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# Displacing Marginalized Bodies: How Human Rights Discourses Function in the Law and in Communities

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**Abstract** In this article, we examine disability and eugenics discourses and the ways they function in spaces where vulnerable persons have been historically excluded by the state and blamed for their own "immiseration." We ask how queer theories of repudiation, abjection, and vulnerability lend insight into the ways that people with intellectual disabilities are discursively located outside normative discourses of home, care, and quality of life, and whether these discourses shifted to serve this vulnerable population when historically the very places in question repudiated them, infringed on their human rights, and questioned their sexuality. To address these questions, we focus on the recent and impending closures of Virginia's Training Centers, residential institutions for persons with intellectual disabilities now scheduled for staggered closures before 2020.

**Keywords** Displacement · Human rights · Disability studies · Americans with Disabilities Act · Virginia · Eugenics

In this article, we examine the recent and impending closures of Virginia's Training Centers—residential institutions for persons with intellectual and developmental disabilities. When the US Department of Justice found that Virginia's management of its five residential training centers was in violation of the 1990 Olmstead Act, Virginia settled the case by agreeing to close four centers, moving more than 4000 residents into group homes or assisted living. Some families have protested to keep the centers open, citing human rights violations and concerns about quality of care. However, community of care advocates, also citing human rights, advocate for the closures. While some families report feeling abandoned by the law, while

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community of care advocates insist that laws are consistent with disability rights concerning equal access.

Using a rhetorical approach as applied to human rights discourses present in interviews, social media discussions, and the law, this article examines the ways that human rights concepts are used by institutions, families, and lawmakers to construct rationales for either displacing residents or keeping them in state facilities. Informed by theories of ableism (Clare, Butler) and discursive power (Foucault), we examine human rights, disability, and eugenics discourses surrounding this controversy and the ways they function in spaces where vulnerable persons have been historically excluded by the state. We suggest that queer theories of repudiation, abjection, and vulnerability also lend insight into the ways that people with intellectual disabilities have been discursively located outside normative discourses of home, care, and quality of life and that as a consequence, the closures of the Training Centers highlights an ongoing debate about adequate and appropriate care for individuals. The historical debates surrounding the Centers are also important to this analysis: the rhetoric used to advocate for state-run facilities stands in stark contrast to the history of these institutions. With eugenics practices such as forced sterilization and the systematic institutionalization of the poor, the "peculiar," and "promiscuous" women, the training centers have long been controversial as physicians, judges, lawmakers, and social workers were steeped in discourses of normativity. Despite great advances and changes in the centers in the last several decades, however, deinstitutionalization has generally been accepted as the appropriate path for persons with disabilities.

In 2012, the Commonwealth of Virginia agreed to a settlement with the United States Department of Justice (DOJ). Having been found non-compliant with the *Olmstead v. L.C. Decision* of the Americans with Disabilities Act of 1990, Virginia established a timeline to close four out of five of its "Training Centers," large residential institutions in which persons with intellectual and developmental disabilities (ID/DD) lived. Similar to the situations of twenty-four other states also found in violation of *Olmstead,*[1] Virginia was compelled by the DOJ to "transition" qualifying residents to smaller group homes so that they could have access to "the most integrated setting appropriate to the needs of qualified handicapped persons" [3].

The transition of long-time residents of the Training Centers, lauded by many advocates for persons with intellectual and developmental disabilities, has concomitantly begun a process of displacing marginalized or vulnerable bodies. For many, the impending displacements represent a long-awaited enforcement of the law for equal access. But for some, the displacements represent something more—imposing forced relocation on vulnerable bodies. The tension, one where the law advances equities but in the process creates further inequities, is indicative of other paradoxes inherent in the law [35]. This article examines these tensions and paradoxes, citing the ambivalence [17] of human rights discourses at the heart of the debate. As [17] suggests, the ambiguity in human rights discourses allows for several sides to use the same discourse to make an argument. In addition, human

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[1] See http://www.ada.gov/olmstead/olmstead_cases_list.htm#one.

rights discourses can be understood as narratives, where audiences are influenced by connections to individuals, as in the sentimental novel (we discuss this in more detail later). Furthermore, the article decodes languages of resistance used in objection to closing the training centers. While on the one hand objectors evoke the language of resistance, at the same time their Western view of human rights discourse as a concept reifies victimization rhetorics.[2] It is precisely at these intersections that our analysis enters the discussion.

Protracted debates have occurred among families of the residents, the authorities tasked with managing the transition, and the lawmakers and judges in charge of implementing the DOJ settlement. Since 1978 each training center instituted a Human Rights Division, with each center identifying its own human rights advocate. According the website of one center, "Each individual receiving service at [the center] shall be assured the freedom to exercise their [sic] legal, civil, and human rights related to those services. Persons receiving services shall be assured respect for basic human dignity and that services provided are consistent with sound therapeutic practice."[3]

Human rights discourse on the websites of the training centers sites is used as a way to ensure that reporting of neglect and abuse at the centers is conducted pursuant to 37.1-1 of the Code of Virginia. Similarly, however, human rights discourse has also been used by some family members of residents in the centers. Parents and guardians who oppose the mandatory transition to smaller group facilities cite concerns for the health and well-being of their family member, using human rights discourse when voicing their concerns. For instance, one reader responded to a news article about the impending moves: "The injustice [of displacement] of the residents of the Training Centers equals no less than that of severe abandonment. Isn't this a human rights violation?" [41]. This comment and others like it suggest that some families are concerned about how the transition will impact their loved ones in the near- and long-term and that they see those concerns as questions related to human rights, even though human rights are not always mentioned explicitly.

Advocacy groups such as the Arc of Virginia have applauded the recent ruling and pending transitions precisely because they view institutionalization of persons with intellectual and developmental disabilities as a violation of their human rights. The mission statement of the Arc stresses its mission of, "advocating for the rights and equal inclusion of people with intellectual and developmental disabilities" and "actively support[ing] their full inclusion and participation in the community throughout their lifetimes."[4]

Each of these groups, each with varying positions concerning residents living at the training centers, use human rights discourse to make their case. Their competing concerns suggest a complicated network of governmental and disciplinary agents able to constitute the bodies in question (the residents) as vulnerable and therefore

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[2] See Erin K. Baines *Vulnerable Bodies: Gender, the UN, and the Global Refugee Crisis* where she explains the paradox of being labeled a victim and the resistance to that label.

[3] See SEVTC website at www.sevtc.dbhds.virginia.gov.HRADVOCATE (accessed January 2, 2015).

[4] See www.thearcofsouthside.org.

displaceable. How, then, is it possible to reconcile the positions of these disparate groups that use human rights discourse to promote their cause? Below is an examination of rhetorical and symbolic uses of human rights discourse by the Centers, the families, and community care advocates and the ways that "human rights" (and human rights narratives) function within each discourse community (Swales). Further, we examine the historical, rhetorical, and narrative underpinnings of human rights as a "universal" concept, using the Foucauldian notion of "regulatory powers" of discourse, and explore ways that these underpinnings influence how the individual groups define the function of human rights language. In order to explore how human rights rhetoric functions in these competing communities, we review: (1) the history of Virginia's training centers and the recent legislation to close them; (2) the history of ADA, the *Olmstead Decision*, and paradoxes within the law; and (3) competing uses of human rights discourse and disciplinary practices of rights discourse in general.[5] Human rights discourse in intersection with discourse on disability has implications for ways persons with intellectual and developmental disabilities are recognized by the law, their communities, and their families, and consequently how individual personhood intersects with a discursive body.

## 1 History of Virginia's Training Centers and Recent Closures

The institutions known as Virginia's Training Centers have a long-standing history in the Commonwealth of Virginia. One of the oldest Centers, located in Lynchburg, was founded in 1910 as the "Virginia State Colony for Epileptics" and was later expanded in 1914 to include the "Feebleminded." Its early proponents and first superintendent were staunch advocates of the Eugenics Movement, which led to its infamy during the 1927 Supreme Court case, *Buck v. Bell*. Carrie Buck was a resident of the Colony, and as a result of her case, the Colony was authorized to forcibly sterilize residents, using the pseudo-science of eugenics as a rationale.[6] Over time, the institution underwent a number of name changes: the Lynchburg State Colony (1940), the Lynchburg Training School and Hospital (1954), and the Central Virginia Training Center (CVTC) (in 1983, and continuing to the present). One of five training centers in the state, the CVTC has the longest and most dubious history.

Carrie Buck's case, where "peculiar" bodies, particularly women's bodies, were held in abjection, symbolizes the difficult history of the institution. Eugenics practices were abandoned at the Center 1979, but nearly 8000 were performed at the Colony between 1924 and 1960 [14]. This longevity reflects the ubiquity of eugenics discourses over time, discourses that maintained that persons with intellectual and developmental disabilities were "deficient." Even though "emerging social values seemed to outpace the lingering eugenics practices in state run

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[5] Here we refer to Wendy Brown's discussion of rights discourse in *States of Inquiry*.

[6] See Lombardo [24] etc. for complete history of American Eugenics Movement and Virginia's role in that movement.

facilities," discourses of deficiency lingered and had lasting material impacts on residents [36]. Moreover, housing persons with disabilities in large institutions has long troubled community care advocates. Access to equitable quality of life is arguably less likely afforded at large institutions, as residents are often "invisible" to the local community.

Though many advances were made in the 1960s, 70s, and 80s, the lingering effects of eugenics discourses, where residents were removed from society and often sterilized so as not to "infect" the larger society, remained in the consciousness of many As these attitudes were criticized and the laws revoked, shifts in procedures for care occurred. In part to reduce the invisibility of such persons as well as the inherent disparities they created, the Americans with Disabilities Act (ADA) of 1990 was passed due to the tireless efforts of disability rights activists who pressed for equal access to living in communities. In 1999, the landmark *Olmstead v. LC* Supreme Court decision enforced Title II of the ADA, reasoning that housing people with disabilities in large institutions without equitable access to community services constituted discrimination.

Nearly 12 years later, in February 2011, the DOJ found that Virginia's management of its five residential training centers was in direct violation of the 1999 *Olmstead* enforcement of Title II, citing the state's inability to provide adequate resources to the residents, inappropriate use of restraints, and over-sedation of its residents to be out of compliance with the *Olmstead* mandate to provide community-based services. In Virginia's settlement with the DOJ, the state agreed that the approximately 5000 residents residing in the centers should be relocated to less restrictive environments so that the one remaining center, in Lynchburg, would house fewer than 500 residents by the year 2020. Further, the centers were to use a staggered approach to the closures and develop relocation plans to assist residents and their families with the transition to smaller group homes.

## 2 History of the 1999 Olmstead Decision of the Americans with Disabilities Act of 1990 and Paradoxes of the Law

For decades, the focus of disability advocacy has centered on community integration and independent living. Before the passing of the ADA in 1990, cases regarding community placement were brought to courts through the Fourteenth Amendment and the Rehabilitation Act of 1973 [10]. These cases were argued unsuccessfully because the Fourteenth Amendment only required minimally adequate treatment, while the Rehabilitation Act required that the claimed discrimination should be based solely on disability. Therefore, when the *Olmstead* case was brought to the Supreme Court in 1999, prosecutors sought to obtain a favorable precedent on the recently enacted ADA of 1990, which states, "No qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs or activities of a public entity or be subject to discrimination by such entity" (ADA 1990). *Olmstead* concerned two women with intellectual and psychiatric disabilities whose treatment, according to advocates, represented typical experiences of people with disabilities housed in large, state-run facilities. The women had been denied their request to transfer from the state institution in which they were living to community-based housing even though staff of the institution charged with their care agreed that they were suitable candidates for community placement [10]. The *Olmstead* decision, therefore, marked a significant moment for advocates of community integration. Largely seen as a victory for people with disabilities, *Olmstead* challenged a long history of marginalizing persons by placing them in large institutional facilities because of state funding priorities impelling institutionalization rather than provision of community-based services [27, 33].

The premise of the State reflected predominant attitudes that encouraged warehousing persons with disabilities and cutting costs [48]. Historic attitudes steeped in eugenics terminology labeled residents as “unfit,” “peculiar,” and “feebleminded,” terms highly influential in guiding the State’s decision to dedicate funding to large institutions, with the consequence that many of the residents were living far away from their families and communities [12, 24]. Because many communities could not provide the level of care required by some persons with disabilities, institutions were often deemed the most appropriate of offering a particular level of care [43]. In addition to separating persons with disabilities from their families, persons with disabilities were pushed to the periphery of their communities, reflecting the characterization of institutions described by Goffman [16] as large and total institutions that took ever-increasing control over the bodies of individuals in the institutions [49]. Procedures and legislation concerning their care, including forced sterilizations such as those conducted at the Colony in Lynchburg, continued, in some cases, until the 1970s [49]. Institutionalization and paternalistic attitudes regarding protection for persons with disabilities peaked in the late 1950s but persisted until much later [4].[7] By the 1960s, community care advocates prevailed in their argument that institutionalization denies people with disabilities the opportunity to live their own lives and have the freedoms that other people enjoy [28]. In addition, segregating the population of adults with disabilities reinforces stereotypes about persons with disabilities as being dependent on others and needing to be protected and “hidden away” in order to live a full life [4]. Using human rights rhetorics, community care advocates argued for the full equality of access for persons with disabilities. However, as rhetoric scholars Arabella Lyon and Lester Olson point out, human rights rhetorics have their own limitations:

> Viewed narrowly as legal obligations or frameworks, human rights discourses, at times, are viewed skeptically as tools by which elites manage or control otherwise already disenfranchised or marginalized, ostensibly ‘autonomous’ individuals and other communities—oftentimes behind a persona or mask of

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[7] James Trent [48, 49] explains that also during this time in the United States, resources from states began to decline after the 1950s, which resulted in more instances of abuse and neglect. The 1970s is where advocates promoted “for moving intellectually disabled people from public residential institutions and from segregated schools and classes to communities and to integrated classes in community-funded schools…they were strange bedfellows—cost cutters and civil libertarians. The mix of their motives has continued to trouble services of intellectually disabled citizens to the present” [48, p. 119].

> beneficence. However, at the same time, broad-based, grassroots organizers, advocates, and educators from within disenfranchised communities, at times, find human rights vocabularies to be powerful resources for revealing hypocrisy, making radical claims on elites for recognition, inclusion, and justice within communities, and affirming their stature as fully human within dehumanizing and oppressive cultures" (206).

In each case advocates and parents are using human rights discourses as a given, without skepticism. Disability rights, framed as human rights, demonstrates the Foucauldian notion that "regulatory powers of identity" "become the vehicle for the imposition and regulat[ion] of a discursive body [17, p. 11]. Understood this way, the ADA at once ensures rights while paradoxically imposing regulation on particular bodies. Because human rights discourse imposes a particular kind of identification, in this case a "disabled body," that body is consequently subject "to intense forms of bureaucratic domination and regulatory power even at the moment that we assert them in our own defense" (Wendy Brown qtd. in Golder 12). However, a focus on the rhetorical dimensions of the law should not limit recognition of material conditions of an individual's body as it is being regulated.

The shift in practices toward community care programs and relevant advances in the law coincides with theories about able bodiedness. Disability and queer studies scholar Eli Clare states, "the disability rights movement has created a new model of disability, one that places emphasis on how the world treats disabled people: Disability, not defined by our bodies, but rather the material and social conditions of ableism" [11, p. 360]. The emphasis on the able bodied as the center of normativity and as a location for critiquing discourses about persons with disability or differently abled has provided valuable insights into ways discourses of ableism and normativity[8] serve to discriminate against particular bodies. Theories of repudiation, abjection, and vulnerability, heavily informed by queer theory, permit new understanding of the ways people with disabilities are often situated outside discourses of home, care, and (their own) quality of life [22]. Indeed, theories of normativity, critiques of ableism, and more recent theories of "community care" [52] have contributed to the commitment to providing equitable care for persons with intellectual and developmental disabilities and consequently to the recent changes in federal law and state policy.[9] According to Clare and others who theorize

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[8] Eli Clare and other scholars also point to the ways notions of sexual normativity functions in similar ways to notions of bodily normativity. In this way, sexuality studies scholars and disabilities studies scholars sometime intersect, using theories of abjection, vulnerability, and precarious to illustrate the ways some groups are marginalized in society. Robert McRuer [30] has outlined a theory of compulsory able-bodiedness, which is based upon and intertwined with Adrienne Rich's [40] theory of compulsory heterosexuality. Both of these situate people with disabilities and non-heterosexuals outside the norm in similar ways. This system of compulsory heterosexuality has coerced women into heterosexual relationships by eliminating the element of choice. One does not choose to be heterosexual, that is just the norm. Compulsory able-bodiedness draws on this theory and even points out that able-bodiedness is even more prevalent as a non-identity, and is viewed as the natural way of being. Both non-heterosexuality and disability are outside the same norm that includes able-bodied heterosexuality.

[9] James Trent also points out that with reduced state funding and increased federal funding for equal and guaranteed education resulted in the eventual closing of most residential institutions: "Some have become institutions of an alternative incarceration—usually prisons…Although states have maintained some

ableism, the focus should shift to systems of regulation that allow for discrimination and unequal access, rather than an emphasis on any perceived lack of a particular body. In this way ADA, Olmstead, and the Virginia Training Centers (VTCs) closures can be framed as an advancement in policy for persons with disabilities. However, despite this advancement, broader systems of "ableism" remain, and as this analysis suggests, the law paradoxically allows it.

Since the Supreme Court's *Olmstead* decision, the DOJ has brought actions against or signed on to existing cases in more than two-dozen states in an attempt to enforce the community living initiative [33]. In addition, plaintiffs have used *Olmstead* to file lawsuits alleging discriminatory practices concern voting rights, insurance coverage, need for a guardian, and reduction in services, all with varying results [46].

Because prior to *Olmstead*, public policy typically favored institutionalization rather than services in communities, the Medicaid program paid for care in nursing homes and for stipulated hours of home health care provided in community settings. However, funding for home and community-based services (HCBS) was optional [19]. Waivers provide a "bundle of critical services, like medical care and respite, that care takers describe as the difference between living in peace, or living in perpetual fear and anxiety" (Brock). Although the federal government established the Home and Community Based Services (HCBS) waiver program to expand services provided in community settings, many states reported long waiting lists for receipt of waiver benefits.

Every state participates in some kind of waiver system and in 2011, 44 states participated in the Money Follows the Person Project (MFP) [23]. People currently residing in institutions automatically qualify for Home and Community Based Service waivers through the MFP program. Many of the funds provided through HCBS are specific to residents able to work and/or travel outside their home and into the community. For example, the MFP was developed to help people in institutions transition to community living. Each state is required to establish a program that identifies Medicaid beneficiaries in institutional care who wish to live in the community. States are required to implement a rebalancing program whereby additional Medicaid long-term care expenditures flow into community services and supports [23].

When a resident leaves an institution as an MFP participant, he or she is supposed to receive HCBS and the state's MFP grant funds finance the federal matching payment for these services [23]. Once someone participates for 12 months in the demonstration project, he or she will remain on the waiver as long as they meet criteria for waiver eligibility [51]. Some states use MFP to offer employment services and supports to participants through the MFP service package [23]. These

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Footnote 9 continued
institutions, most of the facilities are small, usually not having more than a few hundred residents. In most cases, these residents have severe or profound intellectual disabilities [31]" (120). Trent points out that while many residents transition well, "many people left the public institution only to live in large group facilities of over 15 beds [mostly] nursing homes [where] residents often experience boredom and neglect, not unlike what they experienced in the large institution" (120–121). The social security and disability services provide lower financial funding.

five broad categories constitute employment supports offered by states: (1) services that help people gain and keep employment; (2) transportation to take persons with disabilities to and from a community activity; (3) equipment, modifications, and technology to improve someone's ability to function in their home; (4) services to help individuals acquire skills to use in the workforce; and (5) counseling and other supports to promote health, community integration, and employment [23]. However, many states still struggle with challenges to support people beyond what Medicaid covers. For example, Medicaid does not pay for housing or meals for people who receive care in their own homes or in adult foster homes [2]. Therefore, employment and the subsequent earnings of persons with intellectual and developmental disabilities remain an important gap to fill between the needs of the individual and the services covered by Medicaid.

Currently in Virginia people have to wait about 5 years for an ID/DD waiver for home and community based services (M. Shelor, personal correspondence, March 10 2015). In the past, this extensive waiting list puts people in the community at risk for institutionalization if they lack the resources and support to care for themselves. The lengthy wait times to receive the benefits offered by waivers contributed to the concerns of many Virginia families for their loved ones who are transitioned from state institutions to group homes.

This program can be greatly beneficial to those eligible for and able to participate. However, it does not address the needs of some residents who are unable to use such services, who are not able to leave their home to work, or who have limited mobility and therefore require more assistance than covered by waivers in accessing community activities and services. Therefore, if someone is not able to use these services, he or she is in danger of not being eligible for Waivers at all, thus jeopardizing equal access to programs for which they are legally entitled. This tiered system suggests that systemic discrimination remains in place even when some programs are successful for certain individuals.

## 3 Competing Uses of Human Rights Discourses

Although the closure of the VTCs in Virginia was intended to assure community integration for persons with disabilities, and consequently, to assure their right to equal services and quality of life, the lack of adequate resources to provide those services has families of VTC residents concerned about the quality of care their loved ones might receive during and after their transitions. This access to quality of care is a predicate to human rights violations that some families claim as they express their concerns. Several family members have expressed concern in televised news stories, blogs, and FaceBook pages over whether smaller group homes would provide the same level of care as larger state-run facilities—and their worry about a tiered system of care translates into human rights discourse. For instance, in a FaceBook page entitled, “Keep VTCs Open,” concerned parents, families, and friends share their dismay over what they argue is political bullying, the DOJ's ignorance of the day-to-day needs of their loved ones, and fears of abuse. The vice president of this group, whose 19-year-old twins reside at one of the Centers, confined to their beds, and reliant on oxygen and feeding tubes, stressed that the "omission of care for them could mean death" [41] and she also, "defended CVTC's efforts to help residents be part of the community" [38, 39]. In addition, many advocates see the VTCs as a community, one that is predictable and consistent, and that provides opportunities for interactions with volunteers, service groups, and schools in one centralized place. Not convinced that the state will be able to provide adequate resources should her sons be moved, she supported a petition to keep the Centers open. "I feel like they're trying to push us out," she said. "I'm going to fight it…It's political, they want to cheapen care, and they want to drive a one size fits all philosophy, and I'm going to stand up for my sons and for other people" [38, 39]. Her call to "stand up" as a social justice and rights issue focuses on individuals with acute physical needs and points out the potential inequities in the required relocations.

> A legal guardian for another VTC resident explained in one news story, "He is totally unable to speak or do anything for himself physically. His bones are very fragile. It takes three people to lift him. You're not going to get facilities that have three people available to lift somebody. Nobody knows how to deal with him. The hospitals are afraid of him" [41].

This parent's concern is that a group home will not be able to provide his son the same level of care as provided by his current living arrangement at the CVTC. Raising this concern as a human rights concern elevates the legal discussion: simply moving all residents into the community, this parent suggests, does not necessarily comply with ADA.

One parent of a training center resident interviewed said, "civil rights is being used against us."[10] According to her, the center had created an environment where her son is safe, given that he has pica and can also be destructive to himself and others. In her assessment is that this environment, though it might appear restrictive to others, indeed gives her son more "freedom" because "there's nothing there for him to run into." She said, "congregate care doesn't necessarily mean you're not doing human rights…no one would say to an Alzheimer's [sic] family 'you can do this at home.'" For her, moving her son out of an environment where several staff are always aware of her son's activity is what provides him human rights.

The majority of news stories focus on residents who require 24-h physical care. These examples, among others, illustrate the opinions of many parents who believe that state and federal authorities do not understand the complexity of care needs of various residents. Charles Falles, president of a parents group states, "The DOJ report was written by persons who don't have even a rudimentary understanding of real-world conditions at CVTC in terms of the levels of residents' intellectual and physical disabilities or of the special care and treatments they require" [38, 39]. The lack of expertise, whether real or perceived, fuels parents' discourses of inadequate care for their loved ones and thus their turn to human rights arguments. Their fears about the ability of group homes to provide adequate care overlaps with their fears of the potential for abuse. Ken Gans says of his adult son, "if he's abused in any

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[10] Interview with Jan Thomas (pseudonym), August 3, 2015.

kind of way, who's going to talk about it? He's going to be moved out without his consent or the consent of his guardians—that's a violation of civil rights" [15]. The emphasis on consent and the transition highlight families' very real concerns about how such a significant change will impact their loved one's overall health and well-being.

Residents' health and well-being might also be significantly impacted by the process of transition, which may mean making multiple moves. According to one parent, if "a community placement is not found for a resident by the stated closure date, Virginia's Department of Behavioral Health and Developmental Services (DBHDS) will send the resident to another training center that could be many hours away from family and their communities, only to await *its* closure" (www.change.org). The impacts of relocation will engender substantial material consequences for families and warrant attention to the issues, even if the overall goal of increasing autonomy runs parallel to normative values of concerning community care. Because many families do feel a sense of community within the centers, many of the comments by family members reflect a move from discourses of adequate care and relocation to discourses of human rights. This rhetorical move suggests that they feel abandoned by the government, or to a lesser extent, a lack of trust in government to provide adequate care during and after the transition. Regardless of the intention of the legislation, feelings of abandonment, lack of actual material resources, and fear of inadequate care are the concerns that precipitate families' use of human rights discourse.

Parents of residents are not the only stakeholders using human rights discourses addressing the transition of VTC residents. Each VTC has a "Human Rights Advocate" who is "independent of the training center Director and reports directly to the Office of Human Rights of the Department of Behavioral Health and Developmental Services" and who "monitors an advocacy system…to promote compliance with individual rights" (SEVTC website). However, services are specific to individuals living in those institutions. As residents are transitioned to smaller group homes and the administration of programs is de-centralized, questions arise about how the human rights advocate will function and whether adequate resources to fund such a position will be allocated.

Since the passage of ADA in 1990, the focus of care for people with disabilities has shifted toward community integration and supported decision-making. As mentioned before, the Olmstead decision focused not only on how people were able to live their lives, but also where. As Sarah Ahmed suggests, "home and away are divided, not as different spaces but as different ways of being in the world" [1]. Stated earlier, the legality may suggest an advancement of the law for particular individuals with particular intellectual and developmental disabilities; however, for residents who regard the Virginia Training Centers as their home, the ADA and the rights afforded them through it may in fact run counter to the safety and security they might feel in a new home that is forced on them.

The emphasis on human rights from each of the stakeholder groups interested in the care of persons with intellectual and developmental disabilities suggests a particular understanding of what "human rights" as a concept symbolize within those groups and within broader Western society. In order to understand this in the contexts of broader human rights discourses, we now turn to the history of human rights discourse and the narrative use of human rights to enact political and social change. The resistance of parents to the closures of the VTCs, despite how the closures are regarded by some as an indication of progress in the law, indicates their understanding of how discourses of victimhood might function for legislators and other decision-makers. By invoking human rights as a concept, which includes an imperative for the victim to be saved, they also invoke "a set of values, frames and terminology, which at a fundamental level are non-negotiable. For individuals, there are a limited number of access points to the law" [17]. Who "deserves" access to the law, who is deemed worthy to benefit from the law, is a paradoxical system revealed through the resistance of the VTC closures, exposing a tiered system of unequal benefit.

## 4 Understanding Human Rights Discourses

Whether in legal and political contexts, or in individual or community context, using "human rights" as a concept constitutes a set of assumptions and values influencing those discourses. However, each of these contexts intersect and interact, and narrative and rhetorical structures influence each context. As several scholars of human rights literature have suggested, since the Universal Declaration of Human Rights in 1948, human rights discourses have emphasized individual testimony and overcoming insurmountable odds [9, 13, 21, 45]. This emphasis has had the effect of making individuals "save-able" or "rescue-able" by those with the power to do so [20, 25, 29, 42].

This perception often translates into narratives about who is worthy of saving, as refugees, exiles, and asylum seekers are judged by their ability to poignantly narrate their particular stories of human rights violations [6, 20, 26, 32]. Narratives are often bound up in class, race, access to literacy, and gender [36]. As a consequence, stories told about human rights use "traditional, sentimentally inflected, and linear plot lines [that] may negatively impact movements to stop human rights abuses or aid people in crisis situations by facilitating emotional catharsis in the reader," thus making action a less likely result [9, p. 642].

Human rights scholars Lynn Hunt [21] and Joseph Slaughter [45] focus on the ways that the sentimental novel and the *Bildungsroman* have influenced (and been influenced by) human rights legal testimony, policy, and legislation. As Kerry Bystrom explains in her overview of literature and human rights, social, legal, and political human rights narratives have intersected with literary texts with human rights themes. In her analysis of autobiographical narratives, truth and reconciliation commissions, and sentimental novels, Bystrom discusses Hunt's conclusion that identifying with "potential equals" in sentimental novels is what has created the potential for a human rights "community." As a result, contemporary human rights literature is aesthetically influenced by the emotion of the sentimental novel, in addition to rhythms, forms, and dialogues included through the voices of narrators. In this way, "human rights" represents to audiences a way to symbolize an emotional connection to an individual or group suffering from a particular kind of trauma. Similarly, Coundouriotis and Goodlad [13] point to Hunt's discussion of the development a "human rights sensibility" (122) that emphasizes the individual and her equality. By using "human rights" rhetorics, one evokes these emotional connections to particular kinds of wrongs. However, as Joseph Slaughter [45] and others [18] point out, "individual formation" in the *bildungsroman,* devolve into "depoliticized sentimentality" (125) whereby no particular action is taken.

More recently, critical legal studies and literary scholars have examined the narrative qualities of legal testimonies at trials and various truth and reconciliation commissions [7, 45, 53], studying ways that people narrate stories describing their experiences. By focusing on individual stories and displaying images of persons with disabilities online and in televised news stories, the news media actually further alienates audiences from the broader issues of governmental control and regulation of vulnerable bodies. By stratifying who has access to particular services, the (perhaps unintended) consequence is "that some people deserve human rights and some people don't" [32]. Quality of care and compliance with ADA and the *Olmstead* decision are thus reduced or transformed into a personal narrative about individual patients to ostensibly make the public "care" about this issue. However, as human rights rhetoric scholars suggest, the dissociation from an individual's story, despite feelings of empathy it might evoke, regularly occurs in audiences and has the counter effect of desensitizing audiences about systemic inequities in the law. The focus on their potentiality as victims, their physical challenges and limitations and their "lack" of rights discursively and physically, further cement in audiences' minds the othered-ness of individuals with disabilities and therefore, their relative "worthiness" as recipients of protection under the law.

To complicate matters further, the institutions like VTCs are often fraught with histories of not protecting its residents. The question remains, is it a human right to live in a large institution that has the adequate staff and facilities to care for persons with certain physical disabilities, especially when formulations of community within that space matter to some families? We turn now to the law itself and examine the paradoxical aspects of the law that make this question one of class and social stratification.

## 5 Human Rights Discourse in the Law

> The *Olmstead Decision* states,
>
> "On June 22, 1999, the United States Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons *do not oppose* community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the *resources available* to the public entity and the needs of others who are receiving disability services from the entity" (www.ada.gov, emphasis added).

In each of the three conditions listed above, the VTC parents protesting the closures could reasonably assert that these aspects of the law are not met. As some parents suggested, whether or not the services are “appropriate” for their loved ones is questionable and raises concerns about who is authorized to determine the services that are appropriate for a particular individual. In addition, as parents quoted earlier suggest, there are “affected persons” who oppose the community-based treatment. Finally, because of the instability of the Waiver program, the “resources available” remain uncertain for many families, particularly for those who are not physically able to participate in certain programs.

For these reasons, several parents’ groups outside of Virginia filed suit to resist the relocation of their family members. They maintained that community services cannot be “reasonably accommodated” because of lack of current or in-place funding. In *Sciarillo v. Christie* in New Jersey, the state Supreme Court ruled that the “ADA does not confer a civil right to remain in any given institution.” In addition, “Medicaid law also does not require that States operate a particular institution. States, such as New Jersey, that participate in Medicaid’s HCBS program must offer participants the *choice* of community-based or institutional services, but those institutional services can be offered in a public institution (like a State Developmental Center) or a private institution at the option of the state, 42 C.F.R. § 441.302(d). Here, the State provided plaintiffs who wish to receive services in another State Developmental Center the option to do so, which accords with their rights under Medicaid to choose a type of displacement” (*Sciarillo v. Christie*). The argument here focuses on the notion of choice—that under the law, persons have a choice between a public or private institutions. Indeed, discourses of choice are powerful rhetorically and families attempt to emphasize their relative lack of choice even if in the law there is the appearance of choice. However, because there is an appearance of choice, the suit was ruled as invalid.

In reality, families faced with relocating their loved ones because of a facility’s closure have no choice but to move. The New Jersey Supreme Court ruled in this case that the state is under no obligation to provide any particular institution, as long as there is a choice. Nonetheless, when choices are limited in location and type, residents are often unduly traumatized as some are forced to move far away and become unable to be visited by their family members or to homes ill-equipped to handle their specialized needs.

However, a consequence is decentralizing care provision, a result of the relocation with impacts similar to any person being relocated unexpectedly and against his or her will. Being moved against one’s will is not a choice. Additionally, if abuse or neglect does occur at a decentralized location, families fear that lack of centralized reporting and investigation of the abuses might occur. While the closures of the institutions is certainly in keeping with community-based practices, the Commonwealth of Virginia’s track record of ensuring due process, and providing adequate waivers give parents cold comfort as they move their adult children. As one parent said, “I don’t want my son to be the statistic while they figure out if it’s going to work.” The advocacy group, The Arc of Virginia, though supportive of community-based programs legislated through ADA generally, also points out how critical it is to provide adequate funding for those programs to fully realize quality of life for residents. According to their website, Virginia must “amend its Intellectual Disability and Developmental Disability waiver programs in order to facilitated access to integrated services for all Virginians with ID/DD and comply with the DOJ agreement.” The issue of adequate resources exposes a tiered system where those with “severe” physical disabilities are not provided equal care.

## 6 Competing Uses of Human Rights Discourses as Regulatory Practice

The multiple uses of human rights discourses across competing groups indicates a tension about whether it is a human right to have access to facilities like the VTCs available to persons with disabilities. However, the use of human rights discourses, no matter the intention, relegates the discussion to broader narratives of abjection, repudiation, and displacement. Ostensibly, advocates of transitioning to smaller group/community care homes are attempting to alleviate the historical abjection and repudiation of persons with disabilities through legislation. The ADA law seeks to ameliorate these wrongs by enforcing community care programs. However, from a rhetorical and narrative standpoint, histories of forced displacement, particularly government-induced displacement, are also forms of human rights violations. Forced displacement, even if coming from intentions of advocacy and equal access, has impacts with similarities to any other forced displacement, where persons can experience abandonment, fear, and life-altering changes that heighten their vulnerability. Indeed in this case, their vulnerability makes discursive abjection possible and therefore puts their precarity at a higher risk [36].

If the body is marked as abject, and thus displaceable, by extension it can be regulated and controlled. By decentralizing care outside state institutions and moving residents into communities, the state adheres to the law but *de facto* lessens its financial responsibility and decenters the mechanisms in place to ensure “human rights advocacy.” As [34] points out, “the rhetoric of disability, benevolence and care (both of the individual and the nation) combined with and sometimes masked the broader impulse of social control.” The institution functions as a place that regulates bodies. With the intervention of the law, though adhering to ADA, bodies became displaceable, subject to the law, and thus still remained vulnerable. This paradox of the law cautions us to consider ways that human rights discourses are used and understood in the transition of long-time residents of Virginia’s training centers to group homes.

Framing the argument around bringing voice to the so-called “voiceless” obscures the efforts of the people with disabilities who fought for the implementation of these policies in the first place. People arguing against the closures employ the bodies of persons with intellectual and developmental disabilities in their arguments through news stories and social media, citing their special needs, care, and risks of non-institutional living. These arguments focus on structures of victimhood, relegating their lives to an othered status and therefore potentially dismantling their broader arguments for attention to the waiver program, adequate funding for relocation, and community-based care. Using victim/other status is a common trope that misfires in humanitarian aid communities. Indeed, this approach to rhetorical fashioning of the disabled is at odds with disabled activists/scholars who argue that the inequalities "caused" by "disability" are actually caused not by the disability itself but by an unaccommodating and discriminatory society.

The subtlety here is understanding that the focus on the disabled body, rather than the social, political, and economic structures that are discriminatory, actually fails to forward their agenda. By focusing on the individual disabled body, bodies are seen as vulnerable and dependent and are thus precarious in their perceived need to be controlled, warehoused, and regulated. If residents are classified as vulnerable, weak, or victimized, powerful decision-makers are more likely to see them as the other. This rhetorical fashioning can reify in lawmakers' minds predominant and erroneous assumptions about persons with disabilities, thereby making it easier for them to ignore the larger social and economic conditions surrounding community-based care. Much like human rights rhetorics [5, 20, 26], lawmakers can easily dissociate themselves from persons with disabilities, seeing them as helpless rather than steeped within multiple relationships of power.

On the other hand, family members' use of human rights discourses might also serve to separate them from decision-makers by claiming that no community care situation could attend to their loved ones' needs. Placing persons with disabilities in a savior-rescueable relationship risks inattention to other issues. Merely relocating residents and making them more visible hardly protects them from abuse or reduces their vulnerability: "Vernaculars of human rights should be more diverse…To recognize human diversity—including the diversity of ethics and rights traditions—critical interpretations and representations of human rights should acknowledge viewed based in cultural difference, human capacity, and communitarian rights models as well" [25]. A person with a disability only exists insofar as she or he is named and recognized by others; however, paradoxically, this naming places the "disabled" into a category that can be regulated and controlled because "the assertion of the subject of [human] right is simultaneously a subjection" [17]. Western views of human rights as victim-centered can actually serve to counter the work intended. Focusing on the bodies of people with disabilities casts them as vulnerable at an individual level, which takes away the power of people with disabilities as a minority group with meaningful and material civil rights.

## 7 Conclusion and Call for Future Research

The emotional debate over the VTCs closures is emblematic of competing understandings of human rights as a concept. Although the move to close the centers can be a positive one, increasing overall rights for persons with disabilities to have rights to equal access and greater freedom of action and habilitation, the lack of sufficient resources relegated to these programs historically and in the present continue the problem of "unequal distribution of precarity" (Butler qtd. in [37,

p. 170]).[11] However, despite this limitation in protection of the law, individual stories expose networks of power relations and the relatively little power that persons with disabilities have over their lives, even as Virginia complies with ADA/ DOJ. As a consequence, resisters of the closures have succeeded in having the closures delayed, so that, at least, they might be able to transition their loved ones more slowly.

Finally, aspects of this debate not adequately represented are the voices of the very people being transitioned, as most representations of residents come through their families or advocates. Can our analyses be based solely on what advocates say on behalf of their loved ones? How do we more deeply understand what residents might be experiencing, good or bad, without exploiting them? Does the presumption of exploitation indeed take away their agency, their ability to speak for themselves, or their desires and wishes during their transitions? Careful attention to loved ones' concerns could further reveal the elements of their discourses that have been ignored or dismissed, thereby creating a community conversation about transitions and adequate care. As legislators and advocates continue to develop ways to transition residents from VTCs in equitable ways, we suggest directly asking this population about their experiences of transition through life course theories and methodologies that address these important issues that directly affect their health and well-being.

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[11] See Butler's, "Post Two" in Jasbir Puar's (ed.) "Precarity Talk", p. 170. Precarity and vulnerability are often used interchangeably. In general, however, precarity is inclusive of vulnerability, where "precariousness [is] a function of vulnerability…and precarity as differentially distributed" (in Puar, p. 169). For Butler, precariousness is corporeal vulnerability in general and precarity is the vulnerability imposed on various groups by others.

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