

This document includes a transcript of the text on each slide of “Marriage, Self-Sufficiency, & Disability” By Madison Bigelow, posted on the DAC Blog on July 3, 2024. You can access the full blog post [here](#).

Slide 1: Marriage, Self-Sufficiency, & Disability: Disability Marriage Equality Now Rally + “The Jimmy File” in Conversation by Madison Bigelow

Slide 2: Disability Marriage Equality Now Rally.

"According to the Disability Rights Education and Defense Fund, the nonprofit group that organized the rally, around 7.6 Americans receive S.S.I. About a million more are classified as disabled adult children, a designation that qualifies recipients for Medicare and a small monthly Social Security stipend. They are also at risk of losing some or all of their benefits, if they become their partners' legal spouses" ([NY Times source](#))

Slide 3: Images of married couples are attributed to:

<https://nytimes.com/2023/09/15/fashion/weddings/disabled-couples-marriage-equality-rally.html>

Slide 4: Marriage as Institution.

- Historically, marriage has been regarded as a highly oppressive institution for non-normative identities:
 - Denial of agency (for women, historically) or denial of legal marriage at large (for same-sex partners, historically).
- Despite legal advances, the terms and conditions surrounding marriage continue to ostracize non-normative identities, which are, in this case, disabled people receiving government assistance. This includes:
 - Indirectly prohibiting marriage by expanding financial barriers for Medicare recipients further preventing participation in their community, sense of self-autonomy, and respect from other people and systems within their greater society.
 - Infantilization of disabled adults. Author’s note: Reminds me of 'kids and children' rhetoric in Mansfield training school archives.

Slide 5: The Marriage Equality for Disabled Adults Act. This slide contains a long quote attributed to representative Jimmy Panetta (D-CA): "The marriage equality for disabled adults act introduced today includes the following four provisions to ensure that DAC's

(Disabled adult children) who would like to marry don't need to sacrifice their much-needed health care and benefits from Social Security.

- 1: The act eliminates the requirement that a DAC beneficiary be unmarried.
- 2: The act eliminates the rule that removes DAC benefits should a beneficiary marry.
- 3: The act changes Social Security's rules about common law marriages.
- 4: The act ensures that, in a marriage between a DAC beneficiary and any other person, both spouses may continue to receive SSI and Medicaid as if they were unmarried.

Slide 6: Why has this taken so long? Why is the ability to marry and have access to government assistance mutually exclusive? The author provides a list of hypotheses:

- Prevent the 'threat' of ruining 'marriage sanctity' by those of non-normative identities.
- Prevent the economic participation of disabled adults as a 'familial' unit plus benefits that come with marriage status.
- Deny disabled adults their 'adulthood' slash self-sovereignty slash agency slash autonomy slash right to make decisions for themselves.
 - Evident in the fact that **even** in Panetta's proposed bill, they're **still** called Disabled Adult Children.
- Invalidate personhood to disabled adults who've been historically marginalized.
- Draw an impermeable boundary between disabled and nondisabled individuals.
 - Either you **are** disabled, need government assistance, and cannot get married for financial reasons, or you are not disabled **enough or at all**, will not receive government assistance, and are allowed to get married.
- A final hypothesis or conclusion: add another impressive bullet point to America's long resume of human rights abuses.

Slide 7: "The Jimmy File." Synopsis: "A college student makes a friend and then, over the years, learns about friendship's duty in matters of mental retardation, the horrors of Mansfield Training School, and the family secrets held by an impersonal bureaucracy."

Slide 8: "About a year after I met him, Jimmy and Mary Tarquinio, a resident in his group home, got their own apartment on Zion Street, abutting the Trinity campus. **Cheerful and easygoing, Mary is a natural counterpoint to Jimmy's intensity. He's easily agitated; she's hard to ruffle. He talks constantly; she listens and laughs. She even balances**

him out physically. Where he is a wiry bundle of sharp angles, she is a softly contained square, tiny and plump. Mary is the one person who can tell Jimmy to knock it off when his ramblings and repetitions get to be too much. She also could read, write and cook--skills Jimmy lacked and desperately needed to live on his own. At 59, she was 20 years his senior, but somehow, that never seemed to matter. He clearly adored her, and in time it transformed him."

Slide 9: "In the spring of 1979, Jimmy and Mary decided to get married and surprised me by asking me to be maid of honor. I feared I wouldn't be able to make it back from a summer job out of state, so I turned them down. **Ben and other Trinity friends attended and watched Mary take her place beside her niece instead; Jimmy's cousin served as best man in the Meriden church his grandparents attended.**

The reception was held downstairs, with Jimmy's aunt arranging for flowers (all silk), food (prepared by her friends) and music (a record player, Ben recalls). For their honeymoon, they visited another of Jimmy's aunts in California, the only time either of them has been on a plane."

Author's note: This is key! -- I think it really exemplified the entire point I'm trying to make. Maybe their marriage didn't look like the typical American wedding, but they still DID IT. Their disabilities did not prevent them from planning the wedding, having people show up or actively participate in the ceremony. Just because marriage 'conventions' might not strictly apply here doesn't mean that Jimmy and Mary weren't able to get married. Instead, they adapted the milestone to better suit themselves.

Slide 10: "Jimmy and Mary moved into their first-floor efficiency in the Alfred Plant Senior Housing when it was brand new; **they were made eligible by Mary's age, then 66.** There was a time when Jimmy was eager to be rid of such help. Now, he appreciates it for what it is: **a resource that can help him build an independent life. As a disabled person, he receives monthly Social Security and federal and state disability checks, which cover his expenses.** His mother sends a little money every month for extras, like going out to eat. For healthcare, he has Medicaid and Medicare. In addition to Sharp and several other DMR employees, **he and Mary also have the support of Connecticut Community Care Inc. and the state Office of Protection and Advocacy for Persons with Disabilities. Jimmy is a master at negotiating the system to get the benefits he and Mary need."**

Author's note: Even in a world where Jimmy and Mary did not get married, these benefits still weren't enough to completely support them. They helped, but they still needed to

collect a myriad of different aids slash supports and Jimmy still sought to bartering around the neighborhood.

Slide 11: “On a sunny afternoon last spring, Jimmy introduced me around at what he likes to call “Lundquist Plaza,” the small strip of family-owned shops across the street from their Farmington Avenue apartment. At the Dairy Plus convenience store, he greeted familiar customers with a buoyant, **“Hey, how you doing?” and a wave of his good hand. “See,” he told me proudly. “Everybody know Jimmy Lundquist.”**

Jimmy has worked out an informal bartering arrangement with the owners, Daksha and Prakash Thaker, sweeping and picking up trash outside the store in exchange for free coffee, soda, an occasional doughnut, or lollipops for the neighborhood kids. He told me he keeps an eye on some of the older children for their mothers, calling them if the kids are smoking or skipping school.

Next door, at the West Hartford Laundromat, Jimmy saved his biggest greeting for owner George Odelius. Soft-spoken, with a kind face and easy manner, Odelius, his wife, Vina, and grown daughters have welcomed Jimmy and Mary into their family, including them in holiday gatherings and lending a hand when needed. **It’s a friendship, like so many of Jimmy’s, built on moments accumulated over years—daily chats over morning coffee and afternoons shooting the breeze around the shop. Jimmy sweeps the sidewalk each day, and has taken to stopping by on Sundays, the one day Odelius isn’t there, to check on the place and straighten up. In exchange, Odelius does his dry cleaning for free. During the long months of Mary’s hospitalization, Odelius did all his laundry for free, and Jimmy called him every night to talk.”**

Slide 12: Understanding Self-Sufficiency:

- Universal Declaration of Human Rights:
 - From discrimination, 2.
 - To recognition before the law, 6.
 - To equality before the law, 7.
 - To marriage and to found a family, 16.
 - To social security, 22.
- Are current conditions sufficient to deem the situation a human rights violation for DAC's?
 - Under UDHR... Yes.
 - Morally, while much more subjective, ... also feels like a yes.

Slide 13: Understanding Self-Sufficiency, The Jimmy File as a model: Independent living for DAC's does not mean individuals are completely severed from institutional or community aid. Survival is a negotiation between social symbiosis and federal support. Support from government and marriage do not need to be mutually exclusive. DAC's are already hyper-aware of income they receive as individuals as to not impact federal medical benefits. This connects to Institutional disabling of already-disabled individuals: work limited hours slash jobs to retain S.S.I. payments, prohibit full economic participation in their community, impact denial of marriage to further prevent social slash political slash economic participation.

Slide 14: What does The Jimmy File prove?

- Disabled adults can and do live independently, all the time.
- Alternate means of living and survival;
 - Jimmy (and Mary's) life does not mimic the typical 'American' life. But also, how could it after you've been institutionalized and dripped into 'mainstream' society with few means of support?
- Challenges ideals of capitalism and the nuclear family.
 - Productivity presents differently; the notion of the family presents differently.
 - Alternative means of living may mean being unable to participate in or benefit from larger capitalist systems at play, Jimmy subverts conventions of livelihood.

Slide 15: What does "The Jimmy File" prove?

- Why the term "self-sufficiency" doesn't really exist; 'help' is not exclusively for disabled individuals.
 - Jimmy necessarily relies on others to support him and his wife.
 - **However**, community members are just as reliant upon him within their social ecosystem.
 - Relationships are constantly evolving, shifting, and changing.
 - While disabled by larger institutional systems, Jimmy is just as much a part of the social fabric of his immediate community as any other able bodied person, and is treated as such.
 - Kinship is key! We all need friends and family to live, not just survive.