

ARTICLES

THE STRUCTURAL DESEXUALIZATION OF DISABILITY

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Sexuality is integral to the human experience. Yet choices related to sexuality—sex, intimate relationships, marriage, pleasure, and childbearing—are often controlled for people with intellectual and developmental disabilities. Discourse on sexuality primarily focuses on acts of sexual violence against this community, emphasizing a victim-perpetrator binary. This binary view directs legal and policy efforts to ameliorate this sexual violence, emphasizing victimhood and protectionism.

But individuals with intellectual and developmental disabilities—like members of the broader population—desire to experience love and intimacy; engage in sexual pleasure and self-expression; and exercise choices around sexuality and reproduction. Legal scholarship has undertheorized how state systems that are central in the lives of people with intellectual and developmental disabilities normalize the subjugation of sexual and reproductive choices.

This Article fills this void by applying a new structural desexualization of disability framework to identify the ways that legal structures and social norms act in concert to harm people with intellectual and developmental disabilities in matters of sexuality. This Article examines three disability systems through this new framework:

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guardianship, special education, and the Home- and Community-Based Services Waiver program.

This is the first legal Article to situate the structural desexualization of disability as a constitutive element in perpetuating sexual violence against people with intellectual and developmental disabilities. This Article aims to encourage discourse, advocacy, policymaking, and organizing around issues that affect sexuality by reframing the victim–perpetrator binary. It further seeks to reposition sexuality as a community integration priority under the Americans with Disabilities Act.

INTRODUCTION	1597
I. THE HISTORICAL AND LEGAL FOUNDATIONS FOR CREATING AND SUSTAINING A CULTURE OF DESEXUALIZING DISABILITY.....	1609
A. The Historical Foundations of the Desexualization of Disability	1609
B. The Promise of <i>Olmstead</i> and Community Integration	1612
C. Modern Laws that Affect the Structural Desexualization of Disability	1618
D. Sexuality and the Unmet Promise of <i>Olmstead</i>	1621
1. The Economic Gatekeeping of Sexuality Supports and Services.....	1622
2. Fostering a Culture of Desexualization	1625
3. Sexuality and Disability Scholarship	1628
II. REFRAMING THE VICTIM–PERPETRATOR BINARY THROUGH THE STRUCTURAL FRAME OF DESEXUALIZING DISABILITY	1629
A. The Inadequacy of the Victim–Perpetrator Binary View of Sexual Violence	1630
B. The Social Machinery that Normalizes the Structural Desexualization of Disability.....	1634
III. THE SYSTEMS THAT MAINTAIN THE STRUCTURAL DESEXUALIZATION OF DISABILITY	1637
A. The Desexualization of Disability Through Guardianship	1637
B. The Desexualization of Disability Through Special Education	1642
1. C.K.M.	1642
2. David M.	1643
3. The School District.....	1644
C. The Desexualization of Disability Through the HCBS Waiver Program.....	1648

IV. THE STATE’S ROLE IN RECONCEPTUALIZING SEXUALITY.....	1650
A. Harnessing the Jurisprudential Advances of the <i>Olmstead</i> Integration Mandate Under Title II of the ADA to Compel Sexuality Supports and Services	1651
B. State Resourcing to Center Sexuality in Community Integration.....	1654
1. Guardianship	1655
2. Mandating Comprehensive Sexuality Education in the Special Education System.....	1656
3. State Resourcing of Sexuality Services and Supports that Confront Ableism	1657
CONCLUSION.....	1658

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.”

— Anne Finger.¹

Sexuality is 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, behavior, thoughts, feelings of self-worth, and interpersonal interactions.³ Legal scholarship has undertheorized how state systems that are central in the lives of people with intellectual and developmental disabilities⁴ normalize the control and subjugation of

1. Anne Finger, *Forbidden Fruit*, *New Internationalist*, July 1992, at 8, 9.

2. *Defining Sexual Health*, WHO, <https://www.who.int/teams/sexual-and-reproductive-health-and-research/key-areas-of-work/sexual-health/defining-sexual-health> [<https://perma.cc/KK8L-VPHH>] (last visited June 29, 2024) (internal quotation marks omitted) (quoting WHO, *Defining Sexual Health: Report of a Technical Consultation on Sexual Health* 28–31 January 2002, Geneva 5 (2006), <https://www.ceslas.lu/perch/resources/whodefiningsexualhealth.pdf> [<https://perma.cc/LCT7-22CG>]); see also Shirley Lin, *Dehumanization “Because of Sex”: The Multiaxial Approach to the Rights of Sexual Minorities*, 24 *Lewis & Clark L. Rev.* 731, 742 (2020) (discussing the fluidity of sexual self-identification and explaining that “for millions of individuals . . . sex cannot be deemed only biologically external, immutable, or dimorphic”).

3. Miriam Taylor Gomez, *The S Words: Sexuality, Sensuality, Sexual Expression and People With Intellectual Disability*, 30 *Sexuality & Disability* 237, 237 (2012).

4. This Article interchanges between using identity-first and person-first language to reflect the differing views on the use of language when writing about disability. In academia, for example, person-first language is largely the default (i.e., people with a disability) when

intimate, sexual, and reproductive choices and how these systems exact enduring harms.

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. These structures and norms then work to create conditions of normalized human suffering.⁵ This framework situates the structural desexualization of disability as a constitutive element in maintaining and perpetuating the sexual violence experienced by 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.

Individuals with intellectual and developmental disabilities share the same desire to experience love and intimacy, engage in sexual pleasure and sexual self-expression, and exercise choices around sexuality and reproduction as the broader population.⁶ “Desexualization is the process

discussing disability. Many in the disabled community choose identity-first language. See, e.g., Lydia X.Z. Brown, *The Significance of Semantics: Person-First Language: Why It Matters*, *Autistic Hoya* (Aug. 4, 2011), <https://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html> [<https://perma.cc/ZY9N-R4QH>] (“In the autism community, many self-advocates and their allies prefer terminology such as ‘Autistic,’ ‘Autistic person,’ or ‘Autistic individual’ because we understand autism as an inherent part of an individual’s identity . . .”).

5. The concept of “structural violence” informs the structural desexualization of disability framework. See *infra* note 230. “Structural violence is a process that works slowly through general misery, diminishing the dignity of human beings . . .” Bandy X. Lee, *Violence: An Interdisciplinary Approach to Causes, Consequences, and Cures* 125 (2019) [hereinafter *Lee, Violence*]. It “occurs through economically, politically, or culturally driven processes that work together . . . to limit [persons] from achieving full quality of life.” *Id.* at 123 (citing Akhil Gupta, *Red Tape: Bureaucracy, Structural Violence, and Poverty in India* 19–25 (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 on Paul Farmer, An Anthology of Structural Violence*, *Sidney W. Mintz Lecture in Anthropology at Johns Hopkins University* (Nov. 27, 2001), *in* 45 *Current Anthropology* 305, 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. Johan Galtung, *Violence, Peace, and Peace Research*, 6 *J. Peace Rsch.* 167, 175 (1969) [hereinafter *Galtung, Violence, Peace, and Peace Research*]; see also Paul Farmer, *Pathologies of Power: Health, Human Rights, and the New War on the Poor* 29–31 (2003) (discussing the conditions of human suffering that are built within the structures of society and are not often “effectively conveyed by statistics or graphs” but are experienced by those “occupying the bottom rung of the social ladder in inequalitarian societies”).

6. See, e.g., Tom Shakespeare, *Disabled Sexuality: Towards Rights and Recognition*, 18 *Sexuality & Disability* 159, 164–65 (2000) (“[O]ne 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 *In re D.D.*, 19 N.Y.S.3d 867, 875 (Sur. Ct. 2015) (“The right to have a family of one’s own is not reserved only for persons

of stripping disabled people of sexual agency and autonomy.”⁷ It is the loss of self-determination in matters of sexual self-expression and reproduction.⁸ It is the erasure of one’s “sexual identity or experience.”⁹ It creates often-insurmountable barriers to engaging in sexual desire or choosing to be the object of sexual desire.¹⁰

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. It is embodied through the erosion of personhood, loss of bodily autonomy, 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 “[t]he magnitude of damage” that flows from the structural desexualization of disability.¹¹ Consider the case of Britney Spears. Spears gained nationwide attention following the release of her testimony in court for the removal of the thirteen-year conservatorship¹² 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 an [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

with no disabilities, and the yearning for companionship, love, and intimacy is no less compelling for persons living with disabilities.”). The *In re D.D.* court reasoned that “these are choices central to . . . personal dignity and autonomy and [the] pursuit of happiness.” *In re D.D.*, 19 N.Y.S.3d at 875.

7. 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, 164 (Andy J. Johnson, J. Ruth Nelson & Emily M. Lund eds., 2017) [hereinafter Brown, *Ableist Shame*]; see also Elizabeth Emens, *Intimate Discrimination: The State’s Role in the Accidents of Sex and Love*, 122 *Harv. L. Rev.* 1307, 1338 (2009) (discussing “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”).

8. Brown, *Ableist Shame*, supra note 7, at 164.

9. *Id.*

10. *Id.*

11. Lee, *Violence*, supra note 5, at 124 (“The magnitude of damage warrants calling [structural violence] violence rather than simply social injustice or oppression.”).

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

children, any more children. So basically this conservatorship is doing me way more harm than good.¹³

To those familiar with conservatorship, Spears's testimony was not a "bombshell"¹⁴ or "stunning assertion[],"¹⁵ 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's testimony illustrates the normalized sexual and reproductive control that is inflicted through the "coercive function[]" of conservatorship.¹⁶

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."¹⁷ Through the appointment of a conservatorship, the court determined that Spears lacked "legal mental capacity" to make decisions about her life.¹⁸ Spears's father became the court-appointed conservator of Spears's "person" and of her estate¹⁹ until the court dissolved the guardianship in 2021.²⁰ Under her conservatorship, Spears reverted to the

13. Reporter's Transcript of Proceedings at 25, *In re the Conservatorship of: Britney Jean Spears*, No. BP108870 (Cal. Super. Ct. filed June 23, 2021) (on file with the *Columbia Law Review*).

14. Erin Snodgrass, *One of Britney Spears' Co-Conservators Says Her Entire Medical Team Agrees Her Dad Should Be Removed From Guardianship*, *Bus. Insider* (July 26, 2021), <https://www.businessinsider.com/britney-spears-medical-team-dad-should-be-removed-guardianship-2021-7> [<https://perma.cc/2N7D-36SM>].

15. Jan Hoffman, *Is the Forced Contraception Alleged by Britney Spears Legal?*, *N.Y. Times* (June 24, 2021), <https://www.nytimes.com/2021/06/24/health/britney-spears-forced-IUD.html> (on file with the *Columbia Law Review*) (last updated Aug. 12, 2021).

16. Claire Spivakovsky & Linda Roslyn Steele, *Disability Law in a Pandemic: The Temporal Folds of Medico-Legal Violence*, 31 *Soc. & Legal Stud.* 175, 177 (2022) (discussing how guardianship laws were used to perpetuate forms of "legal violence" against disabled people during the COVID-19 pandemic in Australia); see also Robyn M. Powell, *Disability Reproductive Justice*, 170 *U. Pa. L. Rev.* 1851, 1854–55 (2022) [hereinafter Powell, *Disability Reproductive Justice*] ("[T]hat 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/> (on file with the *Columbia Law Review*) (reporting on Spears's testimony and the coercive nature of a conservatorship).

17. Britney Spears, *The Woman in Me* 173 (2023); see also Cal. Prob. Code § 1800.3 (2024) (outlining the statutory requirements for the appointment of a conservator).

18. Jan Hoffman, *Testing Britney Spears: Restoring Rights Can Be Rare and Difficult*, *N.Y. Times* (July 23, 2021), <https://www.nytimes.com/2021/07/23/health/britney-spears-conservatorship.html> (on file with the *Columbia Law Review*) (last updated Sept. 30, 2021).

19. Spears, *supra* note 17, at 166–67; see also Cal. Prob. Code § 1800.3.

20. Joe Coscarelli & Julia Jacobs, *Judge Ends Conservatorship Overseeing Britney Spears's Life and Finances*, *N.Y. Times* (Nov. 12, 2021), <https://www.nytimes.com/2021/11/12/arts/music/britney-spears-conservatorship-ends.html> (on file with the *Columbia Law Review*) (last updated Nov. 15, 2021).

legal status of a minor with her father assuming the legal right to make plenary decisions over all aspects of her personal and financial life.²¹

In her memoir, Spears further expressed, “My dad took my boyfriend away and I could not drive. My mom and dad took my womanhood from me.”²² She concluded a chapter of her book by sharing what her father said shortly after he was appointed her conservator: “I just want to let you know, . . . I call the shots. . . . I’m Britney Spears now.”²³ Is it viewed as a form of harm and suffering when the guardianship system strips someone of their choices around intimate relationships, marriage, childbearing, and parenting? How would disability law and policy change if the removal of these vital decisions was viewed as harm that is built into the structures of society?²⁴

The outrage that swelled through the #FreeBritney movement²⁵ was arguably propelled by Spears’s whiteness, wealth, and international recognition, which still could not shield her from having her sexual and reproductive decisionmaking 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 disabilities²⁶—a population that lacks access, privilege, and economic

21. Spears, *supra* note 17, at 166–68.

22. *Id.* at 173.

23. *Id.* at 175 (internal quotation marks omitted) (quoting Britney Spears’s father).

24. This Article is not debating whether guardianship should exist. Rather, it is questioning whether the nature of guardianship would change if certain aspects of the power exercised under guardianship were viewed as structural violence. The idea of abolishing guardianship as a system is, however, gaining traction as guardianship reforms expand across the country. See, e.g., Melissa Hellmann, *Loss of Autonomy: How Guardianships Threaten People’s Rights*, Ctr. for Pub. Integrity (June 24, 2022), <https://publicintegrity.org/inside-publici/newsletters/watchdog-newsletter/autonomy-guardianships-threaten-rights/> [<https://perma.cc/8RLX-2TY3>] (discussing types of abuses that have occurred under guardianship while recognizing that a “desire to abolish” guardianship may hinder reform); Sara Luterman, *Abolish Guardianship, Preserve the Rights of Disabled People, and Free Britney*, *The Nation* (Mar. 6, 2021), <https://www.thenation.com/article/society/guardianship-britney-spears/> (on file with the *Columbia Law Review*) (discussing how guardianship inherently strips disabled people of their humanity and arguing that alternatives to guardianship, such as supported decisionmaking, are necessary to preserve the civil rights of the individual under guardianship).

25. See, e.g., Bianca Betancourt, *Why Longtime Britney Spears Fans Are Demanding to #FreeBritney*, *Harper’s BAZAAR* (Nov. 12, 2021), <https://www.harpersbazaar.com/celebrity/latest/a34113034/why-longtime-britney-spears-fans-are-demanding-to-freebritney> [<https://perma.cc/XM3H-AHQ6>] (“Britney fans have long been wary of the conservatorship terms and have often questioned whether it was in Britney’s best interest.”).

26. 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.” *Developmental Disability Basics*, CDC (May 16, 2024), <https://www.cdc.gov/ncbddd/developmentaldisabilities/index.html> [<https://perma.cc/EV6R-YRMG>]. Autism, Attention-Deficit/Hyperactivity Disorder (ADHD), intellectual disability, and cerebral palsy are examples of developmental disabilities. *Id.* A diagnosis of intellectual disability is

capital²⁷—have long endured control over their intimate, sexual, and reproductive decisionmaking through guardianship and other means. For disabled people who live at the intersection of marginalized identities, such as being Black, Indigenous, transgender, or queer, this control is often rote, exacted through societal processes and norms.²⁸ But, unlike Spears, these deprivations are not elevated to importance in national dialogue.²⁹ They remain in the shadows, viewed largely by society as a natural aspect of what is required to protect this population.³⁰ The

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.” Robert L. Schalock et al., *Am. Ass’n Intell. & Developmental Disabilities Ad Hoc Comm. on Tech. & Classification, Intellectual Disability: Definition, Classification, and Systems of Supports* 28 (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.* at 31. Adaptive functioning “is the collection of conceptual, social, and practical skills that all people learn in order to function in their daily lives.” *Adaptive Behavior, Am. Ass’n on Intell. & Developmental Disabilities*, <https://www.aaidd.org/intellectual-disability/definition/adaptive-behavior> [<https://perma.cc/F6FM-57RX>] (last visited July 28, 2024) (emphasis omitted). Conceptual skills include “language; reading and writing; and money, time, and number concepts.” Schalock et al., *supra*, at 44. Social skills include “interpersonal skills . . . and social problem solving.” *Id.* Practical skills include performing activities of daily living, such as caring for one’s health, maintaining a safe environment, managing finances, and using transportation. *Id.* Though helpful for framing this discussion, this Article also recognizes that precise definitions can fail to capture the full breadth of experiences of people with intellectual and developmental disabilities. See Sarah H. Lorr, *Unaccommodated: How the ADA Fails Parents*, 110 *Calif. L. Rev.* 1315, 1325 (2022) (“In the context of [intellectual disability] . . . 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.”).

27. See Nanette Goodman, Michael Morris & Kelvin Boston, *Financial Inequality: Disability, Race and Poverty in America* 5–6 (2019), <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/02/disability-race-poverty-in-america.pdf> [<https://perma.cc/24KV-JV4E>] (explaining the compounding consequences of the relationship between disability and poverty).

28. See, e.g., Nat’l Women’s L. Ctr., *Forced Sterilization of Disabled People in the United States* 8 (Jan. 24, 2022), https://nwlc.org/wp-content/uploads/2022/01/f.NWLC_SterilizationReport_2021.pdf [<https://perma.cc/F4QG-J83X>] (“Black disabled women are more likely to be sterilized than white disabled women.”); Amanda Collar, *Indigenous Peoples’ Limited Access to Reproductive Care*, 176 *Annals Internal Med.* 408, 408 (2023) (“Many people with the capacity for pregnancy have long faced hurdles to control their own bodies and decide to have children, or not, especially Indigenous peoples.”); Hannah G. Ginn, *Securing Sexual Justice for People With Intellectual Disability: A Systematic Review and Critical Appraisal of Research Recommendations*, 35 *J. Applied Rsch. Intell. Disabilities* 921, 922 (2022) (highlighting that “[a]cross studies, sexual and gender minority people with intellectual disability report experiencing erasure of their [sexual] identity within” the environment where they receive supports and services).

29. See *infra* Part III (discussing the experiences of intellectually and developmentally disabled people whose sexuality was controlled, minimized, or weaponized to cause harm).

30. See, e.g., Michael Gill, *Already Doing It: Intellectual Disability and Sexual Agency* 35–36 (2015) (“[T]he concept of intellectual disability assumes that people are unable to adequately advocate for themselves and need constant supervision and support. Individuals

predominant “focus on violence, abuse, victimization, stigmatization, and control” results in, “at best,” individuals with intellectual and developmental disabilities “receiving little to no education about sexuality and reproduction and/or having their opportunities for sexual expression taken away, and at worst, contributes to eugenic practices.”³¹

When national attention is given to issues of sexuality and people with intellectual and developmental disabilities, the focus is often on stories that sensationalize³² acts of sexual violence³³ against this community. These stories emphasize a victim–perpetrator binary: There is a victim who experienced identifiable harms and a perpetrator to hold accountable.³⁴

are assumed vulnerable to sexual abuse and exploitation . . . [and as such,] their sexual rights should be protected while their sexual expression should be shunned and silenced.”).

31. Carli Friedman, *Sexual Health and Parenting Supports for People With Intellectual and Developmental Disabilities*, 20 *Sexuality Rsch. & Soc. Pol’y* 257, 257 (2022) [hereinafter Friedman, *Sexual Health and Parenting Supports*] (citations omitted); see also Alice Wong, *Introduction to Disability Intimacy*, at xv, xviii (Alice Wong ed., 2024) (discussing how little public information is available on “disability intimacy,” noting that in researching for her book, *Disability Intimacy*, “[a]rticles on stereotypes, stigmas, . . . sexual abuse, and sexual dysfunction abounded”).

32. See Brown, *Ableist Shame*, *supra* note 7, at 167 (observing 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”).

33. Throughout this Article, the term “sexual violence” is used as an umbrella term to include sexual assault and sexual abuse. 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, <https://thearc.org> [<https://perma.cc/NJF3-NWEZ>] (last visited July 15, 2024). As described by The Arc, “Assault 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.” Leigh Ann Davis, *The Arc, People With Intellectual Disabilities and Sexual Violence* (2011), <http://www.thearc.org/wp-content/uploads/forchapters/Sexual%20Violence.pdf> [<https://perma.cc/NTD7-JWEE>]. Sexual assault “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 materials (pornography), and the use of inappropriate sexual remarks or language.” *Id.* Sexual abuse “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.” *Id.*

34. See, e.g., Daniel Engber, *The Strange Case of Anna Stubblefield*, *N.Y. Times Mag.* (Oct. 20, 2015), <https://www.nytimes.com/2015/10/25/magazine/the-strange-case-of-anna-stubblefield.html> (on file with the *Columbia Law Review*) (documenting the case of Anna Stubblefield, a professor criminally convicted of aggravated sexual assault for having sex with D.J., a twenty-eight-year-old man with an intellectual disability who does not communicate verbally and is described as an adult who wears diapers, scoots on the floor, and chirps when excited); Robert Hanley, *Verdict in Glen Ridge; 4 Are Convicted in Sexual Abuse of Retarded New Jersey Woman*, *N.Y. Times*, Mar. 17, 1993, at A1 (discussing a highly publicized case through infantilizing descriptions of the disabled person: “[P]opular high school athletes clustered around a childlike 17-year-old schoolmate who idolized them and

This binary view focuses on an interpersonal, individualized form of harm, which results in a dominant sexual violence narrative. 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, thereby reinforcing a sexual violence narrative.

This view of sexuality 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.³⁵

In recent media, NPR reported on the disproportionate rate at which people with intellectual disabilities experience sexual violence, using unreported data from the DOJ.³⁶ The data showed “people with intellectual disabilities are sexually assaulted at rates more than seven times those for people without disabilities,”³⁷ with NPR using sensationalized language to describe this violence against the intellectually disabled community: “[T]hese women and men are easy prey for predators”³⁸

Further, laws and policies designed to address sexual violence often focus on the victim–perpetrator binary, thereby limiting possibilities for change that addresses structural harms. This emphasis reifies the ascription that a diagnosis of intellectual or developmental disability is incompatible with exercising the range of choices available and related to one’s sexuality—sex, developing and maintaining intimate relationships, marriage, engaging in sexual pleasure, and having children, to name only a few examples.³⁹ This ascription is reflected through laws that limit the

coveted their friendship and then” violently sexually assaulted her); Jeff Bonty, Jacklin Sentenced to 18 Years in Sexual Assault Conviction, *Daily J.* (Jan. 27, 2023), https://www.daily-journal.com/news/crime/jacklin-sentenced-to-18-years-in-sexual-assault-conviction/article_7074974a-9db1-11ed-8fff-7fce2c235490.html (on file with the *Columbia Law Review*) (reporting on a Catholic priest in Illinois who was sentenced to eighteen 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 forty-seven and “suffer[ing]” from partial paralysis).

35. See, e.g., 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> [<https://perma.cc/EB8C-8DFY>] (discussing the need to include disabled women in the #MeToo conversation).

36. All Things Considered, ‘She Can’t Tell Us What’s Wrong’, NPR, at 00:10 (Jan. 10, 2018), <https://www.npr.org/transcripts/566608390> (on file with the *Columbia Law Review*).

37. *Id.* at 02:00.

38. *Id.* at 00:32.

39. See, e.g., *In re Guardianship of Kennedy*, 845 N.W.2d 707, 708, 715 (Iowa 2014) (voicing concern regarding the constitutionality of a guardian’s action to sterilize her twenty-one-year-old son, who was intellectually disabled, without his consent because he was in a relationship with a woman and admitted to having sex but not overturning a lower court’s decision preserving her guardianship of her son); *In re Grady*, 426 A.2d 467, 486 (N.J. 1981) (finding that if a nineteen-year-old with Down syndrome “can have a richer and

sexual and reproductive choices of people with intellectual and developmental disabilities.⁴⁰

Scholars are looking beyond the interpersonal narrative of violence to think more critically about its unseen impact, structural causes, and lasting consequences. 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.⁴¹ Similarly, Professor Allegra McLeod argues for the necessity of “expand[ing] our understanding of violence beyond individualized disorder and the immediate scene of interpersonal harm” to stop gun violence.⁴² Professors Stephen Lee and Rabia Belt are further pushing the boundaries of how violence is conceptualized to surface the mounting—but less visible—harms that are a result of incarceration and immigration detention.⁴³

Social science scholars in the last half century have also developed new ways to think about violence and its root harms beyond the interpersonal.⁴⁴ The structural desexualization of disability framework

more active life only if the risk of pregnancy is permanently eliminated, then sterilization may be in her best interests”).

40. See, e.g., *infra* section I.C and Part III (discussing the range of laws, policies, and state systems that create and sustain the culture of desexualizing disability); see also Powell, *Disability Reproductive Justice*, *supra* note 16, at 1867–81 (describing the current landscape of laws and policies that limit the sexual and reproductive choices of people with disabilities).

41. See, e.g., Erika K. Wilson, *White Cities, White Schools*, 123 *Colum. L. Rev.* 1221, 1235–36 (2023) (arguing that adopting a broader definition of racial violence “jettisons the individual-perpetrator-and-intent paradigm that dominates conceptions of racial violence within the law” because the paradigm “limits the scope of what is considered racial violence [and] limits the conception of who is harmed to individuals only, obscuring the [structural] impact”).

42. Allegra McLeod, *An Abolitionist Critique of Violence*, 89 *U. Chi. L. Rev.* 525, 527 (2022).

43. See Rabia Belt, *The Fat Prisoners’ Dilemma: Slow Violence, Intersectionality, and a Disability Rights Framework for the Future*, 110 *Geo. L.J.*, 785, 827–28 (2022) (“The plight of fat incarcerated people, and indeed, incarcerated people in general, is the embodiment of ‘slow violence.’”); Stephen Lee, *Family Separation as Slow Death*, 119 *Colum. L. Rev.* 2319, 2326, 2384 (2019) (applying the concept of slow violence as a “useful intervention,” which includes gaining a “better understand[ing] [of] how the law contributes to and normalizes immigrant suffering”). 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, 1055–57 (2022) (focusing on a transformative justice approach that addresses the “ongoing, intangible harms” in cases of sexual violence); Alice Ristroph, *Criminal Law in the Shadow of Violence*, 62 *Ala. L. Rev.* 571, 573–76 (2011) (discussing the need to think more carefully about what is meant by violence in the undertaking of criminal law reform efforts).

44. See, e.g., Patricia Hill Collins, *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment* 159 (2d ed. 2000) (discussing how, “[b]y making visible the pain [that sexual violence] survivors feel,” scholars of Black feminist literature reframed the normalized misogyny against Black women as violence); Rob Nixon, *Slow Violence and the Environmentalism of the Poor* 2 (2011) (arguing that there is a need to reframe gradual

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. This 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”⁴⁵ of sexual victimization, this Article proposes strategies for ameliorating sexual violence and its cascading harms. It further aims to encourage discourse, advocacy, policymaking, and organizing around the breadth of issues that affect sexuality by reframing the victim–perpetrator binary to reposition sexuality as a community integration priority under Title II of the Americans with Disabilities Act (ADA) for people with intellectual and developmental disabilities.⁴⁶

and delayed destruction as a form of violence); Lauren Berlant, *Slow Death* (Sovereignty, Obesity, Lateral Agency), 33 *Critical Inquiry* 754, 754 (2007) (describing the phrase “slow death” as the “physical wearing out of a population and the deterioration of people in that population”); Nancy Whittier, *Carceral and Intersectional Feminism in Congress: The Violence Against Women Act, Discourse, and Policy*, 30 *Gender & Soc’y* 791, 793 (2016) (“[A]n intersectional feminist approach emphasizes how social, economic, and political forces interact to shape different experiences and necessary solutions to violence.” (citations omitted)).

45. Barbara Rylko-Bauer & Paul Farmer, *Structural Violence, Poverty, and Social Suffering*, in *The Oxford Handbook of the Social Science of Poverty* 47, 57 (David Brady & Linda M. Burton eds., 2016).

46. See *infra* section I.B. 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 that prohibits disability-based discrimination by public entities. 42 U.S.C. § 12131(1) (2018). The relevant federal regulation 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.” 28 C.F.R. § 35.130(d) (2024). Section 504 of the Rehabilitation Act, the precursor to the ADA, includes a parallel regulatory provision. See 28 C.F.R. § 41.51(d) (“The purpose of this part is to implement Executive Order 12250, which requires the Department of Justice to coordinate the implementation of section 504 of the Rehabilitation Act of 1973.”). Section 504 is a federal statute that prohibits discrimination by entities that receive federal funding. Rehabilitation Act of 1973, Pub. L. No. 93-112, § 504, 87 Stat. 355, 394 (codified as amended at 19 U.S.C. § 794 (2018)) (“No otherwise qualified [disabled] individual . . . shall, solely by reason of [their disability], be excluded from the participation

The use of an expansive definition of sexuality centers the role of interdependence⁴⁷ 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” that emerges from the lived experience of disability, which must be recognized and embraced when examining issues of sexuality and disability.⁴⁸ Disability justice advocate Lydia X.Z. Brown explains, “[T]he 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.”⁴⁹ Individuals with intellectual and developmental disabilities need varying degrees of support⁵⁰ in making informed choices related to sexuality.⁵¹ Supports

in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”).

47. For discussion of interdependence and disability, see Robyn M. Powell, *Care Reimagined: Transforming Law by Embracing Interdependence*, 122 Mich. L. Rev. 1185, 1190–91 (2024) (reviewing Jennifer Natalya Fink, *All Our Families: Disability Lineage and the Future of Kinship* (2022)); Mia Mingus, *Access Intimacy, Interdependence, and Disability Justice*, *Leaving Evidence* (Apr. 11, 2017), <https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/> [<https://perma.cc/89UT-BDBC>] (“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.”).

48. Natalie M. Chin, *Centering Disability Justice*, 71 Syracuse L. Rev. 683, 694 (2021) [hereinafter Chin, *Centering Disability Justice*] (“[A] critical racism/ableism consciousness framework demands an examination of disability through the prism of its intersections—race, class, sexual orientation, gender, immigrant status, and others—and further recognizes with equal weight the physical, cognitive, and psychological impact of disability on one’s bodymind.”); see also Subini Ancy Annamma, David Connor & Beth Ferri, *Dis/ability Critical Race Studies (DisCrit): Theorizing at the Intersections of Race and Dis/ability*, 16 *Race Ethnicity & Educ.* 1, 7–8 (2013) (“DisCrit seeks to understand ways that macrolevel issues of racism and ableism, among other structural discriminatory processes, are enacted in the day-to-day lives of students of color with dis/abilities.”).

49. Lydia Brown, *Disability in an Ableist World*, *Autistic Hoya* (Aug. 12, 2012), <https://www.autistichoya.com/2012/08/disability-in-ableist-world.html> [<https://perma.cc/JC6L-24SP>]; see also Doron Dorfman, *Disability as Metaphor in American Law*, 170 U. Pa. L. Rev. 1757, 1795–97 (2022) (“Disability is an interactive process between the individual, the impairment, the person’s bodymind, and the environment.”).

50. 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, 396–97 (2018) [hereinafter Chin, *Group Homes as Sex Police*] (“The literature . . . often fails to distinguish the unique challenges of individuals with intellectual disabilities in accessing sexual rights.”); see also Martin Lyden, *Assessment of Sexual Consent Capacity*, 25 *Sexuality & Disability* 3, 5 (2007) (“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.”).

51. See, e.g., *Lucy J. v. State Dep’t. of Health & Soc. Servs., Off. Of Child.’s Servs.*, 244 P.3d 1099, 1115 (Alaska 2010) (noting that law and policy requires “family reunification services [to] be provided in a manner that takes a parent’s disability into account”); *In re D.D.*, 19 N.Y.S.3d 867, 870–75 (Sur. Ct. 2015) (denying petitioner guardianship over son

alone, without confronting the systems and structures that maintain the desexualization of disability, will not achieve change.

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 that 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 it. As expressed by political theorist Mathias Thaler, “how we *conceptualize* violence affects what we *do* to contain and mitigate it.”⁵²

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 ADA, 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 this 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 by offering strategies to reconceptualize sexuality as a community integration priority through state and other interventions.

with Down syndrome after finding that, with a network of “family, friends, and supportive services,” he could make medical, financial, and other decisions including those around marriage, family, and relationships); Letter from Vanita Gupta, Acting Assistant Att’y Gen., C.R. Div., DOJ, Jocelyn Samuels, Dir., Off. for C.R., HHS, & Susan M. Pezzullo Rhodes, Reg’l Manager, Off. for C.R., Region I, HHS, to Erin Deveney, Interim Comm’r, Dep’t of Child. & Fams., Exec. Off. of Health and Hum. Servs., Commonwealth of Mass. (Jan. 29, 2015), https://www.hhs.gov/sites/default/files/mass_lof.pdf [https://perma.cc/Y3SQ-RQ38] (finding that a state agency erroneously assumed a mother couldn’t safely parent her newborn daughter because of the mother’s disability).

52. Mathias Thaler, *Naming Violence: A Critical Theory of Genocide, Torture, and Terrorism* 1 (2018); see also Lee, *Violence*, *supra* note 5, at 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.”); Longmore Lecture: Context, Clarity & Grounding, Talila A. Lewis Blog (Mar. 5, 2019), <https://www.talilalewis.com/blog/archives/03-2019> [https://perma.cc/3UU9-RD6Y] (recognizing that violence is a cause and consequence of disability and arguing that “[v]iolence should be understood broadly” to include the “[d]eprivation of language, food, water, shelter, education, health, economic security, etc.”).

I. THE HISTORICAL AND LEGAL FOUNDATIONS FOR CREATING AND
SUSTAINING A CULTURE OF DESEXUALIZING DISABILITY

Disability—whether perceived or actual—has been used throughout history to legitimize the social control of bodies. The labels that law and society attach to people deemed disabled often dictate the level of control that individuals have over their own sexual and reproductive choices. As James W. Trent Jr. expressed in *Inventing the Feeble Mind*, “Intellectual disability is a construction whose changing meaning is shaped both by individuals who initiate and administer policies, programs, and practices and by the social context to which these individuals are responding.”⁵³ The justifications for the desexualization of disability are rooted in this history and appear seemingly immovable, as advancements in disability rights laws have done little to recognize sexuality as central to the lives of people with intellectual and developmental disabilities.

A. *The Historical Foundations of the Desexualization of Disability*

Between 1895 and 1920, the theory of eugenics began to take hold in the United States.⁵⁴ The fields of law, medicine, philanthropy, and academia began to embrace eugenics as a means to control the sexual and reproductive lives of those relegated to the margins of society.⁵⁵ Eugenists sought to prevent the dilution of a “superior human stock.”⁵⁶ They believed that the human manipulation of genetics could rid the world of “inefficient human stock.”⁵⁷ By eliminating the procreation of persons deemed to have “physical and mental hereditary defects that were degrading America’s gene pool,”⁵⁸ eugenists sought to create a superior white race.⁵⁹ To achieve this goal, supporters of eugenics promoted laws and policies that included marriage restrictions, sex-segregated

53. James W. Trent, Jr., *Inventing the Feeble Mind: A History of Intellectual Disability in the United States*, at xvii (2d ed. 2016).

54. See Adam Cohen, *Imbeciles: The Supreme Court, American Eugenics, and the Sterilization of Carrie Buck* 55–57 (2017) (“Eugenics and the mania over feeble-mindedness arrived at a time when America was particularly receptive. The start of the twentieth century was an era of fast-paced, disruptive change.”).

55. *Id.* at 55–56.

56. Trent, *supra* note 53, at 134.

57. See Francis Galton, *Inquiries Into Human Faculty and Its Development* 1–2 (1883); see also Cohen, *supra* note 54, at 78–79.

58. Cohen, *supra* note 54, at 5.

59. See, e.g., Khiara M. Bridges, *White Privilege and White Disadvantage*, 105 *Va. L. Rev.* 449, 465 (2019) (“[T]he eugenics movement was always about protecting the *white race* from degeneration.”); see also Galton, *supra* note 57, at 307 (“The most merciful form of what I ventured to call ‘eugenics’ would consist in watching for the indications of superior strains or races, and in so favouring them that their progeny shall outnumber and gradually replace that of the old one.”).

institutionalization, and compulsory sterilization to restrict the procreation of people whom they deemed “unfit.”⁶⁰

The construction of the labels “feeble-minded” and “mentally defective” by eugenicists created nebulous designations that captured a wide net of people whom society viewed as the direct cause of moral degeneracy in society.⁶¹ These labels provided justification for state control over the sexual and reproductive choices of people given these designations.⁶² As noted by Professor Jamelia Morgan, while these terms do not “closely trace definitions of disability today,” in that time period, “such labels incorporated meanings of disability in that they linked sexual deviance to inherent physiological abnormalities.”⁶³

Women labeled “feeble-minded” were the primary targets of eugenic policies aimed at controlling their sexuality.⁶⁴ 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.’”⁶⁵ Society especially sought to sequester “problem women” from the rest of society, sometimes justifying the lifelong custody of women who were given this designation as “a matter of mere economy.”⁶⁶

The designation of feeble-minded imputed “notions of immorality, criminality, and/or sexual promiscuity and, in turn, [was] used as justification for institutionalizing women.”⁶⁷ Once labeled feeble-minded, women were often relegated to state institutions where they “could then be forcibly sterilized on the grounds that the state had a legitimate interest in preventing women from reproducing children with ‘undesirable traits’

60. Cohen, *supra* note 54, at 5.

61. See Allison C. Carey, *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America* 56, 64 (2009) (“As the eugenics movement grew, however, its proponents portrayed feeble-mindedness as a *direct cause of poverty, crime, sexual deviance, and moral degeneracy.*”).

62. *Id.* at 62 (“[T]he label ‘feeble-mindedness’ activated the potential not only for medical and legal control but also for a host of other social-control systems, including the education system, social welfare, and the family.”).

63. Jamelia Morgan, *On the Relationship Between Race and Disability*, 58 *Harv. C.R.-C.L. L. Rev.* 663, 708 (2023).

64. See Cohen, *supra* note 54, at 25–26 (“The campaign against feeble-mindedness was focused on young women, who were deemed both a moral and a demographic threat. . . . Feeble-minded women were 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 . . .”).

65. Paul A. Lombardo, *Three Generations, No Imbeciles: Eugenics, the Supreme Court, and Buck v. Bell* 11 (2008) [hereinafter Lombardo, *Three Generations*].

66. *Id.* (internal quotation marks omitted) (quoting Walter E. Fernald, *The History of the Treatment of the Feeble-Minded*, in *Proceedings of the National Conference of Charities and Correction at the Twentieth Annual Session Held in Chicago, Ill., June 8–11, 1893*, at 203, 211–12 (Isabel C. Barrows ed., 1893)).

67. Morgan, *supra* note 63, at 706 (citing Michele Goodwin, *Gender, Race, and Mental Illness: The Case of Wanda Jean Allen*, in *Critical Race Feminism* 228 (2d ed. 2003)).

and from supporting disfavored groups that were presumed to be public charges, and strains on the public fisc.”⁶⁸

Sentiment swelled among supporters of eugenics that the spread of feeble-mindedness must be curtailed to prevent future generations of degeneracy and that “public officials and private reformers” bore the responsibility of segregating these people from society to prevent their procreation.⁶⁹ The institutionalization of the feeble-minded and mentally defective, however, was proving too expensive—states could not keep up with the demand of eugenics supporters to segregate these unfit populations to prevent them from having children.⁷⁰ Forced sterilization soon became the policy priority.⁷¹ It “was completely effective, and it could be carried out on a mass scale.”⁷²

Justice Oliver Wendell Holmes Jr. emboldened the eugenics movement with the 1927 decision *Buck v. Bell*,⁷³ further entrenching the labels of “feeble-minded” and “mentally defective” as legitimate disability constructs to justify sexual and reproductive control.⁷⁴ *Buck v. Bell* held as constitutional a Virginia statute that provided state institutions with the right to sexually sterilize patients who were deemed hereditarily unfit if the institutions determined it to be in the patients’ best interest.⁷⁵ Once sterilized, these women could freely return to the community.⁷⁶ Between

68. Id. (quoting Alexandra Minna Stern, *Eugenic Nation: Faults and Frontiers of Better Breeding in Modern America* 107–09 (2d ed. 2015)).

69. Trent, *supra* note 53, at 73, 79; see also Margaret Sanger, *The Pivot of Civilization* 82 (1922) (“[T]here is truly, as some of the scientific eugenicists have pointed out, a feeble-minded peril to future generations—unless the feeble-minded are prevented from reproducing their kind. To meet this emergency is the immediate and peremptory duty of every State and of all communities.”).

70. Cohen, *supra* note 54, at 5.

71. See Paul A. Lombardo, *Medicine, Eugenics, and the Supreme Court: From Coercive Sterilization to Reproductive Freedom*, 13 *J. Contemp. Health L. & Pol’y* 1, 1 (1996) (“Between 1900 and 1970, proponents of eugenic theory drafted and endorsed nearly one hundred statutes that were adopted by state legislatures.”).

72. Cohen, *supra* note 54, at 5. Indiana passed the first sterilization statute in 1907 that authorized state institutions to sterilize “confirmed criminals, idiots, rapists and imbeciles” to prevent procreation when medical professionals determined that there was “no probability of improvement of the [individual’s] mental condition.” Act of Mar. 9, 1907, Ch. 215, Ind. General Acts 377, 378 (permitting states to surgically “prevent procreation of confirmed . . . idiots”). The 1907 Indiana sterilization law set the groundwork for the passage of future sterilization laws, with twelve states implementing similar laws by 1913. Cohen, *supra* note 54, at 5–6 (noting that these laws “called for sterilizing anyone with ‘defective’ traits, such as epilepsy, criminality, alcoholism, or ‘dependency’—another word for poverty”).

73. 274 U.S. 200 (1927).

74. Cohen, *supra* note 54, at 299.

75. See *Buck*, 274 U.S. at 205–08.

76. Id. at 205–06 (“[T]he 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 . . .”).

1907 and 1937, thirty-two states and Puerto Rico had forced-sterilization laws.⁷⁷

The effects of *Buck* endured long after states repealed sterilization laws.⁷⁸ State-sanctioned coercive sterilization programs targeted poor and low-income women of color in the United States well into the 1960s, 1970s, and 1980s.⁷⁹ Eugenics practices have continued into the twenty-first century with government-sanctioned sterilizations targeting disabled people, people of color, and other multiply marginalized populations.⁸⁰ The social constructs and narratives used in the eugenics era to control sexuality and reproduction remain central today. They contribute to the contemporary stigmatizing treatment of sexuality and reproduction in people with intellectual and developmental disabilities, which is reflected in law, policy, and sociocultural norms.⁸¹

B. *The Promise of Olmstead and Community Integration*

Historically, people labeled as “cognitively challenged” who “failed to be converted into workers” were discarded by society—“left to linger in their squalor or incarcerated into various asylums, workhouses, and jails.”⁸² Doctors and teachers who “told parents that institutions were the best place” for their child to “live, learn, and be safe” normalized the idea that

77. Lombardo, *Three Generations*, supra note 65, app. C at 293–94 (identifying thirty-two states that had sterilization laws in effect between 1907 and 1937 but excluding Puerto Rico, which “passed a [sterilization] law in 1937 and repealed it in 1960”).

78. *Id.* at 294.

79. See Melissa Murray, *Abortion, Sterilization, and the Universe of Reproductive Rights*, 63 *Wm. & Mary L. Rev.* 1599, 1618–21, 1627–32 (2022) (discussing how government-sanctioned coercive sterilization programs at both the state and federal level targeted poor and low-income women of color); see also Dorothy Roberts, *Fatal Invention: How Science, Politics, and Big Business Re-Crete Race in the Twenty-First Century* 48 (2011) (“During the eugenics era, a majority of those sterilized were white. But in the program’s final decade, the target shifted to poor black women.”).

80. See, e.g., *Oldaker v. Giles*, No. 7:20-cv-00224-WLS-MSH, 2024 WL 1241359, at *3 (M.D. Ga. Mar. 22, 2024) (recounting allegations that officials at a Georgia immigration detention center subjected detained immigrants to “medical and other abuse” such as “unnecessary gynecological procedures that were performed without their consent,” which “caused Plaintiffs significant pain and left some Plaintiffs infertile”); Erin McCormick, *Survivors of California’s Forced Sterilizations: ‘It’s Like My Life Wasn’t Worth Anything’*, *The Guardian* (July 19, 2021), <https://www.theguardian.com/us-news/2021/jul/19/california-forced-sterilization-prison-survivors-reparations> [<https://perma.cc/V8GL-RAWU>] (“[H]undreds of inmates had been sterilized in prisons without proper consent as late as 2010, even though the practice was by then illegal.”); Molly O’Toole, *19 Women Allege Medical Abuse in Georgia Immigration Detention*, *L.A. Times* (Oct. 22, 2020), <https://www.latimes.com/politics/story/2020-10-22/women-allege-medical-abuse-georgia-immigration-detention> (on file with the *Columbia Law Review*) (last updated Oct. 23, 2022) (covering the forced sterilization of nineteen women by one gynecologist in a south Georgia prison).

81. See, e.g., Powell, *Disability Reproductive Justice*, supra note 16, at 1859.

82. Laura I. Appleman, *Deviancy, Dependency, and Disability: The Forgotten History of Eugenics and Mass Incarceration*, 68 *Duke L.J.* 417, 426 (2018).

children with intellectual or developmental disabilities were unable to learn and thrive in society.⁸³ As a result, between 1947 and 1967, the number of people with intellectual disabilities residing in state-run institutions increased by sixty-five percent, from 116,828 to 193,188.⁸⁴

Most of the children who entered institutions at a young age never left.⁸⁵ The dehumanizing conditions of state-run institutions for people with intellectual and developmental disabilities mirrored society's view of this population as expendable, uneducable, and unworthy.⁸⁶ In 1972, Geraldo Rivera exposed the inhumane treatment of children with disabilities at Willowbrook, a New York State-run institution for children and adults with developmental disabilities.⁸⁷ Through a series of investigative reports that aired on national television, Rivera displayed the deplorable conditions of Willowbrook.⁸⁸ The reports forced the country to confront many of the horrors taking place in large, state-run institutions.

The overcrowded facility purported to care for its residents, but Rivera's footage showed vivid images of countless emaciated children left unattended and naked—or in soiled rags.⁸⁹ Rivera reported on physical and sexual abuse by staff that took place at the institution and broadcast the unsanitary conditions that caused the preventable spread of disease.⁹⁰ The exposé roiled the country, precipitating litigation to protect the health, safety, and civil rights of people with intellectual and developmental disabilities.⁹¹

83. See Sheryl A. Larson, John Butterworth, Jean Winsor, Shea Tanis, Amie Lulinski & Jerry Smith, Admin. for Cmty. Living, 30 Years of Community Living for Individuals With Intellectual and/or Developmental Disabilities (1987–2017), at 7 (2021), <https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/30%20Years%207-13-21.pdf> [<https://perma.cc/R3X9-7K46>].

84. Trent, *supra* note 53, at 240–41.

85. Larson et al., *supra* note 83, at 7.

86. See id.; see also Samuel R. Bagenstos, *The Disability Cliff*, *Democracy* (2015), <https://democracyjournal.org/magazine/35/editors-note-3/> [<https://perma.cc/NH9B-TLFW>] (noting that “schools often simply excluded children with developmental disabilities as uneducable”).

87. See *Willowbrook: The Last Great Disgrace* at 01:46 (Sproutflix 2010) [hereinafter *Geraldo Rivera's 1972 Exposé*] (reporting on poor conditions at Willowbrook).

88. Disability Justice, *The Closing of Willowbrook*, <https://disabilityjustice.org/the-closing-of-willowbrook/> [<https://perma.cc/4CJC-L5VK>] (last visited July 29, 2024).

89. See *Geraldo Rivera's 1972 Exposé*, *supra* note 87, at 01:58.

90. See id. at 2:47–3:20 (reporting that “one hundred percent of patients contract hepatitis within six months of being in the institution”).

91. See *N.Y. State Ass'n for Retarded Child., Inc., v. Rockefeller*, 357 F. Supp. 752, 768–70 (E.D.N.Y. 1973) (granting partial relief to plaintiffs in a class action lawsuit that challenged the conditions at Willowbrook); Disability Justice, *supra* note 88 (“Following the Rivera exposé, parents of Willowbrook residents filed a class action suit in U.S. District Court for the Eastern District of New York on March 17, 1972.”). The litigation resulted in an extensive, multiyear consent decree that required “defendant[s] to improve conditions and treatment for [intellectually disabled] persons at Willowbrook State School, as well as deinstitutionalizing residents and placing them in community homes.” Lloyd C. Anderson,

Additional court challenges in the 1970s;⁹² the creation of the Medicaid Home- and Community-Based Services (HCBS) Waiver program in 1981, which provided states with matching federal funding to administer services, care, and treatment to disabled people outside of institutions;⁹³ and the passage of the ADA in 1990 foreshadowed the impending change in the role of institutions.⁹⁴ Law and policy priorities began shifting focus away from institutional placement and toward community living for people with intellectual and developmental disabilities.⁹⁵

The 1999 Supreme Court case *Olmstead v. L.C. ex rel. Zimring*⁹⁶ 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.⁹⁷ *Olmstead* involved two women, Lois

Implementation of Consent Decrees in Structural Reform Litigation, 1986 U. Ill. L. Rev. 725, 743 n.57.

92. See, e.g., *Welsch v. Likins*, 373 F. Supp. 487, 502–03 (D. Minn. 1974) (recognizing a constitutional right to adequate care and treatment for people with intellectual or developmental disabilities who are involuntarily committed); *Wyatt v. Stickney*, 344 F. Supp. 373, 376 (M.D. Ala. 1972) (finding that a consent decree to improve conditions at an Alabama mental hospital established “constitutional minimums” and establishing a standing human rights committee to oversee compliance), *aff’d in part, rev’d in part sub nom. Wyatt v. Aderholt*, 503 F.2d 1305 (5th Cir. 1974). The court in *Welsch* further found that “[e]xcessive use of tranquilizing medication as a means of controlling behavior,” the practice of “secluding residents in barren ‘isolation’ rooms” without supervision or monitoring, and the use of “physical restraints” may violate a disabled person’s Eighth Amendment right against cruel and unusual punishment. *Welsch*, 373 F. Supp. at 503. It also determined that the state has a responsibility to make a good faith effort to place involuntarily committed persons in “settings that will be suitable and appropriate to their mental and physical conditions while least restrictive of their liberties.” *Id.* at 502; see also Karen M. Tani, *The Pennhurst Doctrines and the Lost Disability History of the “New Federalism”*, 110 Calif. L. Rev. 1157, 1159 (2022) (providing the history of the *Halderman v. Pennhurst State School and Hospital* litigation, which was a class action lawsuit that challenged the “neglect and brutality” that residents with intellectual and developmental disabilities experienced at this state-run institution).

93. See Carol Beatty, Comment, *Implementing Olmstead by Outlawing Waiting Lists*, 49 Tulsa L. Rev. 713, 726–31 (2014) (discussing the 1981 implementation and impact of the HCBS Waiver program on deinstitutionalization for people with intellectual and developmental disabilities).

94. See Larson et al., *supra* note 83, at 10.

95. See, e.g., *id.* at 7–12 (providing an overview of the legal and policy advancements that support the community integration of people with intellectual and developmental disabilities).

96. 527 U.S. 581 (1999).

97. See Beatty, *supra* note 93, at 732–33 (describing *Olmstead* as a “groundbreaking case” that “necessitated massive changes to state and federal government entities”). The deinstitutionalization movement that centered on using *Olmstead* to move people with intellectual and developmental disabilities out of institutions is often contrasted with the failed policies around the deinstitutionalization of people with psychiatric disabilities. For a more complete discussion on the successes and failures of the deinstitutionalization movement for people with psychiatric disabilities, see Rachel E. Barkow, *Promise or Peril?*

Curtis and Elaine Wilson, who were each dually diagnosed with a psychiatric disability and an intellectual disability.⁹⁸ Each was voluntarily admitted into a state hospital for mental health treatment.⁹⁹ After receiving treatment at the hospital, Curtis and Wilson each wished to leave the hospital and receive treatment in the community.¹⁰⁰ The hospital denied their requests, maintaining that they must remain confined in the hospital to receive mental health treatment.¹⁰¹

The Court held that the “unjustified isolation” of people with disabilities qualified as disability-based discrimination under Title II of the ADA.¹⁰² *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.¹⁰³ 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.¹⁰⁴ The implementing regulations under Title II of the ADA, commonly referred to as the *Olmstead* integration mandate, provide that a “public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”¹⁰⁵ The community placement must be deemed appropriate by a state’s

The Political Path of Prison Abolition in America, 58 Wake Forest L. Rev. 245, 306–18 (2023) (noting that while the deinstitutionalization movement was “especially effective in reducing the institutionalized population of those with intellectual and developmental disabilities,” many community mental health centers never got built, “and the ones that were created largely provided services . . . to people who had never been institutionalized”); cf. Liat Ben-Moshe, Why Prisons Are Not “The New Asylums”, 19 Punishment & Soc’y 272, 275–78 (2017) (critically examining claims that the deinstitutionalization of people with psychiatric disabilities led to “incarceration via homelessness,” pointing to the central role that neoliberal policies played in expanding the prison system, and deprioritizing access to affordable and accessible housing).

98. *Olmstead*, 527 U.S. at 593; see also Celebrating 25 Years of the *Olmstead* Decision, The Arc (June 20, 2024), <https://thearc.org/blog/celebrating-25-years-of-the-olmstead-decision/> [https://perma.cc/4JYW-H8YT].

99. *Olmstead*, 527 U.S. at 593.

100. See Celebrating 25 Years of the *Olmstead* Decision, *supra* note 98 (“Lois and Elaine were forced into the state’s mental health hospitals many times, despite wanting to remain at home with the help of community-based services.”).

101. See *Olmstead*, 527 U.S. at 594 (“[Curtis] alleged that the State’s failure to place her in a community-based program, once her treating professionals determined that such placement was appropriate, violated, *inter alia*, Title II of the ADA. . . . [Wilson] intervened in the action, stating an identical claim.”).

102. *Id.* at 597.

103. Stephanie Woodward, Guest Blog Post: The ADA Is Not Enough, Disability Visibility Project (July 26, 2024), <https://disabilityvisibilityproject.com/2014/07/26/guest-blog-post-the-ada-is-not-enough-by-stephanie-woodward/> [https://perma.cc/7UM5-YFJJ].

104. *Olmstead*, 527 U.S. at 592 (quoting 28 C.F.R. §§ 35.130(b)(7), 35.130(d) (1998)).

105. 28 C.F.R. § 35.130(d) (2024). Under Title II of the ADA, a public entity includes “any State or local government” and “any department, agency . . . or other instrumentality of a State or States or local government.” 42 U.S.C. § 12131(1) (2018).

“treatment professionals.”¹⁰⁶ And the person must also agree to the placement.¹⁰⁷

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.¹⁰⁸ 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.¹⁰⁹ 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 beneficiaries and, thereby, avoid institutionalization.”¹¹⁰ 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.”¹¹¹

Today, intellectual and developmental disability is no longer defined as a static condition.¹¹² The “changes in medical practice, psychology, and a burgeoning legal framework of civil rights”¹¹³ support the notion that

106. *Olmstead*, 527 U.S. at 587.

107. *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] service, program, or activity.” *Id.* at 597 (internal quotation marks omitted) (quoting 28 C.F.R. § 35.130(b)(7)(i) (1998)).

108. See Carli Friedman, Medicaid Home- and Community-Based Services Waivers for People With Intellectual and Developmental Disabilities, 61 *Intell. & Developmental Disabilities* 269, 269 (2023) [hereinafter Friedman, Medicaid Home- and Community-Based Services Waivers] (“[O]ver 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.” (citations omitted)); see also Jessica Schubel, Ctr. on Budget & Pol’y Priorities, Medicaid Is Key to Implementing *Olmstead*’s Community Integration Requirements for People With Disabilities (June 22, 2018), <https://www.cbpp.org/blog/medicaid-is-key-to-implementing-olmsteads-community-integration-requirements-for-people-with> [<https://perma.cc/F8G6-2D57>] (noting a shift in Medicaid’s spending away from institutional services and toward HCBS).

109. See Friedman, Medicaid Home- and Community-Based Services Waivers, *supra* note 108, at 269.

110. Ctrs. for Medicare & Medicaid Servs., Application for a § 1915(c) Home and Community-Based Waiver: Instructions, Technical Guide and Review Criteria 1 (2019), https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf [<https://perma.cc/4U9W-95GR>] [hereinafter CMS HCBS Instructions].

111. Friedman, Sexual Health and Parenting Supports, *supra* note 31, at 258.

112. See Karen Andreasian, Natalie Chin, Kristin Booth Glen, Beth Haroules, Katherine I. Hermann, Maria Kuns, Aditi Shah & Naomi Weinstein, Mental Health. *Comm. & Disability L. Comm. of the N.Y.C. Bar Ass’n*, Revisiting S.C.P.A 17-A: Guardianship for People With Intellectual and Developmental Disabilities, 18 *CUNY L. Rev.* 287, 294 (2015).

113. Kristin Booth Glen, Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond, 44 *Colum. Hum. Rts. L. Rev.* 93, 98 (2012).

persons with intellectual and developmental disabilities can thrive in the community with individually tailored supports and services.¹¹⁴

The most recent data reveal the impact of *Olmstead*. Approximately 930,356 people with intellectual and developmental disabilities receive supports and services in the community, compared to 22,869 in 1987—a nearly 4,000% increase.¹¹⁵ Between 1999 and 2019, the number of people with intellectual and developmental disabilities who lived in a residential setting of sixteen or more residents declined by 59% while the number of persons living in community settings with six or fewer people increased by 95%.¹¹⁶ 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 fuller lives with supports. With funding totaling \$45.1 billion in 2019,¹¹⁷ the HCBS waiver program is the “largest funding stream”¹¹⁸ and the primary means for people with intellectual and developmental disabilities—who are also among the nation’s poorest residents¹¹⁹—to secure services and supports in the community.

The extensive services provided under the HCBS Medicaid waiver signify the modern application of the *Olmstead* integration mandate, reflecting the lived experiences of people with intellectual and

114. See, e.g., Dilip R. Patel, Maria Demma Cabral, Arlene Ho & Joav Merrick, A Clinical Primer on Intellectual Disability, 9 *Translational Pediatrics* (Supplemental Issue) S23, S27–28 (2020) (explaining that different levels of support are needed to empower different individuals with intellectual disabilities); Life in the Community Summary, The Arc, <https://thearc.org/position-statements/life-community-summary/> [<https://perma.cc/9RYY-5QTE>] (last visited July 28, 2024) (“People with intellectual and/or developmental disabilities need varying degrees of support to reach personal goals and establish a sense of satisfaction with their lives.” (footnote omitted)).

115. Growth in the Number of HCBS Waiver Recipients, Residential Info. Sys. Project, <https://publications.ici.umn.edu/risp/infographics/how-did-the-number-of-hcbs-waiver-recipients-change-between-1987-and-2018> [<https://perma.cc/4HTT-77ZU>] (last visited July 28, 2024).

116. 20-Year Change in Residence Size, Residential Info. Sys. Project, <https://publications.ici.umn.edu/risp/infographics/how-have-residence-sizes-changed-in-the-last-20-years> [<https://perma.cc/S9Q9-ZHM6>] (last visited August 19, 2024).

117. Medicaid HCBS Spending in FY 2019, Residential Info. Sys. Project, <https://publications.ici.umn.edu/risp/infographics/medicaid-waiver-recipients-and-expenditures> [<https://perma.cc/4HTT-77ZU>] (last visited July 28, 2024).

118. Friedman, Medicaid Home- and Community-Based Services Waivers, *supra* note 108, at 269. 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 (2018). For a more detailed discussion about the HCBS waiver program, see CMS HCBS Instructions, *supra* note 110, at 1 (“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 . . .”).

119. See Goodman et al., *supra* note 27, at 19–20.

developmental disabilities.¹²⁰ As this group gains greater access to supports in the community, however, laws and policies remain barriers to exercising choices around intimacy, marriage, and family. These structural barriers result in a forced relinquishment of these choices.

C. *Modern Laws that Affect the Structural Desexualization of Disability*

Despite advancements in disability rights, desexualization is a collateral consequence of moving people with intellectual and developmental disabilities from institutionalized settings into the community. The sexual and reproductive control of disabled people is justified through laws and policies that effectively limit and create often-insurmountable barriers to exercising choices around issues of love, sex, family, and intimacy.

Under state guardianship laws, a third person may restrict a disabled person's right to marry, engage in intimate relationships, and make reproductive choices.¹²¹ Today, thirty-one states and Washington, D.C., maintain laws that allow for the involuntary sterilization of people under guardianship.¹²² Some states allow for the involuntary sterilization of disabled children.¹²³

These guardianship and sterilization laws are not dormant. In a recent case heard by the Court of Appeals of Michigan, *Morgan ex rel. Ray v. Shah*, a parent sued a doctor for medical malpractice after the doctor performed a vasectomy on her son, Jason, who has Down syndrome.¹²⁴ Jason was in his twenties at the time of the surgery.¹²⁵ The doctor stated that he

120. The diversity and extent of the community-based services offered through the HCBS Waivers reflect that people with intellectual and developmental disabilities are integrating in the community and accessing services that allow them to thrive and live more independently. The community-based services offered through the waivers can include the following: "community transition supports; day habilitation; . . . family training and counseling[;] . . . financial support services; health and professional services [such as] crisis, dental, clinical, and therapeutic services[;] . . . recreation and leisure; . . . 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." Friedman, *Medicaid Home- and Community-Based Services Waivers*, supra note 108, at 274. 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." Day Services: A Variety of Day Services, N.Y. State Off. for People With Developmental Disabilities, <https://opwdd.ny.gov/types-services/day-services> [<https://perma.cc/N3HZ-WTP7>] (last visited July 29, 2024). Waiver services are intended to support the "development of skills and appropriate behavior, greater independence, community inclusion, relationship building, self-advocacy and informed choice." *Id.*

121. See *infra* section III.A (discussing the role of the guardianship system in the structural desexualization of disability).

122. Nat'l Women's L. Ctr., supra note 28, at 15.

123. *Id.* at 34–35.

124. No. 341846, 2019 WL 575371, at *1–2 (Mich. Ct. App. Feb. 12, 2019) (per curiam).

125. *Id.*

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.”¹²⁶ The father did not inform the mother of this decision.¹²⁷ The father later stated that he forced his son to be sterilized because “he wanted no more abominations in this world.”¹²⁸

Other laws specific to disabled people contain additional barriers to parenting,¹²⁹ marriage, and maintaining intimate relationships. Thirty-three states and Washington, D.C., maintain laws that include intellectual and developmental disability as grounds to terminate parental rights.¹³⁰ The removal rates of parents with an intellectual disability by the family regulation system¹³¹ range from forty to eighty percent.¹³² Further,

126. *Id.* at *2.

127. *Id.* at *1 (“James did not inform Jason’s mother, plaintiff Janell Ray, of his intent to have Jason sterilized.”).

128. *Id.* at *2 (internal quotation marks omitted) (quoting Jason’s father). Throughout the court’s decision, Jason’s perspective is absent, effectively silencing his experience. See *id.* at *1–10.

129. 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., Gill, *supra* note 30, at 111, 125–44 (“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.”); Powell, Disability Reproductive Justice, *supra* note 16, at 1872 (noting that disabled people “are rarely seen as sexual beings or as potential parents” (internal quotation marks omitted) (quoting Michelle Jarman, Disability Rights Through Reproductive Justice, in *The Routledge Handbook of Disability and Sexuality* 132, 138 (Russell Shutterworth & Linda R. Mona eds., 2020))).

130. Nat’l Rsch. Ctr. for Parents With Disabilities, Map of State Termination of Parental Rights Laws that Include Parental Disability (Oct. 1, 2022), <https://heller.brandeis.edu/parents-with-disabilities/map-tpr/index.html> [<https://perma.cc/N4CX-8VGW>].

131. The term “family regulation system” was initially coined by Emma Ruth in her Oberlin College Honors Thesis and later adopted by many legal advocates and academics. Emma Peyton Williams, Thesis, *Dreaming of Abolitionist Futures, Reconceptualizing Child Welfare: Keeping Kids Safe in the Age of Abolition* 4–5 (2020), <https://digitalcommons.oberlin.edu/cgi/viewcontent.cgi?article=1711&context=honors> (on file with the *Columbia Law Review*); see also Emma Ruth, Opinion, ‘Family Regulation,’ Not ‘Child Welfare’: Abolition Starts With Changing Our Language, *The Imprint* (July 28, 2020), <https://imprintnews.org/opinion/family-regulation-not-child-welfare-abolition-starts-changing-language/45586> [<https://perma.cc/697E-PBCZ>]. Some advocate for changing the terms “child welfare system” or “child protection system” to “family regulation system.” See Ruth, *supra*; see also Dorothy Roberts, Abolishing Policing Also Means Abolishing Family Regulation, *The Imprint* (June 16, 2020), <https://imprintnews.org/child-welfare-2/abolishing-policing-also-means-abolishing-family-regulation/44480> [<https://perma.cc/X7AV-VHQ9>].

132. Nat’l Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents With Intellectual Disabilities and Their Children* 16 (Sept. 27, 2012), <https://www.ncd.gov/assets/uploads/reports/2012/ncd-rocking-the-cradle.pdf> [<https://perma.cc/6R2P-C7KV>]; see also Robyn M. Powell, Achieving Justice for Disabled Parents and Their Children: An Abolitionist Approach, 33 *Yale J.L. & Feminism* 37, 43

disabled people are “effectively barred from marrying or cohabiting with the partners that they love” due to the financial penalties imposed by federal need-based programs on which millions of disabled people rely.¹³³

Medicaid and Supplemental Security Income (SSI) are programs administered by the state through federal funding. They provide healthcare and financial support, respectively, to targeted populations who are living at or below the poverty level.¹³⁴ Because people with intellectual and developmental disabilities are disproportionately under- or unemployed,¹³⁵ SSI often “provides the income that allows them to secure housing in the community and live independently.”¹³⁶

Federal needs-based programs are often a lifeline to maintain the health and well-being of people with intellectual and developmental disabilities.¹³⁷ If two disabled people marry or cohabit, however, they risk a reduction or loss of their SSI and Medicaid benefits due to the pooling of their combined assets and resources.¹³⁸ The threatened loss of these financial benefits can preclude disabled people from entering romantic cohabitation or marriage. In doing so, these financial barriers effectively foreclose the additional legal benefits that would flow from marriage. Describing this predicament, 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 long term care system.”¹³⁹

(2022) (“[D]espite 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.”).

133. Rabia Belt, *Disability: The Last Marriage Equality Frontier 1* (Stanford Pub. L., Working Paper No. 2653117, 2015), <https://ssrn.com/abstract=2653117> [<https://perma.cc/4PJY-NCER>].

134. The Arc, *Social Security and SSI for People with I/DD and Their Families 4–10*, https://thearc.org/wp-content/uploads/forchapters/NPM-SocialSecurity_SSI_4.pdf [<https://perma.cc/SR2U-7BKA>] [hereinafter *The Arc, Social Security and SSI for People with I/DD and Their Families*] (last visited July 28, 2024).

135. See, e.g., Erik Carter, Emily Lanchak, Laura Berry, Elise McMillan, Julie Lounds Taylor & Laurie Fleming, *Vanderbilt Univ. & Va. Commonwealth Univ., Barriers to Employment for Individuals With IDD: Insights From Families 2* (2020), <https://worksupport.com/documents/RRTC%20Employment%20%2D%20Families%20on%20Barriers%2Epdf> [<https://perma.cc/99QF-YY75>] (“Unfortunately, the majority of individuals with [intellectual and development disabilities] remain unemployed or underemployed.”).

136. *The Arc, Social Security and SSI for People with I/DD and Their Families*, supra note 134, at 9.

137. See *id.* at 3.

138. Andrew Pulrang, *What’s Next in ‘Marriage Equality’ for People With Disabilities?*, *Forbes* (Mar. 31, 2022), <https://www.forbes.com/sites/andrewpulrang/2022/03/31/whats-next-in-marriage-equality-for-people-with-disabilities/?sh=1670cace6eb7> (on file with the *Columbia Law Review*) (“[G]etting married can result in one or a combination of: reduced monthly benefits, loss of eligibility for benefits, and loss of Medicaid, Medicare, or both.”).

139. Kathleen Downes, *Project Shine Narrative Collection*, at 00:37:31–00:37:47 (2022) (unpublished video narrative transcript) (on file with the *Columbia Law Review*); see also

D. *Sexuality and the Unmet Promise of Olmstead*

The shift from institutionalization to community integration following *Olmstead* did not address negative attitudes and punitive treatment toward expressions of sexuality. It also failed to consider what services states could provide to support the sexual lives of this newly integrated community. Views that relied on “contradictory stereotypes” of disability and sexuality reinforced harmful sexual policies within institutional settings.¹⁴⁰ As discussed by Professor Michael L. Perlin and disability rights lawyer Alison J. Lynch, these “contradictory stereotypes” included “infantilization” and “demonization.”¹⁴¹

Institutionalized settings “den[ied] the reality that institutionalized persons with disabilities may retain the same sort of sexual urges, desires, and needs the rest of us have and generally upon which the rest of us act.”¹⁴² At the same time, disabled persons were viewed as hypersexual, requiring “correlative . . . protections and limitations to best stop them from acting on these primitive urges.”¹⁴³

Bernard Carabello, a survivor of the Willowbrook State School,¹⁴⁴ expressed, “When 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].”¹⁴⁵ The inhumane treatment of Carabello reflects the punitive view toward acts of sexuality that pervaded the period prior to *Olmstead*.

Today, the repression of sexuality has moved away from this overt, brutal conduct. The punitive view toward expressions of sexuality, however, remains common even as community integration continues as a central

Dominick Evans, Marriage Equality, Ctr. for Disability Rts., <https://cdrnys.org/blog/disability-dialogue/the-disability-dialogue-marriage-equality/> [https://perma.cc/3R4L-89PZ] (last visited July 28, 2024) (discussing the financial penalties imposed by the federal government that disabled people may be subject to if they choose to marry).

140. Michael L. Perlin & Alison J. Lynch, *Sexuality, Disability, and the Law: Beyond the Last Frontier?* 37 (2016).

141. *Id.*

142. *Id.*

143. *Id.*

144. For more discussion of Willowbrook, see *supra* notes 87–91 and accompanying text; see also Raga Justin, *Former Residents of Willowbrook Recall Its Horrors as Fight for Disability Rights Continues*, *Times Union* (Mar. 27, 2023), <https://www.timesunion.com/state/article/a-disgrace-former-willowbrook-residents-17860905.php> (on file with the *Columbia Law Review*).

145. Jennifer Smith, *Inside the Fight for Developmentally Disabled People’s Right to Sex*, *Vice* (Mar. 19, 2019), <https://www.vice.com/en/article/7xnad9/developmental-intellectual-disability-sex-education-consent> (on file with the *Columbia Law Review*) (internal quotation marks omitted) (quoting Bernard Carabello).

focus of disability advocacy.¹⁴⁶ The prevailing contradictory stereotypes that embedded institutional policies around sexuality endure. They are baked into the laws, policies, and societal norms that disabled people routinely navigate.

1. *The Economic Gatekeeping of Sexuality Supports and Services.* — Despite the strides made after *Olmstead* in securing services in the community for people with intellectual and developmental disabilities, there remain 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 remains 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 the control over “what benefits” the waiver will cover and “the ways those benefits are provided.”¹⁴⁷ As a result, states hold the strings that orchestrate what community-based services are prioritized for waiver funding.

A recent study reflects the inattention of states in providing community-based supports and services focused on issues of sexuality. The study examined 107 HCBS waivers from forty-four states and the District of Columbia and found that only ten percent of those waivers provided sexual health services.¹⁴⁸ The states that did provide sexual health services predominantly focused on reactive services.¹⁴⁹ Reactive services are generally “provided in the form of behavior support for sexually inappropriate behavior.”¹⁵⁰ This “reactive model” for providing sexuality

146. See Perlin & Lynch, *supra* note 140, at 56 (concluding a comparative analysis by observing that “the stagnant, repressive attitudes toward sexuality and sexual expression continue to undermine any great shifts in policy” regarding individuals with disabilities).

147. Friedman, *Medicaid Home- and Community-Based Services Waivers*, *supra* note 108, at 269 (citing Victoria Wachino, Andy Schneider & David Rousseau, Henry J. Kaiser Fam. Found., *Financing the Medicaid Program: The Many Roles of Federal and State Matching Funds* (2004)). The HCBS waiver program is carried out through a complex scheme of federal statutory and regulatory guidelines. See, e.g., 42 U.S.C. § 1396 (2018); see also CMS HCBS Instructions, *supra* note 110, at 1 (describing the range of flexibility that states have in designing Medicaid waivers).

148. Friedman, *Sexual Health and Parenting Supports*, *supra* note 31, at 259. This study describes sexual health services as either “proactive,” which “see people with [intellectual and developmental disabilities] as sexual beings, promote sexual expression and opportunities, [and] emphasi[ze] rights and education,” or “reactive,” which “focus on avoidance, danger, victimization, deviance, control.” *Id.*

149. *Id.* (finding that 87.5% of sexual health services were “reactive services, viewing sexual health negatively”).

150. *Id.* “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*

services “often begins when sexual violence victimization comes to light.”¹⁵¹ This incident-driven response predominates the understanding and acknowledgment of sexuality within disability systems.¹⁵² The study found that states apportioned only \$282,492 of HCBS waiver spending to exclusively provide sexual health services.¹⁵³ The study projected that this allocation only served 0.04% of people with intellectual and developmental disabilities who received services from the HCBS waiver program.¹⁵⁴

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.¹⁵⁵ Some family members may feel that providing sexuality education to their intellectually or developmentally disabled child will “encourage sexual behavior.”¹⁵⁶ Families sometimes restrict or avoid the topic of sexuality out of concern about sexual abuse, pregnancy, and sexually transmitted infections.¹⁵⁷

These views around sexuality conflict with the documented benefits of providing sexuality education and supports. Studies reflect that access to sexuality supports while living in the community “increased sexual

Developmental Disabilities, 10 *Disability & Health J.* 387, 389 (2017). Reactive services engage “exclusively” with “sexually inappropriate behaviors.” *Id.*

151. Nechama F. Sammet Moring, *Rebel Girl Rsch. Commc’ns, State of Affairs in Sex Education for People With Intellectual and Developmental Disabilities (IDD) 5* (2019) (unpublished report), 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 (on file with the *Columbia Law Review*).

152. See, e.g., Lisa Colarossi, Kate L. Collier, Randa Dean, Siana Pérez & Marlene O. Riquelme, *Sexual and Reproductive Health Education for Youth With Intellectual Disabilities: A Mixed Methods Study of Professionals’ Practices and Needs*, 24 *Prevention Sci. (Supplemental Issue)* S150, S159 (2023) (“[I]ncident-driven conversations about sexuality (particularly issues of sexual boundaries, consent, and sexual harassment) are the norm.”).

153. See Friedman, *Sexual Health and Parenting Supports*, *supra* note 31, at 268.

154. See *id.*

155. See, e.g., *id.* at 270 (“[M]any family members do not discuss sex with their children with [intellectual and developmental disabilities], even as adults, and may even serve as gatekeepers to sexual education, sexuality, and intimate relationships.” (citations omitted)).

156. *Id.*

157. See Rhonda S. Black & Rebecca R. Kammes, *Restrictions, Power, Companionship, and Intimacy: A Metasynthesis of People With Intellectual Disability Speaking About Sex and Relationships*, 57 *Intell. & Developmental Disabilities* 212, 213 (2019) (“[R]estrictions and avoidance of the topic of sexuality are often done due to caregiver concern surrounding the high rates of abuse and exploitation this population experiences.” (citations omitted)); see also Michel Desjardins, *The Sexualized Body of the Child: Parents and the Politics of “Voluntary” Sterilization of People Labeled Intellectually Disabled*, in *Sex and Disability* 69, 70–71 (Robert McRuer & Anna Mollow eds., 2012) (“[S]ome . . . 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).”).

knowledge and skills in recognizing abuse, building relationships, maintaining boundaries, and decision-making [which] can help protect against sexual victimization.”¹⁵⁸ Sexuality education and supports increase empowerment in making informed choices that protect a person’s health and safety.¹⁵⁹ Sexual education also “empowers individuals with [intellectual and developmental disabilities] to enjoy personal sexual fulfillment” and can “promote an individual’s self-determination and self-advocacy skills,” which “are indicators of overall quality of life.”¹⁶⁰

Despite these positive findings, states are not offering sexuality education as a standard HCBS waiver service, alongside, for example, education, social development, and employment supports.¹⁶¹ States could provide “[c]omprehensive and culturally competent sex ed” through the HCBS waiver program, which could include training and supports about how to engage in safe sexual practices, develop healthy emotional and intimate relationships, ask for and give consent, and identify and protect oneself from sexual abuse.¹⁶² Sexuality education and programming could further encompass sexual self-awareness, communication and understanding of social cues, bodily autonomy, sexual self-expression, sexual orientation, gender identity, reproduction, and family planning.¹⁶³

158. See Rosemary B. Hughes, Susan Robinson-Whelen, Rebecca Goe, Michelle Schwartz, Lisa Cesal, Kimberly B. Garner, Katie Arnold, Tina Hunt & Katherine E. McDonald, “I Really Want People to Use Our Work to Be Safe” . . . Using Participatory Research to Develop a Safety Intervention for Adults With Intellectual Disability, 24 *J. Intell. Disabilities* 309, 310 (2020) (citations omitted).

159. See Nikita Mhatre, *Nat’l P’ship for Women & Fams., Access, Autonomy, and Dignity: Comprehensive Sexuality Education for People With Disabilities* 6–7 (2021), <https://nationalpartnership.org/wp-content/uploads/2023/02/repro-disability-sexed.pdf> [<https://perma.cc/V7HG-GR7Y>] (explaining how sex education can reduce rates of intimate partner violence and sexually transmitted illnesses); E. Dukes & B.E. McGuire, *Enhancing Capacity to Make Sexuality-Related Decisions in People With an Intellectual Disability*, 53 *J. Intell. Disability Rsch.* 727, 732 (2009) (“[I]mprovements in knowledge [about sexuality] resulted in improved decision-making ability.”); 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-with-developmental-disabilities-form-healthy-relationships/> [<https://perma.cc/NL4V-F3AP>] (discussing a sex education curriculum tailored to the needs of those with intellectual and developmental disabilities); Sammet Moring, *supra* note 151, at 9–11 (discussing how comprehensive sexuality education influences healthy sexual behaviors).

160. James Sinclair, Deanne Unruh, Lauren Lindstrom & David Scanlon, *Barriers to Sexuality for Individuals With Intellectual and Developmental Disabilities: A Literature Review*, 50 *Educ. & Training Autism & Developmental Disabilities* 3, 3, 14 (2015).

161. Friedman, *Sexual Health and Parenting Supports*, *supra* note 31, at 259.

162. See Mhatre, *supra* note 159, at 5, 16 (providing a definition and description of comprehensive sexuality education).

162. *Id.* at 16–18.

163. See, e.g., *Sexuality: Joint Position Statement of AAIDD and the Arc, Am. Ass’n on Intell. & Developmental Disabilities* (2013), <https://aaid.org/news-policy/policy/position-statements/sexuality> [<https://perma.cc/3KLT-GMA8>] (stating that people

2. *Fostering a Culture of Desexualization.* — Minimizing the importance of sexuality supports and services paradoxically fosters community-based environments that place intellectually and developmentally disabled people at a greater risk of 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 people with intellectual and developmental disabilities.¹⁶⁴ Barriers to accessing sexuality education and supports create a greater risk for developing maladaptive sexual behaviors, which may lead to an individual harming others.¹⁶⁵ Further, the lack of recognition of sexuality for intellectually and developmentally disabled people creates barriers to accessing sexual and reproductive healthcare needs, such as Pap smears and cervical cancer screenings, resulting in poorer health outcomes.¹⁶⁶

As reflected in the law,¹⁶⁷ the actions of group homes,¹⁶⁸ and the response of support staff,¹⁶⁹ the erasure of sexuality as a part of community integration creates a culture in which intellectually and developmentally disabled people 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.¹⁷⁰ Paul Forziano and Hava

with intellectual disabilities and developmental disabilities have the right to “[i]ndividualized education and information to encourage informed decision-making, including education about such issues as reproduction, marriage and family life, abstinence, safe sexual practices, sexual orientation, sexual abuse, and sexually transmitted diseases”).

164. See Kathryn Pedgrift & Nicole Sparapani, *The Development of a Social-Sexuality Education Program for Adults With Neurodevelopmental Disabilities: Starting the Discussion*, 40 *Sexuality & Disability* 503, 504 (2022) (“The literature suggests that people with neurodevelopmental disabilities are more likely to experience sexual assault due, in part, to limited access to effective interventions . . .”); see also *infra* sections III.A–B.

165. See *infra* section III.B.

166. Julie S. Armin, Heather J. Williamson, Janet Rothers, Michele S. Lee & Julie A. Baldwin, *An Adapted Cancer Screening Education Program for Native American Women With Intellectual and Developmental Disabilities and Their Caregivers: Protocol for Feasibility and Acceptability Testing*, *J. Med. Internet Rsch. Protocols*, e37801, Feb. 13, 2023, at 2 (“One reason that individuals with [intellectual and developmental disabilities] do not receive cervical cancer screening may be that they have been perceived as asexual . . .”).

167. See *Vaughn v. Ruoff*, 253 F.3d 1124, 1129 (8th Cir. 2001) (noting that “involuntary sterilization is not always unconstitutional” and that people with intellectual disabilities “may be subjected to various degrees of government intrusion that would be unjustified if directed at other segments of society”).

168. See, e.g., Chin, *Group Homes as Sex Police*, *supra* note 50, at 385 (recounting a group home placing indefinite restrictions on its resident’s right to engage in sexual activity after she expressed 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. See *id.* at 381 n.3.

169. See, e.g., Gill, *supra* note 30, at 61 (“[W]hen 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 [them] with knowledge that facilitates and informs [their] sexual choices.”).

170. No. CV 13-0370, 2014 WL 1277912, at *1 (E.D.N.Y. Mar. 6, 2014), *aff’d*, 613 F. App’x 15 (2d Cir. 2015).

Samuels, both of whom have an intellectual disability, fell in love and wanted to live together and get married.¹⁷¹ Paul and Hava lived in separate group homes within the community.¹⁷² 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.¹⁷³

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.¹⁷⁴ The group homes opposed this request, stating that living together in a group home was “unprecedented,’ ‘impossible,’ and ‘fraught with difficulties.’”¹⁷⁵ The representative of the state agency recommended that both Paul and Hava undergo a sexual consent assessment¹⁷⁶ and receive sex education.¹⁷⁷ Neither Paul’s nor Hava’s group home, however, “included sex education”

171. *Id.*

172. Brief for Plaintiffs-Appellants at 3, *Forziano*, 613 F. App’x 15 (No. 14-1147), 2014 WL 4477091.

173. See *id.* (“Paul and Hava met and became friends through Defendant Maryhaven Center for Hope’s . . . Day Habilitation Program in 2004.”).

174. *Forziano*, 2014 WL 1277912, at *1.

175. *Id.* (quoting Amended Complaint ¶¶ 96–97, *Forziano*, 2014 WL 1277912 (No. 13 Civ-0370), 2013 WL 9680392).

176. *Id.* Assessments to determine whether a person with an intellectual or developmental disability 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, 37 *Sexuality & Disability* 633, 635 (2019). But “[t]here is no clear definition, criteria, or standard for determining a person’s sexual consent capacity.” Shaniff Esmail & Brendan Concannon, Approaches to Determine and Manage Sexual Consent Abilities for People With Cognitive Disabilities: Systematic Review, *Interactive J. Med. Rsch.*, Jan.–June 2022, e28137, at 1, 3. Sexual consent “[c]apacity assessments are sometimes weaponized to restrict persons with intellectual disabilities’ right to sexual expression.” Matthew S. Smith & Michael Ashley Stein, Legal Capacity and Persons With Disabilities’ Struggle to Reclaim Control Over Their Lives, *Harv. L. Sch. Petrie-Flom Ctr.: Bill Health* (Sept. 29, 2021), <https://blog.petrieflom.law.harvard.edu/2021/09/29/legal-capacity-disabilities/> [<https://perma.cc/KBQ2-3PSG>]. Assessments are also susceptible to “cultural bias of their administrators when they make sexual capacity determinations.” Onstot, *supra*, at 635; see also Roy G. Spece, Jr., John K. Hilton & Jeffrey N. Younggren, (Implicit) Consent to Intimacy, 50 *Ind. L. Rev.* 907, 910 (2017) (“If incorrectly employed or relied upon as panaceas, . . . [sexual consent assessments] 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 according to an “individualized, fact-specific inquiry based on circumstances of the desired sexuality choice[s] of the individual.” See Chin, *Group Homes as Sex Police*, *supra* note 50, at 405 (footnote omitted).

177. *Forziano*, 2014 WL 1277912, at *1.

or “relationship counseling” as a “goal, service or treatment” in the supports provided to its residents.¹⁷⁸

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.”¹⁷⁹ The group home relied on two outdated sexual consent assessments of Hava to assert her sexual consent incapacity: one that was conducted two years prior and another that was completed ten years prior.¹⁸⁰ The couple decided to find an independent agency to perform an updated sexual consent assessment.¹⁸¹ This assessment determined that Paul and Hava each had the capacity “to give verbal informed sexual consent.”¹⁸² The agency that conducted the assessment provided “specialized educational materials” to Paul and Hava as part of the assessment process.¹⁸³ Hava’s group home, however, rejected the result of her updated independent assessment.¹⁸⁴

The *Olmstead* integration mandate created opportunities for Paul and Hava to live and thrive in the community with supports. They met in the community and fell in love.¹⁸⁵ 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 Paul and Hava by providing

178. *Id.* at *2.

179. Oral Argument at 1:02:25, *Forziano*, 613 F. App’x 15 (No. 14-1147) (on file with the *Columbia Law Review*). 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 Professor Deborah Denno, “Although courts also typically refer to a victim’s ‘mental age’ when evaluating rape” and cases that involve people with intellectual disabilities, organizations and commentators consider “mental age” to be “a misleading concept, 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 (footnotes 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 Gill, *supra* note 30, at 38 (“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.”); cf. Jasmine Harris, *Sexual Consent and Disability*, 93 N.Y.U. L. Rev. 480, 538 (2018) [hereinafter Harris, *Sexual Consent and Disability*] (“[C]ourts routinely review a mix of evidence of IQ, mental age, and adaptive evidence in evaluating a victim’s incapacity to consent.”).

180. See *Forziano*, 2014 WL 1277912, at *1 (noting that Paul and Hava expressed an interest to get married in 2010); Brief for Defendants-Appellees at 44, *Forziano*, 613 F. App’x. 15 (No. 14-1147), 2014 WL 7003967 (noting that the group home relied on assessments from 2000 and 2008).

181. *Forziano*, 2014 WL 1277912, at *2.

182. *Id.* (citing Amended Complaint, *supra* note 174, at ¶ 161).

183. *Id.*

184. *Id.* at *3.

185. *Id.* at *1.

sexuality services to enhance what the group home perceived to be incapacities in Hava's sexual decisionmaking.¹⁸⁶ But they chose not to.¹⁸⁷

It took three years for Paul and Hava to find a group home that allowed them to live together.¹⁸⁸ The couple were married shortly after moving in together, following "a courtship of seven years and an engagement of two years."¹⁸⁹ Paul and Hava's experience reflects the need 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.

3. *Sexuality and Disability Scholarship.* — The development of recent legal scholarship continues to elevate discourse on how to address the sexual and reproductive control of people with disabilities.¹⁹⁰ Disability rights scholar Robyn Powell discusses what she termed "reproductive oppression"—"the myriad ways sexuality and reproduction is weaponized to subjugate people with disabilities."¹⁹¹ She argues for a renewed "jurisprudential and legislative framework" that centers the tenets of reproductive justice and disability justice to "shift attention away from the courts and onto policymaking, organizing, and the electorate."¹⁹²

Professor Jasmine Harris has challenged legislative and judicial approaches in navigating questions of capacity and consent in sexual assault cases.¹⁹³ Professor Harris calls 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."¹⁹⁴ Other scholars have suggested reform efforts to "modern rape law" to

186. *Id.* at *2.

187. *Id.*

188. See *id.* at *1, *3.

189. *Id.* at *1 (citing Amended Complaint, *supra* note 174, at ¶ 2).

190. See, e.g., Emens, *supra* note 7, at 1381–82 ("Sex and relationship education, institutional and residential rules, and welfare laws should all be structured to anticipate and facilitate opportunities for intimate relationships."); Joseph J. Fischel & Hilary R. O'Connell, *Disabling Consent, or Reconstructing Sexual Autonomy*, 30 *Colum. J. Gender & L.* 428, 508, 514, 516, 519 (2015) (suggesting "publicly funded comprehensive sexual education," "publicly funded sexual assistance," facilitated masturbation, and the facilitated purchase of sexual services); Powell, *Disability Reproductive Justice*, *supra* note 16, at 1889–98 (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," protecting autonomy and self-determination, and "ensuring that sexual and reproductive health services and information are accessible").

191. Powell, *Disability Reproductive Justice*, *supra* note 16, at 1860.

192. *Id.* at 1887, 1903.

193. See Harris, *Sexual Consent and Disability*, *supra* note 179, at 488 ("This Article examines fifty state statutes plus the District of Columbia and 172 sexual assault and rape decisions . . . related to cognitive disability and capacity to consent to sex.").

194. *Id.* at 547.

address the failures of the criminal system in prosecuting sexual violence cases against disabled people.¹⁹⁵

Scholarship has further explored the necessity of facilitated decisionmaking and welfare reform efforts in supporting the sexual autonomy of disabled people.¹⁹⁶ Several scholars have also examined issues of sexuality and disability for residents in congregate settings such as nursing facilities and hospitals, proposing tools and strategies to address the complex questions of capacity and consent with the goal of protecting the disabled individual's sexual and bodily autonomy.¹⁹⁷

This expansive discourse has yet to deeply explore how laws, policies, and sociocultural norms work collectively to control the sexual and reproductive lives of people with intellectual and developmental disabilities—or how this control effectuates and maintains a status quo of sexual violence against this community. Thinking about the structural causes of the desexualization of disability provides an opportunity to reimagine how to confront sexual violence and its root causes.

II. REFRAMING THE VICTIM–PERPETRATOR BINARY THROUGH THE STRUCTURAL FRAME OF DESEXUALIZING DISABILITY

The nature of individualized sexual violence against people with intellectual and developmental disabilities generally limits deeper inquiry into its causes and consequences. That is, the primary focus of sexual violence is a victim–perpetrator binary.¹⁹⁸ Sexuality is primarily viewed

195. See, e.g., Fischel & O'Connell, *supra* note 190, at 431–32 (arguing for statutory reform to “modern rape law” by moving away from the conflation of sexual autonomy with consent to recognize “sexual autonomy as the capability to codetermine sexual relations”); see also 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) (arguing that current legislative proposals for reforming this area of law fail to extend the personal autonomy of women with intellectual disabilities); Denno, *supra* note 179, at 321 (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”); 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).

196. See *supra* note 190; cf. Jasmine Harris, *Response, The Role of Support in Sexual Decision-Making for People With Intellectual and Developmental Disabilities*, 77 *Ohio St. L.J. Furthermore* 83, 101–04 (2016), <http://hdl.handle.net/1811/78681> [<https://perma.cc/9EP6-8GAX>] [hereinafter Harris, *The Role of Support*] (questioning the legal implications of applying the legal framework of supported decisionmaking to persons with intellectual and developmental disabilities).

197. See Chin, *Group Homes as Sex Police*, *supra* note 50, at 396–97 nn.89–90.

198. See Gill, *supra* note 30, at 7 (“Advocating for the sexuality of people with intellectual disabilities challenges sexual ableism inasmuch as intellectual disability assumes inability to consent because of the manifestation of an intellectual impairment.”).

through the lens of protecting the disabled person from sexual violence and administering criminal and civil responses to address the harm. As a result, issues of sexuality are rendered invisible in the lives of people with intellectual and developmental disabilities. There is an erasure of “the embodied knowledge and unique epistemology about life and physical maturity of individuals with intellectual disabilities.”¹⁹⁹ This Part 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.’”²⁰⁰ The lives of intellectually disabled women, in particular, are “largely constructed around the twin poles of ‘regulation of pregnancy/reproduction’ and ‘protection from sexual abuse and assault.’”²⁰¹ In the legal context, “vulnerability as a construct”²⁰² creates a presumption of sexual incompetency around sexuality and disability. Take the case of Johnny Timpson, a 60-year-old Black man²⁰³ with “severe intellectual disabilities and cerebral palsy” who lives in a group home.²⁰⁴

Timpson was discovered in his group home “having oral sex with another male.”²⁰⁵ The group home staff explained that “their actions were very inappropriate and asked them to go to their rooms.”²⁰⁶ In response to this incident, Timpson’s family filed a broadly sweeping lawsuit alleging “negligent care and abuse,”²⁰⁷ including “physical, emotional and sexual

199. *Id.* at 3.

200. *Id.* at 7.

201. *Id.* at 19.

202. Sherene H. Razack, *Looking White People in the Eye: Gender, Race, and Culture in Courtrooms and Classrooms* 138 (1998).

203. See Tim Smith, *Intellectually Disabled Man Given Sex Education in Group Home Before Having Sex: Lawsuit*, *Greenville News* (Nov. 12, 2018), <https://www.greenvilleonline.com/story/news/local/south-carolina/2018/11/12/intellectually-disabled-man-given-sex-ed-before-having-sex-lawsuit/1847718002/> [<https://perma.cc/EH78-GVZE>].

204. *Timpson ex rel. Timpson v. Anderson Cnty. Disabilities & Special Needs Bd.*, 31 F.4th 238, 245 (4th Cir. 2022).

205. Plaintiffs’ Motion & Memorandum in Support of Partial Summary Judgment at 26, *Timpson ex rel. Timpson v. McMaster*, 437 F. Supp. 3d 469 (D.S.C. 2020) (No. 6:16-cv-1174-DCC), *aff’d in part, vacated in part sub nom. Timpson ex rel. Timpson*, 31 F.4th 238.

206. Brief of Appellant at 13, *Timpson ex rel. Timpson*, 31 F.4th 238 (No. 20-1163), 2021 WL 633290 (quoting Joint Appendix at 1651–52).

207. *Timpson ex rel. Timpson*, 437 F. Supp. 3d at 472.

abuse, neglect and financial exploitation.”²⁰⁸ The family asserted that the group home and state agency that provides services to people with intellectual and developmental disabilities “encouraged” this “risky sexual behavior[]”²⁰⁹ by providing Timpson with “sexual awareness . . . training.”²¹⁰

Timpson “received sex education courses from 2010 to 2013”²¹¹ after signing consent forms to participate in these classes.²¹² The sexuality education included teaching Timpson to “[a]lways use a latex condom during sex,” “[l]imit the number of partners you have,” and “recognize the symptoms of [sexually transmitted diseases].”²¹³ It also included information related to “responsible decisions about sex” and other ways to “build a loving relationship.”²¹⁴ The family claimed that Timpson “had the mental capacity of a four or five year old child” and that the sexuality education included “concepts a child that age cannot and should not comprehend.”²¹⁵ In response, the former director of Timpson’s group home testified to taking “measures . . . in confronting the dilemma of providing safe sex education while not encouraging sexual activity, and still respecting . . . Johnny Timpson’s liberty interests as an adult.”²¹⁶ Due to the absence of Timpson’s perspective, thoughts, and feelings throughout the litigation, it is unclear what he felt or experienced at the group home related to this sexual encounter and what impact sexuality education had on his sexual actions.²¹⁷

The *Timpson* case reflects what is customarily conceived as sexual violence, presenting difficult questions. If examining this case through a victim–perpetrator binary, the inquiry may explore the following: Did

208. Amended Complaint at 3, *Timpson ex rel. Timpson v. Haley*, 2017 WL 588497 (D.S.C. Feb. 14, 2017) (No. 6:16-cv-01174-DCC), 2016 WL 11658111.

209. Plaintiffs’ Motion & Memorandum in Support of Partial Summary Judgment, *supra* note 205, at 26.

210. *Id.* at 8 (internal quotation marks omitted) (quoting exh.7).

211. *Timpson ex rel. Timpson*, 31 F.4th at 245.

212. Plaintiffs’ Motion & Memorandum in Support of Partial Summary Judgment, *supra* note 205, at 8.

213. *Id.* at exh.7.

214. *Id.*

215. *Id.* at 25–26.

216. Brief of Appellees at 21, *Timpson ex rel. Timpson*, 31 F.4th 238 (No. 20-1163), 2021 WL 510613.

217. The district court reprimanded Plaintiffs’ counsel for its failure to properly present issues specific to Timpson and the level of care, treatment, and services he was receiving at the group home. The court noted, “Federal courts resolve cases and controversies, not crusades. . . . Plaintiffs’ counsel in this case have sought to wage a ground war against the South Carolina disability and Medicaid system. In the process of this crusade, Plaintiffs’ counsel have neglected to focus on what is important: Johnny Timpson.” *Timpson ex rel. Timpson*, 437 F. Supp. 3d at 472. The district court entered directed verdicts on several of Plaintiffs’ claims with the jury returning verdicts on the remaining claims. See *id.* at 478. The Fourth Circuit Court of Appeals sustained the verdicts, vacating only the District Court’s dismissal of Plaintiffs’ retaliation claim. *Timpson ex rel. Timpson*, 31 F.4th at 251.

Timpson engage knowingly and willingly in sexual conduct? What was the capacity of each person involved to consent?²¹⁸ Did the encounter constitute sexual assault? Did sexuality education “encourage” Timpson, as the family posits, or provide the tools for an informed sexual encounter? Is there a perpetrator? Is there a victim? Should someone be held accountable? Is “mental age” something to rely on in determining capacity to consent to sexual activity?²¹⁹

These questions, and many others, are often the starting and stopping place of inquiry for discussions on sexuality and intellectual and developmental disability. Answering these questions may resolve issues around criminal culpability and negligence but does little to interrogate the foundations that support sexual violence. 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 affected by sexual violence. They also fail to examine the root causes of this violence.

In her article, “#UsToo”: *Empowerment and Protectionism in Responses to Sexual Abuse of Women With Intellectual Disabilities*, Holly Jeanine Boux critically examined several legislative proposals that focused on sexual assault against women with intellectual disabilities. These proposed reforms followed shortly after the early swell of the #MeToo movement that captured national attention in 2017.²²⁰ The reforms largely focused on addressing sexual violence through “law enforcement and judicial practices.”²²¹ They included increasing training, funding, and other resources for criminal investigations and prosecutions and strengthening care provider abuser registries and mandatory reporter requirements for employees working with people with intellectual disabilities.²²² The reforms, Boux noted, sought to “remedy[] the symptoms, rather than the

218. State criminal laws on determining sexual capacity and consent vary. See, e.g., *People v. Cratsley*, 653 N.E.2d 1162, 1165 (N.Y. 1995) (“The law does not presume that a person with [an intellectual disability] is unable to consent to sexual intercourse, and proof of incapacity must come from facts other than [intellectual disability] alone.” (citation omitted)). A discussion of capacity and consent in matters of sexual conduct, and the criminal legal standards that may apply, is beyond the scope of this Article. For an in-depth discussion on issues of capacity, consent, and people with intellectual and developmental disabilities, see Ann Linder, Stan. Intell. & Developmental Disabilities L. & Pol’y Project, *Capacity to Consent to Sexual Activity Among Those With Developmental Disabilities* 7–12 (2018), <https://law.stanford.edu/wp-content/uploads/2018/11/Ann-Linder-Capacity-to-Consent-to-Sexual-Activity-Among-those-with-Developmental-Disabilities.pdf> [<https://perma.cc/B7ZP-346N>].

219. See *supra* note 179 (discussing how courts often use the term “mental age” despite critiques that this term reinforces notions of incompetency).

220. Boux, *supra* note 195, at 141.

221. *Id.* at 149.

222. *Id.* at 143–45.

root causes” of sexual violence,²²³ with a majority of state statutes further marginalizing intellectually disabled survivors of sexual assault through “infantilizing language [that] entrench[es] disempowering and paternalist norms and practices.”²²⁴

Enhanced surveillance is another measure that states propose to deter or identify perpetrators of sexual violence. During the course of the *Timpson* litigation, the South Carolina state legislature proposed the implementation of surveillance cameras in group homes and the enhancement of a caretaker abuser registry.²²⁵ Twelve states currently allow surveillance monitoring in congregate care settings, including nursing and group homes,²²⁶ which both raises privacy and additional civil rights concerns and conflicts with the goal of protecting the disabled individual’s sexual and bodily autonomy.²²⁷ Cultivating efforts to remediate sexual violence

223. *Id.* at 134.

224. *Id.* at 133. Boux additionally notes that in thirty-two states, “[T]he same laws that protect children from physical and sexual abuse are used to protect adults with intellectual disabilities.” See *id.* at 146–47 (quoting Joseph Shapiro, *The Sexual Assault Epidemic No One Talks About*, NPR (Jan. 8, 2018), <https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about> [<https://perma.cc/4A5X-T83H>]).

225. Tim Smith, *Control of South Carolina Disabilities Agencies Must Change*, House Panel Says, *Greenville News* (Nov. 12, 2018), <https://www.greenvilleonline.com/story/news/local/south-carolina/2018/11/12/south-carolina-ddsn-disabilities-agency-should-change-house-panel-says/1752727002/> [<https://perma.cc/TU5A-GDAC>].

226. See, e.g., 210 Ill. Comp. Stat. Ann. 32/10 (West 2024) (“A resident shall be permitted to conduct authorized electronic monitoring of the resident’s room through the use of electronic monitoring devices placed in the room pursuant to this Act.”); 12 Mo. Ann. Stat. § 198.612 (2024) (“Residents of long-term care facilities in this state shall have the right to place in the resident’s room an authorized electronic monitoring device that is owned and operated by the resident or provided by the resident’s guardian or legal representative.”); Okla. Stat. tit. 63, § 1-1956 (2024) (“A resident or the representative of a resident may conduct authorized electronic monitoring of the resident’s room through the use of authorized electronic monitoring devices placed in the room”); Wash. Admin. Code §§ 388.97.0380, 388.97.400 (2024) (“For the purposes of consenting to video electronic monitoring without an audio component, the term ‘resident’ includes the resident’s surrogate decision maker.”); see also Prianka Nair, *Surveilling Disability, Harming Integration*, 124 *Colum. L. Rev.* 197, 231 n.229 (2024); Marisa Saenz, *Esther’s Law, Allowing Families to Install Cameras in Ohio Nursing Homes, Goes Into Effect Wednesday*, WKYC (Mar. 23, 2022), <https://www.wkyc.com/article/news/local/ohio/esthers-law-cameras-ohio-nursing-homes-goes-into-effect-wednesday/95-7549798d-a65b-4719-a94e-ffb573b35f7a> [<https://perma.cc/YD7B-FLM9>]; Terry Tang, *Arizona Health Facility Rape Spurs Video Surveillance Push*, *Associated Press* (Feb. 8, 2019), <https://apnews.com/article/766df61d860e44a39df163799e5daeb6> [<https://perma.cc/7YCU-N4B7>]; 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/> [<https://perma.cc/Z2SU-ASH4>].

227. Nair, *supra* note 226, at 202–05 & n.22 (arguing that surveillance systems over people with disabilities could constitute violations of the ADA’s antidiscrimination mandate and the integration mandate).

against people with intellectual disabilities primarily through criminal, prosecutorial, and surveillance efforts has largely proven ineffective.²²⁸

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 reflects a type of “social machinery” that engages to normalize the structural desexualization of disability.²²⁹ 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. 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.²³⁰ Structures include “broad-scale cultural and political-economic

228. See, e.g., Elizabeth A. Armstrong, Miriam Gleckman-Krut & Lanora Johnson, *Silence, Power, and Inequality: An Intersectional Approach to Sexual Violence*, 44 *Ann. Rev. Socio.* 99, 110–12 (2018) (discussing the “consequences of the criminalization and medicalization of sexual violence”); Denno, *supra* note 179, at 321; Fischel & O’Connell, *supra* note 190, at 431–33; Shelton, *supra* note 195, at 223.

229. Paul Farmer, *An Anthropology of Structural Violence*, 45 *Current Anthropology* 305, 307 (2004) [hereinafter Farmer, *Structural Violence*].

230. Rylko-Bauer & Farmer, *supra* note 45, at 47. This definition and application of structures draws directly from the concept of structural violence. The foundational ideas of structural violence evolved from liberation theology in Latin America. Lee, *Violence*, *supra* note 5, at 125. Norwegian anthropologist Johan Galtung introduced the concept of structural violence to the field of sociology in 1969. See Galtung, *Violence, Peace, and Peace Research*, *supra* note 5, at 171. Galtung described structural violence as “violence [that] is built into the structure and shows up as unequal power and consequently as unequal life chances.” *Id.* It is “indirect” compared to “personal” or “direct” violence, which is when an actor or actors commit the harm. *Id.* at 169. Structural violence is often applied when examining healthcare disparities and the human toll of living in poverty. See, e.g., Akhil Gupta, *Red Tape Bureaucracy, Structural Violence, and Poverty in India* 35 (2012) (discussing poverty as structural violence and writing that “an essential part of combating acute poverty involves changing the narratives through which structural violence is normalized and hence changing the expectations of what bureaucrats can do and what they can be expected to do”).

structures”²³¹ such as ableism,²³² racism, homophobia, poverty, transphobia, misogyny, slavery, and eugenics.²³³

These structures cause violence and other forms of harm because they are maintained by institutional policies and practices; choices of resource allocation; and legal, historical, sociopolitical, and culturally driven processes and norms. These policies, practices, and norms coalesce to inflict harms as a matter of course by way of society’s day-to-day collective actions.²³⁴ Due to the quiet workings of these structures, their harms are less likely to elicit moral outrage or garner strong positions to mitigate the harms.²³⁵ Because these disability systems “operate normatively,” the suffering that flows from the structural desexualization of disability is continuous. They occur through the general course of one’s life.²³⁶ As a result, the harms are “taken for granted” and “no one is held accountable except, perhaps, the [individuals] themselves.”²³⁷ This routinization of the harm that flows from the structural desexualization of disability effectively erases this harm’s social, political, and historical origins,²³⁸ which surface when applying the structural desexualization of disability framework.

In the case of Paul and Hava, the decision of Hava’s group home, upon reliance of the outdated sexual consent assessments, effectively stripped Hava of her sexual personhood.²³⁹ This action by the group home limited Hava’s choices of who she could interact with intimately, where and with whom she could live, and created potential legal uncertainty around whether she could marry. The harms experienced by Hava are structural because the loss of her sexual personhood occurred as a result of the coalescing of structures that limit the sexuality of persons with intellectual and developmental disabilities.²⁴⁰ These structures include the

231. Rylko-Bauer & Farmer, *supra* note 45, at 47.

232. “*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.” Liat Ben-Moshe, *Decarcerating Disability: Deinstitutionalization and Prison Abolition* 16 (2020). For a more expansive definition of ableism, see *Working Definition of Ableism: January 2022 Update*, Talila A. Lewis Blog, (Jan. 1, 2022), <https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update> [<https://perma.cc/MF3B-LANV>].

233. Rylko-Bauer & Farmer, *supra* note 45, at 47.

234. See, e.g., Lee, *Violence*, *supra* note 5, at 126; Rylko-Bauer & Farmer, *supra* note 45, at 47.

235. Cf. Johan Galtung, *Twenty-Five Years of Peace Research: Ten Challenges and Some Responses*, 22 *J. Peace Rsch.* 141, 145–46 (1985) (explaining that if structural violence “works quickly it is more likely to be noticed and strong positions for and against will build up so that moral stands emerge”).

236. Lee, *Violence*, *supra* note 5, at 123.

237. Nancy Scheper-Hughes, *Dangerous and Endangered Youth Social Structures and Determinants of Violence*, in *Youth Violence: Scientific Approaches to Prevention* 13, 14 (John Devine, James Gilligan, Klaus A. Miczek, Rashid Shaikh & Donald Pfaff eds., 2004).

238. *Id.*

239. See *supra* notes 179–180 and accompanying text.

240. See Lee, *Violence*, *supra* note 5, at 123 (“The harm is structural because it is a product of institutions and other structures . . .”).

restrictive role of law in matters of sexuality for people with intellectual and developmental disabilities;²⁴¹ the inequitable distribution of resources directed at sexuality supports and services by the HCBS waiver program, the institutional policies (whether formal or informal) and practices of the group home in choosing not to provide sexuality supports and services to Hava; and the embedded ableism, bias, and stigma that normalize the restriction of people with intellectual disability and women, in particular, in making sexual and reproductive choices.²⁴²

Confronting this history's role in creating this "fretwork of entrenched structures" is necessary in any examination of the structural desexualization of disability.²⁴³ The form of harm experienced by Hava is further reinforced by the history of sexual and reproductive control of women with intellectual disabilities. Eugenicists sought to label women with actual or perceived intellectual disability as licentious or perpetual children,²⁴⁴ requiring protection by the state to control their sexual and reproductive desires. Hava's group home challenged the finding of only her updated sexual consent assessment, even though the assessments determined that both Paul and Hava had the capacity to consent to sexual conduct.²⁴⁵ This decision by Hava's group home affected Paul by situating him as a potential predator, exposing him to possible criminal penalty, and foreclosing any opportunity for him to engage intimately with Hava. The structural desexualization of disability framework requires exploration of the subjugation, indignity, loss of autonomy, and other forms of direct and indirect harms that people with intellectual and developmental disabilities can experience by interacting with disability systems.

241. See *supra* section II.A (discussing the contemporary laws that limit choices around reproduction, parenting, cohabiting, and marriage).

242. See, e.g., Sam R. Bagenstos, *Disability and Reproductive Justice*, 14 *Harv. L. & Pol'y Rev.* 273, 284 (2020) ("If medical professionals and prospective parents have an unduly negative understanding of life with a disability, driven by widespread societal stereotypes, then their decisions will be driven by bias unless the state steps in to counteract those stereotypes."); Doron Dorfman, *Penalizing Prevention: The Paradoxical Legal Treatment of Preventative Medicine*, 109 *Cornell L. Rev.* 311, 320 (2024) ("[S]tereotypes can have a relationship with reality because they make generic, exaggerated statements about social phenomena.").

243. Farmer, *Structural Violence*, *supra* note 229, at 308–09.

244. Trent, *supra* note 53, at 139, 224.

245. "Sexuality Consent Assessments were conducted of Paul and Hava on June 14, 2012 and June 21, 2012, respectively. Both Paul and Hava were found to be able to give verbal informed sexual consent." *Forziano v. Indep. Grp. Home Living Program*, No. CV-13-0370, 2014 WL 1277912, at *2 (E.D.N.Y. 2014) (citation omitted). Hava's group home rejected the 2022 sexual consent assessment and instead "rel[ied] on the previous assessments performed in 2000 and 2008." *Id.* at *2–3.

III. THE SYSTEMS THAT MAINTAIN THE STRUCTURAL DESEXUALIZATION OF DISABILITY

This Part 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 structures that influence each of these disability systems to present how they 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 forty-five and fifty-five percent of people with intellectual and developmental disabilities are under guardianship.²⁴⁶ The guardianship system developed based on notions of *parens patriae*, or “parent of the country.”²⁴⁷ The government assumes a protectionist role to secure the health and safety of people deemed unable to care for themselves due to diminished mental capacity.²⁴⁸ Courts may appoint a guardian—most often a family member or a public guardianship provided by the state—for an individual who it determines lacks mental capacity.²⁴⁹

The National Council on Disability²⁵⁰ referred to guardianship as a “kind of civil death” because people subject to guardianship are “no

246. Nat'l Council on Disability, *Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People With Intellectual and Developmental Disabilities* 42 (2019), https://www.govinfo.gov/content/pkg/GOVPUB-Y3_D63_3-PURL-gpo121724/pdf/GOVPUB-Y3_D63_3-PURL-gpo121724.pdf [<https://perma.cc/HP64-497R>] [hereinafter Nat'l Council on Disability, *Turning Rights Into Reality*]. This percentage reflects the “overall average [annual] state percentages of people with [intellectual and developmental disabilities]” over the course of a ten-year period. *Id.* There is limited data to accurately assess the number of people with intellectual and developmental disabilities who are under guardianship, therefore, this percentage is likely not the complete picture. In 2001, in an effort to gather data on the prevalence of guardianship in the United States, Senators Elizabeth Warren and Robert P. Casey Jr. wrote a letter to HHS and the DOJ. The letter requested that the agencies provide guardianship and conservatorship data that it collected and information on how the agencies collected this data. Letter From Sen. Elizabeth Warren and Sen. Robert P. Casey Jr. to Xavier Becerra, Sec'y, HHS, and Merrick Garland, Att'y Gen., DOJ (July 1, 2021), <https://www.warren.senate.gov/imo/media/doc/2021.07.01%20Letter%20to%20DOJ%20and%20HHS%20re%20Conservatorship.pdf> [<https://perma.cc/R4C7-9USW>].

247. Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans With Disabilities Act*, 81 *U. Colo. L. Rev.* 157, 164–67 (2010).

248. *Id.*

249. *Id.*

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

longer permitted to participate in society without mediation through the actions of another if at all.”²⁵¹ They are stripped of their legal capacity, reverting them to the status of minors under the law.²⁵² In guardianship proceedings, a court may appoint a third party (guardian) with the legal authority to make decisions such as where the person who is under guardianship may live, whether they can vote, how much control they have over their sexual and reproductive choices, who they can interact with, what intimate and social interactions they may have, and whether the person may marry.²⁵³ As a result of guardianship, people are divested of opportunities to exercise self-determination and agency in choices that most affect their lives.²⁵⁴ In areas of medical care and treatment, they “may get little information” related to their “condition or treatment options, eventually becoming disregarded as a participant in the decision-making process.”²⁵⁵

Despite increasing recognition that alternatives to guardianship are necessary to prevent undue restrictions on a disabled person’s right to control their own life,²⁵⁶ guardianship remains central as a disability system that legitimizes third-party control over the sexual and reproductive choices of disabled people. A recent Massachusetts case, *In re Guardianship*

Mission and History, Nat’l Council on Disability, <https://www.ncd.gov/about-us/> [<https://perma.cc/BK7Y-CPQM>] (last visited Sept. 26, 2024).

251. Nat’l Council on Disability, *Turning Rights Into Reality*, supra note 246, at 24 (internal quotation marks omitted) (quoting Robert D. 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 Rts. Brief, January 2012, at 8, 8–9).

252. Kristin Booth Glen, *Not Just Guardianship: Uncovering the Invisible Taxonomy of Laws, Regulations and Decisions that Limit or Deny the Right of Legal Capacity for Persons With Intellectual and Developmental Disabilities*, 13 *Alb. Gov’t L. Rev.* 25, 25–26 (2020).

253. Emily DiMatteo, Vilissa Thompson, Osub Ahmed, Mia Ives-Rublee & Ma’ayan Anafi, *Rethinking Guardianship to Protect Disabled People’s Reproductive Rights*, Ctr. For Am. Progress (Aug. 11, 2022), <https://www.americanprogress.org/article/rethinking-guardianship-to-protect-disabled-peoples-reproductive-rights/> (on file with the *Columbia Law Review*).

254. See Salzman, supra note 247, at 159–60; Marie Bergum, *It Took Me 12 Years to Get Out of My Conservatorship. Now I’m Finally Free.*, ACLU (June 26, 2023), <https://www.aclu.org/news/disability-rights/it-took-me-12-years-to-get-out-of-my-conservatorship-now-im-finally-free> [<https://perma.cc/TP9Q-6QS2>].

255. Salzman, supra note 248, at 168.

256. See *In Your State*, Nat’l Res. Ctr. for Supported Decision-Making, <https://supporteddecisionmaking.org/in-your-state/> (on file with the *Columbia Law Review*) (last visited July 28, 2024) (listing the current status of supported decisionmaking laws in all states, including thirty-two jurisdictions that have passed supported-decisionmaking laws); see also Emily Largent, Andrew Peterson & Jason Karlawish, *Opinion, Britney Spears Didn’t Feel Like She Could Live ‘a Full Life.’ There’s Another Way.*, N.Y. Times (Apr. 3, 2023), <https://www.nytimes.com/2023/04/03/opinion/guardianship-britney-spears-decision-making.html> (on file with the *Columbia Law Review*) (discussing the nonpartisan support of supported decisionmaking as an alternative to guardianship).

of *Moe*, provides a good example.²⁵⁷ There, the Department of Mental Health petitioned the Probate and Family Court to appoint the parents of a thirty-two-year-old woman with a psychiatric disability (identified as “Mary Moe” in court documents) to serve as guardians of their daughter for the purpose of consenting to an abortion.²⁵⁸

Mary Moe’s parents felt that the termination of their daughter’s pregnancy was in her best interest.²⁵⁹ Moe opposed the abortion for religious reasons.²⁶⁰ The trial court agreed with Moe’s parents and granted them coguardianship.²⁶¹ The trial 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.²⁶² The trial judge, without provocation, also directed the facility performing the abortion to sterilize Moe “to avoid this painful situation from recurring in the future.”²⁶³ The presumed vulnerability of intellectually disabled women as “passive[] or helpless”²⁶⁴ or overly sexual is a purported justification to sterilize and engage in other means of control over the sexual lives of girls and women.²⁶⁵ This view of sexuality is embedded within the guardianship system, yet sterilization is not a panacea to protect people with intellectual and developmental disabilities from sexual violence.²⁶⁶

257. 960 N.E.2d 350 (Mass. App. Ct. 2012).

258. *Id.* at 352.

259. *Id.* at 353.

260. *Id.*

261. *Id.*

262. *Id.* (alteration in original) (internal quotation marks omitted) (quoting the lower court judge).

263. *Id.* (internal quotation marks omitted) (quoting the lower court judge). 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 not to have an abortion. *Id.* at 355. The Court remanded the case for an evidentiary hearing that considered Moe’s wishes. *Id.*

264. Marta Codina, Diego A. Díaz-Faes & Noemi Pereda, Women With Intellectual Disabilities: Unraveling Their Victim–Offender Status, *in* The Emerald International Handbook of Feminist Perspectives on Women’s Act of Violence 109, 113 (Stacy Banwell, Lynsey Black, Dawn K. Cecil, Yanyi K. Djamba, Sitawa R. Kimuna, Emma Milne, Lizzie Seal & Eric Y. Tenkorang eds., 2023).

265. Catalina Devandas Aguilar, Special Rapporteur, Promotion and Protection of Human Rights: Human Rights Questions, Including Alternative Approaches for Improving the Effective Enjoyment of Human Rights and Fundamental Freedoms, ¶ 30, U.N. Doc. A/72/133 (July 14, 2017), <https://www.ohchr.org/en/documents/thematic-reports/a72133-sexual-and-reproductive-health-and-rights-girls-and-young-women> [<https://perma.cc/J83Q-ZNUU>].

266. *Id.* (discussing how “sterilization neither protects [girls and young women] against sexual violence or abuse nor removes the State’s obligation to protect them from such abuse”). This United Nations report emphasizes that “[t]he practices [of sterilization] are often conducted on a purported precautionary basis.” *Id.* Sterilization practices have been justified because of the “vulnerability of girls and young women with disabilities to sexual abuse, and under the fallacy that sterilization would enable girls and young women with

A structural desexualization of disability framework exposes the concerted ways that structures and systems interact to control the sexuality of people under guardianship. Consider the following. Several doctors and practitioners from the Division of Plastic 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?*²⁶⁷ In this brief case report, the authors discuss the case of a woman with an intellectual disability who was born with “breast asymmetry.”²⁶⁸ The woman felt “distress and embarrassment” because of this congenital condition.²⁶⁹ In efforts to minimize these feelings, before going in public, she “would often attempt to symmetrize her breasts with homemade breast inlets.”²⁷⁰ Her mother, who was also her daughter’s guardian with the legal authority to make her medical decisions, consulted with a surgeon.²⁷¹ The surgeon informed the mother that a procedure to augment her daughter’s smaller breast was the most common approach.²⁷² But her mother opposed the breast augmentation surgery.²⁷³

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.”²⁷⁴ Rather than the augmentation surgery, the mother requested that the doctor perform a mastectomy “to reduce [her daughter’s] sexuality.”²⁷⁵ The medical complications of the surgery would likely result in a loss of “nipple sensation and the ability to breastfeed.”²⁷⁶ 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.”²⁷⁷

disabilities who are ‘deemed unfit for parenthood’ to improve their quality of life without the ‘burden’ of a pregnancy.” Id.

267. 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?*, *Plastic & Reconstructive Surgery–Glob. Open*, e4347, May 23, 2022, at 1.

268. Id. at 1.

269. Id.

270. Id.

271. Id.

272. Id.

273. Id.

274. Id.

275. Id.

276. Id. at 2.

277. 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.

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 the interaction of social and legal structures. First, the mother wanted to protect her daughter from sexual victimization because of the documented evidence that people with intellectual and developmental disabilities are disproportionately affected by sexual violence.²⁷⁸ Second, the legal system provided the mother with the legal right to make healthcare decisions for her daughter through guardianship, which secured the legal grounds to authorize a surgery.²⁷⁹ 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.²⁸⁰

The court-ordered appointment of a guardian occurs in an instant moment of time. But the guardianship system lawfully permits bodily, sexual, and reproductive control at any time. The exercise of this control throughout the individual's lifetime reflects the structural, slow nature of the harm experienced.²⁸¹

278. See Sex Abuse Against People With Disabilities Is Widespread—And Hard to Uncover, PBS News Hour (Jan. 17, 2018), <https://www.pbs.org/newshour/show/sex-abuse-against-people-with-disabilities-is-widespread-and-hard-to-uncover> (on file with the *Columbia Law Review*) (“People with developmental disabilities become victims of sexual assault at a rate seven times higher than those without disabilities . . .”).

279. State guardianship laws contain standards that are intended to guide guardians concerning how medical decisions are made and what court approval is necessary to make medical decisions for the person under guardianship. See Kim Dayton, Standards for Health Care Decision-Making: Legal and Practical Considerations, 2012 Utah L. Rev. 1329, 1329–30 (detailing how most states legally charge guardians with healthcare decisionmaking). Despite statutory guidance, persons under guardianship remain susceptible to a guardian making medical decisions that extend beyond their statutory authority as guardian. See, e.g., *In re Guardianship of Kennedy*, 845 N.W.2d 707, 713 (Iowa 2014) (determining that a vasectomy did not qualify as a “nonemergency medical procedure” under the state guardianship law and therefore required court approval).

280. 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. See DEE-P Connections, Growth Attenuation Therapy—Everything You Want and Need to Know, YouTube (May 18, 2022), <https://youtu.be/-oiEKt3KPTM> (on file with the *Columbia Law Review*). Growth-attenuation procedures include hysterectomies, mastectomies, and other procedures. See Growth Attenuation, Am. Ass'n on Intell. & Developmental Disabilities (June 10, 2020), <https://www.aidd.org/news-policy/policy/position-statements/growth-attenuation> [<https://perma.cc/W9SG-KAS6>].

281. See Spivakovsky & Steele, *supra* note 16, at 181 (“Th[e] specification of time disperses the perpetration of lawful violence across time and space, enabling it to become a defining condition for those under guardianship . . .”).

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 an intellectual disability who was sexually assaulted during her freshman year by another student, David M., who was also in her special education class.²⁸² 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.²⁸³ 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.²⁸⁴ Arguably, the litigation achieved a level of justice for C.K.M.'s family. 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 eleven-day trial, a jury found that the school district violated C.K.M.'s due process and equal protection rights and acted with negligence.²⁸⁵ 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” in her being sexually assaulted by this same student, David M.²⁸⁶ The vice principal's response to the allegations included expelling C.K.M. and David M. as an “intervention technique.”²⁸⁷ The school district further argued, with support from expert testimony, 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”²⁸⁸ or express that the sexual behavior was “unwanted.”²⁸⁹

The vice principal explained, “I would not characterize it as sexual harassment. . . . [T]he person has to object to what's going on for it to be harassment. . . . I don't know that [C.K.M.] knew better.”²⁹⁰ 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

282. See *Berg ex rel. C.K.M. v. Bethel Sch. Dist.*, No. 3:18-CV-5345-BHS, 2022 WL 796315, at *1, *5–6 (W.D. Wash. Mar. 16, 2022) (“There is substantial evidence adequate to support the jury's conclusion that the District's failure to report David M.'s harassment of C.K.M. was a moving force of her injury.”).

283. See *L.K.M. v. Bethel Sch. Dist.*, No. 3:18-CV-05345-BHS, 2020 WL 7075209, at *2 (W.D. Wash. Dec. 3, 2020).

284. *Berg ex rel. C.K.M.*, 2022 WL 796315, at *4–6.

285. *Id.* at *1; Jury Verdict Form at 2, *Berg ex rel. C.K.M.*, 2022 WL 796315 (No. 3:18-CV-05345-BHS), 2021 WL 5571110.

286. *L.K.M.*, 2020 WL 7075209, at *3.

287. *Id.* at *4.

288. *Id.*

289. *Id.*

290. Plaintiff C.K.M.'s Trial Brief at 14, *Berg ex rel. C.K.M. v. Bethel Sch. Dist.*, No. 3:18-cv-05345-BHS, 2022 WL 796315 (W.D. Wash. Mar. 16, 2022), 2021 WL 5571007.

toward her.²⁹¹ 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.”²⁹² The vice principal similarly expressed that “the physical reality of . . . hormones” was “driving” their behavior.²⁹³

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.²⁹⁴ This school’s emphasis of C.K.M. as both “too sexual”²⁹⁵ and too cognitively disabled to “know better” and object to David M.’s conduct²⁹⁶ reflects a modern application of eugenics ideologies. Eugenicians viewed “feeble-minded” women as “excessively interested in sex”—the unrestrained feeble-minded women—who required protection from themselves.²⁹⁷

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 feeble-mindedness, which is a characterization that eugenicians used to control the sexual and reproductive choices of the “manifestly unfit” population.²⁹⁸ The emphasis by the school district on this constructed view of C.K.M. shifted the attention away from the school district to an individualized focus on C.K.M. as the victim who was also responsible for the harm done to her. It drew attention away from the responsibility of the school district to ensure that its students with intellectual and developmental disabilities were equipped with the knowledge, information, and related services and supports to be safe in an educational setting, which is discussed in more detail below.

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.²⁹⁹ This identification

291. *L.K.M.*, 2020 WL 7075209, at *4.

292. *Id.* at *3.

293. Plaintiff C.K.M.’s Trial Brief, *supra* note 290, at 14. 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. *Id.* at 16.

294. See Cecilia Benoit, Andrea Mellor & Zahra Premji, Access to Sexual Rights for People Living With Disabilities: Assumptions, Evidence, and Policy Outcomes, 52 *Archives Sexual Behav.* 3201, 3211 (2023) (observing that society views women living with intellectual disabilities as “sexually vulnerable and unable to be sexually autonomous for fear of exploitation by others”).

295. See *supra* note 292 and accompanying text.

296. See *supra* note 290 and accompanying text.

297. Cohen, *supra* note 54, at 6; Trent, *supra* note 53, at 136.

298. *Buck v. Bell*, 274 U.S. 200, 207 (1927).

299. The parties do not dispute David M.’s past history of violent sexual conduct against others. See *L.K.M. v. Bethel Sch. Dist.*, No. C18-5345 BHS, 2020 WL 7075209, at *1–2 (W.D.

alone, however, does little to inform efforts to maintain student safety against sexual victimization or to engage with preventive and treatment strategies to avert 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 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 affected 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 twenty-one.³⁰⁰ According to recent available data, the U.S. special education system serves approximately 6.5 million students between the ages of six and twenty-one.³⁰¹ The purpose of the IDEA is to provide

Wash. Dec. 3, 2020) (listing four undisputed instances of David M.'s prior violent sexual conduct).

300. See Individuals with Disabilities Education Act of 1997, Pub. L. No. 105-17, 111 Stat. 37 (codified as amended at 20 U.S.C. §§ 1400–1482 (2018)).

301. See U.S. Dep't of Educ., 44th Annual Report to Congress on the Implementation of the Individuals With Disabilities Education Act 41 (2022), <https://sites.ed.gov/idea/files/44th-arc-for-idea.pdf> [<https://perma.cc/8QK7-77E3>] [hereinafter DOE Report] (“In 2020, a total of 6,464,088 students ages 6 through 21 were served under IDEA . . . in the 49 States for which data were available, the District of Columbia, Bureau of Indian Education schools, Puerto Rico, the four outlying areas, and the three freely associated states.”); see also Laura Graham Holmes & Sexual Information and Education Council of the United States (SIECUS): Sex Ed for Social Change, Comprehensive Sex Education for Youth With Disabilities: A Call to Action 9–10 (2021), <https://siecus.org/wp-content/uploads/2021/03/SIECUS-2021-Youth-with-Disabilities-CTA-1.pdf> [<https://perma.cc/U798-UFUM>] (“In 2016, over six million youths ages 6–21 were served by the U.S. special education system.”). 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

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.”³⁰² These unique needs “include learning differences, social inexperience, and social naiveté that could lead to vulnerability, and warrant education programs” that provide “accurate and accessible information about social-sexual behavioral norms.”³⁰³

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 study, “Anywhere 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.”³⁰⁴ 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 lead[] to difficulty achieving the healthy relationships that many desire.”³⁰⁵

The lack of a national mandate for comprehensive sexual education leaves it up to states to determine whether to provide sex education, and what type of education to offer. As such, there is a patchwork of curriculums offered with only thirty-eight states and Washington, D.C., mandating that schools teach sex education.³⁰⁶ The range and comprehensiveness of the sex education offered also varies. For example, thirty-nine states and Washington, D.C., require that information be provided on abstinence, with twenty-nine of these states requiring that abstinence be stressed.³⁰⁷ Forty percent of states do not require evidence-based sexual education programs.³⁰⁸ For disabled students, access to

language impairment, (12) traumatic brain injury, (13) visual impairment, and (14) developmental delay.” Kyrie E. Dragoo, Cong. Rsch. Serv., R46566, *The Individuals With Disabilities Education Act: A Comparison of State Eligibility Criteria* (2020), <https://crsreports.congress.gov/product/pdf/R/R46566> [<https://perma.cc/DQE7-ZXPB>].

302. See 34 C.F.R. § 300.1 (2024).

303. Pedgrift & Sparapani, *supra* note 164, at 504.

304. Holmes & SIECUS, *supra* note 301, at 26.

305. *Id.* at 9.

306. State Laws and Policies: Sex and HIV Education, Guttmacher Inst. (Sept. 1, 2023), <https://www.guttmacher.org/state-policy/explore/sex-and-hiv-education> [<https://perma.cc/S2CF-WNGQ>].

307. *Id.*

308. Holmes & SIECUS, *supra* note 301, at 17; Dianne Morrison-Beedy & Bernadette Mazurek Melnyk, Making a Case for Integrating Evidence-Based Sexual Risk Reduction and Mental Health Interventions for Adolescent Girls, 40 *Issues Mental Health Nursing* 932, 932 (2019) (reporting that evidence-based sexual education programs have been “rigorously evaluated” through research, using “strict systematic criteria set by a credible authority” and have been shown, in at least one program evaluation, to have a positive outcome).

comprehensive sexual education is largely inaccessible; only three states explicitly include disabled students within their sex education requirements.³⁰⁹ There is a lack of information, however, as to what extent sexual education programs that do include disabled students offer comprehensive sexual education that is tailored to the learning needs of students with intellectual and developmental disabilities.³¹⁰

Studies indicate that tailored sex education that “emphasize[s] the importance of communication, boundary-setting, and decision-making skills,”³¹¹ can: provide young people with intellectual and developmental disabilities “with necessary social skills that can prepare them for fulfilling future interactions,”³¹² afford “opportunities to experience a sexually satisfying life,”³¹³ and improve “capacity to make decisions about sex and sexuality.”³¹⁴ Further, the development of decisionmaking skills through sex education contributes to “greater capacity to protect oneself from harm” and “an ability to be cognizant of the sexual boundaries and expectations that are prevalent within society.”³¹⁵ Tailored sex education also “contribute[s] to reducing vulnerability” and “inappropriate sexual expression.”³¹⁶

In contrast, a lack of access to sexuality services places intellectually and developmentally disabled students “at risk for demonstrating unexpected social-sexual behavior.”³¹⁷ The behaviors include “public masturbation, touching people’s private body parts without permission, and interacting in a sexually inappropriate manner with children.”³¹⁸ Intellectually and developmentally disabled young people may not

309. Holmes & SIECUS, *supra* note 301, at 17.

310. See Abrams, *supra* note 159 (explaining that even in the few states that mandate sexuality education, “there’s no requirement that such instruction be accessible to all”).

311. 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*, 41 *Sexuality & Disability* 619, 637 (2023); see also Holmes & SIECUS, *supra* note 301, at 22.

312. Bradley W. McDaniels & Allison R. Fleming, *Sexual Health Education: A Missing Piece in Transition Services for Youth With Intellectual and Developmental Disabilities?*, 84 *J. Rehab.* 28, 29 (2018).

313. *Id.* at 31.

314. Rachele Hole, Leyton Schnellert & Gloria Cantle, *Sex: What Is the Big Deal? Exploring Individuals’ With Intellectual Disabilities Experiences With Sex Education*, 32 *Qualitative Health Rsch.* 453, 461 (2022).

315. Anna C. Treacy, Shanon S. Taylor & Tammy V. Abernathy, *Sexual Health Education for Individuals With Disabilities: A Call to Action*, 13 *Am. J. Sexuality Educ.* 65, 87 (2018).

316. Amy Swango-Wilson, *Caregiver Perceptions and Implications for Sex Education for Individuals With Intellectual and Developmental Disabilities*, 26 *Sexuality & Disability* 167, 168 (2008) (citations omitted).

317. Pedgrift & Sparapani, *supra* note 164, at 504.

318. *Id.*

understand their right to bodily autonomy and how to recognize sexual harms.³¹⁹

This inattention to sexuality in special education leaves a gap for young people with intellectual and developmental disabilities 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.³²⁰ It fuels the suppression of sexual awareness and healthy sexual exploration, increases the possibility of developing improper sexual behavior,³²¹ and perpetuates increased vulnerability to sexual violence.

An education advocate for students with intellectual and developmental disabilities provided examples of the tangible harms experienced by students with intellectual and developmental disabilities when comprehensive sexuality education is not prioritized as an essential component to securing sexual and reproductive health and safety.³²² She discussed the following:

Students I work with have been . . . denied basic information about their sexual and reproductive health . . . they've been trafficked [and] . . . catfished; sexually abused; suspended for bungled attempts to engage with crushes; harassed and threatened at school and home by intimate partners . . . and disciplined unknown times for “sexually inappropriate behaviors.”³²³

These tangible harms are compounded by the racism, heterosexism, homophobia, and transphobia experienced by LGBTQ+ people of color with disabilities and LGBTQ+ people with disabilities who encompass other marginalized identities. LGBTQ+ people with intellectual disabilities, for example, experience rejection from family and fear that they may lose services such as housing or put “valued relationships with

319. Holmes & SIECUS, *supra* note 301, at 26 (mentioning researchers who argue that some young people with disabilities might “not know they have a right to bodily autonomy”).

320. Scholars have explored the necessity of sex positive education in developing healthy sexual behaviors in young people. See, e.g., Charisa Smith, #WhoAmI?: Harm and Remedy for Youth of the #MeToo Era, 23 U. Pa. J.L. & Soc. Change 295, 347 (2020) (“Feminist theorists and juvenile law scholars alike assert that the development of sex positivity requires a balance of self-confidence, personal agency, and external boundaries. This healthy sexual personhood also requires increased awareness of the risks of violence, exploitation, boundary-crossing and oppression.”).

321. See *supra* sections III.B–C (discussing role of sexuality education in minimizing the development of inappropriate sexual behaviors).

322. Katherine (Kate) Hoy, Sex Ed Is Not (Just) About Sex, AHRC N.Y.C. (Feb. 28, 2022), <https://www.ahrcnyc.org/news/sex-ed-is-not-just-about-sex/> [<https://perma.cc/S6RQ-6KD9>].

323. *Id.*

staff” at risk by expressing their authentic selves or for seeking out support related to questions about their sexuality and gender.³²⁴

Someone looking to view the *C.K.M.* case through the structural desexualization of disability framework could confront ableist assumptions around issues of gender, race, sex, and intellectual and developmental disability; conduct 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 examine how comprehensive sexuality education can enhance the safety and healthy sexual behaviors of intellectually and developmentally disabled students. In doing so, the hope is to recenter the analysis and open new avenues for structural change in addressing sexual violence against intellectually 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.³²⁵ States and the agencies that administer the HCBS program drive “the culture, expectations, resources, and available accommodation options” that largely dictate the life choices of disabled people who receive these services.³²⁶ The case of Alex illustrates this point.

Alex³²⁷ is a thirty-two-year-old man who identifies as autistic. He receives community-based services through the HCBS 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.³²⁸ Over the years, Alex expressed his deep desire to have meaningful relationships. He requested, without success, developmentally appropriate sex education and sexuality supports. He acknowledges that

324. Ginn, *supra* note 28, at 922 (citing D. Abbott & J. Burns, *What’s Love Got to Do With It?: Experiences of Lesbian, Gay, and Bisexual People With Intellectual Disabilities in the United Kingdom and Views of the Staff Who Support Them*, 4 *Sexuality Rsch. & Soc. Pol’y* 27 (2007)).

325. See *supra* section II.C (discussing the HCBS waiver program).

326. Renáta Tichá, 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 *Intell. & Developmental Disabilities* 486, 502 (2012).

327. The facts related to Alex have been modified and the name changed.

328. 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* 7 (2020), <https://www.macpac.gov/wp-content/uploads/2021/01/Medicaid-Services-for-People-with-Intellectual-or-Developmental-Disabilities-%E2%80%93Evolution-of-Addressing-Service-Needs-and-Preferences.pdf> [<https://perma.cc/Q269-DHRN>].

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 him 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.³²⁹

Through a structural desexualization of disability framework, the barriers that Alex faces to accessing 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, places Alex at a greater risk of developing inappropriate sexual behaviors.³³⁰ Exercising sexual behavior in nonhealthy 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 community impact.

The social worker in Alex's case has already expressed these concerns as it relates to his needs for sexuality supports. Such consequences may include arrest, conviction, and placement on the sex offender registry.³³¹ Placement may lead to indefinite detention and houselessness.³³² Further, being ill-equipped to navigate one's sexual feelings and behavior may also lead to depression, anxiety, and self-harm, as Alex has already experienced. The emotional and psychological impact of an "inability to

329. Facts and quote changed to protect client identity.

330. Pedgrift & Sparapani, *supra* note 164, at 504–05.

331. See, e.g., Brian Kelmar, Kelmar Story, Legal Reform for the Intellectually & Developmentally Disabled (Aug. 6, 2021), <https://lrid.org/kelmar-story/> [<https://perma.cc/MAK9-MSHD>] (discussing a father's experience of his twenty-four-year-old autistic son's involvement in the criminal legal system and placement on the sex offender registry).

332. See Allison Frankel, Pushed Out and Locked In: The Catch-22 for New York's Disabled, Homeless Sex-Offender Registrants, 129 *Yale L.J. Forum* 279, 282–83, 295, 300 (2019), <https://www.yalelawjournal.org/forum/pushed-out-and-locked-in> [<https://perma.cc/ARX5-M4HB>] (discussing the collateral consequences experienced by sex-offender registrants that include exclusion from federally subsidized housing and other residency restrictions, which may "lead to homelessness, unemployment, and isolation").

access meaningful relationships” may leave people “vulnerable to isolation” and “feelings of hopelessness.”³³³

As a further consequence of the desexualization of disability through the HCBS waiver program, families, support providers, and others whom persons with intellectual and developmental disabilities engage with for supports are also not equipped with information, awareness, or knowledge on how to navigate issues of sexuality with the disabled population that they serve. The biases that may exist toward sexuality and disability—infantilization, deemed sexually predatory or overly sexual—therefore are not challenged. As such, intellectually and developmentally disabled adults are “held to rigid standards of sexual morality and receive messages from families, professionals, and society that marriage, children, and an active sexual life are forbidden.”³³⁴

Reframing the victim–perpetrator binary to reconceptualize sexuality is a critical next step in addressing sexual violence against people with intellectual and developmental disabilities and the structural harms that lead to this violence. Implementing state interventions, prioritizing cross-movement building, centering the lived experiences of this community in any advocacy and policy efforts, and confronting ableism within society and disability systems on issues of sexuality are the preliminary steps for moving the issue of sexuality rights forward.

IV. THE STATE’S ROLE IN RECONCEPTUALIZING SEXUALITY

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

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.

333. Pedgrift & Sparapani, *supra* note 164, at 505.

334. Sarah H. Ailey, Beth A. Marks, Cheryl Crisp & Joan Earle Hahn, Promoting Sexuality Across the Life Span for Individuals With Intellectual and Developmental Disabilities, 38 *Nursing Clinics N. Am.* 229, 233 (2003).

Julie: So we will know how to protect ourselves.³³⁵

As expressed throughout this Article, states play an outsized role in the lives of people with intellectual and developmental disabilities. This Part 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 twenty-five years since the Court decided *Olmstead*, litigation, DOJ investigations, and other advocacy efforts have changed the landscape of how people with intellectual and developmental disabilities live and receive services.³³⁶ The central role of states in supporting community integration under Title II of the ADA entails an affirmative duty to administer its programs to avert the unjustified isolation of people with intellectual and developmental disabilities.³³⁷ 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.”³³⁸

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.”³³⁹ Despite these mandates, through a lack of HCBS waiver funding allocation, states deprive people with intellectual and developmental disabilities of opportunities to acquire knowledge—

335. Self-Advocates Speak Up About Sex, Elevatus Training, <https://www.elevatustraining.com/selfadvocates/> [<https://perma.cc/3LLS-EAWD>] (compiled by Karen Topper & Katherine McLaughlin) (“Members of Green Mountain Self-Advocates in Vermont held a discussion group about sexuality . . . 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.”).

336. See, e.g., Robert D. Dinerstein, *The Olmstead Imperative: The Right to Live in the Community and Beyond*, 4 *Inclusion*, no. 1, 2016, at 16, 19 (discussing the role and impact of *Olmstead* enforcement on the federal, state, and local level).

337. Courts have not applied Eleventh Amendment immunity to states in *Olmstead* integration claims under Title II of the ADA. See, e.g., *Seum v. Osborne*, 348 F. Supp. 3d 616, 628 (E.D. Ky. 2018) (“A ‘court may enter a prospective suit that costs the state money . . . if the monetary impact is ancillary, i.e., not the primary purpose of the suit.’” (alteration in original) (quoting *Boler v. Earley*, 865 F.3d 391, 413 (6th Cir. 2017))); *Martin v. Taft*, 222 F. Supp. 2d 940, 964 (S.D. Ohio 2002) (“[V]irtually any prospective relief against a state will affect the state’s budget. For this very reason, courts have held that an ancillary effect of prospective relief on a state’s treasury does not violate Eleventh Amendment immunity.”).

338. *Guggenberger v. Minnesota*, 198 F. Supp. 3d 973, 1026–27 (D. Minn. 2016) (alteration in original) (quoting 42 U.S.C. § 12101(a)(2) (2012)); see also *Steimel v. Wernert*, 823 F.3d 902, 911 (7th Cir. 2016) (holding that the ADA “bars unjustified segregation of persons with disabilities, wherever it takes place”).

339. 28 C.F.R. § 35.130(b)(3)(ii) (2024).

and develop and strengthen skills—around issues related to sexuality. Sexual isolation further maintains a culture that makes people with intellectual and developmental disabilities more susceptible to sexual violence.³⁴⁰ Critically, sexual isolation leads to the desexualization of disability.

In discourse around securing and expanding 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 provide sexuality supports and services. More intentionality is needed in using the courts as a tool to confront the structural desexualization of disability³⁴¹ as states are held accountable—or are sought to be held to account—through creative litigation strategies that push the parameters of *Olmstead*.³⁴²

In recent decades, advocates have utilized opportunities to expand the reach of *Olmstead* in ways previously unimagined. 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 state agencies' administration of community-based mental health services and housing to formerly incarcerated individuals;³⁴³ state provision 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;³⁴⁴ state implementation of mental health services,³⁴⁵ and states'

340. Chin, *Group Homes as Sex Police*, *supra* note 50, at 383.

341. See, e.g., Britney R. Wilson, *Making Me Ill: Environmental Racism and Justice as Disability*, 170 U. Pa. L. Rev. 1721, 1751 (2022) (“The lack of an intent requirement similar to that in racial discrimination law makes the ADA an attractive alternative for challenging structural harm.”).

342. See *supra* section I.C.

343. *M.G. v. N.Y. State Off. of Mental Health*, 572 F. Supp. 3d 1, 6 (S.D.N.Y. 2021) (denying a motion to dismiss a claim 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 housing and supportive services”).

344. Fact Sheet on Proposed Agreement Over Oregon Supported Employment, DOJ, https://archive.ada.gov/olmstead/documents/lane_fact_sheet.pdf [<https://perma.cc/BK5V-VNXX>] (last visited July 28, 2024).

345. *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); cf. *United States v. Mississippi*, 82 F.4th 387, 398 (5th Cir. 2023) (“The possibility that some un-named individual with serious mental illness or *all* such people in Mississippi could be unjustifiably institutionalized in the future does not give rise to a cognizable claim under Title II.”).

policies of segregating disabled students in public education.³⁴⁶ Transformative lawyering requires the kind of imagination that these novel cases harnessed in pushing the boundaries of *Olmstead*.³⁴⁷

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.³⁴⁸

Sexual isolation and segregation manifest through the failure of states to expend resources through the HCBS waiver program for sexuality supports and services, which unjustifiably suppresses the sexual and reproductive lives of people with intellectual and developmental disabilities.³⁴⁹ In 2014, the Centers for Medicare & Medicaid Services (CMS)³⁵⁰ issued regulations to specify that community integration for people with disabilities as required under *Olmstead* must “ensure[] an individual’s rights of privacy, dignity and respect, and freedom from coercion and restraint” and must “optimize[] but . . . 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.”³⁵¹ This expanded definition of community integration is incompatible with state policies that exclude access to sexuality supports in providing community-based services.

Approaching this issue through a rights-based framework that relies primarily on the civil rights enforcement of the ADA will likely fail.³⁵² Any

346. *United 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).

347. Amna A. Akbar, *Non-Reformist Reforms and Struggles Over Life, Death, and Democracy*, 132 *Yale L.J.* 2497, 2507 (2023) (discussing how legal reforms can be imagined to “rethink the kinds of laws, policies, norms, relationships, and modes of organization that we might build to govern society, and an effort to democratize relations of power: to have fundamentally different people at the helm”).

348. Chin, *Group Homes as Sex Police*, *supra* note 50, at 382, 420–37.

349. For the application of sexual isolation as an integration-mandate violation against group homes, see *id.* at 382–84.

350. CMS is the federal administrative agency that approves HCBS state waiver applications. CMS HCBS Instructions, *supra* note 110, at 6.

351. 42 C.F.R. § 441.301(c)(4)(iii)–(iv) (2024); see also 42 U.S.C. § 12101(b)(3) (2018) (“[T]he Federal Government plays a central role in enforcing the standards established [by the ADA] . . .”).

352. See, e.g., Dean Spade, *Normal Life: Administrative Violence, Critical Trans Politics, and the Limits of Law* 43 (rev. ed. 2015) (“Narrowing political resistance strategies to seeking inclusion in anti-discrimination law makes the mistaken assumption that gaining recognition and inclusion in this way will equalize our life chances and allow us to compete in the (assumed fair) system.”); Ani B. Satz, *Disability, Vulnerability, and the Limits of*

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.³⁵³ The intersectional nature of sexuality and intellectual and developmental disability implicates areas of disability, race, housing, sexuality, gender, sexual and reproductive health, social welfare, and other intersecting areas.³⁵⁴ Supporting efforts in cross-movement building that engage justice-based movements is central to any advocacy strategy.

B. *State Resourcing to Center Sexuality in Community Integration*

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).³⁵⁵ VAWA “funded the criminal legal response to gender-based violence”³⁵⁶ while focusing on carceral interventions to violence.³⁵⁷ The primary purposes of VAWA are to “prevent violent crime; respond to the needs of crime victims; learn more about crime; and change public attitudes through a collaborative effort by the criminal justice system, social service agencies, research organizations, schools, public health organizations, and private organizations.”³⁵⁸

Antidiscrimination, 83 Wash. L. Rev. 513, 522 (2008) (“[D]isability law requires a blend of the civil rights and social welfare models . . .”).

353. See, e.g., Chin, *Centering Disability Justice*, supra note 48, at 688 (“The future of disability rights requires advocacy and discourse that holds racism/ableism and interlocking systems of oppression at its center to better assess who is being left out . . . and what steps future disability rights strategies can take to more intentionally center racism/ableism in its framework.” (footnote omitted)); Powell, *Disability Reproductive Justice*, supra note 16, at 1887 (“[T]o achieve reproductive justice, legal and policy solutions must be aimed at disrupting the intersecting oppressions experienced by multiply-marginalized people with disabilities[,] [and] . . . activists, scholars, legal professionals, and policymakers must actively engage people with disabilities in establishing legal and policy responses.”).

354. See, e.g., Lorr, supra note 26, at 1328–29 (arguing that “there is evidence of the cocreation of race and disability and its relationship to family regulation: Black children who are more likely to be given a disability label, and therefore placed in special education, then grow up and are more likely to have their families forcibly separated”); Morgan, supra note 63, at 688 (“[W]hen viewed intersectionally, each case, law, or policy is situated in ‘historical contexts and structural conditions within which the identity categories of race and disability intersect.’” (quoting Nirmala Erevelles & Andrea Minear, *Unspeakable Offenses: Untangling Race and Disability in Discourses of Intersectionality*, 4 J. Literary & Cultural Disability Stud. 127, 131 (2010))).

355. Violence Against Women Act of 1994, Pub. L. No. 103-322, 108 Stat. 1902 (codified as amended in scattered sections of 8, 16, 18, 28, and 42 U.S.C.).

356. Leigh Goodmark, *Assessing the Impact of the Violence Against Women Act*, 5 Ann. Rev. Criminology 115, 116 (2022).

357. *Id.* at 118 (noting criticism that VAWA “increased criminalization on communities of color”).

358. Lisa N. Sacco & Emily J. Hanson, Cong. Rsch. Serv., R45410, *The Violence Against Women Act (VAWA): Historical Overview, Funding, and Reauthorization* 12 (2019).

In critiquing VAWA, Leigh Goodmark notes that while it “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.³⁵⁹ Goodmark concludes that “a noncarceral VAWA, one that shift[s] 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.”³⁶⁰ 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 people subject to guardianship must be educated on the retention of the right of persons under guardianship to make choices around sexuality. Illinois provides an effective roadmap for this process.³⁶¹ 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.³⁶² This effort harnessed support from the disability community, parents of people under guardianship, service provider agencies, advocacy organizations, and politicians.³⁶³ The law creates sex education curricula³⁶⁴ with train-the-trainer modules³⁶⁵ and provides access to “sex education, related resources, and treatment planning that supports [their] right to sexual

359. Goodmark, *supra* note 356, at 121–22.

360. *Id.* at 116.

361. See 2021 Train the Trainer—What’s Right About Sex Education: Transcript for Module 1, Ill. Dep’t of Hum. Servs., <https://www.dhs.state.il.us/page.aspx?item=136090> [<https://perma.cc/JD7V-C94F>] [hereinafter 2021 Train the Trainer] (last visited July 28, 2024) (transcribing one of eight modules on Illinois sex education legislation and the sexual rights of people with disabilities).

362. See 405 Ill. Comp. Stat. Ann. 5/4-211 (West 2024) (“A person admitted to a developmental disability facility and receiving habilitation shall have access to sex education, related resources, and treatment planning that supports [their] right to sexual health and healthy sexual practices and to be free from sexual exploitation and abuse.”).

363. See 2021 Train the Trainer, *supra* note 361 (detailing broadly attended “stakeholder meetings” on input for proposed legislation as well as elected officials who sponsored the amendment).

364. See Curriculum Committee Survey, Ill. Dep’t of Hum. Servs., <https://www.dhs.state.il.us/page.aspx?item=124394> [<https://perma.cc/R72N-XKZD?type=image>] (last visited July 28, 2024) (“The Curriculum committee identified seven sexuality education curricula designed for educating individuals with intellectual and developmental disabilities.” (emphasis omitted)).

365. See, e.g., 2021 Train the Trainer, *supra* note 361.

health and healthy sexual practices and to be free from sexual exploitation and abuse.”³⁶⁶

In recent years, states have passed supported-decisionmaking laws to provide a less restrictive alternative to guardianship. Supported decisionmaking is a legal process that allows a disabled person to identify people to support them in making legal and other personal decisions, thereby allowing the disabled person to retain their legal decisionmaking capacity.³⁶⁷

Some agencies that provide services to people with intellectual and developmental disabilities are engaging in trainings that focus on sexual self-determination and supported decisionmaking.³⁶⁸ Still a nascent area of the law, evidence-based trainings and guidance are necessary to ensure that different models of supported-decisionmaking are utilized in ways that do not cause harm or exploitation when navigating issues of sexuality.³⁶⁹

2. *Mandating Comprehensive Sexuality Education in the Special Education System.* — State legislations can mandate guidelines for implementing comprehensive sexuality education in students’ individualized education plans.³⁷⁰ As an example, Virginia enacted a law that requires its Department of Education to establish “guidelines for individualized education program (IEP) teams to utilize when developing IEPs for children with disabilities to ensure that IEP teams consider the need for age-appropriate and developmentally appropriate instruction related to

366. 405 Ill. Comp. Stat. Ann. 5/4-211.

367. See *In Your State*, supra note 256; see also Harris, *The Role of Support*, supra note 196, at 84–85 (“The addition of [supported decisionmaking] as an alternative means of demonstrating legal capacity expands the possibilities for greater sexual access for people with cognitive disabilities.”).

368. See, e.g., *Sexual Self-Determination and Supported Decision-Making*, The Arc Oregon, <https://thearcoregon.org/event/1664-ssdsdm/> [<https://perma.cc/Z7HL-94LX>] (last visited Aug. 20, 2024); *Sexual Self-Determination and Supported Decision-Making*, Or. Dep’t of Hum. Servs. Off. of Developmental Disabilities, https://center.uoregon.edu/CaseManagement/2023/program/search/detail_session.php?id=13872045# [<https://perma.cc/8RQF-6XD4>] (last visited Aug. 24, 2024); *Among Friends: Sexual Self-Determination and Supported Decisionmaking*, Wash. State Dep’t of Soc. & Health Servs. Developmental Disabilities Admin., https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/Among-Friends-Sexual-Self-Determination-Flyer-October-Trainings_1.pdf [<https://perma.cc/8RQF-6XD4>] (last visited Aug. 20, 2024).

369. See, e.g., Emily DiMatteo, Osuh Ahmed, Vilissa Thompson & Mia Ives-Ruble, *Reproductive Justice for Disabled Women: Ending Systemic Discrimination*, Ctr. for Am. Progress (Apr. 13, 2022), <https://www.americanprogress.org/article/reproductive-justice-for-disabled-women-ending-systemic-discrimination/> (on file with the *Columbia Law Review*) [hereinafter DiMatteo et al., *Reproductive Justice for Disabled Women*] (“[I]t is essential to study different models of supported decision-making to create more guidance around implementation and create evidence-based policies.”).

370. See *Virginia’s Sex Education Snapshot*, SIECUS, https://siecus.org/state_profile/virginia-state-profile/ [<https://perma.cc/2TMN-B6HU>] (detailing the efforts to make comprehensive sex education a legislative mandate in Virginia).

sexual health, self-restraint, self-protection, respect for personal privacy, and personal boundaries of others.”³⁷¹

The legislation succeeded in large part due to parent advocacy efforts.³⁷² In advocating for this legislation, parents of young people with intellectual and developmental disabilities “shared common experiences of their children . . . not receiving more comprehensive instruction on sexual health within their IEP.”³⁷³ In addition to guidelines, states can mandate that developmentally appropriate comprehensive sexual education is incorporated into student IEPs based on an individualized assessment of a student’s needs.

3. *State Resourcing of Sexuality Services and Supports that Confront Ableism.* — Community-based service-provider agencies that seek to support the sexuality of people with intellectual and developmental disabilities often lack resources and knowledge to navigate these issues.³⁷⁴ A lack of standardized, fact-based sexuality training for the support staff of community-based provider agencies may result in misinformation and the reinforcement of biases around disability and sexuality.³⁷⁵ Kate Napolitano, who is a sexuality educator for people with intellectual and developmental disabilities, explained:

What [state provider agencies can do is] train all their workers so that when someone . . . has a question they can be a little more prepared to respond, or if not give a direct answer, to be able to help direct [a person with an intellectual disability] to where [they] can find an answer.³⁷⁶

Napolitano expressed that support staff “feel . . . nervous” and need to feel more informed about navigating issues of sexuality and people with intellectual and developmental disabilities.³⁷⁷

Many provider agencies, however, do not have the resources to invest in sexuality supports and services.³⁷⁸ The failure of states to provide resource-backed mandates that agencies provide sexuality education and

371. Va. Code § 22.1-217.03 (2024).

372. See Virginia’s Sex Education Snapshot, *supra* note 370 (“The legislation was successfully implemented through the tireless advocacy efforts of a parent led subcommittee of The Arc of Virginia . . .”).

373. *Id.*

374. See, e.g., Pedgrift & Sparapani, *supra* note 164, at 504 (“[S]ervice providers report a lack of adequate support to handle serious sexual behavior problems with confidence. A lack of professional expertise and a lack of accessible education programs are severe service gaps for social service providers.” (citation omitted)).

375. *Id.*

376. Interview by Justin Engles with Kate Napolitano, Social Relationships and Sexuality Educator, Wildwood Programs (Sept. 23, 2022) (on file with the *Columbia Law Review*).

377. *Id.*

378. See *supra* section I.D.

supports leaves agencies with few options for providing these supports.³⁷⁹ In response, some agencies engage in creative ways to build coalitions and enhance sexuality education outreach efforts by accessing funding outside the HCBS waiver program.³⁸⁰

To centralize the importance of sexuality as an essential aspect of community integration and health, states can implement regular trainings, policies, and education efforts throughout their disability service systems. State resources can build the capacity for community-based service 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 “dismantl[e] ableist assumptions about disability and sexuality.”³⁸¹ Sexuality training that (i) is informed by the lived experiences and needs of people with intellectual and developmental disabilities and (ii) creates opportunities for this community to act as peer-to-peer sexuality educators must be implemented.³⁸² 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 by society as the

379. See, e.g., Carli Friedman, Catherine K. Arnold, Aleksa L. Owen & Linda Sandman, “Remember Our Voices Are Our Tools:” Sexual Self-Advocacy as Defined by People With Intellectual and Developmental Disabilities, 32 *Sexuality & Disability* 515, 528–29 (2014) (observing that “much work remains to enact policies at the community, state, and federal levels to ensure that sexual self-advocacy is practiced”); see also section I.D.

380. See, e.g., Project Sexual Health Innovation Network for Equitable Education, Planned Parenthood Greater N.Y., <https://www.plannedparenthood.org/planned-parenthood-greater-new-york/learn/community-programs/project-shine> [<https://perma.cc/FR44-YHS6>] (last visited July 28, 2024) (consisting of a three-year program funded through a grant from HHS to create sexuality education tools and resources for youth ages sixteen to twenty-four with intellectual and developmental disabilities). Project SHINE was led by a community-based consortium in New York State, which included youth with intellectual and developmental disabilities (I/DD), parents, other family caregivers of persons with I/DD, and service providers and educators who serve the I/DD community. See Press Release, Project SHINE Launches to Address Inequities in Sexual Health of Youth With Intellectual and Developmental Disabilities Across New York, Planned Parenthood of Greater N.Y. (Mar. 29, 2021), <https://www.plannedparenthood.org/planned-parenthood-greater-new-york/about/news/project-shine-launches-to-address-inequities-in-sexual-health-of-youth-with-intellectual-and-developmental-disabilities-across-new-york> [<https://perma.cc/SS4B-WAD9>].

381. DiMatteo et al., *Reproductive Justice for Disabled Women*, supra note 369.

382. For an example of people with intellectual and developmental disabilities leading efforts to advance legislative change in access to sexuality education and resources, see *id.*

normal course through embedded structural systems.³⁸³ Viewing the desexualization of disability through a structural framework serves several goals. It “shifts attention” away from the momentary act of the individualized harm to examine larger questions as to “what puts people *at risk of risks*.”³⁸⁴ It further allows for a reframing of sexuality as a central aspect of community integration and as a sexual and psychosocial health priority.

Such a reframing provides a renewed lens for advocates, policymakers, lawyers, judges, and scholars by expanding the victim–perpetrator binary of sexual violence. This broader understanding seeks to expose how the structural desexualization of disability causes indirect harms that maintain and perpetuate sexual violence. Confronting the structural desexualization of disability is a “collective responsibility”³⁸⁵ 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 central to community integration.

383. Lee, *Violence*, supra note 5, at 124.

384. Rylko-Bauer & Farmer, supra note 45, at 57 (internal quotation marks omitted) (quoting Bruce G. Link & Jo Phelan, *Social Conditions as Fundamental Causes of Disease*, 35 *J. Health & Soc. Behav. (Extra Issue)* 80, 80 (1995)).

385. Lee, *Violence*, supra note 5, at 130.

