing state-sanctioned violence that continues to elude the review of the Court apparent, but it also reveals nondisabled society's horror of becoming disabled. Further, the PA makes apparent nondisabled society's willingness to commodify institutional violence through its scenes and performances of disability as horror. On one hand, this repeated and performed repertoire of violence as care reinforces to society that such acts are acceptable and entertaining, thus reifying nondisabled society's abjection of disability. On the other, the PA creates a space and a mode of performance—haunting where dis/abled people unsettle nondisabled ontological assumptions of disability while also compelling the revenants of former PSSH inmates into existence. Haunting serves as both an act of reclaiming agency, but also compulsion and companionship, in which the haunter compels the spirits of dead PSSH inmates to appear as the subject of revision and revenge, while simultaneously accompanying the dis/abled haunter in the act. For those that want a simplistic answer for whether the PA is moral or ethical, right or wrong, this Act argues no such answers exist when haunted by the spectre of institutionalization. Instead, what the PA and the community of dis/abled haunters who perform here reveal, is an aspect of what it means to live with, through, and alongside this systematic process of institutionalization that continues to oppress dis/abled people. To haunt at the PA is more than to simply perform, commodify, caricature, or empower; it is to appear within a system designed to make dis/abled people—our political agency, our personhood, and our very humanity—disappear. By its very essence, haunting, then, is a subversive act, but when performed under the spectre of institutionalization, it is always already impure and unvirtuous. As one haunter describes, "Going into our 'Asylum,' and having experience with disability, managing it, and the way it manifests in your life, umm, it's weird... showcasing the symptoms of disability. You're almost prostituting them out, in a way. But, in another way, that's reclamation for me."⁵¹³

For the dis/abled haunters of the PA, the issues that Pennhurst and institutionalization raise are not only about remembering the past but also about what it means to live in the spectre of institutionalization in the present and look towards the future. Indeed, the fear *is* real at Pennhurst. But that fear comes from the terror of knowing we—dis/abled people—could be forced to return to the institution, at any time, but not under our own control. Hauntings reveal the need to preserve both the PSSH campus and the history of the people of Pennhurst past and present because they give a fuller understanding of what life in a dis/ability community can look like.

⁵¹³ Interview with Nick, July 17, 2022.

The next <u>Act</u> explores this need for preservation alongside the tensions of the spectre of institutionalization by examining the community of dis/abled people at the PA, as they work to preserve the PSSH's history and build community on this site once designed for their segregation and slow death.

RECITATIVE

Satisfaction

A dis/abled haunter and I stare up at the stars—each of us laying on our own coarse wooden bench on opposite sides of the same picnic table—in a former employee parking lot at Pennhurst. We sit in silence as we enjoy a momentary break from a paranormal investigation on a clear midsummer night in 2022.

"May I ask you a question, Nathan?"

"Sure. What's on your mind?"

"Do you have anything that still bothers you—you know, from the hospital? Like anything that just makes you sick or angry?"

Beat.

I laugh a little to myself before answering.

"Yeah. You know what I hate? Bathtubs. ... And those damn juice cups. You

know, the plastic ones with the tinfoil covers they put the straws in."

We both let out a short little sigh.

Beat.

"For me, it's apples—especially Red Delicious apples. When I was in the institution, doctors use to give them to us as a 'reward' if we complied with the rules. A reward! Can you believe that?! *Fuckin' tasteless*—like plastic pretending to be fruit. I

used to throw them against the wall. That was the only thing they were good for. To this day, if someone ever gives me a apple, I just get so angry."

Beat.

"It's really hard to talk about this stuff to people," I remark. "People just don't get it—they don't even know where to begin."

"Yeah, it is. I don't think people get how it seeps into every bit of your life. Who

you are. How you experience the world. I guess that's what's nice about being here."

Beat.

A group of ghost hunters approaches, shattering the tranquility of the moment.

"We're not getting a lot of activity. I thought you said Rockwell was a paranormal

hot spot?!" We're cold and tired, so we're going to head home."

At least you get to choose when you leave.

I hold my tongue as the patrons turn and walk towards the parking lot from

whence they came.

Pennhurst: Always #1 in customer satisfaction. They served us a pureed "mass of food" with food coloring in it back in the day.⁵¹⁴ "Attractive to the eye," they said. "...Eye appeal and taste appeal is—that's what we strive for."⁵¹⁵ That's what we still

strive for: your comfort, your satisfaction, not ours.

 ⁵¹⁴ Suffer the Little Children (Philadelphia, PA: NBC-10, 1968), <u>https://www.youtube.com/watch?v=ZIepqvHii-M</u>, 14:28-14:50.
 ⁵¹⁵ Suffer.

A man with an intellectual disability is awakened by the doorbell at 11 am.

He stumbles out of bed, pulls on his Superman bathrobe, and shuffles to the front door, his paraplegic boyfriend wheeling behind him.

He opens the door.

A man is standing there. He takes in the scene and says sternly, "You should eat breakfast by 7, that outfit is not appropriate for an adult, and an abled professional girlfriend could do so much more for your social standing."

The man with the intellectual disability slams the door shut, slams home the bolt, and shrieks, "The Wolfensberger is at the door!"

Cal Montgomery⁵¹⁶

ACT IV

Remembering and Redefining a House of Horrors: Advocacy, Crip Historiography, and Community Living at the Pennhurst Asylum

⁵¹⁶ Cal Montgomery, "Wolfensberger at the Door," *Cal's Blog: A Blog About Disability* (blog), February 27, 2021, <u>https://montgomerycal.wordpress.com</u>.

Introduction: The Razor's Edge

On March 18, 2023, members of the Pennhurst Asylum (PA) community flocked to the campus to volunteer their time and clean debris out of Quaker Hall, preparing it for an upcoming paranormal investigation. Quaker was one of the first three buildings constructed at the Pennhurst State School & Hospital (PSSH) and notorious for the violence that occurred within its walls. Despite its notoriety, Pennhurst Limited Liability Corporation (LLC) kept Quaker closed to the public because of safety concerns regarding structural issues and asbestos contamination. Originally slated for demolition, Autumn Werner and other PA community members convinced the ownership to save and remediate the building, so that it could be used for both history tours and paranormal investigations.

This was the first time most members of the PA community, including myself, entered Quaker. Some members found excitement in getting to enter the previously forbidden space. For others, they believe Quaker is a spiritual "hot spot" for communing with the spirits of PSSH inmates. Finally, some members feel drawn to the space because they know PSSH authorities would have likely assigned them to that ward. As one dis/abled haunter and tour guide expressed to me, "It's oddly peaceful. You understand just how much people like us defined this space—literally made this space. I would have been here in this building, would have likely died in this building, and now I'm here giving it care."⁵¹⁷

⁵¹⁷ Conversation with Nick, March 18, 2023.

The bitter irony of this care*giving*, however, is that Quaker would host ghost hunters for a "lockdown"—an overnight paranormal investigation on April 1, 2023. Many of the paranormal investigators come to Pennhurst clueless of its history and often disrespect the property and people of Pennhurst. These disrespectful acts range from investigators attempting to steal artifacts to using microaggressions and slurs when engaging the spirits of PSSH inmates and PA staff. "I've been going through and apologizing to the spirits", Autumn told me.⁵¹⁸ "I know that the money from the ghost hunts is what keeps these buildings up, but it's hard to watch [how the paranormal investigators treat the space.]"⁵¹⁹ The preservation of Quaker serves as a poignant example of how the PA community puts the diverse histories of Pennhurst, and its people, into shared context and navigates the line between commemoration and commodification.

The PA community members fulfil a number of roles in and outside of the PA haunted attraction, including collectively curating the Pennhurst Museum (Museum)—a grassroots museum of dis/ability history and culture located in the former institution. While the PA haunted attraction only operates from September to November, Pennhurst LLC holds several events and activities throughout the year. The LLC profits from and pays employees for staffing events such as public and private paranormal investigations, large paranormal conventions, private film productions, and public and private photography tours. But the LLC also holds fundraisers for local community groups and charities, which often rely on volunteer labor from the PA community. The Museum

⁵¹⁸ Conversation with Autumn Werner, March 18, 2023.

⁵¹⁹ Conversation with Autumn Werner, March 18, 2023.

hosts visitors and leads history tours from March until December. While Pennhurst LLC ownership remains supportive of the Museum and its paid staff, individuals working at the Museum often volunteer their time and labor to assist in various projects such as cleaning out and searching spaces for artifacts and organizing the Museum itself. Finally, the Pennhurst LLC employs most of their staff exclusively during the haunt season, with a smaller group of about twenty employees working throughout the year to lead tours, support events, and volunteer their time for activities like building cleanups.

This community of mostly dis/abled people working for Pennhurst LLC raises several questions: Who makes up this community? What role does site-specific performance play in the telling of dis/ability history, institutionalization history, the disability rights movement, and future disability justice efforts?⁵²⁰ How does Pennhurst LLC, a for-profit attraction in a former custodial institution, managed and run mostly by dis/abled people, illuminate the inherent tensions involved in our current notions of disability advocacy, home- and community-based living policies (HCBS) and commemoration?⁵²¹ And in what regard does society hold the history of dis/abled people, if the preservation of the Museum must rely on the good intentions of, and profits from, this corporation?

⁵²⁰ I remain skeptical about both disability rights and disability justice as the sole mechanisms for advancing the well-being of the dis/ability community. On the one hand, while the focus on rights-based reform can unintentionally perpetuate ableist, racist, and sexist ideas of citizenship, rights nevertheless form the necessary basis for justice within the context of our nation's government. Conversely, disability justice appears to offer a more comprehensive and applicable platform, yet as performance studies scholar Victor Turner notes, "Justice can be seen only when it is acted out." This leaves an unresolved question: who gets to act out this justice and what does that acting out look like? Dwight Conquergood, "Lethal Theatre: Performance, Punishment, and the Death Penalty," *Theatre Journal* 54, no. 3 (2002): 342-43.
⁵²¹ This terminology was adopted from the nondisabled theorist of "normalization," Wolf Wolfensberger and remains in use within current disability policies, for "Home and Community-Based Living (HCBS)." See Wolf Wolfensberger, *Normalization: The Principle of Normalization in Human Services* (Toronto, CA: National Institute of Mental Retardation, 1972).

This Act investigates the community of dis/abled and nondisabled people who work for Pennhurst LLC's PA and call Pennhurst home through a lens of institutionalization-turned-utopian-performance.⁵²² The dis/abled people who lead paranormal investigations and Museum tours at Pennhurst navigate a razor-thin line between commemoration and commodification, survival and extinction, and kinesthetic memory and kinesthetic amnesia. Pennhurst LLC's paranormal and history tours operate as what performance studies scholar, Kaitlin M. Murphy calls "memory matter," or when embodied memory and objects combine to "create a dialogical space that illuminates hidden pasts and lost futures, a process that helps to shape memory and, importantly, identity in the present."523 Thus, the PA community puts dis/ability epistemology, de/institutionalization history, dis/ability activism, and nondisabled society's lore of institutions in shared context through recalling embodied memories of dis/ability.⁵²⁴ The PA community's ongoing preservation efforts and active engagement with patrons allow for the spectres of our community's history to appear, making space for reflection on what truth claims we make for the past, present, and future.

To account for the nuance of Pennhurst and its people—past and present—I employ performance historiography. This theoretical foundation allows for an examination of how disability history gets arranged—what structures and narratives exist that stabilize constructions of disability advocacy and institutionalization history.

⁵²² Several PA community members use "<u>Life360</u>," an application designed for family location safety, to monitor when another haunter comes to campus. The haunters label Pennhurst simply as "home."

 ⁵²³ Kaitlin Murphy M., "The Materiality of Memory: Touching, Seeing, and Being the Past in Patricio Guzmán's Chile, Memoria Obstinada," in *Theatre/Performance Historiography: Time, Space, Matter*, ed. Rosemarie K. Bank and Michal Kobialka (New York, NY: Palgrave Macmillan, 2015), 164.
 ⁵²⁴ For more on the public memory of Pennhurst in the local community, see Kelly George, "The Shame of Pennsylvania': Public Memory, Local News, and Institutionalization's Contest Past," *The Pennsylvania Communication Annual* 75 (2019): 11–35.

Performance historiography also helps explicate how places like Pennhurst, and the various performances that occur(ed) there, allow for the creation of discursive and embodied understandings of disability and dis/ability, which place preexisting structures and narratives in a place of unrest.⁵²⁵ Performance historiography, thus, illuminates the tension and messiness of both disability history and the people who live it. This Act examines the PA community, their preservation efforts, and their relationship with patrons attending the LLC's history tours and paranormal investigations. In doing so, this Act reveals how they conduct what I call crip historiography. Crip historiography is the embodied historiographical practices that the PA community enacts through their collective inhabitation of and care for this former institution turned attraction venue and museum. The PA community's crip historiography is a practice of care, community-making, and bodymind cohabitation that abides a contradiction resistant to closure. Crip historiography interweaves remembrance and redefinition, from a position not of objectivity, control, or mastery, but through *being-with* the past.

But it is precisely this practice of crip historiography as *being-with* the past rather than attempting to control the past, that causes the disability advocacy community to cast doubt on the legitimacy of the PA community's commemoration efforts. Investigating journalistic accounts from 2008 to 2011, disability and media studies scholar Kelly George examines the feud between disability advocates and original ownership of the PA, Pennhurst Associates. As noted in the Intermezzo, after Pennhurst Associates purchased the property from the Commonwealth in 2008, former PSSH administrator J.

⁵²⁵ Walter Benjamin, "Eduard Fuchs: Collector and Historian," trans. Knut Tarnowski, *New German Critique*, no. 5 (1975): 27–58.

Gregory Pirmann and attorney and preservationist Nathaniel Guest co-founded the Pennhurst Memorial & Preservation Alliance (PMPA). Building a coalition with (mostly nondisabled) state, national, and international disability advocates, PMPA sought to ensure the preservation of the property and advocate for the disability community.⁵²⁶ In analyzing the discourse of advocacy groups such as the PMPA, George argued that disability advocates' desire to find "credible venues' that can be trusted to tell 'the true story'" of Pennhurst illustrated their incredulity of Pennhurst LLC to conduct any form of preservation efforts.⁵²⁷ Further, George demonstrated how Pennhurst LLC threatened the legacy of disability advocates', the validity of HCBS as the sole alternative to institutionalization, and the return of the eugenic fears of disability that enabled institutionalization in the first place.⁵²⁸ George went on to note,

The eagerness of some community members to contribute to the discussion about Pennhurst also shows what is at stake in the contemporary American concept of disability—particularly for those who define themselves as nondisabled. Although local journalism did capture some voices of people who identified disability as a key feature of their subjectivity, there were far more individuals who defined disability as external to their own experience. This orientation of these helpers, advocates, and eyewitnesses lays bare the fact that disability has historically been most useful as a category to be used by the 'non-disabled.' This separation and the nature of the relationships that form around it, particularly between human service employees and those they care for, is part of the legacy of institutionalization.⁵²⁹

George's analysis of the rift between disability advocates and Pennhurst Associates

highlights how crip historiography—and the PA community—stands in sharp contrast to

⁵²⁶ I joined the PMPA's Advisory Board in 2018 and the Board of Directors in 2019. "About the Board and Advisory Board," Pennhurst Memorial & Preservation Alliance, n.d., http://www.preservepennhurst.org/default.aspx?pg=15.

⁵²⁷ Kelly George, "The Birth of a Haunted 'Asylum': Public Memory and Community Storytelling" (Dissertation, Philadelphia, PA, Temple University, 2014), 63-64.

⁵²⁸ George, 62.

⁵²⁹ George, 205.

normative, nondisabled notions of disability advocacy and history. Rather than make definitive claims about Pennhurst's "true history," crip historiography, and the wide range of embodied practices it involves—from cleaning, curating, and guiding tours, to supervising ghost hunters—constitutes a way of *doing* history that is distinctive to dis/abled communities living in the spectre of institutionalization.

The PA community's crip historiography illustrates the conflict between normative constructions of disability history and the embodied dis/ability heritage taking place at the Museum. Museum studies scholars often understand heritage as a mode of constructing and utilizing the past, by partisans in the present.⁵³⁰ For example, disability advocacy groups such as the PMPA have historically used the refrain "tragedy and triumph" to position Pennhurst as a consecrated space, representing a linear narrative of good over evil. The history of deinstitutionalization, as often found in narratives of disability advocates, involves helpless disabled people who became victims of the institution, but were saved by trail-blazing and altruistic (nondisabled) lawyers and parents who advocated on their behalf.⁵³¹ Once institutions closed, disabled people found freedom (in the form of group homes) and they banded together—with the support of nondisabled advocates providing disabled people with the tools of civil rights advocacy—to form self-advocacy organizations. Through these efforts, self-advocates successfully lobbied for and attained a (slightly modified) version of the nondisabled American dream—working full-time (generally for sub-minimum wages) and getting

⁵³⁰ Steven Hoelscher, "Heritage," in *A Companion to Museum Studies*, ed. Sharon Macdonald (New York, NY: Wiley, 2008), 198–218.

⁵³¹ For more on the "triumph and tragedy" narrative of Pennhurst and disability advocates role in streaming narratives around Pennhurst, see Chapter 3 in Kelly George, "The Birth of a Haunted 'Asylum': Public Memory and Community Storytelling" (Dissertation, Philadelphia, PA, Temple University, 2014), 50-96.

married (while having our benefits severely restricted in the process). This narrative not only stabilizes the fluid and complex history of de/institutionalization, but it also assumes that the pinnacle achievement of the deinstitutionalization movement was that dis/abled people get to live a White, heteronormative, nondisabled, working-class, life. Crucially, this telling of institutionalization history whitewashes the experiences of agency, resiliency, trauma, and oppression dis/abled people have and continue to experience in and outside institutions.

Continuing the narrative of tragedy and triumph, the larger disability community and the scholarship addressing Pennhurst continues to position itself as the sole force of good fighting the evil Pennhurst LLC. As PMPA Advisory Board member and historian Dennis B. Downey and PMPA Co-President James W. Conroy wrote in 2020:

The Pennhurst Memorial and Preservation Alliance, in partnership with other regional organizations, has been working to transform [the former PSSH's superintendent mansion—owned by the Commonwealth—] into an interpretative center dedicated to representing and educating about the institution's place in American history. ... If successful, an interpretative center will provide a dignified memorial, in contrast to the Pennhurst Asylum attraction, which in the past has demeaned and degraded the memory of the 10,600 people who lived and died at the institution. Which will win out—the Asylum venue and commercial park or the memorial site—is an open question.⁵³²

This blunt censure of the PA community by disability advocates and members of the

public silences the dis/abled people that work for Pennhurst LLC all the while claiming to

speak on behalf of dis/abled people.⁵³³ While well-intentioned, this not only limits how

⁵³² Dennis B. Downey and James W. Conroy, "Conclusion," in *Pennhurst and the Struggle for Disability Rights* (University Park, PA: The Pennsylvania State University Press, 2020), 226.

⁵³³ Miroddi and Beck, "Opinion: Pennhurst Asylum Is Exploitation"; Beitiks, "The Ghosts of Institutionalization at Pennhurst's Haunted Asylum"; Beitiks, "The Final Indignity"; Linda Mussell, Kevin Walby, and Justin Piché, "Can You Make It out Alive?' Investigating Penal Imaginaries at Forts, Sanitaria, Asylums, and Segregated Schools," *Journal of Qualitative Criminal Justice & Criminology* 10, no. 3 (2021): 1–39; Mike Newall, "Uncovering the Forgotten Lives Lost at Pennhurst State School and

the story of Pennhurst and its people—past and present—gets told, it also robs dis/abled people of the ability to define our own history and knowledge-making processes. This censure, in turn, signals to dis/abled people that if our modes for defining and sharing our history and what it means to be dis/abled do not adhere to the standards of our nondisabled, parent-driven advocacy community, it is not disability history. Thus, this debate not only forces dis/abled people to *wait*, once again, for recognition, but it also delegitimizes the validity of dis/abled people's perspectives and silences us once again.⁵³⁴

In contrast to the "tragedy and triumph" narrative, the crip historiography work of the PA community and the Museum reveals how the spectre of institutionalization instills generational trauma in the embodied memory of dis/abled people. Generational trauma within the dis/ability community remains largely underdiscussed by disability scholars.⁵³⁵ But, other disciplines, such as Black studies, has a larger corpus of work on the topic that sheds further light on how the generational trauma of institutionalization impacts the work of the PA community. For example, Black Studies scholar Christina Sharpe writes about the wake of a slave ship to understand generational trauma and living in the wake

Hospital," *The Philadelphia Inquirer*, April 14, 2023, <u>https://www.inquirer.com/news/pennhurst-state-school-hospital-patient-stories-temple-university-exhibit-20230414.html</u>.

⁵³⁴ For a brief, but poignantly written blog on this topic, see Diana M. Katovitch, "Who Should Tell the Story? The Pennhurst Haunted Asylum and the Pennhurst Museum in Public History," National Council on Public History, *HISTORY@WORK* (blog), June 7, 2022, <u>https://ncph.org/history-at-work/who-should-tell-the-story-pennhurst-haunted-asylum/</u>.

⁵³⁵ For more on the absence of disability in discussions of generational trauma see, Administration for Children & Families, "What Is Historical Trauma," Trauma, n.d., <u>https://www.acf.hhs.gov/traumatoolkit/trauma-concept;</u> for a short piece on generational trauma and multiply-marginalized dis/abled people see, Jocelyn Mondragon-Rosas, "We Don't Talk About Generational Trauma, No, No," *Disability Visibility Project* (blog), April 1, 2022, <u>https://disabilityvisibilityproject.com/2022/04/01/we-dont-talkabout-generational-trauma-no-no/;</u> for a call for combining critical disability studies and critical trauma studies see, Daniel R. Morrison and Monica J. Casper, "Intersections of Disability Studies and Critical Trauma Studies: A Provocation," *Disability Studies Quarterly* 32, no. 2 (2012); for a creative book of poetry examining the bodymind experience of trauma, particularly disability and complex post-traumatic stress disorder (CPTSD) see, Katrina N. Jirik, *Living in the Abyss: Poems* (American Fork, Utah: Kelsay Books, 2023).

of slavery as social death.⁵³⁶ For Sharpe, "To be 'in' the wake, to occupy that grammar, the infinitive, might provide another way of theorizing in/for/from what Frank Wilderson refers to as 'stay[ing] in the hold of the ship.' With each of those definitions of wake... I argue that rather than seeking a resolution to blackness's ongoing and irresolvable abjection, one might approach Black being in the wake as a form of *consciousness*."537 In this way, for the PA community, enacting and embodying dis/ability heritage allows for us "to be 'in" and with the institution's ward.⁵³⁸ And, rather than "seeking a resolution to" dis/ability's "ongoing and irresolvable abjection," the PA community approaches dis/ability "as a form of consciousness."—what I theorize as crip consciousness.539 The Museum and the people that staff it, highlight how concepts of "disability," "advocacy," "institutions," and "community living" operate not as fixed and static, but depend on historically contingent factors such as time, geographical location, culture, and other relations.⁵⁴⁰ The crip historiography of the PA community insists that institutionalization is not past, but rather institutionalization is a wake that still buffets dis/abled people.⁵⁴¹ Through the PA community's crip historiography—giving tours and inhabiting this former institutional space—this community of dis/abled heritage-makers remakes Pennhurst into a communal, commemorative, and educational site of redefinition.

The potency of the PA community and Pennhurst Museum, lies in the every-daypeople who dedicate themselves to preserving Pennhurst's legacy and the crip

⁵³⁶ Sharpe, 13.

⁵³⁷ Sharpe, 13-14 (emphasis original).

⁵³⁸ Sharpe.

⁵³⁹ Sharpe.

⁵⁴⁰ Tremain, Foucault and Feminist Philosophy of Disability, 23.

⁵⁴¹ Christina Sharpe, In the Wake: On Blackness and Being (Durham, NC: Duke University Press, 2016),

historiography they perform. The PA community relies on what philosopher Michel Foucault calls "subjugated knowledge," vernacular, from-the-bottom knowledge, rather than expert, top-down knowledge.⁵⁴² This embodied and enacted knowledge of dis/abled people *choosing* to commune within and give care to this space once intended for their segregation and social death creates the conditions for the subjugated knowledges of Pennhurst to emerge. Enabled through crip historiography, the subjugated knowledges of Pennhurst emerge because the PA community have a bodymind stake in the work. Thus, crip historiography counter-acts the bulk of how scholars, advocates, and the public told PSSH's history in the past: through non-embodied, discursive, expert knowledge.

The work of the dis/abled bodyminds that curate and maintain the Museum illuminate two kinds of performance that occur within this site-specific commemorative space: *performances of remembrance* and *performances of redefinition*. Acts of preservation, such as collecting artifacts found on the site, serve as performances of remembrance. These performances occur in a register familiar to traditional notions of preservation and museology. But these artifacts preserved in the Museum present a static image of the PSSH's past⁵⁴³ and disability.⁵⁴⁴ Some artifacts, such as photographs depicting inmates in idyllic scenes, marble bathroom stalls in the employee's dorm, and dehumanizing portraits of inmates in their patient files, tell the PSSH's history from the perspective of nondisabled caretakers for the "feebleminded," "mental defective" or, later, "mentally retarded" inmates. Others, like toys, stall-less toilets, and restraints, tell a

⁵⁴² Michel Foucault, *Power/Knowledge: Selected Interviews and Other Writings*, 1972-1977, trans. Colin Gordin (New York, NY: Pantheon, 1980), 89.

⁵⁴³ Walter Benjamin, "Eduard Fuchs: Collector and Historian," trans. Knut Tarnowski, *New German Critique*, no. 5 (1975): 29.

⁵⁴⁴ Tremain, Foucault and Feminist Philosophy of Disability.

story at odds with that of the idyllic representation of the PSSH as told by institutional authorities. This perspective reveals how these artifacts served as objects of coercion. These artifacts also create an unresolvable tension. The Museum holds more than just artifacts. Within the confines of the Museum exists a chasm of viewpoints—the inmates, the authorities, the employees, the advocates, the public, the haunters, etc.—that remains impenetrable because the perspectives of each were and remain so wildly dissimilar. In short, depending on how you literally or figuratively enter(ed) the space of the institution, your viewpoint of the institution will change. This chasm remains impenetrable because the bodyminds of Pennhurst's people, and embodied encounters at Pennhurst, remain absent from these artifacts and the history they tell. Without embodiment—or the people whose stories they tell—these artifacts remain artifacts, as a performance of remembrance.

The embodied acts of storytelling and community-making by the dis/abled people of the PA community—such as sharing experiences of dis/ability during Museum tours serve as performances of redefinition in this former institution. As performance scholar Joseph Roach argues, performance takes on an effigial quality, thus filling this void "by means of surrogation, a vacancy created by the absence of an original."⁵⁴⁵ While the dis/abled people explaining this history to and dialoguing with the patrons do not replicate the experiences of those once institutionalized at the PSSH, their physical presence in this space performs a redefinition of Pennhurst's history and who advocates for dis/abled people. Taken together, the PA community's performances of remembrance

⁵⁴⁵ Joseph Roach, *Cities of the Dead: Circum-Atlantic Performance* (New York, NY: Columbia University Press, 1996), 35.

and redefinition, or knowledge that comes from doing, unsettles traditional understandings of commemorating disability and institutionalization history and reframes it as dis/ability heritage.

This Act begins with a vignette detailing the events prior to and following a training for Pennhurst LLC history and paranormal guides in March 2021. This vignette makes the tensions of Pennhurst's commemoration, disability advocacy, and HCBS bare and primes the rest of the theoretical explorations of both the PA community and the Museum. Following the vignette, the Act explores the community of people that make up the PA community in more detail to investigate who these people are and how they navigate those tensions. Following the examination of the community, the Act explores the evolution of Pennhurst LLC's paranormal tours and history tours, and the role the PA community plays in redefining Pennhurst's legacy. Examining these two tours in dialectical tension with one another, the examination reveals how the blatant blend of fact and fantasy in the paranormal tours perpetuates the indiscernibility of state-sanctioned violence against dis/abled people. Finally, the Act ends with an analysis of the Museum and PA community's dis/ability heritage work. In doing so, this analysis elucidates how the PA community not only navigates the tensions between memory, justice, and performance, but living under the spectre of institutionalization.

All In a Day's Work: The Tensions of Pennhurst Past & Present

This section details an auto-ethnographic vignette of a history and paranormal guide training on Saturday, March 13, 2021, to provide historiographical context regarding the

past and present preservation efforts of Pennhurst. In doing so, this vignette exposes the conflict between the disability advocacy community and the PA community and the way each entity comes to tell disability history and define what it means to be dis/abled.

Old Wounds: A Vignette

My car careens down Commonwealth Drive, making its way around the rear of the Mayflower ward towards the old employee parking lot. Parking, I see Autumn, and others already assembled for the annual training day for Pennhurst's History & Paranormal Tour staff. As the crisp mid-March breeze hits my face, I immediately feel overwhelmed with emotion as I exit my car and amble up the steps of the catwalks to the Mayflower.

Standing next to Autumn is James W. Conroy, an internationally renowned deinstitutionalization expert. Conroy authored the landmark *Pennhurst Longitudinal Study* and personally took the last group of PSSH inmates away from the institution and brought them to group homes when the hell hole finally closed its doors.⁵⁴⁶ Tears well up in my eyes. Seeing Autumn standing next to Conroy, I feel respect, sorrow, pain, twinged with pangs of joy and hope. If born just a few decades prior, doctors would have likely committed Autumn (and her two younger sisters) to Pennhurst. Knowing that she holds positions of leadership both at Pennhurst and in the local disability advocacy community brings me hope and joy. But the realities of the historic and ongoing discrimination of dis/abled people haunt this scene.

⁵⁴⁶ James W. Conroy and Valerie J. Bradley, *The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis* (Philadelphia, PA and Boston, MA: Temple University Developmental Disabilities Center and MA Human Services Research Institute, 1985); Conroy, "The Pennhurst Longitudinal Study and Public Policy."

I asked Conroy to attend the training so that he could share his story and expertise with the group, but also so that he could make a showing of good faith. As Co-President of the PMPA, Conroy's presence surprised and intimidated many of the haunters. While Conroy historically maintained a position of cautious optimism regarding a possible partnership between the PMPA and the LLC, the rest of the organization did not.

In the past, PMPA's members and affiliates penned petitions and editorials lambasting Pennhurst LLC and the PA haunters.⁵⁴⁷ The PMPA also attempted to create a museum of its own, honoring the legacy of those who lived and died at the PSSH, but there were unexpected obstacles. These included securing necessary funding and the Commonwealth of Pennsylvania withdrawing their offer to sell the former superintendent's mansion to the PMPA (the proposed site for the PMPA's museum).⁵⁴⁸ The PMPA's actions led to the PA community feeling ostracized, muzzled, and nonexistent. As one haunter expressed to me halfway through the 2020-season, "You're the first researcher to come here and actually get to know us. People just walk through the haunt, leave, and just assume we're a bunch of assholes without even talking with us."549 This sentiment illustrates an assumption made by the larger disability advocacy and preservation community that only nondisabled people work for Pennhurst LLC or the dis/abled people that do work there are not worth investing in as members of the dis/ability community. Further, this sentiment propagates an incorrect assumption that the LLC only wants to commodify the PSSH's history. These beliefs set up a paradigm that

⁵⁴⁷ Downey, "Asylums"; Pennhurst Memorial & Preservation Alliance, "A Statement Regarding the 'Pennhurst Haunted Asylum," August 12, 2010, http://www.preservepennhurst.org/default.aspx?pg=142.

⁵⁴⁸ Downey and Conroy, *Pennhurst and the Struggle for Disability Rights*.

⁵⁴⁹ Stenberg, Fieldnotes.

invalidates the embodied histories of the PA community and their work to preserve the legacy of Pennhurst.

This historic lack of interaction between the PMPA and the PA community allowed visceral wounds of mistrust to fester and the stench of animosity to grow. While Conroy and a small minority of Board members remained open to peace with the LLC, most of the Board remained opposed to any sort of truce. In turn, the PMPA missed an opportunity to connect past and present generations of institutional survivors, dis/abled people, and nondisabled allies together, so that we could learn from one another. Instead, the PMPA claimed authority as the custodians of Pennhurst's legacy. All the while, the PA community went years without recognition for their labor in preserving the property and countless artifacts.

One of the largest contributors to the rift between the PMPA and the PA community is the history of nondisabled advocates claiming the prerogative to determine who speaks and who they speak for regarding disability history, thus recapitulating institutionalization's silencing and defining of its victims. ⁵⁵⁰ In October 2021, for example, Temple University's Institute on Disability held a listening circle on the PSSH campus.⁵⁵¹ Autumn hosted the event as both the LLC's Off-Season Event coordinator and the PMPA Fellow. The group featured a mix of university staff, creative collaborators, local disability advocates and self-advocates (including a former PMPA board member),

⁵⁵⁰ Allison C. Carey, "Citizenship and the Family: Parents of Children with Disabilities, the Pursuit of Rights, and Paternalism," in *Civil Disabilities: Citizenship, Membership, and Belonging* (Philadelphia, PA: University of Pennsylvania Press, 2015), 165–85.

⁵⁵¹ Temple conducted this listening circle as part of their project, "File/Life," a multimedia exhibit which focused extrapolating life stories of PSSH inmates from patient files from the Pennsylvania State Archives. The exhibit ran from April 21-23 in Philadelphia, PA. For more on "File Life" see, "About File Life Stories," Temple Institute on Disabilities, n.d., <u>https://disabilities.temple.edu/programs-</u> services/advocacy/media-arts-culture/about-file-life-stories.

and PSSH survivors. Despite Autumn's excitement to interact with and learn from survivors and others in the group, the nondisabled advocates leading the tour insisted that she not partake in the listening circles. Autumn describes her interactions with the group saying,

It felt very clear that the disdain was still there from [the nondisabled advocates], as there was no room created for me to speak. [The nondisabled advocates] initially avoided me and suggested I let them do their own thing. I, of course, stuck along—as is [the LLC's] policy—and I tried to get in words where I could. Funny enough, the Pennhurst residents that were on the tour were the kindest people to me that day. I don't mean to enforce my perspective, so I really didn't push too hard, but it felt clear I was not wanted.⁵⁵²

Nondisabled advocates' silencing Autumn in a listening circle not only highlights the mistrust between the PA community and the disability advocacy community, but also reveals the bitterly ironic power dynamics between nondisabled advocates and dis/abled people in the disability community. On one hand, nondisabled advocates argue their presence is necessary, and that they champion the voices of dis/abled people (typically their own family members who cannot use speech as their primary means of expression and use other means to communicate). On the other, as illustrated with the listening circle at Pennhurst, the preference towards nondisabled advocates offen leads to the censure of dis/abled people, like Autumn. Recalling Murphey's notion of memory matter, the intention of the listening circle was to "create a dialogical space that illuminates hidden pasts and lost futures," to help "shape memory and, importantly, identity in the present."⁵⁵³ But this listening circle collapsed that space, buried hidden pasts deeper, and burned the map. It not only led to lost futures, but it reinforced the memory of the divide

⁵⁵² Conversation with Autumn Werner via text message, January 16, 2023.

⁵⁵³ Murphy, "The Materiality of Memory," 164.

between the PA community and the disability advocacy and preservation communities. This interaction communicated to Autumn, and other dis/abled people in the group, that only nondisabled people can define disability in the present, as it was in the past. Like the role of nondisabled advocates in the PSSH commitment trials, the censure of the PA community and the dis/abled people within it, results in dis/abled people being made into momentary institutionalized disabled subjects. By silencing the dis/abled people, like Autumn, disability advocates provided dis/abled people no recourse to present our own perspectives. Further, such actions result in dis/abled people losing our humanity when we cannot make claims over our own needs and care, similar to the performances of institutionalized care and habilitation found in the institution.

Building a Bridge

To repair the animosity between the two groups with the hopes of furthering the dis/ability heritage work of the PA community, I asked Conroy to visit the campus during the 2020-haunt season. I knew if Conroy could meet the dis/abled haunters and hear their stories, he too would recognize this community and its shared sense of history with the PSSH. The experience of meeting the Pennhurst haunters profoundly impacted Conroy and brought him to tears. Conroy confessed that despite his desire to make peace with the LLC, he never thought of actually going into the community and getting to know the people that worked at the PA. He vowed his support.

Conroy's stamp of approval brought a new—albeit delicate and guarded relationship between the PMPA and Pennhurst LLC in expanding the Museum and history tours. Despite my reports of the Museum's expansion and the growing number of both regular tours and private education tours requested by primary, secondary,

undergraduate, and graduate educators, both the PMPA and the LLC remained cautious of one another as the wounds of distrust were still clearly healing. (One example of this occurs when I am on campus during a history tour. Donna Samluk, a former PSSH aide and now a museum docent, always requests that I cover the "PMPA exhibit." She concedes that her lingering anger about the treatment and perception she received from PMPA members and affiliates inhibits her ability to meaningfully discuss the PMPA.)

The training in March 2021 marked a turning point in the relationship between the PMPA and the PA community. This new relationship allowed the PMPA and the PA community to work together to build a more accessible environment for the Museum and for the PA community to focus their time and energy on dis/ability heritage work. Since 2021, this new partnership manifested primarily in combating the negative perception of the PA community by the larger disability advocacy and preservation community. This has happened through countless emails and conversations with advocates from across the country, encouraging them to attend the museum. By leading the efforts to correct misinformation, the PMPA provides the PA community with more bodymind energy and time to focus on their dis/ability heritage work and performances of redefinition. Since the LLC is a privately owned for-profit business, the PMPA cannot provide financial support to the Museum. But following the March 2021 training, the PMPA reimburses my travel so that I can help lead history tours when staffing issues arise. Given that most of the tour guides identify as dis/abled, this often results in last minute cancelations due to a dis/abling bodymind experience. Despite their positive support, practical and theoretical tensions still exist in the new partnership between PMPA and the LLC.

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Next, I analyze the PMPA Fellowship to highlight tensions between the PMPA's more traditional approach to both disability preservation and labor. This fellowship underscores how, despite moving out of the institution, we still rely on structures and norms established within the institution to bring about what disability advocates presume is change.

To both rectify the years of lost generational mentorship and cement the budding relationship between the PMPA & LLC, I asked the Board permission to create a fellowship program, which the Board approved in January 2021.⁵⁵⁴ I envisioned the program would support the dis/abled haunters at Pennhurst by admitting one Fellow per year on an annual basis. Further, the program would provide mentorship and financial support to the Fellow without any added responsibilities or work requirements. But the Board took a more regulated approach, stipulating that the fellowship program function like an internship with the Fellow assisting the PMPA in administrative work to helping at the Museum. Since its implementation, the PMPA has required the fellows to perform labor that adhere to normative, nondisabled standards of production—checking in with supervisors, meeting hard deadlines, etc.

PMPA awarded our first Fellow, Autumn, with a small stipend of \$2,000. In return, the PMPA asked that she take 360-degree-photographs of all spaces on campus safe to enter with equipment the PMPA provided for her. In addition to providing Autumn with mentorship and financial support, I knew that the fellowship would provide Autumn with a credential within traditional disability advocacy circles. During the 2020

⁵⁵⁴ The fellowship program is now titled the Pirmann Memorial Fellowship, named after PMPA's cofounder and former PSSH administrator, J. Gregory Pirmann.

season, the LLC promoted Autumn to the management position of Off-Season Events Coordinator. In her new role, Autumn oversees the Museum, history tours, paranormal investigations, and photography tours. Her promotion, combined with the Fellowship, gives Autumn the power necessary to generate significant change at Pennhurst while also soothing the tensions between the LLC and the PMPA.⁵⁵⁵ By March 2021, Autumn and her crew at Pennhurst went above and beyond in their work to preserve the property and mend tensions between the two organizations by cleaning out the Infirmary, pulling artifacts out of all the buildings, and successfully petitioning the ownership team to save most buildings on campus.

The Terror Is Real: A Pennhurst Haunting

The vignette below exposes how the PA community processes the kinesthetic trauma of institutionalization, but also how they use crip historiography to educate the public about the ongoing violence of institutionalization.

After the paranormal and history tour guide training, Autumn approaches me. "Hey, do you want to go see the Infirmary with me? I'm up there doing artifact retrieval for the Museum."

My eyes light up. "Like an AB wants to use an elevator in lieu of stairs—let's go!" ⁵⁵⁶

⁵⁵⁵ Not to mention the significant promise that Autumn and the other Fellows hold to generate in their communities and beyond.

⁵⁵⁶ AB is dis/abled pejorative slang for a "able-bodied," non-disabled person.

Autumn offers to drive us to the hospital campus where the Infirmary is located. The axle and joints of Autumn's aging Dodge Caliber raddle and grunt as its wheels bump along the dilapidated campus roadways. I ask Autumn about the new semester. "How are you adjusting to working at Pennhurst full-time while starting your second semester of junior year?"

"Well, it's a lot, but I sleep sometimes", a pained laugh follows her response.

We share stories about the oddities of being first-generation dis/abled college students. Autumn admits, "Yeah, sometimes I'm not sure what I'm doing. I'm just trying to survive and support my sisters. Eventually, I want to make enough money to move down to Charleston."

As we approach the first building in the hospital complex—Whitman—the campus takes on peaceful stillness. We are both content listening to the music of nature around us—the trees move and crack in the breeze. I find myself struck by the clashing symbolic beauty between organic and inorganic; life and death; new and old; veiled threats and present dangers.

What won't kill me here? How does Autumn navigate these spaces so well... so safely?

As we make our way around Whitman we saunter over to the Infirmary—the former tuberculosis ward turned hospital extension where many of the PSSH inmates came to die.

"I have something to show you," Autumn says.

Autumn leads me into a long corridor of the Infirmary. As we move through the winding hallways, I furiously snap photos as my mouth remains agape. We dodge detritus and shards of glass—the remnants of Pennhurst Past.

We reach our destination: a bathroom. The air is stale and heavy. I stare at a row of three toilets attached to dusty hospital tiles. My chest tightens, my stomach lunges at the floor, and I feel like I am going to vomit. We pause for a few seconds before Autumn explains why she brought me to this place.

"Earlier this week I walked my youngest sister out to the school bus. [Autumn's sister lives with autism.] When she got on, I watched the driver strap her into an 8-point restraint. It was horrific. She has EDS [Ehlers-Danlos Syndrome] too; if she fights against it, she's going to dislocate things and get seriously hurt. Not to mention, if the bus gets into an accident or starts on fire, she's not getting out. No one on the bus, or at the school, thought about this. When I confronted them about it, they said, 'We can't afford to have an aide on the bus, so she needs to wear this.'"



Figure 10: A dirt-covered, white-porcelain toilet with black restraints attached to it is affixed to a dirty, white-tailed bathroom wall in the PSSH's Infirmary building.

"Later that day, I came up to the Infirmary looking for artifacts. I'm not really a spiritual person, but occasionally I just get these feelings in my gut—this intuitional sense when I'm here—that there's something I need to do. When I walked by this bathroom, I felt that. So, I went in and saw these toilets with restraints on them—then I thought of my sister. I was so overwhelmingly angry that I took out my knife and cut the restraints off the toilets. My boyfriend found me here—the seatbelts on the floor—curled up on the floor crying."

Beat.

"I put two of the restraints in the Museum, but I left this one intact. The owners gave me the OK to bring paranormal investigations up here as soon as I get this place cleaned out. I'm going to bring the patrons up here so they can't avoid it. The world needs to know what happened here because it's *still happening*."

Beat.

"We should get back to M and prep for ghost hunts. They'll be here soon."

Autumn turns, waves me on, and leaves the room.

Beat.

Speechless. I remain in the room for a moment longer. The trees creak and the breeze rustles through the old screen window. I attempt to comprehend the incomprehensible scene I just witnessed.

"It's Still Happening": Analyzing the Infirmary Visit

This story highlights the tensions between extinction and survival as well as kinesthetic memory and kinesthetic amnesia by illustrating how institutionalization continues even outside of actual institutions. Despite acting in the name of care and compliance, medical and educational authorities continue to act out the scripts created through the performances of habilitation and institutionalized care. The toilets found in the Infirmary bathroom mirror the 8-point restraint strapped to Autumn's sister. To Autumn and her sister, these scenes perform and transfer embodied knowledge of cruelty, endangerment, humiliation and, ultimately, dehumanization in the name of care. These performances

install embodied reminders to dis/abled people that historical and contemporary notions of care *do not* place our own embodied experience first. Instead, this performance of institutionalized care—outside of the walls of a brick-and-mortar institution— understands our bodyminds as objects that must be handled and contained. The philosophy insists our bodyminds must perform, or be forced to perform, in ways rendering us legible and docile to the nondisabled gaze, as they were in the institution. In this way, Pennhurst not only haunts but *terrifies* dis/abled people. Pennhurst reminds us that institutionalization continues unabated in our lives. All the while, the continued sanctioning of institutionalization renders our generational trauma imperceptible to the nondisabled imagination's notion of disability.⁵⁵⁷

One example of this is legal disability scholars, Rabia Belt and Doron Dorfman claimed, "Compared to other social movements that found it necessary to take to the streets and provoke 'conflict' in order to raise awareness, and to use carefully planned strategic litigation that would redirect them after their victories and loses, the disability rights movement had it relatively easy."⁵⁵⁸ These scholars evidently forgot that, during the period of the American Civil Rights Movements, most dis/abled people could not even get to the streets, even if we wanted to, because of institutionalization. And, for the dis/abled people in society during this time, we still could not make it to the streets because of the lack of accessibility in the built environment. Further, it completely disregards the history of institutionalization (including almshouses in from the 1700s to

⁵⁵⁷ Sharpe, *In the Wake*.

⁵⁵⁸ Belt and Dorfman, "Disability, Law, and the Humanities."

1800s,⁵⁵⁹ institutions for people deemed psychiatrically dis/abled and/or feebleminded from the 1800s to current,⁵⁶⁰ nursing homes in the midst of the ongoing COVID-19 pandemic,⁵⁶¹) the protests of dis/abled people in America to gain or defend what rights we do have (such as the Black-Panther-assisted 504 sit-ins in San Francisco in 1977,⁵⁶² bus sit-ins in Denver in 1978,⁵⁶³ the Capitol Crawl in 1990,⁵⁶⁴ and dis/abled protesters getting dragged out of their wheelchairs in 2017 after protesting proposed cuts to Medicaid.⁵⁶⁵) This comment not only elides the history of strategic deinstitutionalization litigation, such as the Pennhurst litigation, it also illustrates how—even for disability advocates—the enmeshment of institutional violence, racism, and ableism goes unnoticed.⁵⁶⁶

This vignette also highlights the tensions of commemoration and commodification lived through by the Pennhurst community. Autumn's performance of cutting the restraints from the toilet generates three monumental acts. First, by cutting

⁵⁵⁹ Laura I. Appleman, "Deviancy, Dependency, and Disability: The Forgotten History of Eugenics and Mass Incarceration," *Duke Law Journal* 68, no. 3 (2018): 417–78.

⁵⁶⁰ Martin Summers, *Madness in the City of Magnificent Intentions: A History of Race and Mental Illness in the Nation's Capital* (London, UK: Oxford University Press, 2019); Rothman, *Discovery of the Asylum*; Summers, *Madness in the City*; Jirik, "American Institutions"; Chamberlain, "Receiving, Sorting, and Disposing of Children"; Bronston, *Public Hostage*; Goode et al., *Willowbrook*.

⁵⁶¹ R. Tamara Konetzka and Rebecca J. Gorges, "Nothing Much Has Changed: COVID-19 Nursing Home Cases and Deaths Follow Fall Surges," *Journal of the American Geriatrics Society (JAGS)* 69, no. 1 (January 2021): 46–47.

⁵⁶² Susan Schweik, "Lomax's Matrix: Disability, Solidarity, and the Black Power of 504," *Disability Studies Quarterly* 31, no. 1 (2011), <u>https://dsq-sds.org/article/view/1371/1539.</u>

 ⁵⁶³ Danika Worthington, "Meet the Disabled Activists from Denver Who Changed a Nation," *The Denver Post*, July 6, 2017, <u>https://www.denverpost.com/2017/07/05/adapt-disabled-activists-denver/.</u>
 ⁵⁶⁴ Stephen Kaufman, "They Abandoned Their Wheelchairs and Crawled up the Capitol Steps," *Share*

America, March 12, 2015, https://share.america.gov/crawling-up-steps-demand-their-rights/.

⁵⁶⁵ Simone Wilson, "Capitol Police Drag Disabled Trumpcare Protesters from Wheelchairs, Make 43 Arrests," *Patch*, June 22, 2017, <u>https://patch.com/us/white-house/watch-capitol-cops-drag-disabled-trumpcare-protesters-wheelchairs-across-floor</u>.

⁵⁶⁶ For a poignant example of the negative consequences of this unexamined enmeshment unfolding in a law school classroom see, Katherine Pérez, "Full Circle: From Disabled Law Student to Law Professor," *Journal of Legal Education* 71, no. 1 (2021): 39.

those restraints, Autumn performs an act of acknowledgement and release. She both acknowledges the historic pain and trauma experienced by the inmates of the PSSH and the ongoing pain and trauma experienced by dis/abled people in the present because of institutional ideologies of disability. But as a dis/abled person with a (relative) position of power within this former institutional space, she marks a release—the closure of one episode in the PSSH's violent past. After she performs this act of acknowledgment and release her bodymind literally embodies the expulsion of this lament, pain, and trauma by collapsing in tears.

Second, Autumn performs an act of remembrance and redefinition by placing those restraints in the Museum for public view. In the Museum, the restraints serve as a relic, or what performance studies scholar Harvey Young calls a "performance remain."⁵⁶⁷ The restraints thus "reopen or reawaken the embodied experience of prior bodies" and allow the violence of the restraints to pass from one bodymind to the next.⁵⁶⁸ Critically, these restraints now exist in a Museum run by mostly dis/abled people where dis/abled people can direct and narrate the story of these relics. Ultimately, reminding the patrons that these restraints not only pass embodied knowledge of violence but the people subject to that violence.

Third, Autumn uses the commercial imperatives of the LLC brilliantly to guarantee the integrity and preservation of the space. Autumn recognizes the primary way to ensure this monument of trauma remains is to effectively convince the ownership they can profit from using the Infirmary for ghost tours (which they do). After gaining the

 ⁵⁶⁷ Harvey Young, *Embodying the Black Experience: Stillness, Critical Memory, and the Black Body* (Ann Arbor, MI: University of Michigan Press, 2010), 168.
 ⁵⁶⁸ Young, 184.

owners' permission, she then uses her power as the manager of the history and paranormal tours to inform patrons of what happened here.

Autumn's efforts to preserve the Infirmary, and its subsequent transformation into a paranormal investigation site, provide only one illustration of the persistent interplay between commemoration and commodification omnipresent at Pennhurst. In the section that follows, I provide an in-depth demographic analysis of Pennhurst's ownership and management team. This analysis offers valuable insights into how they navigate, endure, and coexist with this dichotomy.

The People of Pennhurst Present

This section offers an overview of the people of Pennhurst present—the haunters, event staff, museum and paranormal guides working under the auspices of Pennhurst LLC. By elucidating details about the people who make up the PA community, this section reveals how the community engages in performances of redefinition—embodied dis/ability heritage work and crip historiography—which counter the PSSH's institutional philosophy of disability. These performances of redefinition involve a constellation of embodied acts, repetition, habitus, politics, labor, community-making, and knowledge production. When enacted in this former institutional space, these performances of redefinition often rub up against and alongside similar embodied acts once performed by past inmates and authority figures of the PSSH. Though analogous to the embodied enactments of PSSH inmates, the performances of redefinition engaged in by the dis/abled haunters cultivate an environment in which their dis/abled bodyminds experience safety, inclusivity, and a sense of belonging. This section begins by detailing

the backgrounds of the original Pennhurst Associates and present Pennhurst LLC owners and managers. From there, it outlines the backgrounds of individuals employed at the PA or that volunteer there to provide a comprehensive understanding of the entire organization and its engagement in dis/ability heritage work.

Pennhurst Asylum Ownership

The story of the ownership team provides a clearer sense of the challenges faced by, and the ingenious perseverance of, the PA community's efforts to preserve Pennhurst. Like the history of the PSSH and the PA, the ownership of Pennhurst has a complicated history. Since my study focuses on the dis/abled haunters, history and paranormal guides, and event staff, my conversations with and observations of the ownership team were limited. For these reasons, I provide only a narrow biographical sketch and a brief analysis of the ownership and their role in the PA community.

As noted in the Intermezzo, Richard Chakejian and Tim Smith—Pennhurst Associates—reached a settlement with the Commonwealth in 2006 that allowed them to purchase the property in 2008. Smith repeatedly leveraged the property to take out several loans despite his inability to maintain regular payments. Skeptical of his business partner's decisions, Chakejian left, and Smith bought Chakejian's stake in the company. In 2016, a new ownership group—Pennhurst LLC—negotiated with the bank to buy-out Pennhurst Associates and take control of the property and its assets.

As of 2016, three separate partners, each with their own percentage of stake in the company, constitute Pennhurst LLC. All three partners are White men who do not openly identify as disabled. The primary partner, Derek Strine, is a wealthy investor who splits

his time between Delaware and Florida, and generally only visits Pennhurst during the haunt season. The second partner, Todd Beringer, an equestrian, lives locally. Despite being a daily presence during the haunt season, Todd removes himself from the property and its engagements during the rest of the year. The third partner, Matt Herzog, takes the most active role in the ownership team. Herzog, along with the management team, plans and implements the attraction's themes, programming, and events for each year. Raised as a dairy farmer, Matt built his first haunted house—a haunted hay-ride—on his family's farm in Chester County, Pennsylvania.

Except for Herzog, the owners exhibit a general disinterest in the day-to-day lives of the PA community. Further, their interest in the property remains focused on maximizing the profit made from the attraction. Yet the owners of Pennhurst LLC have become increasingly favorable towards the preservation of the property since I started my ethnographic fieldwork in 2018. This interest stems from a three-fold dynamic: first, the PA community's petitioning the ownership team regarding the importance of the property, second, Herzog's insistence on maintaining any salvageable property for commemoration and, third, money.

Since 2018, the property has gone through numerous changes, and Pennhurst LLC continues to demolish other buildings for both pragmatic and development purposes. For example, Pennhurst LLC demolished significant portions of the lower-campus including Rockwell (the former school), Hershey (a former ward), and the Dietary complex—due to the unrepairable state of the buildings. This space now serves as additional parking for patrons during the haunted attraction. Further, the township requires Pennhurst LLC to remediate—removing the asbestos from—every building on

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campus prior to demolition. This time between remediation and demolition allows Autumn and her Museum and Paranormal Tour team to enter the buildings and collect any artifacts left in the space. It also gives many of the structurally sound buildings, such as the Infirmary, a "second chance." Though, as buildings come down, this creates a sense of impending crisis for the property. As the once sprawling campus shrinks, and buildings disappear, PA community members often remark feeling grief and anxiety. As of 2023, thanks to the combined efforts of Matt intervening on behalf of the ownership team and the volunteer efforts of the PA community, Pennhurst LLC agreed to save the historic "quad" of original buildings on campus, along with the Auditorium and several wards—all originally slated for demolition. The tradeoff comes at the expense of running paranormal investigations in these spaces, and the continued demolition of sites—such as the hospital complex—to build a planned "data center" on the grounds and additional parking lots for the attraction.

Pennhurst Management

The transition of the PA ownership and management elucidates the tensions involved when a privately owned, for-profit company attempts to operate both a haunted attraction and a place of commemoration at a site of historic trauma. After the ownership transfer in 2016, Pennhurst LLC bought-out the remaining year on Richard Bates' management contract and fired all remaining management under the previous owners. Pennhurst LLC then appointed a new management team, which instituted significant alterations to both the Asylum and the Museum to counteract the harmful actions of the ownership and management under Pennhurst Associates. As Matt Herzog expressed to me in a telephone interview, "I'm trying to make a safe place that's open to all, so that people can get paid, and have fun."⁵⁶⁹ The changes made by Pennhurst LLC's management illustrate several contrasts from management under Pennhurst Associates: attention to transparent communication, implementing access measures for the employees and patrons, removing any explicit themes relating to the PSSH and those confined there (such as actors stimming),⁵⁷⁰ and ensuring the ongoing preservation and commemoration of Pennhurst's legacy. Pennhurst LLC management's philosophy and implementation of access and communication practices have led to the creation and cultivation of the PA community. These practices also set the parameters for the community's performances of redefinition to happen. The management's philosophy and practice create an environment in which the LLC's employees feel their dis/abled embodiments bring value and worth to their community. This stands in stark contrast to the previous philosophies held by institutional authorities, which perceived disability as a deficit or abnormality.

Since 2020, Pennhurst LLC's management team comprises the General Manager, Operations Manager, and the Off-Season Events Coordinator. The General Manager supervises all three attractions, with a role like an Artistic Director of a theatre company. Stephanie P assumed the position in 2016.⁵⁷¹ She also identifies as a dis/abled person who experienced institutionalization and as a single mother of three children—one of whom identifies as dis/abled. She grew up in the area, raised in a single-parent family.

⁵⁶⁹ Matt Herzog, telephone interview by author, July 27, 2023.

⁵⁷⁰ As I discussed in <u>Act III</u>, even with Pennhurst LLC's efforts to sanitize the haunted attraction and make it less offensive, it still depends on themes of disability and horror. In the current iteration, for example, themes of criminal insanity and medical experimentation still permeate the attraction.

⁵⁷¹ This person wishes to remain anonymous. I have anonymized her by giving changing her name and any details that may readily identify her to the public.

Stephanie heard stories about the PSSH and felt an innate sense of curiosity about the space and its history. An avid fan of horror and Halloween, she began her career in the haunted attraction industry by building her own haunted houses in her front-yard for neighbors. When the PA opened in 2010, Stephanie auditioned for the attraction and worked in both make-up and acting. Despite feeling an immense connection to the space, her experience at the attraction under Pennhurst Associates' management quickly soured. Management placed Stephanie in scenes replicating past traumatic experiences. Additionally, Stephanie reported rampant sexual assault and harassment. Stephanie left Pennhurst in 2013 but continued to visit her friends that still worked at the attraction. While she never vocalized it to her former coworkers, Stephanie told me she intuitively knew she would one day take over as General Manager.⁵⁷² After becoming General Manager, Stephanie created the role of "Nurse Betty"—the leader of the fictitious Pennhurst Asylum's coup and the first haunter patrons interact with in the haunted attraction—because she "wanted a woman in charge."⁵⁷³

The Operations Manager, Jim Werner, oversees all day-to-day operations on the property. Raised in a foster-care family in Chester County, Jim describes his childhood as "pretty brutal".⁵⁷⁴ A towering and sturdy, White, self-identifying nondisabled man, Jim attended a local technical high school, specializing in carpentry. (While Jim identifies himself as nondisabled, he has disclosed living with various bodymind experiences, which I consider dis/abling. But I have opted to use the label Jim gives himself.) Jim met his wife in high school, and they have four daughters together—three of whom identify

⁵⁷² Fieldnotes, Saturday, October 24, 2020.

⁵⁷³ Fieldnotes.

⁵⁷⁴ Interview with Jim Werner, April 29, 2021.

as dis/abled. After high school, he worked various low-wage jobs, and eventually became a firefighter and an Emergency Medical Technician (EMT). Jim served as an Emergency Medical Services (EMS) Director until 2021. In 2009, Jim saw an advertisement for auditions at Pennhurst while watching a ghost hunting show on the Travel Channel. A lifelong horror fan, Jim jumped at the opportunity to audition. Since joining the Pennhurst staff in 2012, he has fulfilled numerous roles at the haunt from building sets to raising a family of over 40 rats for the attraction. A self-described "PT Barnum of the haunt world," Jim thrived within the Pennhurst Asylum and became the operations manager in 2017.⁵⁷⁵ In 2021, he became a member of the Board of Directors for the Haunted Attraction Association. For Jim, horror has less to do with the macabre and more to do with the "mystery" of the "eternal struggle between good and evil" and what it means to be human.⁵⁷⁶

The LLC created its most recent management position in 2020, appointing Autumn Werner as the Off-Season Events Coordinator. In this role, Autumn oversees the Museum, the paranormal investigations, and numerous other events ranging from site tours to film shoots. Autumn identifies as a first-generation dis/abled college student. After completing her tenure as Fellow, Autumn later joined the PMPA's Advisory Board. Since the LLC promoted her to a managerial position in 2020, Autumn has become increasingly involved in the preservation and commemoration work at Pennhurst.

When examined together, Stephanie's, Jim's, and Autumn's narratives represent recurring patterns of trauma, resiliency, and a desire to create an accessible and safe

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⁵⁷⁵ "About the HAA."

⁵⁷⁶ Interview with Jim Werner, April 29, 2021.

environment for their employees. Their narratives also illustrate an intentional break away from the practices of Pennhurst Associates' management that resulted in the abuse of employees and the degradation of the former inmates and survivors of the PSSH. They also maintain a clear sense of connection to both the people of Pennhurst Past and Pennhurst Present. Despite the unorthodox afterlife of the PSSH, they see themselves as care*givers* to the space while simultaneously balancing the demands placed on them by the ownership of the LLC. As Jim says,

[I] believe that the history of the site absolutely has to be maintained, I believe that the message of the site is even more important. The message of the site is that inclusion and acceptance should be the hallmarks of society, it should be the idea that a person is a person, regardless of what comes after that first word. "You are a blank person." No. Forget the blank, you are a person. ... Pennhurst has become a place of inclusion; it's become a place of acceptance. And I truly believe that our staff is invested in the idea of acceptance, of inclusion, and of preservation. ... And we're doing great things, we really are. And we're gonna continue doing great things.⁵⁷⁷

This quote illuminates the intention of the management to create an accessible,

"inclusive" community at Pennhurst. This community remains committed to commemorating the legacy of the PSSH, while offering a philosophy that counters institutionalized notions of disability. Instead of reifying performances of habilitation and institutionalized care, which positioned disability as negative, static, and inferior, the PA community's ethos promotes pride in one's dis/abled identity and divergent bodymind experiences. And yet, there remains a significant tension between the legacy of institutionalization (which involves both the history of the PSSH and conceptions of disability) and the PA community. The community resists this legacy of

⁵⁷⁷ Interview with Jim Werner, April 29, 2021.

institutionalization, but also largely remains outside the bounds of nondisabled society and its perceptions of what disability community is. The PA community knows full well that they flourish only because the power structures they operate under allow them to. Their sustained precarious state results from both the looming threat of the spectre of institutionalization and the financial interests of Pennhurst LLC. Despite these uncertainties, during five years of fieldwork, I have observed the management team consistently employing their philosophy of access and transparent communication with their personnel. This approach has undeniably established a robust foundation, enabling the PA community to thrive in the manner that they do. As Jim told me with a large smile and relaxed posture, "we're gonna continue doing great things, as long as [we're] permitted to do so."

Come for the Scares, Stay for the Family: Creating Community & Building Skills

The following section examines the composition of the general employees at the PA, exploring the reasons why people choose to work at Pennhurst, and how the management team cultivates a community that is intentionally accessible, inclusive, and prioritizes effective communication. This section also underlines how the PA community creates opportunities for dis/abled people to learn new skills and appreciate the value of their dis/abled embodiments, presenting a contract to the historical institutional philosophy of disability as an indicator of deficiency and inhumanity. The environment fostered by the PA community compels a reimaging of contemporary policies regarding HCBS for dis/abled people. To demonstrate how the PA community accomplishes this, this section employs an analysis of ethnographic observations and oral history interviews, comparing the experiences of dis/abled PA community members with archival materials from the PSSH. This mixed methodological approach is crucial in comprehending how the PA community redefines this former institutional space and how themes like communitymaking, skill-building, and care*giving* (and care*taking*) get enacted through embodied practices both at the PSSH and PA.

Creating Community

Over the course of a year, Pennhurst LLC employs over 250 people. The wages for LLC staff start at approximately \$14 an hour for haunters (nearly double the state's minimum wage) and vary by experience and position. The LLC pays members of the management team approximately \$30,000 per year in a part-time salary without contracts or benefits. Outside of the management, the LLC maintains a groundskeeper as the only full-time, year-round staff member. The LLC hires haunters primarily through word of mouth and by advertising on their social media pages. ⁵⁷⁸ When hiring, the LLC does not explicitly market itself as a dis/ability friendly employer. In hiring advertisements on social media, however, the LLC promotes itself as "home to some of the kindest, most inclusive and most talented Cast and Crew in the Haunted House Industry."⁵⁷⁹

One way Pennhurst LLC management creates an open and accessible environment for the employees is by hosting multiple events throughout the year. These

⁵⁷⁸ All salary information received from Jim Werner via text message on January 09, 2022. ⁵⁷⁹ Pennhurst Asylum, "THIS FRIDAY (8/26) Pennhurst Asylum is hosting Open Interviews for those interested in joining our 2022 Halloween Team!", *Facebook,* August 22, 2022, https://fb.watch/hZj0HdxDxR/.

events include pumpkin carving for Pennhurst employees and a free, public, familyfriendly "trick-or-treat" event on Halloween day. The LLC also hosts numerous potlucks, movie and game nights, carnivals, as well as ghost hunts, and other activities for the employees. Furthermore, many LLC employees continue to spend time with one another through non-official events. Many haunters play in Dungeon & Dragons (DnD) leagues, bowl together, sing karaoke, go to concerts, make late-night Taco Bell runs, and even share holidays together. For example, I now receive regular invitations to movie nights, "Pennhurst Christmas," and birthday celebrations for members of the community. Since many of the haunters come from non-traditional family settings, they celebrate the holidays and other important dates by assembling—often adorned in black—and passing out simple, thoughtful gifts to one another. These gifts often take the form of mementos related to their haunt characters or favorite scares of the past season. These small acts of community represent the gulf between how the PA community fosters belonging and the "community" the PSSH built. Unlike the PSSH, which produced mass gatherings and celebrations as marketing tools to mask the neglect and dehumanization of institutional existence experienced by inmates, the PA community creates communal events with intentionality, individualization, and purpose.

CHOSEN COMMUNITY VS. COERCED COMMUNITY AT PENNHURST

The sections below illustrate the stark contrast between the PA community and the veneer of community espoused by the PSSH. The first section begins with a vignette which underscores how the PA community fosters a sense of belonging and individuality among its members. Conversely, the section that follows contrasts this with the

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manufactured, dehumanizing environment of the institution, as evidenced by an examination of archival materials from the PSSH.

<u>"I love you, and I want you to know you're not forgotten": Chosen Community & A</u> Pennhurst Birthday Party⁵⁸⁰

On Friday, March 24, 2023, Pennhurst community members gathered to celebrate a birthday for one of their community members, Rodney Hulsey.⁵⁸¹ This section details this birthday celebration to illuminate the contrast between the curated celebrations hosted by the institution for its inmates and those hosted by the PA community. Unlike celebrations hosted by the institution, which reified institutional behaviors and norms, the celebrations hosted by the PA community repeat similar themes but revise what it means to be dis/abled and exist in this former institutional space.

A middle-aged man who lives with a developmental dis/ability, Rodney describes himself as a paranormal investigator and "Pennhurst's #1 Fan." While Rodney first came to Pennhurst as a patron, Pennhurst LLC employees have inducted him into the PA community. Pennhurst LLC anticipates employing Rodney, but logistical barriers have made that difficult. Rodney lives approximately two hours north of Pennhurst. Since he does not drive and Pennhurst is inaccessible via public transit, Rodney's engagement with the community remains—much to his dismay—limited. For his birthday, the haunters drove Rodney from his home to Pennhurst. They also purchased Rodney a hotel room for his stay and drove him back home at the end of the weekend.

Meeting in the Mayflower, a group of approximately fifteen haunters brought a potluck of desserts and snacks for an evening meal. While the main group of haunters set

⁵⁸⁰ Stenberg, Fieldnotes, March 24, 2023.

⁵⁸¹ Rodney Hulsey gave his permission to be identified on a full-name basis.

up decorations and appetizers, Rodney and another haunter made a Taco Bell run for the dinner's main course. A homemade birthday cake, lined with candles and decorated with the words "Happy Birthday Rodney" glistened in the dilapidated hallway in the glow of the sunset.

Returning with a trove of "crunch-wrap supremes" and "seven-layer burritos," the group of haunters greeted Rodney as they sang "Happy Birthday" and lit the candles on his cake. The glow of the candles warmly illuminated Rodney's gleaming face as the sun faded out of view. As Rodney blew out the candles, darkness settled over the group. After, we dined together in one of the former living quarters of Mayflower—now a merchandise area—aptly illuminated with emergency flood lights. Then, on Rodney's orders, we marched out into campus to commence the paranormal investigation he so eagerly awaited.

Rodney, two other haunters, and I made our way across campus to the "Rockwell Tunnels" (the service tunnels under the former school building) to begin our paranormal investigation. Moving down the concrete ramp to the entrance of the subterranean tunnels, one haunter unlocked the entrance. The large sliding-door made an audible thud as it found its home, revealing a cavernous void of darkness—the tunnels awaited us.

Moving through this space, I often feel unnerved—an affective, intuitive feeling of vulnerability—as if there is something or someone in the shadows waiting to put me back in the hospital from which I came. But this time felt different. I felt a sense of security, warmth, and curiosity observing Rodney in this space. His tall frame confidently strode through the tunnels at a steady, unhurried pace, as his face exuded curiosity and excitement. Strolling along, I felt my embodiment change. I did not feel the usual sense of dread that accompanied me in these vast passageways. Instead of feeling my bodymind recoil, I moved along with a sense of ease tinged with an odd sense of excitement. "Perhaps we might just commune with the spirits of our institutional ancestors," I thought to myself.

As we settled into our investigation site—some nondescript location deep within the tunnel system—Rodney pulled out a flashlight and spirit box (a homemade device that scans FM radio waves, through which spirits purportedly communicate through). Rodney announced his presence to any spirits present and said: "This is Rodney. I love you, and I want you to know you're not forgotten."⁵⁸²

Rodney's approach to the spirits of Pennhurst starkly contrasted that of the paranormal investigators' approach I observed in previous fieldwork. As I discuss in further detail in the next section, these investigators generally confronted spirits—or, as investigators more commonly refer to them: "ghosts"—with a combative tone; often swearing and jeering at them. In contrast, Rodney and the other haunters with us sought to converse with the spirits, but only if the spirits chose to engage with them. If spirits in a particular location did not engage with them, the haunters thanked the spirits and moved to another space. This sense of gratitude and patience did not end with the spirits but also extended to the dis/abled haunters in attendance.

Throughout the evening, Rodney and the PA community members present for his party acted out compassion, care, and attentiveness to both one another and the spirits they sought to commune with. Haunters would often stop to verbally and physically check-in on one another. Cognizant of bodymind needs, haunters often helped one

⁵⁸² Stenberg, Fieldnotes, March 24, 2023.

another navigate difficult terrain by offering a hand of support or showed a sense of camaraderie by putting an arm around a shoulder. As the night ended, Rodney and the haunters said goodbye to spirits and to one another. Rodney scarfed down his remaining burrito, and the haunters hugged one another as they parted ways. (Only to return twelve hours later to give the first history tour of the season.)



"Celebrations" at the Pennhurst State School as Coerced Community

Figure 11: A photocopy from the 1953 PSSH Handbook depicting holiday events at the institution.

The archival materials I scoured in my research seldom mentioned birthday parties explicitly. In conversations with the two former PSSH employees who worked in the institution in the 1970s and 1980s that work at the Museum, they describe celebrating several inmates' birthdays fondly. And yet they acknowledge it was the aides who

organized the celebrations and not the institution itself. Despite a lack of archival materials, this section uses the social activities depicted in the photographs from the 1954 handbook to gain a clearer sense of what community functioned as in the institution, and how that differs from the community fostered by the haunters of the PA. Figure 11 displays three photographs that depict how the institution celebrated national holidays, such as the Fourth of July and Labor Day.⁵⁸³

The photographs appear candid but illustrate the sheer size of the inmate population and the impersonal quality of the celebrations. In the top photo, masses of bodies dressed in uniformed clothing huddle around piles of quartered watermelons. The utilitarian uniforms of the inmates, and the masses of both produce and people, illustrate how the dehumanizing philosophy of institution-as-warehouse extended to all areas of life—including celebrations.

The photo on the left, captioned "Labor Day," depicts the male inmates engaging in an ironically physical battle of tug-of-war. This embodied act becomes ironic given it occurred on a holiday intended to commemorate contributions of American laborers to society by resting. While one could make the argument that this game of tug-of-war constituted a leisure activity, it serves as a symbolic embodied gesture of how the institution valued the inmates' labor and their bodyminds. One needs to look no further than the countless patient files citing how inmates—male and female—died from "exhaustion" while working at the institution. To the PSSH, the inmates were nothing

⁵⁸³ The institution also regularly celebrated Thanksgiving, May Day, and Halloween, as well as Christian holidays such as Christmas and Easter. Sources for these events are scattered throughout various archives and mediums. For example, I learned of the haunted house in analyzing newspaper clippings from the Spring-Ford Historical Society. The Pennsylvania State Archives also has several programs for various May Day, Thanksgiving, and Christmas programs the institution hosted.

more than expendable subjects perpetually ready to perform labor at the institution's behest.

Finally, the third photo on the right depicts a watermelon eating contest and demonstrates once again how the institution manufactured a superficial veneer of belonging and community. A line of over 30 inmates runs the length of the recreation fields below the Administration building. All wearing the same uniforms, the expressionless inmates dive into the watermelons, while one person in the center of the photograph—presumably an institutional authority—watches over them. This photo takes on a morbidly ironic quality as it mirrors both the lack of staffing and individualized care and attention received by inmates, but also the constant surveillance of institutional authorities. In this way, the photograph represents the inmates' static life at the PSSH, under the control of authorities who perceived them under a specific, ableist notion of what constituted a dis/abled bodymind.

REFLECTIONS ON CHOSEN & COERCED COMMUNITY AT PENNHURST

The communal activities hosted by the PA community represent a deep sense of identification as both individuals and as a group of people, in the legacy of the space and their identities as dis/abled people. While the PSSH hosted similar events—even a Halloween haunted house of their own—these events served the institution's purpose of coercion, uniformity, and assimilation into nondisabled society. The PA community's events, instead, offer a refuge for many in the community who either feel ostracized by society during these times or do not have safe home environments to celebrate them in. In my own experiences attending these events, I feel they offer a space to be vulnerable. Unlike events hosted by nondisabled people in nondisabled spaces, I do not need to hide

or explain my dis/ability. In this way, these events help to redefine dis/abled knowledge production. They create space to engage others who identify with similar *and* different dis/abling experiences, while also forming relationships that go beyond dis/ability. In short, these events help the employees—individually and collectively—flourish and find purpose in life. These events facilitate a model to craft policy regarding community-living and access because they illustrate how a group of dis/abled people create community. While occurring within a former institution, these practices do not rely on the structures of institutionalization—performances of disabled appearance, habilitation, and care—that so many of the United States' current policies do. Instead, they offer a template for what could be.

Building Skills for Dis/abled People by Dis/abled People

Skill building is one of the many ways that the PA community incorporates a historic parallel to the PSSH's philosophy of institutionalization and makes it part of their dis/abled praxis. At the PSSH, institutional authorities forced inmates to perform peonage—unpaid, enforced labor such as laundry, farming, carpentry, and care*giving*— mostly related to giving care to their fellow inmates and to the institution's grounds. Unlike the PSSH, in which inmates reported massive loss of abilities, behaviors, and life skills because of the constraints of the institutional environment,⁵⁸⁴ many dis/abled people at the PA mention they not only receive opportunities to use existing skills but

⁵⁸⁴ Conroy and Bradley, *Conroy and Bradley, The Pennhurst Longitudinal Study*; Conroy, "The Pennhurst Longitudinal Study and Public Policy."

also gain new technical skills. These skills include learning woodworking and plumbing by building set pieces and maintaining the property, as well as costume and make-up design. Furthermore, many haunters report gaining interpersonal and leadership skills, such as public speaking, negotiation, and self-confidence by learning to act, providing customer service, and managing employees. As Autumn observed,

Pennhurst allows me to have an outlet that—kind of welcomes the abnormality that I have—in the way that I—the way I contort and everything—in all my party tricks. It's like people applaud me for it instead of being like, "oh." And it allows me to express myself, and to be who I want to be, even in the managerial form. They've allowed me to take on all of these responsibilities and realize, "Hey, I actually can take on these responsibilities and it makes me feel better about myself." I feel like I have—talent and that I can do these things. And if I eventually end up moving on from Pennhurst, I feel like that will carry over a lot in the fact that I am confident in what I can do. And I understand that I have all these skills that I wouldn't have known about prior.⁵⁸⁵

Autumn's case illustrates how what nondisabled society perceives as an abnormality becomes welcomed as a special skill in the space of the haunted attraction. The PA community gives dis/abled people a sense of confidence, not spite or shame, in their dis/abled identity and the skills that come out of their dis/abling bodymind experiences. Further, the way Autumn brings these two elements together in her comment shows that, for her, the full manifestation of her bodymind experience is the *condition* that allows her to develop these other skills. The PA allows her to occupy a leadership position without the need to bracket her identity and bodymind experiences, which she would need to do in a nondisabled workplace. Many people do not report their dis/ability to employers out of fear of not getting hired or facing workplace discrimination. For example, while 30% of American workers surveyed in 2019 met federal requirements for disability, only 39%

⁵⁸⁵ Interview with Autumn Werner, March 22, 2021.

of those workers disclosed their dis/ability to their manager, and only 4% disclosed their

dis/ability to their clients.586

Another haunter, history and paranormal investigation guide, Joey Vanderloop,

who identifies as transgender and dis/abled, attributes her newfound passion for

dis/ability activism and dis/ability history, and shift in how she cares for her own

dis/abled bodymind to working at Pennhurst.587

Being at Pennhurst, seeing firsthand the places where people were institutionalized, hearing from people who had worked there, made the history and the importance of that history really feel alive and personal.

Not only that, though, at Pennhurst I've heard my coworkers speaking plainly about disability – about *their* disabilities – in a way that I have never really experienced before. It made me reflect on how I treat myself and my disability. I have neurological and chronic pain issues, but they are currently very well controlled with medication and lifestyle changes. Most people would never know I had any health problems unless they caught me in the middle of a flare.

Despite the fact that I will be dealing with this for the rest of my life, and that I would be mostly housebound without modern medicine, I never really thought of myself as disabled until relatively recently. A lot of that was due to pressure from my family – they did not want the stigma of having a child that was labeled "disabled" even if that label would have gotten me more attention and treatment at a younger age. After hearing some of the stories and societal beliefs behind what happened at Pennhurst, though, I can kind of draw a line from that historical stigma that was associated with having a disabled family member, and the societal pressure to hide that family member away, and connect that line straight to my family's desire to have me hide my disability and appear nondisabled, even at the cost of my health.⁵⁸⁸

For Joey, becoming a history tour guide not only taught her valuable skills in historical

research and activism but also the importance of that historical interpretation on her own

 ⁵⁸⁶ Pooja Jain-Link and Julia Taylor Kennedy, "Why People Hide Their Disabilities at Work," *Harvard Business Review*, June 3, 2019, <u>https://hbr.org/2019/06/why-people-hide-their-disabilities-at-work</u>.
 ⁵⁸⁷ Joey Vanderloop gave their permission to be identified on a full-name basis.

⁵⁸⁸ Joey Vanderloop, email message to author, April 10, 2023.

dis/ability identity and care for her bodymind. Through learning about and *being at* Pennhurst, Joey feels connected not only to the history of the PSSH and institutionalization, but processes how historical and contemporary attitudes about disability continued to affect dis/abled people.

Autumn's and Joey's stories show how dis/abled haunters gain employment, life skills, and community, but on their terms. These every-day performances of learning skills in community become what performance studies scholar Shannon Jackson calls "collective formations of embodied performances."⁵⁸⁹ In this way, dis/abled haunters learn skills in a dis/abled space often taught by dis/abled people. Additionally, the PA employees do not need to hide their dis/abilities for fear of workplace discrimination. Most significantly these embodied social performances differ from the performances of habilitation discussed in <u>Act II</u>. Instead of learning skills designed to assimilate dis/abled people into nondisabled society in an institutional space, dis/abled haunters are learning skills while freely entering a dis/abled community. In turn, these performances help build a community at Pennhurst where bodyminds deemed as "abnormal" by nondisabled society find acceptance, connection, and growth.

This notion of community-living differs from commonly accepted practices for the dis/ability community in the United States. In the United States, the standards for HCBS were shaped primarily by three major reforms: Judge Raymond Broderick's order in *Halderman*, Wolf Wolfensberger's philosophy of normalization,⁵⁹⁰ and the United States Supreme Court's ruling in *Olmstead v. L.C.* (1999). In *Olmstead*, the Supreme

⁵⁸⁹ Shannon Jackson, "Civic Play-Housekeeping: Gender, Theatre, and American Reform," *Theatre Journal* 48, no. 3 (1996): 339.

⁵⁹⁰ Wolfensberger, Normalization.

Court ruled that states have an obligation to provide dis/abled people with services in the most integrated settings possible, but only when three conditions are met:

- 1. such placement is appropriate;
- 2. the affected person does not oppose such treatment; and
- the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of other individuals with disabilities.⁵⁹¹

Despite the major victory that *Olmstead* represented for the dis/ability community, it presents numerous theoretical and practical barriers. The language of the ruling, for instance, creates significant barriers to providing care. The first condition, "such placement is appropriate" often requires a state-provided medical professional to confirm whether a person should be placed in the community. As discussed in <u>Act I</u> and <u>Act II</u>, medical professionals—historically and contemporarily—have little incentive to prioritize the needs of dis/abled people. Moreover, requiring a medical professional to determine whether such placement is appropriate disempowers dis/abled people, inhibiting us from making informed choices about our own care needs. In contrast, Pennhurst LLC management does not require their employees to justify their access requests, and management integrates the process for requesting access measures into their hiring process, thus reducing the pressure on individuals to request so-called "reasonable accommodations." The language of the second condition creates a slippery slope.

⁵⁹¹ U.S. Department of Health and Human Services, "Serving People with Disabilities in the Most Integrated Setting: Community Living and Olmstead," Civil Rights for Individuals and Advocates, June 22, 2023, <u>https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-andolmstead/index.html</u>.

Dis/abled children and/or dis/abled people with legal guardians must rely on their parents and/or guardians to make such decisions for them. As examined in the first two Acts of this dissertation, many parents and/or guardians make those decisions with *their own* best interests in mind and not the best interests of dis/abled children and people. Third, to gain life in the community, the state must interpret a dis/abled person's request for HCBS as "reasonably accommodated" based off resources available to the state and the needs of other dis/abled people.⁵⁹² As of 2021, more than 656,000 dis/abled people in the United States are on waiting lists to receive HCBS, with people waiting on average 45 to 65 months to receive services.⁵⁹³ Many states cannot (or will not) keep up with the demands of dis/abled people to live and receive supports in the community. In turn, in light of a lack of resources, states may be less willing to concur an individual's accommodations are reasonable.

Finally, policy makers and service providers often fail to implement such practices. For example, many dis/abled people living in HCBS settings, especially individuals living with mental dis/abilities, often spend their time relegated to sheltered

⁵⁹² While there appears to be a gap in critical disability studies scholarship with regard to "reasonable accommodations," some scholars have addressed the topic in relation to educational settings. See, for example, Dolmage, *Academic Ableism*. Legal scholars have conducted more in-depth discussions on the concept of reasonableness. Specific to the ADA, see Elizabeth F. Emens, "The Sympathetic Discriminator: Mental Illness, Hedonic Costs, and the ADA," *The Georgetown Law Journal* 94, no. 2 (2006): 399–488; "Integrating Accommodation," *University of Pennsylvania Law Review* 156, no. 4 (2008): 839–922; Christine Jolls, "Antidiscrimination and Accommodation," *Harvard Law Review* 115, no. 2 (2001): 642–99; Pamela S. Karlan and George Rutherglen, "Disabilities, Discrimination, and Reasonable Accommodation," *Duke Law Journal* 46, no. 1 (1996): 1–41; Michael Ashley Stein, "The Law and Economics of Disability Accommodations," *Duke Law Journal* 53, no. 1 (2003): 79–192; Amy Wax, "Disability, Reciprocity, and 'Real Efficiency': A Unified Approach," *William & Mary Law Review* 44, no. 3 (2003): 1421–52.

⁵⁹³ Kaiser Family Foundation, "A Look at Waiting Lists for Home and Community-Based Services from 2016 to 2021," Medicaid, November 28, 2022, <u>https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-home-and-community-based-services-from-2016-to-2021/ - :~:text=In 2021, people on the,services, 67 months on average.</u>

workshops laboring at a subminimum wage or taking part in tightly supervised "outings" into the "normal," nondisabled world. Further, group home activities and other HCBS programming emphasizes—implicitly or explicitly—performances of habilitation, which came from institutional philosophy, that assimilate dis/abled people into nondisabled society. Instead, the dis/abled people in the Pennhurst LLC community push against these performances of habilitation in that they learn practical and professional skills, earning above minimum wage, and choosing the community they participate in. The performances of how these dis/abled haunters work and find community at this institution-turned-attraction create new ways of understanding what dis/ability community looks like.

Caregiving & Crip Consciousness: Connecting with a Space of Communal Trauma

The following details an oral history interview I recorded with Kaity Furdak, a Pennhurst LLC employee who experienced institutionalization in the past.⁵⁹⁴ Kaity's story highlights not only the lingering affective experience of institutionalization, but how the PA community creates a space in which formerly dis/abled people can process their experiences of institutionalization through embodied practices of giving care to space and creating new spaces through actions like making sets and cleaning out remediated buildings. I met Kaity in the months leading up to the 2020 haunt season. Kaity worked as a member of the "build crew," building and maintaining the attraction's set pieces,

⁵⁹⁴ Kaity Furdak gave her permission to be identified on a full-name basis.

special effects, and animatronics. At the time, she lived in Buffalo, New York, and made the six-hour (one-way) trip to Pennhurst weekly during the 2020 haunt season.

Meeting over Zoom—an online communications service that allows users to record conversations using both video and audio—in March 2021, Kaity sat comfortably on her couch, eager to catch up. Throughout our conversation together, Kaity touched on myriad themes relating to past and present discrimination against dis/abled people, especially institutional survivors. Kaity's narrative drove home how one can never really *leave* the institution, instead a survivor lives that legacy through their kinesthetic bodymind memory.⁵⁹⁵ Yet she also highlighted how dis/abled people process the haunting traumas of institutionalization. Through returning to the institution, dis/abled members of the PA community heal through finding a shared identity within the genealogy of dis/abled people by reclaiming a former institutional space. By literally healing the space of Pennhurst through embodied acts of dis/abled heritage work, dis/abled members of the PA community find healing of their own.

Like other members, Kaity pointed to the demographics of the PA community and how it contributes to the commemoration work at Pennhurst. Kaity explained the PA community, describing, "It's nice, because Pennhurst attracts the same type of people you are. So, you do have a lot of people, like I said, that are disabled or that have mental disorders... and [we] kind of calm each other down."⁵⁹⁶ In this comment, Kaity poignantly reveals how the PA community *gives* care to one another. This care*giving* also serves as a performance of redefinition to the historic care*taking* foundational to

⁵⁹⁵ For more on "survivorship" see, Kate Rossiter and Jen Rinaldi, "Embedded Trauma and Embodied Resistance," in *Institutional Violence and Disability: Punishing Conditions* (Routledge, 2019), 77–94. ⁵⁹⁶ Interview with Kaity, March 15, 2021.

institutionalization. Unlike the PSSH, this care does not stem from seeing the people of Pennhurst as problematic or inferior. Instead, the PA community nurtures and accepts one another in their various bodymind experiences. Finally, the community, combined with the intentionality of the management's philosophy of access and communication, also lends itself to preserving Pennhurst's legacy.

Kaity also highlighted the need to preserve Pennhurst, and the PA community's motivations to engage in that work. Kaity explained her drive to preserve the property saying, "When I stand outside, and I look at all of those buildings, and I think of all the people that were in there, and that were just like me, and that went through what they went through to make people like me have a better life, it makes me feel like I owe something to them. Like I owe them to preserve this property and to get this story out."597 Kaity adamantly reminded me that the Pennhurst community "comes together to really try to, you know, get the story out. ... We want it to be a historical place and a place that we learn from, so people like us don't end up back in the same type of environment. ... What's to say if we shut down all of these institutions, and we demolish all these buildings, then it won't happen again. Like I said, I just really feel like it is the community as itself that just comes together to really try to, you know, get the story out."598 Kaity's commentary illustrates the haunters' keen awareness of the historic horror and ongoing terror of institutionalization. Further, how the former PSSH campus acts as a physical reminder—a warning—of how American society outcasts and segregates dis/abled people. In this way, Kaity's observations demonstrates how the PA

⁵⁹⁷ Interview with Kaity, March 15, 2021.

⁵⁹⁸ Interview with Kaity, March 15, 2021.

community creates performances of remembrance and redefinition regarding the commemoration of Pennhurst's legacy. The community not only wants Pennhurst preserved so that mass institutionalization "won't happen again," they want to "get the story out." This desire to preserve the legacy of Pennhurst comes out in embodied ways, particularly in how haunters come to the campus to clean out newly remediated buildings such as Quaker and Philadelphia (former administration building turned ward and print shop). The embodied act of giving care to these spaces shows how the dis/abled members of the PA community acknowledge and process both their own pain of past medical and educational traumas and those experienced by the inmates of the PSSH. In getting the story out, the PA community melds the story of the PSSH with their own story. In turn, the historic and contemporary trauma and pain shared between the people of Pennhurst Past and Pennhurst Present become something acknowledged, felt, and processed through embodied action; not vicariously digested through dates and facts.

Throughout our conversation, Kaity pointed out how the dis/abled haunters also feel a strong sense of relation to the people of Pennhurst Past and find a sense of healing that makes them return each year. This relationship provides a sense of connection and respect for the property, those who lived and died there, and the legacy of the deinstitutionalization movement. The sense of connection to Pennhurst also grounds the PA community in their shared positionality—individually and collectively—within the legacy of de/institutionalization. Kaity details this connection saying, Pennhurst "really feels like it's peaceful, knowing that all the people that were there and all the negative sounds that were there are no longer there. So, to me, it kind of feels like those people are at peace now. I don't know, for me, I just love it [Pennhurst]. I think it's beautiful. I think

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the architecture is beautiful. I love the people there. Like I said, I love the history behind it. When I walk through, I feel safe...⁵⁹⁹ This sense of safety contrasts the sense of terror that the haunted attraction markets itself on and that the spectres of disability and institutionalization provoke. Instead, it becomes an anti-haunting that provides comfort, belonging, and community; not the fear, rejection, and isolation espoused by the PSSH.

Kaity's memories of institutionalization, her connection to the PSSH, and those formerly institutionalized there illustrate how historical events do not cease to exist. Performance scholar Rebecca Schneider argues history never completes itself, rather it continues through embodied cycles of memory that make up the "immaterial labor of bodies in and with that incomplete past."⁶⁰⁰ Kaity's connection to Pennhurst comes from, in part, her memories of institutionalization and dis/ability. Kinesthetic, embodied memory draws her to Pennhurst and allows her to recognize her positionality in the evolution of custodial institutionalization. This embodied cycle of institutionalized memory immaterially connects the Pennhurst LLC community to those who lived and died at the PSSH. Kaity acknowledges her own traumas and the relationship with the similar yet distinct experiences of PSSH inmates and survivors by pointing to a shared desire by the Pennhurst community to preserve and commemorate the space. This desire also stems from a larger sense of connection to the PSSH inmates and survivors.

Kaity affectingly portrays how the critiques of the PA do not go unnoticed by the community. Moreover, faced with continued ostracization by the disability advocacy community, Kaity describes how dis/abled haunters rely on the PA community, and the

⁵⁹⁹ Interview with Kaity, March 15, 2021.

⁶⁰⁰ Rebecca Schneider, *Performing Remains: Art and War in Times of Theatrical Reenactment* (New York, NY: Routledge, 2011), 32-33.

space, to find healing. "So, some people, like I said, view it as we're making fun of the people that are, you know, mentally challenged, or mentally disabled, or you know, but for somebody who was in an institution... as weird as it sounds, like, when I'm at Pennhurst, and I hear those noises [from the haunted attraction], or I see things that remind me of being in the institution, myself, it's not a trigger. For me, it's kind of a blanket, like it makes me feel safe. Like I'm at home, you know?"⁶⁰¹ Kaity's comments underscore how Pennhurst functions as a dis/abled space that brings dis/abled people together to heal from past traumas and find a sense of belonging regardless of diagnosis or labels. The PA community also helps bring the public to Pennhurst to learn about that historic and ongoing trauma. Unlike contemporary HCBS policies, which were generated by nondisabled advocates using paradigms from nondisabled society, the PA community offers a glimpse of what dis/abled community looks like when created by dis/abled people.

The experiences Kaity describes also demonstrates how the PA community fosters crip consciousness—"to be 'in" and with the institution's ward.⁶⁰² Unlike the disability advocacy community, which adamantly acts as if the deinstitutionalization movement ended institutionalization, members of the PA community do not attempt to close the circular loop of institutionalization and its history. This crip consciousness does not attempt to resolve the historical and contemporary—individual and communal—traumas the dis/ability community has experienced. Instead, crip consciousness is *to be in and with* the affective, incomplete, cyclical and, at times, temporally simultaneous history

⁶⁰¹ Interview with Kaity, March 15, 2021.

⁶⁰² Sharpe, In the Wake, 13-14.

and memory of institutionalization and its spectre. Finally, the PA community illustrates how crip consciousness is a practiced and embodied historical consciousness that is realized through acts of collective care to both the people and the space of Pennhurst. The embodied acts of communally giving care to this space—cleaning buildings, leading tours, etc.—helps to, in part, rectify the violence of this space.

Instead of abandoning or destroying the PSSH's past of segregation and inhumane care, dis/abled people return to this former institution. Some come because they appreciate the aesthetic beauty of the campus grounds and the architecture of the remaining buildings, while others come because they want to learn to act. Ultimately, they stay because of the community they find, the skills they learn, and the desire to preserve and promote the people of the PSSH. Thus, Pennhurst LLC creates a sense of community for dis/abled (and nondisabled) people on this former site of trauma and injustice.

The Pennhurst Dialectic: Hunting Ghosts and Getting History

This section examines the dialectical relationship between the paranormal investigations and the Museum's history tours. Such a dialectic delineates the contours between commemoration and commodification, survival and extinction, and kinesthetic memory and kinesthetic amnesia within which the PA community must navigate. Further, these tensions exemplify how the PA community, particularly the dis/abled guides leading the tours, operate within this dialectical space. The tension between paranormal and history tours creates a space that reveals not only the hidden pasts of the PSSH but also a lost future where the Commonwealth preserved the PSSH campus in its entirety instead of selling it to a privately owned LLC. But in the wake of this tension, I also uncover how this community of dis/abled and nondisabled people use performance, and the material space of Pennhurst itself, to heal memories of trauma and form identities of dis/ability.

While I did not focus as extensively on the paranormal investigations in my fieldwork as I did on the history tours, the two operate in clear tension with one another. On one hand, the preservation of the property relies almost entirely on the profitability of the paranormal investigations, which generate revenue for the LLC. On the other, the Museum and the LLC's subsequent preservation projects exist largely because of the ownership team's goodwill and the unquantifiable labor of Autumn, the broader PA community, and other actors such as the PMPA.

This section begins with an ethnographic vignette of a joint paranormal and history tour guide training I observed in March 2022, spotlighting the harmful assumptions patrons bring into the space. It subsequently examines how Autumn trains her staff to counter these assumptions while still providing ample customer service, catering to the needs of the LLC. Following this, the section delves into the LLC's paranormal investigations, its patrons, and the employees tasked with guiding those investigations. The section concludes with an investigation of the Pennhurst Museum's historical tours, often led by the same guides. These tours reveal how the PA community puts crip consciousness, crip historiography, dis/ability knowledge-making, de/institutionalization history, disability advocacy, and nondisabled lore of institutions in conversation together by recalling kinesthetic memories of dis/ability and disability.

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Working with "Intolerable People": Pennhurst History & Paranormal Guide Training

The following comes from the Pennhurst History & Paranormal Guide Training I observed in March 2021. This ethnographic vignette demonstrates how Autumn, and her team, navigate their relationship with LLC patrons. This vignette also reveals how the guides balance performances of remembrance and performances of redefinition in educating patrons about dis/ability history and institutionalization. Performances of remembrance take the form of procuring artifacts and memorizing dates and facts. While performances of redefinition involve sharing the stories of the dis/abled people of Pennhurst Past and incorporating the narratives of the former inmates' own narratives into Pennhurst Present. Thus, these performances of redefinition come to shape what Pennhurst Future could look like: dis/abled history told by dis/abled people.

Autumn corrals the group history tour guides, investigators, and Museum docents together. Still new to the group, I saw familiar faces mixed in with new ones (mostly paranormal investigators guides hired after the haunt closed its doors in November). Some employees lead both history tours and paranormal investigations, but most only lead one or the other. Likewise, almost all the employees also perform in the haunted attraction, and only a small minority—such as former PSSH "Mental Retardation Aides" Donna Samluk & Bernie Essick—do not.⁶⁰³ Representative of the larger Pennhurst community, most of the staff assembled identify as dis/abled, but some guides identify as

⁶⁰³ Bernie Essick gave her permission to be identified on a full-name basis.

nondisabled. Strikingly, most in the group identify as women or LGTBQ+. The racial and ethnic backgrounds of tour guides also mirror the larger community—mostly White, with a smaller number of Black and Brown guides.

Though most of the staff identify as dis/abled, most paranormal guides do not disclose their dis/ability to investigation patrons. Autumn, for example, observes "A lot of the time I feel like having a disability inherently gives an individual 'ownership' over the space. Folks come in like, 'I would've been here!!' And it seems to excuse some of the behavior they exhibit while there. I try to lead by example. A nondisabled person can and should respect and see the space for what it is without having that lived experience, without it being about them."⁶⁰⁴ Another haunter who identifies as autistic explained, "On occasion I do, it really depends on the vibe of the group. Sometimes people have taken note of my self-presenting behaviors [and] called me out. When it comes to history tours, I am fully transparent about diagnosis."⁶⁰⁵

"I'd like to welcome y'all to another fantastic year of tours, this is very exciting, and we've got some big changes coming..." The haunters' cheers and claps interrupt Autumn's salutation.

Autumn begins the training with "housekeeping." She explains the status of the property—which buildings are under abatement to remove asbestos or have become inaccessible because of structural or environmental damage—and reminds her employees to file "end of the day" reports.⁶⁰⁶ Beaming, Autumn informs the group: "We're about to add the Infirmary to our tours, which is really, *really* exciting. But this is *very important*:

⁶⁰⁴ Text conversation with Autumn Werner, April 10, 2023.

⁶⁰⁵ Text conversation with Nick, April 12, 2023.

⁶⁰⁶ These reports detail how many people attended a tour or investigation and if any incidents occurred.

when you bring patrons up there, make sure to remind them to leave us reviews sharing how much they love the new space..." Autumn's fervent reminder highlights the urgency and precarity of the preservation efforts of the campus—the razor-thin line between commemoration and commodification. Like other places of dark tourism, the PA community intuitively understands that in order for Pennhurst to remain, they must curate their performance to balance both the desires of their audience and the economic demands of the private company they work for.⁶⁰⁷ Autumn knows the Infirmary's fate rests on whether the owners can profit from it. Through her research, she also knows the Infirmary served as the space in which most of the PSSH inmates died. To keep that space available for history tours, it must also remain open for paranormal tours. Ultimately, it will only remain open if the patrons express their appreciation for the locale.

Autumn reminds the guides: "we have the substantial privilege in that we get to educate people and they have to listen to *us*." Autumn's declaration illuminates the uniqueness of the Pennhurst Museum. Every-day, vernacular dis/abled people lead this Museum, and its tours—not professionals or academics. The power of the Museum, and its tours, lies in the vernacular rawness of the guides. As such, the guides use their own personal narratives, combined with the history of the PSSH, to tell the story of Pennhurst to the patrons visiting the museum. This story, in turn, helps the patrons understand Pennhurst's legacy on both a personal and theoretical level. The guides put a human experience—past and present—to Pennhurst and dis/ability. This becomes especially

⁶⁰⁷ Emma Willis, *Theatricality, Dark Tourism and Ethical Spectatorship: Absent Others* (London, UK: Palgrave Macmillan, 2014).

important when dealing with the paranormal investigation patrons who come not for

education, but cheap thrills or a ghost safari to build their own prestige by engaging with

and capturing Otherness.

Autumn continues the training by discussing guidelines for those leading

paranormal investigations.

Ultimately, there are going to be some pretty intolerable people that we'll have to deal with because that's just ghost hunting. But remember we're here to facilitate knowledge and give them a good time. If you're investigating, and nothing is happening, this is a fantastic moment to insert history about Pennhurst. The Asylum has a more romanticized effect for patrons, but there was tragedy that happened here, and there are legitimate people for them to talk to [referring to the spirits of PSSH inmates].

They need to know *we* cared for individuals with all types of disabilities not mental illness specifically—but people with hydrocephaly, downs syndrome, tourette's, and you name it, intellectual, cognitive, developmental, and physical disabilities, were here.⁶⁰⁸ It's not this romanticized version of disability that we see [in the haunted attraction and horror genre broadly]. For example, I'll often see that ghost hunters have a misconception that when they hear grunts or noises like that, that its evil demons trying to get them. No. That's not demons, that's non-verbal communication.

Ghost hunters have a rather problematic way of seeing disability and Pennhurst. It's our job to slowly—very carefully—guide them in the right direction. We've [Pennhurst LLC] done really well in creating awareness of disability in our tours, and now we need to move towards acceptance. We do that by sharing our stories of disability and by bringing other disabled people in to join our tours. Whether that's Pennhurst survivors or disabled folks from the local community, we give them space to be themselves and share their stories with us and our patrons. Patrons need to understand that the ways disabilities are going to represent themselves may not be 'nice to you' [nondisabled patrons]. Right? It may not be 'socially appropriate *to you*.' But we [society as a whole] need to adjust ourselves to make it so and make it a comfortable environment for everyone.⁶⁰⁹

⁶⁰⁸ I make the deliberate choice *not* to capitalize these terms while quoting Autumn. In doing this, I refuse to dignify the nondisabled doctors and researchers who "discovered" the supposed conditions (often through unethical experimentation and exploitation of dis/abled people).

⁶⁰⁹ Stenberg, Fieldnotes, March 5, 2022. All references to the training are from my fieldnotes from that day.

As the training winds down, the haunters swap stories about patrons' assumptions. "Oh, they always ask me: 'Is this where they keep the criminally insane people?' Or 'Is this where they boiled the babies?'" one haunter laments. Another haunter discusses how while "most of the people on the history tours just want to learn, 95% of the ghost hunters are thrill-seekers."

"We can't really let them play-up their fantasies. A little fantasy is okay, but if it conflicts on history, you need to tell them", Autumn reminds the group.

Autumn's discussion with the guides about the ghost hunters reveals several crucial elements of the PA community's crip consciousness and performances of redefinition. First, Autumn highlights the divide between the average history tour attendee and the average ghost hunter. Both history tour patrons and paranormal investigators bring assumptions regarding what Pennhurst was and who the people forced to exist there were. But paranormal investigators tend to have a more problematic view of institutions and dis/ability because of misinformation and lore. This misinformation gets fed through tropes used in the horror genre and public memory of the site as well as a lack of general historical acumen of the paranormal investigators.⁶¹⁰ These assumptions highlight tensions regarding the kinesthetic memory of dis/abled people, the significance of institutional spaces like Pennhurst, and the obliviousness of the patrons in commemorating dis/ability history. For example, I observed paranormal investigators ask the spirits what their favorite game to play was and later sing "Happy Birthday" to them in the physical therapy room in the basement of the Mayflower ward.⁶¹¹ Growing up, we

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⁶¹⁰ George, "The Birth of a Haunted 'Asylum," 100.

⁶¹¹ Stenberg, Fieldnotes.

referred to physical therapy as "pain and torture" in the hospital. Therapy rooms were not sites of malicious intent necessarily, but they were often sites of bodymind pain and trauma. If uncorrected, that obliviousness can become harmful in that the patrons will continue to spread misinformation about dis/ability and the PSSH, especially for those investigators who post their investigations to YouTube and other social media platforms. Autumn's awareness of this, as overseer of the tours, illustrates her leadership skills. Her comments demonstrate how she, and other guides, balances the need for customer service while maintaining clear boundaries regarding the continuation of harmful assumptions brought about through ghost hunting lore and misinformed patrons.

Second, this discussion demonstrates how, for the PA community, the line of separation between Pennhurst Past and Pennhurst Present barely exists. This becomes apparent in how Autumn uses "we" and "us" pronouns when giving tours and discussing the PSSH's history with other Pennhurst community members. This pronoun usage illustrates Autumn's—and other dis/abled PA community members'—connection to the space and its people. Dis/abled people exist under the spectre of institutionalization—a systematic process that dehumanizes and devalues dis/abled people, even though most institutions have closed their doors. Therefore, the experiences of Pennhurst Present are eerily similar experiences to those of Pennhurst Past. Combined, these experiences fuel the connection felt between the PA community and the memories of PSSH inmates.

Third, this discussion highlights how the PA community models access and inclusivity. As Autumn says, often dis/abling experiences do not represent themselves in "nice" or "appropriate" ways to nondisabled society. That does not, however, revoke nondisabled society's responsibility to implement universal access and make "a

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comfortable environment for everyone." Even so, the PA community does not wait for nondisabled society to change. Instead, they model these principles of access, advocacy, community, and commemoration on their own terms. They do not rely on the institution's tools to tear down the institution.⁶¹² Rather, they occupy the institution and use performances of redefinition to model what dis/ability history and access by and for dis/abled people can look like. While the PA community undoubtedly models access, it does not come without its costs. For example, the dis/abled haunters must exist within the tension of the delimiting norms of performances of disability. While haunters-turnedparanormal-guides must insist that nondisabled paranormal investigators recognize vocalizations that occur during an investigation as "socially appropriate," haunters use those same vocalizations to invoke the spectre of disability and create an Othering horror aesthetic within the confines of the haunted attraction.

The popularity of and proceeds from Pennhurst's paranormal investigations helps to maintain the space, but Museum staff must also mitigate misinformation brought by patrons. As dark tourism scholar Tiya Miles notes, "Ghost stories index disturbing historical happenings that have often been excluded from conscious social memory, but they also limit the full recognition of those very happenings."⁶¹³ The Museum's tours, and the people who lead them, become essential for widening the patrons' social memory to include the atrocities of institutionalization and the complicated legacy of the PSSH. The Pennhurst LLC employees, and their dialogues with paranormal investigators, model

⁶¹² Audre Lorde, *The Master's Tools Will Never Dismantle the Master's House* (London, UK: Penguin Books, 2018).

⁶¹³ Tiya Miles, *Tales from the Haunted South: Dark Tourism and Memories of Slavery from the Civil War Era* (Chapel Hill, NC: The University of North Carolina Press, 2015), 15.

a dis/ability worldview by ensuring the full recognition of the PSSH's violent history does not get erased by patrons' lust for paranormal performances.

Paranormal Investigations

As I examined in Act III, the slippage between the PA's marketing for the haunted attraction and the Museum's profile generates a clear gulf of understanding for the patrons. The LLC offers weekly public paranormal investigations on Saturday evenings. They also host private investigations throughout the year. While most Museum patrons want to learn the history of the PSSH, in any public tour there are always several patrons who attend only for Pennhurst's reported paranormal qualities. For example, "Paranormal investigators" often purchase tickets to attend the Museum during the day and a paranormal tour in the evening. Pennhurst LLC employees remark that the paranormal investigators only care about experiencing something "scary." The various backgrounds of the patrons, and their differing motives for attending the Museum, lead patrons to ask their guides a plethora of questions about the institution's past, who existed there and died there, and why the institution closed in the first place. The competing motivations for attending the Museum place significant importance on the role of the guides to provide an engaging experience for the patron while also ensuring that the tours inform their guests about the history of the PSSH for the dis/ability community. This remains important because it illustrates the way that the PA community's dis/ability heritage work must not only preserve the legacy of institutionalization and the PSSH, but also do so in a way that continues to bring in patrons (and thus profits) for Pennhurst LLC.

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Like the history tours, Pennhurst LLC advertises investigations through its website and social media. That said, the paranormal investigations bring in larger audiences due to the lore of Pennhurst. The format of the paranormal investigations has remained largely the same since Pennhurst LLC began offering tours. Before 2020, the paranormal investigations did not include a history tour. Since being promoted in 2020, however, Autumn has required all paranormal investigation guides undergo history guide training and include an abbreviated history tour in their investigations.

Pennhurst LLC operates both private group investigations, and public investigations. The private investigations occur Sunday through Thursday evenings, from 19:00 until 01:00. They accommodate up to 10 people, and rates start at \$1,200 (US) per group. The public investigations start at 19:00 on Saturday evening and run to 01:00 on Sunday morning. The public investigations cost \$99 (US) per ticket, and average approximately 70 to 100 people in attendance. Before splitting the patrons up into smaller groups based on experience, Autumn gives the patrons a brief introduction and safety reminder. Autumn reminds patrons to not disrespect the former inmates, not stray from their group and wander the property, and not to ghost hunt while intoxicated. Finally, Autumn gives a provocation to the group: to do the investigations *not* as frivolous entertainment, but as an opportunity to enfranchise those who died. As one nondisabled investigation guide told me, "Before every ghost hunt Autumn tells [patrons] the rules, she mentions that tonight is the chance that we let those that suffered speak out. Take their voices back because they've been stomped on for over 100 years."⁶¹⁴ This

⁶¹⁴ Text Conversation with Kaeden Hoisington, January 19, 2023. Kaeden gave his permission to be identified on a full-name basis.

provocation—whether or not fully appreciated by the patrons—further reveals the motivations of the PA community to remember *and* redefine what happened at the PSSH; to recognize the tragedy of Pennhurst and the suffering experienced by the institution's inmates, but also to reclaim their humanity—their joy, sorrow, and humor. Following the safety speech, each guide leads their individual group of investigators on an abbreviated history tour of the campus. Shortened from the regular two-hour history tour, the paranormal investigator's tour lasts only forty-five minutes and does not include the Museum. The paranormal investigation guide leading the tour provides an overview of the PSSH from opening to closure, the opening of the haunted attraction and how it differs from the PSSH, and a brief overview of current issues facing the dis/ability community. Crucially, as noted in the earlier vignette of tour guide training, the guides inform investigators what language is considered acceptable or offensive, and the decorum of the space.

After the history tour, armed with various gadgets and recording devices, the groups then rotate between various buildings on campus—including Mayflower, Devon, Infirmary, the tunnels connecting to the Rockwell building, and the basement of Philadelphia—throughout the evening. Once in a location, investigators typically roam freely throughout the space, often with space between them and fellow investigators to avoid "contaminating" their evidence. Investigators often mill about the wards and tunnels with a slow, steady pace, almost always remaining on their feet. They seldom verbalize other than summon the spirits, and the space often takes on an almost impenetrable level of silence. When the investigators do attempt to verbally communicate with the spirits, they frequently ask questions such as: "Can you play with/activate

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[whatever device they are investigating with]?" "What's your name?" "How old are you?" "Are you a boy or a girl?" "Were you abused?" "What happened to you here/did you die here?"⁶¹⁵ While the LLC's investigation guides generally succeed in preventing investigators from taunting or provoking spirits, investigators occasionally still refer to spirits with ableist slurs or microaggressions. One haunter and paranormal investigation guide notes, however, "The sad part is when devices get activated ghost hunters will typically say 'it's playing with it.' I always follow up with "THEY are playing with it."⁶¹⁶ This language highlights a two-fold dynamic regarding the investigators' perceptions about the spirits: first, by referring to the spirits not as a person but as "it" reifies the same dehumanizing rhetorical performatives of institutional authorities. Second, it highlights the notions of spirits as disembodied, nonhuman entities.⁶¹⁷

THE PERFORMANCE OF PARANORMAL PATRONS

Like the Museum patrons, the paranormal investigators comprise a wide variety of gender and socio-economic identities. In my fieldwork, I have noticed the racial and ethnic identities of most paranormal investigators are predominantly White,⁶¹⁸ and patrons flock from across the globe to investigate any paranormal activity on the site. This parallels themes consistent at the PSSH as well. While the inmate population was quite racially diverse with many inmates coming from Philadelphia, the employee

⁶¹⁵ Stenberg, Fieldnotes.

⁶¹⁶ Text conversation with Kaeden, April 10, 2023.

⁶¹⁷ Rebecca Schneider, "'Possession & Performance', A Conversation with Paul C. Johnson and Nick Ridout," July 25, 2020, <u>vimeo.com/441583242</u>.

⁶¹⁸ For more on the performance of spiritualism and Whiteness, particularly in the nineteenth century, see Hazel Rickard, "Spiritual Matter: Nineteenth-Century Spiritualism, Whiteness, and Material Performance" (PhD Dissertation, Minneapolis, MN, University of Minnesota, 2022), <u>https://hdl.handle.net/11299/241611</u>.

population was predominately White. Further, medical researchers, educators, and students would come to the PSSH to observe operations and partake in internships.

Paranormal investigators come with their own regalia and costuming. The least experienced—often the young college students out for a good time—generally come dressed in open-toed shoes and apparel better-suited for a nightclub or restaurant. The most experienced—the self-proclaimed "professionals"—come often in matching uniforms and supply their own investigation equipment. For example, many professional investigators wear military surplus fatigues, headlamps, and MOLLE (Modular Lightweight Load-carrying Equipment) rucksacks filled with cameras and various other investigating tools. These professionals also often wear tags or clothing indicating which paranormal investigation club they belong to.

The costuming of the paranormal investigators represents a clear distinction between the accessible notion of popular culture's ghost hunting phenomenon and the pseudo-militarism of the professional paranormal investigators. On one hand, the amateur investigators want simple and consumable entertainment—a pay-per-view approach to whatever spiritual elements of the PSSH may remain. In this way, the casual, almost entirely out-of-place attire of the lesser experienced patrons reveals a level of disregard for the people and property of the PSSH. An expectation that, by merely paying admission and coming to the site, the spirits of the PSSH must entertain the patrons by making their non-material presence material. One dis/abled paranormal guide and institutional survivor calls this, "the inherent performance of ghost hunting." Elaborating, the guide says, "In fact, the term I use to gently remind people is that it is a ghost hunt… Pennhurst is not a ghost petting zoo. Things don't just happen because you will it to, nor do I have such power in my hands."⁶¹⁹ This guide acutely recognizes the pay-per-view expectations of the patrons attending the investigations, while also respecting their own worth in not bending to the patrons. If thought of as characters in a larger genealogy of Pennhurst, these patrons mirror the passive societal observers of the PSSH. Not intending to create harm, their ambivalence towards dis/abled people and the oppressive mechanism of institutionalization nonetheless perpetuates it.

On the other, the professional investigators represent the opposite—they must perturb, flush out, and capture the spirits of former PSSH inmates and employees through the most verifiable means possible. Unlike the lesser experienced ghost hunters, the professional investigators come to Pennhurst as pseudo-colonizers, literally *hunting* and *taming* the spirits of the PSSH. This approach to Pennhurst positions the history and people of the PSSH as something feared, violent, *but controllable*. In this way, the professional investigators parallel the institutional professionals of the PSSH. The professional investigators—like the institutional professionals—protect themselves with costuming, credentials endowed by professional clan or discipline, so-called "scientific objectivity," and use the latest scientific tools and measures to categorize and quantify the unquantifiable—the humanness of the *other's other*.⁶²⁰ Like the institutional professional reviewing an inmate, the professional paranormal investigator finishes their investigation,

⁶¹⁹ Text conversation with Rebecca, January 19, 2023. (I have anonymized this person's name out of respect for their privacy.)

⁶²⁰ For further readings on the critique of objectivity within Critical Disability Studies see, Snyder and Mitchell, *Cultural Locations of Disability*; Margrit Shildrick, *Dangerous Discourses of Disability*, *Subjectivity and Sexuality* (New York, NY: Palgrave Macmillan, 2009); Dan Goodley, *Disability Studies: An Interdisciplinary Introduction* (Los Angeles, CA: SAGE, 2011); Dwight Conquergood, "Rethinking Ethnography: Towards a Critical Cultural Politics," *Communication Monographs* 59 (1991): 179–94; Dwight Conquergood, "Performance Studies: Interventions and Radical Research," *The Drama Review* 46, no. 2 (2002): 145–56; Soyini Madison, *Critical Ethnography: Method, Ethics, and Performance*, 3rd ed. (Thousand Oaks, CA: Sage, 2020).

records their findings, and makes (often tautological) prognoses about what they experienced: the remnants of what once was or never truly came to be human.

Getting the Story Out: The Evolution of the Pennhurst Museum

This section elucidates the evolution of the Pennhurst Museum, from its initial existence under the supervision Pennhurst Associates, through to its current state under the aegis Pennhurst LLC. Initially, Pennhurst Associates positioned the museum within the confines of the haunted attraction, relying on performances of remembrance that caused harm due to the lack of distinction between the haunted attraction and the museum. Now functioning independently from the haunted attraction, the Pennhurst Museum affords visitors a distinct experience, markedly different from the versions previously discussed in academic discourses on Pennhurst.⁶²¹

⁶²¹ Beitiks, "The Ghosts of Institutionalization at Pennhurst's Haunted Asylum"; Beitiks, "The Final Indignity"; George, "The Birth of a Haunted 'Asylum"; Mussell, Walby, and Piché, "Can You Make It Out Alive?"

The Museum under Pennhurst Associates

Under the management of the Pennhurst Associates, the museum tokenized the memory of those institutionalized at the PSSH by conflating the living history performance of the museum with the pseudo-freak show performance of the haunted attraction. Located within the Asylum attraction, the museum included the first three spaces patrons encountered upon entering. Touring the attraction in 2010, disability and memory studies scholar Kelly George describes her encounter of the museum in her field notes. Arriving at the steps of the administration building, a former PSSH aide wearing a red wig and costumed as a nurse "welcomes us to Pennhurst and says the doctor is seeing patients now (we are the patients). She says he's doing his lobotomies."⁶²² The aide also tells patrons that she worked for the PSSH, and that "Everything in the first three rooms is real. Those are the historical rooms. ... Everything else after is fake."⁶²³ With this opening provocation, the aide attempts to set the distinction between fact and fiction. But this scene also reveals several elements which create slippage in the reality of the PSSH and PA.

By combining the set background of the institutional buildings, the casting of a former employee, and displaying various historical artifacts, Pennhurst Associates' managers constructed a tenuous sense of historical authenticity—that the fear was and remains real at Pennhurst. The museum artifacts featured framed photocopies of a handbook created by the PSSH in 1954 that the PMPA also posted on their website at the

⁶²² Kelly George, "The Birth of a Haunted 'Asylum': Public Memory and Community Storytelling" (Dissertation, Philadelphia, PA, Temple University, 2014), 122.

time, "a strip of cloth with buttons on one side and button holes on the other [likely used in occupational therapy], and a large wooden loom.⁶²⁴ Moving through the space, George reported hearing "old-timey music...designed to give visitors a sense that they are stepping into another time, but I can't be sure which one."⁶²⁵ The attraction's designers also incorporated several elements of horror within the spatial design of the museum. In between rooms, George noted that a "monitor play[ed] a loop of an actor appearing to be banging frantically on the window, screaming to be let out."⁶²⁶ The final room featured a soundless loop of the 1968 exposé, Suffer the Little Children projected on a screen.⁶²⁷ As visitors passed through the "museum" on their way into the rest of the attraction, "the red-wigged nurse explain[ed] that Pennhurst was 'a good place."⁶²⁸ When patrons asked about the conditions, the aide responded, "I didn't witness any abuse." The backdrop of the dilapidated institutional buildings, stationing a former PSSH aide in the museum, and placing artifacts from the PSSH all provided a sense of authenticity to the patrons. For some PA devotees, like Donna Samluk, a former PSSH employee and Pennhurst Museum docent, the original museum demonstrated the LLC's intentions to preserve the history of the PSSH since the attraction opened. But careful analysis of the museum's spatial relationship with the haunted attraction suggests otherwise.

Pennhurst Associates' incorporation of the museum into the spatial layout of the haunted attraction created slippage between the fictional Asylum and the reality of the

⁶²⁴ George, 123; according to Donna Samluk—former PSSH employee turned Museum docent—many of the artifacts in the current Museum existed in the museum under the management of Pennhurst Associates. Stenberg, Fieldnotes.

⁶²⁵ George, 122.

⁶²⁶ George, 122-23.

⁶²⁷ George, 128.

⁶²⁸ George, 123.

⁶²⁹ George, 123.

PSSH by creating a quasi-living-history museum. Most patrons entered the PA haunted attraction with little awareness of what the PSSH was. Since the museum was the first space patrons encountered—replete with a former PSSH employee in costume as a tour guide—Pennhurst Associates' museum created a space in which deciphering the factual history of the PSSH and the fantasy of the attraction became impossible. As performance studies scholar, Scott Magelssen attests, [t]he institutional reinscription of time perpetuates the notion in visitors' minds that accuracy is, indeed, possible, and that high-profile museums ... are examples of such accuracy."⁶³⁰ By not bracketing the experience for the patrons, the living-history-style museum—whether intentionally or not—conflated facts of the PSSH into the timeline and plot of the haunted attraction and patrons had no reason not to trust the accuracy of the information presented to them.⁶³¹

The original Asylum attraction relied solely on doctor-on-patient violence and disability tropes to produce its aesthetic of horror, and nondisabled haunters would openly caricature disability. Additionally, management under Pennhurst Associates would put dis/abled haunters in scenes replicating their past medically induced traumas. Patrons moved through the space voyeuristically observing that violence. It was also common for patrons to touch or harm haunters under the management of Pennhurst Associates. This experience perpetuated institutional notions of disability as what performance scholar Petra Kuppers calls, "outside 'normal' society and bodies."⁶³² With

⁶³⁰ Scott Magelssen, *Living History Museums: Undoing History Through Performance* (Lanham, MD: Scarecrow Press, 2007).

⁶³¹ Disability scholar Emily Smith Beitiks, criticizes the old museum for conflating facts with fantasy and cheapening the importance of the PSSH's impact on the de/institutionalization and disability rights movements. See, Beitiks, "The Ghosts of Institutionalization at Pennhurst's Haunted Asylum"; Beitiks, "The Final Indignity."

⁶³² Petra Kuppers, *Disability and Contemporary Performance: Bodies on Edge* (New York, NY: Routledge, 2004), 4.

the museum within the bounds of the haunted attraction, at its best, the museum functioned to play into nondisabled society's fantasized lore of institutions generated from the horror genre and the spectre of disability. At its worst, the museum combined with the attraction's performances, elided fact with fantasy, and both legitimized and caricatured performances of institutionalized care—state-sanctioned violence against dis/abled people. The museum remained in this configuration until 2017, when Pennhurst ownership changed.⁶³³

The Museum under Pennhurst LLC

In 2014, Pennhurst LLC moved the Museum out of the Asylum attraction into the neighboring Mayflower building to expand the haunted attraction.⁶³⁴ When the ownership changed in 2016, the new owners expressed a willingness to fund preservation efforts. In turn, Pennhurst LLC's management aggressively expanded the historical efforts to differentiate the two modes of representation and solidify the "fantasy" of the Asylum attraction and the "fact" represented by the Museum.⁶³⁵ Given the new ownership's team openness to support preservation efforts and their own experiences with dis/ability, Pennhurst LLC management wanted to ensure the separation between the museum and the attraction. Since the transition, the Museum, and the Mayflower building that houses it, have undergone significant transformation.

 ⁶³³ I received this information through conversations with both former and current Pennhurst haunters, and former PSSH employee turned museum staff Donna Samluk.
 ⁶³⁴ Text supersection with Versex April 12, 2022

⁶³⁴ Text conversation with Jim Werner, April 13, 2023.

⁶³⁵ Text conversation with Jim Werner, April 13, 2023. Haunters who have been employed at the PA since the inception of the haunt have unanimously expressed that preservation of the campus has always been a principal objective. Nevertheless, the Pennhurst Associates' ownership team was not as supportive of these efforts as the Pennhurst LLC.

The Museum advertises itself primarily through Pennhurst LLC's webpage and word of mouth.⁶³⁶ For example, many patrons learn of the Museum while attending the haunted attraction and/or a paranormal investigation and return at a separate time. The Museum opens in March and closes in December. Weekly public tours occur on Saturday mornings and average approximately 40 patrons.

Patrons pay \$40 (US) for a three-hour tour of the grounds and the Museum.⁶³⁷ After covering personnel expenses, the proceeds support Pennhurst LLC's preservation efforts. Furthermore, the current management actively partners with the PMPA to create materials for the tour guides that incorporates one of the PMPA's "traveling exhibits" on permanent loan—a set of ten banners with text and photographs detailing the PSSH's impact on the deinstitutionalization and disability rights movements. The PMPA often uses the other traveling exhibit to display at international, national, and regional conferences. Additionally, the exhibit has traveled to the United States Capitol, the Pennsylvania State Capitol, the National Constitution Center, and the Philadelphia City Hall.

From my fieldwork, I observed that the patrons' demographics vary as widely as their motivations for attending the Museum. Most groups represent an array of racial, gender, and socio-economic identities. While Pennhurst is more widely regarded on the tourism market for its reported paranormal qualities, patrons come from across the globe to visit the grounds and learn about its history. Some patrons want to learn more about

 ⁶³⁶ "Daytime Tours & Museum," Pennhurst Asylum, n.d., <u>https://pennhurstasylum.com/visit/</u>.
 ⁶³⁷ Although the Museum does not advertise an approximation for the tour duration, the tours often extend beyond three hours, depending on the specific tour guide leading the group. This not only attests to the vast size of the physical campus but also showcases the substantial number of artifacts that the Museum staff has amassed.

the place a family member lived and died, while others hope to glimpse a ghost, or photograph a place they read about on a road sign passing through town. This range of patron demographics and motivations for attending the tours make the work of the PA community even more essential in dispelling misinformation and emphasizing the dis/ability heritage work of the community to redefine and reclaim the legacy and future of Pennhurst.

I first visited Pennhurst in the summer of 2018, shortly after the Museum was established in the Mayflower. The Museum included the same photocopied parent handbook featured in the previous rendition of the museum and a smattering of other artifacts found on campus, such as dining trays, gurneys, and wheelchairs. To create a safer and more respectful environment, Pennhurst LLC remediated the Mayflower and cleared out most of the graffiti on its walls. With a more suitable space to hold the artifacts, the Museum staff continues to rescue new artifacts from buildings slated for demolition and place them in the Mayflower.

When I attended my first history tour in 2019, the museum did not have dedicated staff. The tour guides assembled their own historical information about the site using sources they primarily found on the internet.⁶³⁸ When Autumn became the Off-Season Events Coordinator in 2020, she implemented mandatory training for all history and paranormal tour guides and, with the help of the PMPA, created a template for both sets of guides to follow. As of 2023, the two former PSSH aides—Donna Samluk and Bernadine Essick—serve as docents for the museum and six haunters serve as history tour guides, and twenty serve as paranormal investigation guides.

⁶³⁸ Stenberg, Fieldnotes.

Since moving to the Mayflower in 2018, the Museum's collections expanded from the first floor eating area to all three floors of the former ward. As of 2023, Pennhurst LLC started to move the ever-expanding Museum's collections to the former boys' ward, Limerick. (Limerick was slated for demolition, but the PA community successfully petitioned the ownership team to keep it.) The LLC continues to invest in the Museum's expansion for three reasons: first, the increasing revenue generated by the historical tours. Since 2018, attendance at the museum has increased. In fall 2022, the history tours set a new single-day attendance record at over 100 people. Second, the new partnership between the PMPA and the PA community continues to generate numerous private tours of the Museum, in which University students as well as medical and educational professionals tour the site for continuing education. Finally, Pennhurst LLC and the PA community wanted a designated space for the Museum and to hold historyfocused events. In its current layout, the Mayflower hosts both paranormal investigations and Museum tours—which includes a small merchandize area for patrons to purchase souvenirs. The Mayflower building is not sealed and so the elements and rodents often threatened many of the artifacts. Limerick, the new Museum building, will also have a space for public events such as lectures and forums related to Pennhurst history. The PA community has also made display cases to keep artifacts safe. The continued expansion of the Museum illustrates yet again the PA community's dedication to the space and to its shared history with the former inmates and survivors of the PSSH. It also highlights how the PA community uses embodied action—such as building display cases—to reimagine, reclaim, and care-fully build a home for the history of Pennhurst with their own bodyminds.

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Giving Care & Redefining: Dis/ability Heritage at Work at the Pennhurst Museum

This final section turns to the work of Autumn and her team in collecting, curating, and commemorating artifacts and giving care to the physical spaces on the campus as the Museum expands. I employ and analyze several photographs either taken by myself or Autumn. In doing so, I not only give a visual depiction of Pennhurst, but I also use these photographs as a form of performance to analyze how the PA community creates a dis/ability epistemology. This epistemology from the PA community positions itself in relationship to Pennhurst Past and how it hopes to define Pennhurst Future through its dis/ability heritage work. They use both performances of remembrance and redefinition to generate a new way of producing knowledge about dis/ability culture, history, and heritage—a dis/ability epistemology. This epistemology almost becomes utopian, but the spectre of institutionalization mars it.

"We Die You Profit?" & "THIS IS MY HOME": The Tension Between Commodification & Commemoration

This first grouping



Figure 12: Graffiti on the first floor of Quaker Hall, a former Pennhurst State School & Hospital Ward. An entrance door to the dorm with the words "History over \$" can be seen in the background. Photograph credit: Autumn Werner.

of photographs—both taken in Spring 2022—demonstrates the perennial tension of the PA community's efforts to preserve the campus while the private company they work for operates a for-profit haunted attraction on the property. Autumn took the photograph above (Figure 12) in Spring 2022 while collecting artifacts from Quaker. In the left of the



photograph, on the door, someone spray-painted the words "History over \$" and on the

Figure 13: Autumn talks with a history tour patron in a hallway of the Infirmary at the Pennhurst State School & Hospital. Photograph by author.

adjacent wall, they spray-painted the words "We Die you profit ?" in red. I later witnessed this graffiti in person when assisting with the cleanup of Quaker, to prepare for paranormal investigations and history tours, in March 2023. The graffiti art powerfully articulates the most common and poignant critique of the PA. Rather than preserving the space after it closed and dedicating it as a reminder to society of the historic horror and ongoing terror of institutionalization, the Commonwealth of Pennsylvania opted to sell the property, which now functions primarily as a place of entertainment. This graffiti reminds all those that witness it of the ethical and moral ramifications of our choice and intentions of coming to Pennhurst. The graffiti, emblazoned on the literal foundation of the oldest building, forces the viewer to reckon with the past actions of nondisabled society, in the present.

I took the second photograph above (Figure 13) in April 2022, as I accompanied a private tour of the Infirmary Autumn gave to a local businessperson familiar with the principal partner of Pennhurst LLC, Derek Strine. The tour had a simple but significant purpose: enlist the support of someone with direct communication with the owners to preserve the Infirmary. When I saw Autumn standing next to this door with the words, "This is my home", graffitied on it likely by trespassers at some unknown time, I selfishly snapped photographs, hoping to capture this moment.

Autumn and her team fervently petitioned the ownership to save the Infirmary, and in Winter 2022 the owners granted a temporary stay of demolition. The PA community collectively cleaned out the Infirmary and removed both debris and graffiti on February 9th, 2022. This photograph captured a reality experienced by so many in the PA community devoted to engaging in the dis/ability heritage work of the Pennhurst Museum: planted firmly in the middle of this dilapidated yet debris-free hallway, between a brightly lit, half-open exit door and the dark shadows of the unknown future, a dis/abled haunter makes her plea to a nondisabled audience she hopes is listening: "this is my home. Please help us save it and the memory of those it holds."

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While no one in the PA community knows exactly who created the graffiti or when, both Figure 12 and Figure 13 uncannily voice what PSSH inmates might have written themselves.⁶³⁹ What remains important is not who authored these statements, but that the PA community opted to preserve them. In the intervening years between the PSSH's closure and Pennhurst Associates' purchase of the property, an untold number of people trespassed on and vandalized Pennhurst.⁶⁴⁰ Even by the time I first came to Pennhurst in 2018, the campus remained littered with graffiti—most of it profane and irreverent-and Pennhurst LLC continues to remove graffiti on the property. By leaving these statements intact and not covering them up, the PA community allows this graffiti to share in the work of interpretation. These pieces of graffiti become epitaphs written on the literal and figurative infrastructure of the PSSH. As such, they interrupt the assumptions many patrons—especially paranormal investigators—make about who existed at and what went on at the PSSH. Finally, these statements insist on the complexity and contemporaneousness of the struggle between commodification and commemoration at Pennhurst. This struggle is not the black and white narrative of "right and wrong" or "good and evil" that many critics and researchers claim.⁶⁴¹ Instead, the truth—like the statements graffitied on the walls of Pennhurst—remain materially in a place of unrest.642

⁶³⁹ Though, it is likely that trespassers protesting the Commonwealth selling the property to Pennhurst Associates created the graffiti sometime around 2009-2010.

 ⁶⁴⁰ For more on the rise of Urban Explorers and how Pennhurst gained notoriety as a site of exploration from 1990-2008, see Hofmeister and Cadwalader, "Touring the Ecology of the Abandoned."
 ⁶⁴¹ Beitiks, "The Final Indignity"; Mussell, Walby, and Piché, "Can You Make It Out Alive?"

⁶⁴² Benjamin, "Eduard Fuchs."

Reuniting with the Absent Other: Artifact Retrieval as Touching Time

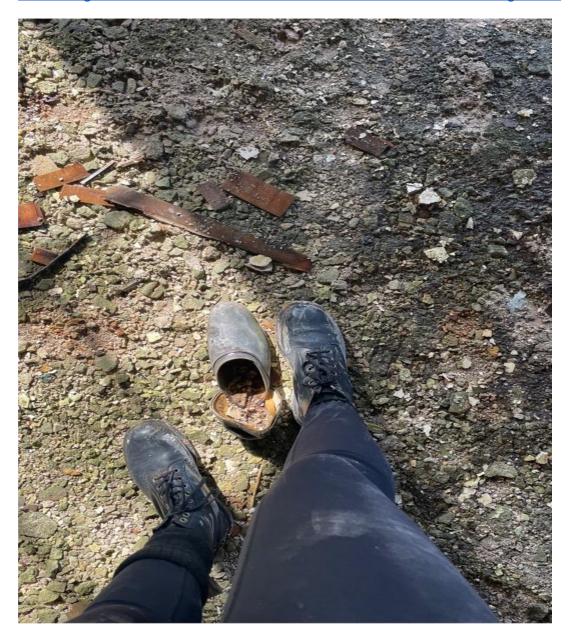


Figure 14: Autumn Werner stands next to a female inmates' shoe found in Quaker Hall, a ward at the Pennhurst State School & Hospital. Photograph Credit: Autumn Werner

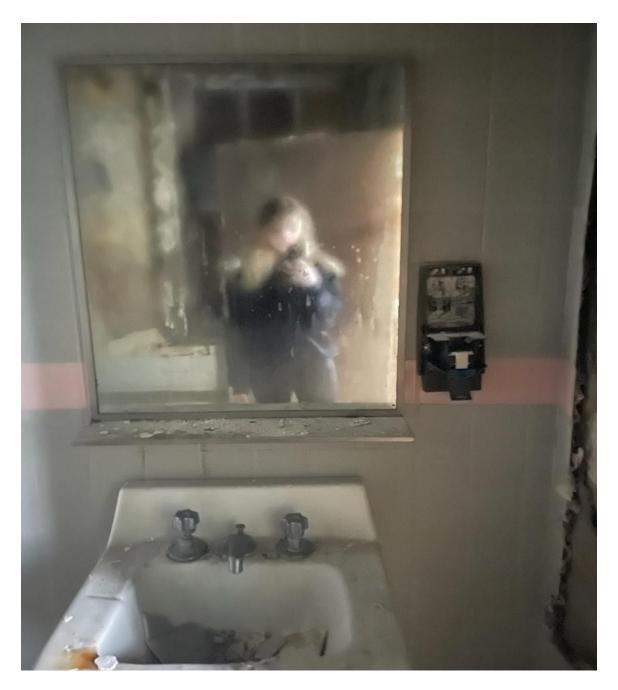


Figure 15: Autumn poses for a mirror selfie in a Quaker Hall bathroom at the Pennhurst State School & Hospital.

The two photographs I analyze in this section reveal how the remnants of people of Pennhurst Past—those literally and figuratively absent from both this text and the space itself—haunt the lives of the people of Pennhurst present by the way our bodymind experiences touch and remind us of the ever-looming spectre of institutionalization. While most of this dissertation addressed *how* care became violence in the institution and how that violence continues to repeat, these photographs reveal what gets left behind in the wake of that violence.

Autumn Werner took both photographs while conducting artifact retrieval on the "Bad Girls Floor" of Quaker in Spring 2022. In the first photograph (Figure 14), Autumn stands with her right foot next to a female inmate's right shoe of the same size. In this moment of encounter, the shoe, filled with debris, is not just an inanimate object. Rather, it brings into being what historiographer and psychologist, Eelco Runia calls "presence," or "'being in touch'—either literally or figuratively—with people, things, events, and feelings…"⁶⁴³ The shoe then serves as metonymic evidence and it "function[s] not by giving an account of an event, but by forcefully 'presenting an absence' in the here and now" to Autumn about what could have been and *still be* in her life: an experience of institutionalization.

In the second photograph (Figure 15), taken by Autumn in a bathroom on the "Bad Girls Floor," Autumn stands in front of a mirror. Taken in any other place, this photograph would serve as a mere "bathroom selfie," something mundane and innocuous. Instead, this self-portrait, taken in the reflection of a mirror not of glass, but metal, contorts Autumn in a way that even her own dis/ability-induced-contortions cannot. This mirror functions as yet another form of metonymic evidence which makes manifest the contorted reality in which dis/abled people must live under the spectre of institutionalization. As Runia elaborates,

Whereas metaphor 'gives' meaning, metonymy insinuates that there is an urgent *need* for meaning. Metaphor...weaves interrelations and makes

⁶⁴³ Eelco Runia, "Presence," History and Theory 45 (2006): 5.

'places' habitable. Metonymy, on the other hand, disturbs places. When fresh, it questions meanings, awakens us from what we take for granted, and draws attention to what we don't like to be reminded of: that the implicit rules of the place are far from natural and self-evident, are indeed a system of habits and conventions.⁶⁴⁴

What this abstracted self-portrait does is remind both Autumn and the PA community of the "urgent *need* for meaning" of what it *means* to be dis/abled within a space of disability. The PA community and the Museum "questions meanings" about dis/ability community, advocacy, and HCBS.⁶⁴⁵ Who gets to claim and define dis/ability community? Who holds power, and how do they receive that power in our community and advocacy? Pennhurst's legacy and its existence as a haunted attraction that happens to foster a dis/ability community requires the larger disability community to interrogate the histories we tell.

Pennhurst also "awakens us [the dis/ability community] from what we take for granted..."—that the reality of institutionalization is, somehow, a docile remnant of a bygone time. It is not. This dissertation demonstrates that the "rules" which keep institutionalization alive rely on a deeply ableist "system of habits and conventions" that even disability advocacy struggles to upend.⁶⁴⁶ Therefore, the work of the PA community not only commemorates the legacy of Pennhurst, but it also flushes out the insidious spectre of institutionalization. Importantly, the combination of the haunted attraction, alongside the commemoration work of the Museum reveals how dis/abled people continue to find community, make culture and knowledge, and survive under the constant looming threat of what always already was: our abjection from nondisabled society.

⁶⁴⁴ Runia, 19, emphasis original.

⁶⁴⁵ Runia, 19.

⁶⁴⁶ Runia.

Conclusion: Raising Consciousness & Problematizing Preservation

Autumn and I sit behind the front counter of the unheated Pennhurst Museum on March 14, 2021. (Autumn filled the counter—a former "Carolina Panthers" merchandize booth she repurposed—with various pieces of merch sold to support the Museum.) We chat while awaiting the first ghost hunt of 2021 to end. The group was supposed to finish by 01:00, but they requested more time. Autumn kindly obliged (even though she had already been on campus for over eighteen hours).

As steam rose from my cup of watered-down coffee, I drank to forget I was at Pennhurst in March, Autumn turns to me and asks, "Do you think we would have known each other... Been friends... Had all these conversations... If they had committed us here? ... I mean, you would have been on M1 [Mayflower] or Q1 [Quaker], and I likely woulda been on C [Capitol Hall – on the segregated 'female colony'] or Q4."

I cannot speak. My throat clenches and my heart races. I become numb as I feel my senses pull away from my body.

Beat.

"I don't know. Most likely not, but I'd like to think we would."

Beat.

"Me too."

Beat.

A paranormal investigator ruins the moment. "You won't believe this *awesome* response I got just now. I was down in the basement, and I asked the ghosts what their favorite ice cream flavor was, and they said 'chocolate'!"

Beat.

Autumn and I look at the paranormal investigator, forcing a blank smile. Beat.

"Hey, do you have any more of these dope sweatshirts in a size XXL?"

Many former institution sites get redeveloped into spaces unrelated to the history of dis/abled people. This erases the histories and cultures of institutionalized dis/abled people. Pennhurst LLC's Asylum attraction undoubtedly relies on the commodification of a horror aesthetic that intrinsically "others" dis/ability to create the fright that the (mostly) nondisabled patron population loyally pays for. But the proceeds of this commodification allow the PA community to preserve the campus, maintain the Museum, give regular historical tours and events, and keep dis/abled people employed and in community with one another.

The lack of interest by the Commonwealth in preserving the property, combined with the continual setbacks of other advocacy organizations, such as the PMPA, further compounds both the importance of Pennhurst LLC's Museum efforts, but also the inherent tensions of these efforts. These tensions become even more explicit when confronted with the reality that Pennsylvania still operates two custodial institutions for people deemed developmentally disabled and six institutions for people deemed

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psychiatrically disabled.⁶⁴⁷ Scholars and the public must consider who is responsible, or, rather, who *should* be responsible, for preserving the legacy of these institutions and what the duties of that responsibility entail. Pennhurst LLC and their grass-roots Museum, at the very least, offers a model for what dis/ability heritage work is.

Pennhurst's legacy and current existence as a for-profit attraction staffed by many dis/abled people force the disability community to problematize the histories we tell. Pennhurst requires us to interrogate how we conclude what it means to be dis/abled, to be institutionalized, to live in community, to commemorate or commodify. The Museum, as it exists currently, does not espouse the definitive history of the PSSH, nor what it means to live with a dis/ability. Using crip historiography and performances of remembrance and redefinition allows for a community of dis/abled and nondisabled people to explore that history together, to ask questions, share stories, and to think in between the gaps of dominant models of disability.

Ultimately, for the PA community, Pennhurst is about people—living and dead. Pennhurst—through the PA community's embodied care*giving*—creates a space for people who feel ostracized, providing a sanctuary where they are welcome and safe. Furthermore, it is about preserving the legacy of the PSSH, to ensure society does not return to large-scale custodial institutionalization again. As one dis/abled and transgender haunter expressed, "We preserve the property and we're doing our best to educate people about what happened here. I want people to come and investigate what happened here and learn from it. I don't want them to just walk through here and just think it's

⁶⁴⁷ Commonwealth of Pennsylvania, "State Centers"; Commonwealth of Pennsylvania, "State Hospitals."

something scary."⁶⁴⁸ The PA community maintains both a creative and educational space, not by identifying as a dis/abled community, using performance as acts of political resistance, or undoing the ongoing institutional violence experienced by dis/abled people. Instead, they use their vernacular performed heritage efforts to live in, through, and alongside the lingering spectre of institutionalization.

⁶⁴⁸ Stenberg, Fieldnotes, September 14, 2020.

RECITATIVE

Elegy for a Pennhurst Haunter

My phone blows up as I am writing a draft of Act IV on the Pennhurst Asylum community on the morning of July 6, 2022. As texts pour in with the news, I become numb: Katt Savoca, a dis/abled Pennhurst haunter, died by suicide earlier that morning.

I first met Kat during my fieldwork in the 2020 haunt season. She was the lead actor trainer. Kat trained me—and many others—how to haunt. She was a mentor and friend to so many within the community.

Soon after receiving the notification of Kat's death, I got word that the community would host a candlelight vigil at Pennhurst for her that evening. I packed my bags and made the three-hour drive from Washington, DC, to Spring City, Pennsylvania, arriving at the campus around 19:30. By this time, haunters had already assembled and created a small, alter-like area around the front portico of the Administration Building.

Flowers, candles, and photos of Katt lined the portico and the front steps. Along the pathway that leads to the building, haunters set up tables and brought in food, tissues, and flowers. Distraught and mourning, the haunters—almost all of them wearing Pennhurst-branded clothing—literally held each other up, huddling together in groups crying, lamenting, and sharing stories.

At around 20:00, Jim Werner—dressed in a black baseball cap, a Pennhurst tshirt, and grey basketball shorts—climbed the steps of the Administration Building and called us all together. I sat down next to several haunters sitting in a row of folding chairs that lined the front of the building, while other haunters sat or stood in the grass behind us.

Jim's voice wavered as he spoke—something I had never witnessed before. Jim always had a commanding yet comforting presence—one that gave you the sense that everything was going to be okay no matter what was going on. This time *felt* different. Even the seemingly unshakeable Jim Werner appeared physically and emotionally unmoored by the terrible news. Jim pulled out a folded piece of lined notebook paper from his pocket and read a poem written by several haunters about Katt. After, he reminded us to lean on each other—our Pennhurst *Family*—to grieve and survive in the wake of this tragedy. He also informed us that the management had brought in two crisis counselors for us to talk to.

At the end of his speech, Jim announced we would all take part in a small ritual in honor of Katt. As he spoke, several haunters passed out roses and lilies to each of us. He instructed us all to line up in front of the portico and place our flowers in a pile next to the stoop. After doing so, we took candles from a plastic storage bin and lit them from the candelabra resting on top of the stoop. We then gathered in a semi-circle around the portico and observed a moment of silence to mourn our friend and fellow haunter.

The sun had set as the last haunters lit their candles—the flicker of flames reflected off our tear-strewn faces. After standing in silence for several minutes, a haunter picked up the flowers we laid down, brought them around to the grassy area that separates the foundation of the Administration building and the concrete pathway leading up to the steps, and placed them in a pre-dug hole. Another haunter then instructed us to

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bring our candles to the flowers, drip our wax in the ground, and blow our candles out. As one haunter replaced the dirt back into its original place, another haunter announced to the group that the flowers we planted would bloom again in the spring, reminding us of Katt's presence in our lives.

As we hugged one another and said our goodbyes, the power of the moment arrested me. One of my most beloved features of the Pennhurst campus are the perennials—the daisies—planted by the former PSSH inmates that continue to spring out from the ground year after year. These delicate little flowers poke through brush, building debris, and layers of blood and trauma soaked into the ground. Their beauty and resilience serve as both an act of protest and rebellion. In this moment, Pennhurst Past touched Pennhurst Present, and gave a glimpse of Pennhurst Future, binding the people of Pennhurst together in grief, loss, and hope. And yet, that hope remains marred by the reality that we live under the ongoing spectre of institutionalization. "It is a prophecy of the triumph of modern bureaucracy where minor gatekeepers wield absolute power in the protection of an authority with which neither they nor we will ever come face to face: the social security officer, the immigration official, the bank manager, and millions like them who worry obsessively about the completion of formalities, while they make you wait; who will cancel your pension, to mention one example, for 'failing to attend an interview' though you were having an epileptic seizure in the waiting room at the time. ... But this strange story is also about a man from the country. As we talk about law as a system or a structure, with the excited confidence of insiders, we should never forget that this system, to those who are caught within it against their will, most often feels like a nightmare, its logic indistinguishable from a nightmare's relentless illogic. Law's subjects too often feel like law's victims; and their experience ought not to be ignored...

After all, when we say 'before the law', what do we mean? Temporally, it means prior to the law; spatially, subject to the law; and politically, protecting the law. And these two men, then, the gatekeeper and the country man, find themselves in a stand-off in which neither can see the law while both are ignorant of it yet already subject to it. In the 'illumination which breaks inextinguishably out of the gateway of the law' we might take from the countryman's experience that though we cannot ever reach the radiance of justice, we should not wait to try. And that the law is the instrument of this striving, while it might seem well guarded, nevertheless exists only in the manifestations and responses of our own lives.

- Desmond Manderson⁶⁴⁹

⁶⁴⁹ Desmond Manderson, "Desert Island Discs (Ten Reveries on Pedagogy in Law and the Humanities)," *Law and Humanities* 2, no. 2 (2008), 257-58. Emphasis original.

FINALE

The Pennhurst Asylum (PA), located in Spring City, Pennsylvania, is a haunted attraction established on the grounds of a former state custodial institution managed and staffed predominately by dis/abled people—some of whom are survivors of institutionalization. The nondisabled owners of this attraction profit from the very trauma many of these employees, the inmates of the former Pennhurst State School & Hospital (PSSH), along with the wider dis/ability community, have endured and continue to confront. Paradoxically, dis/abled people are drawn to this place because it offers a sense of community and purpose, which many find lacking in the supports provided for by "Home- and Community-Based Services" (HCBS) policies in the United States. While profoundly disturbing, Pennhurst is emblematic of the insidious and ubiquitous, yet elusive, spectre of institutionalization.

Institutionalization is an ongoing structural and performative process—a discrete and repetitive social performance that relies on and is enacted through embodiment. This process—one wherein nondisabled people view dis/abled bodyminds and expect dis/abled people to manifest certain signifiers of disability—continually propagates dehumanizing and violent ideologies, logics, and practices towards dis/abled people today. In the context of the institution, individualized, embodied, and material acts—such as restraint and neglect—convey to both nondisabled and dis/abled people that disability is a biological marker of inferiority. These repeated performances in institutional settings normalize abuse and construct the dis/abled body as impervious to pain, injury, and harm.

But, unlike its inmates, institutionalization is not confined to the walls of physical spaces of incarceration. Instead, it seeps into the outside world via popular entertainment, particularly the horror genre, shaping broader social understandings of what should, does, and is feared to happen within institutional spaces. This, in turn, reifies dis/abled people as inhuman, disposable, and something to be feared.

Examples of the spectre of institutionalization in dis/abled people's lives abound. Cindy Hagen, a physically dis/abled woman living in Blue Earth County, Minnesota, writhed in pain as medical and legal professionals deliberated her future in court. The issue under consideration was her capability, or in legal terms, her competence. Was she able to make decisions autonomously and live independently, or was she in need of a guardian? Despite Hagen's desire to testify on her own behalf, the hearing which would decide her fate, concluded before she had the opportunity to present her case. In the aftermath of the hearing, the judge ruled Hagen be placed under emergency guardianship, thereby depriving her autonomy.

This scene may seem strikingly similar to the commitment trial transcripts examined in <u>Act I</u>. But this courtroom drama is not a mere sequel in the multi-billion-dollar franchise known as institutionalization within the United States.⁶⁵⁰ Instead of taking place over a century ago, Hagen's hearing was held in the winter of 2023. Prior to her hospitalization, Hagen lived independently with assistance from a personal care assistant and was considered fully competent. Furthermore, the Mayo Clinic only sought legal action to deem Hagen incompetent because she refused their attempt to transfer her to a

⁶⁵⁰ For more on the historic and contemporary costs of custodial institutionalization to both state and federal governments, see Bronston, *Public Hostage*, specifically "Part II: Public Ransom."

nursing home—another form of institutionalization. The Mayo Clinic finally released Hagen to her apartment in April 2023 after a judge vacated the terms of her guardianship—following nearly nine months of hospitalization.⁶⁵¹

Also in April 2023, the estate of Joshua McLemore filed a lawsuit against Jackson County, Indiana, and several medical professionals and law enforcement officials.⁶⁵² On July 20th, 2021, McLemore, a 29-year-old mentally dis/abled man experiencing an "acute psychotic episode", was arrested and detained by police after pulling a nurse's hair at a local hospital.⁶⁵³ Once transferred to the police station, authorities failed to follow the standard booking procedures. They neglected to photograph or fingerprint McLemore and promptly placed him in solitary confinement. Stripped naked, McLemore existed in a small, bare, windowless space lacking a toilet, sink, and bed for twenty days, often covered in his own feces and urine.⁶⁵⁴

Mirroring the performances of institutionalized care analyzed in <u>Act II</u> and citing the "professional judgement" standard from *Romeo v. Youngberg* (1982) examined in the <u>Intermezzo</u>, authorities mechanically restrained McLemore's whole body for extended periods of time just to bathe him.⁶⁵⁵ As a result of the lack of direct care support—despite being monitored via a 24/7 security camera feed—McLemore lost 45 pounds while in police custody. On August 8th, 2021, McLemore became motionless, prompting

⁶⁵¹ The information regarding Hagen's case described in both this paragraph and the preceding come from two journalistic reports: Elizabeth Flores, "'I Just Want to Go Home': Inside a Minnesota Woman's Fight to Overturn a Guardianship," *Star Tribune*, February 4, 2023, <u>https://www.startribune.com/i-just-want-to-go-home-inside-a-minnesota-womans-fight-to-overturn-a-guardianship/600249179/</u>; Catharine Richert, "Woman in Legal Limbo at Mayo Cleared to Go Home," *Minnesota Public Radio News*, March 29, 2023, <u>https://www.mprnews.org/story/2023/03/28/woman-in-legal-limbo-at-mayo-cleared-to-go-home.</u>

⁶⁵² Estate of Joshua A. McLemore v. Jackson County, Indiana, et. al., No. 4:23-cv-57.

⁶⁵³ McLemore v. Jackson County, 7.

⁶⁵⁴ McLemore v. Jackson County.

⁶⁵⁵ McLemore v. Jackson County.

authorities to call an ambulance. When Emergency Medical Technicians (EMTs) arrived on the scene, they noted in their report that his cell "smelled like old urine and the blanket he was covered up with was covered in urine. There was urine all over the floor."⁶⁵⁶ Due to the inadequacy of services at the local hospital and the immediacy of his care needs, McLemore was airlifted to a regional hospital, where he died two days later of malnutrition.⁶⁵⁷

Drawing on legal scholar Desmond Manderson's quote above, both Hagen and McLemore were quite literally persons "from the country.....caught in the [system of institutionalization law] against their will... [and, for them,] its logic [is and was] indistinguishable from a nightmare's relentless *il*logic."⁶⁵⁸ While they fell victim to this system, their experiences have not been completely ignored. Their experiences—or the nearly identical fictionalized representations of institutional violence—are restaged in the PA haunted attraction for the sake of entertainment. As examined in Act III, many of the scenes in the PA depict institutional violence to an audience mostly oblivious to the actual events that occurred within the former institution's walls. Thus, the haunted attraction becomes a spectacle of mass entertainment that reinforces the notion that dis/abled people are insusceptible to pain, while also suggesting that restraint and abuse remain acceptable forms of care. While many disability advocates, educators, lawyers, medical professionals, and policymakers dismiss the PA, perhaps its existence-and the fact that people willingly pay for a safe and bracketed immersive performance experience of institutionalization—can provide insights into why and how institutional violence

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⁶⁵⁶ McLemore v. Jackson County, 25.

⁶⁵⁷ McLemore v. Jackson County, 24.

⁶⁵⁸ Manderson, "Desert Island Discs, 257-58."

persists. Nonetheless, the PA, particularly the dis/abled members of the community of people that work at the attraction and preserve the property, also offer a model on how to envision a more holistic approach to care*giving* and community-making—one that does not *reform* institutionalization and HCBS policies but starts anew by restoring dis/abled people's autonomy, humanity, and political agency.

As demonstrated in both <u>Act III</u> and <u>Act IV</u>, PA community members fulfill multiple roles both in and outside of the PA haunted attraction. These roles span from acting in the attraction, to giving care to the space itself and collectively curating the Pennhurst Museum—the only operating museum of dis/ability history and culture within a former institution in the United States. These roles not only equip community members with new skills and employment opportunities but also cultivate a sense of community for dis/abled people that they often do not experience in the "normal," nondisabled world. Critically, though, the haunted attraction and the act of "haunting"—the embodied performance used by the scare-actors in the attraction—also recovers the political agency and power of dis/abled people that institutionalization revoked. Haunting thereby becomes a fusion of individual reclamation, political agency, and kinesthetic memory transfer. Hauntings build a community for the staff at the PA, while commemorating PSSH inmates and reshaping Pennhurst's legacy. Hence, when the haunters chant "We are Pennhurst!!!" every night before taking their places in the attraction, something happens that goes beyond a rallying cry. These words morph into a rhetorical performative, expressing a transformative power of re-inheritance, using the same tools that once sentenced the ancestors of our community to a slow, social death within this very institution.

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And yet, what the experiences of Hagen, McLemore, the former PSSH inmates, and the members of the PA community emphasize is that the spectre of institutionalization—and its ongoing violence—lives on. Despite landmark legislation and civil rights protections like the Developmental Disabilities Act, the Individuals with Disabilities Education Act, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act, the dis/ability community often finds itself in a mindset of scarcity, isolated by diagnostic labels and tragically willing to sacrifice large-scale, long-term progress for immediate, individual gains. One such example of dis/ability community favoring small-scale reform over systematic change can be found in Pennhurst's litigation history and *PARC v. Commonwealth* (1971) examined in the <u>Intermezzo</u>, where nondisabled parental advocates settled for reform and educational opportunity rather than demanding an end to institutionalization.

As a community, we must move past the reactive posture of incessantly defending our rights to a proactive model of strategizing, building coalitions, and positioning dis/ability as the all-encompassing political force and culture-maker that it is. Only then will the dis/ability community witness the changes it strives for. In the words of PSSH survivor Roland Johnson, "Get off my back; let me be in charge; let me have control over my life!"⁶⁵⁹ Pennhurst, and institutionalization, provides scholars, lawyers, educational and medical professionals, policymakers, and dis/ability activists with a pivotal starting point to understand not only how control was lost, but more importantly, how to reclaim it.

⁶⁵⁹ Johnson, Lost in a Desert World: An Autobiography (as Told to Karl Williams), 73.

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