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A GROUP HOME EXCLUSIVELY FOR MARRIED COUPLES WITH DEVELOPMENTAL DISABILITIES: A NATURAL NEXT-STEP

by Marissa DeBellis*

I. Introduction

Q: Why do you want to get married?

A: We love each other. That's why. I want to get married, and live with him, and I'll be there for him, and he'll be there for me . . .

Q: What do you think it means to be married?

A: To be in love and complete.

Q: What do you think your life will be like after you are married?

A: I want to live on my own. I want to move on, get my own life with [him, he is] my partner in life. He'll be there for me, no matter what.

Q: [Are you afraid of moving away from your home?]

A: I'm a twenty-six year old woman and I want to get married and move on. . . . He want[s] to get married. And the point is the he [has] fallen in love with me and not anyone else. He wants me. That's what he wants. That's what I want. We want to get married . . . as soon as possible. 1

^{*} Juris Doctor Candidate, Touro College Jacob D. Fuchsberg Law Center, May 2012; B.A. Fairfield University. I would like to express my deepest gratitude to my family and friends for their unconditional love and support throughout my educational career, with particular thanks to my loving parents. Special thanks go to the talented members of the *Touro Law Review* for their advice, support, assistance, and friendship. Lastly, I would like to dedicate this Comment to my cousin, Amanda, for providing me not only with the inspiration to write about this topic, but also for a lifetime of inspiration to live to my fullest potential, something I hope she will be able to do as a result of this Comment.

¹ Interview with Amanda Baldwin, in Yaphank, N.Y. (Oct. 3, 2010) (on file with author).

Vol. 28

The responses above came from my cousin, Amanda Baldwin, a woman with Down syndrome² considered to have mild mental retardation.³ She and her boyfriend of three years are engaged and plan to marry. He is also developmentally disabled⁴ and currently lives in a group home.⁵ The two plan to live a life that they consider "normal," including a wedding, cohabitation, and a sexual relationship. Although Ms. Baldwin's responses show that she has a clear understanding of the emotional commitment of marriage and its meaning, she will face the possible dissolution of her upcoming marriage due to her lack of capacity to give consent,⁶ and will have great difficulty finding an appropriate residence in which both she and her future husband can live as a married couple.⁷

² See generally Down syndrome, GENETICS HOME REFERENCE (Sept. 26, 2010), http://ghr.nlm.nih.gov/condition/down-syndrome ("Down syndrome is a chromosomal condition that is associated with intellectual disability The degree of intellectual disability varies, but it is usually mild to moderate.").

³ See GEORGE S. BAROFF & J. GREGORY OLLEY, MENTAL RETARDATION: NATURE, CAUSE, AND MANAGEMENT 8 (Brunner/Mazel, 3d ed. 1999) (identifying four characterizations of mental retardation: mild, moderate, severe, and profound). While many degrees within mental retardation are often described in terms of the range of abilities the person may have or the responsibilities he or she understands, the initial determination typically begins with Intelligence Quotient (IQ) test performance. *Id.* at 8. Persons with mild mental retardation fall within an IQ range of 52-69, while those with moderate mental retardation fall within an IQ range of 36-54, those with severe mental retardation typically have an IQ range of 20-39, and those with profound mental retardation typically have an IQ range of 0-24. *Id.* at 9.

⁴ See id. at 247 (describing developmental disabilities as "disorders presented at birth or arising in childhood that are chronic in nature and require similar habilitative services [T]he term now encompasses all developmental disorders—sensory and physical as well as cognitive—that significantly affect major areas of daily living.").

⁵ Group homes, or community residential facilities, are homes in residential areas housing anywhere from four to fifteen unrelated individuals with similar disabilities (mental, physical, or addiction) staffed with people that provide supervision and services to the residents. Stephen F. Hayes, *The "Usual Incidents of Citizenship": Rethinking When People with Disabilities Must Participate in Public Variance Proceedings*, 109 COLUM. L. REV. 2044, 2047 (2009); N.Y. COMP. CODES R. & REGS. tit. 14, § 686.99(1) (2012) (defining a community residence as "[a] facility providing housing, supplies and services for persons who are developmentally disabled and who, in addition to these basic requirements, need supportive interpersonal relationships, supervision, and training assistance in the activities of daily living.").

⁶ See N.Y. Dom. Rel. Law § 7(2) (McKinney 2011) ("A marriage is void if either party . . . [i]s incapable of consenting to a marriage for want of understanding.").

⁷ See Interview with Bonnie Guimela, Senior Ed. Specialist for The Cody Ctr. for Autism and Developmental Disabilities at Stony Brook Univ., in Stony Brook, N.Y. (Feb. 10, 2011) (on file with author). Bonnie Guimela is a social worker with extensive experience working with the developmentally disabled. She currently heads the Sexual Education and Relation-

In an attempt to make their plans a reality, Ms. Baldwin and her boyfriend, along with two other interested couples with similar disabilities, seek to create a group home designed exclusively for married couples with developmental disabilities. While this kind of group home may seem to some like a wonderful service, and even a fairly logical concept, such a group home does not yet exist, and finding support for its creation has proven to be an incredibly daunting task. While there are married couples with developmental disabilities that live in group homes with other unmarried individuals, there are no group homes in the United States designed specifically to provide a supportive environment exclusively for married couples.

This Comment advocates for the development of this unique and unprecedented group home, establishing the basis for its creation by demonstrating that public policy supports providing this type of environment as a necessary service for the distinct group of individuals seeking it. This Comment will discuss the history of how the law has treated those with mental disabilities and will demonstrate that with the vast progression in the treatment of, and the rights afforded to, individuals with developmental disabilities, a group home designed specifically for married couples is a natural next-step in the expansion and personalization of the services provided to these individuals. Additionally, because Ms. Baldwin and her boyfriend will marry and live in New York, this Comment will not only discuss general guidelines governing this unique situation, but will also pay particular attention to New York regulations.

Section II will outline the progression of marital rights of the developmentally disabled in order to demonstrate the evolution of rights afforded to the developmentally disabled while also revealing one of the many hurdles the couple will face in attempting to have the "normal" life they so desperately seek. Section III will identify the housing options available for married couples with developmental disabilities unable to live independently and the popularization of group homes. Lastly, section IV will address, and subsequently dis-

ship Training Division of The Cody Center for Autism and Developmental Disabilities at Stony Brook University, and is currently working with couples seeking to get married and live together in a group home setting. See generally The Cody Center For Autism and Developmental Disabilities, STONY BROOK UNIVERSITY MEDICAL CENTER, http://www.stonybrookmedicalcenter.org/codycenter (last visited Feb. 2, 2011).

⁸ Interview with Bonnie Guimela, *supra* note 7.

Vol. 28

credit, the likely opposition to the construction of this type of residential facility.

The analysis in this Comment will focus primarily on the rights of individuals with mental retardation and other developmental disabilities who are unable to live independently and require the services of at-home care, institutions, or other residential facilities. It will not discuss services for the mentally ill or individuals with cognitive disabilities considered to be "high-functioning" or merely "mentally weak" because individuals in these classifications have additional living options and tend to face fewer restrictions due to their heightened capacity to understand the consequences of their decisions.

II. MARITAL RIGHTS OF THE DEVELOPMENTALLY DISABLED

As humans, we have social and biological desires to marry, live together, and create a family. Unsurprisingly, individuals with developmental disabilities share these same ambitions. However, societal views have historically resisted the idea of the developmentally disabled engaging in romantic relationships. While the treatment of individuals with developmental disabilities has evolved extensively in the past few decades, with the trend toward deinstitutionalization and the recognition of their right against discrimination, there is still significant room for growth, particularly in attempting to change society's views of this often stigmatized group.

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⁹ J. Dale Munro, *Couple Therapy and Support: A Positive Model for People with Intellectual Disabilities*, NADD, http://www.thenadd.org/cgi-bin/checkmember.pl?page=pages/membership/bulletins/v10n5a1 (last visited Jan. 22, 2012).

¹⁰ Id. (attributing this resistance largely to fears of sexual relationships that will result in pregnancy).

¹¹ See Laura E. Hortas, Asylum Protection for the Mentally Disabled: How the Evolution of Rights for the Mentally Ill in the United States Created a "Social Group," 20 CONN. J. INT'L L. 155, 161-62 (2004) (discussing the trend moving away from the institutionalization of those with mental disabilities and toward community care, with the government adopting the position that moving the mentally ill to an institution "should only be used as a last resort").

¹² See Americans with Disabilities Act, 42 U.S.C. §§ 12101 et seq. (2006). The Americans with Disabilities Act specifically mandates "the elimination of discrimination against individuals with disabilities" on a national level as a result of several findings warranting a need for such legislation. *Id.* at § 12101(a), (b)(1).

455

2012 A NATURAL NEXT-STEP

A. Historical Background

It is well known that the developmentally disabled have a substantial history of mistreatment and degradation in the codification of American law.¹³ Thankfully, there has been a steady trend among Congress and state legislatures toward removing the stigma traditionally placed upon the developmentally disabled and "actively encourag[ing] the 'normalization' of people with disabilities."¹⁴ However, this "reform movement has had little effect on the right of the people with mental retardation to marry."¹⁵

For much of American history, individuals with mental disabilities were essentially uninhibited by state legislation regarding marriage and procreation. 16 The same standard of determining whether a marriage would be upheld applied equally to both the mentally disabled population and the rest of society, with the only deciding factor being whether the two individuals "were able to understand the basic concept of marriage." However, by the beginning of the twentieth century, this outlook changed severely with the rise of the Eugenics movement.¹⁸ During this movement, eugenic ideals inspired laws restricting the right of developmentally disabled persons to marry based upon "a belief that social engineering through controlled or selective reproduction could help purify the human race."¹⁹ In 1896, Connecticut enacted the first piece of legislation prohibiting the mentally disabled community from marrying, and by 1914, over twenty states had followed the trend.²⁰ With an interest in "societal productivity," states disallowed marriage of people with mental dis-

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¹³ See id. at § 12101(a)(2)-(5) (finding that individuals with disabilities have had a long history of discrimination, both socially and politically, that persisted leading up to the enactment of this legislation, for which these individuals "often had no legal recourse to redress such discrimination.").

¹⁴ Brooke Pietrzak, Marriage Laws and People with Mental Retardation: A Continuing History of Second Class Treatment, 17 Dev. IN MENTAL HEALTH LAW 1, 1-2 (1997).

¹⁵ *Id.* at 2.

¹⁶ See Matthew D. Martin III, *The Dysfunctional Progeny of Eugenics: Autonomy Gone AWOL*, 15 CARDOZO J. INT'L & COMP. L. 371, 375 (2007).

¹⁷ Ia

¹⁸ Jonathan Matloff, *Idiocy Lunacy, and Matrimony: Exploring Constitutional Challenges to State Restrictions on Marriages of Persons with Mental Disabilities*, 17 Am. U. J. GENDER SOC, Pol'Y & L. 497, 501 (2009).

¹⁹ *Id*.

²⁰ Hortas, *supra* note 11, at 159.

abilities and forced sterilization because of the belief that mental retardation would be passed on to their children.²¹ Some courts also based their decisions on unreliable scientific data, stating that, "idiocy, insanity, imbecility, and criminality are congenital and hereditary,"²² in order to promote the state's interest in protecting the public from "afflicted" offspring.²³ In 1927, the United States Supreme Court showed its official support of this state interest by upholding the validity of a Virginia law that gave the superintendents of mental institutions the authority to sterilize patients in order to prevent the transmission of "imbecility" through procreation.²⁴

The Court's decision, among other things, marked a shift in American culture, after which much of society began to view people with mental disabilities as outcasts, forcing sterilization and creating mental institutions with the hidden agenda of further isolating this population from society and, in effect, from the opposite sex.²⁵ This practice stigmatized the group and indoctrinated Americans with the belief that this group of people needed to be isolated, both from society and from each other; a stigma that, in many ways, still perpetuates today in the discouragement of marriage through legislation.²⁶

The end of World War II marked a call for reform that resulted in substantial changes to the health care system for the mentally disabled.²⁷ However, the reform was focused primarily on improving the quality of care provided by institutions and was not reflected in marriage statutes.²⁸

²¹ Matloff, *supra* note 18, at 501-02.

²² State v. Feilen, 126 P. 75, 76 (Wash. 1912) (upholding a sentence requiring a man found guilty of rape to be subjected to a vasectomy); *see also* Smith v. Command, 204 N.W. 140, 142 (Mich. 1925) (citing to medical studies that show "a reasonable degree of certainty that feeble-mindedness is hereditary").

²³ Matloff, *supra* note 18, at 501.

²⁴ Buck v. Bell, 274 U.S. 200, 207-08 (1927) (referring to "imbeciles" as a class of people that "sap the strength of the State," and remarking that "[t]hree generations of imbeciles are enough").

²⁵ See Martin, supra note 16, at 375; Matloff, supra note 18, at 500.

²⁶ See discussion infra Part II.B (discussing many current marriage laws that severely restrict and even prohibit marriage of a person with mental disabilities).

Hortas, supra note 11, at 161.

²⁸ See id.; Pietrzak, supra note 14, at 2.

B. The Current Status of Marriage Laws and New York's Voidable Marriage

Unfortunately, some statutes still harbor the language of the eugenics-era in their text.²⁹ Using words such as "imbecile," "idiot," "feeble-minded," "lunatic," or "mental deficients" to classify all degrees of mental incapacity, states have lumped all those with mental disabilities into one group in which all "person[s] of any degree of unsoundness of mind" would be restricted in their ability to marry, further allowing the eugenic-era perspective that people with mental disabilities are sub-human or in some way defective to be perpetuated even in modern society.³⁰ Most states have attempted to deviate from this outlook by amending the terms used within the statutory text, but there has been little substantive change in the law.³¹

At common law, and under codification in certain jurisdictions, the marriage of a person of "unsound mind," who would therefore be deemed incapable of understanding the nature, duties, and consequences of a marriage, is absolutely void. When a marriage is said to be completely void, it may never be validated. In essence, because no marital rights are secured and the couple would be able to act as if the marriage never occurred, issues such as the legitimacy of children and property disputes have proven to be cumbersome and unjust. However, in most United States jurisdictions, a marriage involving at least one party with a mental disability is not void, but rather voidable, and will remain valid until either party contests the marriage contract or seeks an annulment.

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457

²⁹ See, e.g., 23 PA. CONS. STAT. ANN. § 1304(c) (West 2010) (prohibiting a marriage license to be issued to an individual that is "weak minded, insane, [or] of unsound mind"); TENN. CODE ANN. § 36-3-109 (West 2010) (indicating that a marriage license cannot be issued to someone that "appears . . . at the time drunk, insane, or an imbecile"); VT. STAT. ANN. tit. 15, §512 (West 2010) (declaring that a marriage contract may be annulled when either party was "an idiot or lunatic" at the time of the marriage); W. VA. CODE ANN. § 48-3-103(a)(3)(A) (West 2010) (stating that marriages are voidable, and void when declared by the court to be so, when either party "was an insane person, idiot, or imbecile").

³⁰ Pietrzak, *supra* note 14, at 2-3.

³¹ *Id.* at 3, 33.

³² *Id.* at 33.

³³ *Id*.

³⁴ *Id*

³⁵ See Pietrzak, supra note 14, at 33.

Vol. 28

In New York, a marriage is void from its nullity, and therefore voidable, when either party "[i]s incapable of consenting to a marriage for want of understanding." The statute does not attempt to define "want of understanding," nor does it clearly separate the mentally ill from the developmentally disabled in its general rule. However, the two groups are treated substantially differently when one party seeks an annulment of his or her voidable marriage, ³⁷ signifying the need for more specificity in the voidable marriage statute. The broad language dangerously forces a spectrum of disabilities, and abilities, to fall within the statute.

Significantly, the statute does not require an initial showing of capacity before a couple with developmental disabilities obtains a marriage license or has a wedding. Instead, it merely provides remedies for the party seeking to annul or void a marriage due to lack of capacity,³⁸ resulting in case law that only explains how to get out of marriage as opposed to how to enter into one.³⁹ This has left many people with disabilities clueless about the process of getting married and has allowed private agencies caring for these individuals to control the process by requiring each person seeking marriage to pass a test "proving" that he or she has the capacity to consent to a marriage and to engage in a sexual relationship.⁴⁰

C. The Capacity Requirement

The "unsound mind" and "want of understanding" standards imply a requirement of a certain mental capacity in order for the marriage to be valid. A problem arises, however, as a result of the va-

458

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³⁶ N.Y. Dom. Rel. Law § 7(2).

³⁷ See N.Y. Dom. Rel. Law § 140(c). In an action to annul a marriage on the grounds that a party to the action was mentally retarded at the time of the marriage, the only guideline enumerated in the New York Domestic Relations Law is that any relative of the mentally retarded party with an interest in avoiding the marriage may bring the annulment at any time during the lifetime of either party. *Id.* However, there are several specific guidelines, distinguishable from the solitary instruction given for mental retardation, listed regarding an annulment involving a party that is mentally ill. *See id.*

⁵⁸ *Id*.

³⁹ See, e.g., Levine v. Dumbra, 604 N.Y.S.2d 207, 208 (App. Div. 1993) (providing only guidelines for showing incompetence rather than competence).

⁴⁰ See Interview with Bonnie Guimela, supra note 7; discussion infra Part II.C.ii (focusing on the consent testing requirement and providing examples of tests used in New York).

459

2012 A NATURAL NEXT-STEP

gueness of these standards because they encompass a significantly broad spectrum of mental disability. While courts have recognized the lack of a precise definition of "unsound mind," they have further insisted upon the difficulty, and have been reluctant to develop a comprehensive definition.⁴¹ However, in an attempt to narrow a statute's constraint on an overly broad group of people, some courts have specifically stated that mere mental weakness or low intellect is insufficient to fall within these statutes. 42 Most significantly, many jurisdictions have declared that the individual must have the specific inability to understand the special nature of the contract of marriage, and the duties that accompany such a contract, at the time of the marriage in order for the marriage to be void or voidable. 43 As one court described, "[o]rdinarily, lack of mental capacity, which renders a party incapable of entering into a valid marriage contract, must be such that it deprives him [or her] of the ability to understand the objects of marriage, its ensuing duties and undertakings, its responsibilities and relationship."44 Likewise, an individual may have the specific capacity to understand the special nature of the contract of marriage while potentially lacking a similar capacity to enter into other contracts, and vice versa.⁴⁵

Typically, mental capacity must relate specifically to the contract of marriage, not necessarily the capacity to contract generally. Courts often make the distinction between the two levels of capacity, many finding that the capacity to enter into a marriage contract is lower than that required for a business transaction. However, this seems like an unnecessary distinction because the Law of Contracts

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⁴¹ See, e.g., Johnson v. Johnson, 104 N.W.2d 8, 13-14 (N.D. 1960).

⁴² See, e.g., Ertel v. Ertel, 40 N.E.2d 85, 89 (Ill. App. Ct. 1942).

⁴³ See Johnson, 104 N.W.2d at 14.

⁴⁴ *Id*.

⁴⁵ See id. at 17 (stating that different tests apply for determinations of capacity for guardianship purposes and for marriage, resulting in the ability of a person found to be incompetent under a guardianship standard to potentially have sufficient mental capacity to enter into a valid marriage contract).

⁴⁶ See Edmunds v. Edwards, 287 N.W.2d 420, 422 (Neb. 1980) (denying the plaintiff, a man found by the Court to be "mentally retarded," the ability to annul his marriage because, at the time of its inception, the degree of his mental incapacity was not of the nature that rendered him incompetent to enter into a marriage due to the fact that he had adequate capacity to understand the marriage contract and the duties that follow).

⁴⁷ See, e.g., Ertel, 40 N.E.2d at 89 (stating that Illinois requires less capacity for a marriage contract than for executing an ordinary business contract).

Vol. 28

focuses on an understanding of the specific transaction and whether the "transaction in its result is one which a reasonably competent person might have made." 48

The ways in which courts classified the differences between marriage and business contracts became more creative over time. For example, one court relied upon emotional factors rather than mental abilities, stating that, "marriage depends to a great extent on sentiment, attachment, and affection which persons with equal, as well as those with stronger intellects feel and . . . it does not depend, to the extent that ordinary contracts do, on the exercise of clear reason, discernment, and sound judgment." Another court went even further as to say that while marriage is referred to as a civil contract under the law, it is actually nothing of the sort. Rather, "[w]hat persons establish by entering into matrimony, is not a contractual relation, but a social Status; and the only essential features of the transactions are that the participants are of legal capacity to assume that Status, and freely consent so to do." 51

1. Measuring Capacity

Whether explaining mental incapacity by analogizing it to the links of a chain, ⁵² or simply ignoring degrees of developmental disability, state courts have consistently struggled to create specific guidelines in order to determine whether a party is incompetent and the degree to which the individual's disability contributes to this lack of understanding. ⁵³ In an attempt to create a standard for entering into a marriage, Maine adopted legislation stating that, "[a] person who is impaired by reason of mental illness or mental retardation to the extent that he lacks sufficient understanding or capacity to make, communicate or implement responsible decisions concerning that

⁴⁸ RESTATEMENT (SECOND) OF CONTRACTS § 15 cmt. b (1979).

⁴⁹ Griffin v. Beddow, 268 S.W.2d 403, 405 (Ky. Ct. of App. 1954).

⁵⁰ Edmunds, 287 N.W.2d at 425.

⁵¹ *Id.* (quoting Univ. of Mich. v. McGukin, 89 N.W.2d 778, 779 (Neb. 1902)).

⁵² Rawdon v. Rawdon, 28 Ala. 565, 567 (1856) (attempting to explain degrees of "unsoundness" by stating, "[t]he faculties of a sound mind are links, composing a chain. These links may be worn and weakened, and still the chain exists. Break or destroy one of them, and the unity and continuity are gone.").

Matloff, *supra* note 18, at 504.

person's property or person is not capable of contracting marriage"54 However, this language completely ignores an individual's specific ability to appreciate the marriage contract and marital relationship, and creates a standard that rests solely on general disabilities, reminiscent of those requirements necessary for the appointment of a guardian.⁵⁵

California made an attempt to provide statutory guidance by developing a list of factors for analyzing an individual's capacity to perform certain acts.⁵⁶ The list includes the ability to concentrate, understand, communicate, reason, and recognize objects and people.⁵⁷ This statute, however, is not specific to marriage, and instead applies to a broad list of contractual abilities, including the capacity to contract, execute a will, and make medical decisions.⁵⁸ While this is a step in a positive direction, general skills such as the ability to communicate cannot effectively measure an individual's specific capacity to enter into a marriage contract as required by the courts.

Each state legislature has therefore relied upon case law to further define the meaning of statutory text. However, many courts, including the United States Supreme Court, refuse to make such interpretations.⁵⁹ In City of Cleburne v. Cleburne Living Center.⁶⁰ the Court stated that legislation affecting "this large and diversified group" of mentally disabled persons "is a difficult and often a technical matter, very much a task for legislators guided by qualified professionals and not by the perhaps ill-informed opinions of the judiciary."61

Despite this seesawing between the courts and the legislature,

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ME. REV. STAT. ANN. tit. 19-A, § 701(3) (West 2011). The statute also includes a definition of both mental illness and mental retardation, specifically making them separate. Id. at § 701(3)(A)-(B).

⁵⁵ Generally, statutes guiding the guardianship appointment for a disabled person require the individual to lack appreciation and understanding of his or her disability such that it limits his or her ability to care for his or her person or property. See, e.g., N.Y. MENTAL HYG. LAW § 81.15(b)(1)-(2), (c)(2)-(3) (McKinney 2011).

⁵⁶ CAL. PROB. CODE § 811(a)(1)-(3) (West 2011).

⁵⁷ *Id.* at § 811(a)(1)(C), (2)(B)-(E).

⁵⁸ *Id.* at § 811(a).

⁵⁹ See City of Cleburne v. Cleburne Living Ctr., 473 U.S. 432, 442-43 (1985).

⁶⁰ *Id*.

⁶¹ *Id.* at 442-43.

a general standard requiring the individual to understand the nature and consequences of marriage, and comprehend the significance of being married, at the time the marriage contract was made has emerged among jurisdictions. The conflict here is that case law in this area focuses on presenting evidence that the individual was incompetent in order to void or annul a marriage rather than presenting guidelines and standards necessary to demonstrate the proper capacity to contract.

In practice, particularly among agencies charged with the care of individuals with mental disabilities, those seeking to marry must first be tested on their capacity to consent to marriage.⁶⁴ However, in actuality, this test does not measure the specific capacity to consent to the contract of marriage, but instead evaluates the individual's capacity to consent to a sexual relationship. 65 Unfortunately, many of the standards used to measure sexual capacity that are acknowledged in New York come from rape cases in which one of the parties had a mental defect that rendered him or her incapable of giving consent. 66 As a result, much of the focus in this evaluation rests upon the voluntary aspect of the individual's behavior. 67 New York has also identified a "morality standard," under which "a person must be mentally capable of understanding the social mores of sexual behavior . . . [and] the non-criminal penalties (e.g., ostracism, stigmatization) that society may impose for conduct it labels as sexually immoral . . . [such as] sexually exploitive behavior."68 In practice, this translates

⁶² *Johnson*, 104 N.W.2d at 14. It is also well accepted among jurisdictions that this information must be ascertained by the facts on a case-by-case basis. *Id.* One court stated that, "[i]t is difficult to lay down any general comprehensive test for determining the degree of mental capacity required to contract a marriage. Each case must of necessity be decided on its own facts." De la Montanya v. De la Montanya, 281 P. 825, 825 (Or. 1929).

⁶³ Levine, 604 N.Y.S.2d at 208 (providing only guidelines for showing incompetence rather than competence).

⁶⁴ See Interview with Bonnie Guimela, supra note 7.

 $^{^{65}}$ Id

⁶⁶ See, e.g., People v. Easley, 364 N.E.2d 1328 (N.Y. 1977) (discussing how the victim was unable to consent to sexual activity due to mental incapacity); People v. Cratsley, 653 N.E.2d 1162 (N.Y. 1995) (dealing with the rape of a 33-year-old woman who was incapable of consenting to sexually activity).

⁶⁷ BAROFF & OLLEY, *supra* note 3, at 251 (stating that consent may be obtained verbally and behaviorally as long as there is a clear indication that the sexual activity is voluntary).

⁶⁸ Martin Lyden, *Assessment of Sexual Consent Capacity*, 25 SEXUALITY AND DISABILITY 3, 5 (2007). Additionally, this article mentions that some other states do not require this

to the individual knowing and understanding the difference between appropriate public and private behavior.⁶⁹ The New York Court of Appeals emphasized that:

An understanding of coitus encompasses more than a knowledge of its physiological nature. An appreciation of how it will be regarded in the framework of the societal environment and taboos to which a person will be exposed may be far more important. In that sense, the moral quality of the act is not to be ignored.⁷⁰

In a later case, the same court asserted that proof of incapacity could not be evidenced by the individual's disability alone, as the law does not presume that an individual with disabilities is unable to consent to sex. This instruction has led to reliance on consent testing that examines other traits and indicators of an individual's ability to understand the nature of a sexual relationship.

2. Testing Capacity

Although the New York statute governing marriage does not require proof of capacity before obtaining a marriage license, ⁷³ non-governmental agencies that serve as legal guardians for the mentally disabled require that these individuals pass consent tests demonstrating the individual's ability to give consent to a sexual relationship. ⁷⁴ Despite the lack of a requirement to prove capacity to marry by the

added understanding of the morality of the sexual act, and instead only demand an understanding of the nature of sexual behavior and its potential consequences. *Id.* at 6.

⁶⁹ See Interview with Bonnie Guimela, supra note 59 (discussing the need for individuals to know the difference between private and public acts); Interview with Amanda Baldwin, supra note 1 (demonstrating her understanding of public and private conduct: "Un-private is like, public, like we're going out somewhere and we can't do that when we're going out . . . in private you can do anything you want in our room, just me and him together, not me and the staff . . . [b]ut me and him are husband and wife and that's different. That's private stuff.").

⁷⁰ Easley, 364 N.E.2d at 1332 (internal citations omitted).

⁷¹ Cratsley, 653 N.E.2d at 1165.

⁷² See Interview with Bonnie Guimela, supra note 7.

⁷³ See N.Y. Dom. Rel. Law § 10; N.Y. Dom. Rel. Law § 13 (requiring only a marriage license before the solemnization of the marriage).

⁷⁴ See Interview with Bonnie Guimela, supra note 7.

Vol. 28

state legislature, private agencies feel entitled to compel these individuals to satisfactorily pass a consent test according to their professional judgment by manipulating the consent requirement of the New York Penal Law⁷⁵ to give them such a power.⁷⁶ Because an individual may lack consent under the statute because of an incapacity resulting from a mental disability,⁷⁷ agencies' fear of liability and the potential for criminal charges has led the agencies to resort to consent testing, often using tests drafted by the individual agency or those given by the New York State Office for People with Developmental Disabilities ("OPWDD"),⁷⁸ in order for the couple to gain permission from the agency to marry.⁷⁹

To say that there is no clear test for evaluating the capacity to consent to a sexual relationship is an understatement, making these testing requirements quite problematic. Not only do the criteria for measuring capacity to consent to sexual activity vary across jurisdictions, but they also vary within jurisdictions. In fact, some states have no significant guidelines whatsoever. This means that not only can an individual be deemed to have capacity in one state and not in another, but he or she can also be deemed to have capacity by one agency and not by another within the same state, or even within the same county. Additionally, of the tests that do exist, all are com-

⁷⁵ N.Y. PENAL LAW § 130.05(1) (McKinney 2011) (requiring consent to engage in sexual activity).

⁷⁶ See Lyden, supra note 68, at 4.

⁷⁷ See N.Y. Penal Law § 130.05(2)(b), (3)(b).

⁷⁸ See NYS OFFICE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, http://www.omr.state.ny.us (last modified Nov. 10, 2010). The OPWDD only recently received this name in July, 2010. Governor Paterson Signs Historic Name Change Into Law, NYS OFFICE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, (last modified Nov. 17, 2010) http://omr.state.ny.us/news/name_change.jsp. Note that because this name change is new, New York statutes conferring authority upon this office to monitor residences and develop rules and regulations governing services for the developmentally disabled may still use its previous name, the Office of Mental Retardation and Developmental Disabilities ("OMRDD").

⁷⁹ See Interview with Bonnie Guimela, supra note 7.

⁸⁰ Lyden, *supra* note 68, at 5.

⁸¹ See Carrie H. Kennedy, Legal and Psychological Implications in the Assessment of Sexual Consent in the Cognitively Impaired Population, 10 ASSESSMENT 352, 353 (2003), available at http://asm.sagepub.com/cgi/content/abstract/10/4/352 (stating that some states lack any precedent on record).

⁸² See id. at 353; Interview with Bonnie Guimela, supra note 7 (stating that examiners can be swayed by the agency he or she works for, often making their opinion outcome determin-

pletely subjective and lack any form of standardization.⁸³ This lack of objectivity can easily lead to grave consequences with the undeserved denial of an individual's right to engage in a sexual relationship.⁸⁴

465

Although there is no consistent standard, some evaluators are directed to examine and establish five principles of consent before deeming an individual capable of consenting:

[1] Awareness of the nature of sexual acts and the ability to choose to engage or abstain; [2] understanding of how you prevent unwanted pregnancies and STI's; [3] understanding of the need to restrict sexual behavior to certain times and places; [4] understanding that certain sexual behaviors are illegal in this state; and [5] the ability to identify harmful situations and to avoid being exploited and harmed. 85

The general purpose of evaluating these five principles is to allow the individual to demonstrate an understanding of the conduct in which he or she seeks to engage, and that he or she comprehends and will accept responsibility for the consequences that may result from the sexual conduct.⁸⁶

A consent assessment generally employs one or more of three information gathering methods: 1) a review of medical records; 2) assessments made by people who know and have worked with the individual, usually including staff members at an agency with which he or she is closely associated; and/or 3) interviews with a person able to evaluate the individual's mental status, perceivable knowledge, and

ative because many agencies do not like to allow individuals to pass the test).

⁸³ Interview with Bonnie Guimela, *supra* note 7 ("Q: So the test is not standardized? A: It's not even objective.").

⁸⁴ Kennedy, *supra* note 81, at 353; *see generally* Lyden, *supra* note 68, at 3-4 ("There is a presumption in American law that an individual has the prerequisite capacity to engage in a sexual relationship once he/she reaches the age of consent. An adult is entitled to all of his or her rights and privileges under the law, unless limitations are imposed by a court of law ").

⁸⁵ Interview with Bonnie Guimela, *supra* note 7. In the interview, Ms. Guimela further discussed a couple that she is currently working with and their failure of the consent test despite adequate knowledge: "Now, I will tell you that the two people that I saw, I could sit down and talk to them and they could answer all of those things appropriately, and yet their individual agencies said that they did not pass their consent test." *Id*.

⁸⁶ *Id*.

Vol. 28

understanding of consequences.⁸⁷ However, the most likely assessor is a representative of the agency providing services to the individual, or the agency to which the individual has the closest personal connection.⁸⁸

Some consent assessments use pictures, videos, and examples to evaluate an individual's level of understanding. One test utilized in New York examines whether the individual understands the physical aspects of sex and sexual organs as well as the different levels of intimacy, pregnancy, birth control, and sexually transmitted diseases. However, many tests also include observations gathered by a team of people that are closely associated with the disabled individual, such as counselors and staff of his or her school or day program, in order to create an assessment based upon the observer's personal knowledge of the disabled individual's understanding of a sexual relationship.

Agencies that are governed by OPWDD regulations have the responsibility to both protect those receiving its services while also encouraging their sexual rights. Often, these two notions live in conflict with one another. Although staff and examiners have a duty to affirm individual sexual rights and are "tasked with promoting patient rights to include sexual rights," in practice, very few patients pass the consent test. Unfortunately, a common outcome is the improper determination of incapacity. This may be the result of improper training, or the notion that facility representatives charged with giving the assessment worry more about the potential liability

466

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⁸⁷ Lyden, *supra* note 68, at 10.

⁸⁸ See Kennedy, supra note 81, at 353.

⁸⁹ See, e.g., Dorothy Griffiths, Ph.D. & Yona Lunsky, Ph.D., Socio-Sexual Knowledge and Attitudes Assessment Tool-Revised (on file with author) [hereinafter Griffiths Consent Test]; see also Kennedy, supra note 81, at 354, Table 2 (identifying that the test used for the study in the paper used pictures and anatomically correct dolls).

⁹⁰ Griffiths Consent Test, *supra* note 89, at 2-3, 5-9.

⁹¹ See Interview with Bonnie Guimela, supra note 7.

⁹² Lyden, *supra* note 68, at 17.

⁹³ Kennedy, *supra* note 81, at 353; N.Y. COMP. CODES R. & REGS. tit. 14 § 633.4(a)(3) (2011) ("It is the responsibility of the agency/facility or sponsoring agency to ensure that rights [of sexuality] are not arbitrarily denied.").

⁹⁴ Interview with Bonnie Guimela, *supra* note 7 (indicating that many agencies purposefully make it very difficult to pass the assessments).

⁹⁵ See Lyden, supra note 68, at 9.

467

2012 A NATURAL NEXT-STEP

upon the agency than a true evaluation of capacity. ⁹⁶ Often, "the rights of people with intellectual disabilities have been abridged [by agencies] under the guise of protecting [other] individuals" within their care. ⁹⁷ Once an individual is deemed capable to engage in sexual conduct, the responsibility lies with the agency charged with his or her supervision should any problems, such as deviant sexual behavior, arise. ⁹⁸ Agencies tend to weigh these competing interests by showing preference for protection of others over the empowerment of sexual rights. ⁹⁹

With many people being unable to pass the consent tests, it seems as though there is a hidden agenda within this testing process. The lack of standardization and objectivity allows for significant deference to be given to the assessor and permits agencies to develop tests that are too difficult to pass. By finding each individual unable to consent, the agency can avoid extra staff training to assist those in sexual relationships and a group home may then deny making any modifications to their residences to accommodate the couple. 100 With the high risk of error in the potential hindrance of an individual's sexual rights, there is a clear need for reform in this practice. Most critics suggest standardization of the tests, or at least the creation of an objective standard on which to evaluate these cases. 101 Much of the issues that arise with the subjective assessor can be avoided by requiring that the assessor be an objective third party, working independently of a private agency, to conduct the tests. However, while some argue that consent testing is an absolute necessity, 102 consent test procedures imposed by agencies should be abolished completely because of the undue burden placed upon the right to marry. Only when a state legislature decides that consent testing should be a prerequisite to obtaining a marriage license does this practice seem ethi-

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⁹⁶ Kennedy, *supra* note 81, at 353 ("Unfortunately, there is usually no assessment completed, and decisions are made by nonprofessionals, such as direct care workers, and tend to be polarized (i.e., either ignore the activity or completely restrict all intimate activity)."); Interview with Bonnie Guimela, *supra* note 7.

⁹⁷ Lyden, *supra* note 68, at 17.

⁹⁸ See Interview with Bonnie Guimela, supra note 7.

⁹⁹ See Lyden, supra note 68, at 17.

¹⁰⁰ Interview with Bonnie Guimela, *supra* note 7.

¹⁰¹ See, e.g., Lyden, supra note 68, at 16 (suggesting a standard that would be appropriate across jurisdictions).

¹⁰² *Id.* at 9.

Vol. 28

cal.

468

One glaring problem with the practice of consent testing is the unfair burden placed on individuals seeking to engage in activities for which they have affirmative rights, including the fundamental right to marry 103 and the right of individuals with developmental disabilities to have a sexual relationship. 104 Agencies are requiring disabled individuals to demonstrate that they have the capacity to engage in such an activity while no such process exists for non-disabled individuals. As one social worker involved in the field of sexual education and consent testing elaborates:

The law does not require you to prove that you can iron, and wash clothes, and cook dinners, and balance a budget, and wash the floor before you can get married. You don't have to prove that you're competent in any of those areas, and yet that's what we're telling them. So we're not treating them like everyone else. We're singling them out and we're denying them their rights based on criteria that have nothing to do with marriage. ¹⁰⁵

However, in the likelihood that the consent testing practice will continue, there is an increased need for sexual education among the mentally disabled, particularly for those seeking to engage in sexual relationships. While this may seem like a taboo and uncomfortable topic for many, sexual activity among the disabled is unavoidable. Interestingly, "those about whom society has the greatest ambivalence with respect to sex education have the greatest need for it." Because an individual's lack of knowledge and understanding can lead to being deemed incapable, "[i]t is reasonable to presume that the persons whose sexual consent capacity is in question have an implied right to access services to assess their capacity and support

¹⁰³ See Loving v. Virginia, 388 U.S. 1, 12 (1967) (holding that the right to marry is a fundamental constitutionally protected right that may not be inhibited without a rational basis for a legitimate state interest).

See tit. 14 § 633.4(a)(4)(xi)(a) (stating that no person receiving services from the state "shall be denied . . . [the] freedom to express sexuality").

¹⁰⁵ Interview with Bonnie Guimela, *supra* note 7.

¹⁰⁶ See Munro, supra note 9.

BAROFF & OLLEY, *supra* note 3, at 290.

them in achieving capacity if identified deficiencies can be ameliorated."¹⁰⁸ It is clear, and even expected, that the empowerment of sexual rights should be fully supported by providing adequate services. Such sexual education services would be necessary on a regular basis for the occupants living in the group home proposed by this Comment.

469

III. LIVING OPTIONS FOR MARRIED COUPLES WITH DEVELOPMENTAL DISABILITIES IN NEW YORK

The right to live with one's spouse in one's preferred environment should naturally be included with the right to marry. Married couples with developmental disabilities may live together, but their options for residences in which they can cohabitate while also receiving the services they each require is lacking, to say the least.

Several options are available for unmarried individuals with developmental disabilities who are unable to live independently and require some sort of continuing home care. These options can include: living with a family member, in a state-operated institution, in a supportive residential facility (also known as a supportive apartment), or in a group home. This list, however, shrinks significantly when a married couple, requiring continuous care, seeks a residence in which they can cohabitate as a married couple. For this group, choice of residence is essentially limited to two options: living with a family member or living in a group home, assuming that the pair can find a group home that has available space and will allow them to live there. However, because the majority of group homes are operated by independent organizations, most will not welcome a married couple. 110

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Lyden, supra note 68, at 9.

¹⁰⁹ See N.Y. Comp. Codes R. & Regs. tit. 14 § 686.99(1)(2)(ii) (2011) (defining "supportive community residence" as "a facility providing independent living under variable amounts of oversight delivered in accordance with the person's needs for such supervision"). Supportive community residences, however, do not apply to the groups within the scope of this Comment, as these groups require a "supervised community residence" with a staff that typically lives within the facility and is "available at all times when the persons are present." See id. at (1)(2)(i).

 $^{^{110}}$ Interview with Bonnie Guimela, supra note 7.

Vol. 28

A. Option One: Living with a Family Member

In the care for children and adults with mental disabilities, there is an emphasis on rearing the child in the family home and delaying out-of-home placement. "Although out-of-home placement is virtually inevitable for all dependent [mentally disabled] adults."112 many choose to remain in the family home as long as possible and continue to live with their parents after leaving the public school system, typically at the age of twenty-one. While the parents of disabled children are given cash subsidies to aid with finances, providing adequate care for a person with developmental disabilities can be significantly burdensome on a family member in many ways; financially, emotionally, and in some cases, physically. 114 This is particularly true for elderly parents of adult children with severe mental and/or physical disabilities. 115 As the life expectancy of those with mental disabilities continues to rise, so too does the responsibility placed on the aging parent. 116 Parents of children with mental disabilities are often referred to as "perpetual parents" because their parental responsibilities never seem to diminish, unlike how those of parents with non-disabled children naturally do. 117 Many disabled adults will permanently require assistance with basic life skills such as bathing, dressing, and cooking, placing a significant burden on parents and family members, and particularly on those parents who do not receive family support services. 118

Parents of disabled children experience the same worries as

BAROFF & OLLEY, *supra* note 3, at 300.

¹¹² *Id*.

Janet Elder, Retarded Adults Test Autonomy, N.Y. TIMES, July 10, 1986, at C1.

Disabilities - Impact of Disabilities on Families, MARRIAGE AND FAMILY ENCYCLOPEDIA, http://family.Jrank.org/pages/396/Disabilities-Impact-Disabilities-on-Families.html (last visited Jan. 22, 2012).

¹¹⁵ See Nancy P. Kropf & Timothy B. Kelly, Stigmatized and Perpetual Parents: Older Parents Caring for Adult Children with Life-Long Disabilities, 24(1/2) J. OF GERONTOLOGICAL SOC. WORK 3, 3-4 (Jan. 1, 1995), available at http://digitalarchive.gsu.edu/cgi/viewcontent.cgi?article=1017&context=ssw_facpub.

¹¹⁶ *Id.* at 4.

¹¹⁷ *Id.* at 5.

See id.; BAROFF & OLLEY, supra note 3, at 300. Some family support services include respite care (temporary care, either within or outside of the family home, giving families the opportunity to take a break from the stresses of continuous care), parent counseling, parent training, and case management. *Id.*

471

2012 A NATURAL NEXT-STEP

all parents. 119 Nevertheless, these stressors are heightened when caring for a disabled child—because of his or her innate vulnerability and are indefinitely prolonged. 120 "Such fears can be crippling to both parents and children."¹²¹ However, when living with parents, mentally disabled individuals have a high potential for being denied the important developmental services provided by a community residential facility. 122 A dangerous result can be a lack of stimulation necessary for the growth and development of the mentally disabled adult: "Some mentally retarded people have not been stimulated in the right ways [when living with parents], and appear to be less capable than they really are." The absence of services, such as those provided by a group home, can be detrimental to the development of an individual's vocational and life skills. 124 Some say that life at home with a family member has the potential to be equally as restrictive as life in an institutional setting, resulting, in essence, in these individuals becoming a prisoner in their own homes. 125 While this may be extreme, the possible impact of these restrictions is heightened when a parent must care for a married couple that should be receiving individualized services specific to meet their needs. 126

If a couple with developmental disabilities decides to marry and a group home is an unlikely option for them, they will likely be forced to reside with a parent or family member—assuming that the parent is willing to take on the responsibility of caring for yet another disabled person. This action effectively causes every fear, anxiety, and stressor innate in caring for a person with mental disabilities to

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Elder, *supra* note 113 (including such stressors as, "fear of financial exploitation, sexual involvement, even simply not eating balanced meals").

¹²⁰ Id.

¹²¹ *Id*.

¹²² Mark C. Weber, *Home and Community-Based Services*, Olmstead, *and Positive Rights: A Preliminary Discussion*, 39 WAKE FOREST L. REV. 269, 278 (2004).

¹²³ Elder, *supra* note 113 (quoting Jim Young, whom, at the time of the interview, was the deputy executive director of the President's Commission for Mental Retardation); *see also* Weber, *supra* note 122, at 278 ("Often, parents or other caregivers are elderly and cannot provide life-enriching activities including access to recreation, habilitation training, and employment.").

¹²⁴ Weber, *supra* note 122, at 278.

¹²⁵ Id.

¹²⁶ See discussion infra Part III.B.ii.c (discussing the public policy of providing services to meet individual needs in order to allow a disabled individual to function at his or her highest level).

Vol. 28

be doubled. An attempt to then take on the responsibility of caring for yet another individual with a mental disability can seem like an incredibly overwhelming task. Because of this, a much healthier and viable option would be for a married couple to live in a group home.

B. Option Two: Group Homes

The lack of parental willingness to take on the responsibility of caring for two disabled adults naturally creates a significant reliance upon community residential facilities, commonly known as group homes. These homes are facilities that provide "housing, supplies and services for persons who are developmentally disabled and who, in addition to these basic requirements, need supportive interpersonal relationships, supervision, and training assistance in the activities of daily living." Typically, these homes are located in residential areas and house a maximum of fourteen occupants. 129 Group homes of this kind, mostly classified as "supervised community residence[s]," are fully staffed around the clock to assist residents with all of their daily functional needs. 130 These needs typically include preparing meals, bathing, bringing residents to doctor visits, shopping, and recreational activities. Most importantly, group homes seek to "provide a home environment" and have a policy of encouraging residents "to live as independently as possible." ¹³¹

1. The History of Group Homes

For a large part of America's history, the mentally disabled and mentally ill populations were segregated from society and institutionalized because of a belief that they should remain isolated due to their inadequate contribution to society. ¹³² It was not until the 1950's

¹²⁷ But cf. Monica and David (CineMia 2010). This documentary followed the lives of a two individuals with Down syndrome in their journey of beginning a life together. *Id.* The pair married and David, the new husband, moved in with his new wife's parents. *Id.* Her parents accepted David and provided adequate care for him without hesitation. *Id.*

¹²⁸ N.Y. COMP. CODES R. & REGS. tit. 14, § 686.99(1) (2011).

 $^{^{129}~}$ See N.Y. Comp. Codes R. & Regs. tit. 14, § 686.3(a)(5)(i) (2011).

¹³⁰ Id. at § 686.99(1)(2)(i).

¹³¹ *Id.* at § 686.99(1)(1)-(2).

¹³² See Richard Rapson, The Right of the Mentally Ill to Receive Treatment in the Com-

that there was a call for reform and an attempt to eliminate the stigma attached to the mentally disabled community. Prompted by exposés revealing the appalling conditions, overcrowding, and neglect of patients by American mental hospitals, the deinstitutionalization movement called for the removal of patients from state mental institutions with preference for placement in less-restrictive environments. The healthcare system for the mentally disabled underwent major changes, with reformers specifically seeking to develop new alternatives to mental hospitals and institutions, including community care. The state of the mental hospitals and institutions, including community care.

Out of this movement grew a focus on community-based care as a desirable alternative to institutional treatment. In the 1960's, the government took the position that the confinement of the mentally disabled in institutions should be a last resort. In 1963, President John F. Kennedy "proposed a bold new program for establishing community based treatment facilities," resulting in the Mental Retardation Facilities and Community Mental Health Centers Construction Act. Though the Act has since been repealed, it represented a significant step away from institutionalization, as it was the first official sign of federal commitment to creating community residence alternatives.

Another significant act of Congress was the enactment of the Home and Community-Based Services ("HCBS") Waiver Program, which provides Medicaid reimbursement to states for the purpose of funding community-based services for the developmentally disabled that states would not otherwise receive through Medicaid. The states then administer these waivers to individuals who

munity, 16 COLUM. J.L. & SOC. PROBS. 193, 198 (1980-81).

¹³³ Hortas, *supra* note 11, at 161.

Nancy K. Rhoden, *The Limits on Liberty: Deinstitutionalization, Homelessness, and Libertarian Theory*, 31 EMORY L. J. 375, 378-80 (1982).

¹³⁵ See Hortas, supra note 11, at 161.

¹³⁶ *Id*.

¹³⁷ *Id*.

¹³⁸ Rhoden, *supra* note 134, at n.14.

¹³⁹ See id.; Rapson, supra note 132, at 203.

 $^{^{140}}$ Pub. L. No. 97-35 § 2176, 95 Stat. 813 (1981) (codified as amended at 42 U.S.C. $^{1396n(c)(1)}$ (2006)).

¹⁴¹ Luana Olivas, Note, *Helping Them Rest in Peace: Confronting the Hidden Crisis Facing Aging Parents of Disabled Children*, 10 ELDER L.J. 393, 402 (2002). In order for a state

Vol. 28

have chosen community care over institutional living in order to provide them with individualized support services. With this federal incentive, many states began reorganizing their programs, further deinstitutionalizing many patients and providing them with a community-based alternative for their treatment. Particularly within the last twenty years, with the enactment of the Americans with Disabilities Act and the decision of the landmark case, *Olmstead v. L.C.*, are group homes have become an essential function of the healthcare system and the services provided for the developmentally disabled, and are now a necessary preference to institutional living.

a. The Americans with Disabilities Act and the Community Integration Mandate

In 1990, Congress enacted the Americans with Disabilities Act ("ADA") after finding that, "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem . . . in such critical areas as . . . institutionalization"¹⁴⁶ This congressional finding marked the first time that Congress expressly referred to segregation via institutionalization as a form of discrimination. ¹⁴⁷ "Institutionalization almost by definition entails segregation and isolation. Not only is segregation of the sexes prevalent, but segregation from families, normal society and peer groups is also a product of institutionalization." ¹⁴⁸

to receive these waivers, it must apply for a specific number of waiver slots and show that the cost of providing the community-based services is less than the cost of providing institutionally-based services per capita. *Id.*

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¹⁴² See Home and Community Based Services Waiver (OPWDD), N.Y. STATE DEP'T OF HEALTH, http://www.health.ny.gov/health_care/medicaid/program/longterm/omrdd.htm (last visited Feb. 17, 2012) (explaining the HCBS in New York).

¹⁴³ Brief for Respondent at *4, Olmstead v. L.C., 527 U.S. 581 (1999) (No. 98-536), 1999 WL 144128, at *4.

¹⁴⁴ 527 U.S. 581 (1999).

 $^{^{145}}$ Id. at 607 (holding that states have an affirmative obligation to provide community-based living options to those who would benefit from them as opposed to institutional living).

¹⁴⁶ 42 U.S.C. § 12101(a)(2)-(3).

¹⁴⁷ Olmstead, 527 U.S. at 589 n.1.

¹⁴⁸ Brief for Respondent, *supra* note 143, at *9.

In drafting the ADA, Congress recognized that even with the notable progress made in the area of the rights of the mentally disabled, the stigma that accompanies this handicap remains prevalent in today's society. 149 The pervasiveness of this stigma has caused isolation and substantial discrimination against those individuals with disabilities, often resulting in "outright intentional exclusion, . . . overprotective rules and policies . . . [and] segregation." Similarly, Congress asserted that the proper goals in achieving a positive view of the disabled population should be "to assure equality of opportunity, full participation, independent living, and . . . [to impose a] national mandate for the elimination of discrimination against individuals with disabilities." This has since become a pervasive theme in legislation throughout the country.

In enacting the ADA, Congress instructed the Attorney General to implement anti-discrimination regulations in order to enforce the legislation.¹⁵² The Department of Justice then implemented the "integration regulation," which requires public entities to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." ¹⁵³ However, an entity may escape making modifications to its programs "necessary to avoid discrimination on the basis of disability" if it shows that "the modifications would fundamentally alter the nature of the service, program, or activity." 154 It is clear from this instruction that Congress had the intent to hold federal and state agencies accountable for providing these vitally important integration services.

b. Olmstead: Applying the Integration Regulation

In June of 1999, the United States Supreme Court issued a

See 42 U.S.C. § 12101(a)(2)-(3), (5). In its findings, Congress officially acknowledged this stigma by stating that, "census data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally." Id. at § 12101(a)(6).

¹⁵⁰ 42 U.S.C. § 12101(a)(5).

¹⁵¹ *Id.* at § 12101(a)(8), (b)(1).

¹⁵² *Id.* at §12134(a).

¹⁵³ 28 C.F.R. § 35.130(d) (emphasis added).

¹⁵⁴ *Id.* at § 35.130(b)(7).

landmark decision, in Olmstead v. L.C., involving two mentally disabled women that were voluntarily admitted to a psychiatric hospital. 155 The plaintiffs sought removal from institutional living after an evaluation determining that each would benefit from a communitybased setting under the ADA. 156 Despite having received this evaluation, both reluctantly remained institutionalized and challenged their "continued confinement in a segregated environment," maintaining that the State's refusal to allow them to move to an integrated community-based setting violated their rights under Title II of the ADA. 157

The Court held that a State's confinement of individuals with disabilities to institutions when a community-based setting would be more appropriate (what the Court refers to as "unjustified isolation") constitutes discrimination based upon disability and, therefore, violates Title II of the ADA. 158 Additionally, the Court held that states are required to make reasonable modifications to their services unless it would fundamentally alter the state's delivery and implementation of its services and programs, 159 reinforcing the Department of Justice's enforcement of the ADA. In evaluating whether a state may use this defense, a court may take into account "the resources available to the State and the needs of others with mental disabilities." ¹⁶⁰ This holding thereby gave states an affirmative obligation to provide treatment in a community setting when such a setting is deemed more appropriate and within reason. 161

In its reasoning, the Court stated that this holding emphasizes two important principles: "First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life [and] . . . [s]econd, confinement in an institution severely diminishes the everyday life ac-

476

https://digitalcommons.tourolaw.edu/lawreview/vol28/iss2/7

26

TOURO LAW REVIEW

Vol. 28

⁵²⁷ U.S. at 593.

¹⁵⁶ *Id*.

¹⁵⁷ Id. at 593-94.

¹⁵⁹ *Id.* at 603-04. This defense cannot be established by mere cost, and must instead create an "undue hardship" upon the state in order for its compliance with the mandate. Olmstead, 527 U.S. at 606 n.16.

¹⁶⁰ *Id.* at 607.

¹⁶¹ *Id*.

tivities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." ¹⁶² In keeping with the goals enumerated in the ADA, the Court continued to place a focus on promoting the independence and social wellbeing of the mentally disabled.

After *Olmstead*, a call for significant change extended to state legislatures in an attempt to comply with the Court's community integration mandate; however, the response was, and continues to be slow. 163 With the increased demand for group homes and other residential facilities, already lengthy waiting lists for group homes continued to grow, causing a housing crisis that is still felt today. 164 This is due, in large part, to a lack of guidance and clarity in which state changes will "cross the line from reasonable modification to fundamental alteration, when a waiting list is moving at a reasonable pace, or what constitutes an effectively working plan." ¹⁶⁵ By using the fundamental alteration defense, states have been able to skirt some responsibility in making modifications. Unfortunately, "[1]ower courts have generally decided that evidence of states' active commitment, yet slow progress towards community integration, satisfies the ADA," which in effect supports, rather than sanctions a state's reluctance to change. 166

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27

Id. at 600-01.

On the fifth anniversary of the Olmstead decision, the director of the Bazelon Center for Mental Health Law stated, "[m]ost states are enacting reforms at a snail's pace, defying the spirit of the ruling and preventing Americans with mental illnesses from participating in their communities . . . these [limited efforts] have produced little actual movement of people . . . into integrated community settings." Legal Advocate Cites Ongoing Segregation on Eve of Olmstead Anniversary, BAZELON CENTER FOR MENTAL HEALTH LAW (June 21, 2004), http://bazelon.org.gravitatehosting.com/LinkClick.aspx?fileticket=bRBHCViwpf4%3d&tabi d=328.

¹⁶⁴ See The Housing Crisis for New Yorkers with Disabilities, NEW YORK STATE (Nov. DEPARTMENT OF HEALTH 17. http://www.health.ny.gov/health_care/medicaid/redesign/docs/miller_nyail_barriers_to_aai_ housing.pdf (finding that there is very limited housing available to people with disabilities, keeping them from living independently, and resulting in "22,248 New Yorkers living in nursing facilities who have indicated they wish to return to the community").

¹⁶⁵ Samantha A. DiPolito, Deinstitutionalization and Community Integration: An Awakening of the Nation's Conscience?, 58 MERCER L. REV. 1381, 1399 (2007).

Vol. 28

2. How Group Homes Operate

Most group homes are not operated by the State, but instead are typically developed, owned, and managed by authorized providers—usually private agencies that receive state funding. Regardless of their private status, group homes must function within the overarching guidelines enumerated by the state agency given the authority to enact such guidelines by the state legislature. 168

a. Funding

States have traditionally received federal funding for the purpose of operating institutions. 169 However, in 1981, Congress enacted the Home and Community Based Services ("HCBS") Waiver Program, which "allows [a] state to utilize a portion of its Medicaid funds, which would have been for institutional use, to provide community-based services instead."¹⁷⁰ To obtain a waiver, the State must show that the funds will go to community-based treatment for those who would otherwise need institutional care, and that the cost of those community services will not exceed the annual cost of the institution-based services.¹⁷¹ However, this waiver program is optional and it is within the State's discretion to determine the ways in which it will use its federal funding. 172 Additionally, "when individuals with developmental disabilities move from an institution into the community, federal law allows them to take with them the dollars used for their care in the institution. Thus, the 'money follows the person' through the transition." 173 Moreover, under *Olmstead*, in order for the State to use federal funding for community-based pro-

¹⁶⁷ See generally N.Y. COMP. CODES R. & REGS. tit. 14, § 671.99(t) (2012) (defining an authorized provider as "[a]n incorporated or State government entity, holding a facility-specific operating certificate from [OPWDD] . . . to deliver community residential habilitation services").

¹⁶⁸ See generally N.Y. MENTAL HYG. LAW 13.07(a), (c) (McKinney 2011) (giving OPWDD the authority to develop programs and provide housing for people with developmental disabilities).

¹⁶⁹ Olivias, *supra* note 141, at 401.

¹⁷⁰ DiPolito, *supra* note 165, at 1402.

¹⁷¹ Id

¹⁷² *Id*.

¹⁷³ *Id*.

479

2012 A NATURAL NEXT-STEP

grams—while remaining in accordance with ADA mandates requiring that reasonable modifications be made—a State may "demonstrate that it ha[s] a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that move[s] at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated" 174

In New York, OPWDD has the responsibility of developing effective services for the developmentally disabled by adopting rules and regulations necessary to implement the delivery of these services to the mentally handicapped population. 175 OPWDD relies upon other agencies from the public and private sectors, including non-profit and for-profit organizations, to carry out community-based programs and establish residential facilities for the developmentally disabled. 176 When a private agency opens a group home, the start-up funding and daily costs initially come from private entities, giving each group home the ability to create its own guidelines for the home's operation, so long as those guidelines satisfy the general requirements enumerated by OPWDD.¹⁷⁷ In order to receive funding from OPWDD, the provider must be authorized and certified by OPWDD and have a qualified staff. 178 In addition to the administrative requirements, the group home must also sufficiently show that its services promote each of the four goals listed in the statute: independence, integration, individualization, and productivity. 179

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¹⁷⁴ Olmstead, 527 U.S. at 605-06.

¹⁷⁵ N.Y. MENTAL HYG. LAW 13.07(a) (McKinney 2011) (conferring authority upon OPWDD to "assure development of comprehensive plans, programs, and services . . . [for] individuals with developmental disabilities").

¹⁷⁶ See Frequently Asked Questions, NYS OFFICE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES, http://www.opwdd.ny.gov/hp_faqs.jsp (last modified June 17, 2011).

¹⁷⁷ See generally N.Y. COMP. CODES R. & REGS. tit. 14 § 686.2(a) (2012) (stating that the guidelines enumerated by OPWDD "set forth the specific minimum requirements with which a facility . . . in the community residence . . . class, certified by [OPWDD], shall comply").

¹⁷⁸ N.Y. COMP. CODES R. & REGS. tit. 14 § 671.4(a)(1)(i)-(ii) (2012).

¹⁷⁹ N.Y. Comp. Codes R. & Regs. tit. 14 § 671.6(a)(6)(ii)(a)-(d) (2012).

Vol. 28

b. OPWDD Regulations for Group Homes in New York

OPWDD "set[s] forth specific *minimum* requirements with which a facility . . . in the community residence . . . class, certified by [OPWDD], shall comply." While there are several regulations with what seems like a lot of language, there are only a few basic requirements. An authorized provider (public, private, and state agencies) must obtain, and continue to maintain, a certificate of operation from OPWDD, regardless of whether that entity is receiving, or plans to receive, funding from the State. In order to maintain its certificate of operation, an authorized provider will not be subject to regular inspection; however, OPWDD reserves the right to survey the facility at any time. Additionally, staff must be qualified and, in a supervised community residence, must be available at all times while residents are present. Is

Many of the OPWDD regulations provide general guidelines for the start-up and operation of a group home, as well as administrative requirements and remedies. By establishing only minimum requirements, there is significant deference given to the private agencies to develop their own regulations. However, group home staff members and care providers are also tasked with affirming the rights of persons receiving services, such as being provided with a safe and sanitary environment, having an individualized plan of services, ¹⁸⁴ and freedom from unnecessary restraint or medication. ¹⁸⁵ Also included in these rights is the access to sexual instruction and family planning services, which necessarily encompasses the "freedom to express sexuality" and "make decisions regarding conception." ¹⁸⁶ Unfortunately, this right is statutorily limited by the competing right

¹⁸⁰ tit. 14 § 686.2(a) (emphasis added).

¹⁸¹ *Id.* at (e).

¹⁸² *Id.* at (e)(2).

tit. 14 § 671.4(a)(1)(ii); N.Y. COMP. CODES R. & REGS. tit. 14 686.9(a)(4) (2012).

Persons with disabilities living in residential facilities must have a written and individualized treatment plan with the goal of "maximization of the person's abilities to cope with his or her environment, foster[] social competency . . . [and] enable[] him or her to live as independently as possible." tit. $14 \S 633.4(a)(4)(viii)$.

 $^{^{185}}$ *Id.* at (a)(4)(i), (iv)-(v), (viii).

¹⁸⁶ *Id.* at (a)(4)(xi)(a)-(b).

of facilities enabling the entity to limit sexual expression in order to maintain proper management of the group home. 187

Even with this limitation on sexual expression, there are no statutory roadblocks that would prevent a married couple from living in a group home, nor are there any statutory references to the denial of a group home specifically for married couples. The only opposition to the development of this type of group home would essentially have to be generated by the independent agencies using their professional judgment to deny its creation.

c. Policy of Individualized Treatment and Maximum Independence

One goal of community integration is to administer services in the least restrictive environment: an environment that "permits the greatest degree of independence consistent with one's decisionmaking capacity." The key in implementing this goal is to find a balance between independence and control. 189 Many agencies choose to promote independence through "normalization," a practice that "seeks to reduce the 'differentness' associated with disability and to promote personal competence such that the disabled individual can live a life that more nearly approximates that of his or her nondisabled counterpart." With special attention given to the means and contexts of the services provided, the goal is to improve that person's quality of life, promote independence, and encourage personal autonomy by allowing the individual to exercise greater freedom of choice. 191 With this type of person-centered planning, "there is a concerted effort to build the service around the person's wishes" In this context, "[s]upport means not only honoring choices but *enabling* them" ¹⁹³ A person-centered program will attempt to encourage normal life and tailor services around the individual's specif-

¹⁸⁷ *Id.* at (a)(4)(xi)(c).

¹⁸⁸ BAROFF & OLLEY, *supra* note 3, at 246.

¹⁸⁹ Id

¹⁹⁰ *Id.* at 252.

¹⁹¹ *Id*.

¹⁹² *Id.* at 254.

BAROFF & OLLEY, *supra* note 3, at 254.

Vol. 28

ic needs. 194 Additionally, there is a focus on "shift[ing] the emphasis away from the person's disabilities and toward [his or her] capabilities." 195

In its regulations, OPWDD has a clear policy of focusing on services that will "promote and encourage . . . independence, integration, individualization, and productivity." With an intent to create a family atmosphere that most resembles a home for its residents, the main goal in the group home setting is for each individual to feel comfortable in his or her new living situation in order to promote an atmosphere of growth and self-development. One method of reaching this goal is through the creation of a specific individualized service plan for each resident. While such a plan may typically deal with medical care for the disabled individual, it will also necessarily include any other services and programs essential to his or her development.

With a policy of creating an individualized plan, it should logically follow that living environments be modified to create an optimal living situation for each individual. For a person seeking to marry and live with his or her spouse in a group home setting, a group home exclusively for married residents is likely an ideal living situation. Not only will it furnish an appropriate setting in which to provide individualized services, such as sexual education and relationship training, but it will also promote the sense of autonomy that each group home strives to achieve for each of its residents. By requiring group homes to operate with these personalized policies in mind, the OPWDD regulations can even be seen to require that this type of group home be made available to this distinct group of people simply because they request it.

¹⁹⁴ *Id.* at 255.

¹⁹⁵ *Id*.

¹⁹⁶ N.Y. Comp. Codes R. & Regs. tit. 14, § 671.5(a)(3) (2011). The State wants residents to strive to become autonomous by asserting their values: "activities . . . which promote the person's ability to assess and utilize his or her strengths and capacity to make life status changes and to increase self-awareness about his or her values and preferences. *Id.* at (a)(4)(vi).

¹⁹⁷ See N.Y. COMP. CODES R. & REGS. tit. 14 § 633.4(a)(4)(viii).

483

2012 A NATURAL NEXT-STEP

IV. LIKELY ARGUMENTS AGAINST A GROUP HOME FOR MARRIED COUPLES

A. The Fundamental Alteration Defense

When evaluating whether to develop a new group home, such as the one proposed in this Comment, the State or the private agency¹⁹⁸ will attempt to argue that the requested accommodations will amount to a fundamental modification in the State's services and programs.¹⁹⁹ Initially, the State and/or agency will do a cost-benefit analysis,²⁰⁰ and likely conclude that the costs of hiring new employees, training, and potentially constructing a new building for the home will outweigh the benefits for the individuals seeking this living accommodation.²⁰¹

The State's responsibility to accommodate individuals with appropriate community-based care is not without limits. To avoid implementing a modification, the State may show that the modification is unreasonable because it would create a "fundamental alteration" to the State's services and programs. In *Olmstead*, the Court acknowledged that a fundamental alteration under the ADA should be interpreted pursuant to previous readings of section 504 of the Rehabilitation Act of 1976, which includes the defense of undue hardship. Under this section, evaluation of an undue hardship requires more than a mere assessment of the program's projected cost in relation to the state's total budget. It also requires a:

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¹⁹⁸ For the purpose of this Comment, it should be assumed that a private agency will be subjected to the same regulations as the State because it carries out a public function that is historically an exclusive function of the government, as required for state action under the Due Process Clause of the Fourteenth Amendment. *See generally* Flagg Brothers v. Brooks, 436 U.S. 149, 158 (1978).

¹⁹⁹ See Olmstead, 527 U.S. at 603.

²⁰⁰ See id. at 597 (requiring that the State "not only [review] 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").

²⁰¹ See Interview with Bonnie Guimela, supra note 7.

²⁰² Olmstead, 527 U.S. at 603.

²⁰³ Id

²⁰⁴ 29 U.S.C § 794 (1994).

²⁰⁵ Olmstead, 527 U.S. at 606 n.16.

²⁰⁶ Id

Vol. 28

case-by-case analysis weighing factors that include: (1) [t]he overall size of the recipient's program with respect to number of employees, number and type of facilities, and size of budget; (2) [t]he type of the recipient's operation, including the composition and structure of the recipient's workforce; and (3) [t]he nature and cost of the accommodation needed.²⁰⁷

Additionally, the State has the burden of showing that the requested accommodation "would be inequitable in light of available resources and the State's responsibility to care for a large and diverse population of other persons with disabilities as well as the State's responsibility to provide services in an equitable manner." Furthermore, cases relied upon by Congress in enacting the ADA hold that cost defenses may only outweigh ADA duties when the cost is *substantially* higher than the projected benefits. ²⁰⁹

Here, it is unlikely that the projected costs of providing a small number of these group homes would outweigh the potential benefits to the residents. While hiring and training will certainly be required, it is doubtful that there will be a high demand for several of these group homes within the state due to the rarity of married couples with mental disabilities. This requires only a limited number of homes to be developed. Furthermore, the individuals that would be living in the group home would all be entitled to community-based care and would inevitably require out-of-home placement, therefore already necessitating the hiring of new employees and additional training. The most significant cost would be the actual construction of the group home or renovation of a current structure in order to accommodate the unique living arrangements required by a married couple. However, it is difficult to see how this cost will outweigh the benefits of autonomy, independence, and individualized services that each resident will receive. Even if the cost is determined to outweigh the benefits, it is unlikely that it will meet the lofty threshold as to substantially outweigh the benefits.

²⁰⁷ Id.

²⁰⁸ DiPolito, *supra* note 165, at 1396.

²⁰⁹ Weber, *supra* note 122, at 288.

B. Liability for Improper Sexual Behavior

The State or agency operating a group home has the often-conflicting responsibilities of protecting those within its care from harm, while also promoting the sexual expression of its residents. As a result, the State and/or agency may attempt to rely on its ability to limit a resident's sexual expression when it conflicts with the proper management of the home. This reaction would likely be based upon some fear of the potential for sexual aggression and sexually deviant behavior. However, such a fear is unfounded and based upon an assumption that a person capable of consenting to sexual activity will become a sexual deviant, putting other residents of the group home in danger.

This belief is reminiscent of the Eugenics Era, when the public viewed "the mentally retarded as criminally oriented and sexually promiscuous." This is precisely the viewpoint that Congress and state legislatures have been trying to wipe clean from society's palette. Additionally, "there is no indication of an increased frequency of sexual offenses in retarded youth relative to their non-handicapped counterparts." In fact, several studies have found that married mentally disabled individuals are generally happier and have fewer social and personal problems, such as breaking the law and issues with substance abuse. Furthermore, it is even less likely that a married person in a group home will develop sexual aggression due to the fact that he or she has already demonstrated an understanding

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485

²¹⁰ Lynden, *supra* note 68, at 17.

²¹¹ See N.Y. COMP. CODES R. & REGS. tit. 14, 633.4 (a)(4)(xi)(c).

²¹² See Elizabeth J. Reed, Note, Criminal Law and the Capacity of Mentally Retarded Persons to Consent to Sexual Activity, 83 VA. L. REV. 799, 806 ("Retarded individuals are believed to be at greater risk of being sexually abused, especially in institutional settings, making it difficult [for the State] to grant them too much sexual autonomy for fear of abuse.").

²¹³ See Interview with Bonnie Guimela, *supra* note 59 (discussing the potential for sexual misconduct in a group home setting, but stating that this is not plausible here because of the nature of the marital relationship).

²¹⁴ Reed, *supra* note 212, at 803.

²¹⁵ BAROFF & OLLEY, *supra* note 3, at 292. In 1996, Baroff and Olley conducted a study of North Carolina adult prison inmates. *Id.* Only two percent of the mentally disabled adults that were imprisoned were charged with sexual offenses, which is approximately the same percentage as the nondisabled population. *Id.*

See Munro, supra note 9.

Vol. 28

of sexual activity and of the sanctity of marriage, having been deemed capable to give consent.

The argument that individuals able to consent to sexual relationships will cause a danger within the group home is surprising, to say the least, because of the contradiction it presents. Many group homes have both male and female residents. ²¹⁷ Is there not the same danger in those group homes as there would be for having married couples living in a group home together? In fact, it can be argued that the danger is even greater in a home with unmarried individuals, because they likely have not been determined to have capacity to engage in sexual relationships, and are therefore less likely to have had any formal sexual education training. Even with this clear danger, the State and private agencies still made the decision to open the group home to opposite sex residents. What exactly is stopping them with a group home for married couples?

V. CONCLUSION

486

Treatment of the developmentally disabled has improved significantly throughout American history. With a new outlook geared towards promoting independence and cultivating individual needs, Congress and state legislatures have taken pro-active steps to improve the quality of life for the disabled population. While marriage statutes may still reek of eugenics ideals, mentally disabled couples have become more prevalent and marriage has become a more accepted notion. ²¹⁸

With the ultimate goals of normalization, improving quality of life, and empowering autonomy while providing a family-like setting, a group home exclusively for married couples with developmental disabilities seems like the natural next-step in the progression of rights and services provided for this population. The benefit of the creation of such a group home will far outweigh any financial burden it may impose on the state or private agency. Additionally, with New York's focus on personalizing services and developing individualized plans, it makes logical sense to provide what seems like the most personal accommodation available. These OPWDD regulations can

²¹⁷ Interview with Bonnie Guimela, *supra* note 7.

²¹⁸ See Munro, supra note 9.

487

even be read as to require that this accommodation be provided for this small group of people, simply because they are requesting it.

Unfortunately, the general public may not receive the proposition made in this Comment well, because of its somewhat taboo nature. However, there are no group homes of this kind in the country, and any state or agency that may decide to develop such a group home will be on the forefront of the expansion of civil rights for the developmentally disabled, potentially creating a national trend. Hopefully, the future will bring even more empowering change for this group of people in need of a particular service, so that they too can have the "normal" lives we all take for granted.