Saint Louis University Journal of Health Law & Policy

Volume 14 Issue 2 Health Equity and Justice Challenges of the COVID-19 Pandemic

Article 17

2021

Rights Not Fundamental: Disability and the Right to Marry

Gabriella Garbero

Follow this and additional works at: https://scholarship.law.slu.edu/jhlp

Part of the Health Law and Policy Commons

Recommended Citation

Gabriella Garbero, Rights Not Fundamental: Disability and the Right to Marry, 14 St. Louis U. J. Health L. & Pol'y (2021).

Available at: https://scholarship.law.slu.edu/jhlp/vol14/iss2/17

This Student Comment is brought to you for free and open access by Scholarship Commons. It has been accepted for inclusion in Saint Louis University Journal of Health Law & Policy by an authorized editor of Scholarship Commons. For more information, please contact Susie Lee.

ABSTRACT

Disabled people have long been systematically excluded from marriage, despite its personal, religious, cultural, and symbolic importance, and despite it being treated as a fundamental right in other contexts. This exclusion has been perpetuated by arcane laws that require Social Security and Medicaid beneficiaries to include their spouse's income and assets in eligibility calculations. Since eligibility is contingent upon very little income and very few assets, couples who marry and intend to keep benefits are forced to live far below the poverty line in order to meet income and asset criteria, and many people are unable to make such a serious financial sacrifice. As a result, disabled people who are dependent on benefits are often forced to choose between a long-term relationship and needed health care services that are exclusively offered by Medicaid. This disability marriage penalty runs afoul of both disability rights and marriage policies that assure, on one hand, that presence of a disability does not preclude a person from enjoying full rights to inclusion in the United States, and on the other, that marriage is a fundamental right that should not be curtailed for most reasons related to identity. Partial solutions to the disability marriage penalty have been proposed and, in some cases, implemented, but no complete solution yet exists. However, there is some promise that the Biden administration and Congress as it currently stands will begin to take legislative or executive action to abolish this outdated penalty and finally allow people with disabilities the freedom to marry without fear of losing the benefits that enable their continued independence and survival.

I. INTRODUCTION

Imagine that you have to choose between two paths in life. The first path includes a happy marriage to someone you love, but your life is shortened by a health condition that you need special tools to manage, and those tools are out of reach. The second path gives you those tools, but the path is long and lonely, and you will never be allowed to create a home with someone you love. For many disabled people who are dependent on public benefits, this choice is anything but hypothetical.

Medicaid is the only public health care program that provides necessary tools for survival for many disabled people in the United States.¹ It is the only government program that pays for long-term nursing care and other benefits like personal care attendants, certain medications, durable medical equipment, and transportation to medical appointments.² It provides critical benefits for ten million disabled people.³ In many states, a person is automatically eligible for Medicaid if they receive Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI), though states may impose additional standards.⁴

Twelve million disabled Americans receive SSI or SSDI, and most have no other major source of income.⁵ Eligibility for either program is contingent on a very low income and very few assets.⁶ Although income limits vary widely by state, most states impose an asset limit of \$2000 for individuals and \$3000 for couples, figures that have not changed since 1989 and do not adjust for inflation.⁷ When counting income and assets for disability benefits, regulations explicitly state that the Social Security Administration (SSA) "expect[s the non-disabled] spouse to use some of his or her income to take care of some of [the disabled spouse's] needs."⁸ As a result of the financially demanding eligibility

588

^{1.} E.g., Carly Stern, Forced to Divorce: Americans with Disabilities Must Pick Marriage or Health Care, OZY (Apr. 24, 2019), https://www.ozy.com/the-new-and-the-next/forced-to-divorce-americans-with-disabilities-must-pick-marriage-or-health-care/92284 [https://perma.cc/7S5Q-9A 72].

^{2.} Julia M. Hargraves, *Financing Long-Term Care in Missouri: Limits and Changes in the Wake of the Deficit Reduction Act of 2005*, 73 MO. L. REV. 839, 841 (2008); B.J. Stasio, *People with Disabilities and the Federal Marriage Penalties*, IMPACT (Spring/Summer 2010), https://publications.ici.umn.edu/impact/23-2/people-with-disabilities-and-the-federal-marriage-penalties.

^{3.} People with Disabilities, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, https://www.macpac.gov/subtopic/people-with-disabilities/ (last visited Feb. 24, 2020) [https://per ma.cc/44XR-C4V2].

^{4.} SHAWN FREMSTAD & REBECCA VALLAS, CTR. FOR AM. PROGRESS, THE FACTS ON SOCIAL SECURITY DISABILITY INSURANCE AND SUPPLEMENTAL SECURITY INCOME FOR WORKERS WITH DISABILITIES 2 (2013).

^{5.} Id. at 1, 2.

^{6.} Supplemental Security Income (SSI) Marriage Penalty, DISABILITY RTS. N.C. 1 (2015), https://disabilityrightsnc.org/wp-content/uploads/2018/05/SSI-Marriage-Penalty.pdf.

^{7.} FREMSTAD & VALLAS, supra note 4, at 8-9.

^{8. 20} C.F.R. § 416.1160(a)(1) (2005).

criteria, marriage to or by a disabled person is a financial undertaking that is impossible for many to endure. If parties do get married, they face a severe penalty that can result in significant financial loss and, potentially, a catastrophic loss of health care coverage.⁹ Additionally, if an unmarried couple lives together and is judged to be "holding out" in order to keep benefits while pooling resources, the couple is treated as if they are married, and they still face a penalty.¹⁰

The disability marriage penalty defies the assurance of the Americans with Disabilities Act (ADA) that "physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society."¹¹ American society highly values marriage, as evidenced by decades of policy attention and legal significance. American legal policy lauds marriage as "the relationship that is the foundation of the family in our society" and affords it many benefits and protections.¹² Likewise, Article 16 of the Universal Declaration of Human Rights asserts that "[m]en and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family."¹³ Despite these legal and policy declarations, many disabled people are effectively deprived of those rights.

No complete solution to the disability marriage penalty currently exists. However, some partial solutions, like voluntary impoverishment, civil unions, and spousal refusal, have come from elder law.¹⁴ In addition, the proposed Supplemental Security Income Restoration Act of 2019 was a promising solution, and President Joe Biden made a campaign promise when running for President in 2020 to "[r]eform the SSI program so that it doesn't limit beneficiaries' freedom to marry, save, or live where they choose."¹⁵ However, there has not been significant scholarship on this topic from the disability law

^{9.} Rabia Belt, *Disability: The Last Marriage Equality Frontier* 2 (Stan. Pub. L., Working Paper No. 2653117, 2015), https://ssrn.com/abstract=2653117.

^{10.} *Id*.

^{11. 42} U.S.C. § 12101(a)(1). For an excellent explanation of the disability marriage penalty and a concise argument in favor of abolishing it, see Andrew Pulrang, *A Simple Fix for One of Disabled People's Most Persistent, Pointless Injustices*, FORBES (Aug. 31, 2020, 2:04 PM), https://www.forbes.com/sites/andrewpulrang/2020/08/31/a-simple-fix-for-one-of-disabled-peoples-most-persistent-pointless-injustices/?sh=152abc886b71.

^{12.} Obergefell v. Hodges, 576 U.S. 644, 666 (2015).

^{13.} G.A. Res. 217 (III) A, Universal Declaration of Human Rights (Dec. 10, 1948).

^{14.} See John A. Miller, Voluntary Impoverishment to Obtain Government Benefits, 13 CORNELL J.L. & PUB. POL'Y 81, 81 (2003); Heidi L. Brady & Robin Fretwell Wilson, The Precarious Status of Domestic Partnerships for the Elderly in a Post-Obergefell World, 24 ELDER L.J. 49, 51 (2016); LAWRENCE A. FROLIK & MELISSA C. BROWN, ADVISING THE ELDERLY OR DISABLED CLIENT ¶ 14.03[3][c] (2019), Westlaw.

^{15.} Supplemental Security Income Restoration Act of 2019, H.R. 4280, 116th Cong. § 2 (2019); *The Biden Plan for Full Participation and Equality for People with Disabilities*, JOE BIDEN, https://joebiden.com/disabilities/ (last visited Feb. 17, 2021) [hereinafter *The Biden Plan*].

perspective, and existing solutions lack the perspective of disabled people who would be most affected by new policies.

Nevertheless, a solution to the disability marriage penalty is possible and would likely involve a patchwork of partial solutions from other areas of law. Part II of this Article explores two foundational issues: (1) the importance of acquiring and keeping disability benefits for those who need them, and (2) marriage as a highly valued policy priority in the United States. Part III examines the parallel development of marriage equality and disability rights and then joins both histories in a discussion of disability marriage rights and the origins of the disability marriage penalty. Part IV is a discussion of existing solutions from other areas of law and how these solutions may apply to the disability marriage penalty. Part V analyzes recent direct solutions, like the Supplemental Security Income Restoration Act and President Biden's campaign promise to eliminate the disability marriage penalty. It also offers a set of principles that must inform any new solution.

II. FACTUAL BACKGROUND

At the heart of the disability marriage penalty lay two important values that have been thrust into unnecessary conflict: the need for health care and the cultural and social significance of marriage. Disability rights activists have long stressed the necessity of and need for Medicaid,¹⁶ as it is often the only program that offers important health-related supports for disabled people.¹⁷ On the other hand, modern sociologists have recognized marriage as a health-promoting institution and American federal policies have enforced its importance.¹⁸ The forced conflict between health care and marriage is one major reason that the disability marriage penalty should be repealed.

A. Disability and the Need for Medicaid

Medicaid is a federal insurance program designed to address the unique health care needs of the aged, blind, and disabled.¹⁹ As the primary taxpayerfunded program for long-term care and the only government program that pays for long-term nursing care, Medicaid provides critical benefits for ten million

^{16.} See, e.g., Alice Wong, My Medicaid, My Life, N.Y. TIMES (May 3, 2017), https://www.ny times.com/2017/05/03/opinion/my-medicaid-my-life.html [perma.cc/97WT-BHZF].

^{17.} See Stern, supra note 1.

^{18.} Debra Umberson & Jennifer Karas Montez, Social Relationships and Health: A Flashpoint for Health Policy, 51(S) J. HEALTH & SOC. BEHAV. S54, S59 (2010). See generally Linda C. McClain, Federal Family Policy and Family Values from Clinton to Obama, 1992-2012 and Beyond, 2013 MICH. ST. L. REV. 1621, 1661 (2013).

^{19.} JULIA PARADISE ET AL., KAISER COMM'N ON MEDICAID & THE UNINSURED, MEDICAID AT 50, at 1 (May 2015).

disabled people in America.²⁰ Benefits include personal care attendants, medications, durable medical equipment, and transportation to medical appointments.²¹ For many disabled people, the loss of Medicaid can be "devastating, life changing, and even life threatening."²² Disabled activist and blogger Dominick Evans elaborated:

I would lose home healthcare services, which pay for personal care attendants to come into my home and get me out of bed, get me dressed, help me to take a bath, give me my medication, eat my meals, and pretty much any other activity of daily living. Without these services, I would end up stuck in bed.²³

For many Medicaid recipients like Dominick, losing Medicaid is not an option.

1. Eligibility for Medicaid Through SSI and SSDI

Medicaid eligibility in most states is tied to SSI or SSDI, and some states impose additional requirements.²⁴ Eligibility requirements for SSI and SSDI assure that it is the "income source of last resort" for disabled people, requiring beneficiaries to exhaust all other resources before qualifying.²⁵ SSI also imposes strict asset limits—\$2000 for an individual and \$3000 for a couple—that force beneficiaries to remain in poverty, preventing them from establishing enough of a savings to, for example, pay for unforeseen expenses like home repairs.²⁶ Some resources, however, are exempt from asset calculations, including a life insurance policy worth less than \$1500, a burial plot, a wedding and engagement ring, a car worth less than \$4500, and "property which is so essential to the patient's support that it warrants exclusion."²⁷ Though this may provide some breathing room for those who can invest in a protected asset like a house, a national housing study from 2007 found that the average rent for a studio or efficiency apartment was more than the maximum SSI monthly benefit.²⁸ Thus,

^{20.} Michael Farley, When "I Do" Becomes "I Don't": Eliminating the Divorce Loophole to Medicaid Eligibility, 9 ELDER L.J. 27, 29 (2001); Hargraves, supra note 2, at 839; People with Disabilities, supra note 3.

^{21.} Stasio, supra note 2.

^{22.} Id.

Dominick Evans, *Disabled People Penalized for Getting Married*, AUDACITY MAG. (Jan.
 2019), https://www.audacitymagazine.com/disabled-people-penalized-for-getting-married/ [https://perma.cc/A8FP-M2WM].

^{24.} *Eligibility*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/eligibility/index.html (last visited Mar. 5, 2021) [https://perma.cc/4RF4-W6SW].

^{25.} Richard Balkus & Susan Wilschke, *Treatment of Married Couples in the SSI Program*, SOC. SEC. ADMIN. 1 (Dec. 2003), https://www.ssa.gov/policy/docs/issuepapers/ip2003-01.pdf.

^{26.} FREMSTAD & VALLAS, *supra* note 4, at 8–9.

^{27.} Farley, supra note 20, at 34.

^{28.} Supplemental Security Income (SSI) Marriage Penalty, supra note 6, at 2.

even if a beneficiary wishes to invest in a protected resource, they are often priced out from doing so.

As a result of harsh income requirements, SSI and SSDI beneficiaries are rarely able to maintain a standard of living comparable to those living above subsistence-level.²⁹ A survey from 2015 found that median earnings for nondisabled people was over \$30,469 per year, which is nearly 150% the median for disabled people (\$20,250 per year).³⁰ SSDI typically replaces less than half of a beneficiary's earnings from before they became disabled.³¹ If a person receiving SSI can work at all, any earned income beyond a very small threshold (\$65 per month in 2019) creates a dollar-for-dollar decrease in SSI, effectively taxing earned income by 50%.³² As a result of these factors, many disabled people receiving either benefit have a low standard of living that they are unable to increase by working. Since one in four American adults identifies as disabled, this means a quarter of the population has a much higher chance of experiencing significant economic hardship than the rest of the population.³³

2. The Impact of Marriage on Eligibility for SSI and SSDI

Contemplating these options and limitations, one may consider sharing expenses and pooling resources by getting married or living with another person. However, in dealing with complicated eligibility rules, a beneficiary may struggle to calculate how a marriage (actual or perceived) would impact their benefits.³⁴ Furthermore, administrators and support workers can commit errors that affect beneficiaries' continued eligibility, sometimes by giving bad advice and sometimes by giving no advice at all.³⁵ Simply searching "disability marriage penalty" on the internet results in dozens of questions from and stories about disabled people who were unaware of the disability marriage penalty before getting engaged and were forced to postpone their wedding, cancel their

^{29.} FREMSTAD & VALLAS, supra note 4.

^{30.} Disability & Socioeconomic Status, AM. PSYCH. ASS'N, https://www.apa.org/pi/ses/re sources/publications/factsheet-disability.pdf (last visited Mar. 5, 2021) [https://perma.cc/GKA5-CAD7].

^{31.} Id.

^{32.} See, e.g., Understanding Supplemental Security Income SSI Income, SOC. SEC. ADMIN. (2020), https://www.ssa.gov/ssi/text-income-ussi.htm [https://perma.cc/4Y2Q-ZLZY].

^{33.} Debra L. Brucker et al., More Likely to Be Poor Whatever the Measure: Working-Age Persons with Disabilities in the United States, 96 Soc. Sci, Q. 273, 287 (2015); Catherine A. Okoro et al., Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults — United States, 2016, 67 MORBIDITY & MORTALITY WKLY. REP. 882, 882 (Aug. 17, 2018); FREMSTAD & VALLAS, supra note 4, at 1.

^{34.} W. BRADFORD WILCOX ET AL., INST. FOR FAM. STUD., MARRIAGE, PENALIZED: DOES SOCIAL-WELFARE POLICY AFFECT FAMILY FORMATION? 1, 16 (2016).

^{35.} David C. Stapleton et al., *Dismantling the Poverty Trap: Disability Policy for the Twenty-First Century*, 84 MILBANK Q. 701, 714 (2006).

wedding, or even break up upon realizing that marriage would lead to financial ruin for them and their potential spouse.³⁶

Both SSI and SSDI beneficiaries are penalized if they choose to marry. When a person receives the Childhood Disability Benefit (CDB)—a type of SSDI for those who were disabled before age twenty-two-they automatically lose their benefits if they marry someone who is not also a Social Security beneficiary.³⁷ For SSI beneficiaries, the rules are more complicated. When an SSI beneficiary marries a non-beneficiary, the non-beneficiary's income and assets are factored into the beneficiary's eligibility determination.³⁸ Regulations require that this must happen, regardless of whether the spouse's income or assets are actually available to the beneficiary.³⁹

When two SSI beneficiaries marry each other, their combined income and asset allowances decrease by 25% per person, meaning their combined allowances will equal 150% of their individual allowances, rather than the 200% they would have if they did not get married.⁴⁰ SSA justifies that decrease by arguing that married couples can live more frugally by combining resources.⁴¹ However, this claim does not acknowledge that people often live with another person to economize expenses without getting married and that dual-income, non-beneficiary couples can get married without taking a pay cut.⁴² As a result of the dual-beneficiary marriage cut, the poverty rate for that type of couple is 45.1%, rather than the much lower 9.8% rate for unmarried individuals on SSI.43

36. See, e.g., Edward V. Wilcenski & Laurie Hanson, What Happens When Persons Living with Disabilities Marry?, SPECIAL NEEDS ALL .: THE VOICE (June 2010), https://www.spe cialneedsalliance.org/the-voice/what-happens-when-persons-living-with-disabilities-marry-2/ (answering common questions from people with disabilities seeking to understand what would happen to their benefits if they were to get married); Asaf Shalev, The Government Is Still Telling Disabled People Whom They Can Marry and This Woman Has Had Enough of It., MONTEREY CNTY. WKLY. (June 4, 2020), https://www.montereycountyweekly.com/people/831/the-govern ment-is-still-telling-disabled-people-whom-they-can-marry-and-this-woman-has/article f26b397 6-a5f1-11ea-ab78-83504e6e570f.html (describing the predicament of an SSDI beneficiary who was advised by SSA not to marry her non-beneficiary fiancé if she needed to keep her benefits); Stern, supra note 1 (relating several stories of beneficiaries affected by the disability marriage penalty).

^{37.} Sparrow Rose Jones, Disabled People Have the Right to Live Happily Ever After, ROOTED IN RTS. (Sept. 6, 2017), https://rootedinrights.org/disabled-people-have-the-right-to-live-happilyever-after/ [https://perma.cc/A4SQ-44TM]. See also Shalev, supra note 36.

^{38. 20} C.F.R. § 416.1160(a)(1) (2005).

^{39. § 416.1160(}a).

^{40.} Jones, supra note 37.

^{41.} Balkus & Wilschke, supra note 25, at 3.

^{42.} Id. at 4.

^{43.} Id.

Type of Benefit	Marriage to	
Received	Fellow beneficiary	Non-beneficiary
SSI	Asset and income allowances decrease by 25% per person (household totals 150% of individual amounts)	Spouse's income and assets are included in calculation (must remain below 83% of poverty level)1
SSDI	No longer eligible	No longer eligible
SSDI (CDB)	Still eligible	No longer eligible

 TABLE 1: EFFECTS OF MARRIAGE ON SOCIAL SECURITY BENEFITS

Perhaps due to this penalty, only twenty-four percent of adult disabled SSI beneficiaries are married, compared to fifty-seven percent of all adults in the United States.⁴⁴ SSI beneficiaries, particularly those with medical needs or disabilities that are best served by Medicaid, are deterred from marrying out of fear that the crucial services that keep them healthy and barely financially afloat will be cut.⁴⁵ Furthermore, divorce rates among disabled people are significantly higher than those of the greater population. Between 2009 and 2018, almost 11.1 million disabled Americans got divorced, almost twice the number that got married.⁴⁶ In the same period, 1.5 million non-disabled Americans got divorced, less than a third of the number that got married.⁴⁷ In the words of one disabled writer, "SSI and Medicaid rules are set up to make marriage and having necessary healthcare benefits incompatible."⁴⁸

Furthermore, the disability marriage penalty can be imposed even if no marriage exists.⁴⁹ SSA considers someone a spouse if they are legally married to the beneficiary, if SSA has previously decided that they are entitled to the beneficiary's Social Security benefits, or if they are cohabitating with the

^{44.} Id. at 3.

^{45.} Supplemental Security Income (SSI) Marriage Penalty, supra note 6. See also Gabriella Garbero, The "Fundamental" Right to Marriage, THE GIRL WHO SITS (Jan. 10, 2021), https://thegirlwhosits.com/2021/01/10/the-fundamental-right-to-marriage/.

^{46.} Stern, supra note 1.

^{47.} *Id*.

^{48.} Eryn Star, *Marriage Equality Is Still Not a Reality: Disabled People and the Right to Marry*, THE ADVOC. MONITOR (Nov. 14, 2019), http://www.advocacymonitor.com/marriage-equal ity-is-still-not-a-reality-disabled-people-and-the-right-to-marry/?fbclid=IwAR3gIf3cuzSBhWBp Gru47Oeo8QaMCJEHA1rZOaZAYg29Avsy9VhoaQOAp4k [https://perma.cc/3FMV-9LTZ].

^{49.} Robert E. Rains, *Disability and Family Relationships: Marriage Penalties and Support Anomalies*, 22 GA. ST. U. L. REV. 561, 570 (2006).

beneficiary and the couple is holding themselves out as married.⁵⁰ The question of whether a couple is "holding out" is always subjective and includes factors like how mail is addressed and how partners introduce each other, as perceived by the assigned SSA employee.⁵¹ Many disabled beneficiaries fear even acknowledging a relationship publicly, feeling that public recognition is not worth the risk to such important benefits.⁵²

B. Benefits of Marriage

Despite the lack of consideration given to couples with disabilities, SSA has acknowledged the importance of benefit policies that promote social ties like marriage.⁵³ Federal policy discussions have been couched at the intersection of welfare and family promotion, beginning with President Clinton's insistence on giving people tools to succeed at home and at work.⁵⁴ He wanted to eliminate false choices (i.e. the choice between a job and family) and wanted to end welfare dependence "as a way of life."⁵⁵ Implicit in this intention is a pointed avoidance of the fact that some disabled people need Medicaid to survive. Additionally, Clinton's family policy encouraged marriage for some, but excluded same-sex couples with the Defense of Marriage Act.⁵⁶ Thus, in a way it was "an end to the era of false choices" because some populations were given no choice at all.⁵⁷

Under the George W. Bush administration, a tax-related marriage penalty was eliminated.⁵⁸ President Bush also stated that his administration was "working to make sure that the Federal Government does not penalize marriage" and would alleviate regulations that made it difficult for families to climb out of poverty.⁵⁹ However, no policies under this administration did anything for the disability marriage penalty.

One positive policy trend during the Clinton and Bush administrations was the recognition that social and family ties, including marriage, are associated with increased health and well-being.⁶⁰ Beginning with the Clinton administration, the language of family became more prevalent in policy discussions.⁶¹ Additionally, the Healthy Marriage Initiative of the Bush era

- 53. Balkus & Wilschke, supra note 25.
- 54. McClain, supra note 18, at 1624.
- 55. Id. at 1624, 1628.
- 56. Id. at 1624.
- 57. Id. at 1629.
- 58. Rains, supra note 49, at 595–96.
- 59. Id.
- 60. Umberson & Montez, supra note 18.
- 61. McClain, supra note 18.

^{50.} Id.

^{51.} Stern, supra note 1.

^{52.} Evans, supra note 23.

recognized that the health of children and spouses are improved when marriages are characterized by supportive interactions.⁶²

Correspondingly, social science research has found that marital status may shape many different health outcomes, including chronic conditions and depressive symptoms.⁶³ While this can include beneficial outcomes like marriage and children fostering a greater sense of responsibility to stay healthy, there is also a correlation between marital strain and damage to health over time.⁶⁴ Additionally, the effects of marriage are not limited to the adult generation. Children are much more likely to achieve the American Dream (i.e. to have academic success, gainful employment, and upward mobility) if they have been raised by parents in a stable marriage.⁶⁵

As a result of this research, policymakers must see that policy decisions affecting social ties have the potential to undermine public health.⁶⁶ Being excluded from marriage in the years before *Obergefell v. Hodges* had an observable negative impact on members of the LGB community.⁶⁷ Scholars argued that the government was "undermin[ing] their capacity to make healthy and responsible choices" since they were denied the healthy choice of marriage.⁶⁸ Similarly, forcing disabled people to choose between health care and marriage does not lead to a happy, healthy family life.⁶⁹

III. LEGAL BACKGROUND

The positioning of marriage as a fundamental legal right occurred alongside the independent living movement for disabled people.⁷⁰ As marriage became increasingly embedded into the public consciousness as a right that should be accessible to all citizens, disabled people were initiating widespread advocacy to move out of institutions and into the community. The independent living

^{62.} Umberson & Montez, supra note 18.

^{63.} See id. at S55; Theodore F. Robles, Marital Quality and Health: Implications for Marriage in the 21st Century, 23 CURRENT DIRECTIONS PSYCH. SCI. 427, 428 (2014).

^{64.} Umberson & Montez, supra note 18, at S57.

^{65.} WILCOX ET AL., supra note 34, at 6.

^{66.} Umberson & Montez, supra note 18, at S60.

^{67.} In this Article, the term "LGB" will be used instead of "LGBTQIA+" when describing the populations that are defined by sexual orientation, not gender identity or expression, and who are more likely to seek access to same-sex marriage. *See, e.g.*, David S. Buckel, *Government Affixes a Label of Inferiority on Same-Sex Couples When It Imposes Civil Unions & Denies Access to Marriage*, 16 STAN. L. & POL'Y REV. 73, 78–79 (2005) (discussing how LGB youths learn their future committed relationships are marked as unworthy through exclusion from marriage).

^{68.} Id. at 79.

^{69.} Farley, supra note 20, at 45.

^{70.} Compare TIM MCNEESE, DISABILITY RIGHTS MOVEMENT 98–99 (Melissa York ed., 2014) (ebook), with Jill Shenker, A Selective History of Marriage in the United States, AGAINST THE CURRENT (Sept.–Oct. 2004), https://againstthecurrent.org/atc112/p370/ [https://perma.cc/Y9 TC-LFYT].

movement has not been mainstream for much longer than the movement toward full marriage equality.⁷¹

A. The Fight for Marriage Equality

The fundamental right to marry has been contested throughout many periods of U.S. legal history beginning in the twentieth century, most notably in four cases: *Loving v. Virginia*, *Zablocki v. Redhail*, *Turner v. Safley*, and *Obergefell v. Hodges*.⁷² In the 1967 *Loving* decision, the Supreme Court determined that state laws prohibiting interracial marriage violated the Due Process Clause of the Fourteenth Amendment, and that such prohibitions violated a "fundamental freedom."⁷³ The Court also reasoned that the post-War Amendments, namely the Fourteenth, were intended to remove legal distinctions among "all persons born or naturalized in the United States."⁷⁴ As such, any racial restrictions on the right to marry are now seen as unconstitutional.

Eleven years later in Zablocki, the Supreme Court overturned a Wisconsin statute that prevented noncustodial parents from being granted a marriage license if they were delinquent on child support payments or if they could not show that the child would never require welfare benefits.⁷⁵ In this particular case, the child had received public benefits since birth and would continue to qualify, even if the noncustodial parent had been current in his support payments.⁷⁶ As a result, he and others in his position were effectively deprived of the right to marry, in violation of the Equal Protection Clause of the Fourteenth Amendment.⁷⁷ In its reasoning, the Court applied a strict scrutiny standard, meaning the limitation on the right to marry had to be closely tailored to advance state interests.⁷⁸ Since the statute was intended to operate as a "collection device" and yet it merely prevented the applicant from marrying without directly enforcing any support obligations, the Court determined that the statute did not meet the standard set forth and was unconstitutional.⁷⁹ Piggybacking off of the language from Loving, the Supreme Court reiterated the fundamental importance of marriage as a building block of society.⁸⁰

Similarly, in *Turner*, the Supreme Court found that a Missouri marriage regulation prohibiting prison inmates from marrying unless the prison

^{71.} Compare MCNEESE, supra note 70, with Shenker, supra note 70.

^{72.} See generally Loving v. Virginia, 388 U.S. 1 (1967); Zablocki v. Redhail, 434 U.S. 374 (1978); Turner v. Safley, 482 U.S. 78 (1987); Obergefell, 576 U.S. 644 (2015).

^{73.} Loving, 388 U.S. at 12.

^{74.} Id. at 9.

^{75.} Zablocki, 434 U.S. at 377.

^{76.} Id. at 378.

^{77.} Id. at 377, 382.

^{78.} Id. at 388.

^{79.} Id. at 389.

^{80.} Zablocki, 434 U.S. at 383.

superintendent approved the marriage was also unconstitutional.⁸¹ Even applying a lesser standard of scrutiny, the Court found that the regulation was not reasonably related to penological objectives.⁸² Additionally, the Court noted that, in addition to the regulation being an "exaggerated response" far beyond what would be reasonably related to a penological objective, the regulation also had an unintended effect of restricting the fundamental right of civilians to marry a person they love, in this case a prisoner.⁸³

Nearly half a century after the foundation was laid in *Loving*, the Court extended constitutional protection to same-sex marriages in *Obergefell*.⁸⁴ In the opinion, Justice Kennedy described marriage as an institution that has evolved over time but has nevertheless had a "transcendent importance" to all people, regardless of their station.⁸⁵ He stated that over time, "new dimensions of freedom" may become apparent to future generations and newer laws respecting those freedoms will take shape in the political sphere before becoming part of the judicial process.⁸⁶

In *Obergefell*, the Court made a subtle yet profound shift in how it discusses marriage, asserting that access to marriage respects the dignity and autonomy of those involved and, importantly, that this right opens the door to other rights and privileges.⁸⁷ First in *Lawrence v. Texas*, then a few years later in *Obergefell*, the Court acknowledged that policing intimate behavior raised dignitary concerns.⁸⁸ Relatedly, the *Obergefell* Court recognized that same-sex couples were not merely asking for the ability to marry, but for "equal dignity in the eyes of the law[,]" which consists of two contradictory aspects: the right to privacy and the right to public recognition of family relationships.⁸⁹

Before the *Obergefell* decision, many states recognized the unfairness and inequality of state restrictions that prohibited same-sex marriage. These states created a similar institution called a civil union, sometimes called a domestic partnership.⁹⁰ A civil union had marriage-like qualities and was traditionally a status offered exclusively to same-sex couples.⁹¹ However, a civil union was

^{81.} Turner v. Safley, 482 U.S. 78, 99–100 (1987).

^{82.} Id. at 99.

^{83.} Id. at 97-98.

^{84.} Obergefell v. Hodges, 576 U.S. 644 (2015).

^{85.} Id. at 656-57.

^{86.} Id. at 660.

^{87.} *Id.* at 666. *See also* Nelson Tebbe & Deborah A. Widiss, *Equal Access and the Right to Marry*, 158 U. PA. L. REV. 1375, 1394 (2010) (discussing how dignity concerns implicated by laws that selectively deny marriage rights to same-sex couples have consistently been disregarded by courts in the past).

^{88.} See Lawrence v. Texas, 539 U.S. 558, 567 (2003); Obergefell, 576 U.S. at 666.

^{89.} Obergefell, 576 U.S. at 681; Tebbe & Widiss, supra note 87, at 1406.

^{90.} Heidi L. Brady & Robin Fretwell Wilson, *The Precarious Status of Domestic Partnerships* for the Elderly in a Post-Obergefell World, 24 ELDER L.J. 49, 50 (2016).

^{91.} Id.

still viewed as an "inferior status, with an impact that diminishes the sum of its parts."⁹² Marriage's superior status was emphasized in the *Obergefell* opinion, in which Justice Kennedy poignantly stated that marriage "embodies the highest ideals of love, fidelity, devotion, sacrifice, and family. In forming a marital union, two people become something greater than once they were."⁹³

B. The Disability Rights Movement

Laws concerning disabled people in America date back to 1636, when the Plymouth Colony passed a law to provide for men who had become disabled when serving in the military.⁹⁴ Beginning in the 1700s, some American communities began establishing institutions for the care of disabled people in an environment that was cut off from the rest of society.⁹⁵ This segregationist goal was perhaps most clearly exemplified in the late 1800s with the advent of "ugly laws."⁹⁶ These laws, which rose sharply in popularity immediately after the Civil War, prohibited disabled people with visible disabilities from being seen in public places.⁹⁷

After World War II, the tide began to turn. Rather than hiding disabled Americans, many of whom were veterans, the government developed programs intended to mainstream disabled people and otherwise encourage their integration into society.⁹⁸ By 1972, an advocacy organization for disabled people called the Center for Independent Living sprouted up on the campus of University of California – Berkeley.⁹⁹ The trend toward full societal integration of disabled people, known as the independent living movement, eventually led to the ADA, which was signed into law in 1990.¹⁰⁰

The ADA states in part 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."¹⁰¹ Federal regulations further require that public entities "shall make reasonable modifications in policies, practices, or procedures" necessary to avoid discrimination unless the modifications would "fundamentally alter" the

99. *History of TheCIL*, THECIL, https://www.thecil.org/history (last visited Mar. 7, 2021) [https://perma.cc/5ZEV-M54X].

100. Stapleton et al., supra note 35, at 706.

^{92.} Buckel, supra note 67, at 79.

^{93.} *Obergefell*, 576 U.S. at 666.

^{94.} McNEESE, supra note 70, at 98.

^{95.} Id.

^{96.} Susan M. Schweik and Robert A. Wilson, *Ugly Laws*, EUGENICS ARCHIVE, https://eugen icsarchive.ca/discover/tree/54d39e27f8a0ea4706000009 (2015) (last visited Mar. 3, 2021) [https://perma.cc/BPK2-KQ42].

^{97.} Id.

^{98.} MCNEESE, supra note 70, at 99.

^{101.} Americans with Disabilities Act, 42 U.S.C. § 12132 (2009).

service.¹⁰² At times, however, courts have taken a narrow view of what "policies, practices, or procedures" may be included in this mandate, with some having held that the accessibility mandate does not extend to custody hearings or other court proceedings.¹⁰³ Marriage policies, however, have not been challenged on ADA grounds.

In 1999, less than a decade after the ADA was passed, the Supreme Court extended the ADA mandate to include full community integration wherever possible, as opposed to the institutional, segregated treatment that had been the norm.¹⁰⁴ Respondents in that case, *Olmstead v. L.C. ex rel. Zimring*, insisted that Title II of the ADA's purpose is to overcome barriers to the full participation of disabled people in "all aspects of community life."¹⁰⁵ A Senate report even stated that discrimination includes "*exclusion*, or denial of benefits, services, or other opportunities that are as effective and meaningful as those provided to others."¹⁰⁶ Marriage and its connected benefits must be included in this consideration.

C. Disability Marriage Rights Throughout History

Discouraging disabled people from marrying and from being marriage partners has a long-standing history in America.¹⁰⁷ The eugenics movement reinforced and legitimized false cultural beliefs that led to disabled people being relegated to the outside of most personal relationships. These false assumptions informed policies that were written in a different era and have not been updated to reflect modern American values, particularly since the independent living movement.

1. Eugenic Origins

For upwards of 150 years, marriage restrictions based on disability have been part of U.S. legal history.¹⁰⁸ Beginning in 1846, states passed laws barring marriage if one or both partners had a disability.¹⁰⁹ These laws often had the

^{102. 28} CFR § 35.130(b)(7) (1998); Americans with Disabilities Act, 42 U.S.C. § 12132 (2009).

^{103.} Compare Belt, supra note 9 (discussing the fact that some courts have exempted custody proceedings from ADA requirements) with Chapter 7: The Family Law System: Custody and Visitation, NAT'L COUNCIL ON DISABILITY, https://ncd.gov/publications/2012/sep272012/ch7 (last visited Mar. 7, 2021) (asserting that custody proceedings are covered by Title II of the ADA) [https://perma.cc/ZW9F-DHYK].

^{104.} Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581, 607 (1999).

^{105.} Respondent's Brief at 27, Olmstead v. L.C. *ex rel*. Zimring, 527 U.S. 581 (1999) (No. 98-536), 1999 WL 144128 at *28.

^{106.} Id. at *27.

^{107.} Belt, *supra* note 9, at 3.

^{108.} Id.

^{109.} Id.

intent of preventing procreation or "the spread of disease through marriage," and as such, applied to women only if they were under forty-five years old, presumably to coincide with their assumed fertility.¹¹⁰ Violators could be sent to prison.¹¹¹ In 1905, the Connecticut Supreme Court determined that such a law could be upheld when one or both partners had epilepsy, because it was a "conviction of modern society that disease is largely preventable by proper precautions," and certain liberties may be narrowed to prevent the spread of disease.¹¹²

Restrictions on the right to procreate became more prevalent in the early twentieth century.¹¹³ In the infamous *Buck v. Bell* decision, the Supreme Court officially condoned forced sterilization of people with physical and mental disabilities.¹¹⁴ "It is better for all the world," said Justice Holmes, "if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind."¹¹⁵ As a result of this decision, over 60,000 disabled people have been involuntarily sterilized in the United States (500,000 worldwide) and the *Buck v. Bell* decision has still never been formally overturned.¹¹⁶

Although openly eugenic laws have fallen out of official favor, the perceptions and opinions that led to, or perhaps arose from, the eugenics movement still have echoes in marriage and family planning policies that dissuade disabled people from approaching legal marriage.¹¹⁷ These cultural beliefs find their roots in representations of disabled people as either non-sexual or hypersexual.¹¹⁸ Either extreme has been used as a reason to wrongfully deny disabled people the right to marry and procreate in order to prevent disability from "potentially tainting the human race."¹¹⁹ Now, disability is often used as a joke in the mainstream dating environment to signify a laughable lack of sexual

^{110.} J.P. Chamberlain, *Eugenics and Limitations of Marriage*, 5 J. COMP. LEGIS. & INT'L L. 253, 254 (1923).

^{111.} Id.

^{112.} Gould v. Gould, 61 A. 604, 605 (Conn. 1905).

^{113.} Elof Axel Carlson, *The Hoosier Connection: Compulsory Sterilization as Moral Hygiene*, *in* A CENTURY OF EUGENICS IN AMERICA: FROM THE INDIANA EXPERIMENT TO THE HUMAN GENOME ERA 11, 11, 21 (Paul A. Lombardo ed., 2011) (ebook).

^{114.} Buck v. Bell, 274 U.S. 200, 207 (1927).

^{115.} Id.

^{116.} PAUL A. LOMBARDO, THREE GENERATIONS, NO IMBECILES x, xiii (2008) (ebook).

^{117.} E.g., Lorna Collier, Seeking Intimacy, AM. PSYCH. ASS'N: MONITOR ON PSYCH. (Dec. 2017), https://www.apa.org/monitor/2017/12/seeking-intimacy. See Kimberly Mutcherson,

Disability, Procreation, and Justice in the United States, 6 LAWS 2017, at 5–6.

^{118.} Elizabeth F. Emens, *Intimate Discrimination: The State's Role in the Accidents of Sex and Love*, 122 HARV. L. REV. 1307, 1325 (2009).

^{119.} Id.

desirability.¹²⁰ Whether this opinion led to the eugenics movement or was borne out of it, it has had its place in the public consciousness for many years.

2. Contemporary Cultural Barriers

Despite popular misconceptions, disabled people are as capable of falling in love as non-disabled people, and often have the same desire to be married and start a family.¹²¹ However, some "barriers to entry" surrounding intimate relationships—including the disability marriage penalty, concerns about public perception, and even physical accessibility—can affect the decision to enter or remain in a relationship with a disabled partner.¹²² As a result, the rate of first marriages for disabled people ages eighteen to forty-nine is 41.1%, considerably less than the 71.8% overall rate.¹²³

Since intimate relationships are considered a social good, exclusion from that domain has welfare consequences.¹²⁴ These consequences include fewer or different interactions in other domains, such as employment.¹²⁵ In fact, the persistent unemployment rate (meaning unemployed for at least twelve consecutive months) for disabled people is 59.8%, which may be caused, at least in part, by misconceptions about disabled people that are in turn perpetuated by their lack of inclusion in other domains.¹²⁶ Because so few disabled people are present in any given workplace (and by extension, other public spaces), disabled people have fewer opportunities to socialize—either formally or informally—with people with whom they might want a relationship of any kind.¹²⁷ The social isolation that results from these factors hides the realities of declining health and welfare—and the lives of disabled people—from the view of the wider community.¹²⁸

^{120.} Id. at 1327.

^{121.} Evans, supra note 23; Stasio, supra note 2.

^{122.} Emens, *supra* note 118, at 1370.

^{123.} Philip Cohen, *Marriage Among People with Disabilities (Save the Data Edition)*, THE SOC'Y PAGES (Nov. 24, 2014), https://thesocietypages.org/ccf/2014/11/24/marriage-rates-among-people-with-disabilities-save-the-data-edition/ [https://perma.cc/4CF8-AN2K].

^{124.} Emens, supra note 118, at 1310.

^{125.} Id.

^{126.} DANIELLE M. TAYLOR, U.S. CENSUS BUREAU, CURRENT POPULATION REPORTS: AMERICANS WITH DISABILITIES: 2014, at 14 (2018). According to a 2015 study finding pervasive disability discrimination in employment, applicants with disabilities were twenty-six percent less likely to be hired than their non-disabled counterparts, even when their disability was not expected to affect their productivity or their ability to meet the job-related needs of the employer. Mason Ameri et al., *The Disability Employment Puzzle: A Field Experiment on Employer Hiring Behavior* 9, 14–15 (NBER Working Paper No. 21560), https://www.nber.org/papers/w21560.

^{127.} See, e.g., Loring Jones, Unemployment and Social Integration: A Review, 15 J. SOCIO. & SOC. WELFARE 161, 164 (1988) ("The loss of work dislodges people from a social role that may have made them feel a part of a larger social community and given their lives a purpose Consequently[,] the loss of work is bound to have negative ... social consequences.").

^{128.} Miller, supra note 14, at 108.

3. Policy Neglect

The requirements to which beneficiaries continue to be held have not kept pace with changes in the economy or inflation. Most Social Security programs were developed in the era of single-income households, when fewer women worked outside the home.¹²⁹ Furthermore, healthcare costs composed twenty-five percent of the maximum SSI payout for couples in 1980, while today these costs total eighty-three percent of the maximum payout.¹³⁰ Additionally, if the \$3000 SSI asset cap for couples were adjusted for inflation, the amount would total more than \$6000 in 2019.¹³¹ The average annual cost of a nursing home stay also rose from \$8268 in 1977 to \$46,692 in 1999, a six-fold increase that does not match up with Social Security increases.¹³²

There might not be much logic to the amount requirements as, according to Michael Tanner, a specialist in social welfare policy at the Cato Institute, "[t]here wasn't a group of philosopher economist kings who were developing the perfect eligibility level These things are thrown together by congressional committees on the basis of what can get votes."¹³³ Nevertheless, of the three major income assistance programs—SSI, Temporary Assistance to Needy Families (TANF), and the Food Stamp program—only SSI differentiates eligibility and benefit amount based on marital status alone.¹³⁴

In addition, some have found that inconsistent standards apply to Social Security programs and Medicaid. For Medicaid specifically, a non-disabled spouse's income is factored in, but they do not automatically share the benefits of Medicaid.¹³⁵ There is no way to pool Medicaid as a resource, yet eligibility is partially determined by marital status.¹³⁶ While private and public insurance are meant to serve the same purpose, public insurance considers income but private insurance does not. As Lori O'Haver, the non-disabled fiancée of a disabled Medicaid beneficiary said, "[m]y employer doesn't look at his income for my benefits."¹³⁷ In fact, in 1996 the Health Insurance Portability and Accountability Act of 1996 (HIPAA) amended the Employee Retirement Income Security Act

^{129.} Stern, supra note 1.

^{130.} Id.

^{131.} *Id*.

^{132.} Miller, supra note 14, at 89.

^{133.} Stern, supra note 1.

^{134.} Balkus & Wilschke, supra note 25, at 3.

Teresa McMinn, Wife or Caregiver? Quadriplegic Faces Decision, CUMBERLAND TIMES-NEWS (Oct. 22, 2019), https://www.times-news.com/news/local_news/wife-or-caregiver-quadriple gic-faces-decision/article_58e8e8b6-f462-11e9-b855-cbe4ddb01ea7.html [https://perma.cc/EZK3 -MGU3].

^{136.} See id.

^{137.} Id.

(ERISA) to make that consideration illegal.¹³⁸ Still, when a Medicaid beneficiary is married to a non-beneficiary, marriage assets are split 50–50 when determining eligibility, regardless of who has actual access to the assets or how the assets would be split in the case of a divorce.¹³⁹

Additionally, it has not gone unnoticed that in 2010, Congress repealed the estate tax and raised exemption levels to allow the extremely rich to pass on their wealth to their loved ones without paying estate taxes.¹⁴⁰ This stands in contrast to estate recovery, in which, after a Medicaid beneficiary's death, the state may collect any assets that were not counted in determining eligibility, including the decedent's home.¹⁴¹ That is, while laws applied to the rich have kept pace with modern sensibilities, those that affect Medicaid beneficiaries have remained mostly unchanged since 1972.¹⁴² Perhaps unsurprisingly, benign neglect has long been a hallmark of the political and legislative approach to disability.¹⁴³

IV. PRIOR EFFORTS AT REFORM

There has not been much direct legislative effort by either political party to alleviate the disability marriage penalty, despite its disparate impact.¹⁴⁴ This may come down to, on one hand, a Republican reluctance to spend money on welfare and, on the other, a Democratic reluctance to single out disabled people when everyone in poverty needs support.¹⁴⁵ Regardless of the reason, disability benefits have not been significantly discussed by legal commentators, and so

^{138.} FAQs on HIPAA Portability and Nondiscrimination Requirements for Workers, U.S. DEP'T OF LAB. 1, 3, https://www.dol.gov/sites/dolgov/files/EBSA/about-ebsa/our-activities/re source-center/faqs/hipaa-consumer.pdf (last visited Mar. 12, 2021) [https://perma.cc/8QXD-2P 4R].

^{139.} Miller, supra note 14, at 87.

^{140.} Id. at 99.

^{141.} Id. at 87.

^{142.} Shaun Heasley, *Lawmakers Look to Update SSI Program*, DISABILITY SCOOP (Sept. 23, 2019), https://www.disabilityscoop.com/2019/09/23/lawmakers-look-update-ssi-program/27200/ [https://perma.cc/ZU86-ML3Y].

^{143.} See, e.g., Kitty Cone, Short History of the 504 Sit In, DISABILITY RTS. EDUC. & DEF. FUND, https://dredf.org/504-sit-in-20th-anniversary/short-history-of-the-504-sit-in/ (last visited Feb. 18, 2021) [https://perma.cc/45JH-ALW4] (describing the extensive efforts of disability activists over three years to get regulations issued for Section 504 of the Rehabilitation Act of 1973); Michelle Diament, 80 Arrested in Nation's Capital at Disability Rights Protest, DISABILITY SCOOP (May 21, 2019), https://www.disabilityscoop.com/2019/05/21/80-arrested-disability-rights -protest/26651/ [https://perma.cc/KX9K-AMP6] (discussing two 2019 disability rights protests seeking fulfillment of Olmstead's community integration mandate that had been made twenty years prior).

^{144.} See Stern, supra note 1. But see infra Part V.A.

^{145.} Stern, supra note 1.

little to no attention has been paid to potential changes and updates to programs.¹⁴⁶

Because the disability marriage penalty exists at the intersection of welfare, health law, disability law, elder law, and family law, potential solutions may be found in all corners. Part of the difficulty in determining potential solutions to the penalty is that no single solution can make everyone happy or include everyone it should. For now, we have a few existing policies that may be applied to assuage the penalty.

A. Solutions from Elder Law

Many older Americans, like disabled adults, depend on benefits like SSI and Medicaid.¹⁴⁷ However, unlike many disabled adults, the elderly often have a lifetime's worth of assets that prevent them from meeting Medicaid's financial eligibility criteria, which is sometimes the best option for managing the costs of a nursing home.¹⁴⁸ As a result of these factors, special considerations have been made to enable eligibility for the elderly population. Some previous solutions include voluntary impoverishment, civil unions, and spousal refusal.

1. Voluntary Impoverishment

For some time, financial and legal advisors encouraged elderly clients to give away all of their assets as gifts and get divorced—to voluntarily impoverish themselves—before they needed a nursing home so that they could qualify for Medicaid when that time came.¹⁴⁹ Children and others to whom the elderly person gifted their assets could then help pay the elderly person's expenses, allowing them to maintain a reasonably familiar quality of life.¹⁵⁰ Congress was so frustrated by this practice, they made it a crime for citizens to practice it and for lawyers to advise their clients to do it.¹⁵¹ However, such a punitive measure was quickly repealed in part to not target the elderly and courts have not upheld the part that punishes lawyers.¹⁵² The practice still remains popular as it seems to be the most straightforward way to qualify for Medicaid.¹⁵³ Even so, the complexity of look back period rules (rules regarding how far back Medicaid is allowed to look at your finances to determine whether you have been giving

153. See Miller, supra note 14, at 108.

^{146.} Kathy P. Holder, In Sickness and in Health? Disability Benefits as Marital Property, 24 J. FAM. L. 657, 658 (1985); Rains, supra note 49, at 562.

^{147.} Evans, *supra* note 23.

^{148.} Miller, supra note 14, at 89-90.

^{149.} Id. at 81.

^{150.} Id. at 83.

^{151.} Id. at 81-82.

^{152.} Id. at 82.

away assets) makes voluntary impoverishment akin to "walking through a minefield blindfolded."¹⁵⁴

Furthermore, even if a person successfully sheds all their assets and does not have an income, this practice assumes that they have assets in the first place. Since there is both an income limit and an asset limit when qualifying for Medicaid, younger disabled people may not even earn a high enough amount to make giving away their assets possible. SSI and SSDI rules do not allow for a substantial savings or much outside income, so many disabled people live in persistent poverty.¹⁵⁵ Additionally, in eligibility determinations, SSA includes any housing or financial assistance from friends or family members.¹⁵⁶ Thus, even receiving outside help (assuming a person has that option) may hurt the person's eligibility for Medicaid.

2. Civil Unions

Another option in some states allows elderly Americans who need to get divorced or cannot be married for Medicaid reasons but who want some public recognition of a relationship to be granted a civil union—the same institution that was open to some same-sex couples pre-*Obergefell*.¹⁵⁷ This status was granted to same-sex couples and couples in which at least one participant was elderly before the *Obergefell* decision was made.¹⁵⁸ Legislators loosened the requirements for civil unions to include the elderly because they were worried about protecting the Social Security and retirement benefits of elderly couples who wanted to get remarried.¹⁵⁹ Significantly, the Social Security Act does not mention civil unions or domestic partnerships in any provision, so no penalty would be directly applicable.¹⁶⁰

In the years leading up to the *Obergefell* decision, however, a lot of sociological scholarship was done about the effects of civil unions on the LGB community. Civil unions were widely thought to give same-sex relationships "second-class" status compared to the traditional, more privileged status that marriage allowed.¹⁶¹ In deciding *Obergefell*, the Supreme Court even stated as much: "Without the recognition, stability, and predictability marriage offers, [the] children [of same-sex couples] suffer the stigma of knowing their families

160. *Id.* at 87. But see Rains, *supra* note 49 for a description of the holding out provision. Whether domestic partnerships or civil unions are considered "holding out" is not specified.

^{154.} Id. at 86.

^{155.} TAYLOR, *supra* note 126, at 15.

^{156.} Supplemental Security Income (SSI) Living Arrangements, SOC. SEC. ADMIN., https://www.ssa.gov/ssi/text-living-ussi.htm (last visited Mar. 11, 2021) [https://perma.cc/YEJ9-XBK6].

^{157.} Brady & Wilson, supra note 14, at 53.

^{158.} Id. at 50, 51.

^{159.} Id. at 62.

^{161.} Buckel, supra note 67, at 81.

are somehow lesser."¹⁶² There is no reason to think that an option deemed morally and socially unacceptable for the LGB community should be acceptable for the disability community. Furthermore, the "holding out" provision may consider couples in a civil union to be holding out as married, which would force them to face the same penalty that they would if they had gotten legally married, essentially excluding disabled people from this option.

3. Spousal Refusal

Similar to voluntary impoverishment, legislators have created "spousal refusal" as a protective measure against spousal impoverishment when only one spouse needs Medicaid.¹⁶³ Spousal refusal allows a non-Medicaid spouse to sign a waiver rejecting all financial responsibility for their spouse, which then excludes their personal income and assets from eligibility calculations.¹⁶⁴ Historically, spousal refusal was only offered to a community spouse when the other spouse was institutionalized.¹⁶⁵ However, recent changes to legislation have allowed couples with one spouse who receives home- and community-based Medicaid services (HCBS) to also utilize spousal refusal.¹⁶⁶ This technique to avoid impoverishment is not widespread; it is only available currently in New York and Florida, but it is gaining notoriety.¹⁶⁷

If spousal refusal were to become an option in all states, it would be a partial, but not full, cure for the disability marriage penalty. Spousal refusal for an institutionalized spouse is a permanently available legal fixture, but extending that refusal to a non-institutionalized spouse who needs Medicaid is not.¹⁶⁸ Spousal refusal rules that cover spouses who wish to live in the community by utilizing HCBS were first established by the Affordable Care Act (ACA) and are set to expire in 2023 absent an extension from Congress.¹⁶⁹ More than just an inconvenience, this means that at any point, standards could change and couples would be denied the security of knowing that their marriage would not affect their Medicaid eligibility in the future. Similarly, spousal refusal is effectively a

^{162.} Obergefell v. Hodges, 576 U.S. 644, 646.

^{163.} FROLIK & BROWN, supra note 14, at 19.

^{164.} Id.

^{165.} Star, supra note 48.

^{166.} *Id*.

^{167.} How Spousal Refusal Works as a Strategy to Medicaid Eligibility, MEDICAIDPLANNINGASSISTANCE.ORG, https://www.medicaidplanningassistance.org/spousal-refusal/ (last updated Jan. 5, 2021).

^{168.} Star, supra note 48.

^{169.} Spousal Impoverishment Rules | Protecting the Income, Assets & Homes of Medicaid Applicants' Spouses, MEDICAIDPLANNINGASSISTANCE.ORG, https://www.medicaidplanningassis tance.org/spousal-protections/#:~:text=Spousal%20impoverishment%20rules%20are%20federal, for%20long%2Dterm%20care%20Medicaid. (last updated Jan. 6, 2021).

state law concept¹⁷⁰ and, unless it is uniformly adopted in all states, married couples may face differing standards regarding community property.

B. An Unlikely Possibility

The issue becomes more complicated when considering that both Medicaid and marriage are primarily state-controlled institutions with small but significant differences in requirements.¹⁷¹ Scholars have noted that one potential solution to all marriage inequality issues is for states to refuse to grant a marriage status at all, and instead leave that determination to religious groups or other private entities.¹⁷² This proposal was made in February of 2020 by Missouri State Representative Adam Schnelting.¹⁷³ Such a bill would nullify the disability marriage penalty because it would be impossible to be married and hold out as married if marriage does not exist in the state. However, this proposal and those like it have historically been bad faith attempts to disallow same-sex marriage,¹⁷⁴ without consideration of how it would affect the whole range of benefits and rights linked to marriage. Since "the right to marry is fundamental as a matter of history and tradition," such a controversial change is unlikely without major upset.¹⁷⁵

V. POTENTIAL NEW SOLUTIONS

At the current crossroads, many options are available moving forward to alleviate the disability marriage penalty. At the end of 2019, Representative Raúl Grijalva presented a bill called The Supplemental Security Income Restoration Act of 2019 to Congress.¹⁷⁶ This bill purported to completely repeal the disability marriage penalty.¹⁷⁷ President Biden made a campaign promise to repeal the penalty as well.¹⁷⁸ Regardless of specifics, some kind of repeal must be implemented. In the meantime, several steps can be taken to soften the disability marriage penalty's impact.

A. The Supplemental Security Income Restoration Act of 2019

The Supplemental Security Income Restoration Act of 2019 (H.R. 4280) was one recently proposed solution to the disability marriage penalty problem.

^{170.} See FROLIK & BROWN, supra note 14, at 19.

^{171.} Balkus & Wilschke, supra note 25, at 4; Miller, supra note 14, at 85.

^{172.} Tebbe & Widiss, *supra* note 87, at 1378.

^{173.} See H.B. 2173, 100th Gen. Assemb., 2d Reg. Sess. (Mo. 2020).

^{174.} See Michael C. Dorf, *Does the Constitution Permit a State to Abolish Marriage*?, JUSTIA (Mar. 21, 2018), https://verdict.justia.com/2018/03/21/constitution-permit-state-abolish-marriage [https://perma.cc/3K4C-VGUJ].

^{175.} Obergefell v. Hodges, 576 U.S. 644, 647.

^{176.} Supplemental Security Income Restoration Act of 2019, H.R. 4280, 116th Cong. (2019).

^{177.} See id.

^{178.} The Biden Plan, supra note 15.

The bill would have updated the asset and income limits for individuals and couples on SSI and would require that the limit update yearly in line with inflation.¹⁷⁹ Most importantly, it would have repealed any penalty for marrying or receiving any kind of assistance from family members or friends.¹⁸⁰

This bill would have increased the asset limit for individuals from \$1500 to \$10,000 for the calendar year 2020 and would require that the amount increase in line with inflation every subsequent year.¹⁸¹ For couples in which both spouses receive SSI, the asset limit would have increased from \$2250 to \$20,000 for the calendar year 2020, and that amount would also increase in line with inflation.¹⁸² Thus, asset limits would dramatically increase and people with disabilities could have a small savings without fear of losing their health care benefits. In the context of marriage, the bill would have allowed disabled spouses to retain some community property and personal assets within their marriage.¹⁸³ Furthermore, the twenty-five percent decrease in benefits that occurs when two beneficiaries marry each other would have been eliminated.¹⁸⁴ As a result, the amount that dual-beneficiary's income to 200% of a single beneficiary's income.

Additionally, beneficiaries would not have been required to report "in-kind maintenance and support" to SSA.¹⁸⁵ This means that non-employment related income or assistance would not be included in a beneficiary's eligibility determination. SSA would have no reason to investigate whether a couple is "holding out" under this provision because pooling resources would not be prohibited.

Next, this bill would have repealed the penalty for disposing of assets for less than fair market value.¹⁸⁶ If one spouse wants to give away assets in order to qualify for Medicaid, even to their spouse or other family member, they currently may do so only if they sell their assets for fair market value.¹⁸⁷ When trying to decrease the value of assets, selling things for fair market value would serve little purpose. Thus, voluntary impoverishment would have become easier under this provision.

Finally, this bill would have eliminated any consideration of a nonbeneficiary spouse's income or assets in eligibility determinations.¹⁸⁸ When

186. Id. § 4.

188. Id. § 5(a).

^{179.} H.R. 4280 § 2.

^{180.} Id. §§ 3, 5.

^{181.} Id. § 2(c)(2).

^{182.} Id. § 2(c)(1).

^{183.} See id. § 5(a).

^{184.} See H.R. 4280 § 2(c)(2).

^{185.} Id. § 3(a)(1).

^{187.} See id.

asked, Representative Elissa Slotkin, a cosponsor of the bill, stated that "this bill brings the Supplemental Security Income (SSI) program's outdated limits up to speed with inflation—a common-sense adjustment that will make a huge difference for individuals and families caring for someone with disabilities."¹⁸⁹ Although she did not specifically mention the marriage aspects of the bill, the freedom to marry without losing benefits would be of profound importance to beneficiaries with disabilities.

However, the Supplemental Security Income Restoration Act of 2019 was introduced during the 116th Congress, which adjourned on January 3, 2021.¹⁹⁰ The bill was referred to the Subcommittee on Worker and Family Support in September 2019 but unfortunately never received a vote.¹⁹¹ Curiously, Representative Grijalva has proposed a nearly identical bill at every congressional session since 2013.¹⁹² Each time, it has died in its first or second committee without any record giving a reason for its failure.¹⁹³ At the time of writing, no one has yet introduced a similar bill during the 117th Congress, although Representative John Katko of New York has recently proposed a bill that would eliminate the disability marriage penalty but only explicitly for people with developmental or intellectual disabilities.¹⁹⁴

B. A Presidential Priority?

In contrast to previous presidents, President Biden mentioned the disability marriage penalty during his campaign and made a promise to work to eliminate it.¹⁹⁵ More generally, he has promised to prioritize breaking down societal and economic barriers for people with disabilities, including encouraging economic self-sufficiency and ensuring access to long-term services and supports.¹⁹⁶ In addition, President Biden has specifically vowed to offer everyone the choice to purchase public health insurance, which might function as a successful workaround that allows people to keep Medicaid benefits no matter their income

^{189.} Heasley, supra note 142.

^{190.} H.R. 4280 (116th): Congress: Supplemental Security Income Restoration Act of 2019, GOVTRACK, https://www.govtrack.us/congress/bills/116/hr4280 (last visited Mar. 12, 2021) [https://perma.cc/JP3V-6K4Z] [hereinafter GovTrack H.R. 4280].

^{191.} *Id.*; *H.R.* 4280 – Supplemental Security Income Restoration Act of 2019, CONGRESS.GOV, https://www.congress.gov/bill/116th-congress/house-bill/4280 (last visited Mar. 12, 2021) [https://perma.cc/F7RX-TLLD].

^{192.} GovTrack H.R. 4280, supra note 192.

^{193.} See id.

^{194.} H.R. 761, 117th Cong. (2021).

^{195.} *The Biden Plan, supra* note 15. In addition to specifically eliminating the disability marriage penalty, President Biden has also vowed to make spousal impoverishment protections permanent, rather than the current system of needing to be recertified on a yearly basis. *Id.*

^{196.} Id.

or that of their spouse.¹⁹⁷ Finally, he has promised to increase income and asset limits to more reasonable levels for people who receive SSI and SSDI.¹⁹⁸

In his first month in office, President Biden took action to protect SSDI beneficiaries from a Trump-era regulation that was projected to lead to a \$2.6 billion decrease in benefits.¹⁹⁹ Additionally, he has proven to prioritize access needs of disabled Americans by prominently including an American Sign Language (ASL) interpreter during his inauguration ceremony, by including ASL interpreters in livestreamed briefings, and by expanding accessibility features of the White House website.²⁰⁰ Although President Biden has not yet approached the disability marriage penalty, he is poised to be a leader who is eager to listen to and learn from the disability community.

C. Principles of Change

The simplest, most straightforward solution to the disability marriage penalty is for SSA to eliminate marriage as a factor in determining eligibility for SSI or SSDI. However, SSA has balked at any proposal to eliminate the couple as an eligible unit, finding that such a change would be too expensive.²⁰¹ SSA has even calculated that the change would cost "approximately \$900 million annually for current married couple beneficiaries alone."²⁰² However, when this amount is considered in light of the SSI program's FY 2020 budget of nearly \$42 billion, \$900 million—2.15% of the total—is a small price to pay for fundamental rights.²⁰³ Additionally, the \$900 million figure may not include the fact that couples who live together "assist the State by [assuring] support for the financial, physical, and emotional health of their participants," ultimately saving money by maintaining higher levels of health and wellness than they would have alone.²⁰⁴ The \$900 million may also not include the savings from the regulatory expense of investigating whether couples are holding out.

^{197.} Id.

^{198.} Id.

^{199.} Rules Regarding the Frequency and Notice of Continuing Disability Reviews, 84 Fed. Reg. 63596 (Nov. 18, 2019). See Annie Reneau, Biden Withdraws 'Horrific' Trump Rule Attacking Social Security Disability Recipients, GOOD MAG. (Jan. 29, 2021), https://www.good.is/biden-social-security-disability [https://perma.cc/9LNA-4KRJ].

^{200.} For a summary of accessibility efforts made by the Biden administration in its first month, see Jeanine Santucci, *Early Commitment to Accessibility for Disabled Americans Has Advocates Hopeful for Biden's Tenure*, USA TODAY, https://www.usatoday.com/story/news/politics/2021/02/01/biden-white-house-prioritizing-accessibility-disabled-americans/6662321002/ (last updated Feb. 1, 2021, 2:27 PM) [https://perma.cc/B4HV-DF4V].

^{201.} Balkus & Wilschke, *supra* note 25, at 5–6.

^{202.} *Id.* at 6.

^{203.} FY 2020 President's Budget, SOC. SEC. ADMIN., https://www.ssa.gov/budget/FY20Files /2020BST 1.pdf (last visited Feb 24, 2020) [https://perma.cc/HQV2-H222].

^{204.} Brady & Wilson, supra note 90, at 53-54.

In the meantime, without making any drastic or expensive changes to the system, better benefits counseling for disabled people must be a higher priority.²⁰⁵ Currently, the disability marriage penalty is not publicized and information about it is difficult to track down. In one case, a Medicaid beneficiary who was considering marriage called her local Medicaid office to ask about her options.²⁰⁶ An employee told her that no one would help her personally, but she could mail in some documents and await a decision.²⁰⁷ In another case, a couple repeatedly tried to contact their county office to learn about their future options as a couple, but no one who they spoke with would commit to a meeting.²⁰⁸ Medicaid and Social Security should not be denying information to people who want to be well-informed before making a major life decision.

Another option that would encourage healthy marriages and discourage Medicaid divorces is to eliminate policies that shift the burden of caregiving responsibilities to family members.²⁰⁹ This burden creates stressful family dynamics and puts unnecessary pressure on relationships.²¹⁰ If divorcing for Medicaid-related reasons is a "perversion of the law" then the government should do more to encourage happy, healthy families in which all people can get married and have their health care needs met, without having to choose between the two.

It cannot be the case that the progressive mandate of the ADA was designed to prop up and continue the legacy of poverty among the disability community. In fact, Congress predicated the ADA in part on the Commerce Clause, determining that it was unfair and discriminatory to "depriv[e] the economy of [disabled people's] working potential and their patronage."²¹¹ This does not comport with SSA's conscription of those who receive disability benefits to being pushed below the poverty line, and pushed even farther once they choose to marry.²¹²

This "stigma of exclusion" has been acknowledged by the Supreme Court in the *Olmstead* decision and by Congress in forming the ADA, but disability marriage equality has not yet captured the attention of the Supreme Court, other than to hold that the disability marriage penalty does not violate the Due Process

^{205.} FREMSTAD & VALLAS, supra note 4, at 9.

^{206.} David Lapp, *The Strivers Punished by Marriage Penalties*, INST. FOR FAM. STUD.: BLOG (Aug. 8, 2016), https://ifstudies.org/blog/the-strivers-punished-by-marriage-penalties/ [https://per ma.cc/4P7Z-28TX].

^{207.} Id.

^{208.} Id.

^{209.} Umberson & Montez, *supra* note 18, at S60–S61.

^{210.} Id.

^{211.} Respondent's Brief at 50, Olmstead v. L.C. *ex rel*. Zimring, 527 U.S. 581 (1999) (No. 98-536), 1999 WL 144128.

^{212.} Rains, supra note 49, at 568.

Clause of the Fifth Amendment and, in 1977, to alleviate the penalty for some SSDI beneficiaries who marry SSDI or SSI beneficiaries.²¹³

613

VI. CONCLUSION

In the *Obergefell* decision, Justice Kennedy said, "The nature of injustice is that we may not always see it in our own times."²¹⁴ For a long time, the injustice of the disability marriage penalty was not seen. The pain and shame of being forced to choose between marriage and health care was held silently and solely by those who made the choice. Since the *Olmstead* decision, disabled people have had a recognized right to inclusion in all aspects of the community.²¹⁵ Even before that right was established, Congress asserted in the ADA 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."²¹⁶ But such a simple mandate has complicated exceptions.

Acknowledging the repeated assurances by the Supreme Court that the right to marriage is fundamental, it is also not without conditions or limitations as prescribed by the state or other entities. Medicaid, which was originally intended as a health care resource of last resort for the disabled, blind, and poor, may currently place legal conditions on beneficiaries based on marital status, as may the Social Security Administration. Although disabled people are not directly legally barred from marriage, they "must pick only two out of three: marriage, economic security and comprehensive health coverage."²¹⁷

Regardless of these limitations, it is not difficult to imagine a system that does not force disabled people into unnecessary predicaments. Despite the emotional difficulty, ultimately the choice disabled people must make is always simple: it is a choice between marital happiness and medical necessity, regardless of whatever small concessions the system could muster after enough pushing.²¹⁸ The American Dream is supposed to be open to everyone, regardless of status, and achieving it includes having a fully formed family to come home to at the end of the day. "Marriage," as Justice Kennedy put it, "responds to the universal fear that a lonely person might call out only to find no one there. It offers the hope of companionship and understanding and assurance that while both still live there will be someone to care for the other."²¹⁹ Hopefully one day all disabled people might be able to know that comfort as well. Hopefully,

^{213.} Supplemental Security Income (SSI) Marriage Penalty, supra note 6. See Califano v. Jobst, 434 U.S. 47, 55 (1977).

^{214.} Obergefell, 576 U.S. at 664.

^{215.} Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581, 600.

^{216. 42} U.S.C. § 12132.

^{217.} Stern, supra note 1.

^{218.} Farley, supra note 20, at 30.

^{219.} Obergefell, 576 U.S. at 667.

instead of being forced to choose between two paths, disabled people will be offered a forward-facing life path that has room for two.

GABRIELLA GARBERO*

^{*} Juris Doctor, Saint Louis University School of Law (2021); Bachelor of Arts in Film Studies, University of Missouri – Columbia (2013). This comment is published with immeasurable gratitude for everyone who has supported my journey in life, despite its detours. In particular, I would like to thank Professor Elizabeth Pendo for being a better mentor than I could have hoped for, and for her constant patience, guidance, and encouragement in all things. I would also be remiss if I did not thank the Staff Editors, Lead Editors, Managing Editors, and our fearless Editor-in-Chief, who I was lucky to work closely with this year. Next, I would like to thank my parents, Kelley and Matt Garbero, for teaching me to push forward when problems look insurmountable. I also owe a special debt of gratitude to my good friend Aimee Wehmeier for encouraging me to carve out space for a life that makes me truly happy. Finally, I would like to thank my fiancé, Juan Johnson, for his praise and encouragement throughout this process, and for wanting to spend his life with me.