



Forced To Divorce: Americans With Disabilities Must Choose Marriage Or Health Care

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Susan approached her husband, heart thumping, as he sat in their living room. Days earlier, on Valentine's Day, she had been diagnosed with colon cancer. Now, her world was about to further unravel. Susan mustered up all her courage and told her husband that they needed to divorce.

Married for nearly three years, they were still in love and wanted to stay together. But to remain married would risk losing the health care Susan desperately needed. Diagnosed with rheumatoid arthritis at age 4, she has lived with chronic pain for as long as she can remember. Susan struggles to get around without a cane or power chair during flare-ups. She didn't have private insurance at the time of her diagnosis, so Medicaid was critical for her to get the care she needed to manage her disability.

Her husband worked as a roofer and earned \$12 an hour. His seasonal income fluctuations left Susan hovering near the Medicaid eligibility cap, which came out to around \$20,600 annually at the time, in 2007. She already had briefly lost coverage during their marriage because her eligibility was based on household income. The cancer diagnosis was the tipping point. Susan's husband had recently switched companies and earned a pay increase to \$14 an hour. Warmer spring months would bring additional construction work. But more income wasn't necessarily good news. Instead, it surfaced the nagging anxiety that Susan could lose Medicaid eligibility again, just when her medical bills were about to skyrocket.

Divorce, they decided, would eliminate the month-to-month possibility of losing coverage — and the fear that came with it.

Susan's part of a growing number of America's 61 million people with disabilities facing acute trade-offs between health care and marriage. Couples with disabilities historically have faced greater barriers to marriage. But an OZY investigation reveals 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disparity in marriage rates between those with and without disabilities in the years since Susan's divorce, spawned by outdated eligibility thresholds and a convoluted web of health care programs that many find difficult to navigate.

Between 2009 and 2018, nearly 1.1 million Americans with disabilities got divorced, almost twice the number — 593,000 — that got married, U.S. Census Bureau data show. In the same period, 1.5 million people without disabilities divorced — less than a third of the 5.2 million who

got married. This “divorce gap” raises the question of how many more like Susan are ending happy marriages to secure health care.

Experts say the system has been stacked against marriage for people with disabilities for decades, stretching back to the eugenics movement. Between the 1920s and ‘70s, more than 60,000 people with disabilities were forcibly sterilized to gradually rid the human gene pool of traits that were then considered undesirable. The 1927 Supreme Court decision upholding sterilization, *Buck v. Bell*, 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.

But across the country, couples with disabilities face the added burden of complex regulations that critics say are out of step with the times. Supplemental Security Income (SSI), a federal program meant for Americans with disabilities with limited resources or over age 65, is only available to couples with \$3,000 or less in assets. This cap has remained in place since 1989 — although the equivalent of \$3,000 then would be more than \$6,000 in 2019. And for a couple with disabilities, monthly SSI cash benefits are reduced by 25 percent upon marriage to account for the efficiency of shared expenses like housing, according to the Office of the Chief Actuary.

Individuals who qualify for the Disabled Adult Child program, which is linked to their parents’ work history, lose benefits upon marriage. What’s more, the Office of Inspector General and Social Security Administration (SSA) can determine that a cohabiting couple is “holding out to the community as though they are married” — which would strip them of the benefits they sacrificed marriage to protect. “When two people consider themselves to be married and convey that to the community, they are considered married for SSI purposes whether they are legally married or not,” says Nicole Tiggemann, a public affairs specialist at the SSA.

Some states are trying to avoid the marriage-or-health-care dilemma. Certain ones have raised Medicaid income and asset caps for people with disabilities who are able to work. Some offer specific buy-in programs or assess eligibility based on the applicant’s income alone. But even with those higher thresholds, the annual eligibility caps for workers with disabilities in 30 out of 50 states are below \$34,489, America’s per capita income, according to the Census Bureau’s latest available data from 2017. Then there’s the legal morass of complex regulations that advocates say are poorly communicated by the responsible agencies.

In effect, all of this means that many Americans with disabilities must pick only two out of three: marriage, economic security and comprehensive health coverage. “As we see amazing strides in marriage equality, disabled people are still being excluded from the conversation,” says Robyn Powell of Brandeis University’s Lurie Institute for Disability Policy.

Susan, who is now in her 50s and whose name has been changed to protect her identity, recalls listening to a doctor tell her parents when she was 15 that she’d never marry or give them grandchildren. He spoke like she wasn’t in the room, she says. Not long after, she met the man who would much later become her husband. “I didn’t think he would ever like me, because I didn’t think any boys liked me,” Susan says. He was the neighborhood paperboy, her first boyfriend and her first kiss.

She never expected to bump into him 29 years later, sitting on a bench at an amusement park, as her two sons rode a roller coaster. Hours after they parted ways, he called to ask her on a date. They sat in a park together, watching her sons and his daughters play in the sun. In 2004, they married at a local church on a windy October day. He helped Susan climb up seven steps to reach the altar, her tennis shoes concealed underneath her white wedding gown.

Susan knew then that her partner's income and assets meant she could lose Medicaid and SSI checks she'd been getting since age 18. But her health had felt manageable back then. She was willing to make that trade-off for marriage. Cancer, however, changed the equation.

Following same-sex marriage legalization in 2015, Rabia Belt, a legal historian at Stanford Law School, called marriage for people with disabilities "the last marriage equality frontier." Four years later, those regulatory barriers still haven't been framed as a civil rights issue, says Dom Evans, a filmmaker, public speaker and activist who is multiply disabled and transgender.

"There's a bubble around the disabled community," Evans says. "We don't often get to talk for ourselves."

Evans represents the other side of the coin: Those who avoid ever marrying because of the impact it would have on their benefits. He was 18 when he met the love of his life online. It was three years before she reciprocated. Their connection culminated in an eight-hour bus ride so she could cook Thanksgiving dinner with him, sparking a relationship that's 16 years strong. Yet he can't marry his girlfriend without losing Medicaid, which is the only insurer that fully covers the home and community-based services he needs.

He is meticulously private about his relationship with his girlfriend to people outside his close circle and corrects those who joke that she's basically his wife. He worries about the SSA concluding that he and his partner are "holding out" as a married couple, and he can't afford to lose the Medicaid coverage he's forgone marriage to have. On top of all this, he also needs to carefully limit his income.

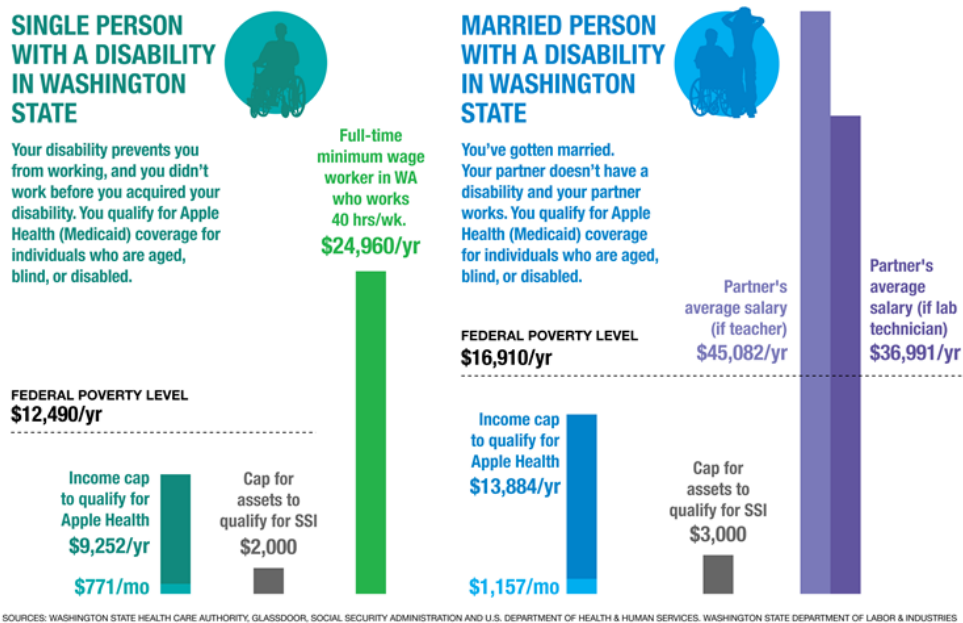
Evans has spinal muscular atrophy, a blood disorder, OCD, chronic pain and respiratory issues and is hard of hearing. He cannot walk and needs help eating, bathing and going to the bathroom. But to keep Medicaid, his income can't cross a threshold of roughly \$31,200 annually. Once he touches that bar, Evans — who is self-employed — takes on assignments for free. His yearly home-care costs of more than \$50,000 would otherwise be untenable. "People assume we're lazy and don't want to work," he says. "I'm one of the hardest working people making under \$30,000 a year. I can guarantee it."

For others, religion can add another layer of complexity. When Leila Ahmouda, who has cerebral palsy, first started getting SSI checks at the age of 22, she wasn't aware she could lose those benefits if she got married, she says. She must choose between her faith and the disability benefits she needs. "As a Muslim woman, I cannot live with a man unless I am actually legally married to him," she says. Ahmouda would choose to drop SSI benefits if she found someone she wanted to marry, she says.

The government isn't blind to these dilemmas. The home and community-based services financed through Medicaid are a "lifeline" for those with disabilities, says James Capretta, a

health care and budgetary specialist at the conservative American Enterprise Institute. However, even those who are eligible for home and community-based services — either because they aren't married or their household income is below the state threshold — can't count on them. Some 700,000 people across the U.S. are on waiting lists, according to the Kaiser Family Foundation. The federal benefit rate for SSI also hasn't kept pace with the actual cost of living. In 1980, the per capita health-care cost ate up 25 percent of the maximum SSI payout for couples with disabilities, leaving the rest for other expenses. Today, average health costs would devour 83 percent of the SSI's current maximum payout.

So why has the system ended up like this? Most Social Security programs were developed with the assumption of single-income households when fewer women worked outside the home, says Michael Tanner, who specializes in social welfare policy at the Cato Institute, a libertarian think tank. Not only have social norms evolved, but life expectancy for people with disabilities has also dramatically advanced. For people with Down syndrome, for example, it rose from 25 years in 1983 to 60 years in 2018.



Capretta says public policy discouraging marriage disadvantages society, but he points out that expanded coverage would strain the already stretched federal budget. The rules attempt to limit expenses by targeting the neediest, likely to be single-income households, Tanner says. But there's "no logic" to how income caps were set. "There wasn't a group of philosopher economist kings who were developing the perfect eligibility level," Tanner says. "These things are thrown together by congressional committees on the basis of what can get votes."

On the surface, concern about deteriorating marriages should win the attention of both pro-family Republicans and liberal Democrats. "But we haven't seen a lot of legislative effort," Tanner adds. On the right, he chalks this up to reluctance to spend money and a belief that social welfare programs are abused. Democrats, conversely, might hesitate to single out people with disabilities given that everybody living in poverty needs support, he says.

But ending a marriage — or never starting one — isn't always a fix. Michael Liner, a Social Security disability attorney, has an unmarried client who identified his partner as his wife when he was hospitalized for a stroke so she'd have power of attorney. When later answering questions for his SSI application, the client joked about that incident and believes this is why his disability claim was denied, Liner says.

The SSA, for its part, has repeatedly told courts that it carries out a thorough investigation in each case. For instance, it determined that a legally unmarried Tennessee couple was considered married for the purpose of SSI — and thus ineligible for benefits — because they had filed income tax returns as “married, filing joint return” and received mail by the same last name. It didn't matter that Tennessee does not recognize common-law marriage.

But ultimately, the SSA's assessment of whether a couple is “holding out” as married is always subjective, Liner says. The SSA's “Statement of Marital Relationship” form asks applicants how their partner “introduced” them to others and “how mail was addressed” to them. Neighbors, employers and relatives can be asked if they “consider them husband and wife” and “In your opinion, did (do) they maintain a home as husband and wife?” Appeals against SSA rulings can take years, says Liner.

Evans, for one, was in the closet as trans and queer for decades. But in 2019, it's the “layers of bureaucracy” — rather than the law — that prevent him from getting married. He recalls when others celebrated finally being able to come out after the 2015 Supreme Court ruling legalizing same-sex marriage. “There were some of us standing behind, saying ‘what about us?’”

Rowan is torn between the difficult path Susan took and the sacrifice Evans has made. And emotion is only part of what's complicating a decision on whether to move forward with a divorce.

Rowan and Alex first hit it off on a rainy winter night in 2010. They were driving up from Olympia to Seattle with friends to see a Pink Floyd laser show. In the misty darkness, Rowan's friend rear-ended their car on I-5 North. They ended up missing the show, but Rowan and Alex — whose names have been changed to protect their identities — spent the night together. In 2012, the two got married.

Now 28, Rowan was diagnosed in 2015 with POTS, a disorder that affects involuntary processes like breathing, blood pressure and digestion. Unable to work, Rowan needs Medicaid for home-care, otherwise unaffordable at a median cost of \$64,000 in Washington. But Alex earns nearly four times the monthly state household income threshold of \$1,157.

Divorcing — even though they still love each other — could solve that problem and yield financial independence. “Our relationship does not have an equal power dynamic anymore,” Rowan says. On the other hand, staying married and having Alex's private insurance allows Rowan a greater choice of doctors, though it means higher out-of-pocket costs. Teetering on the brink, Rowan must determine how marriage measures up with practical survival.

Experts suggest the first step toward changing a system that deters marriage is mainstream awareness of policies that force people like Rowan and Alex to make these choices. Americans

as a whole must stop viewing disability through a charity lens, Powell says. “This isn’t a matter of helping,” she says. “You have a civil right.”

Not everyone agrees. Financial penalties aren’t the same as denial of a fundamental right, Tanner says, and he doesn’t expect the courts to see it that way. To him, making marriage easier is “a matter of desirable social policy rather than a civil rights question.” Powell, though, hopes the “ADA generation” — who came of age after the Americans with Disabilities Act passed in 1990 — will shift attention toward marriage equality. While older Americans with disabilities celebrated victories like the ability to live in homes rather than institutions, this younger generation expects more, she says.

And as the 2020 election approaches, their potential to influence change is growing — particularly as the number of eligible voters with disabilities has increased at a rate faster than those without. In all, 35 million people with disabilities — about a sixth of the total electorate — were eligible to vote in November 2016, according to Rutgers University research. Add voters with household members who have a disability and this number jumped to more than 62 million, a quarter of the total electorate. These voters could impact both major parties: A 2016 Pew survey of voters with disabilities found 52 percent leaned Democrat, while 43 percent leaned Republican.

Some legislators are taking note. Two Medicare-for-all bills introduced in Congress in 2017 and in February this year aim to include home and community-based services, which Medicare currently doesn’t cover. Additionally, the Disability Integration Bill introduced in Congress in January highlights Powell’s distinction, demanding that states view such services “from a civil rights perspective.”

Meanwhile, the recently introduced Marriage Access for People with Special Abilities Bill would ensure that only the applicant’s income and resources are counted toward SSI eligibility, rather than household income. Qualifying individuals could access Medicaid even if they would normally cross the income or assets limit. However, the bill only applies to those with intellectual or developmental disabilities. None of the bills has advanced out of committee in either chamber of Congress.

Many Americans have never had to weigh love against their health. But a sudden accident or illness that causes disability could thrust unexpected choices upon anyone. Susan, for one, found herself staring at divorce papers she didn’t want to sign for two months after her cancer diagnosis in 2007. Eventually, she forced herself to sign them.

She and her partner still love each other and keep up their cherished rituals, stealing brief escapes to sit together at their favorite park, where it feels like the rest of the world is far away. But to Susan, that marriage certificate was especially meaningful because she’d been told that marriage and a family wouldn’t be possible for her. Even though her partner knows she didn’t want to get divorced, she still feels responsible.

She mourned this choice but saw no other path forward. “I took that sacred part of being a wife to heart,” she says. “That means everything to me.”