

Access to Sex:

Sexuality Support for Adults with Intellectual &
Developmental Disabilities

SHOSHANA RUBIN[†]

I. INTRODUCTION

Every Monday night, Jillian goes for dinner with her friends at Pietro's. She picks Pietro's because there is a waiter there who looks like Justin Bieber. She has been in love with Justin Bieber since she was five. The waiter's name is Anthony. Anthony says hello to Jillian when she comes in. He does not know it, but this makes Jillian happy for approximately seven days.¹

Jillian does not drive to Pietro's because she does not have a license or a car. Jillian's mother organizes the dinner outings by emailing a list of Jillian's friends. Ten people respond. Fred cannot come. His support staff cannot work that night and there is no one else to take him. So, he stays home. Fred likes Anthony too. He is afraid to tell his parents. He tried to tell

[†]J.D. Candidate, 2021, City University of New York School of Law. The author thanks Professor Ruthann Robson for her encouragement, guidance and suggestions. Thank you to Professor Sofia Yakren and Professor Natalie Chin for their insight into disability law. Many thanks to the editorial team at CPILJ for their careful edits and suggestions. Finally, the author thanks her family for their support and inspiration.

¹ The names and some facts of the stories have been changed to protect the identities of all individuals.

his support staff, but his support staff changed the subject.

Sam drives to Pietro's. Sam has a girlfriend. Her name is Athena. They first met in Ms. Stephanie's special education class, thirty years ago. Athena's parents do not let her go into Sam's car. When she wants to see him, they drive her to meet him in public places only. This bothers both of them.

On Saturdays, Maria has dinner with her parents. Sometimes her siblings join them, if they are not in their own homes, with their own partners, or with their own children. Sometimes everyone is together. On one of those nights, when everyone is studying their menu, Maria makes an announcement. "I want to have sex!" Everyone's menu drops.

Ask a group of young adults with intellectual and/or developmental disabilities what they think about dating, sexuality, and relationships, and their answers will be just as diverse as any other group of people. But they share a common theme:

I like spending time with a friend.²

I can get to know the person.³

I have never dated . . .⁴

What I like about dating is the feeling of it and so you won't have to be alone. Also, you can do things together to make living easier.⁵

They want to connect. Some of them just need guidance to get there.

The World Health Organization gives a working definition of sexuality as a "central aspect of being human throughout life" encompassing "sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction."⁶ Yet, the sexuality of people with intellectual and developmental disabilities has long been ignored or outright denied.⁷ The American Association on Intellectual and Developmental Disabilities calls it a loss which has had a negative impact on "gender identity, friendships,

² E-mail from Anonymous, Self-Advocate, to Shoshana Rubin, J.D. Candidate, 2021, City University of New York School of Law (Apr. 19, 2020, 1:19 EST) (on file with the author).

³ *Id.*

⁴ E-mail from Anonymous, Self-Advocate, to Shoshana Rubin, J.D. Candidate, 2021, City University of New York School of Law (Apr. 19, 2020, 5:46 EST) (on file with the author).

⁵ E-mail from Anonymous, Self-Advocate, to Shoshana Rubin, J.D. Candidate, 2021, City University of New York School of Law (Apr. 21, 2020, 12:55 EST) (on file with the author).

⁶ WORLD HEALTH ORG., *Defining Sexual Health: Report of a Technical Consultation on Sexual Health* (2002), https://www.who.int/reproductivehealth/publications/sexual_health/defining_sexual_health.pdf.

⁷ See *Sexuality: Joint Position Statement of AAIDD and The Arc*, AM. ASS'N ON INTELL. AND DEV. DISABILITIES (Nov. 8, 2008), <https://www.aaid.org/news-policy/policy/position-statements/sexuality>

self-esteem, body image and awareness, emotional growth and social behavior.”⁸

This note argues that people with intellectual disabilities who are living independently with support are overlooked when it comes to sexuality. While much has changed since the days of *Buck v. Bell*, when the Supreme Court had upheld the practice of sterilization of people with disabilities,⁹ much of the stigma has remained the same. While there has been a movement away from institutionalization towards independent living and community integration, there remains a lack of support services when it comes to intimacy and sexuality for individuals with disabilities. Part One of this note will look at the history of discrimination and desexualization of people with disabilities. Part Two will discuss consent, the way courts handle consent, and different theories on how to handle consent. Part Three will cover Medicaid’s Home and Community Based Services Waiver Program and The Americans with Disabilities Act. Part Four looks at *Olmstead*,¹⁰ the integration mandate and how the integration mandate has been expanded. Part Five considers ways of making sexuality services more accessible to people with disabilities. The conclusion shows that for community integration to be fully realized, sexuality support should be included for those who want it.¹¹

II. DISABILITY DOES NOT ERASE SEXUALITY

A. *Defining Intellectual and Developmental Disability*

There are many different types of disability. This note focuses on adults with intellectual and/or developmental disabilities who are living independently with support services. The American Association of Intellectual and Developmental Disabilities (AAIDD) defines intellectual disability as “a disability characterized by significant limitations in both **intellectual functioning** and in **adaptive behavior**, which covers many everyday social and practical skills.”¹² Intellectual functioning involves

⁸ *Id.*

⁹ *Buck v. Bell*, 274 U.S. 200 (1927).

¹⁰ *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999).

¹¹ It is not the intention of this note to suggest that only people with intellectual disabilities need support when it comes to sexuality, or that all people with intellectual disabilities need support in this area. Everyone benefits from a greater understanding of the issues surrounding sexuality. Where support is wanted by a person, it should be made available.

¹² *Definition of Intellectual Disability*, AM. ASS’N ON INTELL. AND DEVELOPMENTAL DISABILITIES, <https://www.aaidd.org/intellectual-disability/definition> (last visited May 11, 2020), [hereinafter *Definition of Intellectual Disability*].

mental capacity and includes reasoning and problem solving.¹³ Adaptive behaviors are practical,¹⁴ conceptual,¹⁵ and social skills.¹⁶ “Developmental disability” is another term that is sometimes used and includes people with autism¹⁷ and cerebral palsy.¹⁸ Sometimes people have more than one diagnosis.¹⁹ These are basic, scientific descriptions of disability that do not take into account the many theories on disability and the layers that go into someone’s identity.

B. History of Discrimination Against People with Disabilities

People with disabilities were not always welcome in the community and were thought to be “agents of the devil.”²⁰ Beginning in the 1800s, people with disabilities were committed to institutions. Institutions were promoted as a way to prevent what was seen as a genetic and social problem (based on theories that have been discredited), to keep what was considered a “dangerous minority” separate from everyone else.²¹ One of the earliest institutions in the United States, known as the “The Massachusetts School for Idiotic and Feeble-Minded Youth,” opened in 1848.²² People behind these institutions believed disability was a disease that could be cured.²³ The apparent interest in using education to “teach” the residents evolved into

¹³ *Id.*

¹⁴ *Id.* (explaining that practical skills include “activities of daily living” such as caring for oneself, traveling, and using the telephone).

¹⁵ *Id.* (explaining that conceptual skills include language and literacy as well as concepts of money and time).

¹⁶ *Id.* (explaining that social skills include interpersonal skills, social responsibility, self-esteem, the ability to follow rules and to avoid being victimized).

¹⁷ *What is Autism?* AUTISM SCI. FOUND., <https://autismsciencefoundation.org/what-is-autism/> (last visited May 11, 2020) (autism refers to Autism Spectrum Disorders); *What is Autism Spectrum Disorder?*, CTRS. FOR DISEASE CONTROL AND PREVENTION, <https://www.cdc.gov/ncbddd/autism/facts.html> (last visited May 11, 2020) (“Autism spectrum disorder (ASD) is a developmental disability that can cause significant social, communication and behavioral challenges.”).

¹⁸ CTRS. FOR DISEASE CONTROL AND PREVENTION, <https://www.cdc.gov/ncbddd/cp/facts.html> (last visited Jan. 11, 2020) (“Cerebral palsy (CP) is a group of disorders that affect a person’s ability to move and maintain balance and posture.”).

¹⁹ See Hannah Furfaro, *Conditions that Accompany Autism, Explained*, SPECTRUM NEWS (July 25, 2018), <https://www.spectrumnews.org/news/conditions-accompany-autism-explained/>.

²⁰ See *Soc’y for Good Will to Retarded Child., Inc. v. Cuomo*, 572 F. Supp. 1300, 1304 (E.D.N.Y. 1983), *vacated*, 737 F.2d 1239 (2d Cir. 1984).

²¹ See Deborah W. Denno, *Sexuality, Rape, and Mental Retardation*, 1997 U. ILL. L. REV. 315, 332-333 (1997) (describing how the eugenics movement in the twentieth century, spurred by concepts of evolution and natural selection, was a major factor in how people with intellectual disabilities were treated.).

²² *Parallels In Time: A History of Developmental Disabilities*, THE MINN. GOVERNOR’S COUNCIL ON DEVELOPMENTAL DISABILITIES, <https://mn.gov/mnddc/parallels/four/4b/5.html> (last visited June 8, 2020).

²³ See *Soc’y for Good Will to Retarded Child.*, 572 F. Supp. at 1305 (1983).

confinement and restraint.²⁴ From the 1880s to the 1950s, institutions began emphasizing “incarceration rather than treatment.”²⁵ Within these institutions, men and women were kept separate so as to prevent sexual activity.²⁶ The eugenics movement was considered a “hunt for the feebleminded”—as those in power believed those with disabilities should be prevented from reproducing.²⁷

In 1927, the Supreme Court considered *Buck v. Bell*.²⁸ The question before the Court was whether Virginia’s law allowing for Carrie Buck’s sterilization in an institution was a violation of her Fourteenth Amendment rights to equal protection and due process.²⁹ As the Court explained, Buck was “the daughter of a feeble minded mother in the same institution, and the mother of an illegitimate feeble minded child.”³⁰ Declaring that “[t]hree generations of imbeciles are enough,” Justice Holmes found that the sterilization statute was constitutional.³¹ While the *Buck v. Bell* holding has never been overturned, the Virginia statute at the heart of the case was repealed in 1974.³² The decision led to more than 60,000 sterilizations across the country.³³ In many states today, a parent or legal guardian can still apply for the sterilization of their adult children for medical purposes, with approval from a judge.³⁴

Advocates across the country started protesting the segregation and institutionalization of people with disabilities in the late 1960s and 1970s.³⁵ Their protests were modeled after those of the civil rights movement.³⁶ In 1973, Congress passed Section 504 of the Rehabilitation Act, which banned discrimination on the basis of disability by those programs that receive federal funds.³⁷

²⁴ See *id.* at 1312–14, 1325, 1345.

²⁵ Ruth Colker, *Anti-Subordination Above All: A Disability Perspective*, 82 NOTRE DAME L. REV. 1415, 1435 (2013) (“The philosophy underlying these institutions also became more racist,” turning to eugenics as a way to control a growing population that was seen as “defective.”).

²⁶ See Denno, *supra* note 21, at 328, 333 (describing how institutionalization included separating the sexes to prevent sexual activity and the “social burden” that might result from it).

²⁷ RUTH COLKER & PAUL D. GROSSMAN, *THE LAW OF DISABILITY DISCRIMINATION* 2 (8th ed. 2013).

²⁸ See *Buck v. Bell*, 274 U.S. 200 (1927).

²⁹ See *id.* at 205.

³⁰ *Id.*

³¹ *Id.* at 207.

³² See Colker, *supra* note 25, at 3.

³³ *G: Unfit*, WNYC STUDIOSRADIOLAB (July 17, 2019), <https://www.wnycstudios.org/podcasts/radiolab/articles/g-unfit>. [hereinafter *Unfit*].

³⁴ *Id.* at 24:44.

³⁵ See Arlene Mayerson, *The History of the Americans with Disabilities Act: A Movement Perspective*, DISABILITY RTS. EDUC. & DEF. FUND (1992), <https://dredf.org/about-us/publications/the-history-of-the-ada/>

³⁶ Laura L. Rovner, *Disability, Equality, and Identity*, 55 ALA. L. REV. 1043, 1059 (2004).

³⁷ 29 U.S.C. § 794 (2018).

Despite the legislative changes that followed the movement in support of people with disabilities, many of the stereotypes and stigmas surrounding them remain. Sociologist Tom Shakespeare explains, “disability is a very powerful identity, and one that has the potential to transcend other identities ... it has the power to de-sex people, so that people are viewed as disabled” and not as having any other identity.³⁸ Much of that stigma is still felt by members of the disability community—who are seen as either childlike and asexual or hypersexual and out of control.³⁹ Those stereotypes are reflected in high rates of sexual abuse and consent statutes.

III. INTELLECTUAL DISABILITY AND CONSENT

People with intellectual disabilities experience one of the highest rates of sexual assault in the country.⁴⁰ According to Justice Department data, people with disabilities are victims of violence including sexual assault at a rate that is two and a half times higher than that of people who do not have disabilities.⁴¹ It is a global issue too. One study in Australia found women with disabilities experienced sexual violence at “three times the rate” than those who did not have disabilities.⁴²

A. Consent Statutes

A lack of consent is often an element of the crimes of rape and sexual assault.⁴³ Consent laws typically address non-consent to include incapacity on the basis of age, mental disability, physical helplessness, or

³⁸ Tom Shakespeare, *Disability, Identity and Difference*, in *EXPLORING THE DIVIDE: ILLNESS AND DISABILITY* 94, 109 (Colin Barnes & Geof Mercer eds., 1996).

³⁹ See Denno, *supra* note 21, at 321 (explaining how fears of procreation among people with disabilities fueled stereotypes that women with disabilities are either asexual or hypersexual and need to be protected or prevented from having sex); TEDx Talks, *Why Autism is Sexier Than You Think It Is*, YOUTUBE (Sept. 28, 2017), <https://www.youtube.com/watch?v=shgy43CxBX8> [hereinafter *Amy Gravino Talk*] (“Society overall doesn’t like the thought of autistic people getting laid, shagging, screwing, populating, doing the horizontal mambo.”).

⁴⁰ National Organization for Women, *The Disability Community & Sexual Violence*, NOW, <https://now.org/wp-content/uploads/2018/05/Disabled-Women-Sexual-Violence-4.pdf> (last visited May 11, 2020) (citing Rape, Abuse & Incest National Network, *Sexual Abuse of People with Disabilities*, RAINN, <https://www.rainn.org/articles/sexual-abuse-people-disabilities> (last visited May 11, 2020)).

⁴¹ See Erika Harrell, *Crime Against Persons with Disabilities, 2009–2015 - Statistical Tables*, BUREAU OF JUST. STAT. (July 11, 2017), <https://www.bjs.gov/index.cfm?ty=pbdetail&iid=5986>.

⁴² See MEGAN MCCLOSKEY & STEPHEN MEYERS, UNITED NATIONS POPULATION FUND, *YOUNG PERSONS WITH DISABILITIES: GLOBAL STUDY ON ENDING GENDER-BASED VIOLENCE, AND REALIZING SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS* 116 (July 2018), https://www.unfpa.org/sites/default/files/pub-pdf/Final_Global_Study_English_3_Oct.pdf

⁴³ Kristin Booth Glen, *Introducing a "New" Human Right: Learning from Others, Bringing Legal Capacity Home*, 49 COLUM. HUM. RTS. L. REV. 1, 57 (2018).

intoxication.⁴⁴ However, state laws do not consistently define mental disability or incapacity, leaving it up to the courts to decide. Many factors can affect a person’s capacity including age, education, support, and the circumstances of their situation.⁴⁵ In deciding whether a person has capacity to consent to sex, many courts use some type of “knowledge and consequences test” that assesses whether a person has the mental capacity to make a sexual decision.⁴⁶ This “functional” approach⁴⁷ is based on a person’s ability to understand information related to the sexual act.⁴⁸ For example, New York courts require that a person has an “understanding of the nature and consequences of the sexual conduct” and an appreciation of the “moral dimensions” of the decision to have sex.⁴⁹

B. How New York Courts Handle Consent

The issue of capacity to consent was taken up by the New York Court of Appeals in the 1977 case, *People v. Easley*.⁵⁰ The case involved Rita Waller, a woman with intellectual disabilities, who was living with her grandmother.⁵¹ Frank Easley, a family friend, admitted to having sex with Waller and was convicted of rape.⁵² In affirming the trial court’s conviction, the court relied on IQ testing,⁵³ as well as testimony from a school psychologist, who testified that while Waller was “physically capable of ‘indulg[ing] in the concrete act of sexual intercourse’ and of comprehending that it could result in ‘having a baby’, she was incapable ‘of thinking beyond the act in terms of what its consequences could be.’”⁵⁴ Waller’s grandmother testified that she had tried to discuss sex with her granddaughter, but had been met with “almost total incomprehension.”⁵⁵ Waller did not testify under

⁴⁴ See Denno, *supra* note 21, at 340–41, 345–46 (explaining how different states determine consent).

⁴⁵ Natalie M. Chin, *Group Homes as Sex Police and the Role of the Olmstead Integration Mandate*, 42 N.Y.U. REV. L. & SOC. CHANGE 379, 401 (2018).

⁴⁶ Jasmine E. Harris, *The Role of Support in Sexual Decision-Making for People with Intellectual and Developmental Disabilities*, 77 OHIO ST. L. J. FURTHERMORE 83, 98 (2016).

⁴⁷ Stephanie L. Tang, Note, *When “Yes” Might Mean “No”: Standardizing State Criteria to Evaluate the Capacity to Consent to Sexual Activity for Elderly with Neurocognitive Disorders*, 22 ELDER L. J. 449, 468 (2014).

⁴⁸ *Id.*

⁴⁹ Denno, *supra* note 21, at 344–45.

⁵⁰ *People v. Easley*, 42 N.Y.2d 50, 50 (1977).

⁵¹ *Id.* at 52.

⁵² *Id.*

⁵³ *But cf. Definition of Intellectual Disability*, *supra* note 12 (stressing that while an IQ test score of seventy or as high as seventy-five is indicative of a person having an intellectual disability, a more holistic view should be taken when assessing a person’s capacity—by looking at factors such as the community environment, linguistic diversity, and strengths, taking note that a “person’s level of life functioning will improve if appropriate personalized supports are provided over a sustained period”).

⁵⁴ *Easley*, 42 N.Y.2d at 53.

⁵⁵ *Id.*

oath since the court could not ascertain whether she understood what it meant to tell the truth.⁵⁶ The court found her performance as a witness was “replete with shouting, giggling, crying, incoherence, emotionalism and other inappropriate behavior.”⁵⁷

In deciding how to rule on the case, the court looked at the statutory language of subdivision five of section 130.00 of the New York Penal Law⁵⁸ and found that the scheme under which Easley was indicted stated that “mentally disabled” meant a person who “suffers from a mental disease or defect which renders him or her incapable of appraising the nature of his or her conduct.”⁵⁹ The court acknowledged that the breadth of the language in the statute made it difficult to determine a person’s mental capacity and that the “requisite degree of intelligence necessary to give consent may be found to exist in a person of very limited intellect.”⁶⁰ The court found that the issue of “moral quality” concerned whether the person involved was able to appreciate how the sexual act would be “regarded in the framework of the societal environment” including possible taboos that would go along with it.⁶¹ The court clarified that “the law does not adopt the fiction that all persons are mentally or judgmentally equal” but “[e]ven mental retardation [sic] does not mean that an individual is incapable of consenting.”⁶²

In *People v. Cratsley*, a defendant admitted to having sex with a thirty-three-year-old woman who was intellectually disabled, even though he insisted she had consented.⁶³ Unlike *Easley*, the woman involved here—“Sherry K”—had told the defendant, “don’t do no more.”⁶⁴ The court points to how she only reported the incident to her counselors because she had been instructed to do so, and not because she understood that the incident was wrong.⁶⁵ Sherry K also had a boyfriend “with whom she went out to eat.”⁶⁶ The court stated that the evidence did not suggest that “she comprehended what [the] defendant was doing when she asked him to stop touching her” and held that she did not have the capacity to consent.⁶⁷ In its decision, the court acknowledged that “[m]ental retardation [sic] is not necessarily a static condition, for experience has shown that with effective training and support,

⁵⁶ *Id.*

⁵⁷ *Id.*

⁵⁸ N.Y. PENAL LAW § 130.00 (McKinney 2010).

⁵⁹ *Id.*

⁶⁰ *Easley*, 42 N.Y.2d at 54.

⁶¹ *Id.* at 56.

⁶² *Id.* at 54.

⁶³ *People v. Cratsley*, 86 N.Y.2d 81, 84 (1995).

⁶⁴ *Id.*

⁶⁵ *Id.* at 88.

⁶⁶ *Id.* at 84.

⁶⁷ *Id.* at 83.

individuals are able to lead increasingly ‘normal’ lives.’⁶⁸

As Professor Deborah Denno writes, scholars have criticized both the *Easley* and *Cratsley* decisions for requiring too broad a standard of understanding and restricting too many people with intellectual disabilities from being able to engage in sex.⁶⁹ Denno points out, however, that both courts refused to “presume” that a person with intellectual disabilities was incapable of consent, emphasizing that proof of incapacity has to come not from proof of the intellectual disability alone but from other facts that show how the person functions, or participates, in society.⁷⁰

C. How Federal Case Law Handles Consent

Some federal case law addresses the capacity to consent, including one case that took place on Native American land: *United States v. James*.⁷¹ T.C. was a “severely disabled” twenty-eight-year-old woman living with her grandparents on the Fort Apache Reservation in Arizona.⁷² A family member caught Christopher James, the defendant in the case, having sex with her in August 2011.⁷³ He admitted to investigators that he had sex with her and told them it was not her fault.⁷⁴ A written statement was introduced at trial, in which James said, “[i]t was intercourse, but it wasn’t like sex, you know? . . . [W]ith her she’s just laying there but I mean, you are inside her and you are moving up and down.”⁷⁵

James was charged with two counts of sexual abuse in violation of 18 U.S.C. § 2242(2)(B), which applies to cases where a person who is sexually assaulted may have the mental capacity to consent but is “physically incapable” of communicating refusal.⁷⁶ However, James was not charged under 18 U.S.C. § 2242(2)(A), in that it prohibits sex with someone who is “mentally incapable of understanding what is happening.”⁷⁷ The jury convicted him at trial, but the district court granted an acquittal. The court of appeals reversed.

Judge Tallman, on behalf of the majority, wrote how the district court based its opinion on a narrow definition of “physically incapable”—finding that T.C. would have had to have been completely physically helpless to

⁶⁸ *Id.* at 86 (citing William Christian, *Normalization as a Goal: The Americans with Disabilities Act and Individuals with Mental Retardation*, 73 TEX. L. REV. 409, 413 (1994)).

⁶⁹ See Denno, *supra* note 21, at 346.

⁷⁰ *Id.*

⁷¹ *United States v. James*, 810 F.3d 674, 676–77 (9th Cir. 2016).

⁷² *Id.*

⁷³ *Id.* at 677.

⁷⁴ *Id.*

⁷⁵ *Id.*

⁷⁶ *Id.* at 676.

⁷⁷ *Id.*

satisfy this statute.⁷⁸ She was largely non-verbal and used a wheelchair, which she needed to be strapped into.⁷⁹ She needed assistance with all major activities involved in daily living.⁸⁰ Her main way of communicating was through nodding her head or grunting.⁸¹ T.C.'s full-time caretaker testified that her responses were "frequently inappropriate" or "nonsensical."⁸² The court wrote that "physically helpless" and "physically incapable" are different standards.⁸³ The court defined it broadly, explaining someone could "have a physical incapacity to decline participation or be incapable of communicating unwillingness to engage in a sexual act and still not be physically helpless."⁸⁴

The majority emphasized that its holding would not preclude people who are physically disabled from consenting,⁸⁵ but Judge Kozinski dissented.⁸⁶ He pointed out that the majority opinion "will make others more reticent about engaging in sex with people who are physically impaired. Their already difficult task of seeking out a partner for sexual gratification will become even more daunting."⁸⁷ This case, and the two New York cases, offer just brief examples of the difficulty of interpreting consent statutes and the implications these opinions have for people with disabilities.

D. When People with Disabilities are Defendants

People with disabilities who seek consent sometimes find themselves as defendants in criminal prosecutions. Brian Kelmar founded the non-profit "Legal Reform for People Intellectually & Developmentally Disabled"⁸⁸ after his son—who is autistic—was accused of sexually assaulting a minor.⁸⁹ Kelmar says it started when his son got a text from a girl a few years younger than him, inviting him to go out with her.⁹⁰ He thought she would be his

⁷⁸ *Id.* at 679.

⁷⁹ *Id.* at 676–77.

⁸⁰ *Id.* at 676.

⁸¹ *Id.* at 677.

⁸² *Id.*

⁸³ *Id.* at 681.

⁸⁴ *Id.*

⁸⁵ *Id.* at 683.

⁸⁶ Judge Kozinski retired in 2017 after multiple sexual harassment accusations. See Niraj Chokshi, *Federal Judge Alex Kozinski Retires Abruptly After Sexual Harassment Allegations*, N.Y. TIMES (Dec. 18, 2017), <https://www.nytimes.com/2017/12/18/us/alex-kozinski-retires.html>

⁸⁷ *James*, 810 F.3d at 687 (Kozinski, J., dissenting).

⁸⁸ *Legal Reform for People Intellectually & Developmentally Disabled*, LRIDD (2017), <https://lridd.org/>.

⁸⁹ Melinda Wenner Moyer, *When Autistic People Commit Sexual Crimes*, SPECTRUM NEWS (July 17, 2019), <https://www.spectrumnews.org/features/deep-dive/when-autistic-people-commit-sexual-crimes/>.

⁹⁰ *Id.*

friend, so he met her.⁹¹ His father says she initiated oral sex—at which point his son asked her to stop, but later, he was arrested.⁹² Kelmar says people with intellectual and developmental disabilities are “seven times more likely to get up and get caught up in the criminal justice system . . . because of their lack of education” when it comes to sex.⁹³ People with disabilities make up between forty and eighty percent of the population of incarcerated adults.⁹⁴ It is unclear how many of those people are incarcerated for sex crime convictions. However, more education for those with disabilities about consent and healthy relationships—as well as more education for those who work in the criminal justice system about people with disabilities—would likely reduce sex crimes and reduce the number of people who are incarcerated. It is difficult for a person to give or seek consent, or even answer questions about it, if they have never been given a chance to learn about it.

E. Theories on Consent

Scholars have been examining disability and consent for decades. Professor Michael Perlin points out that “capacity” and “competency” are intertwined when courts determine a person’s ability to consent.⁹⁵ Capacity is defined as a person’s ability to “understand, appreciate, and form a relatively rational intention with regard to some act.”⁹⁶ However, people in power—particularly judges, lawyers, and juries—need to understand the people who are in their courts. As Professor Susan Stefan explains, “competence” is “far from being an internal characteristic of an individual” and more of a “value judgment arising from an individual’s conversation or communication” with those in power.⁹⁷ Professor Jasmine Harris points out that it is difficult for many people with intellectual and developmental

⁹¹ *Id.*

⁹² *Id.*

⁹³ See Jessica Wetzler, *Bill Targeting Sexual Abuse Education for Those with Disabilities Moves Forward*, DAILY NEWS-RECORD (Jan. 23, 2020), https://www.dnronline.com/news/local/bill-targeting-sexual-abuse-education-for-those-with-disabilities-moves/article_d56a9e4c-7b16-5443-83a1-4e2c45fe45da.html.

⁹⁴ Talila A. Lewis & Dustin Gibson, *The Prison Strike Challenges Ableism and Defends Disability Rights*, TRUTHOUT (Sept. 5, 2018), <https://truthout.org/articles/the-prison-strike-is-a-disability-rights-issue/>.

⁹⁵ See 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, 263–64 (2014).

⁹⁶ Steven B. Bisbing, *Competency and Capacity: A Primer*, in LEGAL MED. 325, 325 (S. Sandy Sanbar et al. eds., 7th ed. 2007).

⁹⁷ See Susan Stefan, *Silencing the Different Voice: Competence, Feminist Theory and Law*, 47 U. MIA. L. REV. 763, 766 (1993) (Professor Susan Stefan is a scholar and litigator on behalf of people with cognitive disabilities. She has written four books and numerous articles on legal and policy issues for people with disabilities.).

disabilities to pass consent tests because courts may not understand the way a person with a disability is communicating.⁹⁸ Those with disabilities are asked and expected to respond appropriately to questions designed by people who do not communicate or think like them. Consent tests can also send a damaging message. As the Hon. Kristin Booth Glen explains, consent statutes stigmatize people with disabilities “in the most personal areas and reduce them to ‘children’ who also are prohibited, as a matter of law, from consenting to sex.”⁹⁹ Professor Anna Arstein-Kerslake asserts that if the kind of functional tests to assess mental capacity to consent to sex were applied on an equal basis to all people, many people who do not have disabilities would find them difficult to pass.¹⁰⁰

Denno was one of the first scholars to approach the issue of consent. In 1997, Denno studied state statutes and legal tests, concluding that women with intellectual disabilities are held to a higher consent standard than women without disabilities.¹⁰¹ She argues that consent statutes are ambiguous in how they define consent and intellectual disability.¹⁰² Her concern is that too much room is left to the courts to determine whether someone has the capacity to consent.¹⁰³ Denno suggests courts apply a “contextual approach” to determine whether someone has the capacity to consent.¹⁰⁴ It incorporates knowledge about intellectual disability, individual attributes that go beyond the labels imposed by IQ and mental age, and the context of the sexual encounter at issue.

Professor Martha Nussbaum argues that defining the ability to consent ought to follow a capabilities approach, which she developed alongside economist/philosopher Amartya Sen.¹⁰⁵ This definition looks at what people are actually able to do and treats “diverse functions as all important”¹⁰⁶ when

⁹⁸ See Harris, *supra* note 46 (Professor Jasmine Harris is a Professor of Law and Martin Luther King, Jr. Hall Research Scholar at the University of California – Davis School of Law. She is a law and equality scholar with a particular focus on disability.).

⁹⁹ See Glen, *supra* note 43, at 58 (The Honorable Kristin Booth Glen is Dean Emerita at CUNY School of Law. She served as Surrogate Judge of New York County, where she had jurisdiction over guardianships of people with intellectual disabilities, and wrote a number of groundbreaking decisions in that area. Her scholarship focuses on the human right of legal capacity and supported decision making, and she serves as Project Director of Supported Decision-Making New York).

¹⁰⁰ See Eilionóir Flynn & Anna Arstein-Kerslake, *The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?*, 32 BERKELEY J. INT’L L. 124, 128 (2014) (Eilionóir Flynn focuses on the ratification process for the United Nations Convention on the Rights of Persons with Disabilities in Ireland. Anna Arstein-Kerslake is an internationally recognized legal scholar focusing on human rights, disability rights and gender justice).

¹⁰¹ See Denno, *supra* note 21, at 394.

¹⁰² *Id.* at 341.

¹⁰³ *Id.* at 349–50.

¹⁰⁴ *Id.* at 394.

¹⁰⁵ Martha C. Nussbaum, *Capabilities and Human Rights*, 66 FORDHAM L. REV. 273, 275 (1997).

¹⁰⁶ *Id.* at 285.

it comes to quality of life.¹⁰⁷ Nussbaum describes the relationship between capabilities and rights by explaining three different categories of capabilities.¹⁰⁸ There are basic capabilities; such as what we are born with; internal capabilities, such as the ability to use thought within one's own conscious; and combined, defined as "internal capabilities combined with suitable external conditions for the exercise of the function."¹⁰⁹ Nussbaum asserts that the good life is one which is self-directed, given what a person has and is capable of achieving.¹¹⁰ She explains how a person who is secluded and forbidden to leave their home has "internal but not combined capabilities for sexual expression" and the goal should be to move everyone towards possessing combined capabilities.¹¹¹

Professor Alexander Boni-Saenz builds on Nussbaum's theory, arguing that adults with "persistent cognitive impairments" should be granted legal capacity to make sexual decisions as long as they have support.¹¹² Boni-Saenz defines sexual capability as "the opportunity to achieve certain states of being or perform certain activities associated with sexuality, such as experiencing sexual pleasure or forming a sexual identity."¹¹³ His "cognition-plus" test for assessing capacity to consent, particularly for people in nursing homes, includes the use of supported decision-making.¹¹⁴ His theory incorporates a three-step test, asking first whether the person can express a preference for sex that is free from coercion; second, whether the person understands the nature and the consequences of the decision to have sex; and third, does the person have an adequate support network.¹¹⁵ A person who fails on the understanding aspect can still be found capable of consent if an adequate support network exists to help with decision-making.¹¹⁶ For a sexual capabilities approach to work, supported decision-making must be recognized.¹¹⁷

In 2006, the United Nations General Assembly adopted The Convention on the Rights of Persons with Disabilities (CRPD).¹¹⁸ The resolution

¹⁰⁷ *Id.* at 275 (describing how her use of this language was both independent of and reflective of how Aristotle used a notion of human capability and functioning to articulate goals of good political organization).

¹⁰⁸ *Id.* at 289.

¹⁰⁹ *Id.* at 289–90.

¹¹⁰ *Id.* at 290.

¹¹¹ *Id.*

¹¹² Alexander A. Boni-Saenz, *Sexuality and Incapacity*, 76 OHIO ST. L.J. 1201, 1205 (2015) (focusing mostly on people diagnosed with dementia).

¹¹³ *Id.*

¹¹⁴ *Id.*

¹¹⁵ *Id.* at 1234.

¹¹⁶ *Id.*

¹¹⁷ *Id.* at 1233.

¹¹⁸ G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities (Jan. 24, 2007).

recognizes the right of people with disabilities to “enjoy legal capacity on an equal basis with others in all aspects of life.”¹¹⁹ Article 12 of the CRPD calls for the “right to recognition everywhere as persons before the law” and to provide support to people with disabilities that is required so they can exercise their capacity.¹²⁰ The CRPD model preserves the person’s central role in making decisions and calls on a third party to make the best assessment as to what the will and preferences of the person would be.¹²¹ Those decisions are based on knowledge of the person, prior interactions and an existence of an ongoing relationship.¹²² The CRPD is unratified in the United States, but still has potential to influence policy.

There are multiple theories on how to handle consent. Part of what makes it complicated is the lens through which society views disability. There is a need for everyone to move away from biased views of disability as lacking or less than, to acknowledge the diversity and the potential within each person.¹²³ Professor Natalie Chin discusses the theory of human connectedness in the group home context, arguing there should be an initial presumption of competence and an acknowledgement that with support, people with disabilities can safely engage in sex and intimacy.¹²⁴ She does not take a position on what criteria should be used to determine sexual consent capacity but she suggests “an individualized, fact-specific inquiry based on the circumstances of the desired sexuality choice of the individual as a baseline in any capacity determination.”¹²⁵

Every person should have the right to be safe from unwanted sexual activity. Outside of consent, there are other ways to ensure safety for people with disabilities while also promoting sexual autonomy. One way to do that is by improving support for community integration.

IV. THE ROAD TO LIVING IN THE COMMUNITY

A. *The Home and Community Based Services Waiver Program*

¹¹⁹ *Id.* at art. 12.

¹²⁰ *Id.*

¹²¹ *Id.*

¹²² *Id.*

¹²³ See Christopher Kliewer, Douglas Biklen & Amy J. Petersen, *At the End of Intellectual Disability*, 85 HARV. EDUC. REV. 1, 3-9, 11 (2015) (proposing a theory of human connectedness, inclusion, and a presumption of competence, while emphasizing persistence in challenging one’s own bias about the ability of others is crucial towards moving forward).

¹²⁴ Chin, *supra* note 45, at 405-407 (citing Christopher Kliewer, Douglas Biklen & Amy J. Petersen, *At the End of Intellectual Disability*, 85 HARV. EDUC. REV. 1,3-9, 11 (2015) (explaining how human connectedness theory builds on the social model of disability to allow for a demonstration of competence in the context of consent tests used on residents of group homes.).

¹²⁵ *Id.* at 405.

People with disabilities who want to live in the community can receive support services through Medicaid’s Home and Community Based Services Waiver Program (“HCBS”).¹²⁶ In 1981, Congress added section 1915(c) to the Social Security Act.¹²⁷ It allows certain Medicaid statutory requirements to be waived for states receiving federal funding so they can develop community-based programs and services for people with disabilities.¹²⁸ One goal of the program was to challenge the “institutional bias” of Medicaid.¹²⁹ There is no limit to the number of waivers a state may develop, but the average annual cost of a state’s waiver program cannot exceed that of institutionalized services.¹³⁰ Nearly all states offer services through HCBS waivers targeting different populations.¹³¹ Eligibility requirements vary by state and require proof of disability.¹³² The waiver program is just one way for states to comply with the Americans with Disabilities Act.

B. *The Americans with Disabilities Act*

In 1990, Congress passed the Americans with Disabilities Act (ADA).¹³³ In its “findings and purposes” section, Congress pointed to a history of segregation and isolation for people with disabilities as a “serious and pervasive social problem.”¹³⁴ The statute was intended to prevent discrimination against people with disabilities in three areas: employment; public services from government entities; and public accommodations provided by private entities. Title II of the ADA states 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.”¹³⁵ The Justice Department implements the regulations of the ADA for public entities, consistent with the regulations in Section 504 of the Rehabilitation Act of 1973.¹³⁶ Those regulations state “a public entity shall administer services, programs, and activities in the most integrated setting

¹²⁶ *Home & Community-Based Services 1915(c)*, MEDICAID.GOV, <https://www.medicare.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html> (last visited Apr. 24, 2020) [hereinafter *Home & Community Based Services Program*].

¹²⁷ See 42 U.S.C. § 1396n (2018).

¹²⁸ *Home & Community Based Services Program*, *supra* note 126.

¹²⁹ See “Don’t Tread on the ADA”: *Olmstead v. L.C. ex rel. Zimring and the Future of Community Integration for Individuals with Mental Disabilities*, 40 B.C. L. REV. 1221, 1229–30 (1999).

¹³⁰ *Home & Community Based Services Program*, *supra* note 126.

¹³¹ *Id.*

¹³² *Id.*

¹³³ 42 U.S.C. § 12101 (2018).

¹³⁴ 42 U.S.C. §§ 12101(a)(2), (5) (2018).

¹³⁵ 42 U.S.C. § 12132 (2018).

¹³⁶ 42 U.S.C. §§ 12134(a), (b) (2018).

appropriate to the needs of qualified individuals with disabilities.”¹³⁷

The Americans with Disabilities Act (ADA) was the “first comprehensive civil rights law for people with disabilities.”¹³⁸ Numerous cases went before the Supreme Court, where the Court narrowed the definition of “disability,” leading to the amendments of the ADA in 2008 to broaden it again. In 1999, the Supreme Court took up a case that considered whether the anti-discrimination provision in Title II of the ADA¹³⁹ required the placement of people with mental disabilities in community settings rather than institutions. The Court found the answer to be “a qualified yes.”¹⁴⁰

V. OLMSTEAD V. L.C. AND THE INTEGRATION MANDATE

A. *Olmstead v. L.C.*

In the early 1990s, two women with cognitive disabilities were voluntarily admitted to a Georgia psychiatric hospitals for treatment.¹⁴¹ After some time, both women improved enough to live in community-based treatment programs.¹⁴² Instead, they were kept institutionalized.¹⁴³ In 1995, they challenged their confinement in a segregated setting as a violation of Title II of the ADA.¹⁴⁴ In 1999, the case went to the Supreme Court, where Justice Ruth Bader Ginsburg, who wrote the majority opinion, found “unjustified isolation” to be “discrimination based on disability” and held Title II of the ADA requires that people with disabilities be placed in community settings when:

the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.¹⁴⁵

¹³⁷ 28 C.F.R. § 35.130(d) (2020).

¹³⁸ *ADA Findings, Purpose and History*, THE ADA NAT'L NETWORK, https://www.adaanniversary.org/findings_purpose (last visited Apr. 25, 2020).

¹³⁹ 42 U.S.C. § 12132 (2018).

¹⁴⁰ *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 587 (1999).

¹⁴¹ *Id.* at 593.

¹⁴² *Id.*

¹⁴³ *Id.*

¹⁴⁴ *Id.* at 593–94.

¹⁴⁵ *Id.* at 597.

In evaluating the state’s fundamental alteration defense,¹⁴⁶ courts must consider “not only the cost of providing community-based care to the litigants, but also the range of services the State provides others with mental disabilities, and the State’s obligation to mete out those services equitably.”¹⁴⁷ If a state could show a “comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated, the reasonable-modifications standard [of the Americans with Disabilities Act] would be met.”¹⁴⁸

Justice Ginsburg explained two justifications for the Court’s decision. First, placing people with disabilities in institutions when they were capable of living in the community only perpetuated stereotypes.¹⁴⁹ Second, confining them to institutions deprived them of the chance to have “family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”¹⁵⁰ Advocates saw the decision as a victory—with some holes.¹⁵¹ First, the Court did not clarify what a “reasonable pace” would be for states to place people in community settings.¹⁵² Second, the opinion did not address what types of services would be necessary to ensure that people living in the community were getting adequate care.¹⁵³

B. Enforcing the Integration Mandate

In 2009, the Obama Administration launched “The Year of Community Living,” calling for federal agencies to enforce Title II by making sure states were implementing the ruling from *Olmstead*.¹⁵⁴ In 2011, the Department of

¹⁴⁶ *Id.* (The regulations explain states could resist modifications that “would fundamentally alter the nature of the service, program, or activity”).

¹⁴⁷ *Id.*

¹⁴⁸ *Id.* at 605–06.

¹⁴⁹ *Id.* at 600.

¹⁵⁰ *Id.* at 601.

¹⁵¹ See Press Release, Laurie M. Flynn, Supreme Court Gives Incremental Victory to Persons with Mental Illness in *Olmstead* Decision, Nat’l All. on Mental Illness, (June 22, 1999), <https://www.nami.org/Press-Media/Press-Releases/1999/Supreme-Court-Gives-Incremental-Victory-to-Persons>.

¹⁵² *Id.*

¹⁵³ *Id.*

¹⁵⁴ *Olmstead: Community Integration for Everyone*, U.S. DEP’T OF JUST., <https://www.ada.gov/olmstead/> (last visited Mar. 8, 2020); Charles R. Moseley, *The ADA, Olmstead and Medicaid: Implications for People with Intellectual and Developmental Disabilities*, NAT’L ASS’N OF STATE DIR. OF DEV. DISABILITIES SERV. (2013), http://www.nasdds.org/uploads/documents/ADA_Olmstead_and_Medicaid.pdf.

Justice (DOJ) issued a statement on enforcing the integration mandate.¹⁵⁵ It described an integrated setting as:

. . . those that provide individuals with disabilities opportunities to live, work, and receive services in the greater community, like individuals without disabilities. 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.¹⁵⁶

It defines a “segregated setting” as including but not limited to one which limits a person’s ability to “engage freely in community activities.”¹⁵⁷ No showing of facial discrimination is required.¹⁵⁸ The mandate applies to individuals who are “at serious risk” of becoming institutionalized in addition to those who are already living in an institutionalized setting.¹⁵⁹ Since then, the Justice Department has filed or participated in numerous lawsuits based on states’ implementation of the integration mandate as defined in *Olmstead*. Part of that enforcement has been investigating states that are found not to have a plan to end unnecessary segregation.¹⁶⁰ States are obligated to comply with the integration mandate and could be found in violation if a court finds people with disabilities are being unnecessarily excluded as a result of the state’s direct or indirect operation of facilities.¹⁶¹

One example of how this has been applied is *Guggenberger v. Minnesota*.¹⁶² The 2016 case involved a group of people with developmental disabilities who sued Minnesota claiming they were eligible for the Home and Community Based Services Waiver program, but because they were on waiting lists, they were not receiving services.¹⁶³ The four named plaintiffs in the class action suit were in their early twenties and were living at home

¹⁵⁵ See *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.*, U.S. DEP’T OF JUST. (June 22, 2011), https://www.ada.gov/olmstead/q&a_olmstead.html, [hereinafter U.S. DEP’T OF JUST. Statement].

¹⁵⁶ *Id.*

¹⁵⁷ *Id.*

¹⁵⁸ *Id.*

¹⁵⁹ *Id.*

¹⁶⁰ *Id.*

¹⁶¹ 28 C.F.R. § 35.130(b)(1) (2016).

¹⁶² *Guggenberger v. Minnesota*, 198 F. Supp. 3d 973 (D. Minn. 2016).

¹⁶³ *Id.* at 986.

with their parents.¹⁶⁴ One of them was on a waiting list for over fourteen years.¹⁶⁵ All of them claimed they were receiving some services, but their needs required that they receive more, including “independent housing options; services to teach the individual to live on his or her own and access the community; behavioral support services; and services aimed at developing the individual’s independent living skills in areas such as budgeting, nutrition, healthcare, and employment.”¹⁶⁶ They each claimed that the placement on waiting lists created “feelings of isolation and segregation from society,” while exacerbating their disabilities.¹⁶⁷ The court found that the plaintiffs had standing and thus the case moved forward.¹⁶⁸

Another example was *Steimel v. Wernert*, where plaintiffs sued after Indiana officials shifted them to a different program, which meant cuts to funding their time in the community from forty hours a week down to ten to twelve hours a week.¹⁶⁹ The cut resulted in less supervision and assistance for traveling to work.¹⁷⁰ The court held that isolation in the home “may often be worse than confinement to an institution on every other measure of ‘life activities’ that *Olmstead* recognized.”¹⁷¹

There is nothing in either opinion that explicitly references sexuality. But isolation can include sexual isolation. Chin argues that *Olmstead* and Title II of the Americans with Disabilities Act can be used to challenge what is ultimately the “sexual isolation” of people with intellectual disabilities who live in group homes and are prevented from forming intimate relationships.¹⁷² She points to how regulations on residents of group homes, arbitrary denial of a resident’s right to consent to sex, and a lack of access to sexuality services is a violation of the integration mandate, and is disability-based discrimination.¹⁷³ Chin writes that “integrated setting” can be expanded to fully address “the importance of sexuality in the lives of intellectually disabled individuals” since a lack of access to sexuality is a form of isolation.¹⁷⁴ The same could be said for people who are living independently and receiving federally funded support. Any cuts to funding that make it difficult for them to participate in the community, or to understand their own sexuality or develop an intimate relationship, or the denial of access to information about sexuality or opportunities to learn

¹⁶⁴ *Id.* at 987.

¹⁶⁵ *Id.*

¹⁶⁶ *Id.*

¹⁶⁷ *Id.*

¹⁶⁸ *Id.* at 993.

¹⁶⁹ *Steimel v. Wernert*, 823 F.3d 902, 908 (7th Cir. 2016).

¹⁷⁰ *Id.* at 908-09.

¹⁷¹ *Id.* at 911.

¹⁷² See Chin, *supra* note 45, at 382.

¹⁷³ *Id.* at 382-84, 386.

¹⁷⁴ *Id.* at 390.

about or experience intimacy by support staff amount to a form of isolation.¹⁷⁵

Part of living independently is being able to make one's own decisions and to have choices. In New York, the guardianship law calls for the "least restrictive form of intervention" to provide for a person's needs while "affording that person the greatest amount of independence and self-determination in light of that person's understanding."¹⁷⁶ There is a move now to recognize supported decision-making, which allows people to receive support in order to understand what they need to know to make decisions based on their preferences.¹⁷⁷ Booth Glen explains how supported decision-making emphasizes full capacity, does away with substituted decision making seen in guardianship, and calls for providing supports so everyone can make their own decisions.¹⁷⁸ She writes that decision-making is a skill that needs to be taught to people with intellectual disabilities as early as pre-kindergarten.¹⁷⁹ Once they learn this skill, they can make their own decisions, with support.

For community integration to work, support needs to be provided so people with intellectual and developmental disabilities do not just exist in the community, but are able to actually live and interact within the community. That includes being able to make decisions and choices about their sexuality. It means acknowledging everything from identity, to dating and relationships, to intimacy, to sexual orientation, to reproduction and contraception. As Martha Nussbaum's capabilities approach demonstrates, life should be measured not by wealth, but by how much a person can pursue that which is important to that person, including sexuality.¹⁸⁰ Psychologist Alfred Adler identified three major areas of life: life in society or the community, useful work or vocation, and romantic and family love.¹⁸¹ Some people need more support than others to achieve this. Professor Carlos Ball explains how "limitations in companionship, education, social acceptance, and sexual activity . . . are often at the core of what makes [people] disabled."¹⁸² He argues that society has a moral obligation to provide

¹⁷⁵ This would apply only if they are part of the Home and Community Based Services Program and receiving services from the state.

¹⁷⁶ N.Y. MENTAL HYG. LAW § 81.03 (McKinney 2004).

¹⁷⁷ See Michael L. Perlin & Naomi Weinstein, *Said I, but You Have No Choice: Why a Lawyer Must Ethically Honor a Client's Decision About Mental Health Treatment Even If It is Not What S/He Would Have Chosen*, 15 CARDOZO PUB. L. POL'Y & ETHICS J. 73, 110 (2016).

¹⁷⁸ Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93, 98 (2012).

¹⁷⁹ Kristin Booth Glen, *Piloting Personhood: Reflections from the First Year of a Supported Decision-Making Project*, 39 CARDOZO L. REV. 495, 518 (2017).

¹⁸⁰ See Nussbaum, *supra* note 105, at 275.

¹⁸¹ See ALFRED ADLER, *SOCIAL INTEREST* 39 (Colin Brett ed., 1998).

¹⁸² Carlos A. Ball, *Autonomy, Justice, and Disability*, 47 UCLA L. REV. 599, 630 (2000).

assistance where it is needed, particularly with functional capabilities, to live an autonomous life.¹⁸³ This includes sexuality. Some critics might say it is paternalistic to claim people with disabilities need assistance. To them, Ball argues that all people need assistance to gain autonomy, and much of it is just so normalized that we do not realize we are being assisted.¹⁸⁴ The question is how to provide the proper supports so that people with intellectual disabilities—who are unique in all of their interests and needs—can experience sexuality in a way that is true to them.

VI. SEXUALITY SUPPORT AS PART OF COMMUNITY INTEGRATION

For community integration to be fully realized, society needs to do more. Commentator Hannah Hicks writes that there is “no shortage of sex-positive, educational resources for parents of individuals who experience mental disability and are living in deinstitutionalized settings.”¹⁸⁵ The article’s focus was on people who were living in institutionalized settings. However, parents may not be able to adequately or appropriately assist their adult children when it comes to intimacy, particularly if their kids don’t want to talk to them about it.

Parents of people with intellectual and developmental disabilities spend a lot of time, and often face roadblocks, seeking support services for their adult children to begin with—such as a place to live, food to eat, and a job.¹⁸⁶ If those parents are lucky enough to have time and money, they typically meet with lawyers to make sure a support plan is in place for their kids, after they are dead. Some parents are already dead.¹⁸⁷

Some have a hard time accepting that their adult children with intellectual disabilities are sexual, while others have trouble finding resources.¹⁸⁸ Educating parents and caregivers is important, and is one place to start, but leaving it to families is not a good enough solution.¹⁸⁹ The wider

¹⁸³ *Id.* at 604.

¹⁸⁴ *Id.* at 647.

¹⁸⁵ Hannah Hicks, *To the Right to Intimacy and Beyond: A Constitutional Argument for the Right to Sex in Mental Health Facilities*, 40 N.Y.U. REV. L. & SOC. CHANGE 621, 625 (2016).

¹⁸⁶ See Sally Abrahms, *Who Will Care for My Special Needs Adult Child?* THE HARTFORD: EXTRA MILE (Mar. 27, 2018), <https://extramile.thehartford.com/family/parenting/caring-for-my-special-needs-adult-child/> (interviews with parents describing efforts to plan for their adult children’s futures including finding housing options beyond group home placements).

¹⁸⁷ See Joseph Goldstein, *What’s Going to Happen to Junior, Now That His Mother is Dead?*, N.Y. TIMES (May 7, 2020),

<https://www.nytimes.com/2020/05/07/nvregion/nyc-coronavirus-adult-disabled.html>.

¹⁸⁸ See Lorna Collier, *Sex and Intellectual Disabilities*, THE AM. PSYCHOL. ASS’N: MONITOR ON PSYCHOL. (Dec. 2017), <https://www.apa.org/monitor/2017/12/seeking-intimacy-sidebar>.

¹⁸⁹ See Martha Albertson Fineman, *The Vulnerable Subject: Anchoring Equality in the Human Condition*, 20 YALE J. L. & FEMINISM 1, 11 (2008) (explaining how historically dependency is “mistakenly assumed to be adequately managed” for people who need support).

community needs to take a more active role in working towards inclusion that embraces every aspect of life, for every type of person, from jobs to housing, to socializing and sexuality.¹⁹⁰ This has not happened on a large enough scale. As Professor Martha Albertson Fineman writes:

society has historically dealt with dependency by relegating the burden of caretaking to the family, which is located within a zone of privacy, beyond the scope of state concern . . . Thus largely rendered invisible within the family, dependency is comfortably and mistakenly assumed to be adequately managed for the vast majority of people.¹⁹¹

She asserts that everyone is vulnerable in various ways, and can suddenly become dependent at any point in time, but that people's experiences are influenced by the resources they have access to.¹⁹² A wealthy family may be able to provide everything their adult child needs to live independently, but that leaves out a vast majority of the population. Commentator Mia Mingus calls for an awareness of the "interdependence that embraces need and tells the truth: no one does it on their own and the myth of independence is just that, a myth."¹⁹³ Families alone cannot support their adult children with intellectual disabilities in the many ways that they need support. Society needs to take more responsibility for everyone, and that includes supporting sexuality. The place to start is by offering more support through the program that is intended to provide that support in the first place—Medicaid's Home and Community Based Services Waiver program.¹⁹⁴

C. HCBS Services for Sexuality Support

According to a study done in 2015 of 111 HCBS waiver programs, less than 12 percent covered sexuality services for intellectually disabled adults.¹⁹⁵ The researchers found ninety-two percent of those states' programs

¹⁹⁰ See Martha Albertson Fineman, *Cracking the Foundational Myths: Independence, Autonomy, and Self-Sufficiency*, 8 AM. U. J. GENDER SOC. POL'Y & L. 13, 18 (1999).

¹⁹¹ Fineman, *supra* note 189.

¹⁹² *Id.* at 10.

¹⁹³ Mia Mingus, *How Our Communities Can Move Beyond Access to Wholeness*, LEAVING EVIDENCE (Feb. 12, 2011, 1:56 PM), <https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/>.

¹⁹⁴ See Chin, *supra* note 45, at 439-40 (suggesting group home operators work with the agencies that administer HCBS waivers to incorporate sexuality support services into a resident's treatment plan).

¹⁹⁵ 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) (finding only seven states offer sexual health services through their HCBS waiver program, and most of those programs are reactive—focusing solely on preventing harm).

to be reactive (aimed at preventing “sexually inappropriate behaviors”) rather than proactive services (which are aimed at sex education and awareness about safety).¹⁹⁶

According to the study, New Mexico and Washington, DC are the only jurisdictions that explicitly provide proactive sexuality services through their HCBS waiver programs.¹⁹⁷ New Mexico’s program includes classes that teach “social and sexuality skills needed . . . to make the strongest connection possible between individual personal values and informed choices about relationships and sexuality.”¹⁹⁸ Therapists, teachers, family, friends, support professionals, and peer self-advocates serve as role models in the classes.¹⁹⁹ The program also includes attendance at the class for a support staff member, who can help implement the lessons learned outside of the classroom in daily life.²⁰⁰ The program calls for yearly evaluations by participants on the quality of the classes.²⁰¹ Similar programs can be implemented—and funded—in other states.

There are other ways to support people that fall outside of anti-discrimination legislation. Professor Joseph J. Fischel and Hilary R. O’Connell suggest that the way to make sexuality more accessible to people with intellectual and developmental disabilities is to approach it from a social welfare perspective.²⁰² They argue that access to sexuality cannot be something that is made possible through another “reasonable accommodation” but through “cross-sector reforms” such as more state investment into “transportation, healthcare, assistance with contraception, abortion and family planning”²⁰³ Professor Elizabeth Emens explains how “inadequate implementation” of support when it comes to transportation, as well as low employment rates and relative poverty, all lead to a reduction in social capital, limiting people’s ability to go out, meet and connect with other people.²⁰⁴ Emens calls for improving access to public spaces and experiences where relationships can begin and develop, and for welfare laws to acknowledge that forming intimate relationships is a desired goal of people with intellectual and developmental disabilities.²⁰⁵ One self-

¹⁹⁶ *Id.*

¹⁹⁷ *Id.*; N.M. DEP’T HEALTH, DEVELOPMENTAL DISABILITIES WAIVER SERVICES STANDARD, (2019), <https://nmhealth.org/publication/view/regulations/3511/>.

¹⁹⁸ N.M. DEP’T OF HEALTH, *supra* note 197, at 201.

¹⁹⁹ *Id.*

²⁰⁰ *Id.*

²⁰¹ *Id.* at 213.

²⁰² Joseph J. Fischel & Hilary R. O’Connell, *Disabling Consent, or Reconstructing Sexual Autonomy*, 30 COLUM. J. GENDER & L. 428, 506 (2016).

²⁰³ *Id.* at 506-07.

²⁰⁴ Elizabeth F. Emens, *Intimate Discrimination: The State’s Role in the Accidents of Sex and Love*, 122 HARV. L. REV. 1307, 1374-75 (2009).

²⁰⁵ *Id.* at 1391-92.

advocate says, “I think the government can add more social groups that only focus on meeting people and developing romantic relationships.”²⁰⁶ A possible issue with focusing on the “welfare” perspective is that it could increase the stigma around people with disabilities. Professor Samuel Bagenstos argues the expansion of social rights for people with disabilities feeds into public attitudes that people with disabilities are not “entitled to be treated as full citizens” because they are seen as welfare dependent individuals.²⁰⁷ A possible solution to this is to expand social support to all—not just to people with disabilities. Programs like single-payer healthcare, a universal basic income, and free college programs all contribute to the notion that everyone needs support, and helps to eliminate the stigma that exists when programs are designed for only a subset of the population.²⁰⁸

D. Expanding Sex Education for People with Intellectual and Developmental Disabilities

There is a lot of room for improvement in sex education for all students. But where schools do teach sex education, students with disabilities should be included. Often students with disabilities are taught in separate “special education” classes, where sex education is not part of their curriculum at all.²⁰⁹ Advocates emphasize the importance of acknowledging that kids with disabilities are sexual beings too.²¹⁰ Programs should be sensitive and tailored to their learning styles so they can fully understand the material being taught.²¹¹ Additionally, the kind of “informal learning” that takes place among kids outside the classroom is often missing for kids with disabilities; it is harder for them to find people they connect with to discuss sexuality in a natural way because they are often isolated from their peers.²¹² For those who were denied sex education when they were growing up, Emens recommends helping them to develop confidence and relevant social skills

²⁰⁶ E-mail from Anonymous, Self-Advocate, to Shoshana Rubin, J.D. Candidate, 2021, City University of New York School of Law (Apr. 21, 2020, 12:55 EST) (on file with the author).

²⁰⁷ Samuel R. Bagenstos, *Disability, Universalism, Social Rights, and Citizenship*, 39 CARDOZO L. REV. 413, 419, 424 (2017).

²⁰⁸ *Id.* at 425.

²⁰⁹ Jesse Krohn, *Sexual Harassment, Sexual Assault, and Students with Special Needs: Crafting an Effective Response for Schools*, 17 U. PA. J. L. & SOC. CHANGE 29, 33 (2014).

²¹⁰ S. E. Smith, *Where’s the Sex Ed for Disabled Kids? THIS AIN’T LIVIN’* (Nov. 4, 2016), <http://meloukhia.net/2016/11/wheres-the-sex-ed-for-disabled-kids/>.

²¹¹ *Id.* (pointing out there is nothing about sex-positive sex education programs in schools that are “disability-oriented”).

²¹² Katherine Marrone, *The Importance of Expanding Sex-Ed to People with Developmental Disabilities*, BITCHMEDIA (Feb. 18, 2016), <https://www.bitchmedia.org/article/expanding-sex-ed-people-developmental-disabilities>

as adults.²¹³

Advocates are working to provide more access to sex education. The Organization for Autism Research published an online sex education module for individuals with autism,²¹⁴ created in part by Amy Gravino, who is also autistic.²¹⁵ It covers topics including consent, dating, sexual orientation, gender identity, healthy relationships, and puberty.²¹⁶ Katherine McLaughlin leads online workshops for parents and teachers who want to create a sexuality curriculum for students with disabilities.²¹⁷ McLaughlin says when she teaches “sexuality”, the “sex” part is small, and it is more about relationships and communication.²¹⁸ McLaughlin adds that the best way to talk about sex with students who have developmental disabilities is to be concrete and sometimes graphic.²¹⁹ Meantime, parents have pushed for legislation in various states seeking to mandate sex education for students with disabilities.²²⁰ One bill was introduced after a man became involved in an unexpected court case, which his father says was due in part to his lack of education on sexuality.²²¹

E. Access to Reproductive Care and Contraception

People with intellectual disabilities should have equal access to reproductive healthcare and birth control. Medicare, the federal program that provides health insurance to those over sixty-five, also covers younger people with permanent disabilities.²²² Nearly 920,000 women ages eighteen to forty-four were covered by Medicare in 2011.²²³ There is no federal requirement that Medicare cover contraception.²²⁴ This leaves disabled women on the hook for paying out of pocket for birth control, unlike many

²¹³ Emens, *supra* note 204, at 1391-92.

²¹⁴ ORG. FOR AUTISM RSCH., <https://researchautism.org/>, (last visited May 11, 2020).

²¹⁵ *Sex Ed for Self-Advocates*, ORG. FOR AUTISM RSCH. <https://researchautism.org/sex-ed-guide/> (last visited May 11, 2020); see Amy Gravino Talk, *supra* note 39 (“My parents and I never had that birds and the bees talk, which I almost feel cheated out of now in a bizarre way . . . There are many barriers to establishing that conversation and to teaching dating skills.”).

²¹⁶ *Sex Ed for Self-Advocates*, *supra* note 215.

²¹⁷ *About Us*, ELEVATUS TRAINING, <https://www.elevatustraining.com/about-us/> (last visited May 11, 2020).

²¹⁸ Marrone, *supra* note 212.

²¹⁹ *Id.*

²²⁰ Wetzler, *supra* note 93.

²²¹ *Id.*

²²² KAISER FAMILY FOUND., *Private and Public Coverage of Contraceptives in the United States*, KAISER HEALTH NEWS (July 10, 2015), <https://www.kff.org/womens-health-policy/fact-sheet/private-and-public-coverage-of-contraceptive-services-and-supplies-in-the-united-states/>

²²³ *Id.*

²²⁴ See Clair Kaplan, *Special Issues in Contraception: Caring for Women with Disabilities*, 51(6) J. OF MIDWIFERY & WOMEN'S HEALTH 450, 450-56 (2006).

women covered by other types of health insurances. It implies they are not and will not be sexually active and it deprives them of a choice when it comes to whether they want to have kids or not. Some adults with intellectual and developmental disabilities want to have children, which also needs to be recognized. Ivanova Smith is an activist with intellectual disabilities and claims that when she became pregnant, healthcare providers immediately offered her information on how to have an abortion.²²⁵ She told them she was going to have the baby—and she did.²²⁶

F. Amplifying the Voices of People with Disabilities Through Self-Advocacy

People with disabilities know their own needs best. Part of increasing access to sexuality services should include support for sexual self-advocacy. When Gravino was researching how to teach men with autism about how to ask someone out on a date, she found that “not one study” included people with disabilities.²²⁷ Gravino argues for more research to be done on the sexuality of people with disabilities and for that research to include the voices of those with disabilities.²²⁸ Doing so is important, in part, because people with intellectual and developmental disabilities often have a unique perspective which needs to be heard to move forward.²²⁹ Advocates say some of those who need the most education on disability are judges. Professor Lennard J. Davis writes, “For intelligent and just decisions to be made, decisions based on knowledge and rationality rather than impulsive tropisms . . . the judiciary will have to learn a lot more.”²³⁰ Davis recommends courses on disability be available for students in grades Kindergarten through college.²³¹ Another way to improve everyone’s understanding is for people who do not have disabilities to get to know

²²⁵ *Unfit*, *supra* note 33.

²²⁶ *Id.*; see also Robin Wilson-Beattie, *How the ADA Gave Birth to a Black Sexpert*, DISABILITY VISIBILITY PROJECT,

<https://disabilityvisibilityproject.com/2020/07/19/how-the-ada-gave-birth-to-a-black-sexpert/>

(“[P]eople do not recognize the autonomy of people with disabilities in making decisions about their bodies.”).

²²⁷ *Amy Gravino Talk*, *supra* note 39 (“There’s still such a taboo around this topic that it is difficult if not impossible to get funding for these types of studies.”).

²²⁸ *Id.* (“[W]e need more research . . . we need studies on sexuality with autistic researchers . . . See us not as children needing to be taught, but as who we are: intelligent, capable adults, who want to engage in this discussion as equals among you.”).

²²⁹ See Aleksa Owen et al., *Nominal Group Technique: An Accessible and Interactive Method for Conceptualizing the Sexual Self-Advocacy of Adults with Intellectual and Developmental Disabilities*, 15(2) QUALITATIVE SOC. WORK 175-77 (2016).

²³⁰ Lennard J. Davis, *Bending Over Backwards: Disability, Narcissism, and the Law*, 21 BERKELEY J. EMP. & LAB. L. 193, 211 (2000).

²³¹ *Id.*

people who do have disabilities. One researcher says disability “can invigorate sexuality, and disrupt our standard norms of gender and sexuality . . . giv[ing] us the chance to think outside the box.”²³² There is plenty the rest of the world can learn from people with disabilities when it comes to sexuality—or any other aspect of life. By not including those with disabilities, there is a lot that is lost.

VII. CONCLUSION

There are ways to provide support services for people with intellectual and developmental disabilities so they can make decisions when it comes to sexuality. States can include support for sexuality services in their waiver programs. A comprehensive sex education, that is individually tailored to each person’s needs and understanding, can be provided to empower people to make informed choices. At the same time, the rest of society—including judges, lawyers, and caretakers—need to become more educated on disability issues and people’s individual needs.

If sexuality is a “central aspect of being human throughout life”²³³ and an integrated setting is one which “provides opportunities to live . . . and receive services”²³⁴ then sexuality must be included in the services that are provided. Without such support, many adults with intellectual and developmental disabilities will be left with questions to which they do not have answers. For true community integration, sexuality cannot be overlooked.

Whether those supports are provided or not, people with intellectual and developmental disabilities will still be thinking about sexuality and talking about it. Jillian, Sam, Fred, Maria, and the people with disabilities interviewed at the beginning of this note, will still be asking questions, seeking understanding and looking for intimacy in their own ways. It is time for them to be heard.

²³² Katharine Quarmby, *Disabled and Fighting for a Sex Life*, THE ATLANTIC (Mar. 11, 2015), <https://www.theatlantic.com/health/archive/2015/03/sex-and-disability/386866/>; see also, Amy Gravino *Talk*, *supra* note 39 (“The idea that there is a right way to have sex or to be sexual is another misconception that won’t quietly die. The experience of sex . . . is different for every person . . . and while the sensory issues that many autistic individuals face may alter how they have sex, it doesn’t mean that they don’t have it at all.”).

²³³ See WORLD HEALTH ORG., *supra* note 6.

²³⁴ See U.S. DEP’T OF JUST. Statement, *supra* note 155.