DREDF Marriage Equality Toolkit

Advancing Marriage Equality - A Toolkit

Millions of disabled Americans cannot marry without risking access to vital healthcare, community supports, and other disability benefits.

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# Table of Contents

[**Table of Contents 1**](#_ypiiu4d6gk2)

[**Introduction 3**](#_cg24m9arsu78)

**What’s at stake? 4**

[**What terms should I know? 4**](#_qrw4oxbxlzkp)

[Direct Support Professionals 4](#_fqnls0oh6ss6)

[Disabled Adult Child 5](#_1dpz2a9rwyro)

[Durable Medical Equipment 5](#_r1ij4x4q9jw)

[Holding Out 5](#_5xtwzivlp0g4)

[Home and Community-Based Services 6](#_xebmzh1wk317)

[Long-Term Services and Supports 6](#_biragtm28se7)

[Personal Care Attendants/Personal Care Services 6](#_i1zijooa42p2)

[Qualifying Disability 6](#_4pzgbt8zt3h9)

[Secondary Benefits 7](#_67k0o9vcb8be)

[Social Security Administration 7](#_e042jyoscdk1)

[Social Security Disability Insurance 7](#_mmz0dafww646)

[Spousal Deeming 7](#_sf2u0modqleg)

[Title II Benefits or Old-Age, Survivors, and Disability Insurance Benefits 8](#_9d6l7b67vyv)

[**Getting married may affect your disability benefits, depending on what type of benefits you receive. 8**](#_k5czvvs1ffn5)

[Title XVI Benefits 8](#_r0jpjrudezvo)

[Title II Benefits 8](#_hgainm1zltn)

[What are your benefits? 9](#_sbben1drv4ds)

[**Marriage & Relationship Penalties 10**](#_qa1l8nmbtc7a)

[Two People Both Receiving SSI 10](#_pverb0bbqh98)

[One Person Receiving SSI, One Person NOT Receiving SSI 10](#_cdv9l41z7xv)

[One Person Receiving DAC, One Person NOT Receiving DAC 11](#_boxxp6dk0x0)

[**Marriage & romantic partnership may mean losing Medicare or Medicaid, and other things you need. 11**](#_q6lrunbfb63)

[**Supplemental Security Income (SSI) and the 25% Marriage Penalty 12**](#_pzea7s3tucka)

[What is SSI? 12](#_3mtq1xodw2af)

[What happen﻿s when two SSI recipients marry? 13](#_u6kvs02q8hy4)

[Why i﻿s the 25% penalty for SSI recipients unfair? 14](#_m6yhzau4r9n)

[Is there any way to change the law to end the 25% penalty? 15](#_iq9zgs5hk5tj)

[**Supplemental Security Income (SSI) and the “Spousal Deeming” Marriage Penalty 17**](#_lhd666yjikc0)

[What is SSI? 17](#_n46yw3o2urmu)

[What happens if an SSI recipient marries a person who is not receiving SSI? 18](#_8g80ve5z5bv6)

[How does “spousal deeming” affect the cash benefit of an SSI recipient who marries a person who is not receiving SSI? 19](#_j1227toowi3i)

[How does "spousal deeming" affect access to Medicaid? 19](#_ecthwk38r5iu)

[Why is “spousal deeming” unfair to people with disabilities? 20](#_xj9w5ayhidm8)

[Is there any way to change the rules to give disabled people marriage equality? 21](#_5aup3m5i3d37)

[How would a living allowance deduction help some SSI recipients marry without losing their stipend or having it cut so much? 22](#_rld3n9vjrv94)

[Sources: 23](#_wo3g6flfr465)

[**Disabled Adult Child (DAC) Marriage Penalty 24**](#_qcevjiajrgkz)

[What is DAC? 24](#_j7igdp6kmzi0)

[What happens if DAC recipients marry? 24](#_zd7e6nak19dr)

[Is DAC the only SSA benefit with marriage penalties? 25](#_oiftvc4fxgfh)

[Why are the marriage penalties affecting DAC and other disabled recipients of SSA benefits particularly unfair? 25](#_uvk5aj9583jk)

[Is there any way to change the law to give disabled people marriage equality? 26](#_v5ry0g1h2se2)

[Sources: 27](#_q62v4n3054yu)

[**Take Action 27**](#_okau774j2isl)

[Follow DREDF 28](#_x2oqjut5lmeh)

[Amplify Hashtags! 28](#_q01pxmgjrqoo)

[Share your Story 29](#_tsm2ulspugy1)

[**Eliminating or Reducing Marriage Penalties – Bills Currently Introduced in Congress 29**](#_8q0n61vfla6)

[**Legislative Advocacy: What can we do? 30**](#_fnttk1vnbiae)

[Find Your Members of Congress 30](#_k6fnjevs9tgv)

[Version 1: Sample Language to Write to Your Representative 30](#_7jrhz09p8wd4)

[Version 2: Sample Language to Write to Your Representative 31](#_rvknwzc0ncyy)

[**Acknowledgments 33**](#_pxoax6elp30a)

# Introduction

As of December 2023, over 8 million Americans rely on federal benefits, such as Supplemental Security Income (SSI) or Disabled Adult Child (DAC) for their healthcare and to meet other basic needs. Most are people with disabilities. Unfortunately, unfair and outdated federal laws and policies can strip people of these crucial benefits if they get married. DREDF is working alongside organizations and advocates across the country to protect the freedom of people with disabilities to marry and form families with their chosen partners. This toolkit aims to help explain these unfair marriage penalties and share ways that anyone can get involved to help achieve marriage equality for people with disabilities and those they love.

# What’s at stake?

There are many ways that these unfair marriage penalties can impact the lives of people with disabilities and their partners.

* Access to lifesaving healthcare & community supports
* Community participation & integration
* Parenting & Adoption
* Religious freedom
* Immigration status
* Respect & Dignity
* Equality
* Constitutional rights
* Celebrating our love & commitment
* Creating lives with the people we love
* Sharing our love with the world

# What terms should I know?

## Direct Support Professionals

Direct Support Professionals (DSP) provide a type of LTSS for people with intellectual and developmental disabilities (I/DD). DSPs work directly with people with I/DD to help them take part in their communities. Some services that a DSP can provide are: job coaching, help with getting disability accommodations, personal care services, and help with finding affordable housing.

## Disabled Adult Child

The Disabled Adult Child (DAC) benefit is a Title II SSA disability benefit that provides a monthly stipend, access to Medicare, and a pathway to Medicaid. DAC is a “secondary” benefit based on the work record of a parent who is deceased, disabled, or retired. A person receiving DAC must be a dependent “adult child” aged 18 or older with a qualifying disability that began before age 22. Although DAC is technically a kind of “Child’s Insurance Benefit,” everyone who receives DAC is an **adult**. As of December 2023, there are 1.1 million people receiving DAC benefits.[[1]](#footnote-1)

## Durable Medical Equipment

Durable Medical Equipment (DME) is equipment that is used for a medical purpose and can be used repeatedly to help with common life activities such as grooming, eating, and mobility. Examples of DME include wheelchairs, CPAP machines, and blood sugar meters & test strips.

## Holding Out

Romantic partners may be treated as married for SSI purposes if SSA determines that they are “holding themselves out” (a.k.a. presenting themselves) as if they are a married couple to their community. When deciding if a couple is “holding out,” SSA considers evidence such as living arrangements, how the couple publicly refers to their relationship and whether they share finances.[[2]](#footnote-2) SSI marriage penalties for legally married couples also apply to couples found to be “holding out.” [[3]](#footnote-3)

## Home and Community-Based Services

Home and community-based services (HCBS) provide opportunities for Medicaid beneficiaries to receive LTSS services in their own home or community rather than in institutions or other settings that are segregated from the larger community. States can provide these services through Medicaid waivers.

## Long-Term Services and Supports

Long-Term Services and Supports (LTSS) are care provided for older adults and people with disabilities who need support because of physical, cognitive, developmental, or chronic health conditions; or other functional limitations that restrict their abilities to care for themselves. LTSS includes a wide range of services to help people live more independently by assisting with personal and healthcare needs and activities of daily living, such as eating, dressing, or driving. Medicaid is the primary way for people to access LTSS.

## Personal Care Attendants/Personal Care Services

Personal Care Attendants (PCAs) are people who provide Personal Care Services (PCS). PCS are various kinds of human assistance for persons with disabilities and chronic conditions to help them to accomplish activities of daily living, such as dressing or cooking. The services provided by a PCA are a type of LTSS.

## Qualifying Disability

A qualifying disability is a disability that the federal government determines prevents someone from maintaining “substantial gainful employment.” A person may be able to do some work, but the disability seriously limits their ability to maintain paid employment. SSA applies strict rules and standards for determining whether a person has a qualifying disability.

## Secondary Benefits

Secondary benefits are Title II benefits provided based on the work record of another person. Examples are Husband’s Benefits, Widow’s Benefits and DAC Benefits.

## Social Security Administration

The Social Security Administration (SSA) is a federal government agency that runs a variety of benefit programs created by the Social Security Act, including Supplemental Security Income (SSI) benefits and Title II OASDI Social Security benefits.

## Social Security Disability Insurance

Social Security Disability Insurance (SSDI) is a Title II federal disability benefit program that is based on a person’s work history and provides a monthly cash stipend along with access to Medicare. To be eligible for SSDI the government must determine that you have a qualifying disability.

## Spousal Deeming

When SSA counts part of the spouse’s income and assets as belonging to the SSI recipient. This can cause many SSI recipients to be "deemed" to have income or assets that are too high to qualify for SSI or Medicaid, or it can reduce the monthly SSI stipend.

## Supplemental Security Income

Supplemental Security Income (SSI) is Social Security Administration (SSA) program for disabled people, blind people, and older adults who have little to no income and assets. Recipients younger than 65 must have a qualifying disability. SSI provides a modest monthly stipend and in most states SSI recipients receive Medicaid. SSI is NOT a Title II benefit. As of December 2023, there are approximately 7.4 million SSI recipients, most of whom have a qualifying disability.[[4]](#footnote-4)

## Title II Benefits or Old-Age, Survivors, and Disability Insurance Benefits

Title II benefits are awarded based on the work records of individuals who are "insured" under the Social Security Act. Sometimes it’s called: “Old-Age” (retirement), Survivors, and Disability Insurance (OASDI).

# Getting married may affect your disability benefits, depending on what type of benefits you receive.

## Title XVI Benefits

Supplemental Security Income (SSI)

* Marriage penalties

## Title II Benefits

Social Security Disability Insurance (SSDI)

* No marriage penalty

Disabled Adult Child Benefits (DAC)

* Marriage penalty

## What are your benefits?

Call the Social Security Administration by phone at 800-772-1213 or via TTY 800-325-0778, or log in to [my Social Security](https://www.ssa.gov/myaccount/).

Your benefits should also be listed on your Social Security benefit letter.

SSI vs. SSDI

It can be confusing to tell the difference between SSI and SSDI because both are SSA benefits available to people with a qualifying disability. The main differences are:

1. Work record
	1. SSI does not have work record requirements and benefits are not based on prior work history.
	2. SSDI requires a minimum work history. Benefits are based on prior work history.
2. Asset limits
	1. SSI has strict asset limits.
	2. SSDI has no asset limits.
3. Healthcare benefits
	1. SSI usually qualifies a person for Medicaid.
	2. SSDI qualifies a person for Medicare after a two-year waiting period.
4. Freedom to marry
	1. SSI has marriage penalties.
	2. SSDI has no marriage penalties.

SSDI vs. DAC

It can be difficult to tell the difference between SSDI and DAC because both are Title II SSA benefits available to people with a qualifying disability. The main differences are:

1. Work record
* SSDI is based on the disabled person’s *own work record.*
* DAC is based on the disabled person’s *parent’s work record*.
1. Freedom to marry
* SSDI benefits are *not affected by marriage*.
* DAC benefits are *lost with marriage*.

# Marriage & Relationship Penalties

## Two People Both Receiving SSI

* Married or Unmarried “Holding Out”
	+ 25% cut in stipend
	+ 25% cut in asset limit

## One Person Receiving SSI, One Person **NOT** Receiving SSI

* Married or Unmarried “Holding Out”
	+ 25% cut in asset limit
	+ “spousal deeming” of income and assets from non-SSI spouse to SSI spouse. SSI benefits may be reduced or completely lost.
* Unmarried and no “holding out”
	+ resources from non-SSI partner can be potentially considered “in-kind support and maintenance.” SSI benefits may be reduced by one third.

## One Person Receiving DAC, One Person **NOT** Receiving DAC

**DAC benefits end with marriage.** If you marry you cannot receive DAC for the rest of your life.

Exceptions to rule if marrying another adult who receives:

* DAC
* SSDI
* “Old Age” retirement benefits (earliest age 62)
* Another “secondary” Title II benefit

Note: SSI spouse is not within exception

# Marriage & romantic partnership may mean losing Medicare or Medicaid, and other things you need.

SSI and DAC provide access to lifesaving healthcare and community supports through Medicaid and/or Medicare, including:

* **Long-Term Services and Supports (LTSS) like Medicaid Home & Community Based Services**
* **Durable Medical Equipment**

Marriage can also impact:

* **Personal Care Attendants/Direct Support Professionals**: Some states do not allow people to hire spouses to serve as PCA’s or DSP’s. Marriage may mean losing access to your most reliable paid PCA or DSP.
* **Resources Provided by Special Needs Trusts**

# Supplemental Security Income (SSI) and the 25% Marriage Penalty

A Deeper Dive

## What is SSI?

Supplemental Security Income (SSI) is a federal program administered by the Social Security Administration (SSA) for disabled people, blind people, and older adults who have little to no income and assets. Recipients younger than 65 must have a qualifying disability. SSI provides a modest monthly stipend, also known as cash benefits, and in most states SSI recipients receive Medicaid. As of December 2023, there are approximately 7.4 million SSI recipients, most of whom have a qualifying disability.

Whether an individual is eligible for SSI and the amount of their monthly stipend depend on their income and assets. People with more income receive less in cash benefits, and having a certain amount in income or assets makes you completely ineligible for SSI. In 2024 the federal maximum monthly stipend for SSI is $943 for an individual and $1,415 for a married couple. Therefore, to be eligible for SSI, an individual’s countable monthly income cannot exceed $943 and a married couple’s combined countable monthly income cannot exceed $1,415. An individual also cannot have over $2,000 in assets and a married couple cannot have over $3,000 in assets. These asset limits have not been changed in 35 years.

In most states, SSI recipients are also eligible for Medicaid, which covers vital services such as Personal Care Attendants (PCAs), Direct Support Professionals (DSPs), certain durable medical equipment (DME), extended hospital stays, and more. Many people with significant disabilities rely on Medicaid to live in the community with services and supports instead of in institutional settings.

## What happen﻿s when two SSI recipients marry?

When two SSI recipients marry

1) Total monthly stipend

2) Maximum countable income

3) Maximum countable assets

Are 25% less than what the total amounts would be for two unmarried individuals. This is known as the **25% SSI Marriage Penalty**.

When an SSI recipient marries someone who does not receive SSI, the couple also faces a 25% asset limit reduction, compared to two unmarried SSI recipients.

The maximum monthly federal cash benefit for individuals is $943, yet the maximum monthly federal cash benefit for married couples when both spouses receive SSI is $1,415, which means that married couples - when both spouses receive SSI - receive 25% less than the amount that they could have received separately ($943 x 2 = $1,886).

The 25% cut also lowers the amount of gross monthly income the couple can earn and still qualify for SSI. In 2024, an individual whose income came only from wages could still qualify for SSI if they earn a gross income less than $1,971, but for a couple the corresponding number would be only $2,915. Without the 25 percent cut, the couple could still qualify for SSI if they earned a gross income less than $3,857.[[5]](#footnote-5)

Finally, the asset limit for individuals is $2,000, yet the asset limit for married couples - even if only one spouse receives SSI - is $3,000, which means that married couples must own 25% less in assets than the amount that they could have owned separately ($2,000 x 2 = $4,000).

This combined reduction in cash benefit amount, income limit, and asset limit would be devastating for many people with disabilities. As a result, they are unable to marry the person they choose.

## Why i﻿s the 25% penalty for SSI recipients unfair?

The 25% penalty that affects spouses who are both SSI recipients is particularly unfair because:

* People with disabilities who receive SSI are often unable to work at the level that they would need to in order to earn back the benefits that they would lose if they marry. When both spouses are on SSI, this becomes especially concerning, as neither spouse would be able to earn enough income to fully support the other.
* People receiving SSI are required to have little to no income and over 40% live below the federal poverty line. Additionally, SSI beneficiaries are required to have very little assets available to fall back on. Therefore, the partial loss of benefits - although seemingly low - could have dire consequences on them and their quality of life.
* SSI asset limits have not changed for 35 years, but the cost of living has continued to increase, making these limits harsher and harsher over time.
* People with disabilities often have significant disability-related expenses that can make their cost of living higher than that of their non-disabled peers.
* People with disabilities have significantly lower marriage rates and higher divorce rates than people without disabilities. The overall first-marriage rate for people ages 18 to 49 in the United States is 24.4 per 1,000 for people with disabilities and 48.9 for people without disabilities. Additionally, between 2009 and 2018, nearly 1.1 million Americans with disabilities got divorced, while only 593,000 got married. In the same period, 1.5 million Americans without disabilities got divorced, while 5.2 million got married. The 25% penalty no doubt contributes to this disparity, as those with disabilities are not incentivized to marry when it would result in significant losses.

## Is there any way to change the law to end the 25% penalty?

Several bills have been introduced in Congress that would end the 25% marriage penalty for assets.

[S.2767](https://www.congress.gov/bill/118th-congress/senate-bill/2767) & [H.R.5408](https://www.congress.gov/bill/118th-congress/house-bill/5408) - SSI Savings Penalty Elimination Act of 2023 would eliminate the 25% asset penalty for married people when at least one spouse receives SSI. It would also increase SSI asset limits to $10,000 for unmarried couples and $20,000 for married couples.

[H.R.7138- Supplemental Security Income Restoration Act of 2024](https://www.congress.gov/bill/118th-congress/house-bill/7138/titles) would eliminate the 25% asset penalty for married people when at least one spouse receives SSI. It would also increase SSI asset limits to $10,000 for unmarried couples and $20,000 for married couples. This bill would also end the “holding out rule,” allow people receiving SSI to earn more money, reduce spousal deeming of income, and eliminate consideration of in-kind support and maintenance.

[H.R.6640 - Marriage Equality for Disabled Adults Act](https://www.congress.gov/bill/118th-congress/house-bill/6640) would eliminate the SSI “holding out rule,” so that the 25% marriage penalties would no longer apply to unmarried “holding out” couples. The bill would also eliminate the 25% asset penalty for people receiving SSI who marry a person receiving DAC.

Sources:

* 42 U.S. Code § 1382(b)(1), (2)
* 42 U.S. Code § 1382(a)(1)(B), (a)(3)(B)
* 42 U.S. Code § 1382(a)(2)(B), (a)(3)(A)
* 42 USC § 1382a(b)(2),(4)
* Social Security Administration, Income Exclusions for SSI Program, available at <https://www.ssa.gov/oact/cola/incomexcluded.html>.
* Social Security Administration, Monthly Statistical Snapshot, December 2023, available at <https://www.ssa.gov/policy/docs/quickfacts/stat_snapshot/2023-12.html>.
* ORDP & OISP, “Supplemental Security Income (SSI) Overview,” The United States Social Security Administration (2023), available at <https://www.ssa.gov/ssi/text-over-ussi.htm>.
* ORDP & OISP, “Supplemental Security Income (SSI) Benefits,” The United States Social Security Administration (2023), available at<https://www.ssa.gov/ssi/text-benefits-ussi.htm>.
* ORDP & OISP, “Supplemental Security Income (SSI) Resources,” The United States Social Security Administration (2023), available at<https://www.ssa.gov/ssi/text-resources-ussi.htm>.
* Social Security Administration, SSI Federal Payment Amounts For 2024, available at <https://www.ssa.gov/oact/cola/SSI.html>.
* Michelle Stegman Bailey & Jeffrey Hemmeter, “Characteristics of Noninstitutionalized DI and SSI Program Participants, 2013 Update,” The United States Social Security Administration (2015), available at<https://www.ssa.gov/policy/docs/rsnotes/rsn2015-02.html>.
* Wendy Lu, “Dating With a Disability,” The New York Times (Dec. 6, 2016), available at<https://www.nytimes.com/2016/12/08/well/family/dating-with-a-disability.html>.
* Carly Stern, “Forced to Divorce: Americans With Disabilities Must Pick Marriage or Health Care,” OZY (Apr. 25, 2019), available at<http://www.ozy.com/the-new-and-the-next/forced-to-divorce-americans-with-disabilities-must-pick-marriage-or-health-care/92284>.

# Supplemental Security Income (SSI) and the “Spousal Deeming” Marriage Penalty

A Deeper Dive

## What is SSI?

Supplemental Security Income (SSI) is a federal program administered by the Social Security Administration (SSA) for disabled people, blind people, and older adults who have little to no income and assets. Recipients younger than 65 must have a qualifying disability. SSI provides a modest monthly stipend, also known as cash benefits, and in most states SSI recipients receive Medicaid. As of December 2023, there are approximately 7.4 million SSI recipients, most of whom have a qualifying disability.

Whether an individual is eligible for SSI and their monthly stipend depend on their income and assets. People with more income receive less in cash benefits, and having a certain amount in income or assets makes you completely ineligible for SSI. In 2024 the maximum monthly stipend for SSI is $943 for an individual and $1,415 for a married couple. Therefore, to be eligible for SSI, an individual’s countable monthly income cannot exceed $943 and a married couple’s combined countable monthly income cannot exceed $1,415. An individual also cannot have over $2,000 in assets and a married couple cannot have over $3,000 in assets. These asset limits have not been changed in 35 years.

In most states, SSI recipients are also eligible for Medicaid, which covers vital services such as Personal Care Attendants (PCAs), Direct Support Professionals (DSPs), certain durable medical equipment (DME), extended hospital stays, and more. Many people with significant disabilities must have Medicaid to live in the community with services and supports instead of in institutional settings.

## What happens if an SSI recipient marries a person who is not receiving SSI?

SSI recipients can lose their cash benefits and Medicaid if they marry a person with even a modest income or level of assets. This is because SSA counts part of the spouse’s income and assets as belonging to the SSI recipient. For many SSI recipients, this means that they are then considered or “deemed” to have income or assets that are too high for SSI or Medicaid. This counting is called “spousal deeming.”

## How does “spousal deeming” affect the cash benefit of an SSI recipient who marries a person who is not receiving SSI?

When an SSI recipient marries a person who does not receive SSI, a portion of the non-SSI spouse’s gross income is counted by the SSA and can cause the SSI spouse’s cash benefit to go lower. Under 2024 benefit levels, and assuming the SSI spouse has no non-SSI income, the reductions begin once the non-SSI spouse earns about $1,030 in gross income per month. Here are some examples of what happens under the current rules when the SSI spouse has no non-SSI income:

* If the non-SSI spouse earns $1,200 per month, about the earnings of a full-time worker at the federal minimum wage ($7.25/hour), then the SSI spouse’s stipend goes from $943 to $857.50 – a 9 percent cut.
* If the non-SSI spouse earns $2,400 per month, about half of what the median U.S. worker earns, then the SSI spouse’s stipend goes from $943 to $257.50 – a 73 percent cut.
* If the non-SSI spouse earns $2,900 per month, then the SSI spouse’s stipend goes from $943 to $7.50 – a 99 percent cut.
* If the non-SSI spouse earns $2,950 per month – $35,400 a year – then the stipend goes down to $0, the SSI spouse is deemed to have too much income and the SSI spouse loses eligibility for SSI.
* Note: The final numbers may be different in some states where there is a state supplement to the federal stipend. And there are additional reductions if the SSI recipient also has income.

## How does "spousal deeming" affect access to Medicaid?

If the SSI spouse’s stipend goes to $0 due to "spousal deeming," then they no longer qualify for SSI. Losing SSI can mean losing Medicaid unless the SSI spouse can qualify for Medicaid another way.

“Spousal deeming” also applies to assets. If the combined countable assets of the couple exceeds $3,000, then the SSI spouse no longer qualifies for SSI and can lose Medicaid. With such a low asset limit, marrying someone with just $3,500 in savings could cost someone their SSI stipend and Medicaid.

## Why is “spousal deeming” unfair to people with disabilities?

Our society has recognized that individuals have a fundamental right to marry a person of their choice. But spousal deeming and other marriage penalties enforced by SSA mean that people who receive SSI do not have this same freedom. Many SSI recipients cannot survive without their benefits:

* Our country has historically organized much of its systems for the delivery of medical care and support services to disabled people through Medicaid, which means that many people with significant disabilities cannot live without Medicaid. They simply cannot receive the care or services they need any other way.
* Many people receiving SSI do not qualify for Medicare.
* SSI asset limits have not changed for 35 years, but the cost of living has continued to increase, making these limits harsher and harsher over time.
* People with disabilities often have significant disability-related expenses that can make their cost of living higher than that of their non-disabled peers.
* People with disabilities have significantly lower marriage rates and higher divorce rates than people without disabilities. The overall first-marriage rate for people ages 18 to 49 in the United States is 24.4 per 1,000 for people with disabilities and 48.9 for people without disabilities. Additionally, between 2009 and 2018, nearly 1.1 million Americans with disabilities got divorced, while only 593,000 got married. In the same period, 1.5 million Americans without disabilities got divorced, while 5.2 million got married. Spousal deeming no doubt contributes to this disparity, as those with disabilities are not incentivized to marry when it would result in significant losses.
* People under the age of 65 who receive SSI are blind or have a disability that prevents them from engaging in “substantial gainful activity.” This means that SSI recipients generally cannot earn enough money to make up for the stipends and health benefits they lose if they marry.
* Many people cannot afford the extensive healthcare and support costs associated with significant disability.

## Is there any way to change the rules to give disabled people and their partners marriage equality?

Several bills have been introduced which would limit the harm caused by spousal deeming.

[H.R.7138- The Supplemental Security Income Restoration Act of 2024](https://www.congress.gov/bill/118th-congress/house-bill/7138/titles) would reduce spousal deeming of income through increasing income disregards and would increase SSI asset limits to $10,000 for unmarried couples and $20,000 for married couples. Higher asset limits make it less likely for “spousal deeming” of assets to cost someone their SSI benefits. This bill would also end the “holding out rule,” allow people receiving SSI to earn more money, and eliminate consideration of in-kind support and maintenance.

[H.R.6640 - Marriage Equality for Disabled Adults Act](https://www.congress.gov/bill/118th-congress/house-bill/6640) would allow SSI recipients to marry DAC recipients without any spousal deeming applying. The bill would also eliminate the SSI “holding out rule,” so that spousal deeming would no longer apply to unmarried “holding out” couples.

[S.2767](https://www.congress.gov/bill/118th-congress/senate-bill/2767) & [H.R.5408](https://www.congress.gov/bill/118th-congress/house-bill/5408) - The SSI Savings Penalty Elimination Act of 2023 would increase SSI asset limits to $10,000 for unmarried couples and $20,000 for married couples. Higher asset limits would make it less likely for “spousal deeming” of assets to cost someone their SSI benefits.

The SSA can itself change the “spousal deeming” rules for SSI recipients without Congress doing anything. The statute says that a portion of the spousal income must be counted, except where the SSA finds that deeming is “inequitable under the circumstances.” Under this rule, the SSA could count less of the income received by the non-SSI spouse by first deducting a living allowance. This is what the SSA does for parents who do not receive SSI but live with a child who receives SSI.

## How would a living allowance deduction help some SSI recipients marry without losing their stipend or having it cut so much?

If SSA subtracted a living allowance from the non-SSI spouse’s gross income before deeming, then less of the non-SSI spouse’s income would be considered in calculating the SSI spouse’s stipend.

The living allowance could be based on the monthly federal benefit rate (in 2024, $943 per month). Under this option, the non-SSI spouse can earn more before the SSA calculations would reduce the SSI spouse’s cash benefits. If the SSI spouse has no income other than SSI benefits, cash benefit reductions would not begin until the non-SSI spouse earns more than about $1,972 per month in gross income. Assuming the SSI spouse has no non-SSI income, here are some examples of what would happen with a $943 living allowance deduction:

* If the non-SSI spouse earns $1,200 per month, then the SSI spouse’s cash benefit stays the same.
* If the non-SSI spouse earns $2,400 per month, then the SSI spouse’s cash benefit goes down, but by less than under the current system – to $729, or about a 23 percent cut.
* If the non-SSI spouse earns $2,950 per month, then the SSI spouse’s federal benefit goes down to $454 (a 52 percent cut), but this is more than the $0 under the current system.

## Sources:

* 42 U.S. Code § 1382
* 42 USC § 1382a(b)(2),(4)
* Social Security Administration, Income Exclusions for SSI Program, available at <https://www.ssa.gov/oact/cola/incomexcluded.html>.
* Social Security Administration, Monthly Statistical Snapshot, December 2023, available at <https://www.ssa.gov/policy/docs/quickfacts/stat_snapshot/2023-12.html>.
* Richard Balkus and Susan Wilschke, Treatment of Married Couples in the SSI Program, available at <https://www.ssa.gov/policy/docs/issuepapers/ip2003-01.html>.
* Social Security Administration, SSI Federal Payment Amounts For 2024, available at <https://www.ssa.gov/oact/cola/SSI.html>.
* Michelle Stegman Bailey & Jeffrey Hemmeter, “Characteristics of Noninstitutionalized DI and SSI Program Participants, 2013 Update,” The United States Social Security Administration (2015), available at<https://www.ssa.gov/policy/docs/rsnotes/rsn2015-02.html>.
* Bureau of Labor Statistics, Usual Weekly Earnings of Wage and Salary Workers Fourth Quarter 2023, Table 7, available at <https://www.bls.gov/news.release/pdf/wkyeng.pdf>.

# Disabled Adult Child (DAC) Marriage Penalty

A Deeper Dive

## What is DAC?

The Disabled Adult Child (DAC) benefit is a Title II SSA disability benefit that provides a monthly stipend, access to Medicare, and a pathway to Medicaid. DAC is a “secondary” benefit based on the work record of a parent who is deceased, disabled, or retired. A person receiving DAC must be a dependent “adult child” aged 18 or older with a qualifying disability that began before age 22. Although DAC is a kind of “Child’s Insurance Benefit,” everyone who receives DAC is an **adult**. As of December 2023, there are 1.1 million people receiving DAC benefits.

Medicare and Medicaid coverage allow many DAC recipients to receive personal attendant care, direct support professional care, durable medical equipment and other crucial disability-related services.

## What happens if DAC recipients marry?

Individuals receiving DAC benefits lose their monthly stipend and Medicare if they marry; they can also lose their Medicaid. The only exceptions are if the DAC beneficiary marries another person receiving DAC, a person receiving Social Security Disability Insurance, a person entitled to “old age” SSA benefits (earliest age 62), or a person receiving another “secondary” benefit. The loss of Medicare, Medicaid, and the monthly stipend would be life-threatening for many people with significant disabilities. As a result, many DAC recipients cannot marry the person of their choice.

## Is DAC the only SSA benefit with marriage penalties?

No. Recipients of Supplemental Security Income (SSI) can lose their stipend and Medicaid if they marry a person with an ordinary (or higher) income or level of assets, because the SSA counts the spouse’s income and assets. If two SSI recipients marry, both individuals face a 25% reduction in cash benefits and the asset cap.

And every beneficiary of a secondary benefit – not only DAC beneficiaries – can lose their eligibility for benefits through marriage.

## Why are the marriage penalties affecting DAC and other disabled recipients of SSA benefits particularly unfair?

The penalties that prevent DAC and other disabled recipients of SSA benefits from marrying are particularly unfair:

* People with qualifying disabilities are by definition unable to work at a “substantial gainful activity” level, meaning that disabled beneficiaries cannot readily take affirmative steps to make up for the stipends and health benefits they lose if they marry.
* Unlike most secondary benefits, DAC is based upon the disability of the beneficiary. Further, unlike other secondary benefits, the DAC benefit is associated with young age (disabilities beginning before age 22), which means that the marriage penalty applies throughout the years and ages during which many people wish to marry and start families.
* Our country has historically organized its systems for the delivery of medical care and support services to disabled people through Medicare and Medicaid, making the losses of these benefits untenable for people with significant disabilities.
* People with disabilities have significantly lower marriage rates and higher divorce rates than people without disabilities. The overall first-marriage rate for people ages 18 to 49 in the United States is 24.4 per 1,000 for people with disabilities and 48.9 for people without disabilities. Additionally, between 2009 and 2018, nearly 1.1 million Americans with disabilities got divorced, while only 593,000 got married. In the same period, 1.5 million Americans without disabilities got divorced, while 5.2 million got married. The DAC marriage penalty no doubt contributes to this disparity, as those with disabilities are not incentivized to marry when it would result in significant losses.
* People with disabilities often have significant disability-related expenses that can make their cost of living higher than that of their non-disabled peers.
* Many people cannot afford the extensive healthcare and support costs associated with significant disability.

Recipients of DAC and SSI disproportionately live in poverty. More than 40% of SSI recipients and nearly 36% of DAC recipients have incomes below poverty-- the two highest poverty rates of any category of SSA beneficiaries.

## Is there any way to change the law to give disabled people and their partners marriage equality?

In December 2023, Rep. Jimmy Panetta (CA-19) and Rep. Zoe Lofgren (CA-18) introduced [H.R. 6640 - Marriage Equality for Disabled Adults Act](https://www.congress.gov/bill/118th-congress/house-bill/6640), which, if passed, would change current law to allow DAC recipients to freely marry without losing their benefits.[[6]](#footnote-6) In addition, the bill would eliminate spousal deeming of income and assets and the 25% asset penalty for people receiving SSI who marry a person receiving DAC. Finally, the bill would end the “holding out” rule for all SSI recipients.

In 2022, the California state legislature passed [SJR 8](https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=202120220SJR8), which called on the federal government to eliminate DAC marriage penalties.

Other legislation, including [S.2767](https://www.congress.gov/bill/118th-congress/senate-bill/2767) & [H.R.5408](https://www.congress.gov/bill/118th-congress/house-bill/5408) - SSI Savings Penalty Elimination Act of 2023 and [H.R.7138- Supplemental Security Income Restoration Act of 2024](https://www.congress.gov/bill/118th-congress/house-bill/7138/titles), would address marriage penalties faced by people receiving SSI benefits.

## Sources:

* 42 U.S.C. § 402
* 42 U.S.C. § 423
* 42 U.S.C. § 1382(a), (b)
* Benefits Paid By Type Of Beneficiary, https://www.ssa.gov/OACT/ProgData/icp.html (select “Child of retired worker”, “Child of deceased worker”, and “Child of disabled worker”; DAC recipients appear in column labeled “Disabled”).
* U.S. Dep’t of Health & Hum. Servs., Centers for Medicare & Medicaid Services, Groups Deemed to be Receiving SSI for Medicaid Purposes (June 12, 2002), [https://www.hhs.gov/guidance/document/2002groups-deemed-be-receiving-ssi-medicaid- purposes](https://www.hhs.gov/guidance/document/2002groups-deemed-be-receiving-ssi-medicaid-).
* Characteristics of Noninstitutionalized DI and SSI Program Participants, 2013 Update, <https://www.ssa.gov/policy/docs/rsnotes/rsn2015-02.html>.
* David A Weaver, Marriage and Social Security: The Case of Disabled Adult Child Beneficiaries, [https://ssrn.com/abstract=3507766](https://ssrn.com/abstract%3D3507766).

# Take Action

Connect with DREDF to keep up to date as we advance marriage equality.

Image of an Instagram post with “End the #LoveTax” decorated by hearts and the DREDF logo

## Follow DREDF

On Facebook: <https://www.facebook.com/DREDF.org>

On X (formerly Twitter): <https://twitter.com/DREDF>

On Instagram: <https://www.instagram.com/dredf1979>

On TikTok: [https://www.tiktok.com/@disabilityrights](https://www.tiktok.com/%40disabilityrights)

## Amplify Hashtags!

#LoveTax

#EndTheLoveTax

#MarriageEquality

#FreedomToMarry

Connect with your family, friends, and community members!

Outline of people holding hands with text bubbles that read: “HEY! Did you hear about the marriage penalties I have to face if I marry?” and the next replying “WHAT?! That's unbelievable! How can I support you? We need to change this!”

Screenshot of tweet from February 14, 2022 from DREDF “Falling in love should not = poverty. Or the loss of essential benefits like #SocialSecurity Income (SSI) of #Medicaid. Unfortunately many #disabled people in the United States risk losing these supports if they get married. Ending the #Disability #LoveTax is long overdue!” with an image of a disabled couple on their wedding day.

Screenshot of a tweet from June 15, 2023 from Lori @Lorieslaw that reads “In the U.S. marriage forming an interabled relationship and sometimes marriage between 2 disabled people often results in a domino effect of catastrophic loss of needed disability supports. The Marriage Equality For Disabled Adults Act will help correct this. @RepJimmyPanetta”

Engage on social media platforms to reach the public, elected officials and your community members!

Image description: A young African-American woman wearing a bridal veil and glasses poses with two other African-American women. All have wide smiles. The three women are standing in the National Mall with a view of the U.S. Capitol Building in the background.

Caption reads: Tina Woods, Angela Haynes, and Patrice Jetter at DREDF’s Mass Commitment Ceremony & Rally for Marriage Equality in Washington, DC in September 2023.

Learn More at DREDF’s Marriage Equality Webpage

<https://dredf.org/marriage-equality/>

## Share your Story

DREDF is collecting stories about SSA disability marriage penalties. Want to share yours? Complete this survey:

<https://bit.ly/love-tax>

# Eliminating or Reducing Marriage Penalties – Bills Currently Introduced in Congress

118th Congress (2023-2024)

[H.R.6640 - Marriage Equality for Disabled Adults Act](https://www.congress.gov/bill/118th-congress/house-bill/6640) would

* Allow DAC recipients to marry without losing benefits
* Eliminate penalties for SSI recipients who marry DAC recipients
* End the “holding out” rule for all SSI recipients

[S.2767](https://www.congress.gov/bill/118th-congress/senate-bill/2767) & [H.R.5408](https://www.congress.gov/bill/118th-congress/house-bill/5408) - SSI Savings Penalty Elimination Act would

* Eliminate 25% asset penalty for married people receiving SSI.
* Increase SSI asset limits
	+ $10,000 if unmarried
	+ $20,000 if married

[H.R.7138- Supplemental Security Income Restoration Act of 2024](https://www.congress.gov/bill/118th-congress/house-bill/7138/titles) would

* Eliminate 25% asset penalty for married people receiving SSI.
* Increase SSI asset limits
	+ $10,000 if unmarried
	+ $20,000 if married
* End the “holding out” rule for SSI
* End consideration of in-kind support & maintenance

# Legislative Advocacy: What can we do?

## Find Your Members of Congress

<https://www.congress.gov/members/find-your-member>

Contact the national or local office of the Member of Congress you would like to meet with. The phone number and mailing address can easily be found on the House and Senate website or you can call the U.S. Capitol Switchboard at (202) 224-3121 and ask for the office of your Senators and/or Representative.

1. Schedule a meeting with your representatives
2. Write a letter or email your representatives
3. Call your representatives to voice your concerns
4. Ask organizations or groups you’re a part of to send or sign on to a letter of support for marriage equality bills

## Version 1: Sample Language to Write to Your Representative

[Your Name]
[Your Address]
[City, State, ZIP Code]
[Email Address]
[Phone Number]
[Date]

[Representative/Senator’s Name]
[Office Address]
[City, State, ZIP Code]

Subject: Please Support [Bill Number(s)] – [Bill Name(s)]

Dear Representative/Senator [Last Name],

Good morning. I live in your state (if Senator)/congressional district (if Representative) and am writing to ask for your support on [Bill Number(s)] – [Bill Name(s)]. I believe it's important to make sure that everyone, including people with disabilities, has the right to marry the person they love.

This issue is personal to me because I want to marry the love of my life but also need my disability benefits.

I hope we can count on you for your support!

Sincerely,

[Your Name]

## Version 2: Sample Language to Write to Your Representative

[Your Name]
[Your Address]
[City, State, ZIP Code]
[Date]

Please Support [Bill Number(s)] – [Bill Name(s)]

Dear Representative/Senator [Last Name],

Good morning. I live in your state (if Senator)/congressional district (if Representative) and am writing to ask for your support on [Bill Number(s)] – [Bill Name(s)]. Everyone, whether or not they are disabled, has the right to marry the person they love.

I care about this issue because I want to see my child fall in love, get married, and build a loving family of their own. Their need for disability benefits should not stand in the way.

Please support families like ours by supporting [Bill Number(s)] – [Bill Name(s)].

Thank you,

[Your Name]

## What can your state do?

States can provide access to Medicaid, including HCBS, through waivers that are directed at specific populations. They can set the financial eligibility rules for these waivers to allow disabled people to access some healthcare and community supports even if they lose their benefits because of federal marriage penalties. For example, [Idaho](https://healthandwelfare.idaho.gov/medicaid-program-income-limits)’s Medicaid for Workers with Disabilities program is available for couples with incomes less than $102,000 a year and less than $15,000 in assets.

Advocates have successfully championed changes in state laws and policies in recent years that would provide more married people with disabilities some access to healthcare and community supports. [Pennsylvania](https://www.dhs.pa.gov/Services/Assistance/Documents/INDIVIDUAL%20PAGES/MAWD/MAWD-Workers-with-Job-Success-Act-69-FAQ.pdf) changed state law to allow more disabled people to keep Medicaid after marriage. [California](https://www.dhcs.ca.gov/Pages/Asset-Limit-Changes.aspx) has eliminated its state asset limit and raised the income eligibility limits broadly for disabled people and older adults. [New Jersey](https://www.nj.gov/humanservices/dds/programs/njworkability/) has changed the eligibility criteria for the state’s Medicaid program for working people with disabilities–removing asset limits and spousal deeming requirements.

You can reach out to your state elected officials to ask that they use waivers to provide access to Medicaid for disabled people impacted by federal marriage penalties. You can also see if there are any bills currently introduced in your state that would provide access to Medicaid through changing the state’s financial eligibility for HCBS waivers and for all disabled people who need Medicaid. As with members of Congress, you can contact your state elected officials to support state bills, or volunteer to help with advocacy efforts underway in your state.

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Claire Manning

Seamus McKeon

Darcy Milburn

Brittany Owens

Representative Jimmy Panetta

Ted Passon

Elizabeth Platt

Andrew Pulrang

Alex Romain

Claire Raymond

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1. Benefits Paid By Type Of Beneficiary, <https://www.ssa.gov/OACT/ProgData/icp.html> (select “Child of retired worker”, “Child of deceased worker”, and “Child of disabled worker”; DAC recipients appear in the column labeled “Disabled”) [↑](#footnote-ref-1)
2. See Social Security Administration, Program Operations Manual System, SI 00501.152 Determining Whether Two Individuals Are Holding Themselves Out as a Married Couple, available at <https://secure.ssa.gov/poms.nsf/lnx/0500501152>. [↑](#footnote-ref-2)
3. 42 U.S.C. § 1382c(d). [↑](#footnote-ref-3)
4. Social Security Administration, Monthly Statistical Snapshot, December 2023, available at <https://www.ssa.gov/policy/docs/quickfacts/stat_snapshot/2023-12.html>, Table 3. [↑](#footnote-ref-4)
5. The benefit reduction from $3,857 to $2,915 is slightly less than 25 percent (24.4%), because of another minor marriage penalty within the SSI program. The $20 general income and the $65 earned income exclusions are the same for an unmarried person and a married couple. [↑](#footnote-ref-5)
6. This provision is known as “Lori’s Law.” [↑](#footnote-ref-6)