After the Institution: The Professionalized Home Lives of Adults with Intellectual Disabilities

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Thank you to the residents of Lambs Farm who took time out of your days to talk to me; I owe this project to you all.

To the administrative members of Lambs Farm who so kindly helped me to set this project up, thank you for your patience.

Professors Carter and McCloskey, thank you for your encouragement, wisdom, and guidance.

Molly, thank you for always reminding me I can do this.

To my parents, this is one of very few pieces of academic work I have not asked you to proofread, but you are still my forever editors.

This work is dedicated to those who never made it out of the institution, and to the martyred students and scholars of Palestine, many of whom did not survive long enough to create their own bodies of academic work.

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1. Arrival

I always volunteered to join my mom on visits to my Aunt Linda. The nursing home had a distinctive smell, one of bodies being shifted to and from different floors. We signed in on the first floor, where families congregated in the hallways, sharing in sad news about a loved one. I understood the first floor as one for emergencies: a floor where people died. Linda lived a few floors up in a shared room with a curtain down the middle for privacy. My family usually gathered in a common room around a few boxes of pizza and a birthday cake. Some of my cousins were afraid of Linda, perhaps because she used a wheelchair, or because of her slurred speech. I welcomed her hugs…

My Aunt Linda had intellectual disabilities, but she was never diagnosed properly. Her mother did not allow for any interventions in her early life, and her father gave his attention to his son, Scott (my grandfather). Linda repeated kindergarten, first, and second grade, and eventually she graduated from a small private Catholic school in Illinois. She moved out of her mother's house, only to be evicted from her apartment due to her hoarding habits. While living in a low-income housing complex, Linda experienced a stroke that left one side of her body paralyzed. Both of her parents had died, so my mom and her siblings moved Linda north from Peoria to Libertyville, Illinois. My mom found an open Medicaid bed in a local nursing home where Linda would stay until she died. Our family visited Linda around birthdays and holidays. Occasionally my mom and her sisters would stop by, two of them would take Linda out to a common room to visit, and one of them would stay back to clear out the bottom drawer of Linda's dresser where she continued to hoard, albeit to a much smaller degree. My mom and my grandma both credit the nursing home for keeping Linda in the best health of her life. Her diabetes was well-managed and she had access to all of the medication and physical therapy she needed.

When I got the news that Linda died, I was at overnight camp with my older sister, Caitlin. I remember crying, and I convinced my counselors to let me sleep on a mattress on the floor next to Caitlin's bed in the older girls' cabin.

At overnight camp, we shared property with the camp next to us, Camp Pine Tree,[1] which held week-long sessions for adults with disabilities. We often had the option to go to the pool or lake with campers from Pine Tree or participate in their activities. I signed up whenever I got the chance. I shared with many of my counselors and friends that my dream for my early 20s was to work at Camp Pine Tree.

In 2022, during my first year of college, I found out the former director of Camp Pine Tree was running a similar camp in Woodland Park, Colorado. I found the camp while I was recovering from a traumatic back injury and experiencing a jarring shift in my experience at Vassar. I had to learn how to traverse an icy, inaccessible campus in the dead of winter with a large back brace and a backpack on wheels. Applying for this job in Colorado would be both the realization of a childhood dream and a freeing use of my regained mobility. During my summer in Colorado, I discovered a world of services and programming for adults with disabilities, one that my Aunt Linda never had access to. I also learned from and about people who entered and exited my life for just one week at a time.

Ron[2] sang "Don't Think Twice it's Alright" by Peter, Paul, and Mary and made every camper and counselor cry. Harvey bent over in laughter while joking that there was an imaginary chipmunk on my head. Shelly and Carl had been married for twenty years, although they could

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[1] This is not the real name of the camp.
[2] The following names in this paragraph are pseudonyms.

not get legally married without losing their disability benefits. They always gave each other a kiss before splitting off to the men's and women's cabins. Jenny calls me once every week or so to tell me I am still her bunkmate and I am still a "hot mess," even though I haven't seen her in three years.

These realizations about the complex, diverse adult lives of people with intellectual disabilities led me to a central question in my research: when individuals with disabilities age out of high school and transition programs, where do they go? *And why don't we know?* Disabled people have been historically invisibilized through institutionalization, but after a series of institutional closures from the 1970s until now, many take part in community-based or in-home programs to meet their support needs. Over time these community-based services have grown into professionalized organizations that employ hundreds of people to support their participants. The current state of support services for people with intellectual disabilities frames my project, which is guided by the following questions: What does it mean for someone's domestic life to be professionalized? Do the carceral elements of an institution show up in community-living arrangements post-deinstitutionalization? Are community, choice, and independence constructed or created organically? Most importantly, how do the people living in these communities understand their subjectivities? What do they value, what do they want? These questions guided my initial research, but the firsthand accounts of adults with intellectual disabilities are the primary avenue through which this project emerges.

1.1 Entering the Conversation

Vassar does not have an official Disability Studies Program, but there are various classes within the Education Department and Women, Feminist, and Queer Studies Program that engage with disability studies from within their disciplines. I took “Gender, Sexuality, and Disability” while I recovered from my back injury, and for the first time I was introduced to disability through an academic lens. We read from disabled scholars, including Eli Clare, Riva Lehrer, and Rosemarie Garland-Thomson, but something was missing. I had all these experiences with disabled people to reach from within my own life–a Great Aunt with intellectual disabilities, a cousin with Autism, peers from my “integrated” physical education class in high school–but I could not find literature written by them, or studies conducted by them, or art created by them in this disability studies class, much less in classes in any other departments.

Central to my project is breaking through this barrier within disability studies (at Vassar and more broadly) that undermines the intellect and knowledge of people with developmental and intellectual disabilities by hearing from them directly. My project consists of 13 interviews with residents of Lambs Farm, a residential and vocational agency in Libertyville, Illinois. The interviews were conducted with the approval of the Vassar Institutional Review Board (IRB). In email correspondence with members of the IRB, I was asked to write a full proposal to provide information on participants’ ability to give informed consent due to their having “impaired decision-making capacity.” I critically explore the processes of obtaining permission from the IRB and scheduling interviews through the agency in depth in my section titled “Methods and Methodologies.” I was eventually able to conduct interviews, and residents’ insights illuminate various conceptions of community, choice, and independence that exist within the post-institutional, professionalized living setting of Lambs Farm.

Lambs Farm was founded in 1961 with its first residences opening in 1976 (Lena), and it emerged as a desirable alternative to “the cruelest path of all: an institution” (Unsworth 2). The process of deinstitutionalization took place through a series of legal battles starting in the 1970s, and only the embodied knowledge of intellectually disabled people themselves can tell us what that process really meant. This project is a case study of one specific residential and vocational arrangement in a "post-institutional" world, but the words of Lambs Farm residents offer wisdom that remains largely unexplored, especially within the field of disability studies.

Although the wisdom of intellectually disabled people has not been widely tapped into, some scholars have begun the work of examining ways to approach and resist structural ableism. In a blog post entitled "Access Intimacy, Interdependence, and Disability Justice," Mia Mingus encourages us to "tap into the transformative powers of disability, instead of only gaining access to the current system" (Mingus par. 16). Mingus introduces the concept of "access intimacy," describing it as "that elusive, hard to describe feeling when someone else 'gets' your access needs" (Mingus par. 11). Access intimacy is not easy to build and the work to create it is (or should be) shared by disabled and non-disabled people alike. Access intimacy is also intertwined in the project of liberatory access, which "understands addressing inaccessibility and ableism as an opportunity for building relationships with each other" (Mingus par. 31). This project is not about fighting some clear and concise version of ableism, naming it, and eliminating it. Instead this project is about taking up the opportunity to build relationships with the people most directly impacted by structural ableism.

Self-advocates and intellectually disabled people have long been doing the work to fight structural ableism, but there is a tension that I feel I need to attend to within this project between the abolitionist nature of the self-advocacy movement and the lived experience of the group home. The self-advocacy movement emerged in the 1990s as a site of organizing by and for people with intellectual disabilities. Self-advocacy groups have had to overcome the widely held belief that intellectually disabled people are rightly subordinated due to their disability/ies

(Friedman & Beckwith 239). Self-advocates have also faced immense structural and material barriers to their ability to organize. Despite and because of these challenges, self-advocacy groups serve as a powerful collective movement for the liberation and self-determination of people with intellectual disabilities. A core demand of the group Self Advocates Becoming Empowered is the closure of all institutions, which they categorize as “any setting that denies choice and segregates people based on disability,” (Carey & Gu 115) including group homes, day centers, and sheltered workshops. Lambs Farm has all three of these services integrated into its model of support, so how do we reckon with the demand for its closure and its simultaneous support for hundreds of people? Liat Ben-Moshe powerfully suggests that “It would be most useful listening to people who reside in [these sites] to define whether they think of them as institutional in mindset, practice, and procedure” (“Alternatives” 265). We must first understand how the group home is situated within a history of institutionalization, deinstitutionalization, and continuums of care before hearing from those who reside within them.

2. “You want the history side of stuff, I can tell you history” (Lena).

The group home’s existence is preceded by centuries of stigmatization and institutionalization of people with intellectual disabilities. The following is a literature review and chronological account of the language used to label people with intellectual and developmental disabilities; the rationales for and methods of institutionalization; and the movement to emancipate disabled people from institutions, which continues today in various forms. The linearity of this timeline does not account for the truly non-linear nature of institutionalization, institutional closure, or life as a disabled person more generally. This timeline serves to contextualize the existence of Lambs Farm and the people who live there and to connect them to a lineage of disabled resistance and collectivity in the face of isolation and ongoing oppression.

2.1. Confronting Ableist Language

For centuries language has been used to stigmatize disability, and it was not until the rise of the disability rights movement in the 1960s that advocates pushed for legal recognition of disability on their own terms. Most of the terms used to indicate intellectual disability are now considered highly offensive or out-of-date. Throughout my project I use the term “intellectual disability" to describe the diverse group of individuals I interviewed and researched with attention to the limitations of the term and the history that precedes it.

The rise of the medical model of disability in the United States in the 1800s coincided with the rise of the term “feeble-minded” to describe individuals with intellectual disabilities (Ziegler 1188). The medical model assumes that an individual’s disability is a problem to be cured by the medical system in order for the individual to better adapt to the environment

(Arstein-Kerslake et al. 415). In the twentieth-century, the term “mental deficiency” replaced “feeble-minded” as negative connotations for the latter became prominent (Ziegler 1190). In 1943 the term “handicap” was used in the Vocational Rehabilitation Act (1193), and the term continues to be used legally and colloquially to describe a restriction or limitation, even as it has garnered a negative connotation. In 1961 the term “mental retardation” entered mainstream language as a clinical diagnostic term, but over time it became a commonly used slur for people with or without disabilities (1194).

Later in the 1960s, disability rights activists pushed for the social model of disability to be incorporated into legal language to encourage full inclusion into society (Ziegler 1196). The social model implies that disability is a result of social, cultural, and environmental barriers, rather than an individual’s impairment (Arstein-Kerslake et al. 415-416). In 1970, the Developmental Disabilities Services and Facilities Construction Amendments used the term “developmental disability” for the first time (Ziegler 1197), and the Americans with Disabilities Act (ADA) passed in 1990 utilized the term “individuals with disabilities” (1200) and marked profound progress in the inclusion and recognition of disabled people in the United States. Rosa’s Law, signed in 2010 by President Obama, mandated the replacement of the term “mental retardation” with “intellectual disability” in many federal laws (1202).

“Intellectual disability” is typically used interchangeably with “developmental disability,” and definitions of the two terms indicate only small differences in the age of onset, the severity of limitations, and an IQ requirement (“What is an Intellectual or Developmental Disability?”). Both terms are used as clinical diagnoses but are also very broad, so it is impossible to know just how many people in the United States have an intellectual or developmental disability, or both. In my writing I use intellectual disability and developmental disability as umbrella terms to describe the individuals who comprise the focus of my research. I recognize that the term intellectual disability is not perfect, as it still indicates a deficit in intellect, which I hope to challenge through this project by highlighting the insights and wisdom of people considered intellectually disabled. I do not wish to suggest an alternative term to intellectual or developmental disability, as I believe that intellectually and developmentally disabled people should feel empowered to choose their own labels and descriptors.

Beyond the scope of diagnosis and identity labels, within the disability justice community there is an ongoing debate around person-first and identity-first language. The passage of the ADA reflected the use of person-first language, which emphasizes personhood before disability so as not to define someone by their disability (Ziegler 1211). Person-first language has long been considered the "politically correct" way to refer to people with disabilities, but many people within the disability rights community advocate for a reclamation of identity-first language to "reclaim disability and alter its connotation from one of shame to one of pride" (1212). Due to the validity of both claims to person-first and identity-first language, I will use both within my writing to reflect the complexity of desires within the disability justice community and disabled community at large.

2.2. Institutionalization and its Rationales

In "Five Centuries' Material Reforms and Ethical Reformulations of Social Elimination," Chris Chapman walks through the different rationales behind the institutionalization and killing of marginalized groups dating back to the sixteenth century. Chapman outlines the "moral economy" of the sixteenth century, guided by Christianity, which considered discrimination against non-Christains righteous and violence against disabled Christian people "divine justice"

(Chapman 26). This moral economy was challenged during colonial conquests when Indigenous people converted to Christianity, requiring colonizers to find a new justification for their subjugation; scientific racism emerged as a new rationale for colonial violence (27). In the seventeenth century, unapologetic violence was somewhat replaced in Europe and North America by confinement of "undesirable white people" (29). Poor and disabled white people were controlled through mass confinement, but enslaved and colonized people were still subject to "explicit and unapologetic torture and murder" (30). Throughout the eighteenth century the rationale for confinement remained as a method for social elimination of undesirable subjects, which contrasts greatly from later justifications of rehabilitation and assimilation (32).

Chapman notes the development of "the norm" in the mid-1800s, which rationalized the institutionalization of anyone deemed "deviant" or "other" (Chapman 34). Rosemarie Garland Thomson consolidates the nebulous concept of "the norm" into a named social figure: the normate. The normate is the desirable social image through which people can legitimize their humanity (Garland Thomson 8). Although it does not have material substance, the figure of normate underscores the rationale behind institutionalization. Those who did not meet its phantom standards were in need of rehabilitation, and anyone–at any point–could inhabit too much of the "other" and require institutionalization. As narratives of rehabilitation dominated the discourse around institutionalization, death within an institution was considered a "side effect" of confinement (Chapman 35), and an undesired (yet unsurprising) result. From the nineteenth century onward, institutionalization was determined as the method for ridding a person of the parts of them that were "disabled, degenerate, uncivilized, or criminalistic" (36).

The late nineteenth century saw the rise of the "idiot asylum," which was further hierarchized based on the perceived abilities of inhabitants, from those who could learn skills to those who were considered “hopeless” and placed in the “back wards” where they received no programming or training (Ferguson 53). This categorization based on perceived ability is a historical version of the residential, vocational, and educational “continuums” we see today that distinguish what services disabled people receive based on the perceived severity of their disability. Placing the history of institutionalization in a neat(ish) timeline reveals some of the continuities in rationale over time. These violent rationales linger today for disabled and non-disabled people alike in immigrant detention centers, solitary confinement cells, and perhaps even in the separation of the supported-living residential community from the wider community.

2.3. Disability Rights for Some

From 1946 to 1967 the number of individuals with intellectual disabilities held in institutions nearly doubled (Ben-Moshe et al. 10). The Civil Rights Movement along with abhorrent institutional conditions spurred disabled people and their families to seek out alternatives to institutional living. In *The Disability Rights Movement: From Charity to Confrontation*, Fleischer and Zames describe the process of deinstitutionalization as a process led by and for people with significant physical disabilities (33). They chronicle the Independent Living Movement through the profound work of Ed Roberts[3] suing the University of California at Berkeley to assert his right to a college education as a disabled person (38). Roberts’s work of starting the Independent Living Movement led to a proliferation of accessibility efforts across the country for people with significant physical disabilities, especially those who were subject to the dangerous conditions of an institution (43). The Independent Living Movement was vital to the deinstitutionalization of people with physical disabilities and the movement towards accessible cities and housing across the United States. In the wake of the Independent Living Movement,

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[3] Roberts had polio as a young child. He was a wheelchair user and relied on an iron lung.

people with intellectual disabilities remained housed in “idiot asylums,” with many locked away in the back wards.

It was not until the 1972 documentary exposé, *Willowbrook The Last Great Disgrace*, aired on television that people with intellectual disabilities were also considered in the fight for non-institutional, community living. In the film, Geraldo Rivera travels to Willowbrook, a public institution housing 5,300 residents, most of whom did not attend school or receive programming (Sproutflix 00:06:10). Willowbrook exposed the horrendous conditions intellectually disabled people were subject to, and the film advocated for community programming to support families in raising kids with disabilities, highlighting the services at the Children’s Hospital in Los Angeles (00:19:00). Geraldo Rivera’s film sparked a movement among residents, parents, and medical professionals to change–if not totally abolish–the institution. The process of deinstitutionalization began in the 1970s, but disabled people themselves did not yet have the tools or resources to express their personal desires beyond institutional reform and toward abolition.

2.4. (De)Institutionalization and Continuums of Care

The goal of community-based options was to shift from the warehousing logic of the institution to normalization, or the necessity of “making the retarded person act and be perceived as normal” (Wald 18). Materially, and more kindly, the normalization principle is expressed by Bengt Nirje as “making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream society” (Nirje 19). The principle of normalization advanced the movement for deinstitutionalization, but it maintained a logic of separation of intellectually disabled people from their non-disabled community members. Although Nirje's position was against institutions of the time (he wrote on normalization in 1969), he says that institutions and back wards *cannot* offer "facilities of the kind and quality that are essential" (22). What he means by "facilities" is unclear, but the reform-oriented position of most parent and professional advocacy movements reflects a desire to keep disabled people segregated, even if their segregated environments are "normalized."

An important movement against normalization and toward full inclusion could be found in self-advocacy groups. Self-advocacy groups were founded locally in the 1980s as spaces for intellectually disabled people and allies to organize against institutional conditions and for self-determination. Self Advocates Becoming Empowered (SABE) conducted the first national campaign against institutions entitled "Close the Doors" in 1994 (Friedman & Beckwith 238). As momentum grew among self-advocacy groups, individuals with intellectual disabilities began to feel comfortable sharing their experiences of trauma and abuse within institutions. These personal testimonies were instrumental to the litigation that guided the closure of many institutions throughout the United States. A vital aspect of self-advocacy movement members' praxis was the "unfaltering demand for universal emancipation for *all* of their incarcerated counterparts, and not just those perceived to be 'ready' or 'more capable'" (243). This commitment to full freedom for all people with intellectual disabilities continues in self-advocacy movements today, particularly because universal emancipation has *not* yet been achieved, and many people with intellectual disabilities still reside in state-run institutions or large living facilities that closely mimic the environment of an institution.

Emerging from the wave of litigation and institutional closure of the 1990s was the "continuum of care," which was advocated for by parent and professional advocates. Steven Taylor describes the continuum of care in terms of the principle of the least restrictive environment (LRE). The continuum exists as a spectrum of most-to-least restrictive services for people with disabilities. The LRE came about in the 1960s in the context of education, but the principle can now be applied to educational, residential, and vocational services (Taylor 219). Taylor criticizes the LRE principle and the continuum for their inclusion of the institution as an option, but he also worries about the continuation of the continuum after institutional closure. The continuum, regardless of what the most and least restrictive options are, creates a hierarchy of services available to individuals based on their perceived abilities (220). The LRE also assumes that people with significant disabilities cannot receive intensive services in a non-restrictive environment. In short, the existence of any restrictive environment is problematic and values some individuals over others. The continuum does not reflect the range of possibilities of supported-living or the demands of self-advocates for universal emancipation.

Deinstitutionalization is messy and unfinished. The process toggles between the advocacy of parents, professionals, allies, and disabled people themselves and ultimately lands us in a mixture of state-run institutions and private agencies and nursing homes. Lambs Farm does not fit neatly into this process. Lambs was founded in the 1960s first as a unique employment opportunity, then as an appealing alternative to institutional living (mostly for those lucky enough to avoid an institution in the first place). The complex functions and services of Lambs Farm–at present and throughout its history–are perhaps what make it such an important site of investigation. The entanglements of Lambs, the residents, and a history of institutionalization of intellectually disabled people are impossible to tease through fully, but the insights of the residents of Lambs Farm are the most apt place to try.

3. Methods and Methodologies

I spent the summer of 2023 at Lambs Farm earning my Direct Support Professional certification and working 40 hours a week in a few of the nine group homes. It was here that I witnessed the everyday lives of individuals who were much like the campers I spent time with in Colorado. What had once felt like an inaccessible, incomprehensible place quickly became my entire world. I started to understand the staff-resident, staff-staff, and staff-administration dynamics that maintained people's entire lives. Somehow this work felt extremely detached from my life at Vassar. This was technically a summer internship, but I had not met anyone at school who was interested in similar work, and the disability studies classes I had taken hardly touched on intellectual disability, and instead focused on people with disabilities who had produced academic bodies of work to contribute to the field. The category of "mental disability" was often the subject of one class session, covering psychiatric disabilities, mental illnesses, and intellectual disabilities in one fell swoop. Many of the residents of Lambs Farm had graduated high school and gone through a transition program, but many had not. Some could read, others could not. What work do they have to contribute to the field of disability studies? I was curious to find out.

The residents of Lambs Farm are central to this project, for it is only through disabled subjectivities that disabled futures can be imagined. Research itself can be a powerful tool for reasserting the subjectivity of marginalized people (Fonow & Cook 54), but qualitative research has historically harmed marginalized communities. Quantitative research may be useful to understand the adult lives of disabled people, but this project is conducted using qualitative research, with an emphasis on narrative and storytelling, to highlight the voices of the residents of Lambs Farm, which cannot be quantified. Rather than get stuck in this cycle of wondering whether research is helpful or harmful, it is more productive to accept and name everything research offers at once while working to resist oppressive tactics. I intend to interrupt traditional methods of qualitative research by relying on the first-person experiences of residents of Lambs Farm, which I was only able to access with openness and shared vulnerability with interviewees.

In "Feminist Disability Studies as Methodology," Stacy Clifford Simplican argues that our relationships should constantly put into question what we think we know about disability (Clifford Simplican 54); in other words, Simplican suggests that estranging our knowledge over and over again can expand our understanding of disability within our own lives. *Weaving an Otherwise* is a collection of Indigenous, Black, and decolonial methodologies that highlights interconnectedness as a core component of the research process (Tachine & Nicolazzo 10). The various authors in the book ask who we are bearing witness to in our research and what our research forgets, remembers, and reconciles (83, 85). We must attend to the lived experiences of our research participants with care, and we owe our knowledge of collective care practices to Black women. The importance of relationships within research can be summarized by this quote by Jackson et al. in "BlackLove Stories": "If by methodology we mean a fundamental conversation for how we show up with/alongside others in human-to-human encounters, BlackLove is everything" (qtd. in McGuire et al. 112). It is through human-to-human encounters that we can reveal the intricacies of living in a professionalized environment and start to imagine a more liberatory, disabled future.

As much as I try to approach my research with a liberatory framework, there are multiple limitations placed upon me that reinforce the neoliberal agenda of the university. Samuel Museus and Amy Wang acknowledge the pressure to rapidly create quantifiable "things" within scholarly research with no regard for what is truly best for people and their communities (Museus & Wang

16). I have taken this into consideration in my own project, but that does not change the fact that the senior thesis project has to be completed within one academic year and will receive a letter grade. In an ideal world, I would have spent days, weeks, or even months with the individuals I interviewed and even coupled my interviews at Lambs Farm with interviews at a larger state-run institution in Illinois.[4] In "Introducing a Human Rights-Based Disability Research Methodology," Anna Arstein-Kerslake suggests a human rights-based disability research methodology that includes disabled people in all aspects of research (Arstein-Kerslake 424). The involvement of intellectually disabled people in research projects that concern their rights is invaluable, but it is also near impossible within an academic institution that actively excludes those people from the world of scholarly research. Given the scope of my project and the institution I am working within, I can only hope that naming these limitations will begin to do the work of making the academy and qualitative research more largely inclusive and liberatory to the people and communities being researched.

My interviews could not have been conducted without the quintessential stepping stone to human-subject-oriented research at a university: approval from the Institutional Review Board (IRB). My request for exemption was denied in an email from a member of the Vassar IRB, who asked that I submit a full proposal to fully explain the capacity of my participants to give informed consent due to their "impaired decision-making capacity." In the following weeks, I put together a fifteen-page document detailing the information that would be shared with participants prior to conducting my interviews and the precautions that would be put in place to protect their identities and safety. I did not feel that this proposal had room for the teachings of BlackLove, or

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[4] There are six state-run institutions still open in Illinois: Choate, Ludeman, Fox, Mabley, Kiley, and Murray Developmental Centers ("State-Operated")

an inquiry into hauntology,[5] or the power of disability to estrange knowledge. I had to suck it up and prove that my subjects were consenting adults in order to proceed with a project that relied on the certainty that individuals with intellectual disabilities had just as much to offer to my thesis as I did.[6]

Upon receiving approval from the IRB, I engaged in the bureaucratic process that was scheduling interviews with people who I had no direct contact with. The CEO of Lambs Farm excitedly directed me to the Associate Director of Social Services who passed on recruitment and scheduling information to Case Managers within each home. The Case Managers then gave the information to residents, who could choose to participate in an interview. I made it clear in my communications with the Associate Director of Social Services that any resident could participate in an interview, regardless of communication style or literacy level. She assured me that would be taken into account and then passed the information to the Case Managers. This game of telephone resulted in 13 opportunities to sit down with residents of Lambs Farm within their homes and gain insight into how they perceived their lives at Lambs. I assembled a list of semi-structured questions (see Appendix A) to start the conversation with each resident, with space for silence and ample opportunity for them to share *anything* that felt important at that moment. What resulted from these conversations was a deep understanding of what it feels like to live in a setting like Lambs Farm.

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[5] Irene Yoon and Grace Chen explore hauntology as an attendance to the material and immaterial ways of knowing. They suggest that ghosts appear as reminders of institutional, sanctioned violence. They call on researchers to attend to the silences within interactions and make space for ghosts to interrupt cycles of structural violence that haunt pasts and futures.

[6] I would like to still acknowledge the work of the IRB to ensure the safety of vulnerable research participants. My experience only reflects the limitations to recognizing vulnerable people as simultaneously able to make informed decisions.

4. Lambs Farm

My conversations with residents are rooted in the history and geography of Lambs Farm and informed by my time working there. Lambs Farm has a unique history and has grown and developed over the 64 years it has been in operation. The following is a brief account of the creation and development of Lambs Farm, followed by a description of the layout of the Farm, and an account of my time working as a Direct Support Professional. I will then introduce the people who sat down to speak with me and walk through how I interpreted our conversations.

4.1. Lambs Farm as an Alternative to the Institution

> Between 1946 and 1967 the number of residents in institutions for people with intellectual disabilities rose from 116,828 to 193,188–an increase of nearly twice the increase of the general population
> —Ben-Moshe et al.

While the number of institutions in the United States skyrocketed and conditions inside of them deteriorated, Corinne Owen and Bob Terese opened the Lambs Pet Shop in Chicago. Owen and Terese's idea to run a pet shop that employed people with intellectual disabilities was at first fiercely rejected by figures within the world of disability services for adults in Illinois. The two were fired from the Hull House in Chicago for their refusal to forfeit their plan to open the pet shop (Unsworth 58), and in 1961 Lambs Farm was operating on State Street with 12 intellectually disabled employees, or "Lambs." The term "Lambs" comes from John 21:15, where Christ orders his disciples to "Feed my lambs," (3) but the term "Lambs" is no longer used to describe residents of Lambs Farm and the Farm itself has no explicit religious affiliation. Employees of Lambs Pet Shop were keenly aware of their position as non-institutionalized individuals, and they often sent gifts to people institutionalized at the Dixon state institution in Illinois (81).

In 1965, generous donation from philanthropist W. Clement Stone enabled Owen and Terese to purchase 70 acres of farmland in Libertyville, Illinois to expand the mission of Lambs Pet Shop and create “a kind of ideal community where retarded adults could live and work” (Unsworth 105). New and former employees of Lambs Pet Shop began commuting to Lambs Farm to work at the ever-expanding businesses on the property. In my conversation with her, Lena recalls commuting for seven years before the opening of the residential dormitory in 1976. Although she lives off-site now, Lena orients her knowledge of Lambs Farm geographically: “When I came there was nothing south of the pet shop and nothing west of the pet shop.” She remembers the group homes being built in 1980, specifically the construction of House I[7] being followed by House J so the earth between the houses could “settle and stuff” (Lena). Lena is proud to have watched Lambs Farm grow from one pet shop to a network of residences and businesses.

4.2. Getting a Lay of the Land

In high school I participated in a class called Integrated Physical Education (PE), where I took gym class with students in the special education program. I was paired with a “buddy” from the special education class each month and we worked through each PE unit as a pair. Sometimes we went on field trips, one of which was to Lambs Farm. At Lambs Farm we walked through the barn area to see all of the animals, took the “train ride” around the farm, and roamed the thrift shop. Because our time was limited, we missed out on visiting the Magnolia Cafe and Bakery, Visitor’s Center, and Sugar Maple Country Store.

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[7] All house names have been anonymized.

In 2023, around four years later, I found myself back at Lambs Farm driving past the public-facing farmyard and stores to the Founders Building to start orientation for a summer job as Lambs Farm's first ever "Direct Support Professional (DSP) Intern." I would try to complete my DSP certification within three months while working 40 hours each week in the group homes. The Founders Building houses the administration of Lambs Farm, which is made up of professionals within the disability service and non-profit world alongside residents and commuters of Lambs Farm who work as receptionists, janitorial staff, and data entry personnel. The Founders Building also houses the gym, where residents participate in programming and daily exercise.

Past the Founders Building is the Green-Field Intermediate Care Residence, which houses 12 residents who receive around-the-clock support to meet their needs. The W. Clement and Jessie V. Stone Apartment Building stands past Green-Field with around twenty individual apartment units where residents can live more independently with their own kitchens, bathrooms, and bedrooms. On the other side of the road from Green-Field and Stone, there are nine campus group homes, each housing 10-12 residents with staff who work two daytime shifts (7am-3pm and 2pm-10pm) and a sleep shift (10pm-7am). Staff in the group homes prepare three meals each day for residents, with sack lunches packed every night for residents to take with them to work or the Enrichment Center (see Appendix B for definitions of Lambs-Farm-specific terms). Each home has a shared living room, an office for the Case Manager, individual rooms for residents, a few shared bathrooms, a kitchen and dining area, and a laundry room.

Each day I learned something new about Lambs Farm and the people who lived there. My shifts were Monday through Friday, 2:00pm to 10:00pm. My initial work was shadowing other Direct Support Professionals, many of whom kindly explained to me how they went about cooking meals, packing lunches, documenting behaviors, and communicating with residents. I could not legally work alone or administer medication until I received my official DSP certification, which did not happen until close to the end of the summer. Many of my coworkers had been DSP and medication certified for years, if not decades, and fell easily into the routines of the job. Slowly but surely I picked up on the rhythm of the domestic work and grew relationships with the residents, all of which felt conditioned on my leaving at the end of the summer. Once I was DSP certified, I treasured my shifts worked alone. I moved at my own pace and at the pace of the residents and fell into a routine. I had a handle on who showered when, what dinner would look (and taste) like, and once residents went to sleep I documented behaviors from their Individual Support Plans and settled into the couch with a book until the end of my shift. My shifts alone allowed my relationships with residents to grow, but the end of summer loomed, and I knew I would have to leave this world I had been graciously allowed into for just a few months.

4.3. Returning to Lambs Farm; Introductions

I conducted my interviews of Lambs Farm residents over the course of one week in January 2024. Ten interviews took place in the group homes and three interviews were conducted at Lambs Farm-owned homes located within the wider community, about a five minute drive from the Lambs property. These are called Community Integrated Living Arrangement (CILA) homes. Each interview ranged from around five to thirty minutes, depending on how much residents wanted to share and how many of my written questions we discussed. I brought a list of semi-structured questions to each conversation (see Appendix A) but approached the interviews with the goal of letting residents expand wherever they felt necessary and share whatever they felt comfortable sharing. I wrote my questions with the hope of gaining a broad understanding of what a life at Lambs Farm consisted of and how residents felt about living there. In total I interviewed 13 residents of Lambs Farm, and 10 interviewees consented to our conversations being audio recorded.

Deborah is wearing pajamas and her brown hair is still wet. She is a white woman who appears to be in her mid-thirties to early-forties. When I ask how old she is, she takes a long pause and responds, “Uh, uh, I like- I like my house.” She lives in House D, where she recently moved from House F, a CILA house in a nearby neighborhood. Deborah works at the bakery and hopes to work at the greenhouse when its construction is finished. She mentions six times during her 11 minute interview that she “just got outta the shower.”

Maura asks to do her interview early because she is going home to her parents’ house for the weekend. She is a white woman and does not share her age, but she appears to be in her forties or fifties. She moved to Lambs Farm “10 or 12 years ago” from her parents’ house in Ingleside, IL. Originally she lived in House B, which “didn’t go so good,” so she moved to House D. She is wearing overalls, a beanie, and glasses, and she plays with a ring on her finger throughout the interview. Maura works off-site at a shop that grows herbs and microgreens, although she may have worked at the sheltered workshop at Lambs Farm before getting her current job. She describes a simple, happy life at Lambs Farm, saying “I just like it here a lot,” and “I’m just happy here.”

Bethany and I met when I worked at Lambs Farm. She would spend time with her soon-to-be boyfriend, Peter, who lived in a house I spent a few shifts working in. The two of them played Wii in the living room. She is white, likely in her thirties or forties, and has Down Syndrome. Bethany was supposed to move into House H in 2019, but COVID pushed back her arrival to 2023, at which time she moved into House A. She works at the bakery and does filing with Health Services. Bethany worked in the restaurant starting in 2013 and used to commute to Lambs by taking the train. Bethany likes to keep busy with a consistent work schedule and Quest classes. She is currently in a mixed media arts class, on a cheerleading and dance squad, and in a Quest class called “Helping Hands.” Bethany is also the representative of House A, so she attends board meetings with other representatives to talk about what can be fixed or improved around the homes and job sites.

Theresa is 63 years old and has lived at Lambs since she was 40. She is white and very short with gray, short hair. She uses a walker around and outside of the house, and she is wearing a green “Lambs Farm Choir” shirt. She has been retired for a while and spends her days at the Enrichment Center with other retired residents for games, programming, and exercise. Two of her housemates, Dianne and Ali, also attend the Enrichment Center. They coincidentally also use walkers. Theresa recalls living in Houses A, G, and C. I worked in House C often and spent considerable time around Theresa. She does not leave Lambs very often, can appear to have a negative attitude, and her speech patterns can be difficult to understand upon an initial listen. But when given the opportunity to sit down and talk one-on-one, Theresa is able to express her feelings, desires, and opinions with clarity.

Ali’s interview is not audio recorded, but she describes her life at Lambs Farm as “happy…smile” and “help my friends…help Dianne and Theresa.” Ali is 46 years old and Japanese-American. She uses a walker inside and out of the house and lives in House C. She goes to the Enrichment Center during the week where she has free time, talks, and plays games. She sees her mom every Saturday and takes an annual trip to Japan to visit family. I worked with

Ali very closely in House C, and she greets me with a big hug when I come to conduct her and Theresa's interviews. She likes joking and sarcasm and takes good care of the people around her.

Catherine is wearing a leopard print, matching pajama set with no shoes or socks when I arrive at her house at 1pm on a Friday. She is 37 years old, white, and has Down Syndrome. She moved into House A in 2024 and she cleans at the bakery. She is still adjusting to life at Lambs Farm and reminisces on living with her parents. She goes home "once in a while" and recently took a trip to Colorado for her brother's wedding. She does basketball and book club.

Lena started commuting to Lambs Farm in 1969 at 21 years old, before any residential homes were built. She commuted to work until the dormitory opened up, which housed around 32 residents and is now the Health Services building. Lena has worked many jobs at Lambs Farm, but she currently works part-time in Founders Building doing accounting and filing. She had a twenty-year-long career with Allstate on their support staff doing claims filing, beneficiary validation, and name and address changes. Lena is white and has short, gray hair. At 77 years old, she prioritizes working and attending art classes. Lena is proud to be a part of Lambs Farm history as one of the oldest residents, and she enjoys living in a five-person home in a neighborhood off-site (House E) compared to a 12-person group home on campus.

Morrie navigates to the office of his neighborhood home (House F) by guiding his hand against the wall. He is not thrilled with my timing because the Broncos and Bills game is on, but once we begin talking he has much to share about his life. Morrie moved into the dormitory in 1987 after commuting for years. His mom used to drop him off for work on her way to her own job. Morrie prefers to live off-site, and he enjoys going to church on Sundays. He works at the farmyard in the summer and shreds paper at Lambs Industries in the winter. He does not enjoy cleaning but he does enjoy Disney and football.

Margaret came to Lambs Farm in 1980, and has lived in a neighborhood house (House E) since 2000. She is 65. She and Lena are longtime roommates. She enjoys living in the neighborhood because she has more “flexibility” and does not have 24-hour staff. Margaret works two jobs, one at Founders Building doing data entry and the other at the restaurant. She goes to a local church and is participating in a class at Lambs called “Faith in Fellowship.” She has a hard time getting out in the community because it is difficult for her to walk on uneven ground. She values the people she has met through Lambs Farm and plans to work as long as she can. Margaret misses doing plays before the pandemic, and she is looking forward to a theatre class starting up again soon.

Rodney’s hair is more gray than the last time I saw him, and his stomach protrudes slightly further. Rodney has lived at Lambs for “I’m guessing long time,” and he values his relationships with staff. He works at the restaurant and the Visitor’s Center and likes both of his jobs, but he hopes to work at Walmart someday. He would like to go on a Rainbow Run (see Appendix B) and eventually move to the Stone Apartments.

Sasha begins her interview with her early life, and she has much to share about life at Lambs Farm. She moved to Lambs Farm after her father passed away. She makes many choices throughout her interview to keep specific details out, and she clarifies what she does and does not want included. Sasha works at Lambs Industries and loves her job. She explains in great detail the tasks she does and the purpose of her work. Sasha spends ample time going through who is and is not allowed into her room; she values her personal space very much. She lives in House D. The latter part of her interview consists of questions for me, about how I got into “this line of work” and her friends who used to attend Camp Pine Tree.

Ethan answers the door of House B excitedly, and his interview lasts around six minutes. He did not have friends at home, so he is grateful for the friends he has at Lambs Farm. He works at Lambs Industries and has a job off-site doing "hammering and stuff." He leaves Lambs for the bank run and Rainbow Run. His least favorite part of living at Lambs Farm is missing his mom, who he saw the morning of his interview. I run into Ethan many more times over the next few days as I wait for Rachel to free up for her interview. He always answers the door and welcomes me inside.

Rachel is wearing at least two Special Olympics medals around her neck during our interview. She commuted to Lambs Farm starting in 1980 but moved in after her mom moved into a nursing home. She has always lived in House B. She works the same two jobs as Ethan (Lambs Industries and the same job off-site). She enjoys living with other people and leaves the Farm to see her brothers. She also enjoys Special Olympics and likes to keep busy with classes and activities. She hopes to go on more vacations.

4.4. Listening and Interpreting

I utilize Christine Woodcock's "The Listening Guide: A How-To Approach on Ways to Promote Educational Democracy" as a guide for listening back and better understanding the (audio recorded) conversations with residents. Woodcock interprets Gilligan et al.'s The Listening Guide[8] as a "qualitative, relational, voice-centered, feminist methodology" (Woodcock 1) that seeks to intentionally listen to voices who have been historically silenced. Particularly informative to this analysis is Woodcock's understanding of "'I' poems" as a method of listening

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[8] The Listening Guide (LG) is centered around questions on voice, stories, relationship, and societal and cultural frameworks (Gilligan et al. 255). The LG is important because it does not quantify the data, but rather listens to the text and attends to the voice of the subject. Gilligan et al. propose multiple listenings to attend to the multiple voices that may be co-occurring within a person's psyche (256).

for how the informants “speak of themselves in relationship to themselves and others” (4). Woodcock also proposes using other pronouns such as “we,” “they,” “it,” and “you” to enhance the data pulled from “I” poems. Woodcock’s methods for listening are foundational to how I grasp meaning from the conversations I held with residents of Lambs Farm.

My analysis is separated into three overarching themes of community, choice, and independence, which I identified in my initial research as key subjects in the conversation around adulthood and intellectual disability. Within and across these themes are sub-themes of the experience of moving to Lambs Farm; goals and plans for the future; work; interpersonal relationships; strong likes and dislikes; non-work activities; leaving Lambs Farm; old age; attention to dates and details; interaction with the interviewer (me); and pauses, silences, or gaps in memory during conversation. These sub-themes did not all appear in every interview, but they were each present in at least one recorded conversation. These themes guide my analysis of the subjective experience of living in a group home setting.

5. Perceptions of Community

When Bob Terese and Corinne Owen purchased land in Libertyville, Illinois, they envisioned Lambs Farm as “a kind of ideal community where retarded adults could live and work…a desperately needed alternative to the institution” (Unsworth 105). The movement for deinstitutionalization (which picked up around the same time the first residence emerged at Lambs Farm) is framed as a move toward community-living, but what *is* community-living? During deinstitutionalization, “community” was defined as a negation, or any place of living that was “not” a hospital or institution (Ben-Moshe 257), so moving intellectually disabled people out of institutions was enough to be considered community-living, even though adequate supports were not in place within neighborhoods, towns, and cities. In “The Contested Meaning of ‘Community,’” Liat Ben-Moshe encourages moving towards a positive definition of community that combines physical location and feelings of belonging and kinship. She acknowledges the blurry line between “institution” and “community,” considering the various ways segregated or institutionalized people create community within and outside the boundaries of their residences. The residents I spoke with appear to conceive of community in multiple different ways: through their use of “we” when talking about their lives and relationships within Lambs Farm; through the structured communal activities offered by Lambs Farm; and–for CILA residents–through their connection (or lack thereof) with the neighborhoods they live within.

5.1. “We” as an Indicator of Community

The multi-dimensional nature of Lambs Farm as a residence, place of employment, and recreational setting offers different sites where residents feel a part of a group. Residents also conceive of separations between themselves and others living on the Farm, people who they may not feel in community with. Bethany uses “we” when referring to everyone who works at the bakery with her. She says her favorite part of her job is the catalog season, when “we get really, really busy…We bake and decorate cookies” (Bethany). Bethany also uses “we” when talking about her and her boyfriend. Deborah uses “we” to describe her house, telling me “we’re having tacos tonight,” (Deborah) and this is the only time she uses “we” in our conversation. In this statement, Deborah expresses a feeling of connection to a specific part of the house’s routine where they all sit down to eat the same meal together each night. Lena and Rodney both use “we” when referring to themselves and one close friend. Lena talks about her and Margaret as “we,” since they have lived together longer than she lived with her two brothers (Lena). Margaret and Sasha also use “we” when talking about coworkers or residents of their homes. Bethany, Deborah, Lena, Rodney, Margaret, and Sasha all show a distinct identification of a sense of belonging with some group of people, whether coworkers or friends or household members, which is not the case for every resident I spoke with.

Most times Theresa uses “we,” she includes “um” or “uh” shortly after. It is not uncommon for Theresa to stutter when beginning a sentence, or to repeat the first few words twice before finishing her thought.[9] But Theresa has also lived at Lambs for over twenty years, so her conception of who “we” is has likely changed as residents and staff have moved in and out of her house and programs. Although Theresa identifies with some collective “we” who “play games” or decorate a Christmas tree (Theresa), her use of “uh” and “um” may speak to the instability of who truly belongs in that “we,” and who exactly Theresa sees herself in community with in the long term.

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[9] “I am- I am– I’m– Right now, I’m 64,” “I-I-I don’t know,” “They-they used to have the–uh, they used to have the horse races” (Theresa).

Catherine, Morrie, and Maura do not use “we” at all when talking about life at Lambs Farm. Catherine’s lack of the use of “we” may express a lack of identification with any community within Lambs while she acclimates to the environment (she moved to Lambs less than a year before her interview). Morrie and Maura, on the other hand, have lived at Lambs for over a decade. Does their lack of the use of “we” indicate a lack of belonging? Or has their life at Lambs Farm been largely individualized? Morrie moved around to multiple homes within the community and on Lambs property before ending up in the CILA home where he held his interview. Maura has lived in House D the entire time she has lived at Lambs, and she is not without activities and friends to keep her busy. She has an off-site job, mentions her best friend who lives in her house, and is on a golf team (Maura), but she does not seem to view these sites as places of collectivity or community. Is this because her routine is somewhat constructed for her? What would it take for Maura to feel in community with the people she spends her days with?

One of the contributors to individualization at Lambs Farm is the Individualized Service Plan (ISP), which is a tool used by the agency and the individual to track supports needed to achieve personal goals. An ISP looks like a long packet filled with an individual’s life goals, life changes, medical and personal history, assessments (physical and occupational therapy, IQ, etc.), financial status, and visions for the future (*Module* 4, 41-43). A resident meets at least once a year with members of an Interdisciplinary Team (IDT)[10] to update their ISP. ISPs are designed to be person-centered, and to include the resident in the planning of their own life and supports (13). ISPs contain at least one measurable goal and the methods that will be used to achieve that

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[10] One member of the IDT must be a Qualified Intellectual Disabilities Professional (QUIDP). The rest of the IDT may include a psychologist, social worker, doctor or nurse, Direct Support Professional, nutritionist, occupational therapist, residential representative, day program representative, or job coach. Non-professionals can also be invited to an ISP planning meeting, such as family members, guardians, friends, or coworkers (*Module* 9).

goal. Some examples of goals are independent medication administration, cooking skills, or computer skills. In theory, it sounds exciting to be present in developing an individual's ISP and taking an active role in helping that person achieve their realizable goals, but the work of a DSP can override staff members' abilities to work one-on-one with residents on each step of their goals.

Petner-Array and Copeland observe that intellectually disabled residents of supported-living communities expressed dissatisfaction with the rigidity of a formal support plan, especially when they lost interest in the goals identified in their support plans (Petner-Array & Copeland 43). I remember working with one of Sasha's friends, Samuel,[11] on his goal of preheating the oven. Samuel's vision was significantly limited, and he did not show any interest in cooking outside of the times we stood together at the oven trying to preheat it. We could return to the oven as many times as we wanted, but I did not sense any motivation from Samuel to preheat the oven on his own, and there was no way we could will his vision to be any clearer. Bethany was the only resident I interviewed who I spoke with about her ISP goals, but all other residents answered more broadly about goals they had, like moving to the Stone Apartments (Catherine, Rodney) or doing their own laundry (Deborah). The ISP is a guiding document for staff and residents alike, and DSPs are required to document resident's progress on their goals and the occurrence of behaviors identified in the ISP as needing to be tracked. The ISP also individualizes a resident's life at Lambs Farm by closely monitoring specific behaviors and goals, which may be a barrier to residents seeing themselves in community with others on the Farm. I wonder if there are ways to imagine an individual's goals and behaviors in conjunction with the goals and behaviors of their peers, especially those they live in such close proximity to.

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[11] Pseudonym

5.2. Built and Structured Home Lives

There are some parts of life at Lambs Farm that can be barriers to community for some and creators of community for others. The placement into a group home can aid residents in being in relationship with peers but can also be a source of stress or annoyance. Lena–who lives in a CILA home–explains that she much prefers the four to five person setting of her home compared to the 10 to 12 person setting of a group home on-site at Lambs Farm, where she would have to “get used to 12 personalities” (Lena). Lena acknowledges that even in a house of four or five, everything is not perfect: “Sometimes we get along, sometimes we don’t, but that’s family so it’s like that” (Lena). Other residents mention liking the people in their houses: Maura says, in her house, “Everybody’s friendly here,” (Maura) and Rodney says “Me feel like-like my-like I got friends living in this house- this house,” (Rodney). Maura notably describes the people in her house as “friendly,” not as her friends, which could speak to her lack of the use of “we” in her interview. Similar to Lena, Rodney mentions “I get along with some people, some people I don’t get along,” while accepting that that is just the way of life in a group setting.

Some residents mentioned specific issues they had with people in their houses as a source of annoyance or mental health difficulties. Bethany considered moving out “‘cause of all the drama in this house,” (Bethany) and she states that the really “got to” her mental health. Catherine says living in her house (the same house as Bethany, a house with all women) is “just weird” and her roommates can be loud and slam doors, but “they can’t help it” (Catherine). Catherine recognizes that her roommates may not be able to control their volume all the time, but she still feels uncomfortable, as this is her first time having roommates. Catherine hopes to live in a “tiny Stone apartment” (Catherine) to remove herself from the drama she feels a part of within her house. Deborah says she gets annoyed by her roommates in the mornings when she wakes up, and Morrie moved from his last house to his current house because he was having problems with another resident. There are levels to group home living: the agency has to manage who lives in which house and residents have to balance living with people they may not get along with. Catherine mentions Bethany as someone in her house who is nice, and I ask if the two of them are good friends. Catherine responds they are “Just housemates” (Catherine). Catherine seems slightly resigned to the fact that the best version of her current living situation is having housemates who are nice, and they don’t have to be her friends. This is not an uncommon perspective to have in any shared living situation, but Catherine was placed in House A, and the process of moving would likely be lengthy and involve many people in the decision, not just Catherine. Liat Ben-Moshe highlights the importance of relationship in community, and Catherine’s outlook calls to question how relationships can feel important when they are imparted upon a person by geographical proximity, not by choice?

5.3 Keeping Busy and Leaving the Farm

There are a variety of activities that take place on the Farm for residents to participate in voluntarily. There are also some opportunities for residents to leave the Farm on supervised individual or group outings, which include Rainbow Runs (see Appendix B), bank runs, and an occasional house trip to Walmart or another store accompanied by staff. Most of the residents I interviewed mentioned taking part in Quest classes (see Appendix B) and Special Olympics. These activities construct an inner world at Lambs Farm, where residents take part in recreation amongst themselves and the staff running the programming. Bethany keeps very busy with mixed media arts, cheerleading, painting, and an on-site job (Bethany). Rachel does basketball, swimming, snowshoeing, and various Quest classes when they are available (Rachel). The aforementioned activities all take place on Lambs Farm property, aside from Special Olympics meets and tournaments that may be held elsewhere throughout the state. Ethan enjoys leaving Lambs Farm for Rainbow Runs (Ethan), which Rodney wishes he could attend. Rodney cherishes the idea of going on an outing by himself, but he says he doesn't know how to "get into it" (Rodney), indicating some sort of barrier to attending those independent outings. Since Morrie and Margaret live off-site, they attend local churches and are each driven by church members. Morrie enjoys going to church, and he participates in the men's club when it is running (Morrie).

There is no doubt that residents of Lambs Farm keep busy, but they primarily keep busy within their own circles. The construction of a social and recreational world upholds Nirje's idea of normalization, or a replication of the norms and patterns of everyday life for disabled people (Nirje 19). Normalization as an idea was instrumental in the push for deinstitutionalization, but normalization does not discourage segregation of disabled people from their communities. The people of Lambs Farm do not attend community art classes or participate in community theater productions; everything is done within Lambs Farm. Although residents' social lives are vibrant as they are, what is the wider community missing out on from relegating these activities to the confines of Lambs Farm?

6. Perceptions of Choice

The knowledge of residents can be shared beyond the confines of the Farm through my mediation as an outsider, sharing what was shared with me, but this is only made possible through the decision of residents to sit down and tell me about their lives. One of the primary aims of my conversations with residents of Lambs Farm is for residents to choose what to share, when to share it, and who to share it with. Every resident at Lambs Farm was made aware of the opportunity to be interviewed, but I was insistent that I would only like to speak with residents who expressed a desire to speak with me. I prepared to accommodate any communication styles, but it happened that all residents I spoke with conducted their interviews verbally. The one trait that all of the residents I interviewed have in common is that they *chose* to speak with me.

Residents of supported-living settings are typically perceived as highly vulnerable to risk, which can result in their protection being valued over their autonomy (Petner-Arrey & Copeland 42-43), which was apparent in the process of receiving approval from the Vassar IRB (see "3. Methods"). Petner-Arrey and Copeland define autonomy as a person's "freedom from both internal and external constraints, to formulate and pursue self-determined plans and purposes" (39). The people of Lambs Farm, although they live in an environment where their choices are restricted to few options, find unique ways to assert their autonomy, some of which I observed during interviews. Catherine and Theresa did not have much control over their moves to Lambs Farm, so they find moments of agency in the process of telling me about their lives. Rodney and Lena share their opinions on the Stone Apartments and offer some insight into if and how residents choose where they live. Theresa and Sasha both share some of the restrictions on Lambs Farm and how they make choices within those frameworks. Sasha's entire interview serves as an example of asserting agency, as she makes many choices throughout our conversation to maintain control over the stories she tells.

6.1. Moving to Lambs Farm

Maura recalls receiving a call from Lambs Farm that they had an opening in the group homes: “I’m glad that Lambs Farm called me…I was shocked…I was like ‘What! Lambs Farm? What do they want?’ And, they told me they had opening” (Maura). Margaret says Lambs Farm was “the best” her family could find, but she was disappointed to find out that there were no condominiums on-site, “just houses” (Margaret). Sasha’s mom found Lambs Farm after her father’s death: “My mom had to get me into a place where I could be, um, you know, take care of myself and do my own thing…and that’s when they found this place” (Sasha). Rachel similarly moved to Lambs Farm once her mom moved into a nursing home (Rachel). Most residents of Lambs Farm spend over a decade on the waiting list before moving in, and many families jump at the opportunity to move a family member into such a highly coveted residential facility. Not all residents view their moves to Lambs Farm with as much excitement as Maura and Margaret or as much necessity as Sasha and Rachel.

Catherine and Theresa–although they have lived at Lambs Farm for drastically different amounts of time–demonstrate less agency over their moves to Lambs. Theresa says she has lived at Lambs Farm “since 40 [years old]” and she is now 63 years old. She lived at a different institution before Lambs Farm, remembering that “they got different staff” but forgetting the name of the institution (Theresa). When talking about her move to Lambs, Theresa says “I used to live there and-and then they put me over here…they moved me to House, uh, [A]…then moved me to House [G], and then they moved me to House [C]” (Theresa). She never specifies who “they” are, but these anonymous actors were responsible for four different moves of Theresa and everything she takes with her to make a place a home. Theresa says “used to” eighteen times throughout her interview when referring to where she went to school, where she worked at Lambs Farm, and activities that were held on the Farm in the past such as horse races and games. Theresa’s understanding of her life is narrated through her perceptions of her past and the experiences that have brought her to this office, in this house, on this day. Even if she cannot remember the name of where she used to live or where exactly she grew up, the act of sitting down to tell her version of her story is a powerful display of choice. Near the end of her interview, she claims “I like sitting down with you,” which is one of only two times she says “I like” or “I love” in our entire conversation.

Catherine is only 37 years old, and she moved to Lambs Farm on Memorial Day of 2024, not even a full year before her interview. Catherine never says the words “I moved,” or even “They moved me” in relation to her transition to living at Lambs Farm. When asked if she likes living with other people, she responds “Just my parents” (Catherine). She does not hesitate to name other residents or co-workers who bother her. Her troublesome relationships with other residents and employees seem to be the catalyst for her wanting to live in “a tiny Stone Apartment” (Catherine). When asked if she sees herself living at Lambs for a long time, she responds “A little bit,” and that she is “Looking forward to move out of this House [A]” (Catherine). Catherine hardly uses any active language to describe her living situation at Lambs Farm, perhaps reflecting a lack of agency she feels she has over her life. Theresa gives us a glimpse of what this lack of agency can look like twenty years after living at Lambs Farm, but sitting down to tell her story proves to be a powerful way to reassert power over her own narrative.

Catherine demonstrates an assertion of agency when she brings up topics unrelated to the direct questions I ask and asserts a desire to continue her interview. Catherine reflects on being a part of the Special Recreation Association of Central Lake County (SRACLC) and the friends she had within that program. Unprompted, she says “I just made a basketball team here,” (Catherine) drawing a connection between her past and her new life at Lambs Farm. Catherine later talks about how she has been sick the past week, resulting in her missing an activity, but she is with me in the interview now. I tell her we can end the interview at any point if she has somewhere to be, and she responds “No,” (Catherine) actively deciding to continue talking with me. Although she is not as direct as Theresa in saying she enjoys talking with me, Catherine’s decision to continue the interview is a clear display of agency.

6.2. Residential Options

Beyond just living at Lambs Farm, many residents feel particularly about the setting within Lambs in which they reside. Rodney lives in House C with ten roommates, but he expresses a strong desire to live in the Stone Apartments, where residents have their own bedroom, bathroom, and kitchen. Rodney says he likes that in Stone “The-the-the person did– they do their own stuff, cooking, their laundry, all that good stuff” (Rodney). He admires the household tasks that Stone residents complete without assistance. He says he is “gonna try to get good” in order to “move over there” (Rodney). Stone Apartments are only open to current Lambs residents, so everyone who resides in them used to live in a group home or a CILA. The waitlist is long, and it is required that residents of Stone have strong housekeeping skills, as they are responsible for the upkeep of their apartment unit. Rodney perceives this skillset as being “good,” but he also recognizes that he would have to “get good” in order to move to Stone.

Although he does not share exactly why he does not yet live in Stone, Rodney demonstrates an understanding that that option is not currently available to him.

Lena, on the other hand, moved to Lambs Farm long before the Stone Apartments were built. She enjoys the small, family-style CILA home she lives in compared to the 30-person dormitory (which is no longer in use as a dormitory) or a 12-person group home. I ask if she ever considered living in the Stone Apartments. Lena says, “They didn’t have that when I- when I was out around” (Lena). We go back and forth while she considers the Stone Apartments:

> Kelly: Yeah. Would you have been interested in something like that?
> Lena: I don’t know. Wasn't really available. I mean--
> Kelly: Yeah.
> Lena: But it-it-it's nice living with people.
> Kelly: Yeah.
> Lena: Even at Stone-- You’re with them but your apartment’s sort of separate so…
> Kelly: Right. You have your own space. And here you have your own room, so still have your own space.
> Lena: But, yeah, if that was available, maybe. Yeah.
> Kelly: Who knows, right?
> Lena: [laughs] it wasn’t available. (Lena)

Lena seems to understand her goals in terms of the options she knows she has within Lambs Farm. Since she lives comfortably in her CILA home, she does not consider Stone to be an option for her right now, even though it is technically available for any Lambs resident who has the required skills to maintain an apartment. Because the Stone Apartments were not available at a time when Lena was moving residences (or wanted to move residences), she considers the apartments a non-option.

6.3. Finding Agency within Restrictive Frameworks

There are smaller life choices that residents of Lambs Farm make within the limitations of the setting. In each interview I ask residents if there is anything at Lambs Farm they cannot do that they wish they could. Deborah says she “can do pretty much anything” (Deborah). Margaret says, “Not really, because I know I can’t drive” (Margaret); Lena similarly expresses a desire to get a ride more easily (Lena); and Rachel also says she wishes she could drive a car. An inability to drive is likely a result of not being put in driver’s education at a young age, which Lambs Farm has little control over. Theresa responds to this question saying that she would drink beer if she could, but beer is “off limits” (Theresa). She quickly follows this up by saying, “I can drink pop.” This addition is striking to me, as Theresa navigates a limitation of her supported-living situation by mentioning something she does have control over, which is her ability to drink pop. Theresa is recontextualizing this restriction to assert agency over the situation.

Sasha has a unique restriction imposed on her specifically, which is that she does not have a key to the fridge and pantry. The Illinois Department of Human Services (IDHS) requires that individuals living in waiver-funded Home and Community Based Services (HCBS) “must have access to food at any time,” (Illinois) unless they have a specific modification to their personal plan (ISP). There are a number of residents at Lambs Farm who–for reasons ranging from health requirements to hoarding and/or overeating habits–do not have access to food at any time and do not have individual keys to the pantries and fridges. In her interview, Sasha shares, “I used to have a key for the pantry. Because we always- we always get our own,” but she no longer has a key because “Some things went wrong in the past” (Sasha). There are laws in place, such as the IDHS regulations, to ensure that residents of supported-living settings in Illinois are guaranteed access to their wants and needs, but there are also stipulations that allow for those regulations to be changed. Sasha is one such example. She does not spend any more time talking about this restriction, and she moves excitedly onto the next question, possibly indicating that she is embarrassed or uncomfortable talking about a restriction she faces at home.

Aside from this moment of discomfort, Sasha's interview is the longest, most in-depth interview I conducted at Lambs Farm. My interview begins with me asking Sasha to tell me about her life at Lambs Farm, and she begins with her early childhood. It is clear that Sasha feels excited to tell me about her life, and she opens up quickly and easily. Sasha very clearly takes any opportunity she can to assert agency over the conversation and maintain control. She asks for multiple things to be left out of the interview and asks for clarification multiple times:

> You can keep it out of the interview if you want…And this is confidential. Uh, is this confidential?…I-I-I wanna- I wanna share with you, but don't put it in the- in the article…So you can keep it out…So you don't mind doing it, do you?...I just wanted to make sure I can trust you. (Sasha)

I make an effort to explain to Sasha the precautions I am taking to protect her anonymity and that she can share anything with me, but if she clarifies she does not want me to write about something she says, I will not write about it. Once I explain this to her, she says, "Thanks. [chuckles] Now I can trust you" before going on to share information she does not want me to write about. Sasha's trust in me is established over the course of her interview, and she continually brings us back to this point of confidentiality, making it very clear what she does and does not want included in my writing. Whether what she is sharing is truly confidential (she hasn't shared it with others in her life) or not is not of importance. What matters is that Sasha takes every opportunity she can to make a choice, simply because she can.

A prominent theme of the content of Sasha's interview is privacy. At various points throughout our conversation, Sasha mentions the importance of people staying out of her room, at one point listing the names of people who are and are not allowed. She says, “I have a lot of rules, and the main one is, never come into my room and never come in and-and never see what I’m doing here” (Sasha). There are certain regulations around residents’ rooms, specifically that any staff or other resident must have permission to enter, but Sasha frames this regulation as her own to emphasize the importance of privacy to her. Snapshots of Sasha’s use of “I” in her interview demonstrate her insistence on restricting access to her room:

> I have my own space…I have a lot of rules…I am a private person…I allow…I made a list…I need them to understand…I’ll go out there…I need my space…I know she’s staff…I know she works…I know she’s my counselor…I need my space…I have my own…I got TV to watch…I need to get into…I’m gonna keep bringing up her-her name…I respect her…I know she treats me…I respect her…I stand in my personal space…I said her name before…I need my personal space…I need my privacy. (Sasha)

Sasha’s continual mention of privacy demonstrates an area where she takes control within her own life, outside of the boundaries of our conversation. Within the interview she determines what she wants to be included in my writing, and outside of her interview she makes clear choices about who is and is not allowed in her space, which she chooses to bring up multiple times to stress the importance of privacy to her.

The residents of Lambs Farm do not live fully free. They do not receive the autonomy Petner-Arrey and Copeland describe as free from internal and external constraints. Instead, the residents of Lambs Farm find their own ways to make choices and assert their autonomy within a restricted setting. Residents mostly do not express being dissatisfied with the restrictions imposed on them by their life at Lambs Farm, but is this perhaps because they do not know what their other options *could* be? Lena did not move to Stone because it was not an option, but what if apartment living had been an option? Would she have preferred that to a CILA? Lambs Farm is not the only world these people live within, but their lives are constructed with specific options, limitations, and opportunities. If Rodney knew that there are other apartment buildings nearby, would he want to live in one of those with a self-directed aide to help him with household chores? If Theresa knew that an outside community member were willing to take her out for a drink, would she go and get a beer? Residents' perceptions of choice are constructed by their immediate surroundings and the services readily available to them. What might their choices look like if the community outside of Lambs Farm had the resources to fully include them in social, recreational, residential, and communal life?

7. Perceptions of Independence

In order to envision a community that is fully inclusive to adults with intellectual disabilities, we must first consider what restricts these individuals from full participation in the first place. Residents' perceptions of independence defy the commonly held notion that independence is a prerequisite for adult participation in community. In fact, they defy common conceptions of independence itself.

7.1. Alone Time

It is 4:45pm on a Sunday when I get to House C. Everyone is in the dining room while Destiny[12] finishes making dinner in the kitchen. I am welcomed with a lot of energy, a hug from Ali, and a hug from Rodney. *Grease* is playing on a TV in the kitchen that was not there when I worked in the house and a few residents are focused on the movie. I let everyone know I am here to talk to Ali and Theresa, and Rodney quickly interjects, asking when it will be his turn to talk. I tell him he should have been given a form by his case manager, Genevieve, so that he could sign up to be interviewed. I say we can of course talk anyway, like we always do.

After I interview Theresa and Ali, Rodney comes into the case manager's office and sits down to talk. I ask him if he signs his own documents, and he says yes. I tell him I'll be in touch with the Residential Director who can let his case manager know that he'd like to do an interview. When I eventually get his consent form, he has signed it himself, but so has his guardian.

Anytime I go back to visit Lambs Farm I look for Rodney. I met him on my first day of work when I had no idea what I was doing and my boss brought me to House C to shadow Destiny, who has worked at Lambs Farm for close to the amount of time I have been alive. Many

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[12] All staff names are pseudonyms.

of the residents of House C call Destiny "Mama Destiny," and it was quickly evident how she got that name. Her relationship with residents is caring, tough, and respectful. She told me early on that there is no reason to treat these people any differently from anyone else, especially those who are older than us (which, for me, is everyone).

Rodney is like a shadow if a shadow could talk. He spends a lot of time looking for (or at) staff, watching and waiting for his next chance to start up a new conversation. When I ask him if he likes to spend time alone, he answers, "Yeah, I like to be alone. Sometimes [Kimmy] watch TV together, or color together, like that" (Rodney). Rodney's version of being alone is being alone with staff. At the start of my interview with him, I ask him to tell me about his life at Lambs Farm, to which he answers, "I have friends here…I have staffs…I got friends living in this house-this house…Uh, [Jacob] lives in House [I]…my boyfriend" (Rodney).

Rodney's relationships with other residents can be tenuous. When I occasionally worked in House I, which is down the road from Rodney's house, I would see Rodney outside the window, standing across the gravel road from the house and looking in. If I ever asked what he was up to, he would answer that he was waiting for one of his friends. The friends he mentioned would inform me that they weren't interested in going out to spend time with Rodney right now, and they often seemed uncomfortable with him showing up at their house unannounced. Rodney was told repeatedly by staff that he shouldn't stand outside someone's house waiting for them, especially if there was no plan to hang out in the first place. Still he would make his way to House I, waiting. Rodney's relationship with his staff is consistent and enduring regardless of his tendencies toward other residents on the Farm.

Rodney's perception of being alone speaks to a larger phenomenon illuminated by the residents of Lambs Farm: independent living does not always mean living alone. Independence, in a neoliberal sense, means that “we can and should be able to do everything on our own and, of course,” Mia Mingus says, “we know that’s not true” (Mingus par. 34). Mingus heavily criticizes the “myth of independence” as reflective of “a deep level of privilege, especially in this rugged individualistic capitalist society” (par. 34). Disabled people hold the key to understanding interdependence and its necessity in this world. Tobin Siebers recommends we start from disability to best understand our shared vulnerability and, in turn, our shared humanity (Siebers 184). Insights from the residents of Lambs Farm on how they perceive independence illuminate a world where interdependence *is* independence, perhaps in its truest form. Rodney himself holds contradictory views on independence, but nevertheless he has pride in his relationships with both staff and other residents. Other residents describe various aspects of their life within Lambs Farm as independent, even if, from an outside perspective, they are reliant on the support of others. These perceptions of independence demonstrate that disabled people may have a deeper understanding of the feeling of independence, especially when it is obtained through interdependence.

7.2. Feeling Independent

Rodney understands being alone, to him, as being with staff, but he also desires what he considers to be a more independent living setting, contradicting his prior conception of independence. Rodney wants to move to the Stone Apartments, where residents “do their own stuff” (Rodney). He also wants to go on Rainbow Runs (see Appendix B), envisioning “I go by myself, get my stuff and like on the van, and get coffee.” I ask Rodney if he has a job coach to help him at work, and he confidently says, “No, I’m-I’m okay. I don’t need nobody.” To me, Rodney’s answer about spending time alone (with staff) expresses his (and maybe all of our) vulnerability in a significant way. Rodney's answer speaks to our shared dependence on one another,[13] which does not go away if/when someone moves into their own apartment unit or works without a job coach.

Sasha expresses that she understands her life at Lambs Farm to be her version of independence. She moved to Lambs Farm after her dad's death, and she says, "my mom had to get me into a place where I could be, um, you know take care of myself and do my own thing" (Sasha). Sasha and her mom view Lambs Farm as the place where Sasha does her "own thing," and lives her version of independence. Sasha does not share a desire to become any more independent than she is in House D, because for her, life in House D is independence realized.

The residents of the CILAs shared unique perspectives on independence, particularly in their views that the CILAs allow for more independence than the group homes on campus. Lena says, "I liked living on campus but I know that [the CILA] was the way I could get more independent and stuff like this" (Lena). Margaret says, "On the CILAs, you have more flexibility. You-you're more on your own" (Margaret). Morrie prefers the CILAs "because you get more independence" (Morrie). What sticks out to me is that both Lena and Morrie use the word independence but do not explain what exactly about the CILAs makes them any more independent than the group homes. Margaret shares that the CILAs do not have 24-hour staff, so that is why residents are more on their own. Lena and Morrie's responses seem to indicate that independence is felt, not quantified. Sasha's understanding of independence resonates as well, because she *feels* independent in her group home, similar to how Lena and Morrie *feel* independent in a CILA house.

A recurring theme of my conversations with residents when discussing their sense of independence is the importance of staff to residents. Four residents shared that their favorite part

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[13] "A community of dependent frail bodies that rely on others for survival" (Siebers 182).

of Lambs Farm is the staff (Ali, Catherine, Sasha, Rodney), and six residents shared that they feel supported by their staff (Deborah, Maura, Theresa, Catherine, Ethan, Morrie). It is clear that the work of Lambs Farm staff is done with care: "…a multifaceted term. It is labor, an attitude, and a virtue" (Kozak-Oxnard). Mia Mingus describes the difficulty of building interdependence, particularly "with people *you need in order to survive, but who don't need you in order to survive*" (Mingus par. 25). The staff of Lambs Farm contribute to the residents' feelings of independence. Rodney serves as an example, because he enjoys alone time through his time spent with Kimmy, a DSP who works consistently in his house. Kozak-Oxnard identifies a key contradiction of care work (or the performance of care for income), which is that care is considered by many agencies as "a means to an end: independence and autonomy" (Kozak-Oxnard). The reflections of Lambs Farm residents on the importance of their relationships with staff and their understanding of independence as not necessarily being alone help us to rework our definitions of both care and independence. What if care was done merely for the sake of care? What if independence was achieved through interdependence?

8. Conclusion

I approached this project with the following questions: What does it mean for someone's domestic life to be professionalized? Do the carceral elements of an institution show up in community-living arrangements post-deinstitutionalization? Are community, choice, and independence constructed or created organically? Most importantly, how do the people living in these communities understand their subjectivities? What do they value, what do they want? The process of answering these questions cannot be completed in this project alone, but speaking to residents does offer me insight into each of them and knowledge beyond their scope.

In regards to the first question, listening for the use of "we" in residents' interviews indicates that some individuals do not seem to consider themselves as a part of a communal whole within Lambs Farm. An exploration into the Individualized Service Plan and the individualization of residents' lives at large at Lambs Farm leads me to believe that the professionalization of a living setting–or its separation into individual, professionally-overseen aspects–can be a barrier to feeling in community with others. Looking back to the work of Penter-Arrey and Copeland, perhaps the "formal support process takes on a life of its own," (43) rather than being shaped to the unique life of the individual.

Turning to the second question, seeking out carceral elements of the institution was never going to be a straightforward project, especially since "the carceral" itself exists on a continuum (Foucault 297) and is intertwined with our lives in many unseen ways. Lambs Farm was also designed as an alternative to the institution, but Irene Yoon and Grace Chen teach that violent institutional histories can leave impressions, like pencil once erased (79). Residents speak of the restrictions they face at Lambs Farm–which may not seem oppressive or carceral–like not being able to drink alcohol or go on a Rainbow Run. These restrictions, though, rely on an assumption of heightened vulnerability due to residents' disabilities. Residents showed how they asserted autonomy *anyway*, by choosing to drink pop or taking full control within their interviews. This reassertion of agency is not unique to intellectually disabled people living in group homes, and it speaks to a greater lineage of incarcerated and institutionalized people who have found ways to reclaim their personhood over and over again.

Looking toward the third question, residents had the most to share about the ways community specifically is both constructed and created organically. Some residents clearly established who they felt in community with through their use of "we" or mention of close relationships they shared with other people on the Farm. Some residents, though, had communal networks constructed for them through the Enrichment Center, Quest classes, or Special Olympics, yet they did not fully identify with these places as sites of community. The construction of Lambs Farm as a normalized setting that functions parallel to "non-disabled" or "normal" society may leave much to be desired in organic community formation. Even in a world where their community, choices, and senses of independence are somewhat constructed for them, residents still find moments to create their own communities, make their own choices, and assert their own independence. They do so through romantic relationships and choosing to spend social time with staff; asserting their autonomy by designating who can and cannot enter their rooms; and deciding which version of residential living is *their* version of independence, which involves a shared vulnerability many of us non-intellectually-disabled people could benefit to learn from.

My final questions (How do the people living in these communities understand their subjectivities? What do they value, what do they want?) are the most important questions to explore, because they rely entirely on the knowledge of people with intellectual disabilities. Most residents shared positive impressions of their lives at Lambs Farm, which complicates the demand of self-advocacy groups such as Self Advocates Becoming Empowered (SABE) for the closure of all institutions, including the group home. With a hope of joining this call, it is of the utmost importance that I listen closely to the voices of current group home residents about what is working and what is not. The project of abolition is long and messy and requires reckoning with institutions that have long been upheld. Liat Ben-Moshe calls on the wisdom of W.E.B. DuBois, who insists that abolition is not only a negative process, or one of tearing down (Ben-Moshe 257). Abolition is about building something new, and whatever that something is can only be built upon the knowledge and wisdom of the people most impacted by the systems that need to be abolished, which in this case are adults with intellectual disabilities.

Appendix A: Interview Questions

- Are you still comfortable with me audio recording this interview?
- Are you comfortable with me taking notes throughout the interview?
- Can I use your words in my writing?
- What is your name?
- What name would you like to use (pseudonym) when I write about you?
- How old are you?
- Tell me about your life at Lambs Farm.
- Where did you live before living at Lambs Farm?
- When did you move to Lambs Farm?
- What feels different about Lambs Farm from the last place you lived?
- Tell me about your daily routine.
- What is your favorite part of your day?
- Do you like this schedule?
- Do you work?
- Tell me about your job/former job (if retired)?
- Do you enjoy your job?
- Do you feel challenged in your job?
- What different jobs have you had while living at Lambs Farm?
- What do you like about living with other people? What do you like about living alone? (question dependent on residential setting)
- Is there anything you are not allowed to do in your home?
- Do you know why you cannot do this?

- How often do you leave Lambs Farm?
- What do you do when you leave?
- Has anything in your life at Lambs Farm changed recently? (work, housing, activities)
- What do you do for fun? What do you do in your free time?
- Who do you do this with? Do you have friends in other residential settings?
- Who are some members of your community?
- (CILA houses) do you know your neighbors?
- Who do you feel supported by at Lambs Farm?
- What is your favorite thing about living at Lambs Farm? What is your least favorite?
- What are your goals? Do they differ from the goals you set in your annual meetings with your support team? Tell me about your ISP meeting, what kind of goals do you set?

Appendix B: Lambs Farm Terminology

Term/Acronym	Definition
CILA	Community Integrated Living Arrangement, or a house run by Lambs Farm that is placed in a residential neighborhood.
DSP	Direct Support Professional, the certified staff who work within group homes.
Lambs Industries	The sheltered workshop within Lambs Farm that opened in 1981. Employs residents of the Farm and partners with companies to complete projects for them. The founders of Lambs Farm were originally opposed to the concept of a sheltered workshop, but later came around to the idea: “We founded the Lambs to get away from some of this kind of work…But now it's OK. The operation has changed. Now there’s a place for the sheltered workshop” (Unsworth 133). Self-advocates organize around the abolition of the sheltered workshop (Carey & Gu 115) as a site of segregation of people based on disability.
Magnolia Cafe & Bakery	A sit-down restaurant and bakery frequented by members of the public and Lambs Farm residents. Commonly referred to as “the restaurant” or “the bakery.”
Quest Class	Quest classes are voluntary classes residents can take to learn about new topics or skills. Some of the classes residents mention in their interviews are focused on religion, book club, and cheerleading.
Rainbow Run	A Rainbow Run is a type of outing that certain residents are able to participate in. A van picks up a group of residents and takes them to a strip mall or store where they are able to walk around on their own and run errands. It is unclear what qualifies someone to go on a Rainbow Run.
Sugar Maple Country Store	A country store on the Lambs Farm property open to the public. Residents refer to this as “the country store.”

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