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Group Homes as Sex Police and the Role of the Olmstead Integration Mandate

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GROUP HOMES AS SEX POLICE AND THE ROLE OF THE *OLMSTEAD* INTEGRATION MANDATE

NATALIE M. CHIN[∞]

ABSTRACT

Adults with intellectual disabilities who live in group homes possess the same complex range of sexual desires and identities as all adults do. However, in group homes throughout the United States, these adults are denied the ability to express their sexuality. This Article addresses the systematic failure of group homes to modify punitive and overprotective policies and to provide services related to sex and intimacy, creating an environment of sexual isolation. Although legal scholars have explored the complexity of disability and sexual consent capacity and examined sexual rights in the context of institutionalized care, they have yet to explore the ramifications of policies and practices within group homes under federal disability rights law. This Article takes on that task and concludes that group homes have an affirmative duty to support intellectually disabled adults in exercising choices around sex and intimacy.

In particular, this Article argues that *Olmstead v. L.C. ex rel. Zimring* and its mandate for community integration under Title II of the Americans with Disabilities Act provides the framework to challenge the sexual isolation of group home residents as disability-based discrimination under the ADA's older integration mandate-sibling, Section 504 of the Rehabilitation Act. Some courts have begun to expand the reach of the integration mandate beyond the physical walls of confinement. It is through this lens that sexual rights can rise from the shadows as an essential aspect of full community integration alongside supports that include employment, education, and skills for daily living. The Article concludes by proposing reasonable modifications that group homes may undertake to avert sexual isolation, striving to balance the sexual rights of residents against the risk of exploitation and abuse that may arise in intimate relationships. A key modification would require group homes to create or adapt policies and procedures that begin to dismantle the bias, paternalism, and

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ableism that drives group-home decisions and perpetuates the sexual isolation of adults with intellectual disabilities.

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I.

INTRODUCTION

What is a life devoid of sex and intimacy, where “home is not a place but simply an irrevocable condition”¹ of presumed incapacity to engage in decisions related to one’s sexuality? An estimated 184,699 intellectually disabled individuals live in a private group home setting.² For many intellectually disabled adults living in group homes³ throughout the United States, a life without sex and intimacy is the status quo. Twenty-eight years after the passage of the Americans with Disabilities Act, persons with intellectual disabilities⁴ have yet to achieve full community integration because of a form of discrimination that Elizabeth Emens describes as “intimate discrimination at a structural level.”⁵ Michael Perlin, a leading scholar on sexuality and the rights of individuals with disabilities, has long argued that the “suppression of all sexual desire and action is, in fact, a form of social torture” for disabled individuals who reside in institutionalized care.⁶ This Article presents a novel framework for

1. JAMES BALDWIN, GIOVANNI’S ROOM 92 (Dell 2000) (1956).

2. SHERYL LARSON, HEIDI ESCHENBACHER, LYNDA ANDERSON, SANDY PETTINGELL, AMY HEWITT, MARY SOWERS & MARY LEE FAY, IN-HOME AND RESIDENTIAL LONG-TERM SUPPORTS AND SERVICES FOR PERSONS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS THROUGH 2014 58–59 (Inst. on Cmty. Integration, Univ. of Minn.: Nat’l Residential Info. Sys. Project ed. 2017), available at https://risp.umn.edu/media/download/cms/media/risp/2014_RISP_WEB.pdf [<https://perma.cc/6R3T-KKYA>] [hereinafter LARSON 2014]. This number is merely an estimation as seven states (Idaho, Iowa, Kansas, Kentucky, Louisiana, New Mexico and North Carolina) did not furnish data and estimates based on prior years were imputed for Georgia and Washington state. *Id.* The report indicated that Nevada was the only state not to offer services through the HCBS waiver program (also known as the Medicaid waiver program) to residents of privately owned group homes. *Id.*; see also *infra* Part III.B.

3. This Article limits its analysis to private residential facilities that are licensed through the state to provide varying levels of supervised care and other support to individuals with intellectual disabilities who live in that residence; the residence is rented, owned or managed by a residential services provider, or its agent (referred to herein as “group homes”). See LARSON 2014, *supra* note 2, at 30. Group homes vary in size and offer shared housing with up to twenty-four-hour supervised care, instruction and other support. *Id.*

4. See Part IV.B., *infra*, for the definition of intellectual disability. Individuals who have a developmental disability may also have an intellectual disability diagnosis. Developmental disability is an umbrella term that includes “intellectual disability but also includes physical disabilities. Some developmental disabilities may be solely physical, such as blindness from birth. Others involve both physical and intellectual disabilities stemming from genetic or other causes, such as Down syndrome and fetal alcohol syndrome.” *Fact Sheet: Intellectual and Developmental Disabilities*, NAT’L INST. OF HEALTH (Oct. 2010), [https://report.nih.gov/nihfactsheets/Pdfs/IntellectualandDevelopmentalDisabilities\(NICHD\).pdf](https://report.nih.gov/nihfactsheets/Pdfs/IntellectualandDevelopmentalDisabilities(NICHD).pdf) [<https://perma.cc/F469-67Y5>].

5. Elizabeth F. Emens, *Intimate Discrimination: The State’s Role in the Accidents of Sex and Love*, 122 HARV. L. REV. 1307, 1309 (2009).

6. Michael L. Perlin & Alison J. Lynch, “All His Sexless Patients”: *Persons with Mental Disabilities and the Competence to Have Sex*, 89 WASH. L. REV. 257, 262 (2014) [hereinafter Perlin & Lynch, *Sexless Patients*].

analyzing and countering this form of social torture, this intimate discrimination, through the lens of federal civil rights law. This Article describes the ways in which group homes erase the sexuality of individuals with intellectual disabilities through discriminatory policies and outlines how a systematic failure to provide community-based treatment and services around sexuality result in these individuals' sexual isolation.

This Article argues that *Olmstead v. L.C. ex rel. Zimring*⁷ and Title II of the Americans with Disabilities Act⁸ can be applied to challenge the sexual isolation of group homes residents under Section 504 of the Rehabilitation Act.⁹ Although disability scholars are attuned to the harms that intellectually disabled adults experience in relation to their sexuality, scholars have yet to situate this problem in the landscape of federal civil rights law. The issue of whether group homes have an affirmative duty under federal disability rights law to support intellectually disabled adults in exercising choices around sex and intimacy broadly impact the lives and identities of the thousands of adults in the United States who reside in group homes.¹⁰

Sexual isolation manifests in an environment cultivated by group homes where overprotective and punitive policies and lack of access to sexuality

7. 527 U.S. 581 (1999).

8. 42 U.S.C. §§ 12101–12213 (2017).

9. 29 U.S.C. § 794 (2017).

10. An estimated 748,585 people with intellectual and developmental disabilities (I/DD) received HCBS waiver services in 2014. LARSON 2014, *supra* note 2, at 56. Of those, 27% (184,699) lived in a group home operated by a non-state entity, as reported by forty-four states (including Washington D.C.) and estimated for the other seven. *Id.* at 58–59. The number of residents living in non-state group homes varies dramatically throughout the United States. States serving more people in non-state I/DD group homes than in other settings were Alabama (78%), Connecticut (53%), Delaware (99%), the District of Columbia (57%), Montana (58%), New Jersey (62%) and South Dakota (53%). *Id.* at 59. “States with the largest number of HCBS recipients” living in non-state group homes are New York (22,361), California (20,947), Pennsylvania (10,722), and Texas (9,909). *Id.* at 59. Despite the large numbers of individuals with intellectual and developmental disabilities residing in group homes across the United States, it is important to note that some scholars and advocates view “group homes as having characteristics that are uncomfortably similar to those of the institutions.” Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization*, 34 CARDOZO L. REV. 1, 50 (2012) [hereinafter Bagenstos, *Past and Future*]; Kevin M. Cremin, *Challenges to Institutionalization: The Definition of “Institution” and the Future of Olmstead Litigation*, 17 TEX. J. C.L. & C.R. 143, 175 (2012) (“[T]he assumption that . . . group homes are community-based facilities is also increasingly being questioned.”). More recently, group homes are under scrutiny for their failure to keep residents safe from physical and sexual harm. In 2018, a joint report issued by the U.S. Department of Health and Human Services Office of Inspector General, Administration on Community Living and Office for Civil Rights documented widespread abuse and neglect throughout group homes in three states and noted that forty-nine “[s]tates had media reports of health and safety problems in group homes.” U.S. DEP’T OF HEALTH & HUMAN SERVS., OFFICE OF INSPECTOR GEN., ADMIN. FOR CMTY. LIVING & OFFICE FOR CIVIL RIGHTS, *Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight* i–ii, <https://oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdf> [<https://perma.cc/AW86-M2PP>]. For additional discussion of group homes, see also *infra* Part III.B.

services¹¹ unjustifiably suppress the sexual rights of residents.¹² Group homes deny their residents opportunities related to gaining knowledge and information about sex, intimate relationships, marriage, and starting a family. This denial results in a form of sexual isolation, which, in turn, stymies the ability of adults with intellectual disabilities to develop the skills necessary for healthy sexual and intimate relationships.¹³ In addition, sexual isolation further perpetuates an environment where intellectually disabled individuals are more susceptible to sexual abuse and exploitation.¹⁴

11. Throughout this Article, the term “sexuality services” is used to describe what researchers have labeled as “proactive sexuality services.” Carli Friedman & Aleksa L. Owen, *Sexual Health in the Community: Services for People with Intellectual and Developmental Disabilities*, 10 *DISABILITY & HEALTH J.* 387, 389 (2017). Proactive sexuality services take “a more sex-positive approach, assuming that people with [intellectual disabilities] may want to be sexually active, and communicating openly about those possibilities,” “while still attempting to solve sexuality-related issues.” *Id.* at 389. Proactive sexuality services “promote[] healthy sexuality education” and “provide[] education centered on sexuality awareness, reproduction, safe sex, and victimization avoidance.” *Id.* They could include, for example: skills and supports in “[d]evelop[ing] friendships and emotional and sexual relationships”; individualized sexual “education, reflective of [the individual’s] own cultural, religious and moral values and of social responsibility; [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; and [p]rotection from sexual harassment and from physical, sexual, and emotional abuse.” *Sexuality: Joint Position Statement of AAIDD and the Arc*, AAIDD (2013), <https://aaidd.org/news-policy/policy/position-statements/sexuality#WZSZsFGGOUK> [<https://perma.cc/LPA8-QYVK>]. “Reactive sexuality services” are defined as those services that “contain[] elements of sex-negative ideas, including that sex is dangerous, should be avoided, or assuming sexual deviancy.” Friedman & Owen, *supra*, at 389. These services are “exclusively focusing on sexually inappropriate behaviors,” including “assessments and plans to stop current sexually inappropriate behaviors and prevent future behaviors” and “intervention and therapy for sexually inappropriate behaviors.” *Id.*

12. For the purposes of this Article, the terms “sexuality,” “sexual expression” and “sexual rights” are used interchangeably and refer to engaging in intimate acts with a consenting adult, the right to exercise choices in matters of sex, intimate partner relationships, marriage and family, and the right to express one’s sexual identity and gender identity in a safe environment. *See, e.g.*, MICHAEL GILL, *ALREADY DOING IT: INTELLECTUAL DISABILITY AND SEXUAL AGENCY* 1–22 (2015) (contextualizing how the sexual rights of individuals with intellectual disabilities have been denied and regulated within the United States); *see also* Miriam Taylor Gomez, *The S Words: Sexuality, Sensuality, Sexual Expression and People with Intellectual Disability*, 30 *SEXUALITY & DISABILITY* (2012) 237, 237 (“Sexuality is an important part of the personality of every human being, is a basic need and aspect of being human, cannot be separated from other aspects of life, includes the physical, physiological, psychological, social, emotional, cultural and ethical dimensions of sex and gender, influences thought, feelings, actions and interactions and affects our mental and physical health. Sexual expression is choosing to or choosing not to be sexually active and need not necessarily involve another person (self-pleasuring).”). Sexual rights, as presented in this Article, exclude engaging in intimate conduct where there are clear differentials in power dynamics, such as between group home resident and a group home employee. *See, e.g.*, GILL, *supra*, at 33–34 (“Unequal power dynamics, instead of willingness, becomes one of the determinants of abuse. . . . Defining sexual abuse as an issue of power and exploitation rather than an issue of consent underscores that those who experience sexual violence do so not because of a ‘lack’ of intelligence but rather because of unequal power dynamics that might favor professionals, family members, and staff.”).

13. *See infra* Parts III.C, III.D, IV.D.

14. *See infra* Part III.D.

Sexual isolation also manifests through a group home's decision to indefinitely police the sexual decisions of consenting adults who wish to engage intimately. In an article in the *Minnesota Star Tribune*, several group home residents discussed the limitations placed on their sexual activity by group home staff members.¹⁵ One resident discussed a ninety-minute time limit given by the group home on when he can engage privately with his girlfriend in his room.¹⁶ For the first year of the relationship, visits together were supervised.¹⁷ Now, he must seek permission from group home staff for a night alone with his girlfriend. He explains why this night alone is so important: "I want to wake up in the morning and have someone there by my side and feel happy—just like everyone else."¹⁸

In more restrictive instances, a resident's right to consent to sex may be arbitrarily denied, resulting in a potential lifetime without access to sexuality services or the right to engage in sexual intimacy in their own home. Consider the case of Julia R.¹⁹ Julia R. is in her early thirties and is sexually active. She has an intellectual disability and moved into a group home several years ago after becoming estranged from her family. She is friendly, laughs easily, and enjoys shopping with her friends. Julia R. has had a boyfriend for over a year and tries to spend as much time with him as she can. She is aware and knowledgeable of sexually transmitted diseases and decided to have an intrauterine device implanted as a form of birth control. She lived in the same supervised group home with eight other residents for several years and desired to live more independently in a non-group home setting.

One afternoon, Julia R. was speaking to staff at her group home and expressed her excitement about one day getting married and having a baby. The staff grew concerned, asking Julia R. questions about whether she understood how to care for a baby. Feeling that she did not fully grasp the gravity of caring for a baby, the staff member suggested to the group home operators that Julia R. undergo a Sexual Consent Assessment.²⁰ The Sexual Consent Assessment contained a series of questions pertaining to basic anatomy, sexual relationships, protection from sexual abuse or exploitation, and safe sex practices. Julia R. met with a group home employee who asked her a series of questions, which she answered as follows:

Evaluator: What does it mean to be married?

15. Chris Serres, *Intimacy Denied*, MINN. STAR TRIB. (Nov. 12, 2015), <http://www.startribune.com/for-minnesota-s-disabled-adults-freedom-to-be-intimate-is-rare/330697391/#> [<https://perma.cc/V5FW-A8W9>].

16. *Id.*

17. *Id.*

18. *Id.*

19. The facts related to Julia R. have been modified and the name changed to protect client confidentiality.

20. For a discussion on sexual consent assessments, see *infra* Part II.C.

Julia R.: You love that person and want to be with them for a long time.

Evaluator: Who should never touch your private areas?

Julia R.: A stranger.

Evaluator: What can stop pregnancy?

Julia R.: A condom.

Evaluator: How would you feel if someone touched you and you didn't want them to?

Julia R.: Scared.

Evaluator: Who can you tell if the touch caused bad feelings?

Julia R.: Friend or a nurse.

Shortly after the assessment, the group home deemed that Julia R. lacked the capacity to consent to sexual activity. The group home did not have guidelines or policies in place to provide Julia R. with information concerning issues of marriage and family or procedures that would allow her to challenge the sexual consent determination. Instead of deepening their curiosity and exploring Julia's comprehension to see how they could accommodate her, the group home silenced Julia R. by taking away her capacity. As a result of this determination, the group home kept a close eye over Julia's whereabouts to ensure that she did not have the opportunity to engage in any sexual activity with her boyfriend.

On repeated occasions, Julia R. told the group home that she did not want staff watching over her when she was with her boyfriend, and she continued to express her desire to marry and have children. She repeatedly asked the group home to reconsider its decision, without success. The group home ignored Julia R.'s many requests for information, and did not provide a justification for its decision nor offer services to support her desire to marry and have a family. It took one year of legal advocacy for Julia R. to regain her sexual consent status and to receive the services she requested.²¹

Julia R.'s case is not atypical.²² It represents the ease with which group homes can limit the sexual rights of residents and restrict access to sexuality services, and it raises the question of whether a life devoid of opportunities for sex and intimacy—where sexual expression is systematically suppressed and

21. The sexual rights of group home residents are routinely limited due to a presumption of incapacity in matters related to sex and intimacy and overprotective policies that seek to protect disabled individuals from sexual exploitation and abuse. *See infra* Parts II.C, II.D, III.D.

22. GILL, *supra* note 12, at 39 (“[S]ome [group] homes make a blanket determination that all individuals with intellectual disabilities are unable to provide consent. Group home and institutional staff members can be given license to stop the consent determination process before it begins based on their own biases, and staff members may try to ‘manage’ the sexuality of individuals by denying them the recognition of consent even when they understand and can appreciate the risks and potential consequences of the activity.”); *see also infra* Part III.D.

supportive services are withheld in matters related to starting a family or learning how to navigate an intimate relationship—is a life truly integrated into society.

Olmstead and its application of Title II of the ADA²³ provide the framework to challenge the sexual isolation of group home residents as disability-based discrimination under the ADA's older integration integration-sibling, Section 504 of the Rehabilitation Act.²⁴ The "integration regulation"²⁵ under Title II of the ADA provides that a "public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."²⁶

The ADA modeled the integration regulation, which is at the heart of both Title II and the *Olmstead* argument, after 28 C.F.R. § 41.51(d) of Section 504 of the Rehabilitation Act,²⁷ which provides that recipients of federal funding "shall administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons."²⁸ The reach of Title II of the ADA is limited to public entities, making Section 504 the legal mechanism available to

23. 42 U.S.C. §§ 12101–12213. Congress enacted the Americans with Disabilities Act in 1990 to address the pervasive discrimination, isolation and segregation of individuals with disabilities in such areas as employment, public accommodations, and access to public services, benefits, and programs. See 42 U.S.C. § 12101(a)(1)–(3). The application of Title II of the ADA is limited to public entities. See *infra* Part IV.A.

24. The Rehabilitation Act was enacted in 1973 to address disability-based discrimination by recipients of federal financial assistance. 29 U.S.C. § 794(a). The implementing regulations of Section 504 were enacted four years later, following a lawsuit and protests demanding the signing of the regulations. See Mark C. Weber, *Disability Discrimination by State and Local Government: The Relationship Between Section 504 of the Rehabilitation Act and Title II of the Americans with Disabilities Act*, 36 WM. & MARY L. REV. 1089, 1095 (1995). Title II of the ADA modeled its integration regulation after 28 C.F.R. § 41.51(d) of the Section 504 regulations. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 591–92 (1999); 28 C.F.R. § 41.51(d) (2017); see also *infra* Part IV.A.

25. *Olmstead*, 527 U.S. at 592.

26. 28 C.F.R. § 35.130(d) (2017). In enacting the ADA, Congress directed the Attorney General through the Department of Justice (DOJ) to implement regulations for guidance in interpreting the requirements of public entities under the ADA. 42 § U.S.C. 12134(a) (2012). The DOJ's interpretation of the ADA regulations is considered "controlling" and treated with deference absent "conflict with other department regulations or the ADA itself." *Nat'l Fed'n of the Blind v. Lamone*, 813 F.3d 494, 506 (4th Cir. 2016) (internal quotations omitted); see also *Olmstead*, 527 U.S. at 597–98 ("Because the Department [of Justice] is the agency directed by Congress to issue regulations implementing Title II its views warrant respect." (internal citation omitted)); *Shotz v. Cates*, 256 F.3d 1077, 1079 n.2 (11th Cir. 2001) (ADA "regulations 'must [be given] legislative and hence controlling weight unless they are arbitrary, capricious, or plainly contrary to the statute'" (quoting *United States v. Morton*, 467 U.S. 822, 834 (1984) (alteration in original)). Under Title II of the ADA, a public entity includes "any State or local government" or "any department, agency . . . or other instrumentality of a State or States or local government." 42 U.S.C. § 12131(1) (2012).

27. See *Olmstead*, 527 U.S. at 591–92; 28 C.F.R. § 35.130(d).

28. 28 C.F.R. § 41.51(d) (2013).

challenge the unjustified isolation of disabled persons in private settings, such as group homes, that are not operated by state or local governments.²⁹

Following *Olmstead*, Courts consistently analyze integration claims brought under Section 504 and Title II together, focusing on Title II of the ADA for guidance.³⁰ Prior to *Olmstead*, however, “there was no settled judicial or administrative construction of Section 504 on the question” of whether it applied to “the unjustified isolation of persons with disabilities.”³¹ Indeed, the *Olmstead* plaintiffs did not assert a Section 504 claim, leaving this question open.³² Where Section 504 is silent as to the context under which the integration regulation applies,³³ courts have looked to the ADA—with its clear remedial purpose of ending invidious discrimination—for guidance, including when to apply the integration regulation to non-governmental entities.³⁴

In *Olmstead*, two women challenged the decision of a state psychiatric facility to continue their treatment in the confined setting of the hospital despite a determination by treating physicians that a community-based treatment program would be appropriate for their continued care.³⁵ The plaintiffs, Lois Curtis and Elaine Wilson, both dually diagnosed with intellectual and psychiatric disabilities, were voluntarily admitted to a state hospital for mental health treatment; the hospital subsequently confined both women to the psychiatric

29. See *infra* Part IV.A for a discussion on the relationship between the precedent under Title II of the ADA and application of Section 504 of the Rehabilitation Act in integration regulation challenges.

30. *Davis v. Shah*, 821 F.3d 231, 259 (2d Cir. 2016) (“Because the standards imposed by Title II on public entities are generally equivalent to those of § 504, we ‘treat claims under the two statutes identically’” (quoting *Henrietta D. v. Bloomberg*, 331 F.3d 261, 272 (2d Cir. 2003))); *Steimel v. Wernert*, 823 F.3d 902, 909 (7th Cir. 2016) (“Because the relevant provisions of the Rehabilitation Act and its regulations are ‘materially identical’ to their ADA counterparts, courts ‘construe and apply them in a consistent manner.’” (quoting *Bruggeman ex rel. Bruggeman v. Blagojevich*, 324 F.3d 906, 912 (7th Cir. 2003)); *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 607 (7th Cir. 2004)); *Mitchell v. Cmty. Mental Health of Cent. Mich.*, 243 F. Supp. 3d 822, 842 (E.D. Mich. 2017) (“Other than section 504’s ‘limitation to denials of benefits “solely” by reasons of disability and its reach of only federal funded entities, the reach and requirements of both statutes are precisely the same.’” (quoting *S.S. v. Eastern Kentucky*, 532 F.3d 445, 453–454 (6th Cir. 2008))); *Radaszewski*, 383 F.3d at 607 (“Although our analysis shall focus on the ADA, that analysis applies with equal force to *Radaszewski*’s Rehabilitation Act claim.”); see also 28 C.F.R. pt. 35, app. B (“[T]he standards adopted by title II of the ADA for State and local government services are generally the same as those required under section 504 for federally assisted programs and activities.”); cf. *Pashby v. Delia*, 709 F.3d 307, 334 n.4 (4th Cir. 2013) (Agee, J., dissenting in part) (noting that it is an open question whether the integration regulation under the Rehabilitation Act encompasses claims of unjustified isolation as held in *Olmstead*).

31. Brief for the United States as Amicus Curiae at 23–25, *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999) (No. 98-536).

32. See *Olmstead*, 527 U.S. at 601 n.11.

33. See *id.*

34. See, e.g., *Mitchell*, 243 F. Supp. 3d at 841–42; see also *M.R. v. Dreyfus*, 697 F.3d 706, 733 (9th Cir. 2012) (Bea, C.T., dissenting) (discussing Congress’ intent in enacting the ADA was to “remedy society’s history of discriminating” against people with disabilities, including isolation, institutionalization and segregation).

35. *Olmstead*, 527 U.S. at 593–94.

unit.³⁶ Each desired to move from the hospital to a community-based setting where they would continue to receive appropriate treatment.³⁷

Curtis and Wilson argued that, once their treating physicians deemed a community-based placement appropriate for their continued treatment, defendants' decision to require their confinement to institutionalized care violated Title II of the ADA.³⁸ Since "most of the ADA/mental disability case law" that preceded *Olmstead* "focused on questions of professional licensure and examinations and on the range of accommodations necessary in employment situations," *Olmstead* provided the United States Supreme Court with its first meaningful opportunity to examine a regulation that had received little attention since the 1990 enactment of the ADA.³⁹

To this end, the Supreme Court held that the "unjustified isolation" of individuals with intellectual disabilities constituted discrimination under Title II of the ADA—this is commonly referred to as the *Olmstead* integration mandate of the ADA.⁴⁰ The mandate requires states to provide community-based treatment in the most integrated setting appropriate to the needs of the individual as a reasonable modification to avert unjustified isolation.⁴¹ Treatment professionals must deem the "community placement . . . appropriate" and the individual must not object to the placement.⁴² A state may avoid its affirmative duty under Title II only if the modification would fundamentally alter the nature of the State's program, service or activity.⁴³

Olmstead spurred deinstitutionalization policies that were already gaining ground since the 1970s as large-scale institutional settings that once warehoused intellectually disabled individuals steadily closed and community-based settings emerged.⁴⁴ Following *Olmstead*, however, the legal arsenal available to

36. *Id.* at 593.

37. *Id.*

38. *Id.* at 594.

39. Michael L. Perlin, *Make Promises by the Hour: Sex, Drugs, the ADA and Psychiatric Hospitalization*, 46 DEPAUL L. REV. 947, 960 (1997) [hereinafter Perlin, *Promises*].

40. *Olmstead*, 527 U.S. at 597.

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

42. *Id.* at 587. For the proposition that the treating physician must be given "the greatest of deference" together with the "appropriate deference" afforded to the financial costs imposed on the States to ensure that attempted compliance with *Olmstead* does not result in the placement of disabled institutionalized residents into integrated settings that are ill-equipped to handle their level of care and treatment, see *id.* at 610 (Kennedy, J., concurring).

43. *Id.* at 592 (citing 28 C.F.R. § 35.130(b)(7)(i) (1998)). In *Olmstead*, Georgia was entitled to balance the needs of those coming out of institutions with those in danger of being institutionalized; however, the State could not refuse to transfer institutional residents into community-based treatment programs merely because it wanted to keep the institutions open and functioning. *Id.* at 606; see generally *infra* Part V.A.

44. See Bagenstos, *Past and Future*, *supra* note 10, at 7. The deinstitutionalization movement that centered on moving persons with intellectual disabilities out of institutions is often contrasted with the failed policies around the deinstitutionalization of persons with psychiatric disabilities. For a more complete discussion on the successes and failures of the deinstitutionalization movement, see *id.* at 7–14.

challenge the unjustified institutionalization of intellectually disabled individuals strengthened; advocates now had the support of federal disability rights laws and a key Supreme Court decision to challenge how far the deinstitutionalization movement could go. *Olmstead* fostered the creative thinking of advocates to strategize on how the ruling could be applied beyond the context of deinstitutionalization.

Today, the movement for deinstitutionalization is no longer focused on getting people with intellectual disabilities out of institutions, but in utilizing Title II and Section 504 to compel states and private entities to provide adequate and appropriate community-based services to avert the risk of segregation and isolation *within the community*.⁴⁵ In 2010, to mark the eleventh anniversary of *Olmstead*, the Obama Administration launched “The Year of Community Living” tasking federal agencies to more vigorously enforce Title II of the ADA.⁴⁶ DOJ has filed, joined, or participated in over fifty *Olmstead* challenges since then.⁴⁷

As *Olmstead* jurisprudence expanded, one question lingered: What qualifies as an “integrated setting” in compliance with the *Olmstead* integration mandate? Largely as a result of successful litigation to enforce the *Olmstead* integration mandate, the modern definition of integrated setting began to take shape. Post-*Olmstead* litigation gradually established that “integrated setting” encompassed the right of intellectually disabled persons to access opportunities and services that are available to persons without disabilities. As a result, individuals with intellectual disabilities have gained greater access to community-based services, including housing,⁴⁸ mental health support,⁴⁹ educational opportunities,⁵⁰ and

45. See, e.g., CHARLES R. MOSELEY, NAT’L ASS’N OF STATE DIRS. OF DEVELOPMENTAL DISABILITIES SERVS., THE ADA, *OLMSTEAD*, AND MEDICAID: IMPLICATIONS FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES 13 (2013), http://www.nasdds.org/uploads/documents/ADA_Olmstead_and_Medicaid.pdf [<https://perma.cc/3ZAT-5YCF>]; Bagenstos, *Past and Future*, *supra* note 10, at 30; Friedman & Owen, *supra* note 11, at 388 (“While avoiding institutionalization was one of the original intents of the HCBS program, CMS has expanded on the rationale behind HCBS services and has been explicit in the aims of HCBS recipients gaining full access to the benefits of community living.” (internal quotation omitted)).

46. See *Olmstead: Community Integration for Everyone*, ADA.GOV, <https://www.ada.gov/olmstead/> [<https://perma.cc/KL2J-B9F6>] (last visited Nov. 8, 2017).

47. See *id.*; see also Bagenstos, *Past and Future*, *supra* note 10, at 5.

48. See, e.g., *Statement of the Department of Housing and Urban Development on the Role of Housing in Accomplishing the Goals of Olmstead*, U.S. DEP’T OF HOUSING & URBAN DEV., available at <https://www.hud.gov/sites/documents/OLMSTEADGUIDNC060413.PDF> [<https://perma.cc/HW7C-85NX>] (last visited Feb. 16, 2018). Courts are increasingly denying motions to dismiss in *Olmstead* integration claims for access to community-based housing. See, e.g., *Murphy v. Minn. Dep’t of Human Servs.*, 260 F. Supp. 3d 1084, 1118 (D. Minn. 2017) (denying a motion to dismiss a claim brought under the integration mandate for the State’s failure to provide access to individualized housing for eligible consumers); *Dunakin v. Quigley*, 99 F. Supp. 3d 1297, 1319–20 (W.D. Wash. 2015) (denying a motion to dismiss a claim under the integration mandate for the State’s failure to provide a disabled individual with adequate screening for and access to community housing).

49. *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

employment support;⁵¹ and have continued to achieve the meaningful community integration envisioned by Title II and *Olmstead*.

As discussed, *supra*, the definition of integrated setting continues to expand with the growing *Olmstead* jurisprudence to reflect a fuller conception of community integration—the right to self-determination, access to choice and personal development, and the opportunity to interact in all realms of human activity. It is through this holistic definition of community integration that sexuality must be considered. The movement for community integration fails to fully address the importance of sexuality in the lives of intellectually disabled individuals. Sexuality is critical to these goals but remains disregarded or stigmatized, largely due to the presumption that adults with intellectual disabilities are too disabled to engage in intimate or sexual relationships.⁵²

In exploring the sexual rights of group home residents, the question here is not whether adults with intellectual disabilities have a fundamental right to engage in consensual sexual conduct.⁵³ As discussed in Part IV.C, *infra*, the

developing community-based programs for” mental health care); *Olmstead Enforcement*, ADA.GOV, https://www.ada.gov/olmstead/olmstead_cases_list2.htm#lane [<https://perma.cc/J8AX-VECA>] (last visited Nov. 8, 2017) (discussing that in *United States v. New York*, the DOJ and the State of New York filed a settlement agreement ensuring receipt of community-based mental health services for the residents of twenty-three large group homes for disabled adults in New York City).

50. See, e.g., Letter from Vanita Gupta, Principal Deputy Assistant Attorney General, to the Honorable Nathan Deal, Office of the Governor & Sam Olens, Esq., Attorney General of Georgia (July 15, 2015), available at https://www.ada.gov/olmstead/documents/gnets_lof.pdf [<https://perma.cc/NSX4-W9RR>] (finding that the State of Georgia could make reasonable modifications to avoid discrimination by “redirect[ing] existing services, resources, training, and financial and human capital to appropriately integrate students with disabilities . . . into general education schools and offer them full and equal opportunities to participate in the electives, extracurricular activities, coursework, and other educational benefits and services enjoyed by their peers”). The DOJ filed a lawsuit against the State of Georgia after it issued its extensive findings that the state violated the ADA. See *United States v. Georgia*, No. 1:16-cv-03088 (N.D. Ga. filed Aug. 23, 2016). This case is currently stayed pending the resolution of a question in the Eleventh Circuit as to whether the DOJ has standing under Title II to pursue such claims. See *C.V. v. Dudek*, No. 12-cv-60460 (N.D. Fla. filed Aug. 7, 2017); see also *D.L. v. District of Columbia*, 845 F. Supp. 2d 1, 25–30 (D.D.C. 2011) (dictating numerical and programmatic requirements of the D.C. school system in order to cure the Section 504 violations by providing integrated educational services for pre-school-aged children with various disabilities), *vacated and remanded*, 713 F.3d 120 (D.C. Cir. 2013).

51. *Ball v. Kasich*, 244 F. Supp. 3d 662, 679 (S.D. Ohio 2017) (finding that federal law has “clarified that the integration mandate that applies to residential services applies to employment and day programs as well”); *Jensen v. Minn. Dep’t of Human Servs.*, 138 F. Supp. 3d 1068, 1072–73 (D. Minn. 2015) (class action decision approving the State’s court-ordered amended “*Olmstead* Plan” aimed at increasing the integration of supported employment services for individuals with developmental disabilities).

52. See *infra* Part III.D (discussing how the presumption of incapacity drives group home policies that limit access and opportunities for residents to exercise their sexual rights).

53. The question of whether adults with intellectual disabilities have a fundamental right under the Due Process Clause of the Fourteenth Amendment to engage in sexual conduct is beyond the scope of this Article. For a thoughtful discussion on the intersection of sexuality, mental health disability and constitutional rights, see generally Hannah Hicks, *The Right to Intimacy and*

current application of the integration regulations of Title II and Section 504 is based on the notion that disabled persons should have the opportunity to develop and thrive as full human beings with community-based services and other supports in an integrated environment that is tailored to their needs. The integration regulations, for example, do not hinge on whether the person has the fundamental right to work, to have an education, or to interact with non-disabled persons in the community; sexuality is not detached from this notion.⁵⁴

The question is, then, whether group homes provide intellectually disabled individuals with the opportunity to engage in matters related to sexuality through staff support and community-based services that, in turn, strengthen opportunities to create, maintain, and form intimate relationships like individuals without disabilities.⁵⁵ It is with this nuanced understanding of the meaning of an integrated setting that this Article analyzes sexual isolation as disability-based discrimination in violation of Section 504.

This analysis also does not overlook the need to protect adults with intellectual disabilities from sexual exploitation and abuse, but argues that the pendulum has swung too far when group homes presumptively take punitive steps in response to a resident's sexual expression. The Article presumes that adults with intellectual disabilities have the capacity to engage in sexual activity with supports.⁵⁶ This presumption does not negate—and is not mutually exclusive of—the need for persons with intellectual disabilities to receive varying degrees of supports and protection to ensure that sexual choices are consensual and free from abuse and exploitation.⁵⁷

Beyond: A Constitutional Argument for the Right to Sex in Mental Health Facilities, 40 N.Y.U. REV. L. & SOC. CHANGE 621 (2016) (arguing that institutionalized individuals with mental health disabilities maintain a constitutional right to engage in consensual sexual conduct).

54. Joseph J. Fischel & Hilary R. O'Connell, *Disabling Consent, or Reconstructing Sexual Autonomy*, 30 COLUM. J. GENDER & L. 428, 469–70 (2015) (“[T]here is no *prima facie* reason sex, sexuality, and intimacy should be any less important, or any less possible, for persons with intellectual disabilities, than, say, attending school or voting. . . . Enshrining sexual autonomy as a non-fungible central human capability also means that the sexuality and erotic flourishing of persons with (and without) disabilities cannot be so readily trivialized in relation to other human needs, rights, and aspirations.”).

55. See, e.g., U.S. DEP'T OF JUSTICE, CIVIL RIGHTS DIV., STATEMENT OF THE DEPARTMENT OF JUSTICE ON ENFORCEMENT OF THE INTEGRATION MANDATE OF TITLE II OF THE AMERICANS WITH DISABILITIES ACT AND *OLMSTEAD V. L.C.* (June 22, 2011), https://www.ada.gov/olmstead/q&a_olmstead.htm#_ftnref11 [<https://perma.cc/WHB3-LWK5>] [hereinafter DOJ Statement] (“Integrated settings are located in mainstream society; offer access to community activities and opportunities at times, frequencies and with persons of an individual’s choosing; afford individuals choice in their daily life activities; and, provide individuals with disabilities the opportunity to interact with non-disabled persons to the fullest extent possible.”).

56. See *infra* Part II.C.

57. See Perry Samowitz & Thomas-Robert Ames, *A Critique of the Current Status in Social/Sexual Rights for People with MR/DD* (June 2015) (unpublished manuscript) (on file with author); Thomas-Robert H. Ames & Perry Samowitz, *Inclusionary Standard for Determining Sexual Consent for Individuals with Developmental Disabilities*, 33 MENTAL RETARDATION 264, 265 (1995).

Part II gives a brief history of individuals with intellectual disabilities and sexual rights and examines the scholarship in this area of law. This Section further explores issues related to capacity and consent. Part III discusses the interplay of group homes and states in realizing community integration and the relationship between overprotective group home policies and sexual abuse. Part IV lays the framework to establish that sexual isolation constitutes a form of disability-based discrimination in violation of Section 504. The Article concludes by challenging the fundamental alteration defense against a claim of sexual isolation under the integration regulations and proposes reasonable modifications that group homes may undertake to avert sexual isolation. The proposed modifications strive to balance the sexual rights of residents against the risk of exploitation and abuse that may arise in intimate relationships with the need to uproot deeply held ideologies based on bias, paternalism, and ableism that drive group home decisions in matters of sexuality.

II.

INDIVIDUALS WITH INTELLECTUAL DISABILITIES AND SEXUAL RIGHTS

The administration of punitive and overprotective policies toward sexuality and the absence of sexuality services are intrinsically related to—and rooted in—disability-based discrimination that runs deep in the legal and socio-political history of the United States. This Part first discusses the history of sexuality and adults with intellectual disabilities. The discussion then explores how scholars approach the issue of sexual rights and intellectually disabled individuals, analyzing the strongly-held ideology of presumed incapacity as well as issues of capacity and consent, and proposes a theory for how to support the sexual rights of adults with intellectual disabilities in making choices related to sex and intimacy.

A. Historical Treatment of Individuals with Intellectual Disabilities and Their Sexual Rights

Now I am preparing a list of young women for operation. We have not fully decided whether to simply cut and tie the tubes, and thus isolate the ovaries, or remove the ovaries, and see if that will diminish sexual excitement. I rather think we will do the last named operation, or perhaps try each method on a part of the girls and compare results Our Dr. Frost, who has charge of our women's side, believes the removal of the ovaries, may in time diminish, or delay, sexual appetites.⁵⁸

58. JAMES W. TRENT, JR., *INVENTING THE FEEBLE MIND: A HISTORY OF MENTAL RETARDATION IN THE UNITED STATES* 197 (1994) (letter written by a school superintendent in 1916 documenting the planned sterilizations).

Historically, states regulated the sexuality of individuals with intellectual disabilities through the implementation of policies that served two primary purposes: to protect society by containing the “defective strain” that gave “rise to feeble-mindedness and sexual promiscuity”⁵⁹ and as a form of paternalism aimed at “rescu[ing] women from becoming victims of men’s lust and their own ‘weakness of self-control.’”⁶⁰ States initiated policies of forced sterilization, segregation of institutionalized individuals by sex, and prohibition of marriage.⁶¹

Individuals with intellectual disabilities were labeled as “idiots” and “feeble-minded,” with women particularly vulnerable to sexual control.⁶² Women were early targets of what would become a sweeping global eugenics movement that garnered strong early support between 1890 and 1920.⁶³ The goal of the eugenics movement was to create a “superior human stock” by eradicating the reproduction of undesirables, who would perpetuate cycles of “poverty, crime and vice, unwanted children, insanity, and feeble-mindedness.”⁶⁴

Wary of the constitutionality of such laws, states initially tiptoed carefully around enacting compulsory sterilization legislation.⁶⁵ Indiana passed the first involuntary sterilization law in 1907.⁶⁶ This wariness shifted following the 1927 United States Supreme Court case *Buck v. Bell*,⁶⁷ which upheld Virginia’s forced sterilization statute. Under Virginia law, the superintendent of a state institution for “[e]pileptics and the [f]eeble minded” had authority to undertake the involuntarily sterilization of residents.⁶⁸ Justice Oliver Wendell Holmes, a fervent supporter of eugenics, wrote the opinion for the Court. In a short majority opinion, he determined that it was the duty of society to “prevent those who are manifestly unfit from continuing their kind,” and ended the opinion with his now infamous words: “Three generation of imbeciles are enough.”⁶⁹ The United States’ eugenics movement resulted in over thirty states adopting involuntary sterilization statutes.⁷⁰

59. PAUL A. LOMBARDO, *THREE GENERATIONS, NO IMBECILES* 5 (2010).

60. TRENT, JR., *supra* note 58, at 103.

61. DUANE F. STROMAN, *THE DISABILITY RIGHTS MOVEMENT FROM DEINSTITUTIONALIZATION TO SELF-DETERMINATION* 151 (2003); *see also* LOMBARDO, *supra* note 59, at 5.

62. TRENT, JR., *supra* note 58, at 185, 197.

63. *Id.* at 76–77 (“The fear of unrestrained feeble-minded women ultimately found its voice among educators and superintendents” with the belief that “their moral lethargy became threats to common decency and to the well-ordered family.”); *id.* at 136. Women remained targets of eugenics policies well into the twentieth century. *See infra* note 83.

64. TRENT, JR., *supra* note 58, at 136; *see also* MENTAL RETARDATION IN AMERICA: A HISTORICAL READER 226–27 (Steven Noll & James W. Trent, Jr. eds., 2004).

65. *See, e.g.*, TRENT, JR., *supra* note 58, at 194.

66. ADAM COHEN, *IMBECILES* 5 (2016).

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

68. *Id.* at 205.

69. *Id.* at 207.

70. Paul Lombardo, *Eugenic Sterilization Laws*, IMAGE ARCHIVE ON THE AM. EUGENICS MOVEMENT, <http://www.eugenicsarchive.org/html/eugenics/essay8text.html> [<https://perma.cc/F6G8-LUTB>] (last visited Nov. 8, 2017); *see also* LOMBARDO, *supra* note 59, at 294 (listing the

Controlling the sexuality of women with intellectual disabilities was another driving element behind forced sterilizations. Female residents living in institutions endured pervasive oversight by institution staff to ensure they remained sexually virtuous.⁷¹ In 1917, Dr. Lewis Terman, a respected Stanford psychologist and pioneer of the IQ test, wrote “[t]hat every feeble-minded woman is a potential prostitute.”⁷² His argument rested on ethics, claiming that “[m]orality cannot flower and fruit if intelligence remains infantile.”⁷³

The first reported sterilization in a public institution for people with intellectual disabilities occurred in 1892.⁷⁴ The procedure involved the removal of a young woman’s “procreative organs,”⁷⁵ done behind a wall of institutional secrecy when no state had yet enacted compulsory sterilization statutes.⁷⁶ Lauding the success of this procedure, the overseer of the facility, Dr. Isaac Kerlin, remarked about the young woman,

When I see the tranquil well ordered [sic] life she is leading, her industry and usefulness in the circle in which she moves, and know that surgery has been her salvation from vice and degradation, I am deeply thankful to the benevolent lady whose loyalty to science and comprehensive charity made this operation possible.⁷⁷

The United State Supreme Court has not directly overturned *Buck v. Bell*. The biases that drove this nearly century-old decision continue to impact adults with intellectual disabilities in matters of love, intimacy, and family planning. In a recent Iowa decision, the guardian and mother of a twenty-two-year-old man with intellectual disability had her son sterilized without his consent because he was in a relationship with a woman and had admitted to having sex.⁷⁸ The son petitioned the court to remove his mother as guardian.⁷⁹ While the court questioned the constitutionality of the guardianship statute—maintaining that the

sterilization laws of thirty-two states as compiled in Julius Paul, “. . . Three Generations of Imbeciles Are Enough . . .”: State Eugenic Sterilization Laws in American Thought and Practice (1965) (unpublished manuscript). The chart does not include Puerto Rico, which passed a sterilization law in 1937 and repealed it in 1960. LOMBARDO, *supra* note 59, at 293.

71. See TRENT, JR., *supra* note 58, at 193.

72. LEWIS M. TERMAN, THE MEASUREMENT OF INTELLIGENCE 11 (1916), available at <https://archive.org/details/measurementofint008006mbp> [<https://perma.cc/FZZ3-JYQK>].

73. *Id.*

74. TRENT, JR., *supra* note 58, at 193.

75. *Id.*

76. *Id.* Indiana enacted the first compulsory sterilization statute in 1907 in the United States. *Indiana Eugenics History & Legacy 1907–2007*, IND. UNIV.-PURDUE UNIV., INDIANAPOLIS, <http://www.iupui.edu/~eugenics/> [<https://perma.cc/JLD5-Y5RS>] (last visited Feb. 16, 2018). The Indiana Supreme Court eventually found the statute unconstitutional and, in 1927, Indiana revised the statute, which remained in effect until its repeal in 1974. *Id.*

77. TRENT, JR., *supra* note 58, at 193.

78. *In re Guardianship of Kennedy*, 845 N.W.2d 707, 708 (Iowa 2014).

79. *Id.*

mother should have asked permission from the court before having her son sterilized—it upheld the mother’s right to remain as guardian of her son and did not rule on the constitutionality of the statute as applied to forced sterilization.⁸⁰

In *Vaughn v. Ruoff*, a case before a federal appeals court, child welfare agency workers told a parent with intellectual disabilities that if she consented to sterilization she would get her children back.⁸¹ Even though the mother underwent a tubal ligation, the child welfare agency moved forward to file a termination of parental rights action.⁸² The U.S. Court of Appeals for the Eighth Circuit upheld the lower court’s decision (i.e., that the child welfare agency workers violated the parent’s due process rights by coercing her to undergo sterilization), but cited to *Buck v. Bell* to note that “involuntary sterilization is not always unconstitutional if it is a narrowly tailored means to achieve a compelling government interest.”⁸³

The widely held belief that adults with intellectual disabilities cannot safely express themselves sexually is guided by ableist attitudes that perpetuate discriminatory laws and policies.⁸⁴ Ableism is a form of discrimination or oppression against disabled individuals that “can take the form of denial of rights

80. *Id.* at 715.

81. *Vaughn v. Ruoff*, 253 F.3d 1124, 1127–28 (8th Cir. 2001).

82. *Id.* at 1128.

83. *Id.* at 1129. *Vaughn* represents the lasting influence of the *Buck v. Bell* decision as interpreted by courts today. While the views toward sterilization did not begin to change until the 1960s, see LOMBARDO, *supra* note 59, at 319, the forced sterilization of people of color, disabled individuals, immigrants and poor women continued well into the 1960s and 1970s. See, e.g., Lutz Kaelber and students in HCOL195, *Eugenics/Sexual Sterilization in North Carolina*, UNIV. OF VT., <https://www.uvm.edu/~lkaelber/eugenics/NC/NC.html> [<https://perma.cc/4G55-2X6W>] (“By the late 1960s, the sterilization of men was virtually halted, as women made up 99% of those sterilized. African Americans represent 39% of those sterilized overall; by the later 1960s, they made up 60% of those sterilized, even though they made up only a quarter of the population. Of those sterilized up to 1963, 25% were considered mentally ill and 70% were considered mentally deficient. In each of these categories, females account for over 75% of the sterilizations.”); Sally J. Torpy, *Native American Women and Coerced Sterilization: On the Trail of Tears in the 1970s*, 24:2 AM. INDIAN CULTURE & RESEARCH J. 1, 1 (2000) (“Thousands of poor women and women of color, including Puerto Ricans, Blacks, and Chicanos, were sterilized in the 1970s, often without full knowledge of the surgical procedure performed on them or its physical and psychological ramifications. Native American women represented a unique class of victims among the larger population that faced sterilization and abuses of reproductive rights.”); *Relf v. Weinberger*, 372 F. Supp. 1196 (D.D.C. 1974), *vacated as moot*, 565 F.2d 722 (D.D.C. 1977) (lawsuit brought on behalf of two young black girls, ages twelve and fourteen, who were surgically sterilized without consent); see also Complaint at 8–9, *Relf*, 372 F. Supp. 1196 (No. 1557-73), available at https://www.splcenter.org/sites/default/files/d6_legacy_files/Relf_Original_Complaint.pdf [<https://perma.cc/R3WT-ZTEM>]. The *Relf* case exposed that between 100,000 and 150,000 people were forcefully sterilized under federally-funded programs. *Relf*, 372 F. Supp. at 1199. It was subsequently vacated as moot after the District of Columbia agreed to change its policies toward sterilization. See *Relf*, 565 F.2d at 727.

84. See, e.g., GILL, *supra* note 12, at 1–22. Ableist beliefs provide little space to view people with intellectual disabilities as having the same privileges and opportunities as able-bodied people. It is a matter of “what should we take away that they cannot handle?” (medical model of disability) instead of a matter of “how can they live their lives with the same freedoms everyone has by adjusting?” (social model of disability).

and access and the perpetuation of stigma, hatred, and othering.”⁸⁵ These ideologies are historically rooted in structural bias and oppression, wherein persons with intellectual disabilities are viewed as sexual predators or perpetual children who require protection and are incapable of providing a safe and nurturing environment to raise a child.⁸⁶

As documented by a survey of eighty-five adults with intellectual disabilities and caregiver perceptions about sex education, “[t]he individual with [intellectual disabilities] has been denied their right to sexual feelings and has been pictured as a perpetual child who is protected. Society holds to the myth that the individual with ID has not developed an interest in their own sexuality or the sexuality of others.”⁸⁷ Professor Perlin describes the societal attitudes toward sexuality and persons with disabilities as follows:

Society tends to infantilize the sexual urges, desires, and needs of the mentally disabled. Alternatively, they are regarded as possessing an animalistic hypersexuality, which warrants the imposition of special protections and limitations on their sexual behavior to stop them from acting on these “primitive” urges. By focusing on alleged “differentness,” we deny their basic humanity and their shared physical, emotional, and spiritual needs. By asserting that theirs is a primitive morality, we allow ourselves to censor their feelings and their actions. By denying their ability to show love and affection, we justify this disparate treatment.⁸⁸

In present day, explicit eugenics policies are a shameful chapter in history. Yet the power to limit the sexual rights of adults with intellectual disabilities is arguably driven by many of the same views that propelled the eugenics movement of the early twentieth century.

B. Scholarship on the Sexual Rights of Individuals with Intellectual Disabilities

Scholarship explores the issue of sexual rights in the context of state-run institutionalized settings such as nursing homes and hospitals, and focuses primarily on persons with mental illness and elderly individuals with dementia or

85. GILL, *supra* note 12, at 1.

86. See, e.g., NAT’L COUNCIL ON DISABILITY, ROCKING THE CRADLE: ENSURING RIGHTS OF PARENTS WITH INTELLECTUAL DISABILITIES AND THEIR CHILDREN 39–40 (Sept. 27, 2012), available at https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf [<https://perma.cc/X55Q-N37C>].

87. Amy Swango-Wilson, *Caregiver Perceptions and Implications for Sex Education for Individuals with Intellectual and Developmental Disabilities*, 26 *SEXUALITY & DISABILITY* 167, 168 (2008).

88. Michael Perlin, *Hospitalized Patients and the Right to Sexual Interaction: Beyond the Last Frontier?*, 20 *N.Y.U. REV. L. & SOC. CHANGE* 517, 537 (1993–1994) (footnotes omitted) [hereinafter Perlin, *Last Frontier*].

similar cognitive limitations.⁸⁹ The issue of sexuality and disability is also examined with an emphasis on questions of sexual consent capacity and sexual autonomy.⁹⁰ The literature in this area often fails to distinguish the unique challenges of individuals with intellectual disabilities in accessing sexual rights.⁹¹ As one scholar noted, the distinction between intellectual disability and other forms of limited mental capacity such as dementia “matters with respect to assessing sexual decision[making].”⁹²

Scholars have yet to explore the sexual rights of individuals with intellectual disabilities who live in private community-based settings that may resemble institutionalized care, such as group homes.⁹³ When the actor causing harm is not the state but a private entity that provides housing to intellectually disabled adults and plays an instrumental role in the administration of community-based services, what is the remedy and how is it sought? Michael Perlin and Allison J. Lynch recognized the possibility that the ADA could survive a challenge to overprotective policies of institutionalized settings “that prohibit all patients from meaningful, voluntary sexual interaction,”⁹⁴ but this analysis remains unexplored.

89. See generally Perlin & Lynch, *Sexless Patients*, *supra* note 6; Elizabeth Hill, *We'll Always Have Shady Pines: Surrogate Decision-Making Tools for Preserving Sexual Autonomy in Elderly Nursing Home Residents*, 20 WM. & MARY J. WOMEN & L. 469 (2014); Evelyn M. Tenenbaum, *Sexual Expression and Intimacy Between Nursing Home Residents with Dementia: Balancing the Current Interests and Prior Values of Heterosexual and LGBT Residents*, 21 TEMP. POL. & C.R. L. REV. 459 (2012); Evelyn M. Tenenbaum, *To Be or to Exist: Standards for Deciding Whether Dementia Patients in Nursing Homes Should Engage in Intimacy, Sex, and Adultery*, 42 IND. L. REV. 675 (2009) [hereinafter Tenenbaum, *To Be or to Exist*]; Melissa C. White, *The Eternal Flame: Capacity to Consent to Sexual Behavior Among Nursing Home Residents with Dementia*, 18 ELDER L.J. 133 (2010); J. Richard Lindsay, *The Need for More Specific Legislation in Sexual Consent Capacity Assessments for Nursing Home Residents: How Grandpa Got His Groove Back*, 31 J. LEGAL MED. 303 (2010); Michael Perlin, “Everybody Is Making Love/Or Else Expecting Rain”: *Considering the Sexual Autonomy Rights of Persons Institutionalized Because of Mental Disability in Forensic Hospitals and in Asia*, 83 WASH. L. REV. 481 (2008); Winiviere Sy, *The Right of Institutionalized Disabled Patients to Engage in Consensual Sexual Activity*, 23 WHITTIER L. REV. 545 (2001); Perlin, *Promises*, *supra* note 39; Perlin, *Last Frontier*, *supra* note 88.

90. See generally Alexander A. Boni-Saenz, *Sexual Advance Directives*, 68 ALA. L. REV. 1 (2016); Jasmine Harris, *The Role of Support in Sexual Decision-Making for People with Intellectual and Developmental Disabilities*, 77 OHIO ST. L.J. 83, 85 (2016); Alexander A. Boni-Saenz, *Sexuality and Incapacity*, 76 OHIO ST. L.J. 1201, 1234 (2015) [hereinafter Boni-Saenz, *Sexuality and Incapacity*]; Fischel & O’Connell, *supra* note 54; Daniel Pollack, Naphtali Harcsztark, Erin A. McGrath & Karen R. Cavanaugh, *The Capacity of a Mentally Retarded Person to Consent: An American and Jewish Legal Perspective*, 20 N.Y.L. SCH. J. INT’L & COMP. L. 197 (2000); Deborah W. Denno, *Sexuality, Rape, and Mental Retardation*, 1997 U. ILL. L. REV. 315 (1997).

91. See generally Boni-Saenz, *Sexuality and Incapacity*, *supra* note 90; Perlin & Lynch, *Sexless Patients*, *supra* note 6; cf. generally Harris, *supra* note 90.

92. Harris, *supra* note 90, at 86.

93. See generally Marissa DeBellis, *A Group Home Exclusively for Married Couples with Developmental Disabilities: A Natural Next-Step*, 28 TOURO L. REV. 451 (2012).

94. Perlin & Lynch, *Sexless Patients*, *supra* note 6, at 297; see also Jason Travers, Matt Tincani, Peggy Schaefer Whitby & E. Amanda Boutot, *Alignment of Sexuality Education with Self*

In examining the issue of sexual isolation as a violation of the integration mandate, I follow Leslie Salzman's theory that conceptualizes the integration mandate of Title II of the Americans with Disabilities Act as interpreted in *Olmstead v. L.C. ex rel. Zimring*⁹⁵ for disabled individuals who are subject to a form of segregation outside of the physical confines of an institution.⁹⁶ In her Article, Salzman establishes that guardianship is a presumptive violation of the *Olmstead* integration mandate under Title II of the ADA, soundly suggesting what cases only recently determined: "integration mandate cases need not be read to require some connection, however tangential, to isolation in a physical institution as a requirement for bringing an integration mandate challenge."⁹⁷ Salzman reasoned, "these cases can be read to go beyond the paradigm of physical isolation in an institution to support the general requirement of the integration mandate."⁹⁸

This Article expands on Salzman's theory by drawing from *Olmstead* jurisprudence to establish a basis for which the ADA's integration-mandate relative, Section 504 of the Rehabilitation Act, may be used to challenge the unjustified isolation of persons with intellectual disabilities and the denial of their sexual rights by group homes. This argument attempts to further expand the definition of what qualifies as an "integrated setting" under the ADA and Section 504. The hoped-for effect is twofold: on the one hand, it will prohibit overprotective and punitive policies that discriminatorily limit sexual rights; on the other, it will require access to community-based opportunities that will enable intellectually disabled individuals to achieve full community integration in matters related to sex and intimacy.⁹⁹

C. Uprooting the Presumption of Incapacity

In overcoming the deeply held ideology of presumed incapacity, a different lens must be taken up by group home operators, one that allows them to view intellectually disabled adults as sexual beings capable of engaging safely in matters of sex and intimacy. This Part bases its framework on a presumption that, with support, adults with intellectual disabilities have the capacity to consent to matters of sex and intimacy. This presumption is based on two notions: first, the established presumption of capacity that permeates American

Determination for People with Significant Disabilities: A Review of Research and Future Directions, 49 EDUC. & TRAINING IN AUTISM & DEVELOPMENTAL DISABILITIES 232, 242 (2014) (group homes "may have strict privacy policies that effectively prevent designing environments conducive to healthy sexual development, (e.g., restricting dating, masturbation, intercourse)").

95. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 587–607 (1999); see *infra* Part IV.C.

96. 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, 157 (2010).

97. *Id.* at 209; see *infra* Part IV.C.

98. Salzman, *supra* note 96, at 209.

99. See *infra* Part V.A.1.

law and jurisprudence in making fundamental life decisions¹⁰⁰ such as family planning,¹⁰¹ parenting,¹⁰² health care,¹⁰³ marriage,¹⁰⁴ and opposition to guardianship.¹⁰⁵ This presumption is equally applicable in the context of intellectually disabled individuals and their choices around sex and intimacy. Second, this framework rests on a belief that capacity is not a fixed state, but a fluid stream that can strengthen or diminish based on a number of factors; in other words, capacity fluctuates in different contexts with different people with differing abilities.¹⁰⁶ For example, an individual may have capacity to make health care decisions, but may lack capacity to enter into a contract. Or a parent with an intellectual disability may lack capacity to care for their child during a period of time, but gain the skills and tools to enhance any deficits that inhibited this ability.¹⁰⁷ The lack of sexuality supports inhibits intellectually disabled adults from gaining the skills necessary “to make informed choices leading to healthy relationships,”¹⁰⁸ leading to sexual isolation.¹⁰⁹

100. See, e.g., LA. STAT. ANN. § 28:454.3 (2017) (codifying the situations in which there is a presumption of capacity to give consent).

101. See *City of Akron v. Akron Ctr. for Reprod. Health*, 462 U.S. 416, 469 (1983); *Bellotti v. Baird*, 443 U.S. 622, 640 (1979); see, e.g., *Decker v. Carroll Aca.*, 1999 WL 332705, at *14 (Tenn. Ct. App. May 26, 1999).

102. See *Parham v. J.R.*, 442 U.S. 584, 602 (1979).

103. See *In re E.G.*, 549 N.E.2d 322, 324 (Ill. 1989); CAL. PROB. CODE § 4657 (*Deering* 2017); MONT. CODE ANN. § 53-21-1303(1) (2017); UTAH CODE ANN. § 75-2a-104(1)(a) (LexisNexis 2017).

104. See, e.g., *In re Estate of Hendrickson*, 805 P.2d 20, 24 (Kan. 1991); *Goldman v. Goldman*, 336 P.2d 952, 957 (Cal. Ct. App. 1959) (citing *In re Estate of Perkins*, 235 P. 45, 46 (Cal. 1925)); M. C. Dransfield, Annotation, *Mental Capacity to Marry*, 82 A.L.R.2d 1040, § 9 (1962) (“The general presumption is that a person who has contracted a marriage was mentally capable of contracting it, and the burden is on the party alleging mental incapacity to prove it.”).

105. FLA. STAT. ANN. § 393.12 (LexisNexis 2017); N.Y. MENTAL HYG. § 81.12(a) (Consol. 2017).

106. See, e.g., Robert D. Dinerstein, *Sexual Expression for Adults with Disabilities: The Role of Guardianship*, IMPACT, Spring/Summer 2010, at 12, <https://ici.umn.edu/products/impact/232/232.pdf> [<https://perma.cc/YR6F-4KPB>]; Martin Lyden, *Assessment of Sexual Consent Capacity*, 25 SEXUALITY & DISABILITY 3, 5 (2007).

107. See, e.g., U.S. DEP’T OF JUSTICE, CIVIL RIGHTS DIV. & DEP’T OF HEALTH & HUMAN SERVS., OFFICE FOR CIVIL RIGHTS, INVESTIGATION OF THE MASSACHUSETTS DEPARTMENT OF CHILDREN AND FAMILIES BY THE UNITED STATES DEPARTMENTS OF JUSTICE AND HEALTH AND HUMAN SERVICES PURSUANT TO THE AMERICANS WITH DISABILITIES ACT AND THE REHABILITATION ACT (2015), www.ada.gov/ma_docf_lof.pdf [<https://perma.cc/HF4F-KYHZ>] (investigation found that child welfare agency violated Title II of the ADA and Section 504 by failing to provide an intellectually disabled mother with appropriate supports and services that could assist her in achieving successful reunification with her child).

108. Travers, Tincani, Whitby & Boutot, *supra* note 94, at 233.

109. Jennifer Stinson, LeeAnn Christian & Lori Ann Dotson, *Overcoming Barriers to the Sexual Expression of Women with Developmental Disabilities*, 27 RES. & PRAC. FOR PERSONS WITH SEVERE DISABILITIES 18, 21 (2002) (discussing the lack of access to appropriate and comprehensive sex education for people with disabilities).

Group home employees are often the first to question a resident's capacity in matters related to sexuality.¹¹⁰ The issue commonly arises when a resident expresses a desire to exercise choices in their sexuality, whether it is to start a family and get married, as in Julia R.'s case, or to date or engage in a sexual relationship.¹¹¹ Group homes are licensed and receive state, local and federal funding to administer community-based services to their residents, but do not have any oversight mechanism to ensure respect of the resident's sexual rights and choices.¹¹² Fear of abuse and exploitation of individuals with intellectual disabilities, "an overarching paternalistic set of concerns about caretaker liability,"¹¹³ and the historically cemented presumption that intellectually disabled individuals lack capacity in matters of sexuality drive policies that indiscriminately police the sexuality of those in group homes.¹¹⁴

110. GILL, *supra* note 12, at 39.

111. *Id.*

112. For an in-depth discussion on the role of private entities in the administration of traditionally government programs and the enforcement of constitutional constraints and government power, see Gillian E. Metzger, *Privatization as Delegation*, 103 COLUM. L. REV. 1367 (2003). Professor Metzger's article raises questions that are applicable in the context of group homes and their power to limit a resident's sexuality rights and access to sexuality services through the Home and Community Based Services (HCBS) waiver program. See *infra* Part III.A for a discussion of the HCBS waiver program. For example, Professor Metzger argues,

[b]y effectively stepping into the government's shoes in its dealings with third parties, private entities are more likely to have access to powers that are distinctly governmental. These include not simply the ability to exert coercive powers on a nonconsensual basis, but also control over access to government resources and government programs. Particularly when privatization occurs in contexts where program participants or applicants have a great need for the government benefits and services at issue, private entities' roles in implementing government programs may significantly augment their powers over others and enhance their ability to cause harm. Moreover, this enhancement of private powers is often undertaken in lieu of direct government involvement

Metzger, *supra*, at 1462.

113. MICHAEL L. PERLIN & ALISON J. LYNCH, *SEXUALITY, DISABILITY, AND THE LAW: BEYOND THE LAST FRONTIER?* 114–17 (2016); A. Noonan & M. Taylor Gomez, *Who's Missing? Awareness of Lesbian, Gay, Bisexual and Transgender People with Intellectual Disability*, 29 *SEXUALITY & DISABILITY* 175, 177 (2011) ("Sexual consent causes the disability sector great concern and this concern revolves around service provider liability and not about the person's right to sexual expression.").

114. Tenenbaum, *To Be or to Exist*, *supra* note 89, at 680–88, 716; see also, e.g., Brian E. McGuire & Austin A. Bayley, *Relationships, Sexuality and Decision-Making Capacity in People with an Intellectual Disability*, 24 *CURRENT OPINION IN PSYCHIATRY* 398, 398 (2011) ("Recent surveys of caregivers and service providers do show a greater awareness of the fact that sexuality is a central part of personal identity, yet generally restrictive or prohibitive attitudes prevail at both individual and organizational levels. These attitudes appear to reflect a fear of possible legal sanction as well as ethical and moral conflicts."); Gillian Eastgate, Elly Scheermeyer, Mieke L. van Driel & Nick Lennox, *Intellectual Disability, Sexuality and Sexual Abuse Prevention: A Study of Family Members and Support Workers*, 41 *AUSTRALIAN FAM. PHYSICIAN* 135, 135 (2012) ("[A]ttitudes toward sexual expression may remain restrictive. . . . [L]egal rules regarding sexual behaviour may be confusing. Laws addressing sexual exploitation may be interpreted as prohibition of relationships." (footnotes omitted)); cf. *Foy v. Greenblott*, 141 Cal. Ct. App. 3d 1, 11–12 (1983) ("The threat of tort liability for insufficient vigilance in policing patients' sexual

The notion that capacity may be enhanced in different areas of one's life with appropriately tailored supportive services provides the foundation for the accommodation/modification mandates under the ADA and Section 504. Supports and services focused on strengthening adaptive functioning "have proven effective in increasing the mental capacity" of individuals with intellectual disabilities, including in areas of sexual consent capacity.¹¹⁵ Judge Marsha S. Berzon of the Ninth Circuit Court of Appeals recognized the danger in viewing intellectually disabled adults as either having or lacking the capacity to consent to sexual conduct. In her dissenting opinion in *Anderson v. Morrow*, she expressed the view that:

[t]his binary view of mentally retarded individuals . . . might well be an unconstitutional imposition on their sexual liberty. Despite the lack of a consistent clinical definition of what constitutes a 'valid' consent, there is clear consensus among experts in the field of mental retardation that mentally retarded individuals experience sexual desire and can meaningfully consent to sex in *some* situations.¹¹⁶

Age, cognitive abilities and many other factors affect the fluidity of capacity,¹¹⁷ which is likely why states have considerable trouble defining it in criminal and civil contexts alike.¹¹⁸ In the criminal law context, states like Alaska, California, Nebraska, North Dakota, and Utah have adopted the more

conduct and in second-guessing their reproductive decisions would effectively reverse these incentives and encourage mental hospitals to accord patients only their minimum legal rights.".)

115. Karen Andreasian, Natalie Chin, Kristin Booth Glen, Beth Haroules, Katherine I. Hermann, Maria Kuns, Aditi Shah & Naomi Weinstein, *Revisiting S.C.P.A 17-A: Guardianship for People with Intellectual and Developmental Disabilities*, 18 CUNY L. REV. 287, 294 (2015) (citing *Fact Sheet: Intellectual and Developmental Disabilities*, U.S. DEP'T OF HEALTH & HUMAN SERVS. (last updated Oct. 2010), <http://report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=100> [<http://perma.cc/LV7R-D2YH>]). For a definition of "adaptive functioning" see Part IV.B, *infra*.

116. *Anderson v. Morrow*, 371 F.3d 1027, 1045 (9th Cir. 2004) (Berzon, J., concurring in part and dissenting in part). The term "mental retardation" was the prevailing term at the time of this published opinion, but is no longer deemed appropriate in referring to individuals with intellectual disabilities. See, e.g., *Hall v. Florida*, 134 S. Ct. 1986, 1990 (2014) (recognizing the change in terminology from "mental retardation" to "intellectual disability").

117. Lyden, *supra* note 106, at 5 ("Capacity is a state and not a trait. It can vary over time. At one point in time, an individual with intellectual disabilities may be found incapable of having sexual relations due to knowledge deficits. Subsequently, if that individual receives sufficient training, education, counseling, and exposure to various social situations it may be possible to remedy the knowledge deficits."); see also *People v. Cratsley*, 653 N.E.2d 1162, 1165 (N.Y. 1995) (finding that New York "law does not presume that a person with mental retardation is unable to consent to sexual intercourse, and proof of incapacity must come from facts other than mental retardation alone" (internal citation omitted)).

118. See generally *State v. Mosbrucker*, 758 N.W.2d 663, 666–68 (N.D. 2008) (surveying jurisdictions); Lyden, *supra* note 106, at 5; see also Nancy J. Knauer, *Defining Capacity: Balancing the Competing Interests of Autonomy and Need*, 12 TEMP. POL. & CIV. RTS L.R. 321, 326 (2010). A discussion as to the criminal legal standards concerning the capacity to consent to sexual conduct is beyond the scope of this Article. For an in-depth analysis of state criminal sexual consent laws see Boni-Saenz, *Sexuality and Incapacity*, *supra* note 90, at 1217–23.

narrowly focused “nature and consequences” test.¹¹⁹ This test requires the individual to understand the sexual nature of the act itself as well as potential adverse consequences, such as unplanned pregnancy or sexually transmitted infections.¹²⁰ In contrast, states like Illinois, Michigan and New York adopt a an approach that is sometimes referred to as the “morality standard,” which requires an understanding of the nature and consequences of the sexual act itself and of its “moral quality,”¹²¹ while New Jersey and Arizona’s “nature of the conduct” test merely requires that the individual understand the sexual nature of the conduct.¹²²

In the civil context, state guardianship laws in the United States, for example, “start[] with the presumption of capacity”¹²³ before any judicial action may be taken to remove legal decision-making rights from a person subject to the guardianship proceeding. In guardianship, the person who seeks appointment as the legal guardian must overcome the presumption that the person who is subject to the guardianship has capacity. This presumption of capacity is based on standards that vary state-by-state, which have included as many as three different or combined tests to determine capacity: “[d]isabling condition[

119. ALASKA STAT. § 11.41.470(4) (2016); UTAH CODE ANN. 1953 § 76-5-111(m) (Westlaw 2017); *People v. Miranda*, 132 Cal. Rptr. 3d 315, 328–29 (Ct. App. 2011) (citing CAL. PENAL CODE § 261.6 (Deering 2017)); *People v. Griffin*, 49 P. 711 (Cal. 1897); *Mosbrucker*, 758 N.W.2d at 667; *Reavis v. Slominski*, 551 N.W.2d 528, 538 (Neb. 1996) (citing NEB. REV. STAT. ANN. §§ 28-319(1), 28-320(1) (LexisNexis 2017)); *Boni-Saenz, Sexuality and Incapacity*, *supra* note 90, at 1218.

120. ALASKA STAT. § 11.41.470(4) (“‘[M]entally incapable’ means suffering from a mental disease or defect that renders the person incapable of understanding the nature or consequences of the person’s conduct, including the potential for harm to that person[.]”); *Mosbrucker*, 758 N.W.2d at 667 (interpreting N.D. CENT. CODE § 12.1-20-03(1)(e) (2017)) (“[T]he statutory language is surely broad enough to encompass knowledge of the practical consequences of sexual intercourse such as unwanted pregnancy and sexually transmitted diseases, and we conclude the intermediate construction better reflects the legislative intent”); *see also Boni-Saenz, Sexuality and Incapacity*, *supra* note 90, at 1218 (“The physical consequences include the possibility of pleasurable sexual release, pregnancy, or sexually transmitted diseases. Nonphysical consequences consist of the potential feelings of mental pleasure or displeasure from the sexual encounter, mental consequences for one’s sense of self, or social consequences in the form of changes in the nature of relationships with others.”).

121. *People v. Easley*, 364 N.E.2d 1328, 1332–33 (N.Y. 1977) (interpreting N.Y. PENAL LAW § 130.00(5) (Consol. 2017)); *People v. Breck*, 584 N.W.2d 602, 605 (Mich. Ct. App. 1998) (interpreting MICH. COMP. LAWS SERV. § 750.520a(j)–(k) (LexisNexis 2017)); *People v. McMullen*, 414 N.E.2d 214, 217 (Ill. App. Ct. 1980); Lyden, *supra* note 106, at 5. New York’s legal standard, which has been adopted by Michigan and Illinois, is one of the most restrictive and conservative sexual consent capacity standards. *Id.* at 6.

122. *State v. Inzunza*, 316 P.3d 1266, 1272 (Ariz. Ct. App. 2014) (interpreting ARIZ. REV. STAT. § 13-1401(A)(7)(b) (LexisNexis 2017)); *State v. Olivio*, 589 A.2d 597, 600–05 (N.J. 1991) (interpreting N.J. REV. STAT. § 2C:14-2(a)(7) (2017)); *Boni-Saenz, Sexuality and Incapacity*, *supra* note 90, at 1220.

123. AM. BAR ASS’N COMM’N ON LAW & AGING & AM. PSYCHOLOGICAL ASS’N, ASSESSMENT OF OLDER ADULTS WITH DIMINISHED CAPACITY: A HANDBOOK FOR LAWYERS 7 (2005), <http://www.apa.org/pi/aging/resources/guides/diminished-capacity.pdf> [<https://perma.cc/P5HC-6FWW>] (“The criteria for a finding of incapacity differ among the states, but in all states, the law starts with the presumption of capacity.”).

f]unctional behavior . . . [, and c]ognitive functioning.”¹²⁴ If the presumption of capacity is overcome, guardianship is granted and the individual now under guardianship loses some or all of their legal decision-making powers on matters that may include where to live, with whom to socialize, and whether to marry and have children.¹²⁵

The Convention on the Rights of Persons with Disabilities (CRPD) also recognizes the right of “persons with disabilities” to “enjoy legal capacity on an equal basis with others in all aspects of life,”¹²⁶ building on the preamble which “recogniz[es] the need to promote and protect the human rights of all persons with disabilities, *including those who require more intensive support.*”¹²⁷ Although not ratified by the United States, the CRPD influences legal commentators and even some courts,¹²⁸ as well as entities such as the Uniform Law Commission¹²⁹ and the American Bar Association¹³⁰ in recognizing the rights of persons subject to guardianship.

Scholars and researchers suggest varying, but overlapping, criteria for assessing sexual consent capacity. These criteria for sexual consent include the

124. *Id.* at 7. Arguably, this presumption of capacity has fallen short in protecting those who are vulnerable to guardianship. State guardianship systems have failed to respect the right of self-determination for persons who are subject to guardianship by too easily stripping persons of their individual rights whose capacity is challenged under this system. *See, e.g.,* Kristen Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93, 123–24 (2012).

125. *See, e.g.,* N.Y. MENTAL HYG. LAW § 81.02 (McKinney 2012).

126. G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities art. 12 (Dec. 13, 2006).

127. *Id.* at pmb1. (emphasis added).

128. *See In re Guardianship of Dameris L.*, 38 Misc. 3d 570, 579–81 (Sur. Ct. N.Y. Cty. 2012).

129. The Uniform Law Commission (ULC) comprises lawyers, judges, legislators and legislative staff, and law professors who are appointed by state governments (including the District of Columbia, Puerto Rico and the U.S. Virgin Islands) to research, draft and promote the enactment of uniform state laws in areas of state statutory law where uniformity is “desirable and practical.” *About the ULC*, NAT’L CONF. OF COMM’RS ON UNIFORM STATE LAWS, <http://www.uniformlaws.org/Narrative.aspx?title=About%20the%20ULC> [<https://perma.cc/8WNG-N2FF>] (last visited Feb. 16, 2018). The ULC drafted the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (UGCOPAA), which “promotes person-centered planning to incorporate an individual’s preferences and values into a guardianship order, and requires courts to order the least-restrictive means necessary for protection of persons who are unable to fully care for themselves.” *Guardianship, Conservatorship, and Other Protective Arrangements Act*, <http://www.uniformlaws.org/Act.aspx?title=Guardianship,%20Conservatorship,%20and%20Other%20Protective%20Arrangements%20Act> [<https://perma.cc/MWR8-WRDP>] (last visited Feb. 16, 2018).

130. *See, e.g.,* AM. BAR ASS’N, COMMISSION ON DISABILITY RIGHTS SECTION OF CIVIL RIGHTS AND SOCIAL JUSTICE SECTION OF REAL PROPERTY, TRUST AND ESTATE LAW COMMISSION ON LAW AND AGING REPORT TO THE HOUSE OF DELEGATES RESOLUTION 6 (Aug. 2017), *available at* https://www.americanbar.org/content/dam/aba/administrative/law_aging/2017_SDM_%20Resolution_Final.authcheckdam.pdf [<https://perma.cc/XL4R-6TGV>] (last visited Feb. 16, 2018).

“knowing, intelligent, and voluntary agreement to engage in a given activity”¹³¹ and “having access to sexuality education, including information regarding potential risks, having the ability to engage responsibly in sexual behavior, and recognizing that there is a choice when asked to engage in sexual behavior.”¹³²

Other criteria include a “cognition-plus” analysis, which requires an understanding of choice absent coercion to engage in the specific sexual act and, only if volition is established, an examination of the individual’s ability to understand the consequences of engaging in the particular sexual choice.¹³³ If an ability to understand the consequences of engaging in the particular sexual choice is not found, the cognition-plus criteria allows for an inquiry into whether an “adequate . . . support system” is available to facilitate the sexual choice, which could then satisfy the criteria for sexual-consent capacity.¹³⁴

YAI, a network of non-profit agencies in New York City that advocates for the sexual rights of individuals with intellectual disabilities, administers supportive services and programs, including residential placements, to individuals with intellectual disabilities. YAI implemented a sexual consent policy over twenty years ago,¹³⁵ included with this Article online as Appendix 1, that it administers throughout its group homes and other residential settings.¹³⁶ The YAI sexual consent policy provides two criteria for assessing sexual consent capacity. The first category applies to individuals with the “ability to verbally give informed consent.”¹³⁷ The second category is tailored to individuals with

131. Fred Kaeser, *Can People with Severe Mental Retardation Consent to Mutual Sex?*, 10 *SEXUALITY & DISABILITY* 33, 35 (1992); see also Paul F. Stavis & Leslie W. Walker-Hirsch, *Consent to Sexual Activity* 57–67, in *AM. ASS’N ON MENTAL RETARDATION, A GUIDE TO CONSENT* (Robert D. Dinerstein, Stanley S. Herr & Joan L. Sullivan eds., 1999).

132. Carrie Hill Kennedy & John Niederbuhl, *Establishing Sexual Criteria for Sexual Consent Capacity*, 106 *AM. J. ON MENTAL RETARDATION* 503, 504 (2001) (citing Frank Conahan, Teresa Robinson & Brenda Miller, *A Case Study Relating to the Sexual Expression of a Man with Developmental Disability*, 11 *SEXUALITY & DISABILITY* 309 (1993)).

133. Boni-Saenz, *Sexuality and Incapacity*, *supra* note 90, at 1235–36; see also Harris, *supra* note 90 (challenging the applicability of the cognition-plus criteria to persons with intellectual disabilities).

134. Boni-Saenz, *Sexuality and Incapacity*, *supra* note 90, at 1236.

135. See Robert H. Thomas-Ames & Perry Samowitz, *Inclusionary Standard for Determining Sexual Consent for Individuals with Developmental Disabilities*, 33 *MENTAL RETARDATION* 264, 267 (1995) (proposing a model for administering sexual consent assessments for people with developmental disabilities “that is inclusive, realistic, and ethically and clinically responsible.” The assessment proposed by the authors was adopted by YAI).

136. See Appendix 1, Consuelo Senior, *The YAI Policy for Determining Sexual Consent* (June 14, 2017), available at https://socialchangenyu.com/wp-content/uploads/2018/04/Chin_42.3_Appendix1.pdf [hereinafter Appendix 1]. Appendix 1 has been reproduced with the permission of YAI. YAI retains all rights to Appendix 1. Any person or organization seeking to use YAI’s policy for any purpose, including reproduction, must get the express written consent of YAI. For a list of sexuality services offered by YAI, see *Find a YAI Service*, YAI, <https://www.yai.org/find-a-service> [<https://perma.cc/K76D-EXXX>] (last visited Feb. 17, 2018).

137. Appendix 1, *supra* note 136, at 3.

more severe developmental disabilities who can give “informed consent by communicating through responsible interpersonal behaviors.”¹³⁸

The assessments include a range of inquiries such as understanding the nature and consequences of the sexual act, including the choice to abstain; understanding the “need for restriction of sexual behavior as to time, place, or behavior”; and an understanding of voluntariness, avoidance of harm and the ability to stop unwanted sexual behavior.¹³⁹ This Article does not take a position on which particular criterion or set of criteria should be used to determine sexual consent capacity,¹⁴⁰ but argues for the necessity of an individualized, fact-specific inquiry¹⁴¹ based on the circumstances of the desired sexuality choice of the individual as a baseline in any capacity determination.

*D. The Social Model of Disability and the Theory of Human Connection,
Inclusion and the Presumption of Competence*

In framing sexual isolation as a violation of the integration regulations under Section 504, this Article seeks to reframe the perception of sexuality and intellectual disability as a positive right by applying—and integrating—the social model of disability¹⁴² with a relatively new theory of disability that is based on “human connectedness, inclusion, and the presumption of

138. *Id.* at 4.

139. *Id.* at 3.

140. There is no national standard to assess an individual’s capacity to engage in sexual activity. *See, e.g.,* Kennedy & Niederbuhl, *supra* note 132, at 504 (“[I]n the area of sexual consent, capacity standards are vague, psychologists have no agreed-upon guidelines, and the criteria vary depending upon the state in which a person resides.”); Lyden, *supra* note 106, at 16 (“Although there are some legal guidelines for determining sexual consent capacity, there has been a paucity of clinical standards.”). Some scholars have argued that sexual consent assessments are susceptible to bias and abuse by the administrator. *See, e.g.,* Roy G. Spece, Jr., John K. Hilton & Jeffrey N. Younggren, *(Implicit) Consent to Intimacy*, 50 IND. L. REV. 908, 910 (2017) (discussing how sexual consent assessments “[i]f incorrectly employed or relied upon as panaceas . . . can work against residents’ rights and best interests,” particularly in relation to individuals with dementia and similar cognitive impairments).

141. Guidance from the DOJ and the U.S. Department of Health and Human Services in addressing the rights of parents with intellectual disabilities in the child welfare system under Title II and Section 504 lends insight into what an individualized assessment would require. *Protecting the Rights of Parents and Prospective Parents with Disabilities: Technical Assistance for State and Local Child Welfare Agencies and Courts Under Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act*, DEP’T OF HEALTH & HUMAN SERVS. & DEP’T OF JUSTICE (Aug. 2015), https://www.ada.gov/doj_hhs_ta/child_welfare_ta.html [<https://perma.cc/2ZFG-JMQM>]. The DOJ defined an individualized assessment as a “fact-specific inquiry that evaluates the strengths, needs, and capabilities of a particular person with disabilities based on objective evidence, personal circumstances, demonstrated competencies, and other factors that are divorced from generalizations and stereotypes regarding people with disabilities.” *Id.*

142. For a thorough analysis of the social model of disability, and of the various other models of disability, see Arlene Kanter, *The Law: What’s Disability Studies Got to Do with It or an Introduction to Disability Legal Studies*, 42 COLUM. HUM. RTS. L. REV. 403, 419–33 (2011).

competence.”¹⁴³ The social model challenges the once-prevalent medical approach to disability,¹⁴⁴ “plac[ing] the responsibility squarely on society (and not on the individual with a disability) to remove the physical and attitudinal barriers that ‘disable’ people with various impairments, and prevent them from exercising their rights and fully integrating into society.”¹⁴⁵ In essence, under the social model, disability is not viewed through the lens of deficiency, but as an aspect of a person’s identity to which society must adapt.

In a recent essay, *At the End of Intellectual Disability*, the authors espouse a new theory of disability that this Article adopts as a necessary principle to incorporate into the social model to advance the sexual rights of intellectually disabled individuals.¹⁴⁶ In this essay, the authors contend that those labeled as intellectually disabled are channeled into a life of “hopeless disconnection” because the people around them harbor expectations driven by false presumptions of failure and inadequacy.¹⁴⁷ To challenge this narrative, the authors “expose and deconstruct the pessimistic fable of intellectual disability.”¹⁴⁸

In other words, the “social contexts” to which disability is treated as an immutable deficit can be altered to allow for a presumption of competency, connectedness and inclusion.¹⁴⁹ This alteration requires people to “confront their own deeply held deficit ideologies” and “deficit-driven characterizations” that are attached to intellectual disability.¹⁵⁰ Applied to the context of group homes, those that provide supports and services must not only eliminate overprotective policies that penalize sexual expression and provide sexuality services to residents who wish to engage in intimate relationships (social model of disability), but must also support residents’ decisions around sexuality *that allow*

143. Christopher Kliever, Douglas Biklen & Amy J. Petersen, *At the End of Intellectual Disability*, 85 HARV. EDUC. REV. 1, 3 (2015).

144. The medicalized approach, or “medical model,” emphasized the individual’s deficits with the goal of curing the person. See Susan Gabel & Susan Peters, *Presage of a Paradigm Shift? Beyond the Social Model of Disability Toward Resistance Theories of Disability*, 19 DISABILITY & SOC’Y 585, 588 (2004) (describing the medical model as “an objectivist account of disability . . . used to explain, diagnose, treat, and ‘cure’ disability as pathology”).

145. Kanter, *supra* note 142, at 427; see also Kristen Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93, 126 (2012) (arguing that, outside of the *Olmstead* context, intellectually disabled individuals are underrepresented in the advancements stemming from successful ADA litigation even though the passage of the ADA is largely viewed “as a milestone in the struggle for inclusion and integration, explicitly recognizing that socially-created conditions and barriers . . . are the cause of exclusion and nonparticipation”).

146. Kliever, Biklen & Petersen, *supra* note 143, at 2–3.

147. *Id.* at 2; see also GILL, *supra* note 12, at 37 (describing how the social and cultural construct of intellectual disability results in the perception that intellectually disabled individuals are viewed by society as “less than”).

148. Kliever, Biklen & Petersen, *supra* note 143, at 2.

149. *Id.* at 18.

150. *Id.* at 14, 15.

for a “demonstration of competence.”¹⁵¹ Exercising the presumption of competence compels the provider of the supports to identify new ways to allow for engagement and connection, if such efforts are initially unsuccessful.¹⁵²

The social model views the limitations on exercising choice and the inability to realize community integration in areas such as sexuality as byproducts of the barriers erected by a society that promotes ableist and exclusionary power structures.¹⁵³ Title II and Section 504 are legal mechanisms that draw from the social model of disability by placing an affirmative duty on specified entities to adjust policies, procedures and physical barriers to create access and opportunity for persons with disabilities that are equal to those available to persons without disabilities. Nevertheless, the desexualization of intellectually disabled individuals¹⁵⁴ persists despite the successes of the social model to advance community integration.

At the End of Intellectual Disability proposes a presumption of competence and asks support providers to shed their deficit-driven thinking and treat each individual as “a full participant across the breadth of social and cultural opportunities presented in nurturing contexts.”¹⁵⁵ This approach builds on the social model of disability, adding a layer that addresses human connection. Changing policies and providing supports alone, without reframing the capacity standard to include a commitment to build on the individual’s strengths and identify and provide the needed supports (and unpacking the bias, paternalism and ableism that drive group-home decisions in matters of sexuality), will perpetually subject residents with intellectual disabilities to presumed incapacity. In such a status quo, full community integration as it relates to opportunities for human connection and intimacy may never be realized.¹⁵⁶ The post-*Olmstead* cases reflect the limitations of community integration within the social model of disability as applied to sexual rights and intellectually disabled individuals.¹⁵⁷

151. *Id.* at 24.

152. *See id.*

153. *See* Gabel & Peters, *supra* note 144, at 594.

154. *See* Emens, *supra* note 5, at 1325–30.

155. Kliever, Biklen & Petersen, *supra* note 143, at 11.

156. *See, e.g.,* GILL, *supra* note 12, at 3 (“Connected to the ‘we know what’s best’ paternalism is the application of able-bodied standards to adults with intellectual disabilities, who are perceived as perpetual children (as IQ is often translated into mental age), thereby erasing the embodied knowledge and unique epistemology about life and physical maturity of individuals with intellectual disabilities. The erasure of knowledge and experience, especially in relation to purposeful, meaningful, and sexual life, further illustrates” both the devaluation “of disability as a valuable difference that yields unique perspectives of personhood, competence, sexuality, agency, and ability” and the structural bias that impedes access to sex and intimacy for intellectually disabled adults).

157. *See, e.g.,* Suzanne Doyle, *The Notion of Consent to Sexual Activity for Persons with Mental Disabilities*, 31 LIVERPOOL L. REV. 111, 113 (2010) (“Although the last two decades have seen the application of the social model of disability transform societal perceptions of disability, the issue of sexuality and sexual behaviour, particularly for persons with mental disabilities, has not been subject to the same level of debate and advocacy.”). *But see* Ani B. Satz, *Disability*,

III.

THE INTERPLAY OF GROUP HOMES AND STATES IN EFFECTUATING THE
OLMSTEAD INTEGRATION MANDATE

Twenty-eight years after the passage of the Americans with Disabilities Act, persons with intellectual disabilities remain in the shadows of full community integration. This Section provides an overview of the Home and Community Based Services waiver program and examines how the interplay between this joint federal-state program and the role of group homes creates a form of intimate discrimination that perpetuates sexual isolation and fosters the sexual exploitation and abuse of persons with intellectual disabilities.¹⁵⁸

A. The Home and Community-Based Services Waiver Program

Over the last several decades, institutionalized settings have closed their doors, as smaller, community-based settings are made available to provide community-based services to individuals with intellectual disabilities.¹⁵⁹ With the shift from public institutions to private community-based settings, states have taken a hands-off approach in the day-to-day administration of community-based services to individuals with intellectual disabilities. The number of state-run institutions waned to approximately 27,610, as reported in 2012—a decline of 85.5% since the height of institutionalization in 1967.¹⁶⁰ Approximately 92% (443,052) of persons with intellectual disabilities who do not reside with family live in a non-state residential setting versus 8% (35,602) who live in state-operated settings.¹⁶¹

Vulnerability, and the Limits of Anti-Discrimination, 83 WASH. L. REV. 513, 546 (2008) (“The problem, however, is not with the social model of disability, but with its current application under the ADA. It is the restricted scope of the environment rather than the concept of disability as socially constructed, or a civil rights approach more generally, that undermines protections.”).

158. Emens, *supra* note 5, at 1390–96.

159. See DAVID BRADDOCK, RICHARD HEMP, MARY C. RIZZOLO, EMILY SHEA TANIS, LAURA HAFFER & JIANG WU, *THE STATE OF THE STATES IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: EMERGING FROM THE GREAT RECESSION 20–25* (providing a state-by-state report on the services available to individuals with I/DD) (2015) [hereinafter BRADDOCK 2015]; see also Noll & Trent, *supra* note 64, at 4 (“[N]ational awareness of civil rights led to public policy shifts in the late 1960s and 1970s. By the mid-1970s, the segregated public institutions and special classrooms lost favor with politicians, professionals, and the public. State officials eager to shift the funding of services from state to federal sources joined with parents ready to advocate for mainstream services for their disabled children.”).

160. LARSON 2014, *supra* note 2, at 121.

161. See SHERYL LARSON, *IN-HOME AND RESIDENTIAL LONG-TERM SUPPORTS AND SERVICES FOR PERSONS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS THROUGH 2013*, 26–27 (Inst. on Cmty. Integration, Univ. of Minn.: Nat’l Residential Info Sys. Project ed., 2016), https://risp.umn.edu/media/download/cms/media/risp/RISP2013_WEB.pdf [<https://perma.cc/SMZ8-WH6S>] [hereinafter LARSON 2013]. In this national study, forty-nine states reported the number and size of state-operated residential settings while only twenty-five states reported this information on non-state residential settings. *Id.* at 24. As a result, this statistic underrepresents the number of persons with intellectual disabilities living in non-state residential facilities.

In a 1981 amendment, Congress added Section 1915(c) to the Social Security Act, allowing the Secretary of the Department of Health and Human Services (HHS) to waive certain Medicaid statutory requirements for states receiving federal funding to develop tailored, community-based programs and services for persons with intellectual disabilities, and other specified populations.¹⁶² Often referred to as the 1915(c) Medicaid waiver (Medicaid waiver) or the Home and Community-Based Services (HCBS) waiver, the purpose of the waiver program is for states to provide community-based supports and services so that target populations are not unnecessarily institutionalized and segregated.¹⁶³ Through a complex scheme of federal statutory and regulatory guidelines,¹⁶⁴ the HCBS waiver program provides federal funding for states to offer services to qualified Medicaid beneficiaries who need a level of institutionalized care that can be provided through community-based supports.¹⁶⁵

The HCBS waiver program is the principle means for low-income people with intellectual disabilities to secure support services in the community.¹⁶⁶ Prior to the implementation of the waiver program, Medicaid was a primary source of funding for institutions that served people with intellectual disabilities.¹⁶⁷ With the expansion of the HCBS waiver program and the steady closure of large institutions, Medicaid funding that once went to institutionalized care has largely been redirected to community-based supports and services.¹⁶⁸

162. See 42 U.S.C. § 1396n; see also CTRS. FOR MEDICARE & MEDICAID SERVS., APPLICATION FOR A § 1915(C) HOME AND COMMUNITY-BASED WAIVER: INSTRUCTIONS, TECHNICAL GUIDE AND REVIEW CRITERIA 4–5 (2015), <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/downloads/technical-guidance.pdf> [<https://perma.cc/JP89-3AHY>] [hereinafter CTRS. FOR MEDICARE & MEDICAID SERVS.] (listing the groups of individuals that could benefit from such a waiver and noting that “[i]t is entirely a state option to offer waiver services through its Medicaid program”).

163. See, e.g., MaryBeth Musumeci & Henry Claypool, *Olmstead’s Role in Community Integration for People with Disabilities Under Medicaid: 15 Years After the Supreme Court’s Olmstead Decision* 4, KAISER COMM’N ON MEDICAID & THE UNINSURED (June 2014), available at <http://files.kff.org/attachment/issue-brief-olmsteads-role-in-community-integration-for-people-with-disabilities-under-medicaid-15-years-after-the-supreme-courts-olmstead-decision> [<https://perma.cc/86V5-M7TP>]; see also 42 U.S.C. § 1396n(c)(1); 42 C.F.R. § 440.180.

164. Through federal statutory requirements detailed in 42 U.S.C. § 1396n, states develop individualized HCBS waivers; each state chooses what waiver services to provide and devises a statutory and regulatory framework for how its HCBS waiver program is administered to its target populations. See, e.g., CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 162; see also *Guggenberger v. Minnesota*, 198 F. Supp. 3d 973, 1004 (D. Minn. 2016) (“States are not obligated to participate in Medicaid; however, if they choose to do so, states must comply with federal law in administering their Medicaid programs.”).

165. See 42 U.S.C. § 1396n; see also CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 162, at 4–5.

166. BRADDOCK 2015, *supra* note 159, at 32.

167. Musumeci & Claypool, *supra* note 163, at 4.

168. BRADDOCK 2015, *supra* note 159, at 37; CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 162, at 4 (“Prior to the enactment of §1915(c), the Medicaid program provided for little in the way of coverage for long term services and supports in non-institutional settings but offered

Today states receive approximately \$19.5 billion dollars of federal funding for HCBS waiver program spending to serve an estimated 741,285 individuals with intellectual and developmental disabilities in support of community integration.¹⁶⁹ State and local governments contribute to the funding received by the federal government to sustain its supports and services for the intellectually disabled population.¹⁷⁰ Community-based services are delivered primarily through private non-profit agencies to individuals who reside in community-based settings,¹⁷¹ such as a group homes, a family home or the individuals' private home.

The HCBS waiver program covers services that ordinary Medicaid does not cover such as community-based day programs, counseling and residential habilitation,¹⁷² "case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care."¹⁷³

The Centers for Medicare & Medicaid Services (CMS), an agency within the Department of Health and Human Services, is the federal agency that approves state requests for HCBS waiver program funding.¹⁷⁴ There is no limit as to the number of waivers a state may develop and operate if the waiver meets the required qualifications under CMS,¹⁷⁵ and multiple services may be offered under each approved waiver.¹⁷⁶ Participating states must comply with a complex set of requirements outlined in § 1915(c) of the Social Security Act to qualify for waiver funding. Under 1915(c) states must:

full or partial coverage of institutional care. §1915(c) was enacted to enable states to address the needs of individuals who would otherwise receive costly institutional care by furnishing cost-effective services to assist them to remain in their homes and communities.”).

169. See DAVID BRADDOCK, RICHARD HEMP, EMILY SHEA TANIS, LAURA HAFFER & JIANG WU, *THE STATE OF THE STATES IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, STATE PROFILES FOR IDD SPENDING DURING FISCAL YEARS 1977–2015 2* (2017), <http://stateofthestates.org/documents/UnitedStates.pdf> [<https://perma.cc/5UWR-JMQF>] [hereinafter BRADDOCK 2017].

170. For a state-by-state breakdown of state spending for community services during FY 2011–2013, see BRADDOCK 2015, *supra* note 159, at 10–12. The amount of federal HCBS waiver funding received by states varies, anywhere from \$44.5 million (Nevada) to \$2.72 billion (New York). *Id.* at 154, 162. Nevada contributed \$79.1 million and New York contributed \$5.35 billion in spending toward supports and services for the intellectually disabled population. *Id.*

171. BRADDOCK 2015, *supra* note 159, at 6.

172. Residential habilitation services are defined as “individually tailored supports that assist with the acquisition, retention, or improvement in skills related to living in the community. These supports include adaptive skill development, assistance with activities of daily living, community inclusion, transportation, adult educational supports, social and leisure skill development, that assist the participant to reside in the most integrated setting appropriate to his/her needs. Residential habilitation also includes personal care and protective oversight and supervision.” CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 162, at 147.

173. BRADDOCK 2015, *supra* note 159, at 37.

174. See, e.g., *Home & Community-Based Services 1915(c)*, MEDICAID.GOV, <https://www.medicaid.gov/medicaid/hcbs/authorities/1915-c/index.html> [<https://perma.cc/SG8N-75PZ>] (last visited Mar. 13, 2018).

175. See *id.*

176. See *id.*

Demonstrate that providing waiver services won't cost more than providing these services in an institution [, (2)] Ensure the protection of people's health and welfare [, (3)] Provide adequate and reasonable provider standards to meet the needs of the target population [, and (4)] Ensure that services follow an individualized and person-centered plan of care.¹⁷⁷

States must first apply to CMS for approval of the waiver.¹⁷⁸ States direct the precise scope and coverage of the HCBS waiver, determining “what services may be provided, how the services are to be provided, and what types of providers may provide the services.”¹⁷⁹ States must allocate funding for each specific waiver and identify “how many participants will receive those services, how many units of services the average participant will receive, and reimbursement rates.”¹⁸⁰ CMS may approve waivers for additional periods of time upon a renewal application submitted by the State.¹⁸¹ States have the option to amend the services provided under its waivers.¹⁸² CMS has ninety days to approve or deny an application for a new waiver, or a renewal or amendment to a waiver.¹⁸³

B. Group Home Settings

Group homes are licensed by states to administer varying levels of community-based services and supports to intellectually disabled individuals who reside in the community, and are primarily operated by private agencies.¹⁸⁴ Private facilities “operate[] 99.8% of [residential] settings with 1 to 3 people, 97% of the settings with 4 to 6 people, 89% of the settings with 7 to 15 people, and 86% of the settings with 16 or more people.”¹⁸⁵ In 2014, in response to growing concerns that group homes and other community-based residential settings began to resemble a form of institutionalized care in violation of Title II and *Olmstead*, CMS enacted a sweeping set of regulations regarding the

177. *Id.*

178. See 42 U.S.C. § 1396n(c)(3).

179. Carli Friedman, *Day Habilitation Services for People with Intellectual and Developmental Disabilities in Medicaid Home and Community-Based Services Waivers*, 41 RES. & PRAC. FOR PERSONS WITH SEVERE DISABILITIES 244, 245 (2016) [hereinafter Friedman, *Day Habilitation*].

180. *Id.*

181. 42 C.F.R. § 430.25(h)(ii); CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 162, at 20.

182. CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 162, at 282–84.

183. 42 C.F.R. § 430.25(f)(3).

184. See, e.g., *Group Homes for Persons with Intellectual Disabilities*, DC.GOV, <https://doh.dc.gov/service/group-homes-persons-intellectual-disabilities> [<https://perma.cc/TVA5-R4RV>] (last visited Nov. 11, 2017).

185. LARSON 2013, *supra* note 161, at 27.

administration of the HCBS waiver program.¹⁸⁶ More commonly referred to as the “HCBS Settings Rule,” the regulation requires states to submit evidence to CMS that waiver services are being delivered in community-based residential settings that comply with the requirement of the HCBS Settings Rule. If states fail to comply, the federal government may withhold Medicaid reimbursements for services administered through the waiver program.¹⁸⁷

Specifically, states must submit evidence to CMS that the residential settings administering services through the HCBS waiver program are:

integrated in, and support[] full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.¹⁸⁸

In matters of autonomy and choice, the HCBS Settings Rule creates an individualized approach to residential care,¹⁸⁹ shifting the power dynamic¹⁹⁰ so that residents are ensured a “right[] of privacy, dignity and respect, and freedom from coercion and restraint.”¹⁹¹ The rule also requires that residential settings provide an environment that “[o]ptimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.”¹⁹²

186. See 42 C.F.R. § 441.301. In the 1970s and 1980s, as the deinstitutionalization movement progressed, group homes were largely “viewed as the best alternative to institutionalization.” Arlene S. Kanter, *A Home of One’s Own: The Fair Housing Amendments Act of 1988 and Housing Discrimination Against People with Mental Disabilities*, 43 AM. U. L. REV. 925, 932 (1994). For decades prior to the implementation of the HCBS Setting Rule, however, group homes were largely viewed as mini-institutions. See *supra* note 10; see, e.g., Bagenstos, *Past and Future*, *supra* note 10.

187. *Id.*; THE ARC, THE 2014 FEDERAL HOME AND COMMUNITY-BASED SERVICES REGULATION: WHAT YOU NEED TO KNOW 6 (2014), <https://www.thearc.org/document.doc?id=4596> [<https://perma.cc/2N2J-8MYA>] (“In order to receive Medicaid reimbursement from the federal government for providing home and community-based services, states must ensure that the services are delivered in settings that meet the new definition of home and community-based (HCB) setting.”).

188. 42 C.F.R. § 441.301(c)(2)(i).

189. *Fact Sheet: Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings Final Rule (CMS 2249-F/2296-F)*, DEP’T OF HEALTH & HUMAN SERVS. (Jan. 10, 2014), <https://www.medicaid.gov/medicaid/hcbs/downloads/hcbs-setting-fact-sheet.pdf> [<https://perma.cc/AZ5G-FRV9>] (The “final rule establishes requirements for the qualities of settings that are eligible for reimbursement for the Medicaid home and community-based services (HCBS) provided under sections 1915(c). . . . must be supported by a specific assessed need and justified in the person-centered service plan.”) [hereinafter HCBS Fact Sheet].

190. See *infra* Part III.C.

191. 42 C.F.R. § 441.301(c)(4)(iii).

192. *Id.*

CMS provided a time period for states to comply with the HCBS Setting Rule, with a current deadline of March 2022.¹⁹³

The HCBS Settings Rule reflects the understanding that community integration that is devoid of privacy, autonomy and choice is, in effect, a diluted form of institutionalized care. With greater scrutiny now placed on residential settings that purport to comply with community integration under Title II and Section 504, the new HCBS Settings Rule may push group homes to revise their approach to issues of sexuality and provide a greater tool for residents in advocating for their sexual rights.

C. Perpetuating Sexual Exploitation in the Name of Protection

The success of community integration rests largely on the interplay of the state agencies that administer community-based services and the structural systems that are tasked with identifying and administering services to intellectually disabled individuals. Although the general goal of the state agencies and group home operators is successful community integration in all areas of the individual's life, these systems often perpetuate the desexualization of intellectually disabled adults—where “isolation and exclusion from the intimate realm altogether”¹⁹⁴ is the norm. This interplay creates a form of “intimate discrimination at a structural level,”¹⁹⁵ one that reinforces the barriers that prevent persons with intellectual disabilities from developing healthy sexual and intimate relationships.

State agencies shoulder equal power with group homes in how community-based services are administered; “the culture, expectations, resources, and available accommodation options established within individual state, developmental disabilities service systems have significant effect on the extent to which people are actually afforded significant say in the decisions that affect their lives.”¹⁹⁶ With state agencies paying little attention to their day-to-day operations, group homes that are responsible for supporting the independence and self-determination of intellectually disabled individuals have established

193. CMS released a public notice on May 9, 2017, announcing that the deadline for states to be in compliance with the HCBS rule standards will be extended from March 17, 2019 to March 17, 2022. *CMCS Informational Bulletin, Extension of Transition Period for Compliance with Home and Community-Based Settings Criteria*, DEP'T OF HEALTH & HUMAN SERVS. (May 9, 2017), available at <https://www.medicaid.gov/federal-policy-guidance/downloads/cib050917.pdf> [<https://perma.cc/8DQQ-QDFK>].

194. Emens, *supra* note 5, at 1381.

195. *Id.* at 1309.

196. Renáta Tichá, K. Charlie Lakin, Sheryl A. Larson, Roger J. Stancliffe, Sarah Taub, Joshua Engler, Julie Bershasky & Charles Moseley, *Correlates of Everyday Choice and Support-Related Choice for 8,892 Randomly Sampled Adults with Intellectual and Developmental Disabilities in 19 States*, 50 *INTELLECTUAL & DEVELOPMENTAL DISABILITIES* 486, 502 (2012). This role of States in the administration of sexuality services for intellectual disabilities individuals is not directly addressed in this Article.

their role in limiting the sexual rights of their residents.¹⁹⁷ These power structures have buried the voice of adults with intellectual disabilities residing in community-based settings; they cannot participate in choices of sex and intimacy because sexuality is shamed and punished, and proactive sexuality services¹⁹⁸ are not provided.

Although group home operators aim to shield persons with intellectual disabilities from sexual exploitation and abuse, scholars have long believed that overprotective and punitive policies toward expressions of sexuality and the lack of access to sexuality services places individuals with intellectual disabilities at a great risk of sexual abuse and exploitation.¹⁹⁹ Individuals with intellectual disabilities experience sexual exploitation and abuse at a significantly higher rate than persons without disabilities.²⁰⁰

“The professionalization of intellectual disability,” as described by Michael Carl Gill in *Already Doing It: Intellectual Disability and Sexual Agency*, “works to deny individuals the ability to consent to sexual activity.”²⁰¹ Gill describes “sexual abuse as an issue of power and exploitation rather than an issue of consent,”²⁰² suggesting that a closer examination must be given to residential settings where community-based services “are delivered and designed [to] feed into a higher rate of sexual abuse and assault.”²⁰³

While the ADA recognizes “overprotective rules and policies” as a form of discrimination,²⁰⁴ some group homes enforce policies (formal and informal) that withhold sexuality services²⁰⁵ based on historically instilled notions that persons with intellectual disabilities are “perpetual children,”²⁰⁶ predatory, or too disabled to engage safely in intimate acts.²⁰⁷ Yet, instances of sexual abuse are often attributable to the very individuals who are tasked with *protecting*

197. See Metzger, *supra* note 112, at 1380–83.

198. See Friedman & Owen, *supra* note 11.

199. ETHICAL DILEMMAS: SEXUALITY AND DEVELOPMENTAL DISABILITY 33, 309 (Dorothy M. Griffiths et al. eds., 2002); Swango-Wilson, *supra* note 87, at 168.

200. GILL, *supra* note 12, at 33 (citing RICHARD SOBSEY, VIOLENCE AND ABUSE IN THE LIVES OF PEOPLE WITH DISABILITIES: THE END OF SILENT ACCEPTANCE? (1994)).

201. *Id.* at 31.

202. *Id.* at 34; see also Noonan & Gomez, *supra* note 113, at 177 (“Exclusion and powerlessness perpetuate the conditions which make people with intellectual disability vulnerable to sexual abuse and more generally open to exploitation.”).

203. GILL, *supra* note 12, at 36.

204. 42 U.S.C. § 12101(a)(5) (2012).

205. See, e.g., Travers, Tincani, Whitby & Boutot, *supra* note 94, at 234 (citing Marita P. McCabe, *Sexual Knowledge, Experience and Feelings Among People with Disability*, 17 SEXUALITY & DISABILITY 157, 157 (1999)); 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, 523 (2014) (“[F]ears and assumptions of family and professionals . . . related to sexuality information . . . can lead to withholding information, whether intentionally or unintentionally, from people with disabilities.”) [hereinafter Friedman, Arnold, Owen & Sandman, *Remember Our Voices*].

206. GILL, *supra* note 12, at 3.

207. See *supra* Part II.C.

residents.²⁰⁸ Residents, for example, often rely on group home staff to provide transportation and other mechanisms that facilitate socialization, creating an environment of dependency among group home residents.²⁰⁹ This dependency can create a structural power dynamic wherein compliance with the rules of the group home is expected, leading those with power to unduly wield it over residents—sometimes in the form of sexual exploitation or abuse.²¹⁰

Compounding this issue of structural power are the overprotective policies that limit or restrict sexuality, which are driven by a presumption of incapacity based on ableist and paternalistic notions that individuals with intellectual disabilities are innately incapable of engaging in sex and intimacy and, thus, must be protected from themselves and others.²¹¹ As this Article argues above,²¹² this presumption of incapacity must be challenged in order to move forward in recognizing sexuality as an integral aspect of full community integration.

Few group homes have taken purposeful measures to balance the risk of abuse that may arise in the course of a resident's intimate relationship with the duty to provide community-based services to support leading full, meaningful lives; as a result, sexuality is effectively erased from the disabled individual's life. In the nearly two decades since *Olmstead*, the notion of full community integration has come to exclude community-based supports and services aimed at fully integrating intellectually disabled adults into society in matters related to sexuality.

While both men and women are impacted by sexual violence, sexual abuse and exploitation disproportionately impacts women with intellectual disabilities.²¹³ A study of adult women with intellectual disabilities found that protective and punitive policies have proven counterproductive, even harmful, to the health and safety of intellectually disabled women.²¹⁴ Women may not have

208. Denno, *supra* note 90, at 380–81.

209. Donna J. Bernert, *Sexuality and Disability in the Lives of Women with Intellectual Disabilities*, 29 *SEXUALITY & DISABILITY* 129, 134 (2011) (“[T]he women were not able to act autonomously without services or assistance from outsiders, and thus, assistance from outsiders was essential to the women’s autonomy. This inverted relationship between autonomy and dependence held true for all of the women.”).

210. See, e.g., GILL, *supra* note 12, at 33, 36.

211. See, e.g., Rachel Adams, *Privacy, Dependency, Discegenation: Toward a Sexual Culture for People with Intellectual Disabilities*, 35 *DISABILITY STUD. Q.* (2015), available at <http://dsq-sds.org/article/view/4185/3825> [<https://perma.cc/4U6B-2XB5>]; see also Bernert, *supra* note 209, at 138.

212. See *supra* Part H.D.

213. Swango-Wilson, *supra* note 87, at 168; Jennifer Stinson, LeeAnn Christian & Lori Ann Dotson, *Overcoming Barriers to the Sexual Expression of Women with Developmental Disabilities*, 27 *RES. & PRAC. FOR PERSONS WITH SEVERE DISABILITIES* 18, 22 (2002).

214. Bernert, *supra* note 209, at 138 (concluding that certain protective policies “can be counterproductive to the women’s sexual health by placing them at risk”). Another researcher noted that the “lack of attention [given] to develop[ing] sexual skills” places an “increased risk of harm” upon intellectually disabled individuals. Swango-Wilson, *supra* note 87, at 168; see also

the tools to recognize inappropriate sexual conduct or how to establish boundaries when confronted with potentially harmful sexual behavior.²¹⁵ Or, even if the abuse is recognized, reporting may be discouraged.²¹⁶

With sexuality treated as a taboo by group home operators, residents resort to other ways of engaging in intimate conduct.²¹⁷ In one study, a resident acknowledged that the restrictions on her sexual choices led her to find ways to sexually engage with her boyfriend, beyond the watchful eye of group home staff.²¹⁸ Issues concerning sexually transmitted diseases, awareness of power dynamics in intimate relationships and other issues related to sexual health and safety are discussed only when issues of sexual abuse arise and, even then, the victim of the incident is often subject to punishment and shame.²¹⁹ Conversely, conversations related to positive sexuality are “actively ignored and discouraged.”²²⁰

D. Reinforcing the Presumption of Incapacity

The unreported case *Forziano v. Independent Group Home Living Program, Inc.*²²¹ provides insight into counterarguments that group homes and government entities present to justify the limitation of choices related to intimacy between adults with intellectual disabilities. While *Forziano* did not involve an integration regulation claim, it is illustrative of the ability of group homes to limit the sexual and intimate decisions of residents. The backstory of *Forziano* involves Paul and Hava, two adults with intellectual disabilities, who fell in love after meeting in their day habilitation program.²²² After dating for several years, they wanted to live together in the same group home. The group homes argued that New York State regulations provided them with broad discretion to limit the personal choices of residents based on individualized assessments of a resident’s functional capacity.²²³

PERLIN & LYNCH, *supra* note 113, at 83 (“[W]e have known for years that policies suppressing sexual behavior may lead to antisocial behavior, added aggression, and poorer social adjustment.”).

215. See Noonan & Gomez, *supra* note 113, at 177 (discussing how sex education can empower individuals to say no to or report unwanted sexual contact).

216. See Swango-Wilson, *supra* note 87, at 168.

217. Bernert, *supra* note 209, at 134 (discussing how women with intellectual disabilities found alternative ways (“protective behaviors”) of engaging in sexual conduct in response to the threat of interference from caregivers).

218. See *id.* (describing the experiences of one woman who engaged in sexual conduct with her boyfriend in a restroom because she did not want staff to punish her for displaying affection).

219. See GILL, *supra* note 12, at 32.

220. *Id.*

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

222. *Id.* at *3.

223. Defendants-Appellees Brief at 10, *Forziano v. Indep. Grp. Home Living, Inc.*, 14-1447(L) (2d Cir. Dec. 2, 2014) (“[I]ndividualized service plans for people like Paul and Hava require the exercise of professional judgment with respect to the nature of services provided,

As a result, the group homes required Paul and Hava to undergo a sexual consent evaluation following their request to live together; the facilities reasoned that such an evaluation fell under the umbrella of permissible assessments used to determine a resident's functional capacity, and argued that the assessment established legitimate grounds for limiting a resident's choices.²²⁴ The Clinical Director of Paul's group home conducted his sexual consent evaluation, finding that he did not have the capacity to consent to sexual activity.²²⁵ The validity of Hava's prior sexual consent evaluations was disputed.²²⁶

The couple reached out to the State agency that administers community-based services in an effort to obtain sexual education services and to get another sexual consent evaluation, but the agency provided no assistance.²²⁷ In their claim against the group homes, the couple argued that the denial of their right to live together in a state-regulated group home setting violated the ADA, Section 504 of the Rehabilitation Act, the Fair Housing Act, the Medicaid Act, and other state and federal laws.²²⁸

The Court disagreed, dismissing their case for failure to state a claim. During oral argument before the Second Circuit, Hava's group home, Maryhaven, stressed the importance of sexual consent evaluations and the necessity of relying on the professional judgment of such evaluations.²²⁹ Maryhaven relied on the sexual consent assessment determination, which concluded that sexual conduct between Hava and Paul would be "permitting abuse"²³⁰ because a cognitive evaluation concluded that Hava had the mental age of a four-year-old girl.²³¹ The State agency also deferred to the group homes' reliance on the sexual consent assessment determination in finding that Paul and Hava did not have capacity to cohabit.²³²

The group homes manipulated the outcome of Paul and Hava's request to live together by arguing that the idea of two intellectually disabled adults living together in a group home was "'unprecedented,' 'impossible,' and 'fraught with difficulties.'"²³³ A later independent sexual consent evaluation, which included

making the denial of Plaintiffs' personal choice of services outside the scope of the ADA and Section 504.").

224. *Id.* at 2–3. The group home further argued that the refusal to allow Hava and Paul to live together was not tantamount to discrimination, but was merely an inability to offer the couple the type of Medicaid waiver service they desired—the right to live in the same apartment together. *Forziano*, 2014 WL 1277912, at *8.

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

226. *Id.*

227. *Id.*

228. *Id.* at *4.

229. Oral Argument at 1:01:15–1:02:50, *Forziano*, 14-1147(L).

230. *Id.* at 1:02:25–1:02:45, *Forziano*, 14-1147(L).

231. *Id.*

232. *Id.* at 1:15:36–1:16:52.

233. *Forziano*, 2014 WL 1277912, at *1; *see supra* Part III.C (discussing the perpetuation of sexual exploitation and abuse in the name of protecting adults with intellectual disabilities in

“specialized educational materials” to assist Paul and Hava in taking the evaluation, however, determined that “[b]oth Paul and Hava were . . . able to give verbal informed sexual consent.”²³⁴ The group homes rejected the results of the independent evaluation, relying on its own internal expert opinion to support the position that Paul and Hava did not have the capacity to engage in sexual activity.²³⁵

These arguments capitalize on the inaccurate notion that supporting the right of adults with intellectual disabilities to express their sexuality naturally results in “harmful abusive and exploitative sexual behavior.”²³⁶ Moreover, they further propel the misguided notion that purported mental age is a determinative factor in assessing the right of intellectually disabled adults to engage in acts of intimacy. Lastly, *Forziano* exemplifies how a resident’s challenge to a group-home decision or policy can easily devolve into a battle of the experts. As a result, the right to make decisions about personal choices around sex, intimacy, and whether to live together is placed in the hands of so-called experts whose sterile, clinical approach belies the emotional and highly personal nature of the issue.

In *Olmstead*, the Court extended great deference to a state facility’s medical professional in making an eligibility determination as to whether a disabled individual may safely receive continued habilitation services in a community-based setting.²³⁷ The reliance on professional judgment to ascertain the capacity of an adult with intellectual disabilities to engage in sex and intimacy is problematic for several reasons. First, the medical judgment may be tainted by the desire of the group home operator to limit the resident’s sexual rights. In *Forziano*, as in Julia R.’s case, the group home relied on the sexual consent assessment conducted by a professional affiliated with the group home operator, raising doubts as to the independence of this determination.²³⁸ In reference to the application of the professional-judgment standard in areas that include challenges to the care and medical treatment of persons in state institutionalized care, one scholar noted that “professional judgment . . . is distorted beyond recognition by the limited resources, coercive environment, and unavoidable conflicts of interest inherent in the public sector.”²³⁹

matters of sex and intimacy); *infra* Part V.A.1 (identifying training and education on sexuality and the sexual rights of intellectually disabled adults as a means to strengthen the knowledge-base for proactively addressing issues of sexual exploitation and abuse).

234. *Forziano*, 2014 WL 1277912, at *2–3.

235. *Id.* at *3.

236. See Defendants-Appellees Brief at 3, *supra* note 223, *Forziano v. Indep. Grp. Home Living, Inc.*, 14-1447(L) (2d Cir. Dec. 2, 2014) (citation omitted).

237. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 602–03 (1999).

238. See Salzman, *supra* note 96, at 199 n.142 (“[I]n some cases, a medical professional employed by the state in an institutional setting might resist deinstitutionalization, making her judgment of questionable value.”).

239. Susan Stefan, *Leaving Civil Rights to the “Experts”: From Deference to Abdication Under the Professional Judgment Standard*, 102 YALE L.J. 639, 661 (1992).

This distortion in professional judgment is equally applicable in private, group home settings, where sexual rights are often denied or controlled based on several systemic and environmental factors, including “personal beliefs and attitudes of . . . caretakers regarding the sexuality of their clients,”²⁴⁰ restrictive rules and policies concerning relationships, and the oftentimes “threatening” stance caregivers take when issues of sexuality arise.²⁴¹ Fear of group home operator liability may also taint the value of the professional judgment determination. Another scholar noted, “[s]exual consent causes the disability sector great concern and this concern revolves around service provider liability and not about the person’s right to sexual expression.”²⁴²

Second, as evidenced in Julia R.’s case, reliance on sexual consent capacity assessments (or the like) can result in indefinite limitations on residents’ sexual rights. These assessments often engender blanket prohibitions on sexual behavior, thus negating the responsibility of group homes to provide education and training supports to residents who express interest in sex and intimacy. Third, the reliance on a “mental age” that is identified in a cognitive evaluation is “a misleading concept,”²⁴³ providing group home operators with a false sense of rightness when denying intellectually disabled adults supportive sexuality services. The reliance on “mental age” further relegates persons with intellectual disabilities to the status of perpetual children,²⁴⁴ incapable of engaging in acts of intimacy. The reliance on “mental age” is similar to the improper reliance on IQ to determine an intellectually disabled person’s functional and adaptive deficits and abilities.

In *Hall v. Florida*, the Supreme Court rejected a Florida law that conditioned a criminal defendant’s ability to present evidence as to intellectual disability on a showing that the defendant had an IQ of seventy or lower; and, if the defendant could establish his status as an intellectually disabled person, he

240. Amanda Saxe & Tara Flanagan, *Unprepared: An Appeal for Sex Education Training for Support Workers of Adults with Developmental Disabilities*, 34 *SEXUALITY & DISABILITY* 443, 444 (2016).

241. Elizabeth Rushbrooke, Craig Murray & Samantha Townsend, *The Experiences of Intimate Relationships by People with Intellectual Disabilities: A Qualitative Study*, 27 *J. APPLIED RES. INTEL. DISABILITIES* 531, 538–39 (2014).

242. Noonan & Gomez, *supra* note 113, at 177.

243. Denno, *supra* note 90, at 331; *see also* GILL, *supra* note 12, 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.”).

244. Denno, *supra* note 90, at 331 n.95 (“[A] major obstacle to designing functional and appropriate programs for moderately and severely handicapped individuals has been the tendency for programmers to focus on the retarded individual’s mental age, with relative disregard for the individual’s chronological age, a tack that ‘has resulted in the belief that moderately retarded people remain “forever young” or childlike.’”) (citing William Fink, *Education and Habilitation of the Moderately and Severely Mentally Retarded*, in *MENTAL RETARDATION: FROM CATEGORIES TO PEOPLE* 262 (Patricia T. Cegelka & Herbert J. Prehm eds., 1982)).

would be ineligible for the death penalty.²⁴⁵ Defendants with an IQ of seventy or above, by contrast, could not put forth any evidence as to intellectual disability, such as “deficits in adaptive functioning,”²⁴⁶ making them eligible for capital punishment.²⁴⁷ In rejecting the Florida law, the Court reasoned that “[i]ntellectual disability is a condition, not a number,”²⁴⁸ finding that “[a] State that ignores the inherent imprecision of these tests risks executing a person who suffers from intellectual disability”²⁴⁹ in violation of the Eight Amendment of the Constitution.

It stands to reason, then, that the identification of a “mental age” or a specific “IQ” without a more taxing inquiry into a resident’s adaptive functioning, should not act as grounds to deny the sexual rights of intellectually disabled adults. As to the happy ending for Paul and Hava: Despite their court loss, they married (after seven years of dating) and, with the help of their families, found a group home that allowed them to live together.²⁵⁰ The barriers confronted by Paul and Hava almost prohibited the couple from exercising decisions around some of the most intimate and personal aspects of their life. Many group home residents are not as fortunate.

IV.

GROUP HOMES ARE ENGAGED IN A FORM OF DISABILITY-BASED DISCRIMINATION BY SEXUALLY ISOLATING INDIVIDUALS WITH INTELLECTUAL DISABILITIES IN VIOLATION OF SECTION 504

This Section discusses *Olmstead* and the integration mandate of the ADA and lays out how courts rely on the robust statutory and regulatory framework of the ADA in analyzing integration challenges brought under Section 504 as well as under Title II. Recent Title II cases demonstrate the evolution of *Olmstead* and provide guidance for how a prima facie case of disability discrimination under Section 504 may be made against a group home for sexual isolation. In conceptualizing sexual isolation as disability-based discrimination under Section 504, it is first necessary to establish that the integration mandate analysis of Title II of the ADA and its application in *Olmstead* applies equally to a claim against group homes under Section 504.

The first step in making a prima facie case of disability-based discrimination under Section 504 is to establish that an individual with an intellectual disability

245. Hall v. Florida, 134 S. Ct. 1986, 2001 (2014).

246. *Id.*

247. *Id.*

248. *Id.*

249. *Id.*

250. Forziano v. Indep. Grp. Home Living Program, Inc., 2014 WL 1277912, at *3 (E.D.N.Y. 2014); see also Kevin Dolak, *Mentally Disabled Couple’s Legal Battle Ends with New Home*, ABC NEWS (May 23, 2013), <http://abcnews.go.com/US/mentally-disabled-couples-legal-battle-ends-home/story?id=19237103> [<https://perma.cc/5JDJ-LF4U>].

is a “qualified individual with a disability.”²⁵¹ Second, a group home must qualify as a “program or activity receiving Federal financial assistance.”²⁵² Third, the plaintiff must establish that she was “excluded from the participation in, [was] denied the benefit[] of, or [was] subjected to discrimination” by the group home “solely by reason of her or his disability.”²⁵³ Additionally, in proving a prima facie discrimination case, plaintiffs must prove that the community-based service sought already exists and is not new. After establishing a prima facie case of discrimination under Section 504, it is also necessary to identify whether group homes are under an affirmative duty to address the discriminatory conduct and, if so, whether the remedy sought would constitute an undue hardship, thereby relieving a group home of its duty to comply with Section 504.²⁵⁴

A. The Applicability of Title II and the Olmstead Analysis to an Integration Challenge Under Section 504

For guidance in interpreting the ADA integration regulation, the *Olmstead* Court looked to the statute’s Congressional findings and purpose. The Court highlighted Congress’ intent to provide “equality of opportunity, full participation, independent living, and economic self-sufficiency for”²⁵⁵ persons with disabilities and acknowledged the legislature’s broad goals of ensuring that the ADA “provide[d] a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”²⁵⁶ Congress identified as a form of discrimination society’s history of isolating and segregating individuals with disabilities.²⁵⁷

Following the congressional intent of the ADA, the majority in *Olmstead* recognized that segregating persons with intellectual disabilities in institutions “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.”²⁵⁸ The Court emphasized the impact that such segregation has on the emotional health and personal development of persons with disabilities, finding that “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”²⁵⁹

251. 29 U.S.C. § 794(a).

252. *Id.*

253. *See id.*

254. *See generally infra* Part V.A.

255. 42 U.S.C. § 12101(a)(7).

256. 42 U.S.C. § 12101(b)(1).

257. 42 U.S.C. § 12101(a)(5).

258. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 600 (1999).

259. *Id.* at 601.

In *Olmstead*, the Court further determined that people with intellectual disabilities were forced to “relinquish participation in community life” to receive needed medical services when those services could be enjoyed without such persons relinquishing participation if they were given reasonable accommodations.²⁶⁰ The Court reasoned that persons without mental disabilities were not forced to make this “similar sacrifice” of enduring community isolation to receive necessary medical services.²⁶¹

Title II of the ADA and Section 504 contain nearly identical statutory language. Title II provides that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”²⁶² Similarly, Section 504 provides that “[n]o otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”²⁶³

The non-discrimination language of Section 504 differs from Title II in two respects. First, under Section 504, the allegedly discriminatory program or activity must be a recipient of federal financial assistance;²⁶⁴ “program or activity” is defined to include “an entire corporation, partnership, or other private organization . . . which is principally engaged in the business of providing education, health care, housing,” or “social services.”²⁶⁵ Administrators of community-based services rely largely on HCBS waiver funding reimbursements to administer their programs and services to intellectually disabled individuals who reside in the community.²⁶⁶ Courts have found that Medicaid reimbursements qualify as “federal financial assistance” for purposes of Section 504 for entities that include hospitals, nursing homes and group homes.²⁶⁷ In addressing this issue, the Fifth Circuit Court of Appeals in *United States v. Baylor University Medical Center* determined that Section 504 was “explicitly patterned” after Title VI of the Civil Rights Act of 1964 and Title IX of the Education Amendments Act with the purpose of rooting out “invidious

260. *Id.*

261. *Id.*

262. 42 U.S.C. § 12132.

263. 29 U.S.C. § 794(a).

264. 29 U.S.C. § 794(b).

265. 29 U.S.C. § 294(b)(3)(A).

266. The “HCBS Waiver is an essential part of community services funding in the states.” BRADDOCK 2015, *supra* note 159, at 35; BRADDOCK 2017, *supra* note 169, at 4.

267. *Mitchell v. Cmty. Mental Health of Cent. Mich.*, 243 F. Supp. 3d 822, 842 (E.D. Mich. 2017); *Wagner v. Fair Acres Geriatric Ctr.*, 49 F.3d 1002, 1010 (3d Cir. 1995) (“The legislative history of section 504 indicates that Congress clearly contemplated that section 504 would apply to nursing homes that receive federal funding.”); *Vacco v. Mid Hudson Med. Grp.*, 877 F. Supp. 143, 149–50 (S.D.N.Y. 1995) (health clinic that allegedly denied hearing impaired plaintiffs sign language in interpreters during medical examinations considered a federally funded program).

discrimination in federally funded programs.”²⁶⁸ Medicaid reimbursements are considered federal financial assistance for purposes of Title VI and Title IX.²⁶⁹

Second, Section 504 provides that the discrimination must be “solely by reason of . . . disability.”²⁷⁰ Courts have found that “the Rehabilitation Act’s ‘solely by reason of . . . disability’ requirement need not be separately analyzed in cases alleging a violation of the integration mandate because the alleged discrimination—undue isolation—stems from a failure to satisfy an affirmative duty, regardless of discriminatory intent.”²⁷¹ In other words, discriminatory intent is not a required element to prove disability-based discrimination in claims alleging a violation of the integration regulations under Title II and Section 504.

Title II and Section 504 each create an affirmative duty to make reasonable modifications or accommodations to avoid disability-based discrimination, but this duty is not absolute.²⁷² As stated earlier, under Title II, a public entity has an affirmative duty to modify its “policies, practices, or procedures” unless such “modification[] would fundamentally alter the nature of [its] service, program, or activity.”²⁷³ This is generally referred to as the “fundamental-alteration” defense. The reasonable modification regulation of Title II tracks the language of Section 504, which similarly provides that a recipient of federal financial assistance must make reasonable accommodations unless the accommodation would cause an “undue hardship on the operation of its program.”²⁷⁴ Courts apply the reasonable modification/accommodation and undue hardship provisions identically in integration mandate challenges brought under Title II and Section 504.²⁷⁵

268. *United States v. Baylor Univ. Med. Ctr.*, 736 F.2d 1039, 1042–43 (5th Cir. 1984) (comparing 42 U.S.C. § 2000d *et seq.* (1981 & Supp. 1983) and 20 U.S.C. § 1681 *et seq.* (1978 & Supp. 1983)).

269. *See id.* at 1042.

270. 29 U.S.C. § 794(a); *see also* 28 C.F.R. § 41.51.

271. *Guggenberger v. Minnesota*, 198 F. Supp. 3d 973, 1032 (D. Minn. 2016); *see also* Mark C. Weber, *Accidentally on Purpose: Intent in Disability Discrimination Law*, 56 B.C. L. REV. 1417, 1434 (2015) (“[T]he integration regulation does not demand a showing of intent in order to make a claim; the *Olmstead* opinion did not rely on any finding of animus, deliberate indifference, or any other mental state on the part of the government.”).

272. *See generally infra* Part V.A.

273. 28 C.F.R. § 35.130(b)(7)(i).

274. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 606 n.16 (1999); *see also* 28 C.F.R. §§ 41.53, 42.511(c); 45 C.F.R. § 84.12(a).

275. *See, e.g., supra* note 30. In cases where the claim is not based on the *Olmstead* integration mandate, but is a request for reasonable accommodations in order to access services, courts continue to apply the undue hardship analysis as outlined in *Alexander v. Choate*, a decision that centered on whether a state had to provide reasonable accommodation under Section 504 of the Rehabilitation Act. *Alexander v. Choate*, 469 U.S. 287 (1985); *see also, e.g., Colbert v. District of Columbia*, 110 F. Supp. 3d 251, 257 (D.D.C. 2015). The analysis in *Choate* is not appropriate when examining an integration mandate challenge. *Choate* dealt with reasonable accommodation as it applied to the administration of a broad category of Medicaid services. The HCBS waiver program is administered differently and serves a unique purpose to provide individualized services that are not covered by Medicaid. *See supra* Part III.A. The reasoning in *Choate*—that “Medicaid programs do not guarantee that each recipient will receive that level of health care precisely

As *Olmstead* jurisprudence developed, the “federal courts analyzing integration mandate challenges under the ADA and the Rehabilitation Act consistently interpret the provisions together, notwithstanding the ‘solely by reason of . . . disability’ language in the Rehabilitation Act.”²⁷⁶ In moving forward, this Section will similarly apply Title II and *Olmstead* to challenge the conduct of group homes under Section 504. Under this analysis, a group home resident could assert a challenge under Section 504 to argue that group homes have an affirmative duty to avert the unjustified sexual isolation of their residents; this duty requires a modification of both the discriminatory policies that limit expressions of sexuality and the substandard administration of sexuality services.

B. A Person with an Intellectual Disability Is a “Qualified Individual” with a Disability Under Section 504

Assuming then, that group homes are covered programs under Section 504 as recipients of federal funding, the next step in establishing a prima facie case of disability-based discrimination is to establish that an individual with an intellectual disability is a “qualified individual with a disability.”²⁷⁷ Title II of the ADA and Section 504 define disability similarly. An individual with a disability is one who has “a physical or mental impairment that substantially limits one or more major life activities.”²⁷⁸ Individuals with intellectual disabilities can likely establish that their individual impairment creates a substantial limitation in one or more “major life activities.”²⁷⁹ In analyzing whether an intellectually disabled person meets the definition of disabled under

tailored to his or her particular needs,” but “[i]nstead, the benefit provided through Medicaid is a particular package of health care services”—is not applicable to the HCBS waiver program. 469 U.S. at 303; *see also* Samuel Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 48–51 (2004).

276. *Guggenberger*, 198 F. Supp. 3d at 1033; *see also, e.g., supra* note 30. For group homes that are directly operated by the state or local governments, Title II of the ADA applies without question.

277. 42 U.S.C. § 12131(2).

278. 42 U.S.C. § 12102(1)(A); 28 C.F.R. § 41.31(a). Intellectual disability is an enumerated “impairment” under both Title II and Section 504. 28 C.F.R. § 35.108(b)(1)(ii); 28 C.F.R. § 41.31 (using the term “mental retardation”).

279. 42 U.S.C. § 12102(2). Following a line of Supreme Court cases that “created an inappropriately high level of limitation necessary to” qualify as disabled under the ADA, Congress passed the ADA Amendments Act of 2008 (ADAA). ADA Amendments Act of 2008, Pub. L. No. 110-325, 122 Stat 3553, §2(b)(5). The ADAA clarified the statute’s broad scope and meaning of the ADA’s definition of disability by including an expanded list of “major life activities” in the statute, itself. *See* 154 Cong. Rec. S9626-01, 2008 WL 4372186 (“[T]he new law directs the courts toward a broader meaning and application of the ADA’s definition of disability.”); *see also* 42 U.S.C. § 12102(4)(A) (“The definition of disability in this chapter shall be construed in favor of broad coverage . . .”). Under the ADA, “major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.” 42 U.S.C. § 12102(2)(A).

these statutes, it is necessary to understand the cognitive and functional limitations that are often associated with intellectual disability.

A diagnosis of intellectual disability is based on a finding of “significant limitations in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical skills, and age of onset before age 18.”²⁸⁰ Intellectual functioning includes “reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly, and learning from experience.”²⁸¹ Adaptive functioning is a collection of learned behaviors and skills that enable individuals to interact with the world and may impact an individual’s conceptual (e.g., “language; reading and writing; and money, time, and number concepts”), social (e.g., “interpersonal skills . . . and social problem solving”) and practical functioning (e.g., ability to manage money, maintain a safe environment, and perform other activities of daily living).²⁸²

As a result of the limitations that stem from intellectual disability, a group home resident with an intellectual disability requires some supportive services to more independently perform one or more major life activities in areas that may include “learning,”²⁸³ “communicating,”²⁸⁴ and “interacting with others.”²⁸⁵ Therefore, an individual with an intellectual disability who resides in a group home would qualify as “disabled” under Section 504.²⁸⁶

Next, it must be established that the individual meets the standard for being a “qualified” individual with a disability under Section 504. Section 504 provides that a “qualified” individual with a disability is one “who meets the essential eligibility requirements for the receipt of [the federally-funded] services.”²⁸⁷ To establish coverage under Section 504 as a “qualified individual with a disability,” the group home resident must establish that they meet all of the eligibility requirements to receive the programs, services and activities of the group home; or can receive such services with reasonable accommodations.²⁸⁸

280. AM. ASS’N INTELL. & DEVELOPMENTAL DISABILITIES, INTELLECTUAL DISABILITY: DEFINITION, CLASSIFICATION, AND SYSTEMS OF SUPPORTS 28 (11th ed. 2010).

281. *Id.* at 31.

282. *Id.* at 44.

283. 28 C.F.R. § 35.108(c)(1)(i); 28 C.F.R. § 41.31(b)(2).

284. 28 C.F.R. § 35.108(c)(1)(i).

285. *Id.*

286. Given the broad coverage under Title II, and by extension Section 504, the definition of disability would likely extend to a resident who may not have a formal diagnosis of intellectual disability, but manifests the adaptive and cognitive deficits that are generally associated with intellectual disability, if the impairment prong is met. *See* 42 U.S.C. § 12102(4)(A).

287. 28 C.F.R. § 41.32(b). Title II similarly provides that a “qualified individual with a disability” is one “who, with or without reasonable modifications . . . meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity.” 42 U.S.C. § 12131(2).

288. 42 U.S.C. § 12131(2).

For residents who reside in group homes, the facility has already made a determination that the individual displays the ability to live in a community-based setting and to receive tailored supports and services administered by the group home.²⁸⁹ These services provide community-based treatment supports to strengthen the resident's independent living skills. A determination as to what specific, individualized sexuality service is appropriate to meet the needs of a resident's desired goals for sex and intimacy would be determined through the regular course of an individualized service plan assessment.²⁹⁰ Therefore, an intellectually disabled group home resident is a qualified person with a disability under Section 504. To the extent that there are individual issues of capacity related to the sexual expression goals of a resident, the question would shift to whether the group home can accommodate the resident by providing supports and services that address these capacity issues.

C. The Integration Regulations of Title II and Section 504 Are Properly Applied to the Context of Sexual Isolation

Once it is established that the intellectually disabled person is a "qualified individual with a disability" and a group home falls within the coverage of Section 504, it must be shown that the integration regulation of Section 504 is properly applied in the context of sexual isolation as a form of disability-based discrimination. The *Olmstead* majority focused on the unjustified institutional segregation and isolation of plaintiffs. As time passed, cases challenged this limited application of *Olmstead* to successfully argue that the integration mandate of the ADA applied to the "risk of institutionalization," testing the parameters of the *Olmstead* integration mandate beyond the context of institutionalized care.²⁹¹

289. See *infra* notes 365–366 (under federal statutory guidelines outlining the obligations of states and agencies that provide community-based services, recipients of the HCBS waiver program must be assessed and provided appropriate services via an individualized plan of care in order to facilitate community integration).

290. *Id.*

291. *Davis v. Shah*, 821 F.3d 231, 263–64 (2d Cir. 2016) (plaintiffs who reside in the community established that the state's limitations on medically necessary compression socks and orthopedics supported an integration mandate claim because it puts plaintiffs "at a substantial risk of requiring institutionalized care"); *Pashby v. Delia*, 709 F.3d 307, 324 (4th Cir. 2013) (preliminary motion granted after plaintiffs established likelihood of success in establishing that the state's reduction of plaintiffs' in-home personal care services put them at risk of institutionalization); *M.R. v. Dreyfus*, 697 F.3d 706, 720 (9th Cir. 2012) ("We conclude that plaintiffs have demonstrated a likelihood of irreparable injury because they have shown that reduced access to personal care services will place them at *serious* risk of institutionalization." (emphasis added)); *Mitchell v. Cmty. Mental Health of Cent. Mich.*, 243 F. Supp. 3d 822, 842 (E.D. Mich. 2017) (plaintiffs who resided in the community could pursue integration challenge under Section 504 and Title II); *Sanchez v. Johnson*, 416 F.3d 1051, 1053–54 (9th Cir. 2005) (class consisted of "individuals who would be capable of living in the community with properly funded support services but who now live in, or are at risk of living in, state institutions" due to inadequately funded community-based services); *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1184 (10th Cir. 2003) (discussing how as a result of a cap on prescription drugs, community-

A recent line of cases is pushing the *Olmstead* jurisprudence even further, opening the door to applications beyond the four walls of an individual's institutional or community-based placement and asking whether the community-based services provided are sufficient to avert unjustified segregation and isolation.²⁹² By way of example, in *Lane v. Kitzhaber*, the court determined that "segregation in the employment setting" qualified as a cognizable integration claim under *Olmstead* and Section 504.²⁹³ In *Lane*, plaintiffs alleged that they were forced to work in segregated, sheltered workshops²⁹⁴ alongside only other disabled persons (and for less than minimum wage).²⁹⁵ The court determined that defendants violated Title II of the ADA and Section 504 "by denying employment services to plaintiffs for which they are eligible with the result of unnecessarily segregating them in sheltered workshops."²⁹⁶

Focusing on the severe deprivation that an individual experiences as a result of unjustified isolation and segregation (as articulated in *Olmstead*), the court concluded that this harm is equally felt by those who are relegated to segregated employment.²⁹⁷ In expanding the application of *Olmstead* to sheltered workshops, the court acknowledged that no prior cases had applied the integration mandate where the state's conduct did not place the individual at risk of institutionalization.²⁹⁸ However, the court determined that "the broad language and remedial purposes of the ADA, the corresponding lack of any limiting language in either the ADA or the integration mandate itself, and the lack of any case law restricting the reach of the integration mandate" supported

based Medicaid recipients' "high risk for premature entry into a nursing home" constituted an integration mandate violation under Title II of the ADA); *Marlo M. ex. rel. Parris v. Cansler*, 679 F. Supp. 2d 635, 637–38 (E.D.N.C. 2010) ("[p]laintiffs face[d] a substantial risk of institutionalization" as a result of state's reduction of twenty-four-hour in-home care); *V.L. v. Wagner*, 669 F. Supp. 2d 1106, 1119–20 (E.D.N.Y. 2009) ("Plaintiffs have shown a likelihood of success on the merits of their claim that Defendants violated the integration mandate" by placing them at risk of institutionalization by reduction of in-home care services).

292. See, e.g., *Salzman*, *supra* note 96, at 206–09 (discussing the rights-depriving legal construct of guardianship as a parallel to the physical segregation that is experienced within the confines of an institution).

293. *Lane v. Kitzhaber*, 841 F. Supp. 2d 1199, 1205 (D. Or. 2012).

294. *Id.* at 1199. Sheltered workshops are segregated settings where individuals with disabilities conduct basic tasks as a form of employment, such as putting caps on pens, threading a plastic strap through a belt buckle and folding t-shirts and placing them into plastic bags. See, e.g., *id.* at 1201; NAT'L DISABILITY RIGHTS NETWORK, SEGREGATED & EXPLOITED: THE FAILURE OF THE DISABILITY SERVICE SYSTEM TO PROVIDE QUALITY WORK 3 (Jan. 2011), <http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Segregated-and-Exploited.pdf> [<https://perma.cc/8BTC-9W3M>]; NAT'L DISABILITY RIGHTS NETWORK, BEYOND SEGREGATED AND EMPLOYED: UPDATE ON THE EMPLOYMENT OF PEOPLE WITH DISABILITIES 15–22 (Apr. 2015), http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Beyond_Segregated_and_Exploited.pdf [<https://perma.cc/TNQ5-V9CD>].

295. *Lane*, 841 F. Supp. 2d at 1201.

296. *Id.* at 1208.

297. *Id.* at 1205.

298. *Id.*

its applicability to situations of forced isolation of intellectually disabled individuals in sheltered workshops.²⁹⁹

In determining what qualifies as “the most integrated setting,” courts have relied on the ADA’s regulatory guidance, which describe it as “a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.”³⁰⁰ As persons with intellectual disabilities are moving in greater numbers to community-based settings, courts are recognizing that this limited definition of integrated setting is not enough to determine compliance with Title II and *Olmstead*. In *Lane*, for example, the court looked to the DOJ Statement for further guidance towards determining what qualifies as an “integrated setting” under Title II.³⁰¹ As outlined in the DOJ Statement, the most integrated settings are:

those that provide individuals with disabilities opportunities to live, work, and receive services in the greater community, like individuals without disabilities. Integrated settings . . . offer access to community activities and opportunities at times, frequencies and with persons of an individual’s choosing; afford individuals choice in their daily life activities; and, provide individuals with disabilities the opportunity to interact with non-disabled persons to the fullest extent possible. . . . By contrast, segregated settings . . . include . . . congregate settings characterized by regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, or limits on individuals’ ability to engage freely in community activities and to manage their own activities of daily living . . .³⁰²

The DOJ confirmed that compliance with the principles of *Olmstead* requires more than mere assurance that disabled persons have the opportunity to interact with persons without disabilities. Integrated settings must include those aspects of life that all persons enjoy, including privacy, autonomy, the ability to exercise choice and opportunities to engage in activities alongside others in the community.³⁰³ The use of this more expansive definition of integrated setting

299. *Id.* (internal citation omitted).

300. 28 C.F.R. pt. 35, app. B (1991); *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 592 (1999); *Steimel v. Wernert*, 823 F.3d 902, 909 (7th Cir. 2016); *Guggenberger v. Minnesota*, 198 F. Supp. 3d 973, 1023 (D. Minn. 2016); *Lane*, 841 F. Supp. 2d at 1200.

301. *See* DOJ Statement, *supra* note 55. Courts routinely give deference to an agency’s interpretation of its own implementing regulations. *See, e.g., Olmstead*, 527 U.S. at 597–98 (“Because the [DOJ] is the agency directed by Congress to issue regulations implementing Title II, its views warrant respect.” (internal citation omitted)); *Guggenberger*, 198 F. Supp. 3d at 1027 n.21 (relying on the DOJ interpreting guidelines “for [their] persuasive value”); *M.R. v. Dreyfus*, 697 F.3d 706, 735 (9th Cir. 2012) (“We afford DOJ’s view considerable respect” and “defer to an agency’s reasonable interpretation of its own statutorily authorized regulation.”).

302. *See also* DOJ Statement, *supra* note 55.

303. *See id.*

allowed the court in *Lane* to apply *Olmstead* in an unprecedented way, recognizing that isolation and segregation are not necessarily alleviated by relocation to a community-based setting, if an individual is denied the right to engage in life's full palette of experiences and opportunities.³⁰⁴

In a similar case, *United States v. Rhode Island*,³⁰⁵ the DOJ entered into the first statewide consent decree after finding that Rhode Island placed intellectually disabled individuals in segregated sheltered workshops and facility-based day program settings, risking unnecessary segregation in violation of Title II of the ADA.³⁰⁶ The consent decree required Rhode Island to implement mechanisms to ensure that the employment supports and services provided to approximately 3,000 individuals “are adequate and sufficient to achieve integration, increased independence, and increased economic self-sufficiency.”³⁰⁷

Recent cases like *Lane* and *DOJ v. Rhode Island* are reframing the definition of isolation and segregation in integration mandate challenges, extending its meaning to recognize its differing forms. Two additional cases, *Steimel v. Wernert*³⁰⁸ and *Guggenberger v. Minnesota*,³⁰⁹ further illustrate this point. In *Steimel*, plaintiffs argued that they were unjustifiably segregated in their homes as a result of the state's redistribution of Medicaid waiver services programs, which dramatically reduced the number of hours available to participate in community-based activities from forty to twelve hours per week.³¹⁰ A critical aspect of *Steimel* is the Seventh Circuit's analysis of what qualifies as the “most integrated setting” under Title II and Section 504.³¹¹ The court looked beyond the restrictive definition of integrated setting and, much like the court in *Lane*, referred to the DOJ Statement for guidance.³¹²

304. The DOJ joined the lawsuit in *Lane* that was filed by disability rights organizations, adding significant weight to the plaintiffs' argument. The parties ultimately settled under the name *Lane v. Brown*. *Olmstead Enforcement*, *supra* note 49. The terms of the settlement would impact approximately 7000 individuals with intellectual and developmental disabilities who can and want to work in an integrated community setting to avoid unjustified segregation. See *Fact Sheet on Proposed Agreement Over Oregon Supported Employment*, U.S. DEP'T OF JUSTICE (2015), <https://www.justice.gov/opa/file/768236/download> [<https://perma.cc/P2XH-TUY4>].

305. See *Olmstead Enforcement, U.S. v. Rhode Island*, U.S. DEP'T OF JUSTICE, https://www.ada.gov/olmstead/olmstead_cases_list2.htm#ri [<https://perma.cc/AXU7-YAHJ>] (last visited Feb. 16, 2018).

306. See *id.*

307. Consent Decree at 24, *United States v. Rhode Island*, No. CA14-175 (D.R.I. Apr. 9, 2014), available at <https://www.ada.gov/olmstead/documents/ri-olmstead-statewide-agreement.pdf> [<https://perma.cc/Z3N9-G2DC>] (last visited Feb. 16, 2018).

308. *Steimel v. Wernert*, 823 F.3d 902, 914 (7th Cir. 2016).

309. *Guggenberger v. Minnesota*, 198 F. Supp. 3d 973 (D. Minn. 2016).

310. *Steimel*, 823 F.3d at 908. The plaintiffs argued “that the state's policies . . . impermissibly rendered the plaintiffs institutionalized in their own homes, and . . . put them at serious risk of institutionalization.” *Id.* at 910.

311. *Id.* at 909–10.

312. *Id.* at 909.

The court rejected as a “crabbed binary”³¹³ the state’s argument that a setting is limited “to two kinds of physical structures: an institution or a location in the community,”³¹⁴ noting that the word setting “[o]rordinarily . . . denotes an environment or situation rather than any particular physical structure.”³¹⁵ The court also reasoned that the ADA regulation’s “most integrated” language “impl[ies] more than two possibilities.”³¹⁶ In regards to plaintiff’s confinement, the court found that isolation within the home “may often be worse than confinement to an institution on every other measure of ‘life activities’ that *Olmstead* recognized.”³¹⁷

In *Guggenberger v. Minnesota*, the court similarly 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,” finding that “segregation” and “institutionalization” are “separate and distinct” concepts under Title II.³¹⁸ Here, the plaintiffs alleged violations of the integration mandates of Title II and Section 504 as a result of languishing on the statewide waiting list to receive Medicaid waiver services that would enable access to community-based services.³¹⁹

In finding that plaintiffs properly asserted an integration mandate claim, the court in *Guggenberger* held that the integration mandate applies across “a wide range of settings”³²⁰ and, although they resided in their own homes, plaintiffs were “not living, working, and receiving services in” the most integrated setting because they could not “interact with nondisabled persons to the fullest extent possible,” and thus participate in community life.³²¹ This inability to participate in community life goes to the core of what unjustified isolation and segregation means in the evolved definition of setting.

Sexual isolation experienced by group homes residents can be analogized to the isolation experienced by plaintiffs in *Lane*, *Steimel* and *Guggenberger*. In *Guggenberger*, for example, the Court highlighted plaintiffs’ isolation, noting their “feelings of segregation from community,” their “feelings of sadness and isolation,” and their desire “to make more . . . choices” and have “more independence and integration into the community on a social and cultural level,” which they could not do without increased Medicaid waiver service hours.³²²

313. *Id.* at 911–12.

314. *Id.* at 911.

315. *Id.* at 912.

316. *Id.*

317. *Id.* at 911.

318. *Guggenberger v. Minnesota*, 198 F. Supp. 3d 973, 1026–27 (D. Minn. 2016) (alteration in original).

319. *Id.* at 988, 1023–25.

320. *Id.* at 1027.

321. *Id.* at 1029–30.

322. *Id.* at 1029.

To appreciate the extent of the emotional and psychological harm that results from isolation and segregation, one must understand that harm can arise in multiple contexts while living in community-based settings: through forced employment in sheltered workshops, in confinement to one's home, or via severe limitation of access to others in the community as a result of reduced services. This understanding should be applied equally when examining whether a set of overprotective and punitive sexuality policies and/or a lack of access to sexuality services qualify as forms of unjustified isolation under Section 504.

The recently enacted HCBS Setting Rule lends further support for reframing the meaning of "settings" as something beyond the physical.³²³ In implementing the rule, CMS clarified the following in reference to defining community-based settings:

CMS is moving away from defining home and community-based settings by "what they are not," and toward defining them by the nature and quality of individuals' experiences. The home and community-based setting provisions . . . establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics. The changes related to clarification of home and community-based settings will maximize the opportunities for participants in HCBS programs to have access to the benefits of community living and to receive services in the most integrated setting³²⁴

Further, in the HCBS Settings Rule implementing regulations, CMS clarifies that an integrated setting includes an environment that "supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment . . . , engage in community life, . . . and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS."³²⁵ The detrimental and enduring impact that results from the stigmatization of intellectually disabled persons as

323. See CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 162, at 135–36; see, e.g., Friedman, *Day Habilitation*, *supra* note 179, at 245 ("[S]tates may find their day habilitation programs need to be redesigned or terminated altogether if these programs are provided in segregated facilities" in order to comply with the HCBS Setting Rule).

324. HCBS Fact Sheet, *supra* note 189; see also CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 162, at 135–36.

325. 42 C.F.R. § 441.301(c)(2)(i) (2016); see also Bagenstos, *Past and Future*, *supra* note 10, at 51 ("[A]dvocates—in determining what constitutes an institution—have looked to whether individuals in a particular setting have choice, autonomy, and the ability to live lives like everyone else."); *Disability Advocates, Inc. v. Paterson*, 653 F. Supp. 2d 184, 214–19 (E.D.N.Y. 2009), *vacated for lack of standing*, 675 F.3d 149 (2d Cir. 2012) (discussing how the environment of adult homes for persons with mental illness foster "learned helplessness" and are equivalent to institutionalized care).

sexual beings can be recognized in areas that include sexual health,³²⁶ psychological and emotional well-being,³²⁷ and opportunities for socialization.³²⁸

D. Removing the “Existing Services” and “New Services” Analysis as a Requirement to Establish a Prima Facie Case of Discrimination

There is yet another hurdle in establishing a prima facie discrimination claim in the context of sexual isolation: whether the remedy sought is a request for new or existing services. This Part argues that the new-and-existing-services question is no longer applicable in integration challenges under Title II and Section 504 that seek community-based waiver services as a remedy to unjustified segregation and isolation. In *Olmstead*, the Court expressed the view, in a footnote, that states must adhere to the non-discrimination mandate under Title II “with regard to the services they in fact provide,” but clarified that compliance did not “impose a ‘standard of care’” or “require[] States to ‘provide a certain level of benefits’ to individuals with disabilities.”³²⁹

Following *Olmstead*, courts have interpreted this limitation to mean that states are under no obligation to provide the requested services if it results in the creation of “new services.” The Second Circuit case, *Rodriguez v. City of New York*³³⁰ set the trajectory for how courts now interpret integration mandate claims that confront questions of whether requests for community-based services are appropriate under Title II and Section 504.

326. See, e.g., Laurent Servais, *Sexual Health Care in Persons with Intellectual Disabilities*, 12 MENTAL RETARDATION & DEVELOPMENTAL DISABILITIES 48, 51 (2006) (“Research indicates that education and supports are effective in promoting menstrual self-care among women with [intellectual disabilities], even those with severe ID, but many are not provided the opportunity to learn this skill.”). However, the researcher noted that surgical procedures and other invasive pharmacological methods are used to reduce or stop the menstrual flow of women with intellectual disabilities. *Id.*; see also Bernert, *supra* note 209.

327. See, e.g., 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, 236 (2003) (“If healthy sexuality is not promoted and supported, unhealthy and abusive forms of sexuality may prevail. The inability to develop healthy sexuality can lead to mental disorders such as anxiety, depression, and adjustment disorders, as well as impaired self-esteem . . .”).

328. Bernert, *supra* note 209, at 137 (programs and policies “restrict[ed] the women’s socialization . . . to others with intellectual disabilities” resulting in the limitation of “partner selection to primarily men at their agencies or other agencies”).

329. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 603 n.14 (1999) (quoting Thomas, J., dissenting). In a footnote of her majority opinion, Justice Ginsberg clarified this point in response to Justice Thomas’s dissenting opinion where he cited to *Alexander v. Choate*. See 469 U.S. 287, 307 (1985) (arguing that Congress intended for states to maintain responsibility over services).

330. *Rodriguez v. City of New York*, 197 F.3d 611, 619 (2d Cir. 1999). *Rodriguez* did not present a challenge related to HCBS waiver services, but involved an ADA integration challenge to the State’s failure to include safety-monitoring as a personal care service under the State’s Medicaid personal care program.

In *Rodriguez*—a case decided only four months after *Olmstead*—the court rejected plaintiffs claim that New York State must provide safety monitoring as a Medicaid service for individuals with cognitive impairments such as Alzheimer’s, who are at risk of institutionalization without the monitoring.³³¹ In rejecting plaintiffs’ integration claim, the court held that *Olmstead* required adherence to the non-discrimination provision only as to services that the State already provides.³³² In its narrow application of *Olmstead*, the court further reasoned that *Olmstead* applied only “where Georgia should provide treatment, not whether it must provide it,” noting “[u]nder the ADA, it is not [the court’s] role to determine what Medicaid benefits New York must provide.”³³³

In an attempt to distinguish *Rodriguez*, courts developed an additional element that plaintiffs must overcome to make a prima facie case of discrimination under *Olmstead*. This element requires plaintiffs to establish that they are not seeking “new” or “existing” services to address the discriminatory conduct in question; specifically, the plaintiff must seek services that the State currently provides to those in institutionalized care, or services that are the same, or substantially similar, to those received by disabled persons in institutionalized care.

In *Townsend v. Quasim*, the court determined that plaintiff’s requested services were not “new” because plaintiff “simply requests that the services he is already eligible to receive under an existing state program (assistance in dressing, bathing, preparing meals . . .) be provided in the community-based adult home where he lives, rather than the nursing home setting the state requires.”³³⁴ The court reasoned that the services were not new because plaintiff would receive the *same* services through the Medicaid program—whether in an institutionalized or community-based setting. The court further emphasized that the location of the services was central to this determination, reasoning that, “[a]s *Rodriguez* makes clear, where the issue is the *location* of services, not *whether* services will be provided, *Olmstead* controls.”³³⁵

331. *Id.*

332. In *Rodriguez*, the Court relied on a footnote in the *Olmstead* opinion, which stated that “States must adhere to the ADA’s nondiscrimination requirement with regard to the services they in fact provide.” *Olmstead*, 527 U.S. at 603 n.14. Despite the holding in *Rodriguez*, nothing in the language of the *Olmstead* opinion supports the holding in *Rodriguez* that only existing services may be considered in Title II integration challenges. Professor Salzman recognized the limitations of *Rodriguez*’s “existing services” analysis in her scholarship challenging guardianship as a violation of the *Olmstead* integration mandate. Salzman explained, “If the integration mandate were limited to requiring an expansion of only those specific services the state has already chosen to provide, the mandate would be quite limited, if not relatively meaningless.” Salzman, *supra* note 96, at 219.

333. *Rodriguez*, 197 F.3d at 619. The court did not rely on integration mandate cases in its holding. See Salzman, *supra* note 96, at 211 n.172.

334. 328 F.3d 511, 517 (9th Cir. 2003).

335. *Id.*

The Tenth Circuit followed *Townsend* in holding that a State's refusal to provide unlimited medically necessary prescription medications to individuals residing in the community, while extending this same service to those residing in a nursing home, violated Title II of the ADA.³³⁶ Similar to *Townsend*, the court in *Fisher* determined that "Plaintiffs are simply requesting that a service for which they would be eligible under an existing state program, unlimited medically necessary prescriptions, be provided in a community-based setting rather than a nursing home."³³⁷ Like *Townsend*, the court reasoned that because plaintiff would receive the *same* services through the Medicaid program in either an institutionalized or a community-based setting, the services were not new.

In *Radaszewski*,³³⁸ the Fourth Circuit adopted *Townsend* and *Fisher*, reasoning that the services sought by plaintiff were not new "so long as it is possible for the plaintiff to show that the services he seeks to receive at home are, in substance, already provided in the institutional setting."³³⁹ Even in *Steimel* and *Lane*, which significantly expanded the definition of settings, the courts applied the new-and-existing-services analysis narrowly.³⁴⁰

The evolution of the meaning of "integrated setting" as articulated in recent *Olmstead* cases, the enactment of the HCBS Settings Rule, and the individualized, person-centered trajectory of the Medicaid waiver services program make the new-and-existing-services analysis seem anachronistic, out-of-touch with the way the Medicaid waiver program operates today. This outmoded analysis undermines the purpose of the HCBS waiver program.³⁴¹ The purpose of the HCBS waiver program is easily defeated if courts continue to require, as an element of an integration regulation claim, evidence that the requested services would have been available if the individual resided in institutionalized care, or the requested services are the same, or substantially similar, to those received by disabled persons in institutionalized care.³⁴²

336. See *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1183 (10th Cir. 2003) (remanding the case for further consideration).

337. *Id.*

338. *Radaszewski v. Maram*, 383 F.3d 599, 609–10 (7th Cir. 2004).

339. *Id.* at 611.

340. See, e.g., *Steimel v. Wernert*, 823 F.3d 902, 913 (7th Cir. 2016) (in distinguishing the new services reasoning in *Rodriguez*, the court found that "plaintiffs seek services that exist and are given to others"); see also *Lane v. Kitzhaber*, 283 F.R.D. 587, 602 (D. Or. 2012) (in granting plaintiffs' class certification, the court relied on *Townsend*, reasoning that the "plaintiffs are not demanding new services, but seek the provision of existing supported employment services to qualified individuals not only in segregated settings, but also in integrated employment settings").

341. See *supra* Parts III.A, III.B.

342. The HCBS waiver program is built off of the premise that an individual who is eligible to receive services under the program is entitled to services that are individualized and specific to their needs with the goal of supporting community integration. See, e.g., *supra* notes 162, 189; *infra* notes 365–66. Many individualized services are offered through the HCBS waiver program, such as self-advocacy training, financial support services, and family training and counseling. See *infra* note 371 (listing several HCBS waiver services). These individualized services were unlikely provided or available to disabled persons in institutionalized care.

The requirement of individualized assessments and updated service plans for HCBS waiver recipients naturally results in the ebb and flow of new services that are offered to HCBS waiver recipients under individual waivers.³⁴³ If new services were not offered, the individualized assessment that is required for waiver recipients under federal law would be a meaningless exercise.³⁴⁴ Even if the HCBS waiver program, as a policy matter, does not speak directly to what *Olmstead* requires under the ADA, without the individualized implementation of the program, individuals with intellectual disabilities would have little hope of achieving the promise of *Olmstead* in transitioning out of segregated settings and into the community.

The question of whether the requested waiver service imposes an impermissible “standard of care” or requires states to “provide a certain level of benefits” should not be analyzed against whether the service sought is a new or existing service. The analysis must rest on whether the remedy would fundamentally alter the nature of the defendants’ program. Several recent cases provide guidance for analyzing plaintiffs’ requested remedy in this way. In *Guggenberger*, the court looked to the existing waiver program and did not question the services that plaintiffs sought to access from the waiver program.³⁴⁵ Specifically, the court found that plaintiffs properly identified the types of services that would increase their ability to integrate into the community (in areas that include “assistance with financial management and budgeting; nutrition and menu planning; healthcare management; and assistance in obtaining and maintaining gainful employment”³⁴⁶) and determined that plaintiffs’ desired remedy required a close factual examination to decide whether it would fundamentally alter the nature of the State’s program.³⁴⁷

Similarly, in *Murphy v. Minnesota Department of Human Services*, plaintiffs survived defendants’ motion to dismiss because the court determined that plaintiffs were not requesting new services, but merely services that existed under the Medicaid waiver program.³⁴⁸ The court determined that plaintiffs

343. Medicaid “[w]aivers are intended to provide the flexibility needed to enable States to try new or different approaches to the efficient and cost-effective delivery of health care services, or to adapt their programs to the special needs of particular areas or groups of beneficiaries.” 42 C.F.R. § 430.25(b). Further, the Medicaid statute itself encourages States to create new programs that meet the needs of the target population by “allow[ing] exceptions to State plan requirements and permit[ting] a State to implement innovative programs or activities” through the waiver program. 42 C.F.R. § 430.25(b).

344. See, e.g., *infra* notes 365–66 (discussion of individualized service plans and individual assessments).

345. *Guggenberger v. Minnesota*, 198 F. Supp. 3d 973, 1030 (D. Minn. 2016).

346. *Id.* at 1029 (internal quotations omitted).

347. See *id.* at 1031 (“Without a developed evidentiary record on the effectiveness of Minnesota’s *Olmstead* Plan or the manner in which Defendants have utilized appropriated Waiver Services funds, the Court is unable to credit Defendants’ fundamental alteration defense.”).

348. See *Murphy v. Minn. Dep’t of Human Servs.*, 260 F. Supp. 3d 1084, 1122 (D. Minn. 2017). In *Murphy*, plaintiffs resided in community-based settings through an existing Medicaid waiver program, but argued that they sought access to services under the waiver program that

successfully “identif[ied] examples of the specific services they seek to transition to more integrated settings, and . . . allege that these services are already available under the Disability Waivers.”³⁴⁹ The court found that that “[t]o the extent Plaintiffs seek the creation of new services or residential settings or the allocation of additional state funding, the Court can evaluate the propriety of such requests as this case proceeds.”³⁵⁰ The court followed *Guggenberger*, reasoning that “it would be premature to resolve Defendants’ fundamental alteration defense in their favor at the pleading stage.”³⁵¹

Although the integration challenge in *Guggenberger* and *Murphy* involved access to the HCBS waiver program, the courts also considered the types of services sought by plaintiffs to remedy the discriminatory conduct. By focusing on the waiver program versus the appropriateness of the services, the courts honed in on whether the requested services were based on an *existing Medicaid waiver program*³⁵² or were already *available under the waiver program*.³⁵³ There was no further inquiry into whether the plaintiffs were seeking services that the State already provided to individuals in institutionalized care, or whether the services sought were the same as, or substantially similar to, those received by disabled persons in institutionalized care.

In a recent decision,³⁵⁴ a court in the Western District of Texas rejected outright defendants’ new-and-existing-services argument. Citing to *Townsend*, *Fisher* and *Radaszewski*, defendants argued that plaintiffs did not state a discrimination claim under Title II in light of a failure to “identify any Medicaid service that Texas makes available in institutional settings but does not offer in

would enable them to “achieve greater integration in the community.” *Id.* at 1093. Plaintiff identified general waiver services that could potentially assist in this goal. *Id.*

349. *Id.* at 1117. The court found that the facts established that plaintiffs’ remedy would not fundamentally alter the State’s Medicaid waiver program.

350. *Id.* at 1121.

351. *Id.* at 1118.

352. *Id.*; see also *Martin v. Taft*, 222 F. Supp. 2d 940, 974 (S.D. Ohio 2002). *Martin* was decided around the same time as *Fisher* and *Townsend*; the court in *Martin* distinguished *Rodriguez* and determined that plaintiffs were not requesting “new programs” by seeking to participate in the HCBS waiver program. The court found that plaintiffs wanted to participate in “waiver programs that already exist” and held that any inquiry into whether the State could expand the Medicaid waiver program to add plaintiffs must be a fact-based examination considering the circumstances in the case and whether such an expansion would fundamentally alter the nature of the State’s Medicaid program. *Martin*, 222 F. Supp. 2d at 974. Although distinguishable from *Guggenberger* and *Murphy* because the court does not elaborate on the services sought by plaintiffs, the court in *Martin* did not engage in a new and existing services analysis, focusing only on the existence of the waiver program and whether expanding the program would fundamentally alter the nature of defendants’ waiver program.

353. *Guggenberger v. Minnesota*, 198 F. Supp. 3d 973, 1018 (D. Minn. 2016). (“Plaintiffs have plausibly alleged that Waiver Services are . . . ‘available’ but that Plaintiffs are not being offered the choice to receive such services due to Defendants’ mismanagement of the State’s Waiver Services programs.”).

354. *Steward v. Abbott*, 189 F. Supp. 3d 624 (W.D. Tex. 2016).

community-based settings.”³⁵⁵ The court distinguished these cases and determined that defendants’ position was contrary to the integration regulations implemented under Title II and Section 504.³⁵⁶

The analysis of whether the requested services in integration mandate challenges under Title II and Section 504 are appropriate must be considered against the principles of *Olmstead*, its progeny, and the purpose of the HCBS waiver program and Settings Rule. The HCBS waiver program is designed to move beyond the isolated, segregated, and repressive environment of confined care towards integrating intellectually disabled individuals with others in the community through the administration of individualized and tailored services.

The application of the new-and-existing-services analysis effectively creates a simulated institutionalized environment where community integration amounts to the sacrificing of one’s sexuality, permanently driving the right to intimacy and sex into the shadows. The historical suppression of sexuality in institutionalized care allows group homes to simply argue that sexuality services are a new service, thereby alleviating the affirmative duty under Title II and Section 504 to provide these services as a reasonable modification to achieving full community integration. It is time to jettison the existing/new-services analysis and adopt an approach that aligns with the evolution of *Olmstead*. Moreover, it is time to acknowledge that this outmoded analysis contradicts the reality that adults with intellectual disabilities are living longer lives, gaining greater autonomy, marrying, starting families, and accessing education and employment opportunities—largely due to the access of new supports and services provided through the HCBS waiver program itself.³⁵⁷

V.

WHERE DO WE GO FROM HERE?: OVERCOMING THE FUNDAMENTAL ALTERATION DEFENSE THROUGH REASONABLE MODIFICATIONS TO SUPPORT THE SEXUALITY OF GROUP HOME RESIDENTS WITH INTELLECTUAL DISABILITIES

This Section challenges the fundamental alteration defense against a claim of sexual isolation under the integration regulations and proposes modifications to address the sexual isolation of group home residents. The discussion proposes the following modifications to group home policies and the administration of

355. *Id.* at 633.

356. *See id.*

357. Despite the successes of the HCBS waiver program, access to supports and services by intellectually disabled adults vary state-by-state and hundreds of thousands of people across the United States are on indefinite waiting lists to receive HCBS waiver services. *See, e.g., Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act*, S. COMM. ON HEALTH, EDUC., LABOR & PENSIONS 2–3 (July 18, 2013), <https://www.help.senate.gov/imo/media/doc/Olmstead%20Report%20July%2020131.pdf> [<https://perma.cc/GQ27-WEU2>] (report documenting statewide progress in the administration of the HCBS waiver program, with thirty-eight states reporting).

their services to avert disability-based discrimination: (1) a treatment planning process that properly and fairly assesses the individual's ability and interest in issues related to sex, intimate relationships, marriage, parenting, family, and healthy sexual behaviors; (2) a provision of sexuality services to those individuals who qualify for and are interested in them; and (3) agency-wide policy changes, which includes implementing policies and procedures that support sexuality rights that comply with the HCBS Settings Rule and other CMS regulations.³⁵⁸

A. The Fundamental Alteration and Undue Hardship Defense

Once it is established that the group home engaged in a form of disability-based discrimination under Section 504 through the unjustified sexual isolation of its residents, the next step is to determine whether the proposed modifications to address the discriminatory conduct are reasonable, or, if such modifications would fundamentally alter the nature of a group home's programs or activities thereby alleviating the group home of its duty. In *Olmstead*, the Court clarified the limits to a request for reasonable modifications. The Court determined that the evaluation of a fundamental alteration defense rests on the balancing of several factors, including "the cost of providing community-based care . . . , the range of services the State provides others with mental disabilities, and the State's obligation to mete out those services equitably."³⁵⁹ Four Justices joined the majority opinion to further clarify that the modification requirement was "not boundless."³⁶⁰ The plurality in *Olmstead* reasoned that states are not required to provide reasonable modifications to some at the expense of providing appropriate care and treatment to others.³⁶¹

A plurality of Justices also suggested that the reasonable modification standard could be met by demonstrating that a "comprehensive, effectively working plan" was in place to transfer qualified individuals with a disability into community-based settings and where the State implemented "a waiting list that moved at a reasonable pace" to move persons out of institutions.³⁶²

1. Proposed Modifications

The first proposed modification under Section 504 seeks a treatment planning process administered by group homes that properly and fairly assesses the individuals' ability and interest in issues related to sex, intimate relationships, marriage, parenting, family, and healthy sexual and intimate

358. *Cf.* *Lane v. Kitzhaber*, 841 F. Supp. 2d 1199, 1207–08 (D. Or. 2012) (in seeking relief from the court, plaintiffs sought to compel the State to create a supported employment program that complies with federal law).

359. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597 (1999).

360. *Id.* at 603.

361. *See id.* at 604.

362. *Id.* at 605–06.

relationships. Group homes assume the role of supporting intellectually disabled residents on their path toward achieving full community integration by supporting access to community-based services designed to address their individualized needs.³⁶³ In this role, group home operators can work together with the agency that administers HCBS waiver services to provide continued, tailored supports and services to their residents. Just as daily living, employment, education and mental health supports are factored into assessments of the individual's community-based needs, so too must sexuality be incorporated into the planning of a resident's treatment plan, with services administered as appropriate to the resident's evolving needs.³⁶⁴

Federal regulations require that states set guidelines to ensure that each individual recipient of HCBS waiver services is individually assessed by the agency that provides the service to determine what supports and services are needed to develop, maintain and strengthen skills for more independent living.³⁶⁵ To comply with these regulations, group homes, for example, work together with the HCBS waiver recipient to identify the individualized services that are most appropriate to their needs, which is then incorporated in an individualized plan of service specific to a resident's needs and goals.³⁶⁶ This

363. See discussion *supra* Parts III.A, III.B.

364. Friedman, Arnold, Owen & Sandman, *Remember Our Voices*, *supra* note 205, at 523 (arguing that in accessing sexuality service, individuals with intellectual disabilities have a right "to choose *how* they access information and from whom," stating that "[i]nformation should be accessible and include individualized supports that are meaningful and relevant to self-advocates"). Self-advocates are individuals with intellectual and developmental disabilities who engage in advocating for their right to independence and self-determination through public education presentations, public policy initiatives on the state and local level, and other efforts and initiatives. See, e.g., *About Us*, SELF-ADVOCACY ASS'N OF N.Y. ST., http://www.sanys.org/about_us.htm [<https://perma.cc/7MCZ-NFMA>].

365. Agencies that administer HCBS waiver services are mandated under federal law to work together with the individual and their support team to create an individualized plan of care, sometimes called an individualized services plan, which is revised regularly, identifying services and programs that will assist the recipient in meeting their outlined objectives and goals for community integration. See, e.g., 42 U.S.C.A. § 1396n(i)(1)(E)(ii) (2012) ("In the case of an individual who is determined to be eligible for home and community-based services, the State uses an independent assessment, based on the needs of the individual to[] . . . determine a necessary level of services and supports to be provided, consistent with an individual's physical and mental capacity; . . . prevent the provision of unnecessary or inappropriate care; and . . . establish an individualized care plan for the individual in accordance with subparagraph (G)."). We may assume, then, that a determination as to whether specific, individualized sexuality services are appropriate to meet the needs of a group home resident's desired goals for sex and intimacy would be determined through this assessment as well.

366. See, e.g., 42 U.S.C. § 1396n(G)(i)–(ii) (2012) (stating that where individuals are deemed eligible to receive waiver services "the State uses the independent assessment . . . to establish a written individualized care plan for the individual . . . in consultation with the individual, the individual's treating physician, health care or support professional, or other appropriate individuals, as defined by the State, and, where appropriate the individual's family, caregiver, or representative; and . . . taking into account the extent of, and need for, any family or other supports for the individual; . . . identifies the necessary home and community-based services to be furnished to the individual . . . and . . . is reviewed at least annually and as needed when there is a significant change in the individual's circumstances"); 42 U.S.C. § 1396n(G)(iii) (2012) (requiring the State

inquiry involves input and deliberation with the resident and the treatment team that is responsible for providing supportive services, and that may include other “appropriate individuals”³⁶⁷ such as social workers, the group home’s supervisor and any family supports.³⁶⁸ The services identified are then administered to the resident.

For Julia R.,³⁶⁹ it took months of litigation for her support treatment professionals, social worker, and others in charge of her plan of care to agree to meet with her to revise her individualized service plan so that it included appropriate sexuality services aimed at addressing her desire to get married and start a family. It is through this mandated, individualized plan-of-service process that group homes can conduct assessments of a resident’s interest in issues related to sexuality and determine what services may be necessary to support a resident’s particular goals.³⁷⁰

The second modification would require group homes to offer sexuality services under an existing HCBS waiver, or through other funding sources, to those individuals who qualify for and are interested in them. For example, thousands of waiver services may be offered through a select number of HCBS waivers. In one study, 2,850 waiver services were delivered through 111 waivers.³⁷¹ Sexuality services could fall into any number of the categories below:

residential habilitation; individual goods and services; prevocational; transportation; self-advocacy training; day habilitation; community transition supports; respite; health and professional services (crisis, dental, clinical and therapeutic services, nursing and home health); supports to live in one’s own home (companion, homemaker, chore, personal assistance, supported living); care coordination; adult day health; specialized medical and assistive technologies; financial support services; family training and counseling (family training and counseling,

to conduct “an assessment of the needs, capabilities, and preferences of the individual with respect to” the choice to elect “self-directed services”). Self-directed services “are planned and purchased under the direction and control of such individual or the individual’s authorized representative, including the amount, duration, scope, provider, and location of such services.” *Id.*

367. 42 U.S.C. § 1396n(G)(ii) (2012).

368. *Id.* This list of professionals is not exhaustive and is based on the author’s personal experience in individualized service plan meetings.

369. *See supra* Part I.

370. *See Noonan & Gomez, supra* note 113, at 177 (“Service organizations have a responsibility to ensure that sexuality and sexual health are considered in individual planning for people with intellectual disability.”).

371. Carli Friedman, *A National Analysis of Medicaid Home and Community Based Services Waivers for People with Intellectual and Developmental Disabilities: FY 2015*, 55 INTELL. & DEVELOPMENTAL DISABILITIES 281, 299 (2017).

family supports); recreation and leisure; and supported employment.³⁷²

In ascertaining the reasonableness of this modification, an inquiry could be made into whether waivers for “adaptive skill development,” “adult educational supports,” and “social and leisure skill development”³⁷³ may be utilized by the group home to provide individualized sexuality services to residents who are seeking sexuality services and are already eligible to receive services under these specific waivers.

Furthermore, service providers could test whether sexuality services may be administered through other funding sources utilized by the group home, or through another HCBS waiver program.³⁷⁴ By way of example, YAI is able to provide sexuality services, in part, through a grant from New York State’s developmental disabilities agency family support contract (specifically for people who live with families in Manhattan) and as part of bundled services under HCBS waivers.³⁷⁵ Similar to the argument presented by plaintiffs in *Lane*, a request for sexuality services is not a request for a guarantee that adults with intellectual disabilities will, in fact, gain the skills and requisite capacity to engage in sex and intimate relationships; rather, the request asks that service providers give individuals the opportunity to access support and services to which they may already be qualified to receive.³⁷⁶

Group home staff and administrators can access available courses and training on how to provide sexual education to their residents. Tailored sex education has “positive effects . . . on knowledge, skills, attitudes, and behaviors of adults with [intellectual disabilities]”³⁷⁷ and has proven successful to “improve capacity to make sexuality-related decisions.”³⁷⁸ As one researcher noted, sexual education is a “mechanism to promote the ability to make good choices and empower” intellectually disabled adults.³⁷⁹ Further, the development of decision-making skills through sex education contributes to the

372. *Id.* at 292.

373. See CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 162, at 147.

374. States may also apply for Medicaid demonstration waivers through Section 1115 of the Social Security Act. See MaryBeth Musumeci, Robin Rudowitz, Elizabeth Hinton, Larisa Antonisse & Cornelia Hall, *Section 1115 Medicaid Demonstration Waivers: The Current Landscape of Approved and Pending Waivers*, THE KAISER COMM’N ON MEDICAID & THE UNINSURED (Feb. 1, 2018), <https://www.kff.org/medicaid/issue-brief/section-1115-medicaid-demonstration-waivers-a-look-at-the-current-landscape-of-approved-and-pending-waivers/> [https://perma.cc/5RA6-F26K] (last visited Nov. 11, 2017). Section 1115 demonstration waivers allow States the flexibility to propose an “experimental, pilot, or demonstration project” to, for example, enhance community engagement for individuals with intellectual disabilities. *Id.*

375. Interview with Consuelo Senior, Assistant Coordinator of Sex Education Learning & Talent Development, YAI, in New York, N.Y. (July 13, 2017).

376. *Lane v. Kitzhaber*, 841 F. Supp. 2d 1199, 1207 (D. Or. 2012).

377. Travers, Tincani, Whitby & Boutot, *supra* note 94, at 238.

378. E. Dukes & B.E. McGuire, *Enhancing Capacity to Make Sexuality-Related Decisions in People with Intellectual Disability*, 53 J. INTELL. DISABILITY RES. 727, 727 (2009).

379. Swango-Wilson, *supra* note 87, at 168.

ability to make knowledge-based choices and “reinforce[s] the decision to act for the good of one’s health and well-being,” contributing to “reducing vulnerability” and “inappropriate sexual expression.”³⁸⁰ There is, for example, a program specifically designed to train providers on how to teach intellectually disabled adults about issues of sexuality: Planned Parenthood of Northern New England and Green Mountain Self-Advocates’ *Sexuality Education for People with Developmental Disabilities* curriculum.³⁸¹

The final modification would require group homes to create or adapt policies and procedures that unpack the bias, paternalism and ableism that drives group home decisions in matters of sexuality. Studies reflect that in-service training on sexuality services and the implementation of a positive sexuality policy have “the potential to change the culture of the group home to one that is more accepting and has more positive attitudes towards sexuality for individuals with intellectual disabilities.”³⁸² Resources may include in-person and internet-based trainings for agencies and organizations on navigating issues of sexuality and intellectual disability and on becoming sexuality educators who serve the intellectual disabled population.³⁸³

2. Overcoming the Fundamental Alteration Defense

In the years following *Olmstead*, courts have closely followed the *Olmstead* plurality to determine the circumstances under which a modification is appropriate.³⁸⁴ Courts will not interfere with a state’s administration of its

380. *Id.*

381. Katherine McLaughlin, *Sexuality and Developmental Disabilities Workshops*, <http://disabilityworkshops.com/workshops-and-products/sexuality-education-for-people-with-developmental-disabilities-curriculum/> [<https://perma.cc/9BG4-Z2YA>] (last visited Nov. 20, 2017); *Sexuality*, GREEN MOUNTAIN SELF-ADVOCATES (July 24, 2015), <http://www.gmsavt.org/?s=sex> [<https://perma.cc/X4JR-ZFXX>].

382. Roxanna N. Pebdani, *Attitudes of Group Home Employees Towards the Sexuality of Individuals with Intellectual Disabilities*, 34 *SEXUALITY & DISABILITY* 329, 337–38 (2016); see also Travers, Tincani, Whitby & Boutot, *supra* note 94, at 244.

383. For a more detailed list of sexuality training and education resources, see, for example, McLaughlin, *supra* note 381; *Healthy Relationships, Sexuality and Disability: Resource Guide 2014 Edition*, MASS. DEP’T OF PUB. HEALTH & MASS. DEP’T OF DEVELOPMENTAL SERVS. (2014), <http://www.mass.gov/eohhs/docs/dph/com-health/prevention/hrhs-sexuality-and-disability-resource-guide.pdf> [<https://perma.cc/233M-AD57>]; *Tash Resolution on Sexuality*, TASH (Mar. 2000), <https://tash.org/about/resolutions/tash-resolution-sexuality/> [<https://perma.cc/T8W2-MECB>]; *Search: “Sexuality”*, YAI, https://www.yai.org/search/page?search_api_views_fulltext=Sexuality [<https://perma.cc/LT6Q-SFVU>] (last visited Nov. 20, 2017).

384. See, e.g., Mark C. Weber, *Home and Community-Based Services, Olmstead, and Positive Rights: A Preliminary Discussion*, 39 *WAKE FOREST L. REV.* 269, 287 (2004) (“Courts applying section 35.130(d) and *Olmstead* to HCBS cases have applied the plurality’s discussion of the reasonable modification-fundamental alteration defense.”); see also *Martin v. Taft*, 222 F. Supp. 2d 940, 971 (S.D. Ohio 2002) (“[I]n evaluating the fundamental alteration defense, a court must carefully consider the state’s legitimate interest in providing a variety of services for persons with mental disabilities, including institutional-based services, as well as the state’s interest in allocating available resources fairly and evenhandedly.”).

community-based treatment program if there is evidence of a comprehensive or effective plan to ensure individuals with disabilities are receiving services in integrated settings.³⁸⁵

Courts approach the fundamental alteration analysis differently dependent on plaintiff's requested modification in integration mandate challenges. In *Pennsylvania Protection & Advocacy, Inc. v. Pennsylvania Department of Public Welfare*, the court examined whether the state isolated disabled residents in institutions rather than provide persons with available community-based treatment.³⁸⁶ There, the courts considered the state's budgetary constraints and examined whether the state "developed and implemented a plan" to comply with the mandates of Title II and Section 504.³⁸⁷

In finding the state's fundamental alteration defense insufficient, the court pointed to several factors. The court noted the failure of the state to establish how providing community-based services to plaintiffs would result in the reduction of services to other institutionalized individuals.³⁸⁸ The state also did not present evidence of any unsuccessful attempts to access additional funding to comply with integration mandates, or show a commitment to effectuate a plan to bring its actions in compliance with Title II and Section 504 in a timely manner.³⁸⁹ Lastly, the state could not demonstrate that it "responsibly spent its budgetary allocations" toward compliance with the community integration mandates.³⁹⁰

In *Steimel*, as noted earlier, the issue was whether the state could reduce the number of community-based hours available to those who were previously eligible, effectively confining persons to their homes. The court reduced the fundamental alteration analysis to the following question: "what effect will changing the state's practices have on the provision of care to the

385. See *Sanchez v. Johnson*, 416 F.3d 1051, 1067–68 (9th Cir. 2005) ("[W]hen there is evidence that a State has in place a comprehensive deinstitutionalization scheme, which, in light of existing budgetary constraints and the competing demands of other services that the State provides, including the maintenance of institutional care facilities, is 'effectively working,' the courts will not tinker with that scheme." (quoting *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 605 (1999)) (internal citations omitted)). In *Sanchez*, the State provided evidence of its expanding Medicaid waiver program, proof of the decreasing population of institutionalized persons and increased funding for community-based treatment programs. *Id.* at 1067; *Arc of Wash., Inc. v. Braddock*, 427 F.3d 615, 620–21 (9th Cir. 2005) (holding that the State administered an effective and comprehensive deinstitutionalization plan that included a consistent increase of available waiver services and funding and a waiting list for community-based waiver services that moved at a reasonable pace); see also *Disability Advocates, Inc. v. Paterson*, 653 F. Supp. 2d 184, 302 (E.D.N.Y. 2009) (state displayed no efforts to relocate qualified Adult Home residents to more integrated settings in the community).

386. *Pa. Prot. & Advocacy, Inc. v. Pa. Dep't of Pub. Welfare*, 402 F.3d 374, 381 (3d Cir. 2005).

387. *Id.* at 381–86.

388. See *id.* at 383.

389. See *id.*

390. *Id.*; see also *Guggenberger v. Minnesota*, 198 F. Supp. 3d 973, 1031 (D. Minn. 2016) (citing *Pa. Prot. & Advocacy*, 402 F.3d at 383).

developmentally disabled, taking into account the resources available to the state and the need to avoid discrimination?”³⁹¹ The court rejected the state’s argument that its waiver eligibility requirements, which limited the number of people who could access an increased palette of community-based services, were necessary for the administration of the state’s waiver program.³⁹²

In rejecting this argument, the court relied on the ADA regulations to find that the state could not “impose or apply eligibility criteria that” would “screen out” disabled individuals from accessing services unless such criteria are necessary for the provision of that service; there were no such criteria, in this case.³⁹³ The court also found no evidence that apportioning of the waiver services to enable qualified disabled individuals to access additional community-based treatment would increase costs or fundamentally alter the state’s waiver program.³⁹⁴ The following section proposes modifications to address the unjustified sexual isolation of group home residents.

In challenging the proposed modifications, group homes would have to establish that they do not have the resources to adequately assess group home residents for sexuality services; provide appropriate sexuality services; and train staff and administrators through the implementation of policies and procedures that address issues of sexuality and intellectual disability. Group homes ultimately bear the burden under Section 504 to prove that modifications to their programs, services or activities related to sexuality will significantly burden the ability of the group homes to provide equal services to other group homes residents.³⁹⁵

The proposed modifications, *supra*, identify concrete steps and tools that group homes may take to satisfy the affirmative duty under Section 504. The group home would have to establish that the increased cost is too burdensome in relation to the modification sought. Courts have determined that the fundamental alteration analysis requires a “holistic”³⁹⁶ or complex “fact-intensive”³⁹⁷

391. *Steimel v. Wernert*, 823 F.3d 902, 915 (7th Cir. 2016). Ironically, the State defendant in *Steimel* did not assert a fundamental alteration defense and, instead, argued that the remedy sought by plaintiffs (to have the level of community-based services restored from ten to twelve hours to forty hours a week) was unreasonable because it required the state to change its eligibility criteria. *Id.* at 916. The court rejected this argument on several grounds. *Id.* at 916–17.

392. *See id.* at 916.

393. *Id.*

394. *See id.* at 916–17.

395. *See Olmstead v. L.C. ex. rel. Zimring*, 527 U.S. 581, 604 (1999) (construing the fundamental alteration defense under 28 C.F.R. § 35.130(b)(7)); *see also Weber*, *supra* note 384, at 281.

396. *Steimel*, 823 F.3d at 915.

397. *Van Orden v. Schaefer*, No. 09-00971, 2014 WL 5320232, at *7 (E.D. Mo. Oct. 17, 2014) (finding that a fundamental alteration defense inquiry involves “fact-intensive issues that require further development of the record”); *see also Guggenberger v. Minnesota*, 198 F. Supp. 3d 973, 1031 (D. Minn. 2016).

analysis to determine whether applying these changes may alter the group home's ability to serve all of its residents.

Concerns related to costs are not enough to overcome the modification requirements under Section 504: Courts have rejected the argument that financial and budgetary constraints alone absolve the entity of the affirmative duty under the fundamental alteration defense, unless it can be shown that such "costs would, in fact, compel cutbacks in services to other Medicaid recipients."³⁹⁸ As one court noted, if a state could satisfy the fundamental alteration defense by arguing that a modification would be too costly, such a broad reading of this defense would "swallow the integration mandate whole."³⁹⁹ Congress recognized—and courts have agreed—that compliance with the integration mandate may require "substantial short-term burdens, both financial and administrative"⁴⁰⁰ to achieve the goal of community integration.⁴⁰¹ Further, group homes that fail to take meaningful measures to avert the sexual isolation of group homes residents are also unlikely to meet their burden under the fundamental alteration defense when considering the additional factors outlined in *Pennsylvania Protection & Advocacy, Inc.*

Group homes may further assert that the "normalization" of sexuality through the modification of policies and procedures may place other group home residents at risk for sexual abuse or exploitation by other residents, or expose the group home to liability, thereby fundamentally altering the ability of group homes to protect their residents and their staff. Social science research challenges the argument that increased knowledge, information, and awareness of sexuality exposes group home residents to sexual abuse or exploitation.⁴⁰² One court recognized that the "effective hospital policing" and "[t]he threat of tort liability for insufficient vigilance in policing patients' sexual conduct" is not enough to "deprive them of the freedom to engage in consensual sexual relations."⁴⁰³

398. *Townsend v. Quasim*, 328 F.3d 511, 521 (9th Cir. 2003); *see also Pashby v. Delia*, 709 F.3d 307, 358 (4th Cir. 2013); *Steimel*, 823 F.3d at 915; *Radaszewski v. Maram*, 383 F.3d 599, 614 (7th Cir. 2004) (finding that evidence that a modification would "substantially increase" a state's expenditures cannot, alone, defeat an integration claim under Title II).

399. *Pa. Prot. & Advocacy, Inc. v. Pa. Dep't of Pub. Welfare*, 402 F.3d 374, 381 (3d Cir. 2005); *see also Weber, supra* note 384, at 288–89 (in providing community-based supports and services, "Medicaid is a federal-state cooperative program, in which the federal government bears the larger share of the expense; this fact mitigates the state's hardship claim").

400. *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1183 (10th Cir. 2003) (quoting H.R. REP. No. 101-485, pt. 3, at 50 (1990), *reprinted in* 1990 U.S.C.C.A.N. 445, 473.).

401. This Article proposes that States offer sexuality supports and services through the HCBS waiver program, by providing access and opportunities for sexuality services through an existing waiver or creating independent waivers specific to sexuality services. *See, e.g., infra* note 408 (New Mexico's HCBS waiver service for sexuality services).

402. *See, e.g., Noonan & Gomez, supra* note 113, at 177; Travers, Tincani, Whitby & Boutot, *supra* note 94, at 238; *see also supra* Part V.A.1.

403. *Foy v. Greenblott*, 141 Cal. App. 3d 1, 10–12 (1983).

B. Where Do We Go from Here?

There are practical challenges to providing appropriate modifications, including the lack of sexual education training provided to support workers of adults with intellectual disabilities⁴⁰⁴ and the limited number of HCBS waivers and other funding dedicated specifically to sexuality services.⁴⁰⁵ Further, the State is complicit with group homes in the sexual isolation of intellectually disabled adults by failing to provide resources to support access to sexuality supports and services.

1. The Role of State Agencies in Supporting the Sexual Rights of Adults with Intellectual Disabilities

A recent study examined 111 HCBS waivers to find that less than 12% specifically include sexuality services for intellectually disabled adults.⁴⁰⁶ The majority of these waivers focused primarily on how to address negative sexual behaviors.⁴⁰⁷ Two known outliers are New Mexico and the District of Columbia, which provide positive sexuality services to adults with intellectual disabilities through the HCBS waiver program.⁴⁰⁸

Any fundamental change in how group homes approach strategies to support intellectually disabled adults in decisions related to sex and intimacy must begin at the state agency level. State agencies, such as the Office for People with Developmental Disabilities in New York State, wield tremendous power as the gatekeeper of the HCBS waiver program. State agencies can, for example, commit time and money to developing sexual education resources and require staff and administrators of group homes, other residential settings, and service provider agencies to undergo trainings to gain skills for navigating the topic of sexuality with adults with intellectual disabilities. The state agencies can also work to shift the culture of group home settings towards supporting the notion that sexual rights are an integrated aspect of community integration through the implementation of proactive sexuality policies.

404. See, e.g., Saxe & Flanagan, *supra* note 240, at 452 (research study identified a significant lack of sexual education for support workers for developmentally disabled adults, urging that sexual education “training should be included in all support worker education programs so that no individual enters the field without this pertinent knowledge”).

405. Friedman & Owen, *supra* note 11, at 387 (noting that less than 12% of waivers include any kind of sexuality services).

406. *Id.*

407. *Id.*

408. Friedman & Owen, *supra* note 11, at 3; see also DEVELOPMENTAL DISABILITIES WAIVER (DDW) SERVICE STANDARDS 218–23, N.M. DEP’T OF HEALTH (June 15, 2015), available at <https://nmhealth.org/publication/view/regulation/3511/> [<https://perma.cc/XH73-AYJB>] (outlining the description and requirements for an HCBS waiver service that provides “Socialization and Sexuality Education”).

2. Developing a Sexuality Policy

YAI's *Relationships and Sexuality Policy* (YAI *Sexuality Policy*), included with this Article online as Appendix 2, provides guidance for other agencies that administer supports and services to adults with intellectual disabilities in developing policies that proactively, and affirmatively, address sexuality. The YAI *Sexuality Policy* details YAI's philosophy and approach to addressing sexuality in a positive and proactive way, and provides instruction as to the role and responsibility of the agency and staff in supporting the sexuality of the intellectually and developmentally disabled population that YAI services.

The YAI *Sexuality Policy* approaches sexuality through several lenses that more closely define the human experience. For example, the policy describes “[s]exuality” as “an integral part of each individual” and goes on to define “[i]ndividuality” as including “sexual orientation,” “[g]ender [i]dentity,” and “[t]he right to be supported to develop loving and safe friendships and relationships.”⁴⁰⁹ The policy also identifies the philosophy of the organization and its support of “healthy and functional expressions of . . . sexuality” and goes into greater detail about issues including consent, friendships and relationships, education and training, sexual expression, contraception, reproduction, and sexual health, including HIV/AIDS, sexual behaviors, and family. The YAI policy further details the role of YAI's staff, and the agency, itself, in adhering to the policy.⁴¹⁰

Developing a policy that recognizes sexuality as encompassing issues such as consent, relationships, friendships, sexual orientation, gender identity, and family can provide a common language and understanding among agency staff and administrators as to the varying degrees of sexual expression and their shared roles and responsibilities in supporting the healthy sexual choices of intellectually disabled adults. A sexuality policy can also assist in eliminating the personal biases agency staff or administrators may have concerning what constitutes healthy sexuality. This, in turn, can help create a uniform framework for the agency philosophy—including expectations for how employees are to approach issues of sexuality with intellectually disabled adults.

According to Consuelo Senior, Assistant Coordinator of Sex Education Learning & Talent Development at YAI, prior to taking steps to implement a sexuality policy, an agency must first secure support from the executives of the agency, including all of the interrelated departments within the agency—such as

409. Appendix 2, *Relationships and Sexuality Policy*, YAI, available at https://socialchange.nyu.com/wp-content/uploads/2018/04/Chin_42.3_Appendix2.pdf. Appendix 2 has been reproduced with the permission of YAI. YAI retains all rights to Appendix 2. Any person or organization seeking to use YAI's policy for any purpose, including reproduction, must get the express written consent of YAI.

410. *Id.*

residential services (including group homes), day habilitation programs, community habilitation, recreation, and in-home services.⁴¹¹

Agency executives must exercise a commitment to implementing a sexuality policy that supports the healthy sexuality of the intellectually disabled adult population that the agency serves. Senior explains, “when there is a buy-in from executives on the agency board, it frames the philosophy of the program and it shows that they are invested in ensuring that the sexuality policy is followed.”⁴¹² This commitment must include educating and training agency administrators and staff on sexuality and intellectual disability, educational programming for intellectually disabled adults who wish to exercise choices around sexuality, and a recognition that sexuality constitutes a range of human emotions and choices not limited to sexual intercourse.

To successfully develop a sexuality policy, agencies can take steps to assemble a cross-section of individuals from the disability and legal community to help strategize around the content of the policy. These individuals may include experts in the field of sexuality and intellectual disability, the state agency that administers HCBS waiver services to individuals with intellectual and developmental disabilities, legal counsel, the agency’s compliance department, and self-advocates.⁴¹³

An agency can also create an independent body to oversee the implementation of the sexuality policy. For example, YAI created the Sexuality Rights and Advocacy Committee for this purpose. The Committee examines all sexual consent determinations, identifies what sexuality training is needed throughout the agency, gathers input from group home residents as to what sexuality supports are needed, identifies gaps in the sexuality services offered (such as a need to develop support groups for the lesbian, gay, bisexual, transgender, and queer population), and ensures that there is an annual, mandatory staff training on the YAI *Sexuality Policy*. A committee overseeing this process can also ensure that the training includes review of the sexuality policy’s content, roleplaying exercises and scenarios based on the policy, and general training on how to avoid infusing biases into dealing with a range of sexual issues and intellectually disabled adults.

411. Interview with Consuelo Senior, Assistant Coordinator of Sex Education Learning & Talent Development, YAI, in New York, N.Y. (Mar. 15, 2018). Sexual expression that is permitted in a group home may not be appropriate in a public, day habilitation setting, for example, and a sexuality policy should reflect these parameters. Clarifying the role and responsibilities of both the agency and the employees in supporting the sexuality of intellectually disabled adults within various departments of the agency will allow for consistency, transparency and clarity in administering the sexuality policy.

412. *Id.*

413. *See supra* note 364 (defining “self-advocates”).

VI.
CONCLUSION

Conceptualizing sexual isolation as a violation of the integration regulation under Section 504 places sexuality on equal footing with other supports and services that are recognized as essential to support full community integration.⁴¹⁴ Recognizing sexuality as an integral aspect of community integration can further “challenge the assumption that individuals with intellectual disabilities always need protection from sexual abuse”⁴¹⁵ and that such protection requires “denying their sexual lives.”⁴¹⁶ The shift toward sexuality as a positive right could follow the outcomes in *Lane* and *United States v. Rhode Island*, requiring group homes to provide affirmative supports and services to ensure that sexuality and the ability to form and maintain intimate relationships are not subject to indiscriminate policing and/or a lack of community-based supports.

The majority in *Olmstead* rejected defendants’ claims that Title II did not apply because plaintiffs failed to identify a similarly situated class of institutionalized persons who were given preferential treatment.⁴¹⁷ In rejecting this argument,⁴¹⁸ the majority acknowledged the very personal harm of unjustified institutional isolation noting, “Congress had a more comprehensive view of the concept of discrimination advanced in the ADA.”⁴¹⁹

It is this more comprehensive view of Title II of the ADA that is opening the door to the modern evolution of the *Olmstead* integration mandate. In his opening sentence in *Obergefell v. Hodges*, a United States Supreme Court case establishing that same-sex couples had a fundamental right under the Fourteenth Amendment to marry, Justice Anthony Kennedy writes, “The Constitution promises liberty to all within its reach, a liberty that includes certain specific rights that allow persons, within a lawful realm, to define and express their identity.”⁴²⁰

As a civil rights statute, the ADA came with a similar promise, embodying the notion that disabled persons will have the ability to define and express their identity through “equality of opportunity, full participation, independent living, and economic self-sufficiency”⁴²¹ outside the confines of institutionalization and isolation—and “to pursue those opportunities for which our free society is

414. See Fischel & O’Connell, *supra* note 54, at 506–07 (arguing that we should approach sexuality services from a social welfare perspective).

415. GILL, *supra* note 12, at 30.

416. *Id.*

417. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 598 (1999).

418. *Id.* at 598.

419. *Id.*

420. *Obergefell v. Hodges*, 135 S. Ct. 2584, 2593 (2015).

421. 42 U.S.C. § 12101(7) (2009).

justifiably famous.”⁴²² The *Olmstead* decision brought this promise closer for persons with disabilities. But this promise cannot be fully realized if sexuality is silenced in the goal toward community integration.

422. 42 U.S.C. § 12101(8) (2009).