DRAFT - DO NOT CIRCULATE - DRAFT

The Structural Desexualization of Disability

Natalie M. Chin*

TABLE OF CONTENTS

INTROD	DUCT	ION	.1
I.		Historical and Legal Foundations for Creating and Sustaining a Culture of exualizing Disability	.6
	А.	The Historical Foundations of the Desexualization of Disability	.7
	В.	Modern Laws that Impact the Structural Desexualization of Disability	.8
	C.	The Promise of Olmstead and Community Integration	.9
	D.	Sexuality and the Unmet Promise of Olmstead	12
II.		raming the Victim-Perpetrator Binary Through the Structural Frame of exualizing Disability	16
	А.	The Inadequacy of the Victim-Perpetrator Binary View of Sexual Violence?	
	В.	The Social Machinery That Normalizes the Structural Desexualization of Disability	17
III	. The	Systems That Maintain the Structural Desexualization of Disability	
	А.	The Desexualization of Disability Through Guardianship	
	B.	The Desexualization of Disability Through Special Education	
		1. C.K.M	
		2. David M.	23
		3. The School District	23
	C.	The Desexualization of Disability Through the HCBS Waiver Program	25
IV	. The	State's Role in Reconceptualizing Sexuality	27
	А.	Harnessing the Jurisprudential Advances of the Olmstead Integration Mandate Under Title II of the ADA to Compel Sexuality Supports and Services	27
	В.	State Resourcing to Center Sexuality in Community Integration	30
		1. Guardianship	31
		2. Mandating Comprehensive Sexuality Education in the Special Education System.	
		3. State Resourcing of Sexuality Services and Supports That Confronts Ableism	31
CON	CLUS	SION	

* Associate Professor of Law and Director of the Disability and Aging Justice Clinic at the City University of New York School of Law; J.D., George Washington University Law School; B.S., Boston University. I am grateful to Rabia Belt, Doron Dorfman, Jamelia Morgan, and Claire Raj for their insights and guidance in earlier drafts of this article. I would also like to thank Deborah Archer, Alina Das, Robert Dinerstein, Elizabeth Emens, Daniel Harawa, Randy Hertz, Alexis Karteron, Shirley Lin, Sarah Lorr, Nancy Morawetz, Kimberly M. Mutcherson, Prianka Nair, Adam M. Samaha, Jocelyn Simonson, Britney Wilson, Erika Wilson, and participants at the Professional Development Committee workshop at CUNY School of Law, the Clinical Writers Workshop at NYU, the AALS Clinical Conference works-in-progress workshop, the Lutie Lytle Black Women Law Faculty Writing Workshop, the AALS Disability Law works-in-progress workshop, and the Fordham University School of Law faculty workshop for their guidance and comments on various drafts of this Article.

INTRODUCTION

"Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about - and formulate strategies for changing - discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction"

~ Barbara Faye Waxman and Anne Finger¹

Sexuality is as an aspect of one's life that is inseparable from the other complex layers of the human experience. It encompasses sexual self-expression, "sex, gender identities, and roles, sexual orientation, eroticism, [sexual] pleasure, intimacy, and reproduction."² It influences one's actions, self-esteem, thoughts, feelings of self-worth, interpersonal interactions, emotional, behavioral, physical, and mental health.³ Legal scholarship has undertheorized how the control and subjugation of intimate, sexual, and reproductive choices are normalized within state systems that are central in the lives of people with intellectual and developmental disabilities to exact enduring harms.⁴

This Article is the first to apply a *structural desexualization of disability* framework to identify the invisible ways that legal, social, political, historical, and economic structures and norms act in concert within state systems to exact harm on people with intellectual and developmental disabilities in matters of sexuality, creating conditions of human suffering that are often overlooked.⁵ This framework situates the structural desexualization of disability as a constitutive element in maintaining and perpetuating the sexual violence of people with intellectual and developmental disabilities. In doing so, it identifies the structural desexualization of disability as the cumulative root cause of both the interpersonal violence and indirect forms of harm that this community experiences.

Desexualization is the "the process of stripping disabled people of sexual agency and autonomy."⁶ It is the loss of self-determination in matters of sexual self-expression and reproduction. It is the erasure of one's "sexual identity or experience" and having sexual desire or choosing to be the object of one's desire.⁷ Individuals with intellectual and developmental disabilities share the same

Draft --- Do Not Circulate or Cite - Draft The Structural Desexualization of Disability

desire to experience love and intimacy, to engage in sexual pleasure, sexual self-expression, and exercise choices around sexuality and reproduction as the broader population.⁸

The structural desexualization of disability is experienced through the day-to-day indignities that result from the stripping of sexual agency, sexual self-determination, and opportunities to engage in sexual self-expression, pleasure, and desire.⁹ It is embodied through the erosion of personhood, loss bodily autonomy, the diminishment of self-worth, and other losses of dignity that result from this desexualization. It is felt as a result of the barriers erected that limit opportunities to develop healthy sexual and intimate relationships, make reproductive choices, and access sexual health education, supports, services, and reproductive care. It is experienced through the withholding of knowledge and information on how to protect one's body and how to identify when one's body is violated.

The breadth of what sexuality encompasses in one's life speaks to "the magnitude of damage" that flows from the structural desexualization of disability.¹⁰ Consider the case of Britney Spears. Spears gained nationwide attention following the release of her testimony in court for the removal of the 13-year conservatorship¹¹ to which she was subjected by her father. In her hearing to remove her conservatorship, Spears testified:

"I want to be able to get married and have a baby. I was told right now in the conservatorship, I'm not able to get married or have a baby, I have a (IUD) inside of myself right now so I don't get pregnant. I wanted to take the (IUD) out so I could start trying to have another baby. But this so-called team won't let me go to the doctor to take it out because they don't want me to have children – any more children. So basically, this conservatorship is doing me waaay [sic] more harm than good."¹²

To those familiar with conservatorship, Spears' testimony was not the "bombshell"¹³ or a "stunning assertion[],"¹⁴ as maintained by media outlets and pundits who questioned the legality of whether Spears could be forced to maintain birth control under conservatorship to avoid pregnancy.

Rather, Spears' testimony illustrates the normalized sexual and reproductive control that is inflicted through the "coercive function" of conservatorship.¹⁵

As Spears wrote in her 2023 memoir, *The Woman In Me*, "the conservatorship was created supposedly because I was incapable of doing anything at all. Feeding myself, spending my own money, being a mother, anything."¹⁶ Through the appointment of a conservatorship, the court determined that Spears lacked "legal mental capacity" to make decisions over her life.¹⁷ Spears' father became the court-appointed conservator of Spears' "person" and of her estate¹⁸ until the court dissolved the guardianship in 2021.¹⁹ Under her conservatorship, Spears reverted to a minor with her father assuming the legal right to make plenary decisions over all aspects of her personal and financial life. In discussing the conservatorship, Spears stated, "My mom and dad took my womanhood from me."²⁰

The outrage that swelled through the #FreeBritney movement²¹ was arguably propelled by Spears' whiteness, wealth, and international recognition, which conversely still could not shield her from having her sexual and reproductive decision-making rights controlled through a state process. Take these privileges away, however, and the outrage disappears. It is well-documented that people with intellectual and developmental disabilities,²² a population that lacks access, privilege, and economic capital,²³ have long endured control over their intimate, sexual, and reproductive decisionmaking through guardianship, and other means.²⁴ But, unlike Spears, these deprivations are not elevated to importance in national dialogue. They remain in the shadows, viewed largely by society as a natural aspect of what is required to protect this population.²⁵

When national attention is given to issues of sexuality and people with intellectual and developmental disabilities, the focus is often on stories that sensationalize²⁶ acts of sexual violence²⁷ against this community, emphasizing a victim-perpetrator binary: there is a victim who experienced identifiable harms and a perpetrator to hold accountable.²⁸ This binary view focuses on an interpersonal, individualized form of harm, which results in a dominant sexual violence narrative. This

The Structural Desexualization of Disability

view attracts media headlines, which often surface fleeting conversations around what protective measures must be taken to safeguard intellectually and developmentally disabled people from this form of violence.²⁹ In recent media, National Public Radio (NPR) reported on the disproportionate rate at which people with intellectual disabilities experience sexual violence, using unreported data from the Department of Justice.³⁰ The data showed "people with intellectual disabilities are sexually assaulted at a rate that's seven times that of people without disabilities" with NPR using a sensationalized turn of words to describe this violence against the intellectually disabled community: "these women and men are easy prey for predators."³¹

The victim-perpetrator binary consumes and narrows society's view of sexuality for people with intellectual and developmental disabilities. Discourse is confined to the individualized harm, victimhood, and the need for protection. As a result, laws and policies designed to address sexual violence focus on the victim-perpetrator binary, thereby limiting possibilities for structural change in addressing these harms. The law further reifies the ascription that a diagnosis of intellectual and developmental disability is incompatible with exercising the range of choices that are informed by one's sexuality—sex, developing and maintaining intimate relationships, marriage, engaging in sexual pleasure, and having children, to name only a few examples.³² This ascription is reflected through the extent of laws that limit the sexual and reproductive choices of people with intellectual and developmental disabilities.³³

Scholars are looking beyond the interpersonal narrative of violence to think more critically at its unseen impact, structural causes, and lasting consequences.³⁴ Theorists and other social science scholars in the last half century have also developed new ways to think about violence and its root harms beyond the interpersonal.³⁵ The structural desexualization of disability framework builds on this literature by shifting attention away from the victim-perpetrator binary of sexual violence that is most often applied to people with intellectual and developmental disabilities in matters of sexuality. This

Draft --- Do Not Circulate or Cite - Draft The Structural Desexualization of Disability

framework provides for a deeper inquiry into the causes of sexual violence that are not readily visible through a victim-perpetrator binary lens. In doing so, it exposes the extensive and cascading harms that are committed through systems, structures, and the state by the structural desexualization of disability. It further situates what role the state plays in maintaining—and should play in preventing these harms.

Specifically, this Article examines three disability systems through the structural desexualization of disability framework: guardianship, special education, and the government-funded service system that provides community-based supports to people with intellectual and developmental disabilities. These systems dictate the level of control that is relegated to the sexual and reproductive choices of individuals with intellectual and developmental disabilities. By examining the disability systems "that shape [the] risk and local reality" of sexual victimization,³⁶ this Article seeks to guide renewed strategies for how to ameliorate sexual violence and its cascading harms. It further aims to encourage discourse, advocacy, policy making, and organizing around the breadth of issues that impact sexuality by reframing the victim-perpetrator binary to reposition sexuality as a community integration priority under Title II of the Americans with Disabilities Act³⁷ for people with intellectual and developmental disabilities.

The use of an expansive definition of sexuality centers the role of interdependence³⁸ in the application of the structural desexualization of disability framework. In applying this framework, the intellectually and developmentally disabled community is not treated as a monolith. There is a "physical, cognitive, and psychological impact" on the lived experience of disability³⁹ that must be recognized and embraced when examining issues of sexuality and intellectual and developmental disability.⁴⁰ Whereby "the experience of disability and being disabled is the result of the *interaction* of a person's inherent differences *with* a society and its attitudes and policies."⁴¹ Individuals with intellectual and informed

The Structural Desexualization of Disability

choices related to sexuality.⁴³ Supports, alone, may not be adequate to protect an individual from sexual victimization, or harming others. In such instances, protective or restrictive measures on an individual's behavior or sexual choices may be warranted while supports are provided.⁴⁴

The structural desexualization of disability framework does not jettison the victim-perpetrator binary. Rather, it suggests that a broader structural framing that examines the roots of sexual violence on the intellectually and developmentally disabled community is necessary. Any amelioration efforts to address sexual violence against people with intellectual and developmental disabilities must first confront the structures that maintain this violence—and identify the complicit role of government systems in exacerbating this violence. As expressed by political theorist Mathius Thaler, "how we conceptualize violence affects what we do to contain and mitigate it."⁴⁵

Part I of this Article examines the history and role of the law in desexualizing disability. It explores how the structural desexualization of disability is an unintended consequence of the advocacy movement for community integration under Title II of the Americans with Disabilities Act, which prohibits disability-based discrimination by state and local governments. Part II discusses the inadequacy of the victim-perpetrator binary of sexual violence. It then introduces the structural desexualization of disability framework. Part III applies the structural desexualization of disability framework to three central disability systems that people with intellectual and developmental disabilities must navigate: guardianship, special education, and the government-funded system that provides community-based supports and services. Part IV concludes with strategies to reconceptualize sexuality as a community integration priority through state and other interventions.

I. The Historical and Legal Foundations for Creating and Sustaining a Culture of Desexualizing Disability

This Part first provides a brief discussion of the history that influences the sexual and reproductive control of people with intellectual and developmental disabilities. It then discusses forms

of desexualizing disability in modern law. The section concludes by examining the unmet promise of Title II of the Americans with Disabilities Act to include sexuality as an integral aspect of community integration.

A. The Historical Foundations of the Desexualization of Disability

The control of the sexual and reproductive choices of persons with actual—or perceived intellectual and developmental disabilities is rooted in history. Between 1890 and 1920, the theory of eugenics began to take hold in the United States.⁴⁶ The fields of law, medicine, philanthropy, and academia began to embrace eugenics⁴⁷ as a means to control the sexual and reproductive lives of those deemed at the margins of society. Eugenicists sought to prevent the dilution of a "superior human stock."⁴⁸ Eugenicists felt an imperative for the human manipulation of genetics to rid the world of "inefficient stock" that they deemed contributed to moral and racial degeneracy and supplant it with "better strains" to create a superior white race.⁴⁹ To achieve this goal, eugenicists sought to restrict the procreation of persons whom they deemed "unfit"—through marriage restrictions, sex-segregated institutionalization, and compulsory sterilization—because of "hereditary defects" that they determined threatened "the national gene pool."⁵⁰

The construction of the labels "feebleminded" and "mentally defective" by eugenicists created nebulous designations that captured a wide net of persons who society viewed as the direct cause of moral degeneracy in society.⁵¹ Women labeled "feebleminded" were the primary targets of eugenic policies aimed at controlling their sexuality.⁵² These "problem women" were deemed to require "permanent and watchful guardianship' during the child-bearing years" due to their "tendency to become irresponsible sources of corruption and debauchery."⁵³

Justice Oliver Wendell Holmes, Jr. emboldened the eugenics movement with the 1927 decision *Buck v. Bell*, further entrenching the labels of feebleminded and mentally defective as legitimate disability constructs to justify sexual and reproductive control.⁵⁴ *Buck v. Bell* held as

The Structural Desexualization of Disability

constitutional a Virginia statute that provided state institutions with the right to "sexually sterilize" patients who were deemed hereditarily unfit if they determined it in their best interest.⁵⁵ Once sterilized, these women could freely return to the community.⁵⁶ Between 1907 and 1937, 30 states and Puerto Rico had forced sterilization laws.⁵⁷

B. Modern Laws that Impact the Structural Desexualization of Disability

Knowledge of the historical construction and weaponization of sexuality and disability provide the necessary background to understand the structural desexualization of disability in its contemporary form. The sexual and reproductive control of disabled people is justified in the law. Under state guardianship laws, a third person may restrict a disabled person's right to marry, engage in intimate relationships, and make reproductive choices.⁵⁸ Today, thirty-one states and the District of Columbia maintain laws that allow for the involuntary sterilization of persons under guardianship.⁵⁹ Some states allow for the involuntary sterilization of disabled children.⁶⁰ As one example of the application of modern sterilization laws, in a recent opinion by the Court of Appeals of Michigan, a parent sued a doctor for medical malpractice after he performed a vasectomy on her son, Jason, with Down syndrome. Jason was in his 20s at the time of the surgery.⁶¹ The doctor stated that he considered Jason "unable to consent to or understand the contemplated surgery" and relied on the father's "representation that he had been appointed Jason's guardian" as providing the "appropriate consent for the procedure." ⁶² The father did not inform the mother, who was also her son's guardian, of this decision. He later stated that "he wanted no more abominations in this world" as a reason for why he had his son forcibly sterilized.⁶³

The law contains additional barriers to parenting,⁶⁴ marriage, and maintaining intimate relationships. Thirty-three states, and Washington DC, maintain laws that include intellectual and developmental disability as grounds to terminate parental rights.⁶⁵ The removal rates of parents with an intellectual disability by the family regulation system⁶⁶ range from 40 to 80 percent.⁶⁷ Further,

The Structural Desexualization of Disability

disabled people are "effectively barred from marrying or cohabiting with the partners that they love"⁶⁸ due to the financial penalties imposed by federal needs-based programs on which most disabled people rely. Medicaid and Social Security Income (SSI)⁶⁹ are programs administered by the state through federal funding that provides health care and financial support, respectively, to targeted populations who are living at or below the poverty level. People with intellectual and developmental disabilities disproportionately live in poverty and are under, or unemployed.⁷⁰

Federal needs-based programs are often a lifeline to maintain their health and well-being.⁷¹ If two disabled people marry or cohabitate, however, they risk a reduction or loss of their SSI and Medicaid benefits due to the pooling of their combined assets and resources.⁷² As a result, marriage or living together romantically are often foreclosed options due to the financial impact. Also lost as a result of these financial barriers are all of the additional legal benefits that flow from marriage.⁷³ As an example, one woman with a developmental disability said, "I joke around that there should be a show called Married to Medicaid where we all talk about our inability to extract ourselves from the longterm care system."⁷⁴

C. The Promise of Olmstead and Community Integration

The 1999 the Supreme Court case *Olmstead v. L.C. ex rel. Zimring*⁷⁵ represented a watershed moment in the deinstitutionalization movement for people with intellectual and developmental disabilities, centralizing the role of states in the transition of disabled people from institutionalized settings to living in the community.⁷⁶ The case involved two women, Louise Curtis and Elaine Wilson, both dually diagnosed with a psychiatric and intellectual disability.⁷⁷ Each were voluntarily admitted into a state hospital for mental health treatment. After receiving treatment at the hospital, Curtis and Wilson each wished to leave the hospital and receive treatment in the community.⁷⁸ The hospital denied their request, maintaining that they must remain confined in the hospital to receive mental health treatment.⁷⁹

N. Chin

The Structural Desexualization of Disability

The Court held that the "unjustified isolation" of people with disabilities qualified as disabilitybased discrimination under Title II of the Americans with Disabilities Act (ADA). *Olmstead* changed the state's role in the care and treatment of disabled people. States could no longer warehouse disabled people in institutions under the guise of protectionism and care. States were now mandated to provide community-based treatment in the most integrated setting appropriate to the needs of the disabled individual as a reasonable modification to avert unjustified isolation.⁸⁰ The ADA implementing regulations, commonly referred to as the *Olmstead* integration mandate under Tittle of the ADA, provides that a "public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."⁸¹ The community placement must be determined appropriate by the individual's "treating professionals."⁸² And the person must also agree to the placement.⁸³

Olmstead resulted in a shift of government funding away from large-scale state institutional settings "in favor of funding programs that provide supports and services in the community."⁸⁴ The Medicaid Home and Community-Based (HCBS) waiver program is now a central fiscal tool used by states to comply with the *Olmstead* integration mandate.⁸⁵ The HCBS waiver program, created in 1981, is the joint state and federally funded program under Section 1915(c) of the Social Security Act that "permits a state to waive certain Medicaid requirements in order to furnish an array of home and community-based services that promote community living for Medicaid recipients and, thereby, avoid institutionalization."⁸⁶ The HCBS waiver program is "designed to prevent re/institutionalization, promote health and wellbeing, and help people with [intellectual and developmental disabilities] live and thrive in their communities, including to the same degree as nondisabled people who do not receive HCBS."⁸⁷

The most recent data reveals the impact of *Olmstead*. Approximately 930,356 people with intellectual and developmental disabilities receive supports and services in the community, compared

The Structural Desexualization of Disability

to 22,869 in 1987— a nearly 4,000% increase.⁸⁸ Between 2009 and 2019, the number of people with intellectual and developmental disabilities who lived in a residential setting of 16 or more residents declined by 59% while the number of persons living in community settings with six or fewer people increased by 95%.⁸⁹ The steady increase in funding to the HCBS waiver program following the *Olmstead* integration mandate created a new reality for community integration that afforded greater opportunities for disabled people to live a fuller life with supports. With HCBS waiver funding totaling \$45.1 billon in 2019,⁹⁰ it is the "largest funding stream,"⁹¹ and the primary means for people with intellectual and developmental disabilities—who are also "among the nation's poorest residents"⁹²—to secure services and supports in the community.

A recent study examined 3,850 services that were provided through 107 HCBS waivers for people with intellectual and developmental disabilities,⁹³ the breadth of community-based services included the following:

community transition supports; day habilitation; ⁹⁴ . . . family training and counseling . . . financial support services; health and professional services [such as] crisis, dental, clinical and therapeutic services, . . . recreation and leisure; residential habilitation (facility-based); respite; self-advocacy training and mentorship; specialized medical and assistive technologies; . . . supported employment; supports to live in one's own home (e.g., companion, homemaker, chore, personal assistance, supported living); and, transportation.

The modern application of the *Olmstead* integration mandate reflects the lived experiences of people with intellectual and developmental disabilities and the right to live integrated into the community with services and supports. Historically, a diagnosis of intellectual and developmental disability relegated the individual to a life of institutionalization and/or subject to harmful and ineffective medical methods of treatment.⁹⁵ Today, intellectual and developmental disability is no longer defined as a static condition.⁹⁶ The "changes in medical practice, psychology, and a burgeoning legal framework of civil rights"⁹⁷ support the notion that persons with intellectual and developmental disabilities can thrive in the community with individually tailored supports and services.⁹⁸

D. Sexuality and the Unmet Promise of Olmstead

Despite the strides made after *Olmstead* in securing services in the community for people with intellectual and developmental disabilities there remains few opportunities to access supports in areas related to sex, developing and maintaining intimate relationships, marriage, engaging in sexual pleasure, and other related areas. The lack of access to supports and services around issues of sexuality for people with intellectual and developmental disabilities remain the normal course. States are the gatekeepers for the types of community-based services that are provided to people with intellectual and developmental disabilities through its HCBS waiver program. Through HCBS waivers, states have "the flexibility to determine not only who is eligible and how many people are served" by the waiver, but also gives states control over "what benefits" the waiver will cover and "the ways those benefits are provided."⁹⁹ As a result, states hold the strings that orchestrate what community-based services are prioritized for waiver funding.

A recent study reflects the inattention to states in providing community-based supports and services focused on issues of sexuality. The study examined 107 HCBS waivers from 44 states and the District of Columbia to find that only 10% provided sexual health services,¹⁰⁰ which predominantly focused on reactive services.¹⁰¹ Reactive services are generally "in the form of behavior support for sexually inappropriate behavior."¹⁰² This "reactive model" for providing sexuality services "often begins when sexual violence victimization comes to light."¹⁰³ This incident-driven response predominates the understanding and acknowledgment of sexuality within disability systems.¹⁰⁴ In spending allocation, the study found that only \$282,492 was apportioned to exclusively provide sexual health services, which served "less than 0.05%" of people with intellectual and developmental disabilities.¹⁰⁵

The treatment of sexuality by state institutions for people with intellectual and developmental disabilities reflects the punitive view toward acts of sexuality by residents that pervaded the time period

The Structural Desexualization of Disability

prior to *Olmstead*. Bernand Carbello, a survivor of the Willowbrook State School,¹⁰⁶ expressed, "[w]hen I was in Willowbrook, sexuality was a crime . . . If you got caught, you got [beaten] with sticks, belt buckles, metal keychains... It took me a long time to come to terms with my sexuality. I used to feel guilty [about sex]."¹⁰⁷ The shift toward community integration following *Olmstead* did not contemplate how negative attitudes and punitive treatment as a response toward expressions of sexuality would be addressed, or what services states could provide to support the sexual lives of this newly integrated community.

There is also a reticence among society, agencies that serve people with intellectual and developmental disabilities, and family members to support the sexuality of persons with intellectual and developmental disabilities.¹⁰⁸ Some family members may feel that providing sexuality education to their intellectually or developmentally disabled child will "encourage sexual behavior."¹⁰⁹ There are sometimes "restrictions and avoidance of the topic of sexuality" by family out of concerns around sexual abuse, pregnancy, and sexually transmitted infections.¹¹⁰

These views around sexuality conflict with the benefits that providing sexuality education and supports is shown to provide. Studies reflect that access to sexuality supports while living in the community "increased sexual knowledge and skills in recognizing abuse, building relationships, maintaining boundaries, and decision-making [which] can help protect against sexual victimization."¹¹¹ Sexuality education and supports increase empowerment in making informed choices that protect one's health and safety.¹¹² The range of services that states could provide through the HCBS waiver program include "comprehensive and culturally competent sexuality education,"¹¹³ training and supports about how to engage in safe sexual practices, develop safe emotional and intimate relationships, consent, and how to identify sexual abuse and protect oneself from abuse.¹¹⁴ Sexuality education and programming could further encompass sexual self-awareness, communication and

understanding social cues, bodily autonomy, sexual-self-expression, sexual orientation, gender identity, reproduction, and family planning.¹¹⁵

Minimizing the importance of sexuality supports and services paradoxically fosters community-based environments that place intellectually and developmentally disabled people at a greater risk becoming victims of, or perpetrating, sexual violence. The lack of information on how to engage in healthy sexual behavior is shown to increase the likelihood of sexual violence against persons with intellectual and developmental disabilities.¹¹⁶ Barriers to accessing sexuality education and supports create a greater risk for developing maladaptive sexual behaviors, which may lead to an individual harming others.¹¹⁷ Further, the lack of recognition of sexuality for intellectually and developmentally disabled women creates barriers to accessing sexual and reproductive health care needs such as pap smears and cervical cancer exams resulting in poorer health outcomes.¹¹⁸

As reflected in the law,¹¹⁹ by the actions of group homes,¹²⁰ and by the response of support staff,¹²¹ to provide just a few examples, the erasure of sexuality as a part of community integration creates a culture where intellectually and developmentally disabled persons are more vulnerable to constraints on their sexual and reproductive agency as a default reaction. *Forziano v. Independent Group Home Living Program, Inc.* illustrates this point.¹²² Paul Forziano and Hava Samuels, both of whom have an intellectual disability, fell in love and wanted to live together and get married.¹²³ Paul and Hava lived in separate group homes within the community.¹²⁴ They met in a program designed for people with intellectual and developmental disabilities to learn life skills and engage in community-based opportunities that enhanced their personal development.¹²⁵

With the support of their families, Paul and Hava approached their respective group homes (and the state agency that provides supports and services to people with intellectual and developmental disabilities) asking to live together in one of their group homes.¹²⁶ The group homes opposed this request, stating that living together in a group home was "unprecedented," "impossible," and "fraught

The Structural Desexualization of Disability

with difficulties."¹²⁷ The representative of the state agency recommended that both Paul and Hava undergo a sexual consent assessment¹²⁸ and receive sex education.¹²⁹ Neither Paul nor Hava's group home, however, "included sex education" or "relationship counseling" as a "goal, service or treatment" in the supports provided to its residents.¹³⁰

In defending its decision that Paul and Hava could not live together, Hava's group home argued that she had the "mental age of a four-year-old girl" and allowing her to engage in sexual conduct would be "permitting abuse."¹³¹ The group home relied on two outdated sexual consent assessments of Hava to assert her sexual consent incapacity, one that was conducted four years, and another that was completed 12 years prior to the date of when Hava and Paul asked to live together.¹³² The couple decided to find an independent agency to perform an updated sexual consent assessment.¹³³ This assessment determined that Paul and Hava each had the capacity "to give verbal informed consent."¹³⁴ The agency that conducted the assessment provided "specialized educational materials" to Hava and Paul as part of the assessment process.¹³⁵ Hava's group home, however, rejected the result of her updated independent assessment.¹³⁶

The *Olmstead* integration mandate created opportunities for Paul and Hava to live and thrive in the community with supports. They were able to meet in the community and fall in love. But in matters of sexuality, *Olmstead* presents a lost opportunity to support the couple's desire to experience love, intimacy, and marriage in the community. Here, the group homes and state agency had the opportunity to support Hava and Paul by providing sexuality services to enhance what the group home viewed as any perceived incapacities around Hava's sexual decision making.¹³⁷ But chose not to.¹³⁸ The experience of Hava and Paul reflects the necessity to reframe the narrative around sexuality beyond that of vulnerability and victimhood. It also displays the inadequacy of the sexual violence narrative in navigating issues of sexuality and intellectual and developmental disabilities. II. Reframing the Victim-Perpetrator Binary Through the Structural Frame of Desexualizing Disability

This Section discusses the limitations in addressing the sexual violence of people with intellectual and developmental disabilities through a victim-perpetrator binary. It further discusses the necessity to break from this binary to examine more critically the structures that normalize the desexualization of disability.

A. The Inadequacy of the Victim-Perpetrator Binary View of Sexual Violence

In confronting issues of sexuality and intellectual and developmental disability "[m]uch of the discourse . . . can be classified as 'crisis responsive' or 'harm reducing."¹³⁹ The lives of intellectually disabled women, in particular, is "largely constructed around the twin poles of 'regulation and pregnancy/reproduction" and the 'protection from sexual assault."¹⁴⁰ In the legal context, "vulnerability as a construct"¹⁴¹ creates a presumption of sexual incompetency around sexuality and disability.

Responses to sexual violence against people with intellectual and developmental disabilities that are crafted through a victim-perpetrator binary lens have little permanent effect on supporting the health and well-being of the disability community most impacted by sexual violence. It also fails to examine the root causes of this violence. In her article, "#US Too,": Empowerment and Protectionism in Responses to Sexual Abuse of Women with Intellectual Disabilities, Holly Jeanine Boux examined several legislative proposals that focused on sexual assault against women with intellectual disabilities. The reforms largely focused on addressing sexual violence through "law enforcement and judicial practices."¹⁴² They included increasing training, funding, and other resources into criminal investigations and prosecutions and strengthening care provider abuser registries and mandatory reporter requirements for employees working with people with intellectual disabilities.¹⁴³ These efforts largely focused on "remedying the symptoms rather than the roots causes" of the sexual violence.¹⁴⁴

with a majority of state statutes further marginalizing intellectually disabled survivors of sexual assault through "infantilizing language" that embeds "disempowering and paternalist norms and practices" ¹⁴⁵ in the legal process.

Enhanced surveillance is another measure that states' propose to deter or identify perpetrators of sexual violence. Twelve states currently allow surveillance monitoring in congregate care settings, including nursing and group homes,¹⁴⁶ which raise privacy and additional civil rights concerns.¹⁴⁷ Cultivating efforts to remediate sexual violence against people with intellectual disabilities through criminal, prosecutorial, and surveillance efforts have largely proven ineffective. Scholars have also challenged legislative and judicial approaches in navigating questions of capacity and consent in sexual assault cases.¹⁴⁸

B. The Social Machinery That Normalizes the Structural Desexualization of Disability

The central role that the disability systems of guardianship, special education, and the HCBS waiver program play in the lives of people with intellectual and developmental disabilities reflect a type of "social machinery" that engages to normalize the structural desexualization of disability.¹⁴⁹ In applying the structural desexualization of disability framework, structures are the "social relations and arrangements—economic, political, legal, religious, or cultural—that shape how individuals and groups interact" in society.¹⁵⁰ Structures are maintained by institutional policies and practices, choices of resource allocation, and legal, historical, political and culturally driven processes, which coalesce to inflict harm as a matter of course by way of society's day-to-day collective actions.¹⁵¹

The structural desexualization of disability framework examines how each system interacts and can work systematically within structures to minimize, discount, or erase the reality that people with intellectual and developmental disabilities have the same desire for intimacy, love, and connection as people without disabilities. Because these disability systems "operate normatively," as a matter of course, the harms that flow from the structural desexualization of disability are continuous, occurring

The Structural Desexualization of Disability

through the general course of one's life.¹⁵² This routinization of the harm that flows from the structural desexualization of disability effectively erases its social, political, and historical origins.¹⁵³ The structural desexualization of disability framework requires exploration of the subjugation, indignity, loss of autonomy, and other forms of direct and indict harms that can result by interacting with disability systems.

III. The Systems That Maintain the Structural Desexualization of Disability

This section applies the structural desexualization of disability framework to the systems of guardianship, special education, and the HCBS waiver program to illustrate the harms and consequences that flow from desexualization. This analysis considers the historical, legal, societal, and economic structures that influence each of these disability systems to present how each perpetuate and maintain physical, emotional, psychological, and other forms of harm.

A. The Desexualization of Disability Through Guardianship

Guardianship creates conditions that allow for the deprivation of sexual agency, bodily autonomy, and reproductive choice. Guardianship laws are regulated by states. According to the most recent available data, between 45-55 percent of people with intellectual and developmental disabilities are under guardianship.¹⁵⁴ The guardianship regime developed based on notions of *parens patrie* or "parent of the country." The government assumes the protectionist role to secure the health and safety of persons deemed unable to care for themselves due to diminished mental capacity.¹⁵⁵ Courts may appoint a guardian—who may be an individual, most often a family member, or a public guardianship provided by the state—for an individual who it determined lacks mental capacity.

The National Council on Disability¹⁵⁶ referred to guardianship as a "kind of civil death" because persons subject to guardianship are "no longer permitted to participate in society without mediation through the actions of another if at all."¹⁵⁷ They are stripped of their legal capacity, reverting to the status of a minor under the law.¹⁵⁸ In guardianship proceedings, a court may appoint a third

Draft --- Do Not Circulate or Cite - Draft The Structural Desexualization of Disability

party (guardian) with the legal authority to make decisions such as where the person who is under guardianship may live, whether they can vote, the level of control over their sexual and reproductive choices, who they can interact with, what intimate and social interactions they have, and whether the person may marry.¹⁵⁹

Despite increasing recognition by states that alternatives to guardianship are necessary to prevent undue restrictions on a disabled person's right to control their own lives,¹⁶⁰ guardianship remains central as a disability system that legitimizes third-party control over the sexual and reproductive choices of disabled persons. A recent Massachusetts case provides a good example. There, the Department of Mental Health petitioned the Probate and Family Court to appoint the parents of a 32-year-old woman (identified as "Mary Moe" in court documents) to serve as guardian of their daughter with a psychiatric disability for the purpose of consenting to an abortion.¹⁶¹

Mary Moe's parents felt the termination of their daughter's pregnancy was in her best interest.¹⁶² Moe opposed the abortion for religious reasons.¹⁶³ The court agreed with Moe's parents and granted them co-guardianship.¹⁶⁴ The court determined that, to ensure the abortion took place, Moe could be "*coaxed, bribed, or even enticed* . . . *by ruse*" into a hospital where she could undergo the procedure.¹⁶⁵ The judge, without provocation, also directed the facility performing the abortion to sterilize Moe "to avoid this painful situation from recurring in the future."¹⁶⁶

Guardianship normalizes the control of sexual and reproductive choices of disabled people. Consider the following. Several doctors and practitioners from the Division of Plastic Surgery, Department of Surgery at Yale University School of Medicine, recently published a case report titled, *Prophylactic Desexualizing Mastectomy for an Intellectually Disabled Woman: Protective Measure or Disregard for Autonomy?*^{**167} In this brief piece, the authors discuss the case of a woman with intellectual disability who was born with "breast asymmetry." The woman felt "distress and embarrassment" because of this congenital condition. ¹⁶⁸ In efforts to minimize these feelings, before

The Structural Desexualization of Disability

going in public, she "would often symmetrize her breasts with homemade breast inlets."¹⁶⁹ Her mother, who was also her daughter's guardian with the legal authority to make her medical decisions, consulted with a surgeon. The surgeon informed the mother that a procedure to augment her daughter's smaller breast was the most common approach. ¹⁷⁰ But her mother opposed the breast augmentation surgery.¹⁷¹

According to the authors, the mother "believed that the augmentation of [her daughter's] breasts might result in an increased risk of sexual assault should her daughter ever live in an assisted care setting."¹⁷² Rather than the augmentation surgery, the mother requested that the doctor perform a mastectomy "to reduce [her daughter's] "sexuality." The medical complications of the surgery would likely result in a loss of "nipple sensation and ability to breastfeed." ¹⁷³ The authors noted that it could be reasonably argued that a mastectomy was necessary to "desexualize" this young woman citing that "intellectually disabled women are at a 12-fold increased risk for sexual assault."¹⁷⁴

Through the structural desexualization of disability framework, the mother's decision that a mastectomy was the best course to protect her disabled daughter from sexual abuse could not occur but for structures that interacted to maintain the desexualization of her daughter because of her intellectual disability. First, the mother wanted to protect her daughter from sexual victimization because of the documented evidence that people with intellectual and developmental disabilities are disproportionally impacted by sexual violence.¹⁷⁵ Second, the legal system provided the mother with the legal right to make health care decisions for her daughter through guardianship, which secured the legal grounds to authorize a surgery.¹⁷⁶

Third, the medical professionals retained the power to reject the surgery but maintained equal power to move forward with this procedure, as other medical professionals have chosen when confronted with similar family requests to desexualize a disabled loved one. Conducting growth attenuation procedures is but one example.¹⁷⁷ While the court-ordered appointment of a guardian

The Structural Desexualization of Disability

occurs in an instant moment of time, the bodily, sexual, and reproductive control that is lawfully permitted, at any time, under the guardianship regime is exercised throughout the individual's lifetime, reflecting the structural, slow nature of the harm she is experiencing.¹⁷⁸

B. The Desexualization of Disability Through Special Education

In March 2022, a federal court rejected a school district's motion to set aside a \$500,000 jury verdict in favor of C.K.M., a high school student with intellectual disability who was sexually assaulted during her freshman year by another student, David M., who was also in her special education class.¹⁷⁹ Due to his past sexual misconduct, restrictions were placed on David M. for his attendance at his new school. He was not allowed to be left unattended with other students or go to the bathroom alone.¹⁸⁰ According to court documents, the school did not adhere to these restrictions, which resulted in the alleged repeated acts of sexual violence against C.K.M. ¹⁸¹ Arguably, there was a level of justice for C.K.M.'s family achieved through the litigation. Applying the normative victim-perpetrator binary lens to examine the sexual violence in this case, however, stunts a deeper inquiry beyond the narrative of C.K.M. as the victim and David. M. as the perpetrator.

1. C.K.M.

After an 11-day trial, a jury found the school district violated C.K.M.'s due process and equal protection rights and acted with negligence.¹⁸² The jury determined that the school failed to protect C.K.M from repeated peer sexual harassment which, C.K.M.'s family contended, "culminated" into her being sexually assaulted by this same student, David M.¹⁸³ The Vice Principal's response to the allegations included expelling C.K.M and David M. as an "intervention technique."¹⁸⁴ The school district further argued, with support from expert testimony offered by the district, that the school's sexual harassment policy did not apply to C.K.M. because "C.K.M. did not object to what was going on"¹⁸⁵ or express that the sexual behavior was "unwanted."¹⁸⁶

The Structural Desexualization of Disability

The Vice Principle explained, "I would not characterize it as sexual harassment . . . the person has to object to what's going on for it to be harassment . . I don't know that [C.K.M.] knew better.¹⁸⁷ The school district's expert witness similarly stated that the sexual harassment policy did not apply to C.K.M. because "she did not object to" the sexual actions towards her."¹⁸⁸ Despite David M's documented history of sexually violent behavior, school employees also referred to C.K.M. as being "too sexual' toward David [M]."¹⁸⁹ The Vice Principal similarly expressed that "the physical reality of hormones"¹⁹⁰ was "driving" C.K.M. and David M's behavior.¹⁹¹

For C.K.M., the intellectual disability diagnosis imputes a duality around her sexuality that is rooted in history and was used by the school district to defend its inaction in this matter. History has given sustained power to constructs and labels that influence the modern treatment of intellectually disabled girls and women. This school's emphasis of C.K.M. as both "too sexual" and too cognitively disabled to "know better" and object to David M.s conduct reflects a modern application of eugenics ideologies. Eugenicists viewed feebleminded women as "excessively interested in sex"—the "unrestrained feebleminded women"¹⁹²—who required protection from themselves.

This dual assessment of C.K.M.'s sexuality provided the school district with justification to expel her as a purportedly protective measure to keep her safe from her own sexual wantonness and feeblemindedness, which is a characterization that eugenicists used to control the sexual and reproductive choices of the "manifestly unfit" ¹⁹³ population. The emphasis by the school district on this constructed view of C.K.M. shifts the attention away from the school district to an individualized focus on C.K.M. as the victim who is also responsible for the harm done to her. It draws attention away from the responsibility of the school district to ensure that its students with intellectual and developmental disabilities are equipped with the knowledge, information, and related services and supports to be safe in an educational setting, which is discussed in more detail below in the discussion of the school district.

2. David M.

The structural desexualization of disability affects perpetrators and victims alike. It is a cause and consequence of sexual violence. David M. is a perpetrator of sexual violence.¹⁹⁴ This identification, alone, however, does little to inform efforts to maintain student safety against sexual victimization, or engage with preventive and treatment strategies in averting the development of sexually inappropriate behaviors.

While we do not have much information about David M.'s history, it is this lack of information that requires a closer examination in moving through the structural desexualization of disability framework. The inquiry would, for example, explore how the laws, societal norms, the school district, and the special education system interacted to support David M. as he was developing a sexual identity and/or when he first began to exhibit sexually inappropriate behaviors. It would further examine how the intersections of race, socioeconomic class, sexuality, gender, past trauma, and other social and environmental factors in David M's life impacted decisions to provide him, and his family, with early intervention, preventative measures, and other supports. A structural desexualization of disability inquiry does not focus on demonizing the perpetrator for the direct harms caused. Rather, by surfacing the structures that coalesced to cause the harm, it seeks to identify potential strategies for preventing future suffering.

3. The School District

In further applying the structural desexualization of disability framework to C.K.M.'s case, a closer examination is needed as to how the school district and the special education system interact to maintain and perpetuate the sexual victimization of or the victimizing by students with intellectual and developmental disabilities. The Individuals with Disabilities Education Act (IDEA) requires that states provide a free and appropriate public education to disabled school-aged children and young adults until the age of 21. According to recent available data, there are approximately 6.5 million students

The Structural Desexualization of Disability

between the ages of 6-21 who are served by the special education system in the United States.¹⁹⁵ The purpose of the IDEA is to provide students with special education and related services that are tailored to meet their "unique needs" and "prepare them for further education, employment, and independent living."¹⁹⁶ These unique needs "include learning differences, social inexperience, and social naiveté that could lead to vulnerability, and warrant education programs" such as "accurate and accessible information about social-sexual behavioral norms."¹⁹⁷

The services and supports provided under the IDEA are intended to prepare students for transitioning into adulthood. Yet, studies reflect that school districts are failing to keep disabled students safe from sexual violence. According to a recent student, " [a]nywhere from 40% to 70% of girls with disabilities will experience sexual abuse before they turn 18, while up to 30% of boys with disabilities are at risk of sexual abuse during the same period."¹⁹⁸ At the same time, as is similarly reflected in studies focused on adults, there are barriers to accessing accurate and accessible sexuality education that leave disabled young people "more vulnerable to sexual victimization . . . and leads to difficulty achieving the healthy relationships that many desire."¹⁹⁹

As studies indicate, access to consistent comprehensive sexuality education "that emphasize[s] the importance of communication, boundary-setting, and decision-making skills," as some examples, strengthen the skills and knowledge of intellectually and developmentally disabled students in making informed choices around matters of sexuality.²⁰⁰ It further enhances mental and physical health,²⁰¹ empowers and "promote[s] the ability to make of good choices,"²⁰² "enhance[s]" one's "ability to make choices based on knowledge and then reinforce[s] the decision to act for the good of one's health and well-being."²⁰³ It further "contribute[s] to reducing vulnerability" and "inappropriate sexual expression."²⁰⁴

In contrast, a lack of access to sexuality services places intellectually and developmentally disabled students "at risk for demonstrating unexpected social-sexual behavior.²⁰⁵ The behaviors

The Structural Desexualization of Disability

include "public masturbation, touching people's private body parts without permission, and interacting in a sexually inappropriate manner with children."²⁰⁶ Intellectual and developmentally disabled young people may not recognize their right to bodily autonomy and how to recognize sexual harms.²⁰⁷

This inattention to sexuality in special education leaves a gap for young people with intellectual and developmental who seek access to information and knowledge around healthy intimate relationships, bodily autonomy, issues of sexual and reproductive health, and healthy boundary-setting in relationships. fuels the suppression of sexual awareness, healthy sexual exploration, may increase the development of improper sexual behavior,²⁰⁸ and maintains and perpetuates the increased vulnerability to sexual violence.

Confronting ableist²⁰⁹ assumptions on issues of gender, sexuality, and intellectual and developmental disability, conducting a deeper inquiry into the different pathways that David M. took—or could have taken if given the opportunity and resources—in navigating his sexuality as it emerged, and examining how comprehensive sexuality education can enhance the safety and healthy sexual behaviors of intellectually and developmentally disabled students are some ways to view the C.K.M. case through the structural desexualization of disability framework. In doing so, the hope is to recenter the analysis and open new avenues for structural change in addressing sexual violence against intellectual and developmentally disabled students.

C. The Desexualization of Disability Through the HCBS Waiver Program

Through the HCBS waiver program, as discussed previously, states have extensive deference to determine what community-based supports and services are available to individuals with intellectual and developmental disabilities.²¹⁰ In the administration of this program, states, and the agencies that administer the HCBS waiver program, drive "the culture, expectations, resources, and available

accommodation options" that largely dictate the life choices of disabled persons who receive these services.²¹¹ The case of Alex illustrates this point.

Alex²¹² is a 32-year man who identifies as autistic. He receives community-based services through this HSBC waiver program. Like many people with intellectual and developmental disabilities, he is dependent on this program to finance the community-based supports that he receives.²¹³ Over the years, Alex expressed his deep desire to have meaningful relationships. He requested, without success, sex education and sexuality supports that are developmentally appropriate. He acknowledges that he lacks the functional skills to safely engage in intimate relationships, often struggling to understand and recognize boundaries when interacting with people.

Alex experiences suicidal ideations and engages in self-harm due to feelings of loneliness and isolation. His social worker recommended that he receive sexuality support services that will teach the steps necessary to engage in healthy relationships, emphasizing that Alex's behavior puts him at a greater risk of self-harm, sexual and financial exploitation, and incarceration. In seeking sexuality supports, Alex expressed the following to his providers:

I know you don't understand but I need to express my sexual needs and desires. It is a basic human need. Give me the funding for [sexuality supports]. I must be able to express that I am a sexual person and just because I have autism does not make me a non or asexual person like the government would like to believe.²¹⁴

Through a structural desexualization of disability framework, the barriers that Alex faces to access sexuality supports through the HCBS waiver program demonstrate the roots of this inaccessibility and the resulting harms that he is experiencing. The lack of access to gaining the skills that allow for learning proper social cues and norms, sexually appropriate behaviors, and proper boundary setting, for example, place Alex at a greater risk of developing inappropriate sexual behaviors.²¹⁵ Exercising sexual behavior in non-healthy ways may lead to harming others and cascade into other forms of violence, as discussed in the case of C.K.M., that have both individual and

The Structural Desexualization of Disability

community impact. The social worker in Alex's case has already expressed these concerns as it relates his needs for sexuality supports. Such consequences may include arrest, conviction and placement on the sex offender registry.²¹⁶ Placement may lead to indefinite detention and houselessness.²¹⁷ Further, being ill-equipped to navigate one's sexual feelings and behavior may also lead to depression, anxiety, and self-harm, as already experienced by Alex. The emotional and psychological impact of an "inability to access meaningful relationships" may leave persons "vulnerable to isolation" and "feelings of hopelessness."²¹⁸

IV. The State's Role in Reconceptualizing Sexuality

The below passage is from a conversation between people with intellectual and developmental

disabilities, Self-Advocates Speak Up About Sex.

Why do you think people with disabilities need sexuality education? [:]

Roy: So we can learn to have healthy relationships. Rebecca: So we are able to make informed choices. Elizabeth: So we can pick the right person. Adam: For help with the toughest part of the relationship, making it last. Gabrielle: So we can be safe. Andrew: Because we all have desires/needs, and that's okay. Clara: To get the correct information. Kevin: To get resources/tools to make healthy sexual choices. Roy: So that people know their rights. Molly: So people with disabilities don't put themselves in bad situations. Julie: So we will know how to protect ourselves.²¹⁹

As expressed throughout this Article, states play an outsized role in the lives of people with intellectual and developmental disabilities. This Section proposes strategies to confront the structural desexualization of disability.

A. Harnessing the Jurisprudential Advances of the Olmstead Integration Mandate Under Title II of the ADA to Compel Sexuality Supports and Services

In the 25 years since the Court decided Olmstead, investigations by the Department of Justice,

litigation, and other advocacy efforts have changed the landscape of how people with intellectual and

The Structural Desexualization of Disability

developmental disabilities live and receive services. The central role of states in supporting community integration under Title II of the ADA creates an affirmative duty to administer its programs to avert the unjustified isolation of people with intellectual and developmental disabilities.²²⁰ Courts have interpreted the ADA to have "an expansive reach, touching upon all aspects of an individual's life in which 'isolat[ion] and segregat[ion]' may be experienced."²²¹

Further, states "may not, directly or through contractual or other arrangements, utilize criteria or methods of administration . . . [t]hat have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the [state's] program with respect to individuals with disabilities."²²² Despite these mandates, through a lack of HCBS waiver funding allocation, states impede people with intellectual and developmental disabilities of opportunities to acquire knowledge—and develop and strengthen skills—around issues related to sexuality. Sexual isolation further maintains a culture that makes persons with intellectual and developmental disabilities more susceptible to sexual violence.²²³ Critically, sexual isolation leads to the structural desexualization of disability.²²⁴

In discourse around issues to secure and expand the rights of targeted populations to exercise control and choices around sexuality, it is important to consider the expansiveness of the tools available in this effort. One such tool is harnessing the jurisprudential advances of the *Olmstead* integration mandate under Title II of the ADA to compel states to allocate adequate resources to provides sexuality supports and services. Prior scholarship has explored varied suggestions to address the limitations of sexual and reproductive control for disabled people.²²⁵ Disability rights scholar, Robyn Powell, discusses what she termed "reproduction oppression"—the "myriad ways sexuality and reproduction is weaponized to subjugate people with disabilities." ²²⁶ She argues for a renewed "jurisprudential and legislative framework"²²⁷ which centers the tenants of reproductive justice and

disability justice to "shift attention away from the courts and onto policymaking, organizing, and the electorate." ²²⁸

More intentionality is needed in using the courts as a tool to confront the structural desexualization of disability. As states are held accountable—or are sought to be held to account—through creative litigation strategies that push the parameters of *Olmstead*,²²⁹ it is time that sexuality supports and services are included in these efforts. The creativity in advocacy efforts to expand the reach of *Olmstead* has the potential to reach issues of sexuality supports and services. As this author has argued in prior scholarship, "a systematic failure to provide community-based treatment and services around sexuality" results in the unjustified sexual isolation of people with intellectual and developmental disabilities and is a cognizable claim under the *Olmstead* integration mandate as interpreted under Title II of the ADA.²³⁰ Sexual isolation and segregation manifests through the failure of states to expend resources through the HCBS waiver program for sexuality supports and services unjustifiably suppressing the sexual and reproductive lives of people with intellectual and developmental disabilities.²³¹

Since *Olmstead*, courts have interpreted the integration mandate under Title II of the ADA to extend beyond unjustified isolation within the four walls of an institution. The expanded reach of *Olmstead* has resulted in challenges to how state agencies administer and implement community-based mental health services and housing to formerly incarcerated individuals,²³² state implementation of resources to establish supported employment programs, maintain grants, and offer technical assistance to avert people with intellectual and developmental disabilities from working in segregated employment settings,²³³ state implementation of mental health services,²³⁴ and challenging states policies of segregated disabled students in public education.²³⁵

Further, in 2014, the Department of Justice²³⁶ issued guidance to specify that community integration for disabled people as required under *Olmstead* must "ensure an individual's rights of

The Structural Desexualization of Disability

privacy, dignity and respect, and freedom from coercion and restraint" and must "optimize but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact."²³⁷

B. State Resourcing to Center Sexuality in Community Integration

Any state resourcing of sexuality supports and services must further involve a multidisciplinary and community-focused effort that both recognizes and centers the lived experience, knowledge, and expertise of the intellectually and developmentally disabled community.²³⁸ Justice-based movements must engage in cross-movement building to strengthen their knowledge and understanding about sexuality and disability with the goal of building capacity to address the desexualization of disability across disciplines.

In calling on states to resource sexuality supports and services for people with intellectual and developmental disabilities, lessons can be learned from the funding-driven, multidisciplinary approach of the Violence Against Women Act (VAWA).²³⁹ VAWA "funded the criminal legal response to gender-based violence"²⁴⁰ while focusing on a carceral interventions to violence.²⁴¹ In critiquing the VAWA, Leigh Goodmark notes that while VAWA "has been credited with higher rates of arrest, prosecution, and conviction . . . the proliferation of specialized units addressing intimate partner violence; greater collaboration among service providers; and the specialization of bureaucrats focused on gender-based violence," little is documented as to the positive effects on survivors of violence.²⁴² Goodmark concludes that "a noncarceral VAWA, one that shifts funding from the criminal legal system to economic, prevention, and community-based programs, would more effectively meet the needs of people subjected to abuse and address the correlates of violence." ²⁴³ To the point of Goodmark and critics of VAWA, any state efforts to ameliorate sexual violence toward people with intellectual and developmental disabilities must move away from the carceral and punitive as primary responses.

1. Guardianship

Judges, guardians, family members, and persons subject to guardianship must be educated on the retention of the right of persons under guardianship to make choices around sexuality.²⁴⁴ Illinois provides an effective roadmap for this process.²⁴⁵ In Illinois, the statewide Guardianship and Advocacy Commission engaged in a multiyear effort to amend the state statute to require that Illinois provide adults with intellectual and developmental disabilities with the access to developmentally appropriate sexuality education and resources.²⁴⁶ This effort harnessed support from the disability community, parents of people under guardianship, service provider agencies, advocacy organizations, and politicians.²⁴⁷ The law creates a sex education curricula²⁴⁸ with train-the-trainer modules.²⁴⁹ The law provides access to "sex education, related resources, and treatment planning that supports his or her right to sexual health and healthy sexual practices and to be free from sexual exploitation and abuse."²⁵⁰

2. Mandating Comprehensive Sexuality Education in the Special Education System

State legislations can mandate guidelines for implementing compressive sexuality education in students' individualized education plans.²⁵¹ As an example, Virginia enacted two bills in 2021 "that require the Department of Education to establish guidelines for individualized education program (IEP) teams to use while developing IEPs for young people with disabilities to ensure that family life education on sexual health, self-restraint and protection, and respect for personal privacy and boundaries is age and developmentally appropriate." ²⁵² The legislation succeeded due to "advocacy efforts of a parent led subcommittee . . . who shared common experiences of their children with developmental or intellectual disabilities not receiving more comprehensive instruction on sexual health within their IEP."²⁵³

3. State Resourcing of Sexuality Services and Supports That Confronts Ableism

States can implement regular training, policies, and education efforts throughout the disability systems to centralize the importance of sexuality as an essential aspect of community integration and

The Structural Desexualization of Disability

sexual and psychosocial health. State resources must be allocated to build the capacity for communitybased services providers and the intellectual and developmentally disabled community that they serve to create policies, programs, and education materials that support sexuality as a necessary strategy to "dismantle ableist assumptions about disability and sexuality."²⁵⁴ Sexuality training must be implemented that is informed by the lived experiences and needs of people with intellectual and developmental disabilities and creates opportunities for this community to act as peer-to-peer sexuality educators. ²⁵⁵ Through this effort, states would play a central role in changing the culture of ableism, bias, and ignorance around sexuality and people with intellectual and developmental disabilities to reinforce that sexuality supports are a necessary and essential part of one's life.

CONCLUSION

The structural desexualization of disability is not a general acquiescence by society that results in sexual violence. It is fueled by societal arrangements that are accepted and maintained as the normal course by society through embedded structural systems.²⁵⁶ Confronting the structural desexualization of disability is a "collective responsibility"²⁵⁷ within society. Its exacting and sustaining harms must be examined and challenged in any effort to attenuate sexual violence and to begin viewing sexuality as a central aspect of community integration.

¹ Barbara Faye Waxman and Anne Finger, *The Politics of Sex and Disability*, disability studies quarterly, Vol., No. 3 (Summer 1989).

² World Health Organization, Sexual and Reproductive Health Research (SRH), Defining sexual health, available at <u>https://www.who.int/teams/sexual-and-reproductive-health-and-research/key-areas-of-work/sexual-health/defining-sexual-health</u>.

³ Mariam Taylor-Gomez, Sensuality, Sexual Expression and People with Intellectual Disability, 30 Sexuality & Disability (2012) 237, 237.

⁴ The development of recent legal scholarship has elevated discourse on how to address the sexual and reproductive limitations on people with intellectual and developmental disabilities. This expansive discourse has yet to deeply explore these deprivations through a structural framework. See, e.g., Robyn Powell, Disability Reproductive Justice. 170 U. Pa. L. Rev. 1851 (2022); Holly Jeanine Boux, 37 Berkeley J. Gender L. & Just. 131, "#Ustoo": Empowerment And Protectionism In Responses To Sexual Abuse Of Women With Intellectual Disabilities (2022); Sarah Lorr, 110 Cal. L. Rev 1315, 110, Unaccommodated: How the ADA Fails Parents with Intellectual Disabilities (2022); Danielle M. Shelton, Accommodating Victims With Mental Disabilities, 127 Dick. L. Rev. 163, 223 (2022); Shoshana Rubin, Note, Access To Sex: Sexuality Support For Adults With Intellectual & Developmental Disabilities, 20 Conn. Pub. Int. L.J. 131 (2021); Sam Bagenstos, Disability and Reproductive Justice, 14 Harv. L. & Pol'y Rev. 273 (2020); Jasmine Harris, The Role Of Support In Sexual Decision-Making For People With Intellectual And Developmental Disabilities, 77 Ohio St. L.J. Furthermore 83 (2016); Jasmine Harris, Sexual Consent and Disability,

93 N.Y.U. L. Rev. 480 (2018); Robyn M. Powell and Michael Ashley Stein, Persons with Disabilities and their Sexual, Reproductive, and Parenting Rights: An International and Comparative Analysis, 11 FRONTIERS L. CHINA 53, 70, 59, 68-78 (2016); Joseph J. Fischel, Hilary R. O'Connell, Disabiling Consent and Reconstructing Sexual Autonomy, 30 Colum. J. Gender & L. 428, 30 Colum. J. Gender & L. 428 (2016).

⁵ The concept of "structural violence" informs the structural desexualization of disability framework. Structural violence "is a process that occurs slowly . . . through economically, politically, or culturally driven processes that work together [] to limit [persons] from achieving full quality of life." Lee, VIOLENCE 123 (*citing* Akhil Gupta, RED TAPE: BUREAUCRACY, STRUCTURAL VIOLENCE, AND POVERTY IN INDIA (2012)). It encompasses types of violence that are "reworked through the routines of daily life as well as enacted through social relations and social institutions." Linda Green, comment to *Paul Farmer, An Anthology of Structural Violence, Current Anthropology* Volume 45, Number 3, 305-325, 320 (2004). The concept of structural violence is applied to identify forms of violence that are built into structural systems and manifest to create inequality in the distribution of power, wealth, and resources. Galtung, *Violence, Peace* at 175. *See also* Paul Farmer, PATHOLOGIES OF POWER: HEALTH, HUMAN RIGHTS, AND THE NEW WAR ON THE POOR. 29-50 (2003).

⁶ Lydia X.Z. Brown, *Ableist Shame* at 164; *see also* Elizabeth Emens, *Intimate Discrimination: The State's Role in Accidents of Sex and Love*, 122 Harv. L. Rev. 1307, 1338. 1342 (2009) (discusses "normative desexualization" as the "utter exclusion of disabled people from the intimate realm--not just relegation or segregation to pairing only within one's group"

⁷ Id. 8 Sec. -

⁸ See, e.g., Tom Shakespeare, *Disabled Sexuality: Towards Rights and Recognition*, Sexuality and Disability, Vol. 18, No. 3, 164. (2000) ("one of the tasks for us here, and in our work, is to put private desires and personal relationships on the agenda of the disability movement, to make them an arena for change."); see also Matter of D.D., 50 Misc. 3d 666, 676 (N.Y. Sur. Ct. 2015) ("The right to have a family of one's own is not reserved only for persons with no disabilities, and the yearning for companionship, love, and intimacy is no less compelling for persons with disabilities.").

⁹ See supra n 5.

https://www.documentcloud.org/documents/20985067-britney-spears-june-23-conservatorship-hearing-transcript.

¹⁰ Lee, VIOLENCE 124 ("The magnitude of damage warrants calling [structural violence,] violence rather than simply social injustice or oppression.").

¹¹ Conservatorship is also referred to in some states as guardianship. *See* Part III.A (discussing the legal process of guardianship).

¹² In re Conservatorship of: Britney Jean Spears, No. BO108870, Reporter's Transcript of Proceedings. 1-40, 25 (June 23, 2021), https://www.documentcloud.org/documents/20985067-britney-spears-june-23-conservatorship-hearing-transcript.

¹³ Erin Snodgrass, One of Britney Spears' co-conservators says her entire medical team agrees her dad should be removed from guardianship, Business Insider, July 26, 2021, <u>https://www.businessinsider.com/britney-spears-medical-team-dad-should-be-removed-guardianship-2021-7</u>.

¹⁴ Jan Hoffman, *Is the Forced Contraception Alleged by Britney Spears Legal*, THE NEW YORK TIMES, Aug. 12, 2021, <u>https://www.nytimes.com/2021/06/24/health/britney-spears-forced-IUD.html</u>.

¹⁵ Claire Spivakovsky and Linda Steele, *Disability Law in a Pandemic: The Temporal Folds of Medico-legal Violence, Social &* Legal Studies, 176 (2022) (discussing how guardianship laws were used to perpetuate forms of "legal violence" against disabled people during the coronavirus pandemic in Australia); see also Robyn Powell, *Disability Reproductive Justice*, 170 U. Pa. L. Rev. 1851, 1854-1855 (2022) ("that people with actual or perceived disabilities--including physical, intellectual, sensory, and psychiatric disabilities--should be denied reproductive autonomy remains a persistent, unrelenting belief plaguing our nation."); Sara Luterman, *For Women Under Conservatorship, Forced Birth Control is Routine*, The Nation, July 15, 2021, https://www.thenation.com/article/society/conservatorship-iud-britney-spears/

¹⁶ BRITNEY SPEARS, THE WOMAN IN ME 173 (2023); see also Cal. Prob. Code § 1800.3.

¹⁷ Jan Hoffman, *Testing Britney Spears: Restoring Rights Can Be Rare and Difficult*, N.Y. TIMES, July 23, 2021, <u>https://www.nytimes.com/2021/07/23/health/britney-spears-conservatorship.html</u>.

¹⁸ SPEARS at 166-167; *see also* 175. Cal. Prob. Code § 1800.3.

¹⁹ Joe Coscarelli and Julia Jacobs, *Judge Ends Conservatorship Overseeing Britney Spears' Life and Finances*, N.Y. TIMES, Nov. 21, 2021, https://www.nytimes.com/2021/11/12/arts/music/britney-spears-conservatorship-ends.html.

²⁰ SPEARS at 175.

²¹ The #FreeBritney movement launched when by fans who suspected that Spears did not want or need the conservatorship under which she was placed in 2008. Fans took to social media, marched in the streets, and wore #FreeBritney t-shirts for over a decade before the movement gained traction on social media in 2020. Bianca Betancourt, *Why Longtime Britney Spears Fans Are Demanding to #FreeBritney*, HARPER'S BAZAAR (Nov. 21, 2021, 5:39PM), https://www.harpersbazaar.com/celebrity/latest/a34113034/why-longtime-britney-spears-fans-are-demanding-to-freebritney/. *Id.*

²² This Article limits its focus to people with intellectual and developmental disabilities. Developmental disability is an umbrella term that includes "a group of conditions due to an impairment in physical, learning, language, or behavior

areas." Centers for Disease Control and Prevention, Developmental Disabilities, Centers for Disease Control and Prevention, Developmental Disabilities, https://www.cdc.gov/ncbddd/developmentaldisabilities/index.html. Autism, ADHD, intellectual disability, and Tourette's syndrome are examples of developmental disabilists. Center for Disease Control and Prevention, Selected Conditions in Developmental Disabilities, https://www.cdc.gov/ncbddd/developmentaldisabilities/conditions.html. A diagnosis of intellectual disability is assessed based on "significant limitations in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical skills, and age of onset before age 18." INTELLECTUAL DISABILITY: DEFINITION, CLASSIFICATION, AND SYSTEMS OF SUPPORTS 28 (Am. Ass'n Intell. & Developmental Disabilities 11th ed. 2010). A determination of intellectual functioning considers "reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly, and learning from experience." Id. Adaptive functioning "is the collection of conceptual, social, and practical skills that all people learn in order to function in their daily lives." https://www.aaidd.org/intellectualdisability/definition/adaptive-behavior (emphasis included). Conceptual skills include "language; reading and writing; and money, time, and number concepts." Social skills include "interpersonal skills . . . and social problem solving." INTELLECTUAL DISABILITY: DEFINITION, CLASSIFICATION, AND SYSTEMS OF SUPPORTS 28. Practical skills include performing activities of daily living, such as caring for one's health, maintaining a safe environment, money management, and the ability to use transportation. Id. Cf Sarah Lorr, 110 Cal. L. Rev ____, 110, Unaccommodated: How the ADA Fails Parents with Intellectual Disabilities (2022) ("In the context of [intellectual disability], the pitfalls of a medical definition go beyond merely medical versus social, in that the broad diversity of who is included by the medical definition is not well expressed by rigid listings from a medical manual. The group is a heterogenous one with members having very different strengths and needs for supports.").

²³ See, generally, Nanette Goodman, Michael Morris & Kelvin Boston, National Disability Institute, Financial Inequality: Disability, Race And Poverty In America, 5 (2019), available at https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/02/disability-race-poverty-in-america.pdf.

²⁴ See infra n _____

²⁵ See, e.g., Michael Gill, ALREADY DOING IT 35-36 (2015) ("the concept of intellectual disability assumes that people are unable to adequately advocate for themselves and need constant supervision and support. Individuals are assumed vulnerable to sexual abuse and exploitation . . . As such it is assumed that their sexual rights should be protected while their sexual expression should be shunned and silenced").

²⁶ See Lydia X.Z. Brown, *Ableist Shame and Disruptive Bodies: Survivorship at the Intersection of Queer, Trans, and Disabled Existence, in* RELIGION, DISABILITY, AND INTERPERSONAL VIOLENCE, 163, 167 (2017) [hereinafter Brown, *Ableism Shame,*] (arguing that sensationalized news stories that focus on sexual violence against a disabled person are "typically accompanied by an entire panoply of ableist tropes designed to either further accentuate the monstrosity of the perpetrator or to deny any semblance of humanity and personhood to the disabled survivor.").

²⁷ Throughout this Article the term "sexual violence" is used as an umbrella term to include sexual assault and sexual abuse. *See, e.g.* The Arc *People with Intellectual Disabilities and Sexual Violence*, <u>http://www.thearc.org/wp-content/uploads/forchapters/Sexual%20Violence.pdf</u>. This Article is informed by the definitions provided by The Arc, a national organization that focuses on "[p]romoting and protecting the human rights of people with intellectual and developmental disabilities and actively supporting their full inclusion and participation in the community throughout their lifetimes." The Arc, <u>https://thearc.org</u>. As described by The Arc, "[a]ssault is a crime of violence, anger, power and control where sex is used as a weapon against the victim. It includes any unwanted sexual contact or attention achieved by force, threats, bribes, manipulation, pressure, tricks, or violence. It may be physical or non-physical and includes rape, attempted rape, incest and child molestation, and sexual harassment. It can also include fondling, exhibitionism, oral sex, exposure to sexual assault, but is a pattern of sexually violent behavior that can range from inappropriate touching to rape. The difference between the two is that sexual assault constitutes a single episode whereas sexual abuse is ongoing." The Arc, <u>http://www.thearc.org/wp-content/uploads/forchapters/Sexual%20Violence.pdf</u>.

²⁸ See, e.g. Jeff Bonty, Jacklin sentenced to 18 years in sexual assault conviction, DAILY JOURNAL (Jan. 27, 2023) <u>https://www.daily-journal.com/news/crime/jacklin-sentenced-to-18-years-in-sexual-assault-</u>

conviction/article 7074974a-9db1-11ed-8fff-7fce2c235490.html (a Catholic priest in Indiana was sentenced to 18 years in prison after being convicted of sexually assaulting an intellectually disabled resident of a developmental center, who is described as having an IQ of 47 and "suffer[ing]" from partial paralysis.); Daniel Engber, *The Strange Case of Anna Stubblefield*, N.Y. TIMES MAGAZINE (Oct. 20, 2015), <u>https://www.nytimes.com/2015/10/25/magazine/the-strange-case-of-anna-stubblefield.html</u> (documenting the case of Anna Stubblefield, a professor who was initially criminally convicted of aggravated sexual assault for having sex with Derrick Johnson, a 28-year-old man with an intellectual disability who did not communicate verbally. Johnson is described as an adult who wears diapers, scoots on the floor, and chirps when he is excited; Robert Hanley, *Verdict in Glen Ridge: 4 Are Convicted in Sexual Abuse of Retarded New Jersey Woman*, N.Y. TIMES, March 17, 1993, at A1, https://www.nytimes.com/1993/03/17/nyregion/verdict-glen-ridge-4-are-convicted-sexual-abuse-

retarded-new-jersey-woman.html (discussing a highly publicized case through infantilizing descriptions of the disabled person: "popular high school athletes clustered around a childlike 17-year-old schoolmate who idolized them and coveted their friendship and then" violently sexually assaulted her.).

²⁹ See, e.g., Joseph Shapiro, *Abused and Betrayed*, NPR, (Jan. 2018), https://www.npr.org/series/575502633/abused-andbetrayed (a six-part series completed by NPR focusing on the "epidemic" of sexual abuse against people with intellectual disabilities); Victoria Brownworth, *Raped, Abused, and Ignored: Disabled Women are Invisible Victims*, DAME (Jan. 31, 2019), https://www.damemagazine.com/2019/01/31/raped-abused-and-ignored-disabled-women-are-invisible-victims.

³⁰ Joseph Shapiro, "She Can't Tell Us What's Wrong", NATIONAL PUBLIC RADIO (NPR), at 0:10 (Jan. 10, 2018), https://www.npr.org/transcripts/566608390.

³¹ Id.

³² See, e.g., In re Guardianship of Kennedy, 845 N.W.2d 707, 708 (Iowa 2014) (the court voiced concern as the constitutionality of a guardian's action to sterilize her 22-year-old son with Down syndrome without his consent because he was in a relationship with a woman and had admitted to having sex, but maintained that she should remain her son's guardian); In re Grady, 426 A.2d 467, 486 (N.J. 1981) (court noted that if the parents 19-year-old daughter with Down syndrome "can have a richer and more active life only if the risk of pregnancy is permanently eliminated, then sterilization may be in her best interests").

³³ See, e.g., infra, Parts IB and III, discussing the range of laws, policies, and state systems that create and sustain the culture of desexualizing disability. See also Robyn Powell, Disability Reproductive Justice at 1860-1881.

³⁴ By applying a broader understanding of violence, scholars such as Professor Erika Wilson are capturing the extent of violence's hold on maintaining oppressive systems such as racial segregation in the public education system. Erika Wilson, White Cities, White Schools, 123 Colum. L. Rev. 1221, 1225-1226 (2023) (adopting a broader definition of racial violence "jettisons the individual-perpetrator-and-intent paradigm that dominates conceptions of racial violence within the law" because it "not only limits the scope of what is considered racial violence but also limits the conception of who is harmed to individuals only, obscuring the impact of racial violence on marginalized groups, institutions, and societal structures."). Similarly, Professor Allegra McLeod argues for the necessity of "expanding our understanding of violence beyond individualized disorder and the immediate scene of interpersonal harm" in order to stop gun violence. Allegra McCleod, An Abolitionist Critique of Violence, 89 U. Chi. L. Rev. 525, 527 (2022). Scholars such as Professor Stephen Lee and Profess Rabia Belt are further pushing the boundaries of how violence is conceptualized to surface the mounting harms that are less visible as a result of immigration detention, and incarceration. See Stephen Lee, Family Separation As Slow Death, 119 Colum. L. Rev. 2319, 2326, 2384 (2019) (applies the concept of slow violence as a "useful intervention" of which includes gaining a "better understand[ing] of how the law contributes to and normalizes immigrant suffering." Rabia Belt, The Fat Prisoners' Dilemma: Slow Violence, Intersectionality, and a Disability Rights Framework for the Future, 110 Geo. L.J., 785, 827-828, 827 (2022) ("the plight of fat incarcerated people, and indeed, incarcerated people in general, is the embodiment of 'slow violence.""). For other scholars who are challenging the normative definition of violence see, e.g., Jill C. Engle, Sexual Violence, Intangible Harm, and the Promise of Transformative Remedies, 79 Wash. & Lee L. Rev. 1045, 1055 (2022) (focuses on an approach of "transformative justice" that addresses the "ongoing intangible harms" in cases of sexual violence); Alice Ristrophe, Criminal Law in the Shadow of Violence, 62 Ala. L. Rev. 571 (2011) (discussing the need to think more carefully about what is meant by violence in the undertaking of criminal law reform efforts).

³⁵ See, e.g., Emma Russell, Confronting state violence: Feminist histories and abolitionist imaginings, Paper presented at Sisters Inside conference: 'Is prison obsolete?' (2016) ("Through labelling the state and specifically the prison as violent, activists opened up space for alternative conversations about gender violence and oppression that forego, or at least challenge, a 'pragmatic' reliance on criminal justice as any kind of solution to women's oppression."); Nancy Whittier, Carceral and Intersectional Feminism in Congress: The Violence Against Women Act, Discourse, and Policy, Gender and Society, Vol. 30, No. 5, 791-818, 793 (2016) ("an intersectional feminist approach emphasizes how social, economic, and political forces interact to shape different experiences and necessary solutions to violence."); Rob Nixon, SLOW VIOLENCE AND THE ENVIRONMENTALISM OF THE POOR 2 (2011); Lauren Berlant, Slow Death (Sovereignty, Obesity, Lateral Agency), Critical Inquiry, Vol. 33, No. 4, 754-780, 754 (2007); Patricia Hill Collins, BLACK FEMINIST THOUGHT KNOWLEDGE CONSCIOUSNESS AND THE POLITICS OF EMPOWERMENT, 159 (2000) (discussing how, "By making visible the pain [that sexual violence] survivors feel," scholars of Black feminist literature reframed as violence the normalized misogyny against Black women.

³⁶ Barbara Rylko-Bauer, Paul Farmer, Structural violence, poverty, and social suffering 57.

³⁷ See infra Part II. Community integration encompasses the right of disabled people under Title II of the ADA and its implementing regulations to receive government-funded supports and services in the community to avert unjustified isolation and segregation. Title II of the ADA is a federal statute the prohibits disability-based discrimination by public entities. 42 U.S.C. § 12131(1); 28 C.F.R. § 35.130(d) provides that a "public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." Section 504 of the Rehabilitation Act (Section 504), the precursor to the ADA, includes a parallel regulatory provision, 28 C.F.R. § 41.51(d). Section 504 is a federal statute that prohibits discrimination by entities that receive federal funding. 29 U.S.C. 794(a).

³⁸ See, e.g., Mia Mingus, Access Intimacy, Interdependence, and Disability Justice, Leaving Evidence, April 11, 2017 ("Access should be happening in service of our larger goals of building interdependence and embracing need, because this is such a deep part of challenging ableism and the myth of independence."),

https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/; Robyn Powell, *Care Reimagined: Transforming Law by Embracing Interdependence*, reviewing ALL OUR FAMILLES: DISABILITY LINEAGE AND THE FUTURE OF KINSHIP. By JENNIFER NATALYA FINK. Boston: Beacon Press. 2022, 122 MICHIGAN L. REV.

³⁹ Subini A. Annamma, *Dis/ability Critical Race Studies (DisCrit): Theorizing at the Intersections of Race and Dis/ability*, 16 RACE ETHNICITY EDUC. 1, 11-12 (2013).

⁴⁰ Id.

⁴¹ Lydia X.Z. Brown, *Disability in an Ableist World*, Autistic Hoya, Aug. 12, 2012,

https://www.autistichoya.com/2012/08/disability-in-ableist-world.html (emphasis in original).

⁴² Natalie M. Chin, *Group Homes as Sex Police*, 397 n.89 (2001) (citations omitted); *see also* Martin Lyden, *Assessment of Sexual Consent Capacity*, 25 SEXUALITY & DISABILITY 3, 5 (2007) ("Capacity is a state and not a trait. It can vary over time. At one point in time, an individual with intellectual disabilities may be found incapable of having sexual relations due to knowledge deficits. Subsequently, if that individual receives sufficient training, education, counseling, and exposure to various social situations it may be possible to remedy the knowledge deficits.").

⁴³ See, e.g., Investigation of the Massachusetts Department of Children and Families by the United States Departments of Justice and Health and Human Services Pursuant to the Americans with Disabilities Act and the Rehabilitation Act (DJ No. 204-36-216 and HHS No. 14-182176) (Jan. 29, 2015), https://www.hhs.gov/sites/default/files/mass_lof.pdf (joint finding by the U.S. Dep't of Health and Human Services & Dep't of Justice that a state agency violated Title II of the ADA and Section 504 of the Rehabilitation Act when it removed a two-day old baby from the care of her parent because it erroneously relied on the assumption that she could not safely parent her new born daughter because she is disabled. The state agency failed to consider what family supports and other social services could meaningfully assist in safely caring for her daughter); Jessica P. v. Dep't of Child Safety, 251 Ariz. 34, 38 (Ariz. Ct. App. 2021) ("As a public child welfare agency, [the state child welfare agency] must provide a disabled parent in a dependency with reunification services that comply with the [Americans with Disabilities Act]."); Matter of D.D., 2002 WL 31844687 (N.Y. Fam. Ct. 2015) (court denied petitioner guardianship over son with Down syndrome finding that, with a network of "family, friends, and supportive services" he could make medical, financial, and other decisions including those around marriage and relationships."). In recent years, states have passed supported decision making laws as a less-restrictive alternative to guardianship. Supported decision-making is a legal process that allows disabled people to identify persons to support them in making legal and other personal decision, thereby allowing the disabled person to retain their legal decision-making capacity. See In Your State, National Resource Center for Supported Decision-Making, https://supporteddecisionmaking.org/in-your-state/ (listing current status of supported decision-making laws in all states, including 23 states that have passed supported decision-making laws.).

⁴⁴ See e.g., New York State Office for People with Developmental Disabilities (OPWDD), Administrative Directive, Right to Sexual Activity and the Role of Consent, June 28, 2023) ("all adult individuals [with intellectual and developmental disabilities] are assumed to be capable of consenting [to sexual activity] unless there are specific concerns raised in regard to their abilities to exercise informed consent for sexual activity." Id. at 3. An individual's sexual rights may be limited "only when necessary and with justification," and must be limited in time. Id. In response to any restriction on one's right to engage in sexual activity, the directive states that "individuals have the right to access sound education on topics pertaining to sexuality and sexual activity, as well as any necessary supports that may assist them to make an independent informed choice pertaining to sexual activity or exercising their right to engage in sexual activity." OPWDD is the New York State agency that is tasked with providing supports and services, including housing, to people with intellectual and developmental disabilities." Id. at 4. See also generally, The Arc's National Center on Criminal Justice & Disability, Sex Offenders with Intellectual/Developmental Disabilities A Call to Action for the Criminal Justice Community, 1-29, 18-24, https://thearc.org/wp-content/uploads/2019/07/NCCJD-White-Paper-2 Sex-Offenders-FINAL.pdf (discusses persons with intellectual and developmental disabilities who commit sexually violent acts and the considerations that should be taken when, inter alia, conducting risk assessments, safety planning, and in devising "sex offender protocols" that are specific to the person's individualized treatment needs, noting that these protocols may result in rights restrictions).

⁴⁵ Thaler, Naming Violence at 1. *See also* T.L. Lewis, <u>https://www.talilalewis.com/blog/archives/03-2019</u> (in recognizing how violence is the cause and consequence of disability, "[v]iolence should be understood broadly" to include the "[d]eprivation of language, food, water, shelter, education, health, economic security, etc., are all forms of violence."); see also Brandy X. Lee, VIOLENCE AN INTERDISCIPLINARY APPROACH TO CAUSES, CONSEQUENCES, AND CURES, 6 ("An updated definition [of violence] should reflect this urgency so that it can capture conceptually significant dimensions of violence to guide our thinking, research, and action.") [hereinafter Lee, VIOLENCE].

⁴⁶ JAMES W. TRENT, JR., INVENTING THE FEEBLE MIND: A HISTORY OF MENTAL RETARDATION IN THE UNITED STATES 193, 76-77 (1994).

⁴⁷ ADAM COHEN, IMBECILES: THE SUPREME COURT, AMERICAN EUGENICS, AND THE STERILIZATION OF CARRIE BUCK 55-56 (2017).

⁴⁸ PAUL A. LOMBARDO, THREE GENERATIONS, NO IMBECILES: EUGENICS, THE SUPREME COURT, AND BUCK V. BELL 136 (2010). *See* Trent, Jr., at 93.

⁴⁹ FRANCIS GALTON, INQUIRIES INTO HUMAN FACULTY AND ITS DEVELOPMENT 199-200 (1883); *see also* Khiara M. Bridges, *White Privilege and White Disadvantage*, 105 VA. L. REV. 449, 465 (2019) ("the eugenics movement was always about protecting the white race from degeneration.").

⁵⁰ COHEN at 25.

⁵¹ ALLISON C. CAREY, ON THE MARGINS OF CITIZENSHIP, 56 (2010).

⁵² COHEN, Adam. Imbeciles (p. 26) ("The campaign against feeblemindedness was focused on young women, who were deemed both a moral and a demographic threat." COHEN, Adam. Imbeciles at 25. "believed to have unusually strong sex drives and loose morals and, as a result, it was said that they bore more children than other women.").

⁵³ LOMBARDO, THREE GENERATIONS at 11.

⁵⁴ COHEN at 299.

⁵⁵ *Id.* at 206.

⁵⁶ Buck v. Bell, 274 U.S. 200, 201 (1927) ("the Commonwealth is supporting in various institutions many defective persons who if now discharged would become a menace but if incapable of procreating might be discharged with safety and become self-supporting with benefit to themselves and to society").

⁵⁷ LOMBARDO, THREE GENERATIONS at 293-294 (identifies 30 states that had sterilization laws in effect between 1907 and 1937. The listing excludes Puerto Rico which "passed a [sterilization] law in 1937 and repealed it in 1960"). For a detailed analysis of the history and modern impact of eugenics *see* Melissa Murray, *Abortion, Sterilization, and the Universe of Reproductive Rights*, 63 Wm. & Mary L. Rev. 1599, 1609-1610 (2022) ("reorienting the landscape of reproductive rights to include sterilization abuse emphasizes the degree to which the extant discourse of reproductive rights may focus unduly on the rights of those who enjoy race and class privilege while overlooking persistent impositions on the reproductive rights of marginalized communities").

⁵⁸ See infra Part IIIA (discussing the role of the guardianship system in the structural desexualization of disability).
⁵⁹ Id.

⁶⁰ National Women's Law Center, Forced Sterilization of Disabled People in the United States, (Jan. 24, 2022), at 34-35, https://nwlc.org/wp-content/uploads/2022/01/f.NWLC SterilizationReport 2021.pdf.

⁶¹ Morgan by Next Friend, 2019 WL 575371, *2 (Mich. 2019).

⁶² *Id.* (as guardian, the father did not see court approval, as required under Michigan state law, for permission to have elective surgery performed on his son).

⁶³ Id. at *2. Throughout the decision, the perspective of Jason is absent, effectively silencing his experience.

⁶⁴ While this Article does not focus on parents with intellectual and developmental disabilities in applying the structural desexualization of disability framework, this issue is often explored through the lens of sexual and reproductive rights. *See, e.g.* MICHAEL GILL, ALREADY DOING IT: INTELLECTUAL DISABILITY AND SEXUAL AGENCY 161 (2015) ("This increased governmentality in the arena of intellectual disability and reproduction makes it difficult for individuals to retain their rights—sexual, reproductive, parental, and otherwise—thus highlighting one way that discourses of sexual ableism are reinforced."); Robyn Powell, *Disability Reproductive Justice*, 170 U. Pa. L. Rev. 1851, 1878-1881 (2022).

⁶⁵ Map of State Termination of Parental Rights Laws that Include Parental Disability, NATIONAL RESEARCH CENTER FOR PARENTS WITH DISABILITIES, THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT AT BRANDEIS UNIVERSITY (Oct. 1, 2022) https://heller.brandeis.edu/parents-with-disabilities/map-tpr/index.html.

⁶⁶ The term "family regulation system" was initially coined by Emma Williams in her Oberlin College Honors Thesis, and later adopted by many legal advocates and academics. It often replaces the terms "child welfare system" or "child protection system." *See* Emma Williams, *'Family Regulation,' Not 'Child Welfare': Abolition Starts with Changing our Language*, The Imprint, <u>https://imprintnews.org/opinion/family-regulation-not-child-welfare-abolition-starts-changing-language/45586</u>; *see also* Dorothy Roberts, *Abolishing Policing Also Means Abolishing Family Regulation*, The Imprint, <u>https://imprintnews.org/child-welfare-2/abolishing-policing-also-means-abolishing-family-regulation/44480</u>.

⁶⁷ NAT'L COUNCIL ON DISABILITY, ROCKING THE CRADLE: ENSURING RIGHTS OF PARENTS WITH INTELLECTUAL DISABILITIES AND THEIR CHILDREN 39–40 (Sept. 27, 2012), *available at* <u>https://www.ncd.gov/sites/default/files/Documents/NCD Parenting 508 0.pdf</u>. [hereinafter NAT'L COUNCIL ON DISABILITY]; *See also* Robyn Powell, *Achieving Justice for Disabled Parents*, 33 Yale Journal of Law & Feminism 37, 43 (2022) ("despite the increased legislative attention and greater enforcement by the federal government, the number of disabled parents with termination of parental rights cases appears to be growing]").

68 Rabia Belt, Disability: The Last Marriage Equality Frontier, Stanford Public Law Working Paper No. 2653117 (2015).

69 https://thearc.org/wp-content/uploads/forchapters/NPM-SocialSecurity_SSI_4.pdf.

⁷⁰ See, e.g., Erik Carter, Emily Lanchak, Laura Berry, Elise McMillan, Julie Lounds Taylor, and Laurie Flemin, Barriers to Employment for Individuals with IDD: Insights from Families, Vanderbilt University and Virginia Commonwealth University (2020),

https://worksupport.com/documents/RRTC%20Employment%20%2D%20Families%20on%20Barriers%2Epdf.

⁷¹ NANETTE GOODMAN, MICHAEL MORRIS, AND KELVIN BOSTON, FINANCIAL INEQUALITY: DISABILITY, RACE, POVERTY IN AMERICA, (<u>https://www.nationaldisabilityinstitute.org/wpcontent/uploads/2019/02/disability-race-poverty-in-america.pdf</u>.

⁷² Andrew Pulrang, *What's Next in Marriage Equality' for People with Disabilities*, Forbes, March 31, 2022, <u>https://www.forbes.com/sites/andrewpulrang/2022/03/31/whats-next-in-marriage-equality-for-people-with-disabilities/?sh=1670cace6eb7</u>.

⁷³ Get article on legal and emotional benefits of marriage.

⁷⁴ Interview transcript in possession of author. *See also* Dominick Evans, *Marriage Equality*, Center for Disability Rights, <u>https://cdrnys.org/blog/disability-dialogue/the-disability-dialogue-marriage-equality/</u>.

⁷⁵ Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581, 587–607 (1999).

⁷⁶ The deinstitutionalization movement that centered on using *Olmstead* to move persons with intellectual and developmental disabilities out of institutions is often contrasted with the failed policies around the deinstitutionalization of persons with psychiatric disabilities. For a more complete discussion on the successes and failure of the deinstitutionalization movement for people with psychiatric disabilities, *see*, Rachel E. Barkow, "*Promise or Peril?: The Political Path of Prison Abolition in America*," 58 *Wake Forest L. Rev.* 245, 305-318 (2023).

⁷⁷ Olmstead, 527 U.S. at 593.

⁷⁸ Id.

⁷⁹ Id.

⁸⁰ Id. at 592 (citing 28 C.F.R. §§ 35.130(b)(7), 35.130(d) (1998)).

⁸¹ 28 C.F.R. § 35.130(d) (2017). Under Title II of the ADA, a public entity includes "any State or local government" or any "department, agency . . . or other instrumentality of a State or states or local government." 42 U.S.C. § 12131(1) (2012).

82 Olmstead, 527 U.S. at 587.

⁸³ *Id.* Public entities may assert an affirmative defense to compliance with Title II of the ADA by arguing that modification to its programs, services, and activities "would fundamentally alter the nature of the State's program, service or activity." *Id.* at 592 (citing 28 C.F.R. § 35.130(b)(7)(i) (1998)).

⁸⁴ See also Carli Friedman, Medicaid Home and Community Based Services Waivers for People with Intellectual and Developmental Disabilities, Intellectual and Developmental Disabilities, 61(4), 269-279, 3 (2023) ("over the last few decades states have shown a significant decline in institutional Medicaid spending for people with [intellectual and developmental disabilities] in favor of HCBS." [hereinafter Friedman, Medicaid Home and Community Based Services Waivers]; see also Jessica Schubel, Center of Budget and Policy Priorities, Medicaid is Key to Implementing Olmstead's Community Integration Requirements for People with Disabilities (2018), https://www.cbpp.org/blog/medicaid-is-key-to-implementing-olmsteads-community-integration-requirements-for-people-with.

⁸⁵ See also Friedman Medicaid Home and Community Based Services Waivers at 3.

⁸⁶ CTRS. FOR MEDICARE & MEDICAID SERVS., APPLICATION FOR A § 1915(C) HOME AND COMMUNITY-BASED WAIVER: INSTRUCTIONS, TECHNICAL GUIDE AND REVIEW CRITERIA 1 (2019), <u>https://wms-mmdl.cms.gov/WMS/help/35/Instructions TechnicalGuide V3.6.pdf. [hereinafter CMS HCBS INSTRUCTIONS].</u>

⁸⁷ Carli Friedman, *Sexual Health and Parenting Supports for People with Intellectual and Developmental Disabilities*, Sexual Research and Social Policy 20, 257–272 (2023) (citing CMS HCBS INSTRUCTIONS).

⁸⁸ Residential Information Systems Project (2022). Minneapolis: University of Minnesota, , Research and Training Center on Community Living, Institute on Community Integration, *Growth in the number of HCBS waiver recipients*, <u>https://publications.ici.umn.edu/risp/infographics/how-did-the-number-of-hcbs-waiver-recipients-change-between-1987-and-2018.</u>

⁸⁹ Residential Information Systems Project (2022). Minneapolis: University of Minnesota, , Research and Training Center on Community Living, Institute on Community Integration, *20-year change in Residence Size*, <u>https://publications.ici.umn.edu/risp/infographics/how-have-residence-sizes-changed-in-the-last-20-years</u>.

⁹⁰ Residential Information Systems Project (2022). Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration, *Medicaid HCBS Spending in FY 2019*, <u>https://publications.ici.umn.edu/risp/infographics/medicaid-waiver-recipients-and-expenditures</u>.

⁹¹ Carli Friedman, Medicaid Home and Community Based Services Waivers for people with Intellectual and Developmental Disabilities, 61(4), 269-279, 4 (2023). The HCBS waiver program is carried out through a complex scheme of federal statutory and regulatory guidelines. See, e.g., 42 U.S.C. § 1396n. For a more detailed discussion about the HCBS waiver program, see <u>CMS</u>

<u>HCBS INSTRUCTIONS (</u>"Waiver services complement and/or supplement the services that are available through the Medicaid State plan and other federal, state and local public programs as well as the supports that families and communities provide to individuals. States have flexibility in designing waivers.").

⁹² Prianka Nair, Surveilling Disability, Harming Integration, 124 Colum. L. Rev. 1, 40 (2024) (citing, generally, GOODMAN, ET. AL. at 5.

⁹³ Carli Friedman, Medicaid Home and Community Based Services Waivers for people with Intellectual and Developmental Disabilities, 61(4), 269-279 (2023).

⁹⁴ Day Habilitation services "assist people to acquire, retain or improve their self-help, socialization and adaptive skills, including communication, travel and other areas in adult education." These services are intended to support the "development of skills and appropriate behavior, greater independence, community inclusion, relationship building, self-advocacy and informed choice." <u>https://opwdd.ny.gov/types-services/day-services</u>.

⁹⁵ TRENT at 345-346.

⁹⁶ Karen Andreasian, Natalie Chin, Kristin Booth Glen, Beth Haroules, Katherine I. Hermann, Maria Kuns, Aditi Shah & Naomi Weinstein, *Revisiting S.C.P.A 17-A: Guardianship for People with Intellectual and Developmental Disabilities*, 18 CUNY L. REV. 287, 294 (2015).

⁹⁷ Kristen Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93, 98 (2012).

⁹⁸ See, e.g., Dilip R. Patel et al., *A clinical primer on intellectual disability*, 9 (SUPPL. 1) TRANSL. PEDIATR. 23 (2020) ("A diagnosis of intellectual disability is based on clinical history, level of intellectual ability and level of adaptive function . . . The etiology, severity, cognitive abilities, and adaptive function, vary among persons with intellectual disability and need consideration in developing a treatment plan."); *Position Statements, Life in the Community Summary*, The Arc, <u>https://thearc.org/position-statements/life-community-summary/</u> (discussing "the var[ious]degrees of support" that people with intellectual and developmental disabilities need "to reach personal goals and establish a sense of satisfaction with their lives.").

⁹⁹ Friedman, CQL Report 3. <u>https://www.c-q-l.org/resources/articles/medicaid-hcbs-for-people-with-idd/</u>. The HCBS waiver program is carried out through a complex scheme of federal statutory and regulatory guidelines. *See, e.g.,* 42 U.S.C. § 1396n. *See also* CMS HCBS INSTRUCTIONS (describing the range of flexibility that states have in designing Medicaid waivers).

¹⁰⁰ Carli Friedman, *Sexual Health and Parenting Supports for People with Intellectual and Developmental Disabilities*, Sexual Research and Social Policy 20, 257–272 (2022). This study describes sexual health services as either "proactive" ("see people with [intellectual and developmental disabilities as sexual beings, promote sexual expression and opportunities, emphasize rights and education" or "reactive" ("focus on avoidance, danger, victimization, deviance, control.) *Id.* at 3.

¹⁰¹ Carli Friedman, Sexual Health and Parenting Supports for People with Intellectual and Developmental Disabilities, Sexual Research and Social Policy 20, 257–272 (2022).

¹⁰² Carli Friedman, Sexual Health and Parenting Supports for People with Intellectual and Developmental Disabilities, Sexual Research and Social Policy 20, 257–272 (2022). Reactive services "contain elements of sex-negative ideas, including that sex is dangerous, should be avoided, or assuming sexual deviancy." Carli Friedman & Aleksa L. Owen, Sexual Health in the Community: Services for People with Intellectual and Developmental Disabilities, 10 DISABILITY & HEALTH J. 387, 389 (2017). Reactive services engage "exclusively" with "sexually inappropriate behaviors."

¹⁰³ NECHAMA F. SAMMET MORING, CPM, MA, STATE OF AFFAIRS IN SEX EDUCATION FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (IDD), prepared for Planned Parenthood League of Massachusetts by Rebel Girl Research Communications 1-27, 5 (2019),

https://www.plannedparenthood.org/uploads/filer_public/15/ba/15bab9eb-9a2b-4758-87a3-

0b55de8a11f9/pplm_white paper- state of affairs in sex ed for people with idd.pdf.

¹⁰⁴ See, e.g. Lisa Colarossi, Kate L. Collier, Randa Dean, Siana Pérez, Marlene O. Riquelm, *Sexual and Reproductive Health Education for Youth with Intellectual Disabilities: a Mixed Methods Study of Professionals' Practices and Needs*, Prevention Science (2023) ("incident driven conversations about sexuality (particularly issues of sexual boundaries, consent, and sexual harassment) are the norm")).

¹⁰⁵ Carli Friedman, Sexual Health and Parenting Supports for People with Intellectual and Developmental Disabilities, Sexual Research and Social Policy 20, (2022).

¹⁰⁶ In 1972, Geraldo Rivera exposed the inhumane treatment of children with disabilities at the Willowbrook State School, a New York State-run institution for children and adults with developmental disabilities. *See, e.g.,* Raga Justin, *Former residents* of *Willowbrook recall its horrors as fight for disability rights continues,* Times Union, March 27, 2023, <u>https://www.timesunion.com/state/article/a-disgrace-former-willowbrook-residents-17860905.php</u>. Through a series of investigative reports that aired on national television, Rivera displayed the deplorable conditions of Willowbrook to the country. The reports forced the country to confront many of the horrors taking place in large state-run institutions. Rivera's footage showed in vivid images the large number of emaciated children who were left unattended, naked – or kept in soiled rags - in the overcrowded facility, detailed reports of the physical and sexual abuse that took place at the institution by staff, and displayed the unsanitary conditions that caused the preventable spread of disease. *See* WILLOWBROOK: THE LAST DISGRACE, <u>https://www.youtube.com/watch?v=IRK0LO-9ZYk</u>. The expose' roiled the country, precipitating a lawsuit, *New York State Association for Retarded Children v. Carey*, 393 F. Supp. 715 (E.D.N.Y. 1975), and the passage of legislation to protect the health, safety, and civil rights of people with intellectual and developmental disabilities. *See The Closing of Willowbrook*, Disability Justice, <u>https://disabilityjustice.org/the-closing-of-willowbrook/</u>.

¹⁰⁷ Jennifer Smith, Inside the Fight for Developmentally Disabled People's Right to Sex, Vice, March 19, 2019.

¹⁰⁸ Carli Friedman, Medicaid Home and Community Based Services Waivers for people with Intellectual and Developmental Disabilities, 61(4), 269-279, 14 (2023).

¹⁰⁹ Carli Friedman, Medicaid Home and Community Based Services Waivers for people with Intellectual and Developmental Disabilities, 61(4), 269-279, 14 (2023).

¹¹⁰ See, e.g., Rhonda S. Black and Rebecca R. Kammes, *Restrictions, Power, Companionship, and Intimacy: A Synthesis of People with Intellectual Disability Speaking About Sex and Relationships*, Intellectual and Developmental Disabilities, Vol. 57, No. 3, 212-233, 213 (2019); *see also* ROBERT MCCRUER AND ANNA MOLLOW, EDITORS, SEX AND DISABILITY 70-71 ("some [] parents see their intellectually disabled children as asexual and chaste seraphim, juvenile and lacking in any erotic desire, *and* unable to face the many dangers of sexuality (such as abuse, prostitution, illness, and unwanted pregnancies").

¹¹¹ Hughes, R.B., Robinson-Whelen, S., Goe, R., Schwartz, M., Cesal, L., Garner, K.B., McDonald, K.E.: 'I really want people to use our work to be safe"... Using participatory research to develop a safety intervention for adults with intellectual disability, J. Intellect. Disabil. 24(3), 309–325 (2020).

¹¹² MORING at 9-11 (discussing how comprehensive sexuality education influence healthy sexual behaviors); national partnership for women & families and the Autism Self-Advocacy Network, ACCESS, AUTONOMY, AND DIGNITY: COMPREHENSIVE SEXUALITY EDUCATION FOR PEOPLE WITH DISABILITIES, Issue Brief, 1-24, 6-7 (Sept. 20, 2021); national partnership for women & families and the Autism Self-Advocacy Network, ACCESS, AUTONOMY, AND DIGNITY: COMPREHENSIVE SEXUALITY EDUCATION FOR PEOPLE WITH DISABILITIES, Issue Brief, , 1-24, 6-7 (Sept. 20, 2021). E. Dukes & B.E. McGuire, Enhancing Capacity to Make Sexuality-related Decisions in People with Intellectual Disability, 53. J. INTELL. DISABILITY RES. 727, 732 (2009); see also Abigail Abrams, How Accessible Sex Ed Helps Young Adults With Developmental Disabilities Form Healthy Relationships, Mother Jones, Nov.-Dec. 2023, https://www.motherjones.com/politics/2023/10/how-accessible-sex-education-helps-young-adults-withdevelopmental-disabilities-form-healthy-relationships/.

¹¹³ See, e.g., national partnership for women & families and the Autism Self-Advocacy Network, ACCESS, AUTONOMY, AND DIGNITY: COMPREHENSIVE SEXUALITY EDUCATION FOR PEOPLE WITH DISABILITIES, Issue Brief, 1-24, 5, 16 (Sept. 20, 2021), <u>https://nationalpartnership.org/wp-content/uploads/2023/02/repro-disability-sexed.pdf</u> (providing a definition and description of comprehensive sexuality education).

¹¹³ *Id.* at 16-18.

¹¹⁴ Id. at 16-18.

¹¹⁵ See, e.g., Sexuality: Joint Position Statement of AAIDD and the Are, AAIDD (2013), <u>https://aaidd.org/news-policy/policy/position-statements/sexuality#.WZSZsFGGOUk</u>.

¹¹⁶ Kathryn Pedgrift and Nicole Sparapani, *The development of a social-sexuality education program for adults with intellectual and developmental disabilities: starting the discussion*, Sexuality and Disability (2022) 40:503–517, 504 (2022); Carli Friedman, *Sexual Health and Parenting Supports for People with Intellectual and Developmental Disabilities*, Sexual Research and Social Policy 20, 257–272 (2022).

¹¹⁷ See infra Part IIIB.

¹¹⁸ <u>https://www.researchprotocols.org/2023/1/e37801/PDF</u> ("One reason that individuals with IDD do not cervical cancer screening may be that they have been perceived as asexual").

¹¹⁹ Vaughn v. Ruoff, 253 F.3d 1124, 1129 (8th Cir. 2001) (in determining that a state agency violated the due process protections of a parent after she agreed to a tubal ligation based on the promise by a social service work for a state child welfare agency that doing so would lead to the reunification of her children, the court noted that "involuntary sterilization is not always unconstitutional if it is a narrowly tailored means to achieve a compelling government interest.").

¹²⁰ Natalie M. Chin, *Group Homes As Sex Police and the Role of the Olmstead Integration Mandate*, 42 N.Y.U. REV. L. & SOC. CHANGE 379, 385 (2018) (group home resident's right to engage in sexual activity indefinitely restricted after expressing her desire to get married and have children). Group homes are congregate settings where people with disabilities may reside to receive varying levels of daily living supports.

¹²¹ See, e.g., Gill at 61 ("when a person with an intellectual disability becomes pregnant or is diagnosed with a sexually transmitted infection, support staff might try to control the sexual activity of the individual instead of equipping him or her with knowledge that facilitates and informs his or her sexual choices.").

¹²² Forziano v. Indep. Grp. Home Living Program, Inc., 2014 WL 1277912 (E.D.N.Y. 2014), aff'd Forziano v. Indep. Grp. Home Living Program, Inc., 613 Fed. App'x. 15 (2d Cir. 2015).

¹²³ Forziano v. Indep. Grp. Home Living Program, Inc., 2014 WL 1277912 (E.D.N.Y. 2014), aff'd Forziano v. Indep. Grp. Home Living Program, Inc., 613 Fed. App'x. 15 (2d Cir. 2015).

¹²⁴ Forizano, Brief for Plaintiffs-Appellants, United States Court of Appeals for the Second Circuit, 14-1147, 1-64, 3 (2014); see also Maryhaven Day Habilitation Program, <u>https://www.maryhaven.org/day-habilitation</u>.

¹²⁵ Forizano, Brief for Plaintiffs-Appellants, United States Court of Appeals for the Second Circuit, 14-1147, 1-64, 3 (2014); see also Maryhaven Day Habilitation Program, <u>https://www.maryhaven.org/day-habilitation</u>.

¹²⁶ Forziano, 2014 WL 1277912, *1.

¹²⁷ Forziano, 2014 WL 1277912, *1.

¹²⁸ Assessments to determine whether a person with intellectual or developmental disabilities has the capacity to consent to sexual activity "could potentially be utilized by a clinician to determine what gaps in knowledge exist for someone that may inhibit their ability to perform sexual acts safely." Andrea Onstot, Capacity to Consent: Policies and Practices that Limit Sexual Consent for People with Intellectual/Developmental Disabilities, Sex Disabil. 37, 633-644 (2019). However, "[t]here is no clear definition, criteria, or standard for determining a person's sexual consent capacity." Shaniff Esmail, PhD Brendan Cannondale, MSci, Approaches to Determine and Manage Sexual Consent Abilities for People With Cognitive Disabilities: Systematic Review, Interact J Med Res.;11(1) (2022), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8857692/ (citations omitted). As a result, "capacity standards are vague, psychologists have no agreed-upon guidelines, and the criteria vary depending upon the state in which a person resides." Kennedy & Niederbuhl at 504. Sexual consent "[c]apacity assessments are sometimes weaponized to restrict persons with intellectual disabilities' right to sexual expression." Matthew S. Smith and Michael Ashley Stein, Legal Capacity and Persons with Disabilities" Struggle to Reclaim Control over Their Lives, Bill of Health, Examining the Intersection of Health, Law, Biotechnology, and Bioethics, Harvard Law Shool Petrie-Flom Center, Sept. 21, 2021, https://blog.petrieflom.law.harvard.edu/2021/09/29/legal-capacity-disabilities/. Assessments are also susceptible to "cultural bias of their administrators when they make sexual capacity determinations." Onston at ____; see also Roy G. Spece, Jr., John K. Hilton & Jeffrey N. Younggren, (Implicit) Consent to Intimacy, 50 IND. L. REV. 908, 910 (2017) ("[i]f incorrectly employed or relied upon as panaceas" sexual consent assessment "can work against residents' rights and best interests." This Article does not take a position on the adequacy of, or what criteria should be used, to determine sexual consent capacity. Any assessment of consent capacity should be determined based on an "individualized factspecific inquiry based on circumstances of the desired sexuality choices of the individual." See Chin, Group Homes as Sex Police at 405.

129 Forziano, 2014 WL 1277912, *1.

¹³⁰ Forziano, 2014 WL 1277912, *2

¹³¹ Oral Argument at 1:02:25-1:02:45, *Forziano*, 14-1147(L); *Id.* The term "mental age" is often referred to in court proceedings to evaluate cases of sexual assault and rape when the victim is someone with an intellectual or developmental disability. As expressed by Deborah Denno, "Although courts also typically refer to a victim's 'mental age" when evaluating rape" and cases that involve people with intellectual disabilities, "'mental age" is considered "a misleading concept," by organizations and commentators "most particularly because it perpetuates beliefs that the mentally retarded are 'forever young' or 'childlike." Deborah W. Denno, *Sexuality, Rape and Mental Retardation,* 1997 U. ILL. L. REV. 315, 330-31 (1997) (internal citations omitted; quoting William Fink, *Education and Habilitation of the Moderately and Severely Mentally Retarded*, in MENTAL RETARDATION: FROM CATEGORIES TO PEOPLE 260, 262 (Patricia T. Cegelka & Herbert J. Prehm eds., 1982)); *see also* Michael Gill, ALREADY DOING IT: INTELLECTUAL DISABILITY AND SEXUAL AGENCY 38 (2015) ("A medically determined 'mental age' can take legal precedence over physical age of consent Mental age is an ableist notion that can actively discredit individual choice and perpetuate assumptions about incompetence, childhood, and necessity for protection by prioritizing professional medical authority at the expense of individual desire and epistemology."); *of.* Jasmine Harris, *Sexual Consent and Disability*, 93 N.Y.U. L. REV. 480, 538 (2018) ("courts routinely review a mix of evidence of IQ, mental age, and adaptive evidence in evaluating a victim's incapacity to consent.").

¹³² Defendants-Appellees Brief at 44, Forziano v. Indep. Grp. Home Living, Inc., 14-1447(L) (2d Cir. Dec. 12, 2014).

¹³³ Forziano, 2014 WL 1277912 at *2

¹³⁵ Id.

¹³⁶ Id.

¹³⁷ See supra n (OPWDD sexual consent policy)

¹³⁸ Forziano, 2014 WL 1277912, *2, It took three years for Paul and Hava to find a group home that allowed them to live together. *Id.* at *1. Happily, the couple were married shortly after moving in together, following "a courtship of seven years and an engagement of two years." *Id.*

¹³⁹ Michael Gill, Already Doing It Intellectual Disability and Sexual Agency 8.

¹⁴⁰ Gill at 19.

¹⁴¹ Sherene Razack, Looking White People in the Eye 138.

¹³⁴ Id.

¹⁴² *Id.* at 149.

¹⁴³ *Id.* at 143-145.

¹⁴⁴ *Id.* at 135.

¹⁴⁵ *Id.* at 133. Boux identified 32 states where "the same laws that protect children from physical and sexual abuse are used to protect adults with intellectual disabilities." *Id.* at 146 (internal quotations omitted).

¹⁴⁶ Incapacitated Woman's Rape Spurs Push to Catch Up on Cameras, UPPER MICHIGAN SOURCE (Feb. 8, 2019), https://www.uppermichiganssource.com/content/news/Incapacitated-womans-rape-spurs-push-to-catch-up-oncameras-505552281.html; Is it Legal to Install Surveillance Cameras in Nursing Home Rooms?, MILLER KORY ROWE LLP (May 16, 2022), https://www.mkrfirm.com/blog/2022/may/is-it-legal-to-install-surveillance-cameras-in-n/; Prianka Nair, Surveilling Disability, Harming Integration, 124 COLUM. L. REV. 1, 36, 36 n.229 (2024); Electronic Monitoring Devices/Surveillance Cameras. THE NATIONAL LONG-TERM CARE Ombudsman RESOURCE CENTER, https://ltcombudsman.org/issues/electronic-monitoring-devices-surveillance-cameras#state (last visited Sep. 9, 2023); Marisa Saenz, Esther's Law, Allowing Families to Install Cameras in Ohio Nursing Homes, Goes Into Effect Wednesday, WKYZ (Mar. 23, 2022), https://www.wkyc.com/article/news/local/ohio/esthers-law-cameras-ohio-nursing-homes-goes-into-effectwednesday/95-7549798d-a65b-4719-a94e-ffb573b35f7a.

¹⁴⁷ Prianka Nair, *Surveilling Disability, Harming Integration*, 124 COLUM. L. REV. 197, 203-204 (2024) (arguing surveillance systems over people with disabilities could constitute violations of the Americans with Disabilities Act's anti-discrimination mandate and the integration mandate).

¹⁴⁸ See, e.g., Jasmine Harris, Sexual Consent and Disability, 93 N.Y.U. L. REV. 480 (2018) (calling for legislatures and judges to gain a stronger grasp on "the experiences of people with mental disability living in the community," arguing that statutes cannot "capture the way in which people with disabilities encounter and respond to sexual violence.."); Holly Jeanine Boux, "#Ustoo": Empowerment and Protectionism in Responses to Sexual Abuse of Women with Intellectual Disabilities, 37 BERKELEY J. GENDER L. & JUST. 131, 162 (2022); Danielle M. Shelton, Accommodating Victims with Mental Disabilities, 127 DICK. L. REV. 163, 223 (2022) (arguing for legislative reforms that provide "specific accommodations and protections to" people with intellectual disabilities who are survivors of sexual assault to ensure participation in all stages of the criminal process); Joseph J. Fischel & Hilary R. O'Connell, Disabiling Consent, or Reconstructing Sexual Autonomy, 30 COLUM. J. GENDER & L. 428, 432 (2015) (arguing for statutory reform to "modern rape laws" by moving away from conflation of sexual autonomy with consent to recognize "sexual autonomy as the capability to codetermine sexual relations." With this reconceptualizing of sexual autonomy, consent is significant, but not the primary consideration in rape cases that involve disabled people where issues of consent are being scrutinized. Id.); Deborah W. Denno, Sexuality, Rape, and Mental Retardation, 1997 U. ILL. L. REV. 315, 321 (1997) (proposing a "contextual approach to consent that incorporates a range of factors, including modern knowledge about [intellectual disability], individual attributes beyond the labels of intelligence quotient (IQ) and mental age, and, most importantly, the context of the sexual encounter.").

¹⁴⁹ Farmer, An Anthropology of Violence, 307.

¹⁵⁰ Barbara Rylko-Bauer and Paul Farmer, Structural Violence, Poverty, and Social Suffering in THE OXFORD

HANDBOOK OF THE SOCIAL SCIENCE OF POVERTY, OXFORD HANDBOOKS, 47 (2016).

¹⁵¹ Lee, VIOLENCE 126; Barbara Rylko-Bauer and Paul Farmer, *Structural Violence, Poverty, and Social Suffering* in THE OXFORD HANDBOOK OF THE SOCIAL SCIENCE OF POVERTY, OXFORD HANDBOOKS, 47 (2016).

¹⁵² Brandy X Lee at 123.

¹⁵³ Id.

¹⁵⁴ NCD REPORT 41 – lots of caveats to these stats – they don't include [insert states] and also data is likely not the complete picture. Mention Warren's proposed legislation to get more info on guardianships stats.

¹⁵⁵ Salzman, Rethinking Guardianship, 166.

¹⁵⁶ The National Council on Disability is federal administrative agency that focuses on policies, programs, practices, and procedures that affect people with disabilities.

¹⁵⁷ NCD REPORT AT (quoting Robert Dinerstein, "Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making," Human Rights Brief 19, no. 2 (2012): 8–9).

¹⁵⁸ Kristin Booth Glen, Not Just Guardianship, 26

¹⁵⁹ See, e.g., NCD Report 101.

¹⁶⁰ See, e.g., In Your State, National Resource Center for Supported Decision-Making, <u>https://supporteddecisionmaking.org/in-your-state/</u> (last visited Nov. 7, 2023) (listing current status of supported decision-making laws in all states, including 23 states that have passed supported decision-making laws). See also Emily Largent, Andrew Peterson, and Jason Karlawish's article, Britney Spears Didn't Feel Like She Could Live "a Full Life." There's Another Way. Emily Largent, Andrew Peterson, and Jason Karlawish, Britney Spears Didn't Feel Like She Could Live "a Full Life." There's Another Way., N.Y. Times (Apr. 3, 2023), <u>https://www.nytimes.com/2023/04/03/opinion/guardianship</u>- britney-spears-decision-making.html (discussing the non-partisan support by states of support decision making as an alternative to guardianship).

¹⁶³ Id. 353.

¹⁶⁴ Id. 353.

¹⁶⁵ Id. 353 (italic in original).

¹⁶⁶ Id. 353. The appellate court reversed the order to sterilize Moe and vacated the order that required her to undergo the abortion procedure, reasoning that the court's decision was issued without a hearing and in opposition to Moe's express desire to not have an abortion. Id. at 355. The Court remanded the case for an evidentiary hearing that considered Moe's wishes. Id. See also Morgan v. Shah, No. 341846, 2019 WL 575371 (Mich. Ct. App. Feb. 12, 2019).

¹⁶⁷ Omar Allam, Emily Gudbranson, Aaron S Long, Michael Alperovich, Tomer Avraham. *Prophylactic Desexualizing Mastectomy for an Intellectually Disabled Woman: Protective Measure or Disregard for Autonomy?*, Plast Reconstr Surg Glob Open. 2022 May 23;10(5):e4347. (2022).

¹⁶⁸ Id.

¹⁶⁹ Id.

¹⁷⁰ Id.

¹⁷¹ Id.

¹⁷² Id. ¹⁷³ Id.

¹⁷⁴ *Id.* The authors concluded that the legal determination (under guardianship) that the young woman lacked capacity did not diminish her autonomy or erase her desires and refused to perform the surgery. They reasoned that conducting a mastectomy for the purposes of desexualization was an unethical form of "soft sterilization." *Id.*

¹⁷⁵ Sex abuse against people with disabilities is widespread- and hard to uncover, PBS Newshour, Jan. 17, 2018, https://www.pbs.org/newshour/show/sex-abuse-against-people-with-disabilities-is-widespread-and-hard-to-uncover.

¹⁷⁶ Some guardianships require court permission for non-routine medical procedures. Courts are split, however, on what qualifies as routine.

¹⁷⁷ Growth attenuation is a controversial medical procedure that resurfaced in 2006 and involves permanent body manipulation that arrests a child's growth with high-dose estrogen therapy. It represents a relatively unregulated form of social control, raising ethical and legal issues concerning the right to the bodily integrity of intellectually and developmentally disabled children. https://deepconnections.net/2022/05/24/growth-attenuation/. Growth attenuation procedures may include a vasectomy, hysterectomy, removal of breast buds, and other procedures.

¹⁷⁸ See Claire Spivakovsky and Linda Steele, Disability Law in a Pandemic: The Temporal Folds of Medico-legal Violence, Social & Legal Studies, 181 (2022) ("The specification of time disperses the perpetuation of lawful violence across time and space, enabling it to become a defining condition for those under guardianship.").

¹⁷⁹ Berg for C.K.M. v. Bethel School District, 2022 WL 796315, *1, *5-6 (W.D. Wash. 2022).

¹⁸⁰ L.K.M. v. Bethel School District, 2020 WL 7075209, *2 (W.D. N.Y. 2020).

¹⁸¹ Id.

¹⁸² Berg for C.K.M. v. Bethel School District, 2022 WL 7075209, *3 (W.D. Wash. 2020); Berg v. Bethel School District, 2021 WL 557 1110 (W.D. Wash. 2021) (Verdict, Agreement and Settlement).

¹⁸³ Berg for C.K.M. v. Bethel School District, 2022 WL 7075209, *3 (W.D. Wash. 2020); Berg v. Bethel School District, 2021 WL 557 1110 (W. D. Wash. 2021) (Verdict, Agreement and Settlement).

¹⁸⁴ Berg for C.K.M. v. Bethel School District, 2022 WL 7075209, *4 (W.D. Wash. 2020).

¹⁸⁵ L.K.M. v. Bethel School District, 2020 WL 7075209, *4 (W.D. Wash.. 2020).

¹⁸⁶ Id.

¹⁸⁷ L.K.M. v. Bethel School District, 2021 WL 5571007 (W.D. Wash. 2001) (Trial Motion, Memorandum and Affidavit).

¹⁸⁸ L.K.M. v. Bethel School District, 2020 WL 7075209 at *3, *4.

¹⁸⁹ *Id.* at *3

¹⁹⁰ L.K.M. v. Bethel School District, 2021 WL 5571007 (W.D. Wash. 2001), 10 (Trial Motion, Memorandum and Affidavit).

¹⁹¹ L.K.M. v. Bethel School District, 2020 WL 7075209 at *3, *4. Court documents indicate that, after being transferred from C.K.M.s' school, David M. sexually assaulted a seven year old girl and was arrested and jailed. L.K.M. v. Bethel School District, 2021 WL 5571007 (W.D. Wash. 2001), 10 (Trial Motion, Memorandum and Affidavit).

¹⁹² TRENT at 136.

¹⁹³ Buck, 274 U.S. at 207.

¹⁹⁴ There is no dispute by the parties of David M's past history of violent sexual conduct against others. *See L.K.M. v. Bethel School District*, 2020 WL 7075209 at *1-2.

¹⁶¹ In re Guardianship of Moe, 960 N.E.2d 350, 355 (Mass. App. Ct. 2012).

¹⁶² Id. 353.

¹⁹⁵ U.S. Dep't of, 44th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act (IDEA), Jan. 1, 2022 [hereinafter "DOE Report"], <u>https://sites.ed.gov/idea/2022-individuals-with-disabilities-education-act-annual-report-to-congress/</u>; see also Laura Holmes & SEICUS Sex Ed for Social Change, *Comprehensive Sex Education for Youth mith Disabilities: A Call to Action*, 5-38 (2021). The IDEA identifies 14 disability categories: "(1) autism, (2) deaf-blindness, (3) deafness, (4) emotional disturbance, (5) hearing impairment, (6) intellectual disability, (7) multiple disabilities, (8) orthopedic impairment, (9) other health impairment, (10) specific learning disability, (11) speech or language impairment, (12) traumatic brain injury, (13) visual impairment, and (14) developmental delay." <u>https://crsreports.congress.gov/product/pdf/R/R46566</u>.

¹⁹⁶ Individuals with Disabilities Education Act 300.1.

¹⁹⁷ Kathryn Pedgrift and Nicole Sparapani, *The development of a social-sexuality education program for adults with neurodevelopmental disabilities: starting the discussion*, Sexuality and Disability, 40:503–517 (2022).

¹⁹⁸ SEICUS at 26.

¹⁹⁹ SEICUS at 9.

²⁰⁰ Lisa Colarossi, Marlene O. Riquelme, Kate L. Collier, Siana Pérez, Randa Dean, Youth and Parent Perspectives on Sexual Health Education for People with Intellectual Disabilities, Sexuality and Disability, 41:619–641, 637 (2023); see also Laura Holmes & SEICUS Sex Ed for Social Change, Comprehensive Sex Education for Youth with Disabilities: A Call to Action, 22 (2021).

²⁰¹ national partnership for women & families and the Autism Self-Advocacy Network, ACCESS, AUTONOMY, AND DIGNITY: COMPREHENSIVE SEXUALITY EDUCATION FOR PEOPLE WITH DISABILITIES, Issue Brief, , 1-24, 6-7 (Sept. 20, 2021).

²⁰² Swango-Wilson at 168.

²⁰³ Id.

²⁰⁴ Id.

²⁰⁵ Kathryn Pedgrift and Nicole Sparapani, *The development of a social-sexuality education program for adults with neurodevelopmental disabilities: starting the discussion*, Sexuality and Disability, 40:503–517 (2022).

²⁰⁶ Kathryn Pedgrift and Nicole Sparapani, *The development of a social-sexuality education program for adults with neurodevelopmental disabilities: starting the discussion*, Sexuality and Disability, 40:503–517 (2022).

²⁰⁷ SEICUS at 9.

²⁰⁸ See supra Part _____

²⁰⁹ "*Ableism* is oppression faced due to disability/impairment (perceived or lived), which not only signals disability as a form of difference but constructs it as inferior." (emphasis in original). LIAT BEN-MOSHI, DECARCERATING DISABILITY DEINSTITUTIONALIZATION AND PRISON ABOLITION, 16 (2020) (emphasis in the original). For a more expansive definition of ableism, *see*, Talila A. Lewis, Working Definition of Ableism, Jan. 2022-update, https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update.

²¹⁰ See supra n ____

²¹¹ Rena'ta Ticha', K. Charlie Lakin, Sheryl A. Larson, Roger J. Stancliffe, Sarah Taub, Joshua Engler, Julie Bershadsky & Charles Moseley, *Correlates of Everyday Choice and Support-Related Choice for 8,892 Randomly Sampled Adults with Intellectual and Developmental Disabilities in 19 States*, 50 INTELLECTUAL & DEVELOPMENTAL DISABILITIES 486, 502 (2012).

²¹² The facts related Alex have been modified and the name changed to protect client confidentiality.

²¹³ As of 2017, "over 90 percent of people with" intellectual and developmental disabilities receive HCBS waiver services. SARAH BARTH, SHARON LEWIS, TAYLOR SIMMONS, MEDICAID SERVICES FOR PEOPLE WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES – EVOLUTION OF ADDRESSING SERVICE NEEDS AND PREFERENCES, Report To The Medicaid And Chip Payment And Access Commission, 1-61, 7 (Oct 2020), <u>https://www.macpac.gov/wp-content/uploads/2021/01/Medicaid-Services-for-People-with-Intellectual-or-Developmental-Disabilities----Evolution-of-Addressing-Service-Needs-and-Preferences.pdf.</u>

²¹⁴ Facts and quote changed to protect client identity.

²¹⁵ See Kathryn Pedgrift and Nicole Sparapani, The development of a social-sexuality education program for adults with neurodevelopmental disabilities: starting the discussion, Sexuality and Disability, 40:503–517 (2022).

²¹⁶ See, e.g., Kelmar story, Legal Reform for the Intellectually & Developmentally Disabled, <u>https://lridd.org/kelmar-story/</u> (father discussing the experience of his 24-year-old autistic son's involvement in the criminal legal system and placement on the violent sex offender registry).

²¹⁷ See <u>Pushed Out and Locked In</u>.

²¹⁸ Kathryn Pedgrift and Nicole Sparapani, *The development of a social-sexuality education program for adults with intellectual and developmental disabilities: starting the discussion*, Sexuality and Disability (2022) 40:503–517, 504 (2022).

²¹⁹ SELF-ADVOCATES SPEAK UP ABOUT SEX, compiled by Karen Topper and Katherine McLaughlin, "Members of Green Mountain Self-Advocates in Vermont held a discussion group about sexuality for the purpose of sharing their thoughts and experiences. Here are their candid responses to a number of questions about the messages they received about sexuality over the years, and why they think sexuality education is important. This is a record of the conversation as it occurred. In some places they respond to one another, as well as to the questions. Their real names have not been used at their request. <u>https://wnw.elevatustraining.com/selfadvocates/</u>.

²²⁰ Courts have not applied Eleventh Amendment immunity to states in *Olmstead* integration claims under Title II of the ADA. See e.g. ("virtually any prospective relief against a state will affect the state's budget. For this very reason, courts have determined that "an ancillary effect of prospective relief on a state's treasury does not violate Eleventh Amendment immunity.")

²²¹ Guggenberger v. Minnesota, 198 F. Supp. 3d 973, 1026–27 (D. Minn. 2016). See also Steimel v. Wernert, 823 F.3d 902, 911 (7th Cir. 2016) (the ADA "bars unjustified segregation of persons with disabilities, wherever it takes place."). ²²² 28 C.F.R. § 35.130(b)(3).

²²³ Natalie M. Chin, Group Homes As Sex Police and the Role of the Olmstead Integration Mandate, 42 N.Y.U. REV. L. & SOC. CHANGE 379, 383.

²²⁴See, infra Part IVA.

²²⁵ See, e.g., Robyn Powell, Disability Reproductive Justice, 170 U. Pa. L. Rev. 1851, 1888-1898 (2022) (proposing, inter alia, "develop[ing] and implement[ing[legal and policy responses that are aimed at disrupting intersecting oppressions," "[c]entering people with disabilities as leaders," "protect[ing] autonomy and self-determination," and ensuring accessible sexual and reproductive health services and information."; Joseph J. Fischel, Hilary R. O'Connell, Disabling Consent and Reconstructing Sexual Autonomy, 30 Colum. J. Gender & L. 428, 30 Colum. J. Gender & L. 428, 506 (2016) (authors suggest "publicly funded comprehensive sexual education," id. at 508, "publicly funded sexual assistance," id. at 514, and "facilitated masturbation," id. at 516, at "facilitating the purchase of sexual services." Id. at 519; Elizabeth Emens, Intimate Discrimination: The State's Role in Accidents to Sex and Love, 122 Harv. L. Rev. 1307, 1381-1382 (2009) "Sex and relationship education, institutional and residential rules, and welfare laws should all be structured to anticipate and facilitate opportunities for intimate relationships."

²²⁶ Robyn Powell, Disability Reproductive Justice, 170 U. Pa. L. Rev. 1851, 1860 (2022)

²²⁷ Id. at 1887.

²²⁸ Id. at 1903.

²²⁹ See, supra Part IB.

²³⁰ Chin, Group Homes as Sex Police at 382, 420-437.

²³¹ For the application of sexual isolation as an integration mandate violation against group homes, *see,* Natalie M. Chin, *Group Homes As Sex Police and the Role of the Olmstead Integration Mandate*, 42 N.Y.U. Rev. L. & Soc. Change 379, 382-384 (2018).

²³² M.G. v. N.Y. State Office of Mental Health, 572 F.Supp.3d 1, *6 (S.D.N.Y. 2021) (the court denied a motion to discuss claims that the New York State Office of Mental Health and Department of Corrections and Community Supervision placed people at risk of institutionalization and decompensation by failing to provide "community-based mental health and supportive services."

²³³ Lane v. Brown, 12-CV-00138, Settlement Agreement with the Dep't of Justice, https://archive.ada.gov/olmstead/documents/lane_fact_sheet.pdf

²³⁴ McClendon v. City of Albuquerque, No. 95-CV-24, 2016 U.S. Dist. LEXIS 156370, at *70–71 (D.N.M. Nov. 9, 2016) (finding that Defendants "may comply with the ADA by developing community-based programs" for mental healthcare).

²³⁵ States v. Georgia, 461 F. Supp. 3d 1315, 1317 (N.D. Ga. 2020); Ga. Advoc. Off. v. Georgia, 447 F. Supp. 3d 1311, 1315 (N.D. Ga. 2020).

²³⁶ Courts have consistent held that "DOJ regulations and guidance are entitled to deference." *Bennet v. Hurley Medical Center*, 86 F.4th 314, 326 (6th Cir. 2023); *see also Olmstead*, 527 U.S. at 597–98 ('Because the [DOJ] is the agency directed by Congress to issue regulations implementing Title II its views warrant respect.").

²³⁷ 42 C.F.R. § 441.301(c)(4)(iii-iv); see also ADA, 42 U.S.C.§ 12101(b)(3) ("the Federal Government plays a central role in enforcing the standards established] under the ADA.")

²³⁸ See, e.g., DEAN SPADE, NORMAL LIFE: ADMINISTRATIVE VIOLENCE, CRITICAL TRANS POLITICS, AND THE LIMITS OF LAW 43-43 (2015).

²³⁹ VAWA passed in 1994 and was reauthorized three time until it expired in 2018.

²⁴⁰ Leah Goodmark, Assessing the Impact of the Violence Against Women Ac, *Annu. Rev. Criminol*, 5:115–31, 116 (2022).

²⁴¹ Id. at 118 (noting criticism that VAWA "increased criminalization on communities of color.").

²⁴² Leah Goodmark, Assessing the Impact of the Violence Against Women Ac, *Annu. Rev. Criminol*, 5:115–31, 121-122 (2022).

²⁴³ *Id.* at 116.

²⁴⁴ See supra n ____ (Jasmine's quote on judges and community integration).

²⁴⁵ https://www.dhs.state.il.us/page.aspx?item=136090. The legislation passed and was implemented in 2020.

²⁴⁶ Id.

²⁴⁷ Id.

²⁴⁸ <u>https://www.dhs.state.il.us/page.aspx?item=124394</u>.

²⁴⁹ https://www.dhs.state.il.us/page.aspx?item=138759/.

²⁵⁰ 405 ILCS 5/4-211.

²⁵¹ See, Virginia State Profile, SEICUS, May 21, 2021, <u>https://siecus.org/state_profile/virginia-state-profile/.</u>

²⁵² See, Virginia State Profile, SEICUS, May 21, 2021, <u>https://siecus.org/state_profile/virginia-state-profile/.</u>

²⁵³ See, Virginia State Profile, SEICUS, May 21, 2021, <u>https://siecus.org/state_profile/virginia-state-profile/</u>.

²⁵⁴ Emily DeMatteo, Center for American Progress, Reproductive Justice for Disabled Women: Ending Systemic Discrimination, April 13, 2022, <u>https://www.americanprogress.org/article/reproductive-justice-for-disabled-women-ending-systemic-discrimination/</u>.

²⁵⁵ See id. as an example of people with intellectual and developmental disabilities leading efforts to advance legislative change in access to sexuality education and resources.

²⁵⁶ Lee, VIOLENCE at 130.

²⁵⁷ Id.