

TO BE LOVED OR TO BE HEALTHY:  
A DISABLED INDIVIDUAL'S CONUNDRUM OF CHOOSING  
BETWEEN MARRYING SOMEONE THEY LOVE OR CONTINUING  
TO RECEIVE THE HEALTH RESOURCES THEY NEED

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“The freedom to marry has long been recognized as one of the vital personal rights essential to the orderly pursuit of happiness by free men.”

– Chief Justice Earl Warren.<sup>1</sup>

ABSTRACT

Eligibility for Supplemental Security Income and Medicaid is essential for individuals with physical, developmental, intellectual, and other disabilities because it provides access to habilitative care. Habilitative care provides services necessary to maintain a base-level quality of life and facilitates independent living.<sup>2</sup> Some of the benefits provided to disabled individuals through habilitative care are in-home assistance, job support, and adaptive equipment.<sup>3</sup> Unfortunately, for many disabled individuals, the choice of marriage disqualifies them from receiving the benefits they

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1. Loving v. Virginia, 388 U.S. 1, 12 (1967).

2. Stephanie R. Hoffer, Making the Law More ABLE: Reforming Medicaid for Disability, 76 OHIO ST. L.J. 1255, 1255 (2015).

3. Id.

need to live independently with in-home assistance and support. This disqualification from governmental services is referred to as “the marriage penalty.” This marriage penalty forces many disabled individuals to either opt out of marriage or lose their benefits. This limitation can be changed. This note will suggest the exclusion of spousal income for determination of services, passing the SSI Restoration Act, discontinuing the couple rate, assessing individual income, and enacting uniform definitions of “disability” and “habilitative care” to apply in every state which will all help in giving disabled individuals an equal choice when considering marriage.

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## INTRODUCTION

The Supreme Court has historically interpreted the Constitution of the United States of America to give all citizens the fundamental right to marry. In Obergefell v. Hodges, the Supreme Court recognized that marriage is sacred and “[c]hoices about marriage shape an individual’s destiny.”<sup>4</sup> The Court concluded, “that the right to marry is a fundamental right inherent in the liberty of the person, and under the Due Process and Equal Protection Clauses of the Fourteenth Amendment couples . . . may not be deprived of that right and that liberty.”<sup>5</sup> This message has been recognized in many courts, including Virginia v. Loving to Goodridge v. Department of Public Health, in which the Court found that since marriage “fulfil[.]s yearnings for security, safe haven, and connection that express our common humanity, civil marriage is an esteemed institution, and the decision whether and whom to marry is among life’s momentous

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<sup>4</sup>. Obergefell v. Hodges, 576 U.S. 644, 666 (2015).

<sup>5</sup>. Id. at 675.

acts of self-definition.”<sup>6</sup> On top of being a fundamental right, marriage has a crucial and impactful role in society. This is embodied by the Court in Obergefell when stating, “[t]he ancient origins of marriage confirm its centrality, but it has not stood in isolation from developments in law and society. The history of marriage is one of both continuity and change. That institution—even as confined to opposite-sex relations—has evolved over time.”<sup>7</sup> Obergefell further states that “[m]arriage responds to the universal fear that a lonely person might call out only to find no one there. It offers the hope of companionship, understanding, and assurance that while both still live there will be someone to care for the other.”<sup>8</sup> The Supreme Court treats marriage as a fundamental right for all humans. However, Supreme Court opinions and U.S. government policies have resulted in disabled individuals being forced to choose between either the fundamental right of marriage or retaining their ability to receive healthcare support. The right to marry is guaranteed to all citizens, and yet, disabled Americans face many hardships and obstacles that may prevent them from marrying, unlike able-bodied Americans. Why put this extra impediment on the disabled and how they choose to marry?

People with disabilities make up the largest minority population in the United States. There are approximately 57 million adults between

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<sup>6</sup> Goodridge v. Dep’t of Pub. Health, 798 N.E.2d 941, 955 (Mass. 2003).

<sup>7</sup> Obergefell, 576 U.S. at 659.

<sup>8</sup> Id. at 667.

the ages of 18 and 64 living with a disability in the United States.<sup>9</sup> Only a small percentage of disabled people are born with their disabilities. In particular, only 15 percent of the 57 million people with disabilities obtained them at birth most people develop disabilities over time.<sup>10</sup> While issues impacting people with disabilities may not seem germane to the average reader, that reader may one day find that they too must deal with a disability. People with disabilities utilize a variety of federal and state programs for financial, medical care, and other forms of assistance. The federal government offers several programs including Supplemental Social Security Income (SSI), Social Security Disability Insurance (SSDI), and habilitative services to address the needs of those with disabilities.

This note argues that the laws such as SSI, SSDI, and habilitative services create a marriage penalty for people with disabilities who must choose a life without marriage and companionship or a life without services and independence.

Part I of this note will provide an overview of disabled Americans and the challenges they face. This note will review the different types of disabilities and the types of services that the government offers to support those specific disabilities. Mainly this note will discuss what

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<sup>9</sup>. Zachary Morris et al., Working Paper: The Extra Costs Associated With Living With a Disability in the United States (Oct. 14, 2020) (unpublished working paper) (available at <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/10/extra-costs-working-paper.pdf>).

<sup>10</sup>. TOBIN SIEBERS, *DISABILITY THEORY* 71 (2008).

SSI, SSDI, Medicaid, Medicare, and habilitative services are and their importance. It will also briefly introduce how these support systems create a marriage penalty and loss of benefits to disabled individuals.

Part II will present case law that lays out the framework of the marriage penalty, case studies of individuals facing the consequences of the marriage penalty, including how couples may avoid presenting themselves as a couple so they will not lose their governmental benefits,<sup>11</sup> and the decision to enter into marriage.<sup>12</sup> This Part will also provide an argument regarding equal protection and the choice of either marriage or governmental services.

Part III will discuss the difficult choices in forgoing habilitative care altogether, avoiding marriage (including divorce), or seeking expensive solutions such as creating a protection trust.

Part IV will discuss proposals for possible solutions to the marriage penalty by listing potential options and proposed adjustments in the benefits statutory structure.

## I. DISABILITY IN THE UNITED STATES

People with disabilities make up the largest minority population in the United States.<sup>13</sup> However, people with disabilities are not often thought of as a single group, especially as a political group, because their identities

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<sup>11</sup>. See generally Robert E. Rains, Disability and Family Relationship: Marriage Penalties and Support Anomalies, 22 GA. ST. U. L. REV. 561, 562–74 (2006).

<sup>12</sup>. *Califano v. Jobst*, 434 U.S. 47 (1977).

<sup>13</sup>. TOBIN SIEBERS, *DISABILITY THEORY* 71 (2008).

differ significantly from each other.<sup>14</sup> The number of disabled persons in any given society is constantly rising as more and more people age, have accidents, and become ill. This fact is obscured by controlled accounting practices that refuse to admit some disabilities into the statistical record.<sup>15</sup> In the article Why is Data on Disability so Hard to Collect and Understand, the authors note that communities are reluctant to track the participation of people with disabilities.<sup>16</sup> The authors conducted an informal survey of their colleagues who revealed several reasons why disability data is potentially flawed: including an overt focus on other underrepresented minorities, the belief that asking about disability is more “sensitive” than asking about a person’s race or gender, and even that data about disability was not listed on their Institutional Review Board application (IRB).<sup>17</sup> Ironically, the IRB was created under FDA regulations to review and monitor research involving human subjects.<sup>18</sup> Disabled individuals make up the largest minority population in the United States, yet persons with disabilities are overlooked when it comes to

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<sup>14.</sup> Id.

<sup>15.</sup> BRIANNA BLASER & RICHARD E. LADNER, *WHY IS DATA ON DISABILITY SO HARD TO COLLECT AND UNDERSTAND?*, [https://www.washington.edu/doit/sites/default/files/atoms/files/RESPECT\\_2020\\_DisabilityData.pdf](https://www.washington.edu/doit/sites/default/files/atoms/files/RESPECT_2020_DisabilityData.pdf) (last visited Feb. 22, 2022).

<sup>16.</sup> Id.

<sup>17.</sup> Id.

<sup>18.</sup> Id.

research studies.<sup>19</sup> This exclusion is an example of the ableism and the many inequalities that continue to exist today. Bias toward able-bodiedness makes it extremely difficult to embrace and recognize disabled individuals' unnecessary and horrific exclusion from society.<sup>20</sup>

Typically, when people think about issues of accessibility, public buildings come to mind. However, private dwellings are where many extraordinary acts of cruelty related to the inaccessibility of disabled persons and ableism exist. There is a significant exclusion of people with disabilities in "private spaces where most intimate gatherings occur - dinner parties, children's birthday parties, and sleepovers, holiday meals, wakes, Shiva, and celebrations of births."<sup>21</sup> Most houses today are not built to be accessible for disabled persons, such as those with toilets that are too low, entry points that are too narrow, and stairs that prevent entry, among the other challenges faced by disabled people in a private dwelling.

While disabled people face challenges in private life, it is crucial to recognize that they are still affected in public spaces. An example of such a difficulty arises in courthouses, where one would not expect an arduous experience for a disabled person. In Disability Theory, Tobin Siebers discusses Tennessee v. Lane, a 2004 Supreme Court case with long-term impacts on the civil rights of the disabled:

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<sup>19</sup>. Id.

<sup>20</sup>. TOBIN SIEBERS, DISABILITY THEORY 8–11 (2008).

<sup>21</sup>. Id. at 85.

The Court ruled unexpectedly and by a narrow margin that states not making courtrooms and legal services physically accessible to people with disabilities could be sued for damages under Title II of the ADA. George Lane, the plaintiff and a wheelchair user, told how he was summoned to the Polk County Tennessee Courthouse on a minor traffic charge and had to crawl up two flights of stairs to reach the court room, as the judge and other court employees stood at the top of the stairs and laughed at him. “On a pain scale from 1 to 10,” he later explained, “it was way past 10 . . .” When his case was not heard in the morning session, Lane was told to return following lunch for the afternoon session. When he refused to crawl up the two flights of stairs a second time, he was arrested for failing to appear and jailed. A second plaintiff, Beverly Jones, who works as a court reporter, joined the suit, claiming that she had to turn down work in twenty-three Tennessee court houses because they were not accessible to her wheelchair. Once in a court house without an accessible bathroom, the judge had to pick her up and place her on the toilet. Another time, a court employee carrying her to the next floor slipped and dropped her on the stairs.<sup>22</sup>

These anecdotes illustrate the daily hardships experienced by the disabled, even in public settings like a courthouse.

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<sup>22</sup>. Id. at 120.

Historically, in the United States, disability policies have been dominated by assistance programs such as SSDI, SSI, Medicaid, and Medicare.<sup>23</sup> SSDI was created in 1956 through Title II of the Social Security Act.<sup>24</sup> Nine years later, on July 30, 1965, President Lyndon B. Johnson signed Medicaid and Medicare programs into law.<sup>25</sup> The Security Act federalized a collection of state-run programs in 1972 to create Supplemental Security Income for the aged, blind, and disabled.<sup>26</sup> These programs have become essential for the quality of life of disabled individuals. One study estimated that over 65 percent of individuals with disabilities need assistance with daily living, dressing, bathing, eating, using the bathroom, and getting in and out of bed.<sup>27</sup> The failure of the private market to cover this habilitative care is apparent.<sup>28</sup> In another study, only 8 percent of families received private insurance funds to cover the cost of providing such care, and 80 percent of families did not have

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<sup>23</sup>. Richard V. Burkhauser & Mary C. Daly, Policy Watch: U.S. Disability Policy in a Changing Environment, 16 J. ECON. PERSPECTIVES 1, 213–224 (2002).

<sup>24</sup>. Id. at 215.

<sup>25</sup>. Centers for Medicare & Medicaid Services, CMS' Program History, CTRS. FOR MEDICARE & MEDICAID SERV. (last modified Dec. 1, 2021), <https://www.cms.gov/About-CMS/Agency-Information/History>.

<sup>26</sup>. Burkhauser & Daly, supra note 23, at 215.

<sup>27</sup>. Hoffer, supra note 2, at 1271–72.

<sup>28</sup>. Id.

enough money to pay for the care.<sup>29</sup> The United States Social Security Administration expects the number of Disability Claims for SSI and SSDI to increase by almost 300,000 in 2021 due to the need for federal assistance to those with disabilities.<sup>30</sup> Unfortunately, these programs have income requirements, and once recipients pass a certain income threshold, they are cut off from receiving benefits.

The following Subparts will explore the loss of benefits for individuals with disabilities who marry another person who is not relying on governmental services. This note will call this ineligibility or loss of benefits due to marriage the “marriage penalty.” In this context, “marriage penalty” refers to a series of Social Security rules that trigger reduction or complete loss of disability benefits for otherwise qualified individuals when they get married.<sup>31</sup>

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<sup>29</sup>. Id.

<sup>30</sup>. Mary Beth Musumeci & Kendal Orgera, Supplemental Security Income for People With Disabilities: Implications, KAISER FAM. FOUND. (June 23, 2021), <https://www.kff.org/medicaid/issue-brief/supplemental-security-income-for-people-with-disabilities-implications-for-medicaid>.

<sup>31</sup>. Sarah Kim, Marriage Penalty Prevents Marriage Equity for People with Disabilities, WORLD INST. ON DISABILITY, <https://wid.orgmarriage-penalty-prevents-marriage-equity-for-people-with-disabilities> (last visited Feb. 21, 2022).

## A. Different Types of Disabilities and Services

In the United States, over 61 million people have a disability.<sup>32</sup> Their disability types range from those with difficulty walking, using stairs, lifting, grasping, hearing, seeing, or speaking, to those who use a wheelchair or an assistive device to walk (cane, crutches, walker), to those with mental disabilities, learning disabilities, intellectual disabilities, and other developmental disabilities.<sup>33</sup> Disabilities come in multiple forms, and people with disabilities require different levels of care and assistance.<sup>34</sup> Many people with disabilities live in poverty and rely on federal services such as Social Security Disability Insurance, Supplemental Security Income, Medicaid, Medicare, Habilitation, or Habilitative services to live independently.

### 1. Social Security Administration (SSA)

In the United States, there are certain “benefits” offered that are necessities to Americans with disabilities including SSDI and SSI. These programs assist those with disabilities who qualify and meet the strict definition of disability set by the Social Security Administration. For SSDI,

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<sup>32</sup>. National Center on Birth Defects and Developmental Disabilities, Disability Affects All of Us, CENTERS FOR DISEASE CONTROL (Oct. 28, 2022), <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>.

<sup>33</sup>. Disability in United States, GLOBAL DISABILITY RIGHTS NOW, <https://www.globaldisabilityrightsnow.org/infographics/disability-usa> (last visited Apr. 9, 2022).

<sup>34</sup>. See id.

a disabled individual would have to meet the strict definition of disability and have worked long enough in a job covered by Social Security to receive benefits.<sup>35</sup>

The definition of disability under social security is different from other programs because it pays for total disability only, with “[n]o benefits payable for partial disability or short-term disability.”<sup>36</sup> To have a qualifying disability, all of these must be true for the applicant : they “cannot do work and engage in substantial gainful activity because of the medical condition. [They] cannot do work previously [done] or adjust to other work because of [their] medical condition [and it] has lasted or is expected to last for at least one year or to result in death.”<sup>37</sup>

When deciding whether an individual has a qualifying disability, the SSA uses a step-by-step process, including whether they believe the disabled person’s condition is severe and whether it is found on their list of disabling conditions.<sup>38</sup> For a person’s condition to be severe, it must significantly limit their ability to do basic work-related activities, such as “lifting, standing, walking, sitting, or remembering – for at least 12 months.”<sup>39</sup> If a person’s condition meets this first condition, then they

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<sup>35.</sup> Disability Evaluation Under Social Security, SOC. SEC. ADMIN., <https://www.ssa.gov/disability/professionals/bluebook/general-info.htm> (last visited Feb. 21, 2022).

<sup>36.</sup> Id.

<sup>37.</sup> Id.

<sup>38.</sup> Id.

<sup>39.</sup> Id.

look at the list of medical conditions to see if it is listed.<sup>40</sup> If it is not listed, then they have to decide if it is as severe as a medical condition on the list.<sup>41</sup> Listings are separated into two parts on the social security website. Part A includes the adult listings of impairment and Part B includes the childhood listing of impairments.<sup>42</sup> However, an exception under Part A allows these listings to apply “to the evaluation of impairments in children under age 18 if the disease processes have a similar effect on adults and younger children.”<sup>43</sup>

There are 14 disorders listed under Part A, including Musculoskeletal Disorders, Special Senses and Speech, Respiratory Disorders, Cardiovascular Systems, Digestive Systems, Genitourinary Disorders, Hematological Disorders, Skin Disorders, Endocrine Disorders, Congenital Disorders that Affect Multiple Body Systems, Neurological Disorders, Mental Disorders, Cancer (Malignant Neoplastic Diseases), and Immune System Disorders.<sup>44</sup>

Once a disabled individual meets the need requirement for SSI, they are approved for benefits. These benefits are provided if the individual does not exceed the personal asset limits set by law.<sup>45</sup> If married, this note contends that the asset number which ranges at about \$3,000 is far

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40. Id.

41. Id.

42. Id.

43. Id.

44. Id.

45. 20 C.F.R. § 416.1163(d)(1).

too low for two people.<sup>46</sup> For a single person, the asset range is limited to \$2,000.<sup>47</sup> Under § 416.1163 of the Code of Federal regulations, there is a way to deem income to the recipient from their ineligible spouse. If the recipient has an ineligible spouse living in the same household, the following rules related to the ineligible spouse's income will apply.<sup>48</sup> First, they look at determining the spouse's income; second, they look at allocations for ineligible children; third, is allocations for aliens sponsored by the ineligible spouse; and fourth, which is at issue here, is determining the disabled individual's eligibility for SSI. § 416.1163 (d) (1) states that:

the amount of your ineligible spouse's income that remains after appropriate allocations is not more than the difference between the Federal benefit rate for an eligible couple and the Federal benefit rate for an eligible individual, there is no income to deem to you from your spouse. In this situation, we subtract only your own countable income from the Federal benefit rate for an individual to determine whether you are eligible for SSI benefits.<sup>49</sup>

§ 416.1163 (d) (2) states that “[i]f the amount of your ineligible spouse's income that remains after appropriate allocations is more than the difference between the Federal benefit rate for an eligible couple and

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<sup>46.</sup> Squirmy & Grubbs, Was Our Wedding Fake? YOUTUBE (Sep 11, 2020), <https://www.youtube.com/watch?v=rWmPxDQnOZY>.

<sup>47.</sup> Id.

<sup>48.</sup> 20 C.F.R. § 416.1163(e)

<sup>49.</sup> 20 C.F.R. § 416.1163(d)(1).

the Federal benefit rate for an eligible individual, we treat you and your ineligible spouse as an eligible couple.”<sup>50</sup> If the couple’s Federal benefit rate is above the Federal benefit rate, the person who needs SSI would be deemed ineligible.<sup>51</sup> According to the Legal Information Institute, the current federal benefit rate as of 2021 is “\$794 for individuals and \$1,191 for couples.”<sup>52</sup>

Under § 416.1163 (f)(2), there are special rules for couples when a change in status occurs. Specifically, when couples spouses separate or divorce, if the disabled person who needs benefits or had previously obtained benefits separates or divorces from their ineligible spouse, the ineligible spouses income is no longer considered to determine eligibility for benefits following the first month after separation or divorce.<sup>53</sup> If that person remains eligible, then their benefit amount is determined by “following the rule in paragraph (e) of this section provided deeming from your spouse applied in the prior month.”<sup>54</sup> For example, if Sally (a recipient of SSI) had an income of \$300 and she married Pat with an income of \$1,400, Sally would lose her SSI. Overall, this indicates how

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<sup>50.</sup> Id.

<sup>51.</sup> Id.

<sup>52.</sup> Legal Information Institute, Federal Benefit Rate), CORNELL L. SCH., [https://www.law.cornell.edu/wex/federal\\_benefit\\_rate](https://www.law.cornell.edu/wex/federal_benefit_rate) (last visited Feb. 21, 2022).

<sup>53.</sup> 20 C.F.R. 416.1163(f)(2).

<sup>54.</sup> Id.

the Code of Federal Regulations and the SSI rules in totality negatively impact disabled individuals and their ability to marry and stay married.

Under the Social Security Act, Section 1915(c) (OBRA 81, Pub. L. 97–35) allows states to provide home and community-based services (HCBS) “to people who would otherwise be served in an institution.”<sup>55</sup> This would allow states to provide HCBS to eligible individuals who would otherwise require institutional services to be provided for by the Medicaid statute.<sup>56</sup> The Centers for Medicare and Medicaid Services explains that those eligible for the HCBS include: “adults with physical disabilities, individuals with HIV/AIDS, children experiencing a variety of disabling conditions, and individuals with serious mental illness[es].”<sup>57</sup> Different populations and HCBS spending reflected in FY 2018 showed that: 79 percent of total LTSS spending dedicated to HCBS was “for individuals with intellectual and developmental disabilities,” 33 percent was for individuals and adults with physical disabilities, and 49 percent of the Medicaid spending was for individuals with mental health and substance disorders.<sup>58</sup>

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<sup>55.</sup> CTRS. FOR MEDICARE & MEDICAID SERV., LONG-TERM SERVICES AND SUPPORTS REBALANCING TOOLKIT\_1, 5 (2020) <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-toolkit.pdf>.

<sup>56.</sup> Id. at 6.

<sup>57.</sup> Id.

<sup>58.</sup> Id.

## 2. Medicaid and Medicare

Many people with disabilities cannot work because any change in income will affect their health coverage. For this reason, most disabled Americans who have SSI and SSDI are eligible for Medicaid, which provides them with free or low-cost medical benefits to have the resources they need, such as personal aids, medications, equipment, and assistive devices.

Medicaid provides health coverage to 4.8 million people with disabilities that are also enrolled in Medicare.<sup>59</sup> Medicare has four primary forms of coverage:

- Part A: Pays for hospitalization costs
- Part B: Pays for physician services, lab and x-ray services, durable medical equipment, and outpatient and other services
- Part C: Medicare Advantage Plan (like an HMO or PPO) offered by private companies approved by Medicare
- Part D: Assists with the cost of prescription drugs.<sup>60</sup>

If the resources needed and provided by Medicare require premiums and out-of-pocket medical expenses, disabled individuals can get assistance from Medicaid to have those expenses paid off.<sup>61</sup> Medicaid is crucial to those with disabilities and chronic illnesses because it

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<sup>59.</sup> Seniors & Medicare and Medicaid Enrollees <https://www.medicaid.gov/medicaid/eligibility/seniors-medicare-and-medicaid-enrollees/index.html> (last visited Feb. 21, 2022).

<sup>60.</sup> Id.

<sup>61.</sup> Id.

covers additional services that go beyond what is provided under Medicare. It provides them with “nursing facility care beyond the 100-day limit or skilled nursing facility care that Medicare covers, [and covers] prescription drugs, eyeglasses, hearing aids”, and the care and access to Long Term Services & Supports (LTSS).<sup>62</sup> LTSS provides self-care assistance to Americans with disabilities who cannot provide this assistance to themselves and includes crucial tasks such as bathing, dressing, eating, and doing household activities.<sup>63</sup> The asset limit in place for qualified disabled working individuals who need Medicaid is \$4,000 for the individual and \$6,000 for a couple which is too low and puts a penalty on those who would like to be married.

### 3. Disability and Habilitative Services Defined by Federal and State Governments

Healthcare.gov describes the options for health coverage under Medicaid and Medicare including those for disabled persons that have special healthcare needs: from being terminally ill, needing help with day-to-day activities, care at home or any long-term care facility, or if they have a condition that limits their ability to work or care for themselves. Habilitation or habilitative services, also known as essential health benefits, are typically provided for people with disabilities by the government. The American Occupational Therapy Association and the

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<sup>62</sup>. Id.

<sup>63</sup>. Mary Beth Musumeci, Medicaid’s Role for Seniors and People with Disabilities: Current State Trends, 13 ST. LOUIS U. J. HEALTH L. & POL’Y 17, 18 (2019).

Affordable Care Act do not have a definition for such services.<sup>64</sup> Instead, states are permitted to define the services, and some have not done so. In New York, there is no set definition for habilitation and habilitative services; rather, they list the types of services that may be included for people with disabilities. For New York, habilitation refers to “health care services that help a person acquire, keep or improve, partially or fully, and at different points in life, skills related to communication and activities of daily living.”<sup>65</sup>

Some different examples of definitions include Arkansas, which defines them as “services provided in order for a person to obtain and maintain a skilled function that was never learned or acquired and is due to a disabling condition.”<sup>66</sup> Utah calls Habilitative Services “Residential Habilitation Supports” (RHS) and explains that this residential service is designed to assist people in gaining or maintaining skills to live as

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<sup>64</sup>. N.Y. State Speech-Language-Hearing Ass’n, N.Y. Physical Therapy Ass’n, & N.Y. Occupational Therapy Ass’n, New York State Benchmark Plan Recommendations (2012), [https://info.nystateofhealth.ny.gov/sites/default/files/nys\\_ot\\_pt\\_speech.pdf](https://info.nystateofhealth.ny.gov/sites/default/files/nys_ot_pt_speech.pdf).

<sup>65</sup>. Id.

<sup>66</sup>. Am. Occupational Therapy Ass’n, Habilitative Services are Essential Health Benefits: An Opportunity for Occupational Therapy Practitioners and Consumers, 1 (2014), <https://www.aota.org/-/media/corporate/files/advocacy/health-care-reform/essential-benefits/habilitative%20services%20fact%20sheet.pdf>.

independently as possible and participate in community settings.<sup>67</sup>

These services are important because many people would be isolated without them.<sup>68</sup>

In California:

Habilitative services means medically necessary health care services and health care devices that assist an individual in partially or fully acquiring or improving skills and functioning and that are necessary to address a health condition, to the maximum extent practical. These services address the skills and abilities needed for functioning in interaction with an individual's environment. Examples of health care services that are not habilitative services include, but are not limited to, respite care, day care, recreational care, residential treatment, social services, custodial care, or education services of any kind, including, but not limited to, vocational training. Habilitative services shall be covered under the same terms and conditions applied to rehabilitative services under the policy.<sup>69</sup>

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<sup>67</sup>. Utah Dep't of Health and Hum. Serv., Residential Habilitation Supports (RHS Formerly CLS) 1, [https://dspd.utah.gov/pdf/RESIDENTIAL%20HABILITATION%20SUPPORTS%20\(RHS\).pdf](https://dspd.utah.gov/pdf/RESIDENTIAL%20HABILITATION%20SUPPORTS%20(RHS).pdf).

<sup>68</sup>. Id.

<sup>69</sup>. Am. Occupational Therapy Ass'n, Definitions of and coverage requirements for "habilitative services" 1 (2013), <https://www.aahd.us/wp-content/uploads/2013/02/HabilitSrvcsStDefintionsAOTAFeb2013.pdf>.

West Virginia defines habilitative services as those:

Medically necessary services that help a person gain, keep, or improve skills for daily living. Some examples include physical and occupational therapy, speech-language pathology, and other needed services. Therefore, to meet the requirement to provide habilitation services, carriers should provide them: (1) as defined above; and (2) in parity with the rehabilitative services offered under the plan. For example, if the plan offers up to 50 physical therapy visits per year for rehabilitation benefits, the same amount would have to be offered for habilitative benefits pursuant to the definition above (needed to help a person gain, keep, or improve skills for daily living).<sup>70</sup>

Depending on the state, these essential health benefits (EHB) may have coverage limits. Each state has a benchmark plan that establishes the quantitative limits, including the number of visits allowed to rehabilitation centers. Federal regulations allow states to adjust benefits within the EHB categories unless there are prohibitions and restrictions within a specific state.<sup>71</sup> Most states have not prohibited

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<sup>70</sup>. Am. Occupational Therapy Ass'n, Habilitative Services are Essential Health Benefits: An Opportunity for Occupational Therapy Practitioners and Consumers 1 (2014), <https://www.aota.org/-/media/corporate/files/advocacy/health-care-reform/essential-benefits/habilitative%20services%20fact%20sheet.pdf>.

<sup>71</sup>. Id.

benefit substitution. These essential health benefits are important for the inclusion and quality of life of those with disabilities.<sup>72</sup> However, these essential health benefits will be lost if a disabled person chooses to marry. By having a marriage penalty for those with disabilities who want to get married, they are prohibited from choosing between marriage and services that they need for their quality of life. This is because of the additional costs of living as a disabled individual in America.<sup>73</sup>

It has been established that working-aged people with disabilities are more likely to experience poverty than their able-bodied counterparts, and this financial challenge is exacerbated by the marriage penalties in place for those living with disabilities. In the United States, a household containing an adult with a disability must spend an estimated 28 percent more of their income “to obtain the same standard of living as a household with no disability.”<sup>74</sup> This is due to the disability-related expenses that those without disabilities do not require. Typically, disabled individuals need government assistance because their cost of living includes the cost of items such as medical and pharmaceutical care, assistive technologies or mobility equipment such as breathing

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<sup>72.</sup> Id.

<sup>73.</sup> Zachary Morris et al., Working Paper: The Extra Costs Associated with Living with a Disability in the United States, (Oct. 14, 2020) (unpublished working paper) (available at <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/10/extra-costs-working-paper.pdf>)

<sup>74.</sup> Id.

machines, walkers, canes, wheelchairs, orthotics, braces, Hoyer lifts (slings that help people get into and out of the bed or bath), and caregiving services so that persons with disabilities can fully function in society at the same level as non-disabled individuals.<sup>75</sup>

Researchers at the Oxford Institute of Population Ageing, the University of Tennessee, Stony Brook University, and the National Disability Institute estimate that Americans with disabilities have to pay about \$17,690 more a year to obtain the same standard of living as Americans who do not have a disability.<sup>76</sup> Further health spending is more than twice as much for those with disabilities than for individuals with temporary disabilities, and there is a financial burden on people with persistent disabilities. This overspending on necessities and services for those with disabilities makes marriage feel like it is not an option if you are disabled.

## II. CASE STUDIES OF INDIVIDUALS FACING THE CONSEQUENCES OF THE MARRIAGE PENALTY, AND THE DECISION TO ENTER MARRIAGE AND AN EQUAL PROTECTION ARGUMENT

In the United States, marriage is a fundamental right for all as established by Obergefell v. Hodges, but what happens when a disabled person falls in love and wants to get married? Despite the Americans with Disabilities Act clarification that the “[n]ation’s proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such

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<sup>75.</sup> Id.

<sup>76.</sup> Id.

individuals.”<sup>77</sup> Currently, many people with disabilities must choose between marriage and accessing the benefits they receive from federal programs such as SSI and Medicaid.

In Olmstead v. L.C., the Supreme Court held that Title II of the Americans with Disabilities Act (ADA) bans unreasonable segregation of people with disabilities, and public entities must provide community-based services to people with disabilities when: (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of others who are receiving disability services from the entity.<sup>78</sup>

It has been established that working-age people with disabilities are more likely to experience poverty than their able-bodied counterparts, yet this financial challenge is exacerbated by the marriage penalties in place for those living with disabilities who are estimated to spend almost 30 percent more of their income to obtain a standard of care similar to a person without a disability.<sup>79</sup> This is due to the disability-related expenses that those without disabilities do not require.

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<sup>77</sup>. 42 U.S.C. § 12101(a)(7).

<sup>78</sup>. Olmstead v. L.C., 527 U.S. 581, 607 (1999).

<sup>79</sup>. Nanette Goodman et al., The Extra Costs of Disability Resetting the Policy Table, (Oct. 14, 2020), <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/10/extra-costs-living-with-disability-brief.pdf>.

Over the years, Congress has repeatedly responded to concerns about marriage penalties from unmarried, dual-income able-bodied couples (who do not rely on governmental assistance) by using the tax code to encourage marriage by reducing federal income taxes for dual-income couples who ultimately marry. On the contrary, the marriage penalties for disabled individuals under the Social Security Act have been significantly neglected.<sup>80</sup>

In Califano v. Jobst, which was decided in 1977, the Supreme Court construed the Social Security Act and its impact on marriage for people with disabilities.<sup>81</sup> The Court acknowledged that “it is true, as Mr. Jobst urges, that the limited exception may have an impact on a secondary beneficiary’s desire to marry, and may make some suitors less welcome than others.”<sup>82</sup> Mr. Jobst was disabled due to cerebral palsy since his birth in 1932.<sup>83</sup> Several months after his father died in 1957, when Jobst was 23 years old, he qualified for dependent benefits under the Social Security Act because he had been disabled since childhood and was dependent on his father’s income into adulthood.<sup>84</sup> Jobst, at age 38, married an individual who was not receiving benefits. Because of this marriage, Jobst’s benefits were terminated. Jobst challenged the

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<sup>80.</sup> See Rains, supra., at 562.

<sup>81.</sup> Califano v. Jobst, 434 U.S. 47 (1977).

<sup>82.</sup> Id. at 58.

<sup>83.</sup> Id. at 48.

<sup>84.</sup> Id.

constitutionality of the automatic termination on Fifth Amendment due process grounds.<sup>85</sup>

The Supreme Court details an assumption about marriage that is applied in American benefits policies.

Both tradition and common experience support the conclusion that marriage is an event that generally marks an essential change in economic status. Traditionally, the event not only creates a new family with attendant new responsibilities but also modifies the preexisting relationships between the bride and groom and their respective families. Of course, financial independence and marriage do not go hand in hand. Nevertheless, there can be no question about the validity of the assumption that a married person is less likely to be dependent on his parents for support than one who is unmarried.<sup>86</sup>

The Court frames the U.S. Congress as operating under a faulty presumption that marriage increases the income of a disabled person, thereby denying a disabled person's benefits under current law when the disabled person marries. Quite often, this is not the case. Unfortunately, this erroneous thinking is now included in jurisprudence for U.S. disability law as stated in the Court's dicta in Califano.<sup>87</sup>

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<sup>85</sup>. Id. at 49.

<sup>86</sup>. Califano, 434 U.S. at 53 (1977).

<sup>87</sup>. Id. at 53.

This reasoning led to the inequality of marriage rights for individuals with disabilities who rely on benefits but want to get married. B.J. Stasio has provided real-life examples of how the marriage penalty works.<sup>88</sup> In his research, he met and gathered information from multiple individuals living with a disability. He starts his research with Timothy, a 36-year-old man diagnosed with Duchenne Muscular Dystrophy at the age of three.<sup>89</sup> Due to his neuromuscular condition, he is on a ventilator at all times and can only turn his head and move his fingers slightly. Timothy must rely on a nurse to help him with habilitative services and personal care.<sup>90</sup> If Timothy were to marry his girlfriend and their joint assets were to exceed \$3,000, he would lose his Medicaid benefits. With his nursing costs being more than \$300,000 a year, Timothy would not be able to afford those bills, and he cannot afford to lose such benefits.<sup>91</sup> This marriage penalty prevents Timothy and those similarly situated, from marrying.

Kurtlyn is a woman who receives social security disability benefits due to mental illness.<sup>92</sup> Her illness limits her to working part-time; thus, she struggles financially. If Kurtlyn married, she would not want to be a

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<sup>88.</sup> B.J. Stasio, People with Disabilities and the Federal Marriage Penalties, 23 *IMPACT* (FEATURE ISSUE) (2010), <https://publications.ici.umn.edu/impact/23-2/people-with-disabilities-and-the-federal-marriage-penalties>.

<sup>89.</sup> Id.

<sup>90.</sup> Id.

<sup>91.</sup> Id.

<sup>92.</sup> Id.

financial burden on her husband due to losing her social security. She believes that people with disabilities deserve the same rights as everyone else, including marriage.<sup>93</sup> To Kurtlyn, marriage is important, and she does not want to miss out on it because of the risk of losing her benefits, but she also does not “want to have to lose someone in [her] life out of fear of [her] being a financial burden to them.”<sup>94</sup> For Kurtlyn her disability benefits are essential for her current lifestyle.

People with disabilities may rely on funding and support from SSI, SSDI, and Medicaid. However, each program comes with a certain limit regarding the income of married couples causing a marriage penalty to those with disabilities who would like to get married. SSI provides modest income benefits to retirees and children who were permanently disabled as a child and collect benefits as adults.<sup>95</sup> SSDI provides modest benefits to those who have a documented medical impairment and a record of employment and the disability occurring before retirement age.<sup>96</sup> Medicaid is the federal healthcare insurance program for all disabled individuals who have not qualified for SSI at retirement age.<sup>97</sup>

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<sup>93.</sup> Id.

<sup>94.</sup> Id.

<sup>95.</sup> Kathy Ruffing, “Women and Disability Insurance: Five Facts You Should Know,” CTR. ON BUDGET AND POL’Y PRIORITIES – POL’Y FUTURES, March 18, 2018.

<sup>96.</sup> Id.

<sup>97.</sup> Mary Beth Musumeci, Medicaid’s Role for Seniors and People with Disabilities: Current State Trends, 13 St. Louis U. J. HEALTH L. & POL’Y 17,

Shane Burcaw, a novelist, and YouTuber who is physically disabled, explains in a video with his wife that “disabled people rely on SSI and Medicaid for caregivers, for income, for housing help, and medical treatment.”<sup>98</sup> He noted that these benefits vary by state, but regardless of this, the risk of losing benefits when deciding to get married is prevalent.

These programs relied upon by disabled individuals are need-based, and if an individual wants to get married, they risk losing these benefits and having to rely on their spouses’ incomes for services and products that are well above an affordable cost. Since these programs are need-based, “they take into account income and asset limits, and those limits are extremely low, generally around \$2,000.”<sup>99</sup> “[T]he problem is much more complicated when marriage is involved . . . because your partner’s assets and incomes count towards your limits. Your limits can go up from \$2,000 to \$3,000.”<sup>100</sup> These limits are already low, thus an increase by \$1,000 when married is unsustainable. The income threshold limits cause disabled individuals to choose between a loss of services, including medical treatment or marriage. In annual terms, in 2006, According to a 2006 study, an eligible unmarried couple could receive a maximum annual SSI benefit of \$14,472.<sup>101</sup> If the couple married,

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18 (2019).

<sup>98.</sup> Squirmy & Grubbs, Was Our Wedding Fake? YOUTUBE (Sep 11, 2020), <https://www.youtube.com/watch?v=rWmPxDQnOZY>.

<sup>99.</sup> Id.

<sup>100.</sup> Id.

<sup>101.</sup> Robert E. Rains, Disability and Family Relationship: Marriage

“their maximum 2006 SSI benefits would be \$10,848.”<sup>102</sup> To put this into perspective:

[T]he United States Department of Health and Human Services (DHHS) has set the 2006 federal poverty guideline for a two-person family unit in the 48 contiguous states and the District of Columbia at \$13,200. Thus, an unmarried, cohabiting, eligible couple of two indigent, disabled people can receive enough SSI to have income exceeding the federal poverty guideline by \$1,272. But if they marry, their income will fall to a level \$2,352 below the federal poverty guideline.<sup>103</sup>

This does not consider the harsh realities that disincentivize the marriage of disabled individuals. By being below the federal poverty guideline, these services do not allow any financial growth for a marriage and can cause more loss for a couple who loses their services once married.

This benefits scheme penalizes married disabled persons in ways that may seem unintentional but cause more hardship:

Because the SSI framework is intended to provide benefits based upon financial need, Congress determined that married couples should receive lesser benefits; their need is not twice as great as if they were single. Congress chose to

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Penalties and Support Anomalies, 22 GA. ST. U. L. REV. 561, 568 (2006).

<sup>102.</sup> Id.

<sup>103.</sup> Id.

provide a lesser rate of benefits to “eligible couples” than to two single individuals because it determined that, “two people living together can live more economically than they would if each lived alone.” H.R.Rep. No. 231, 92d Cong., 2d Sess. 1548 (1972), reprinted in 1972 U.S.C.C.A.N. 4989, 5136. Furthermore, the legislative history of the provision notes that the “deemed married,” as was discussed in the previous section, classification was created because[i]n the absence of such a provision in the assistance program, there would be a strong incentive for married couples to allege that they were not married (in order to get higher payments) and there would be a difficult, if not impossible, administrative burden of determining whether a marriage existed between two individuals alleging to be single (but who hold themselves out to be married).<sup>104</sup>

In an Instagram Post Hannah Ayl stated:

When we got married last year, we made a video about the lack of marriage equality for disabled people. In short, when a disabled person gets married, their spouse’s income and assets are counted as their own, and they lose their benefits. For example, if a disabled person’s new spouse makes a poverty-level income or has more than \$2,000 in assets, the disabled person is disqualified from the benefits they were receiving before getting married. This effectively

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<sup>104.</sup> Smith v. Shalala, 5 F.3d 235, 239 (7th Cir. 1993).

bans marriage for people who rely on subsidized caregivers, healthcare, or income.<sup>105</sup>

The Social Security Office of Policy notes the importance of marriage in consideration of government benefit policies. They recognize marriage penalties for SSI recipients.<sup>106</sup> While the Supreme Court in Jobst found that these penalties don't "infringe" on a disabled person's right to marry, the consequences of doing so have clearly deterred disabled individuals from marrying. In fact, only 24 percent of SSI recipients over the age of 18 are married compared to 57 percent of all adults in the United States.<sup>107</sup>

The benefit rate for married couples compared to two single people receiving SSI provides incentives for beneficiaries to misreport their living arrangements. "To receive higher benefits, couples may say they have separated when, in fact, they are still living together. Unmarried persons who are living together may argue that they are not presenting themselves to the community as a couple."<sup>108</sup> To prove this in the fiscal

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<sup>105.</sup> Hannah Burcaw @hannahhayl, INSTAGRAM,, [https://www.instagram.com/p/CQ9EQ2-FzGu/?utm\\_source=ig\\_web\\_copy\\_link](https://www.instagram.com/p/CQ9EQ2-FzGu/?utm_source=ig_web_copy_link).

<sup>106.</sup> Richard Balkus & Susan Wilschke, Treatment of Married Couples in the SSI Program, SOC. SEC. OFF. OF POL'Y, Issue Paper No. 2003-01 (Dec. 2003), <https://www.ssa.gov/policy/docs/issuepapers/ip2003-01.html>.

<sup>107.</sup> Id.

<sup>108.</sup> Id.

year 2000, about \$26 million were estimated in overpayments attributed to issues reporting marital status.<sup>109</sup>

The threshold for SSI in 2000 depended on whether or not a person is married. An individual's countable income must be \$512 or less per month to be eligible for SSI because it has to be less than the federal benefit rate. In 2000 this totaled to \$6,144. The countable resources had to be less than \$2,000. For jointly eligible couples in 2000, the countable resource was a maximum of \$769 per month, and the annual income and resource limits were \$9,288 and \$3,000.<sup>110</sup>

For two beneficiaries married in 2015:

[T]he couple [wa]s entitled to up to \$1100 per month and may have countable resources up to \$3,000. The combined countable income is used to reduce the monthly benefit. Compare this to two unmarried SSI recipients who each receive \$733 per month, which would be \$1466 per month for the household, and each is allowed \$2000 in assets, or \$4000 for the household. Marrying would cause this couple to have their benefit decreased to 75% of the total of their two benefits, or \$1100 per month.<sup>111</sup>

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<sup>109.</sup> Id.

<sup>110.</sup> Burkhauser & Daly, supra note 23, at 215.

<sup>111.</sup> Supplemental Security Income (SSI) Marriage Penalty, (2018), <https://adanc.org/wp-content/uploads/2018/08/SSI-Marriage-Penalty.pdf>.

In 2021, the threshold amount for Medicaid for married applicants applying for Aged, Blind, and Disabled Medicaid is considered jointly, and there is an income limit for a household of two.<sup>112</sup> The income limit depends on the state in which the disabled individual lives “most states use 100 percent of the Federal Poverty Level for a household of two (as of 2021, \$1,452 / month) or the SSI Federal Benefit Rate for couples (as of 2021, \$1,191 / month).”<sup>113</sup>

Today, “Social Security requires SSI recipients to have less than \$2,000 in assets, for a single person, and \$3,000 for a couple.”<sup>114</sup> The asset limit is paltry when compared to the federal tax code encouraging single able-bodied individuals to marry with a concomitant reduction in personal income tax rates upon marriage. For disabled persons, asset limits are key to determining their eligibility for any benefits. In this view, marriage is a net positive for able-bodied individuals whose combined incomes are dedicated to paying for their needs and wants as opposed to disabled individuals who must dedicate a significant part of their income to services addressing their disability. For the disabled, this is about whether this combined income will disqualify them from receiving

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<sup>112.</sup> What Counts as Income for Medicaid Long Term Care? Definitions, Exceptions, & Limits, (last updated February 7, 2023), <https://www.medicaidplanningassistance.org/how-medicaid-counts-income>.

<sup>113.</sup> Id.

<sup>114.</sup> Elizabeth Dickey, Income and Asset Limits for SSI Disability Eligibility, NOLO (updated Jan 13, 2021), <https://www.nolo.com/legal-encyclopedia/income-asset-limits-ssi-disability-eligibility.html>.

the benefits they need to live successfully. Without them, disabled individuals can lose their quality of life.<sup>115</sup> Anyone is one accident away from disabilities that could cause them to need LTSS.<sup>116</sup>

### EQUAL PROTECTION

The Fourteenth Amendment is central to our understanding of individual rights. The Fourteenth Amendment states, “nor shall any State deprive any person of life, liberty, or property, without due process of law.”<sup>117</sup> Our society traditionally protects fundamental rights. The right to marry has been protected under the due process clause in Loving v. Virginia and Zablocki v. Redhail. The Court ruled that preventing and interfering with marriage was unconstitutional and that “the right to marry is a fundamental right.”<sup>118</sup>

In Loving v. Virginia, the Court struck down anti-miscegenation laws that interfered with the right to marry.<sup>119</sup> Similarly, in Zablocki v. Redhail, the Court invalidated state laws limiting the ability of individuals with unpaid child support to marry.<sup>120</sup> Furthermore, in Obergefell v. Hodges,

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<sup>115.</sup> What Happens When Persons Living with Disabilities Marry?, THE VOICE (June 2010 – Vol. 4, Issue 9), <https://www.specialneedsalliance.org/the-voice/what-happens-when-persons-living-with-disabilities-marry-2> (last visited Apr. 10, 2022)

<sup>116.</sup> Id.

<sup>117.</sup> U.S. Const. amend. XIV, § 1.

<sup>118.</sup> Zablocki v. Redhail, 434 U.S. 374, 383 (1978).

<sup>119.</sup> Loving v. Virginia, 388 U.S. 1 (1967).

<sup>120.</sup> See supra note 57.

the Court held that same-sex couples have a constitutional right to marry protected by the Due Process and Equal Protection Clauses of the Fourteenth Amendment and that marriage is a fundamental right protected by the Due Process Clause.<sup>121</sup> Based on such history and the right of privacy under the umbrella of marriage as the Court contemplated in Griswold v. Connecticut, the experiences of the disabled and the marriage penalty create a cognizable equal protection claim in violation of the Fourteenth Amendment.<sup>122</sup> Yet despite all of these cases, including more recent cases like Obergefell, the Court has not revised its opinion in Califano. Mere financial disincentives have not risen to the level of a violation of equal protection, and yet for individuals with disabilities, losing benefits could be a matter of life or death. The disabled are disincentivized from pursuing marriage because they face the prospect of losing benefits if they were to marry another person, even a disabled person receiving benefits. In this view, the disabled will evaluate their current financial status against the availability of benefits. Instead of choosing to marry or not to marry for social and relational reasons typical of others who make similar decisions whether to enter a marriage, the disabled are encumbered with an additional layer of decision making: will I lose critical benefits if I marry the person that I love? When faced with this kind of choice, the current scheme of the law does not apply equally to all persons concerning marriage.<sup>123</sup>

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<sup>121</sup>. Obergefell v. Hodges, 576 U.S. 644, 675–76 (2015).

<sup>122</sup>. Griswold v. Conn., 381 U.S. 479, 485–86 (1965).

<sup>123</sup>. Soc. Sec. Admin., Disability Evaluation Under Social Security, <https://>

As noted by the Supreme Court, marriage is a fundamental right protected by the constitution. The decision to marry is an individual choice made by two consenting individuals that the government should not abridge. Given the regulations concerning the distribution of benefits for the disabled, the decision to enter into a marriage is directly affected by the value of benefits a disabled person can receive. No other group faces such a stark choice under the Social Security Act.<sup>124</sup>

This penalty separates the disabled from other groups who receive benefits under this law, such as the elderly who reach retirement age. When a person reaches retirement age, their benefits are not determined by whether they are married.<sup>125</sup> Instead, the calculation of the benefits is made based on their lifetime contributions to the social security program.<sup>126</sup> In contrast, the disabled receive benefits based on a series of calculations where marriage is a factor in the total amount of benefits received.<sup>127</sup> Unlike the elderly who can freely choose marriage at any point without an overarching fear of lost governmental benefits, the disabled must make life or death decisions. Do I marry and later lose

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[www.ssa.gov/disability/professionals/bluebook/AdultListings.htm](http://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm) (last visited Feb. 21, 2022).

<sup>124.</sup> Id.

<sup>125.</sup> AARP, How does marriage affect Social Security benefits?, <https://www.aarp.org/retirement/social-security/questions-answers/does-marriage-affect-social-security.html>. (last visited Feb. 21, 2022).

<sup>126.</sup> Id.

<sup>127.</sup> 20 C.F.R. § 416.1163(d)(1).

vital governmental benefits? Or do I avoid marriage altogether in favor of retaining my benefits but potentially losing a spouse who could support me (e.g., emotional support, physical therapy) in other critical ways? This ought to be viewed as a violation of the Fourteenth Amendment's equal protection clause, as the disabled can be penalized for the simple act of marrying. The disabled are then not equally protected under the law because marriage for the disabled can be a penalty when nondisabled persons are not penalized for the simple act of marriage. Programs supposedly designed to assist the disabled result in stark life decisions that nondisabled persons do not face. When forced to make these kinds of blunt choices, the disabled are not equally protected under the law for governmental benefits.

### III. THE MARRIAGE PENALTY CAUSES DISABLED INDIVIDUALS TO MAKE HARSH CHOICES IN AVOIDING HABILITATIVE CARE ALTOGETHER, AVOIDING MARRIAGE (INCLUDING DIVORCE), OR SEEKING EXPENSIVE SOLUTIONS SUCH AS CREATING A PROTECTION TRUST.

In the article, Forced to Divorce: Americans with Disabilities Must Pick Marriage or Health Care, the authors highlight the plight of disabled Americans who made choices to protect their incomes.<sup>128</sup> Susan is introduced to show how divorce can ensure that a disabled person continues to receive benefits. Susan had to make a tough choice to divorce her husband. After a marriage of nearly three years, she was diagnosed with colon cancer. Prior to this, she had been diagnosed with rheumatoid arthritis at age four and did not have private insurance at the

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<sup>128</sup>. Stern supra note 129.

time of her diagnosis and so, Medicaid was critical for her to get the care needed to manage her disability. Her husband worked as a roofer and earned about twelve dollars an hour, and she had briefly lost coverage during their marriage because their eligibility was based on household income. When her husband switched companies and was given a raise, the fear of losing her Medicaid eligibility resurfaced, and she decided to get divorced to eliminate the month-to-month possibility of losing coverage. Susan is a part of the 61 million Americans with disabilities who are facing the choice between healthcare and marriage.<sup>129</sup> Ozy's investigations reveal "a rapidly widening disparity in marriage rates between those with and without disabilities in the years since Susan's divorce, spawned by outdated eligibility thresholds and a convoluted web of health care programs that many find difficult to navigate."<sup>130</sup>

Within the disabled community, many people must choose between government assistance and care and getting married (or divorced). Dominick Evans, a disabled man from the United States, explained this issue in his tweet on August 3, 2019: "I've been with my girlfriend for almost 17 years, and I will never be able to marry her. Disabled people often can't get married if they need home care." He continues, "[m]

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<sup>129.</sup> Carly Stern, FORCED TO DIVORCE: AMERICANS WITH DISABILITIES MUST PICK MARRIAGE OR HEALTH CARE, Ozy, (April 24, 2019), <https://www.ozy.com/the-new-and-the-next/forced-to-divorce-americans-with-disabilities-must-pick-marriage-or-health-care/92284>.

<sup>130.</sup> Id.

ost people have no idea this is a reality for many disabled people.”<sup>131</sup>

Disabled individuals who rely on the programs such as Medicaid, Social Security Income, and Social Security Disability Income are affected by their spouses, and there are few exceptions to this. Evans further explains that “If you are disabled and marrying a nondisabled person, you will lose SSDI if getting it through a parent. This is because the government says you are a burden on your parent, and when you marry, you become the burden of your spouse.”<sup>132</sup> Evans’ experiences illustrate how this view is one of ableism and the dehumanization that affects disabled individuals that have been legally labeled as a burden. This causes people with disabilities to face dehumanizing decisions between marrying their loved one or having healthcare and habilitative services.

This is a clear result of the marriage penalty reflected by the U.S. Census Bureau data that shows that between 2009 and 2018, nearly “1.1 million Americans with disabilities got divorced almost twice the number—593,000—that got married.” Shockingly enough, experts reason that the system has been stacked against marriage for people with disabilities for decades, starting with the eugenics movement on people with disabilities. Over 60,000 people with disabilities were forcibly sterilized between the 1920s and 1970s to remove traits/genetics considered undesirable.<sup>133</sup> This ableist perspective continued in the 1927 Supreme Court of Buck

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<sup>131</sup>. Dom Evans (@realdomevans), TWITTER (Aug. 2, 2019, 11:33 PM), <https://twitter.com/dominickevans/status/1157540031302643712?s=20>.

<sup>132</sup>. Id.

<sup>133</sup>. Id.

v. Bell, where the Court found the right to reproduce as not being a fundamental liberty.<sup>134</sup> This decision was never formally overturned. In states such as Washington and Michigan, courts continue to accept requests from guardians of people with disabilities for their sterilization. As recent as 1998, in In Re: Lora Faye Wirsing, the Michigan Supreme Court allowed Lora Faye Wirsing to be sterilized at the request of her guardian. These decisions were inhumane, and we have reached a point in time where change is needed. The ableism attached to disabled individuals being able to consider marriage should be changed so that Americans with disabilities do not have to choose from “two out of three: marriage, economic security and comprehensive health coverage.”<sup>135</sup>

In 1993 Congress created Medicaid payback trusts to protect individuals with disabilities from losing their health coverage and government cutbacks in Medicaid spending.<sup>136</sup> There are two types of trusts available noted in 42 U.S.C. § 1396p(d)(4)(A)-(B). The first type of trust was created for those with disabilities under the age of sixty-five and from which<sup>137</sup> “The State will receive all amounts remaining in the trust upon the death of such individual up to an amount equal to the total

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<sup>134.</sup> Buck v. Bell, Superintendent, 274 U.S. 200, 207 (1927).

<sup>135.</sup> Stern, supra note 129.

<sup>136.</sup> See Jacqueline D. Farinella, Come on in, the Water's Fine: Opening up the Special Needs Pooled Trust to the Eligible Elderly Population, 14 ELDER L.J. 127, 137–38 (2006).

<sup>137.</sup> Stephanie R. Hoffer, Making the Law More ABLE: Reforming Medicaid for Disability, 76 OHIO St. L.J. 1255 (2015).

medical assistance paid on behalf of the individual [by\_Medicaid].”<sup>138</sup> This form of trust can only be established by parents, grandparents, legal guardians of the beneficiary, or a court. The trust allows the beneficiaries to receive only a pension, social security, or other beneficiary income.<sup>139</sup> These types of trusts were intended to allow children with disabilities to have money upon the death of their parents without losing their health benefits and habilitative services that they cannot live without and would need. Unfortunately, the trust funds have a limit because they can only be used on supplemental expenses. For example, Professor Stephanie Hoffer notes that in Ohio “if the beneficiary incurs expenses for which a government program is available, such as housing or food, trust funds may not be used to cover the expenses.”<sup>140</sup> In the Ohio code, the law provides that these trust funds cannot be used for “basic necessities” such as “essential food, clothing, shelter, education, and medical care.”<sup>141</sup> In order to use these funds, they would have to be used on expenses that are not covered by the government programs discussed, such as Medicaid and habilitative services. Instead, they would be used on personal expenses such as hobbies, vacations, activities, and television. While these trusts are meant to protect disabled people and allow them to have more funds, they limit them. The trusts are “neither sufficient assurance to worried families nor [do they allow] adult decision-making

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<sup>138</sup>. 42 U.S.C. § 1396(d)(4)(A).

<sup>139</sup>. 42 U.S.C. § 1396(d)(4)(B).

<sup>140</sup>. Hoffer, supra p.1288.

<sup>141</sup>. OHIO ADMIN. CODE § 5123:1–5-01(C)(2)(2018).

power to individuals with disabilities even when those individuals directly earned, through labor, the funds in the trust.”<sup>142</sup> Considering “the goals of promoting autonomy, assisting integrated living to the extent desired and practical, and alleviating harm caused by the improper reliance on norms of the typically abled in Medicaid eligibility law, protection trusts are better than nothing.”<sup>143</sup> These protection trusts may assist disabled people in purchasing things as simple as gifts or as crucial as adaptive equipment not covered by Medicaid, but this is not enough. It limits people with disabilities from having complete freedom over their purchases, and while it would help solve the marriage penalty, there are many other ways to solve the marriage penalty issue that actually provide independence to those with disabilities. While trusts are a step towards equality in funds for those with disabilities, where protection trusts are involved, disabled individuals still are unable to act independently with the resources left for them.<sup>144</sup> When these individuals are left with protection trusts, they are required to request permission for their discretionary expenditures, and if a trust was in place for those to avoid the marriage penalty while married, they would not be able to use the funds left in assets independently.

#### IV. THE POSSIBLE SOLUTIONS

The SSI eligibility rules have not been updated since the program was signed into law by President Nixon over 40 years.<sup>145</sup> During that

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<sup>142.</sup> See Hoffer, supra note 137, at 1288.

<sup>143.</sup> Id. at 1290.

<sup>144.</sup> Id. at 1292.

<sup>145.</sup> Justice in Aging, Supplemental Security Income Restoration Act of

time, the cost of living was significantly lower than it is today, so the amount of income that disabled individuals were allowed to receive being that low made sense. However, the \$2,000 asset limit for the program set in 1989 is not feasible today.<sup>146</sup> In the United States, a household containing an adult with a disability requires almost 30 percent more income to obtain the same standard of living as a household without a disabled house member.<sup>147</sup> For many people with disabilities, these services provide independence and assistance crucial for them to live their lives. By having a marriage penalty and essentially taking away their habilitative services and limited financial independence, reliance on their spouse's income by a disabled person sets a dangerous precedent for disabled individuals who choose to marry. The financial barrier and significant loss of benefits for income support or health coverage make love and marriage extremely challenging and unequal because of the penalty created on marriage.

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2021, <https://justiceinaging.org/wp-content/uploads/2021/06/SSI-Policy-Issue-Brief-Updated-2021.pdf> (last visited Apr. 9, 2022).

<sup>146.</sup> Id.

<sup>147.</sup> Zachary Morris et al., Working Paper: The Extra Costs Associated With Living With a Disability in the United States, (Oct. 14, 2020) (unpublished working paper) (available at <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/10/extra-costs-working-paper.pdf>)

### A. The Exclusion of Spousal Income for Determination of Services

To alleviate the adverse impact on people with disabilities who get married and lose the governmental services they had relied on to gain the independence and care they crucially need, Congress should create a policy that does not look at the income of a disabled person's spouse when determining the eligibility of SSI, SSDI, Medicaid, Medicare, and Federal and State Habilitative Services. Evaluating the person who relies on these services based on the individual's income alone will result in a more accurate representation of whether these individuals still qualify, and this will allow for a more secure choice for individuals with disabilities who desire marriage. Ideally by creating an exception for disabled individuals so that they may continue to receive their services despite their spouse's income, people with disabilities will no longer feel the adverse effects of the marriage penalty. While this type of solution may seem far-fetched, it would mitigate the inequalities that come with marrying a spouse who maintains a salary that is just above the federal poverty benefit. As shown by the individual stories earlier, the services associated with disabilities are quite costly, and having these services are crucial for the survival of people with disabilities.

One of the biggest pushbacks for this policy would be the thought of American taxpayers paying increased amounts for these governmental services. However, by examining only the disabled person's income, there would still be a review of whether they are even eligible for such services based on their financial need. This solution would only apply to people who need the services and are eligible for them, particularly men and women with disabilities who would lose their services only if

they married and were evaluated based on their spouse's income. If the person with the disability is not eligible, the solution would not apply to them. In sum, the elimination of a marriage penalty would not raise costs for the government because those (or most) who would qualify as single or need the benefits, are already choosing to remain single or have potentially divorced.

Of course, the income thresholds themselves are another issue in dire need of change, since these services' eligibility are unfeasible for many due to the required threshold that they be below the federal poverty level. As mentioned herein, the services associated with disabilities are quite essential for many Americans who cannot afford the care they need to live an adequate life. Ideally, by making an exception that does not examine the spouse's income, a disabled person will continue to receive services if they are unable to work due to their disability and will allow them to continue to have the services they need to live independently. This will allow people with disabilities to make the choice to get married instead of avoiding it, so they do not feel like they must rely on their spouses and spouses' income to have the support they need for themselves.

When it comes to marriage, to allow people with disabilities to make this choice safely, Congress should change the federal policies to make an exception in which disabled individuals who rely on these services are evaluated on their own income alone so that they can retain access to essential services despite consideration of the income their spouse receives.

## B. Pass the “SSI Restoration Act”

Congress has indicated its desire to address the marriage penalty in proposed legislation, including solutions to increase the income threshold or remove the penalty altogether. On June 15, 2021, the Senate introduced Bill S. 2065 to amend Title XVI of the Social Security Act “to update eligibility for the supplemental security income program, and for other purposes.”<sup>148</sup> This SSI Restoration Act would raise the sub-poverty-level monthly benefits allowing people with disabilities to possess more in assets so that their penalty is not as high, allowing individuals or couples to have up to “\$10,000 and \$20,000” in assets. The current limit of \$2,000 and \$3,000 is too low,<sup>149</sup> especially since households containing adults with disabilities require an income of over 28 percent to obtain the same standard of living that an adult without a disability would need.<sup>150</sup> Therefore, the limit is not feasible due to the extra costs needed to maintain an independent lifestyle. For example, Edward Mitchell lives with quadriplegia and requires home nursing, home modifications, dictation tools that help with writing, and car modifications that allow him

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<sup>148</sup>. Supplemental Security Income Restoration Act of 2021, S.2065, 117<sup>th</sup> Cong. (2021–2022).

<sup>149</sup>. Press Release, U.S. Senator Sherrod Brown, Brown Leads Senators in Introducing Historic Legislation to Update Long-Neglected Social Security Program to Ensure Older Adults & People With Disabilities are no Longer Trapped in Poverty (Jun. 16, 2021), <https://www.brown.senate.gov/newsroom/press/release/social-security-program-update>.

<sup>150</sup>. Zachary Morris, supra note 147.

to drive himself, all of which cost him extra in comparison to someone who is able-bodied.<sup>151</sup> The asset limit requires a major adjustment to comport with the current realities of life for a disabled person in the 21<sup>st</sup> Century. Increasing the asset limit should be an automatic decision since it is so deleteriously low for a disabled person. This bill will “increase the benefit for married couples to double the individual rate, to put marriage equality within reach for SSI beneficiaries.”<sup>152</sup>

Action on the bill is delayed as it languishes in the Senate Committee on Finance with limited prospects. The public may be unaware of the bill and its purpose, especially those in the disabled community and most affected by it. So, a public media campaign to expose its contents is needed to spur further action on the bill.

#### C. Discontinue The Couple Rate and Assess Income Individually

This note proposes that the government should discontinue the couple rate and treat disabled married couples and recipients of SSI and SSDI as individual members. The Treatment of Married Couples in the SSI Program, recommends eliminating the couple rate and the current rules for determining living arrangements so that disabled individuals could live together and have relationships.<sup>153</sup> As a result, each member of an SSI couple would receive a separate Federal Benefit Rate (FBR).

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<sup>151</sup>. Id.

<sup>152</sup>. Press Release, U.S. Senator Sherrod Brown, supra note 149.

<sup>153</sup>. Richard Balkus & Susan Wilschke, Treatment of Married Couples in the SSI Program, SOC. SEC. OFF. OF POL'Y, Issue Paper No. 2003–01 (Dec. 2003), <https://www.ssa.gov/policy/docs/issuepapers/ip2003–01.html>.

Next, their incomes would be calculated separately so that a person who is disabled and below the poverty line can still receive their governmental services if their spouse meets the threshold. In effect the disabled beneficiary would not have to rely on their spouse or lose services denying them an equal quality of life, as to what they would have or did have before choosing to get married.<sup>154</sup>

Furthermore, all the current rules for determining living arrangements, in-kind maintenance, and support should be eliminated.<sup>155</sup> This would allow recipients living with another adult to keep their benefits and live together efficiently instead of living alone. A set amount should be reduced from the FBR for all adults who live together in which a partner is disabled and relying on governmental services. This would mean doubling the reduced FBR for couples.<sup>156</sup> Doing this would greatly simplify the existing complicated rules of living together and receiving any kind of in-person assistance. The government should also grant each eligible couple a separate general income exclusion. This way both members of a couple will be able to take full advantage of the general income exclusion as opposed to getting a lesser income just because they are married.<sup>157</sup>

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<sup>154.</sup> Id.

<sup>155.</sup> Id.

<sup>156.</sup> Id.

<sup>157.</sup> Id.

#### D. Enact Uniform Definitions Of “Disability” and “Habilitative Care” To Apply in Every State

The American Occupational Therapy Association does not have a solid definition for habilitative care.<sup>158</sup> A definition for habilitative care is currently lacking among industry officials and researchers. The industry should develop a uniform definition for these services. Having a uniform definition of disabled and habilitative service will allow for better care that disabled individuals need. A highly beneficial path for individuals with disabilities would be to establish a uniform definition allowing disabled individuals to receive guaranteed benefits regardless of circumstances, location, or job. Most individuals with disabilities need these benefits and habilitative care to survive and function in life.

While states might protest having a more uniform definition forced on them, having a standard definition set in place across the entire country with a reasonable threshold will assist these individuals in maintaining the benefits that they are entitled to receive despite any circumstance. For example, by allowing states the liberty to choose how they define these habilitative services, it leaves too much room for vagueness and the opportunity to leave essential benefits out. Giving states the broad freedom to define services potentially allows states to be unfair to individuals who need them.

A uniformly regulated definition applied to all states should prevent any unfair treatment to disabled individuals in their domicile. In particular, it would be created to define the terms within the ADA or through some

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<sup>158</sup>. Zachary Morris, supra note 147.

other agency that could focus solely on the definitions and making these services accessible for all with disabilities.

### CONCLUSION

The current governmental support policies for disabled individuals require them to stay below the federal poverty limit and make the tough choice between getting married and losing the health services they need to survive. The decision to marry is a fundamental right that should not be left to the outdated calculations of governmental benefits policies. Government policy should not be based on an outdated assumption that marriage results in financial independence. Instead, health services for the disabled should be provided regardless of relationship status. This decision should not be forced on anyone, and yet current Court precedent in Jobst seems unlikely to enforce equal treatment for people with disabilities.<sup>159</sup> Disabled individuals are not equally protected under the law as promised by the Fourteenth Amendment. Disability advocates and allies must therefore continue to lobby Congress to enact laws and regulations that remove the marriage penalty and allow individuals with disabilities the right to marry without fear of losing lifesaving benefits.

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<sup>159</sup>. Califano 434 U.S. 47, 58 (1977).