Systems Transformation Guide to Disability Economic Justice:

Income, Wealth Building and Basic Necessities

national partnership for women & families

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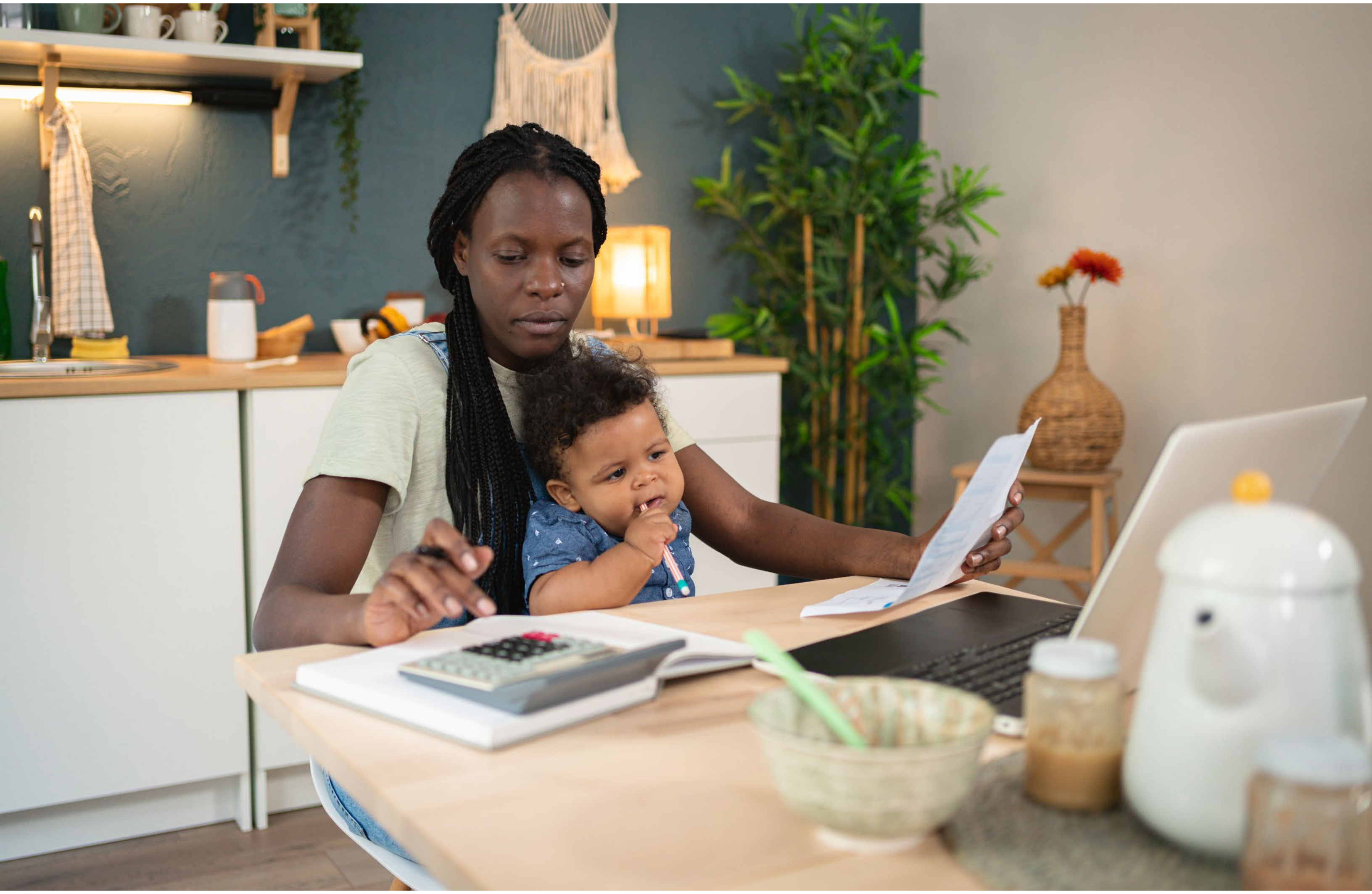
Executive Summary



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The intersection of disability and gender justice has long been ignored in framing economic policy.

At the National Partnership for Women & Families, we recognize the deep history of interactions between disability and gender justice through institutionalization, stripped autonomy and further marginalization. Ultimately, ableism, racism, sexism, imperialism, colonialism and other forms of eugenic thinking have framed economic policies.

Our country's economic system was not designed to allow disabled people, particularly disabled women of color, to survive and secure basic needs, let alone to thrive. Disabled women face significant barriers to wealth building due to public benefit restrictions; debt, expenses and the cost of being disabled; the United States' broken credit system; a lack of access to financial services; and financial abuse and exploitation, among other concerns.

Discrimination, stigma and other factors drive policies and actions that, ultimately, keep disabled people in poverty. For disabled women of color, these concerns are compounded and exacerbated.

In this installment of the "Systems Transformation Guide to Disability Economic Justice," the National Partnership for Women & Families makes the following recommendations:

- **Congress should pass the SSI Savings Penalty Elimination Act and the SSI Restoration Act.** More specifically, Congress should do the following:
  - Eliminate, or raise, the asset limit requirement for Supplemental Security Income (SSI) recipients and tie it to inflation by, at a minimum, passing the SSI Savings Penalty Elimination Act.
  - Increase benefit amounts, particularly for SSI recipients.
  - Eliminate the marriage penalty related to asset limits and benefit amounts for SSI recipients.
- **Congress should adjust income and substantial gainful activity requirements** to keep pace with inflation.
- **Congress should pass the ABLE MATCH** Act to enact a federal dollar-for-dollar match for ABLE account owners who make $28,000 or less per year.
- **The Social Security Administration (SSA) must overhaul its wage reporting system** to ensure that 1) wage reports are updated in a timely manner; 2) all overpayments that are a result of the SSA's reporting delays are automatically waived; 3) wage reporting requirements are always clear and consistent for all benefit recipients; 4) the definition of "without fault" in overpayment waiver

processes is broadened and clarified to take into account the vast number of disabled SSA benefit recipients; and 5) there is a time limit on how far back SSA can go to collect overpayments.

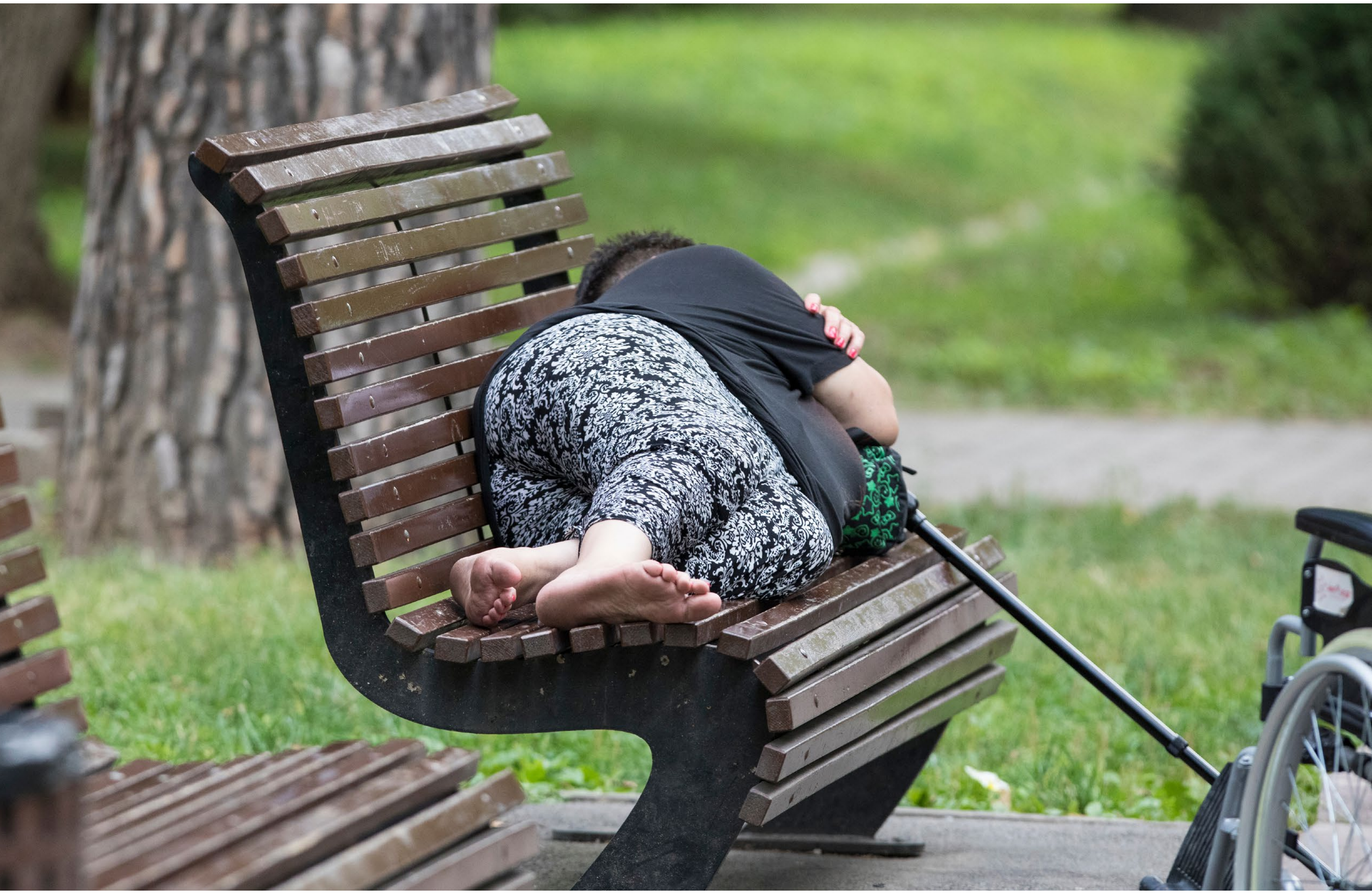
- **The SSA should automatically collect no more than $10 per month in overpayment recoupment** for SSI, the Qualified Medicare Beneficiary program, the Low Income Subsidy and should ensure that beneficiaries are automatically eligible for payment plans of $10 per month.
- **States should eliminate asset limits for working Medicaid recipients.**
- **Congress and/or state governments should support debt jubilees.** A debt jubilee is when debt is canceled and cleared from the public record. Even a medical debt jubilee alone would eliminate at least $220 billion in debt for 20 million people.
- **State offices of attorneys general, the Federal Trade Commission (FTC) and the Consumer Financial Protection Bureau (CFPB) must collaborate** to increase Fair Debt Collection Practices Act (FDCPA) and consumer protection enforcement and education.
- **The Biden administration must fulfill its promise to address the student loan crisis through other legal and administrative means,** despite the Supreme Court's decision to disallow the administration's initial plan to cancel at least $10,000 in student loans for eligible individuals. Moving forward with its plan to expand debt relief to those with high cost burdens, including medical and child care costs, is one avenue. Even then, more is needed. Congress fully canceling federal student debt would better address the inequities posed by student debt, predominantly for women, people of color, people with disabilities and other marginalized individuals. Congress should extend total and permanent disability (TPD) discharge to all private student loans, as proposed in the Private Loan Disability Discharge Act or the amendment proposed in the National Defense Authorization Act.
- **The Department of Education must clarify requirements for TPD discharge** via certification and simplify the process.
- **The Department of Education must continue to automatically cancel student loans** owed as a result of attending specific for-profit colleges with abusive and fraudulent practices. These schools target disabled people, people of color, veterans and other marginalized communities.

- **Congress should pass legislation such as the Protections and Regulations for Our Students (PRO Students) Act** to protect students from predatory practices by for-profit colleges by establishing a student relief fund, prohibiting the use of federal funds for recruiting and marketing, requiring for-profit schools to receive at least 15 percent of revenue from non-federal funding and establishing a complaint tracking system, among other things.
- **The Department of the Treasury must develop and adopt a clear policy and guidance on federal student loan garnishment determinations.** The department must ensure it is publicly available and accessible for disabled borrowers, including by creating plain language and targeted guides.
- **Congress must establish free and/or affordable higher education options** to support disabled women, particularly disabled women of color, who wish to pursue postsecondary education.
- **States should adopt the Model Medical Debt Protection Act and Congress should pass the Strengthening Consumer Protections and Medical Debt Transparency Act** to protect patients from abusive debt collection and reporting practices.
- **State agencies and attorneys general, as well as the CFPB and the FTC, must expand, prioritize and continue enforcement** against abusive medical debt collection and reporting practices.
- **The Department of the Treasury — specifically, the Internal Revenue Service (IRS) — should set standards for hospital financial assistance programs** to prevent inconsistent and opaque hospital practices and make the application process simpler and more transparent for patients.
- **The CFPB should undertake rulemaking under the authority granted to the agency by the Fair Credit Reporting Act (FCRA)** to prohibit reporting of all medical debt or all debt for medically necessary procedures. While Experian, Equifax and TransUnion have agreed to remove medical debt under $500 in collections from credit reports, this alone is not sufficient.
- **Congress should pass the Stop Unfair Medicaid Recoveries Act,** which would prohibit state Medicaid programs from using estate recovery to recoup the costs of benefits.
- **States should cease pursuing Medicaid estate recoveries.**

- **Office of the Comptroller of the Currency (OCC) and the Federal Deposit Insurance Corporation (FDIC) Community Reinvestment Act (CRA) regulations must explicitly address disability and servicing disabled borrowers,** who are disproportionately likely to live in low- and moderate-income neighborhoods contemplated by the act.
- **Congress should establish a public credit registry under the control of the CFPB** to replace the major three private, for-profit credit bureaus — Equifax, Experian and TransUnion.
- **Congress should pass the Comprehensive CREDIT Act,** which would reduce the amount of time that negative information can remain on a credit report, remove medically necessary medical debt from credit reports, provide for free credit score access and more.
- **Congress should limit the use of credit history** in the housing and employment context.
- **The CFPB and the Department of Justice must collaborate** to strengthen enforcement under the Equal Credit Opportunity Act (ECOA), the Fair Housing Act (FHA), the Americans with Disabilities Act (ADA) and other anti-discrimination laws.
- **The CFPB, the FTC and other agencies must continue their efforts to combat discrimination under their authority** to pursue unfair and deceptive acts or practices.
- **Congress must add disability as a protected class under ECOA** to close any loopholes in protections for digital financial services and financial technology (fintech) under the FHA or ADA.
- **Congress should pass an interest rate cap on all consumer loans** to protect consumers targeted by predatory lenders. While the 36 percent cap proposed in the Veterans and Consumers Fair Credit Act was a good start, more protection is needed.
- **The CFPB and the FTC must both continue and increase enforcement actions against predatory lenders.**
- **States should pass anti-predatory lending laws,** and those that have passed these laws should both continue and increase enforcement of them.
- **Congress should create a large-scale public banking system** to provide affordable, low-interest loans and accounts.

- **The Department of Justice, CFPB and other agencies should prioritize enforcement of the ADA, the FHA and the Rehabilitation Act** to ensure that disabled people have access to banking and financial services.
- **OCC and FDIC CRA regulations must incentivize serving disabled people,** particularly disabled people of color, who are more likely to have low incomes.
- **Congress should pass the Guardianship Bill of Rights Act,** which is an important step in establishing 1) standards for when guardianship and less restrictive alternatives to guardianship are appropriate; 2) due process protections; and 3) standards pertaining to fundamental rights that cannot be restricted, among other standards.
- **Congress should invest in services and resources for disabled people** who require financial resources and assistance with handling cases of abuse and exploitation.
- **States should improve enforcement throughout the guardianship decision-making process** to ensure that procedural and substantive due process are guaranteed.
- **States should provide transition services for people with disabilities.**
- **States should reduce guardianship usage and appointments in favor of less restrictive alternatives,** such as supported decision-making.
- **States should adopt a supported decision-making framework.**
- **States should improve guardianship oversight.**
- **States must establish and invest in more extensive programs through Adult Protective Services and/or Offices of Attorneys General** to ensure that disabled adults can pursue claims related to financial abuse and exploitation.

Introduction



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Disability is both a cause and consequence of poverty.

People in poverty may experience disability due to environmental trauma; lack of access to quality, affordable medical treatment; injuries resulting from physical labor and more.[1] Disability may lead to poverty for many of the factors explored in this installment, including the unique challenges disabled women face related to credit access, debt and wealth building.

Gender, race and other aspects of identity play a significant role in whether disability causes, or results from, poverty.

Barriers related to employment,[2] asset building, income limitations and additional expenses (also known as the "crip tax"), among other concerns, contribute to wealth building challenges and increase the likelihood of debt in disabled households.

On average, households with a disabled member require 28 percent (or $17,690) more in income per year to maintain the same standard of living as nondisabled households.[3]

Additional costs may include medical care, assistive technology, a personal care attendant, accessibility adjustments and modifications, adaptive clothing, meals for specialized diets and much more.[4] Data that considers gender and race in these expenses would be beneficial; however, the potential impacts of race, gender and other identities on costs cannot be understated. Meanwhile, critical, life-saving public benefit programs are often accompanied by income thresholds, asset limits and other strict requirements that keep disabled people — particularly disabled women of color — in poverty. All the while, benefit programs such as Supplemental Security Income (SSI) barely provide enough to meet basic necessities — $943 per month for an individual and $1,415 per month for an eligible couple in 2024. Additionally, disabled people are more likely to work in low-wage jobs[5] or be unemployed.[6] This means that, overall, disabled people experience increased costs without additional income; in fact, their income is generally lower.

The lack of wealth and savings makes it difficult to make ends meet. According to a 2017 National Disability Institute report, about one-quarter of disabled adults found it "very difficult" to cover expenses and pay bills, with disabled women having greater trouble making ends meet than men with or without a disability.[7] Disabled women and Black disabled people are also at greater risk of being unable to come up with the money if an unexpected need arises requiring a payment of $2,000 or more.[8]

This installment will address the barriers that disabled women face to building wealth, as well as put forth policy proposals that will help address these concerns. While several of these policy proposals will ease the burden on disabled women, without systemic change, disabled women of color will continue to be forced into — and trapped in — poverty.

Public Benefit Programs Prohibit Disabled People from Saving Money

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Public benefits programs often fail to lift disabled people out of poverty.

As detailed in the Systems Transformation Guide to Disability Economic Justice: Public Benefits, public benefits programs that aim to support disabled people — such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI) and Medicaid — often fail to lift disabled people out of poverty. Modest benefits, asset limits, income limits, work disincentives and the pervasiveness of overpayments are some of the factors that keep disabled people on public benefits in poverty. Overall, in 2022, 55 percent of Social Security beneficiaries were women.[9] Women also make up the majority of adult Medicaid recipients.[10]

The maximum SSI benefit for 2024 is $943 for an eligible individual and $1,415 for an eligible couple. As a result, most SSI beneficiaries remain within 150 percent of the federal poverty level.[11]

The maximum benefit for SSDI recipients is $3,822 per month in 2024. Further, Medicaid and SSI eligibility may be at risk if a beneficiary's assets are above specified limits. For SSI, this amount is $2,000 for an individual and $3,000 for a couple. For Medicaid, this amount varies by state. Strict asset limits are problematic for working and non-working disabled people who rely on these benefits. Eligible disabled individuals can open Achieving a Better Life Experience (ABLE) accounts.[12] Funds in these accounts are excluded from asset limits up to a certain amount.[13] These accounts are available in many states; several states also offer accounts to out-of-state residents.[14] However, these accounts do not address substantial gainful activity limitations that can affect benefit eligibility. While eligibility is currently limited to those whose age of disability onset was before turning 26, thanks to the ABLE Age Adjustment Act, in 2026, the age will increase to 46. Even so, these accounts still leave out many disabled people. These accounts are also generally associated with fees. Finally, accessing these accounts is accompanied by other administrative barriers, including requiring financial literacy.

While the Social Security Administration (SSA) encourages SSI and SSDI benefit recipients ages 18 to 64 to engage in its Ticket to Work Program to help them "move toward financial independence,"[15] there are ample work disincentives built into these programs that perpetuate poverty. Disabled Americans who choose to work while receiving life-saving benefits such as SSI, SSDI and Medicaid often face cuts to these benefits as a result of these earnings.[16]

SSI limits on both earned and unearned income (such as dividends, interest, cash from friends and family, etc.) exacerbate poverty for disabled benefit recipients. SSI has also traditionally counted in-kind income, which includes food or shelter that someone may provide for free or at a reduced cost, as unearned income. However, in 2023, the SSA announced several proposed rules that would address the in-kind support and maintenance policies relating to food[17] and shelter.[18]

Overpayments happen when benefits are paid to an individual but a government agency later claims the benefits should not have been paid. This can occur when someone goes over the asset limit, makes too much (earned or unearned) income, has a change in income or experiences other factors that can impact eligibility or payment amounts. A benefit recipient may then owe money back to a government agency they cannot afford to pay. Women are more likely to be overpaid than men; Black and Hispanic recipients are also more likely to be overpaid.[19] Social Security recipients may find out years after an overpayment occurs that they owe the SSA thousands of dollars[20] they do not have — on top of the work disincentives and extremely modest benefit amounts. The SSA may ultimately withhold money from monthly benefits to satisfy these overpayments.

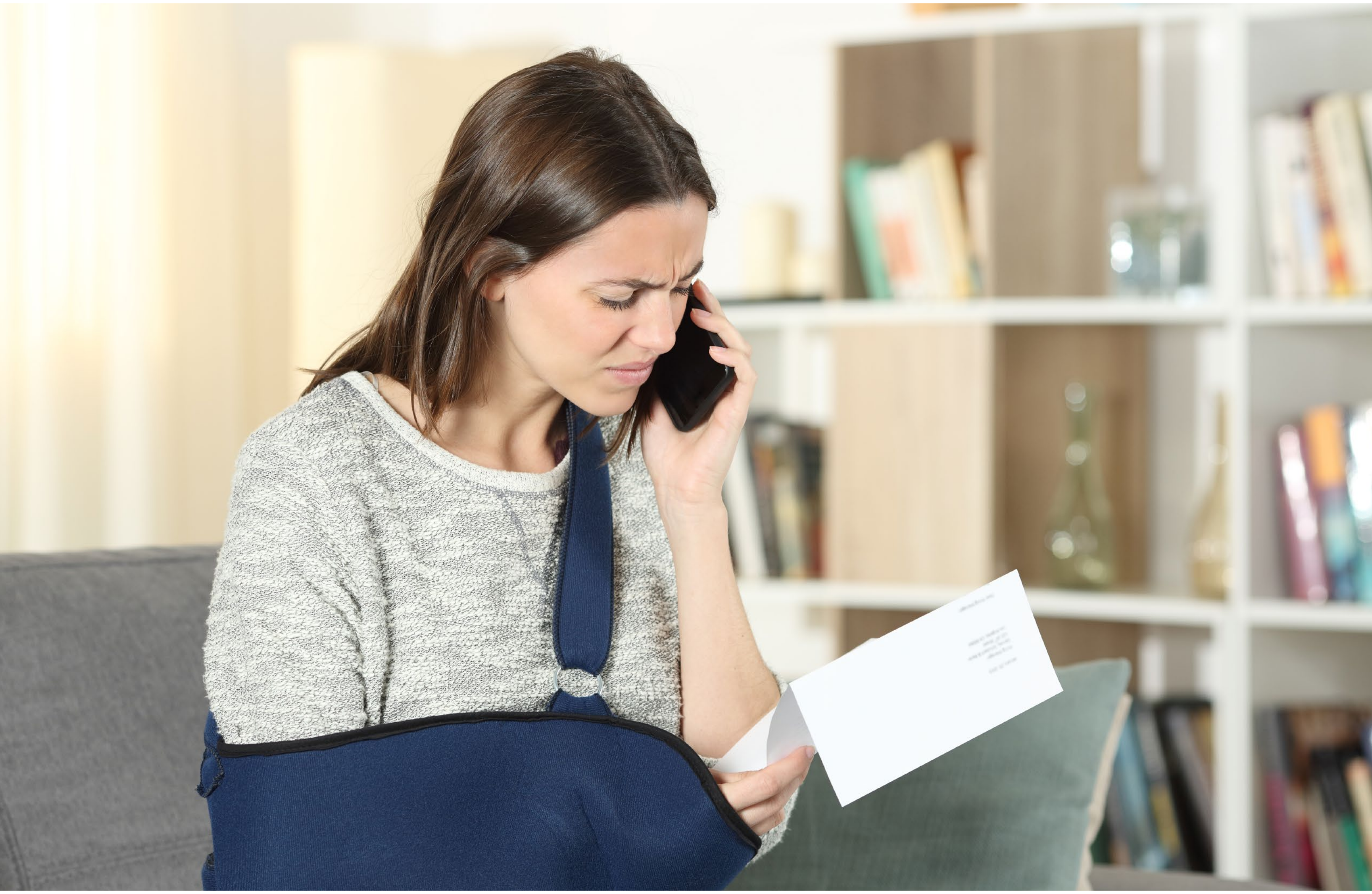
The National Partnership for Women & Families recommends the following:

- **Congress should pass the SSI Savings Penalty Elimination Act and the SSI Restoration Act.** More specifically, Congress should do the following:
  - Eliminate, or raise, the asset limit requirement for SSI recipients and tie it to inflation by, at a minimum, passing the SSI Savings Penalty Elimination Act.
  - Increase benefit amounts, particularly for SSI recipients.
  - Eliminate the marriage penalty related to asset limits and benefit amounts for SSI recipients.
- **Congress should adjust income and substantial gainful activity requirements** to keep pace with inflation.
- **Congress should pass the ABLE MATCH Act** to enact a federal dollar-for-dollar match for ABLE account owners who make $28,000 or less per year.
- **The SSA must overhaul its wage reporting system** to ensure that 1) wage reports are updated in a timely manner; 2) all overpayments that are a result of the SSA's reporting delays are automatically waived; 3) wage reporting requirements are always clear and consistent for all benefit recipients; 4) the definition of "without

fault"[21] in overpayment waiver processes is broadened and clarified to take into account the vast number of disabled SSA benefit recipients; and 5) there is a time limit on how far back the SSA can go to collect overpayments.

- **The SSA should automatically collect no more than $10 per month in overpayment recoupment** for SSI, the Qualified Medicare Beneficiary program, the Low Income Subsidy and should ensure that beneficiaries are automatically eligible for payment plans of $10 per month.
- **States should eliminate asset limits for working Medicaid recipients.**

Debt and Debt Collection



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Disabled people are generally more likely to have "bad" debt.

Disabled people are generally more likely to have "bad" debt (or debt that often comes with high interest rates and no return on investment, such as unpaid credit card or medical debt) and less likely to have "good" debt (or debt that generally comes with lower interest rates and will grow in value or generate long-term income, such as a mortgage or educational loans).[22]

Disabled respondents to the National Financial Capability Study were also more than twice as likely to note they had been contacted by a debt collector within the past year.[23] Disabled women are more likely to experience poverty than disabled and nondisabled men,[24] and those in poverty — women included — are more likely to experience debt.[25] Additionally, job loss due to disability is a common factor contributing to debt.[26]

The inequities in income, assets, wealth and employment previously discussed throughout this guide often increase and compound negative debt outcomes for disabled people, especially disabled people of color.

These inequities are the result of policies rooted in ableism, eugenics, racism, sexism, classism, imperialism, colonialism and other forms of discrimination within U.S. economic, health and other systems.

Debt collectors are also empowered to partake in aggressive, abusive and misleading tactics. Despite specific requirements and prohibitions under the Fair Debt Collection Practices Act (FDCPA),[27] violations are not uncommon. In fact, in 2022, the Consumer Financial Protection Bureau (CFPB) received 115,900 debt collection complaints.[28] For debtors with disabilities who are not aware of or do not understand their rights, these tactics are particularly egregious. For example, many disabled people may not be aware that private debt collectors may not garnish Social Security income,[29] among other types of public benefits on which disabled women are more likely to rely.[30] Disabled debtors may therefore believe they need to make payments they cannot afford and forgo basic necessities. Abusive, aggressive and misleading tactics can lead to anxiety, trauma and other conditions, in addition to potentially exacerbating these conditions.[31] Mental health conditions can also manifest as physical symptoms or cause or exacerbate physical conditions.[32]

The fact of the matter is that disabled people, particularly disabled women of color, cannot afford to pay the enormous debts often entered into just to pay for basic necessities.

- **Congress and/or state governments should enact widespread debt cancellation — or debt jubilees.** A debt jubilee is when debt is canceled and cleared from the public record. Even a **medical debt jubilee** alone would eliminate at least $220 billion in debt for 20 million people.[33] Connecticut, for example, just became the first state to cancel medical debt for eligible residents.[34]
- **State offices of attorneys general, the Federal Trade Commission (FTC) and the CFPB must collaborate** to increase FDCPA and consumer protection enforcement and education.

Debt jubilees, however, are not enough; without permanent and meaningful systemic change, they are a band-aid. Systems creating these insurmountable, massive debts must be overhauled to address these issues completely.

There are a number of different types of debts that impact disabled people, including commercial debt (for cars, credit cards, etc.), student loan debt, medical debt, mortgage debt and other forms of debt. This section will discuss policies that can improve the lives and economic health of disabled women.

Student Loan Debt

Although disabled people are slightly less likely to take out student loans than nondisabled people, they are more likely to miss payments or not complete the education for which the loan was taken out.[35] Borrowers who reported ever having a disability are significantly more likely to default on their student loans.[36] Women generally are more likely to hold student loan debt.[37] Young Black women are more likely to have student loan debt than white men, white women and Black men.[38] Black and Hispanic borrowers are more likely to default on their student loans, than white borrowers and women are slightly more likely to default on their student loans than men.[39] The identities of disabled women of color compound to exacerbate concerns related to student loan debt.

Overall, student loan debt greatly impacts the mental health of disabled women.[40] Anxiety, depression and other mental health concerns women face[41] may rise to the level of disability. As discussed, mental health conditions can also manifest as physical symptoms or cause or exacerbate physical conditions.[42] This is particularly true for first-generation women graduates, who may face greater levels of anxiety and stress navigating a complex system without additional support.[43]

Exploitative for-profit colleges and universities are a particular financial concern for disabled women. Ninety-six percent of students who submitted testimony in a lawsuit against the Department of Education related to claims of being defrauded by for-profit colleges note their lives are worse now than before they went to school.[44] For-profit institutions only enroll about 10 percent of students but account for about 50 percent of student loan defaults.[45] For-profit colleges, which often offer substandard programming, specifically target Black, Latinx,[46] and disabled communities, as well as veterans.[47, 48] They disproportionately enroll women, people of color, veterans and people with low incomes overall.[49] Many for-profit colleges target disabled students seeking transition and employment skills.[50] Single mothers are also more likely to attend for-profit colleges compared to women without children, while also being less likely to complete their degree.[51] Seventy-seven percent of disabled single parents are mothers, compared with 70 percent of nondisabled single parents.[52] Black and American Indian/Alaska Native women undergraduate students are more likely to be single mothers.[53]

Borrower defense discharge is a type of discharge available for students who attended schools that defrauded or misled students or violated certain laws. The Biden administration has taken action to automatically discharge loans of students and alumni

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from certain for-profit institutions[54] and has made improvements to the process that took effect in July 2023, such as permitting group claims, setting timelines, and placing loans in forbearance while rendering a decision.[55]

We support these improvements; however, there is more to be done to protect disabled women of color who are being targeted by these exploitative institutions.

Total and permanent disability (TPD) discharge is another discharge option available to certain disabled borrowers. Disabled borrowers may be eligible for TPD discharge based on receipt of Veterans Affairs (VA) disability benefits, receipt of SSI or SSDI or physician certification.

We applaud the final rules published by the Biden administration on November 1, 2022, that took effect July 1, 2023.[56]

These changes eradicate the three-year income monitoring to maintain TPD eligibility,[57] which was a massive administrative burden that led eligible disabled borrowers to lose their discharge status. The changes also permit nurse practitioners or physician assistants to fill out certification forms and extend eligibility to SSDI and SSI recipients whose next continuing disability review is scheduled at three years, among other improvements.[58] However, qualifying for TPD discharge is still an uphill battle, particularly for those who must apply via physician certification.

For disabled borrowers who cannot qualify for TPD discharge, borrower defense or any other type of discharge, income-driven repayment (IDR) plans, which reduce monthly payment amounts based on the borrower's income, are important tools. However, many borrowers may not be aware of these options — despite Department of Education regulations, servicers often lead borrowers toward deferment or forbearance without providing the long-term solution of IDR as an option (also called "forbearance steering").[59] Regular recertification for IDR plans can also be a burdensome and confusing process, particularly for disabled people already struggling to navigate an unnecessarily complex system. Additionally, even IDR payments are often too high for those with little to spare. The new Saving on a Valuable Education (SAVE) addresses this concern for some, in that payments would only be 5 percent of a borrower's discretionary income and the plan increased the number of borrowers who owe $0 per month, among other changes.[60] Given that disabled women, particularly disabled women of color, are more likely to work in low-wage and service jobs, ensuring that workers who earn $15 or less per hour pay $0 per month is a game changer.

We also commend the Department of Education's final rule for cutting much of what many Americans would pay monthly in half, as well as simplifying the recertification process and automatically enrolling delinquent borrowers in an IDR plan.[61] However, there is still more to be done.

Options for automating the IDR process — such as through information sharing with the Internal Revenue Service — would place less of a burden on low-income borrowers, particularly those who would be eligible for $0 monthly payments based on their income. The Department of Education must also improve and expand enforcement against forbearance steering.

When none of these options are available or pursued (whether due to administrative burden, lack of knowledge or otherwise), disabled women may default on their federal student loans. When that occurs, the borrower's credit may be impacted. The government may also pursue collection of their student loans by garnishing wages, offsetting tax refunds or garnishing Social Security benefits. Department of the Treasury garnishment policies are incredibly unclear,[62] leaving borrowers — who are already financially strained — confused and unprepared.

While discharge and IDR options are important tools for relieving the burden on disabled borrowers, these options are only guaranteed for federal student loans. Those who take out private student loans may have certain options based on the lender, but they are not guaranteed. Several states have also passed legislation that increases oversight over private student loan lenders and protects disabled borrowers.[63] Otherwise, private lenders are responsible for setting the terms of their individual contracts, and only traditional contract defenses are generally available in these cases. Interest rates also tend to be higher, particularly for those with lower incomes,[64] and disabled women of color are more likely to have lower incomes. On top of this lack of safeguards, abuse is rampant among private student loan lenders.[65]

The U.S. higher education system needs a revamp. Too many disabled women are saddled with student loans they cannot afford to pay.

The cost of higher education is unsustainable. We recommend the following:

- **The Biden administration must fulfill its promise to address the student loan crisis** through other legal and administrative means, despite the Supreme Court's decision to disallow the administration's initial plan to cancel at least $10,000 in student loans for eligible individuals.[66] For example, the administration has taken next steps in a rulemaking aimed to expand student loan relief to borrowers with high cost burdens, including child care and medical care[67] — which disproportionately impact disabled women. Even then, more is needed. Congress fully canceling federal student debt would better address the inequities posed by student debt, predominantly for women, people of color, people with disabilities and other marginalized individuals.
- **Congress should extend TPD discharge to all private student loans**, as proposed in the Private Loan Disability Discharge Act or the amendment proposed in the National Defense Authorization Act.
- **The Department of Education must clarify requirements for TPD discharge** via certification and simplify the process.
- **The Department of Education must continue to automatically cancel student loans owed as a result of attending specific for-profit colleges with abusive and fraudulent practices.**
- **Congress should pass legislation such as the Protections and Regulations for Our Students (PRO Students) Act** to protect students from predatory practices by for-profit colleges by establishing a student relief fund, prohibiting the use of federal funds for recruiting and marketing, requiring for-profit schools to receive at least 15 percent of revenue from non-federal funding, and establishing a complaint tracking system, among other things.
- **The Department of the Treasury must develop and adopt a clear policy and guidance on federal student loan garnishment determinations.** The department must ensure these are publicly available and accessible for disabled borrowers, including by creating plain language and targeted guides.[68]

- **Congress must establish free and/or affordable higher education options to support disabled women**, particularly disabled women of color, who wish to pursue postsecondary education.

Medical Debt

The problem of medical debt is compounded by disability, gender and race, resulting in a disproportionate burden on disabled women of color and their families. Despite being equally likely to have health insurance, disabled people are more likely to have unpaid medical expenses.[69] Disabled adults are more likely to report medical debt than nondisabled adults;[70] more than one quarter of households with at least one disabled member had medical debt compared to only 14.4% of households with no members with disabilities.[71] Women are also more likely to experience medical debt, likely related to lower average income and unique medical expenses.[72] Black Americans are more likely than people of other racial and ethnic groups to experience significant medical debt.[73] While intersectional data is limited, disabled women — particularly Black disabled women — are likely at greater risk.

These higher medical debt burdens are the result of a number of factors. In general, disabled people simply tend to have more significant medical needs than nondisabled people.

Coverage denials,[74] inadequate health care coverage and a lack of medical coverage[75] may contribute to medical bills for hundreds, if not thousands, of dollars. Disabled people may also face medical debt for durable medical equipment not covered adequately or at all by insurance, long-term services and supports, necessary procedures, prescriptions not covered adequately or at all by insurance, and more.[76] Given the significant cost of medical care in the United States, about one in four adults say they or a family member they live with have had difficulty paying for health care costs within the past 12 months.[77] Further, the United States is the only high-income country that does not guarantee health coverage.[78]

The exorbitant costs of childbirth and related care are, ultimately, much higher than many families can afford even with health insurance: postpartum people are more likely to have medical debt than those who are pregnant.[79] Costs related to maternal health care are a significant issue for childbearing disabled people. Disabled people are more likely to experience complications during pregnancy.[80] Some disabilities and underlying conditions in particular make bearing a child dangerous or potentially life-threatening.[81] In *Time*, Keeley Knight shared that pregnancy could place fatal levels of strain on her underdeveloped heart.[82] Flora Ellis shared concerns about her connective-tissue disorder leading to potential complications.[83]

Disabled people, particularly those with intellectual/developmental disabilities, are at greater risk for maternal morbidity.[84]

Maternal morbidity, defined by the World Health Organization as "any health condition attributed to and/or complicating pregnancy, and childbirth that has a negative impact on the [pregnant person's] well-being and/or functioning,"[85] can lead to additional health care costs for postpartum people. Postpartum women are even more likely to have medical debt than other women.[86] Women with low incomes and certain conditions, such as gestational diabetes and asthma, have an even greater burden.[87]

Nondisabled pregnant individuals may also become disabled as a result of pregnancy, particularly when adequate care is not provided.[88] This is a particular risk for disabled women and pregnant people of color. Compared with white women, the incidence of severe maternal morbidity from 2012 to 2015 was 166 percent higher for Black women, 122 percent higher for Hispanic women, 117 percent higher for Asian/Pacific Islander women and 148 percent higher for American Indian/Alaska Native women.[89] The costs of childbirth are already great; adding maternal morbidity to the mix is particularly harmful for the financial health of disabled women of color.

Surprise billing, or receiving an unexpected balance bill from an out-of-network provider, also impacts disabled women. One study of 95,384 families with a recent birth showed that almost 19 percent received surprise bills for delivery, newborn hospitalization or both.[90] Danielle Laskey, who was 26 weeks pregnant, visited a specialized clinic for emergency care.[91] Laskey had significant complications with a prior pregnancy, and she was experiencing complications during this second pregnancy.[92] The clinic Laskey visited was in network, leading her to believe the medical center that the clinic admitted her to was also in network.[93] Laskey received an unexpected bill for more than $120,000 for out-of-network care.[94] Following an appeal to Washington state, Laskey's visits were ultimately covered as in network, but it was not without a fight.[95] In 2022, the federal No Surprises Act took effect. The act and accompanying federal regulations limit when surprise out-of-network charges may be assessed.[96] However, these charges still occur, and patients receiving nonemergency care may be asked to waive their rights under the act.[97] Language barriers, disability, education barriers and other factors therefore may lead a patient to waive their rights unknowingly. Even before the No Surprises Act took effect, there were protections for Medicaid and Medicare recipients. Providers are forbidden from sending balance bills to patients for services that Medicare and/or Medicaid cover.[98] Yet this illegal balance billing still occurs,[99] impacting the financial health of disabled women and disabled women of color who rely on Medicaid and Medicare.

Comprehensive and affordable universal health coverage for all that incorporates long-term services and supports and mental health care parity is critical for disabled women.

We also recommend the following:

- **States should adopt the Model Medical Debt Protection Act**[100] and Congress should pass the Strengthening Consumer Protections and Medical Debt Transparency Act to protect patients from abusive debt collection and reporting practices.
- **State agencies and attorneys general, as well as the CFPB and FTC, must expand, prioritize and continue enforcement against abusive medical debt collection and reporting practices.**
- **The Department of the Treasury — specifically, the IRS — should set standards for hospital financial assistance programs** to prevent inconsistent and opaque

hospital practices and make the application process simpler and more transparent for patients.

- **The CFPB should undertake rulemaking under the authority granted to the agency by the FCRA to prohibit reporting of all medical debt or all debt for medically necessary procedures.** While we applaud Experian, Equifax, and TransUnion for agreeing to remove medical debt of less than $500 in collections from credit reports,[101] this alone is not sufficient.

Another aspect of medical debt that is common within the disabled community is "Medicaid debt." Federal law allows states to recoup Medicaid costs for long-term services and supports from an individual's estate.[102] This is known as Medicaid estate recovery. Medicaid estate recovery prevents disabled families from benefiting from generational wealth.[103]

While eligibility requirements vary by state, Medicaid eligibility is generally accompanied by strict income and/or asset requirements. More than 10 million Americans qualify for Medicaid on the basis of disability.[104]

Women also disproportionately rely on Medicaid: 19 percent of women age 19 to 64 are covered by Medicaid, whereas only 14 percent of men age 19 to 64 are covered by Medicaid.[105] Many disabled people rely on Medicaid Home- and Community-Based Services (HCBS) waivers to access vital long-term services and supports.[106] Given the critical nature of these benefits and the strict income, asset and other eligibility requirements that already aim to keep Medicaid beneficiaries poor, it is callous to pursue repayment upon death. The National Partnership recommends the following:

- **Congress should pass the Stop Unfair Medicaid Recoveries Act**, which would prohibit state Medicaid programs from using estate recovery to recoup the costs of benefits.
- **States should cease pursuing Medicaid estate recoveries.**

Broken Credit System and Barriers to Credit

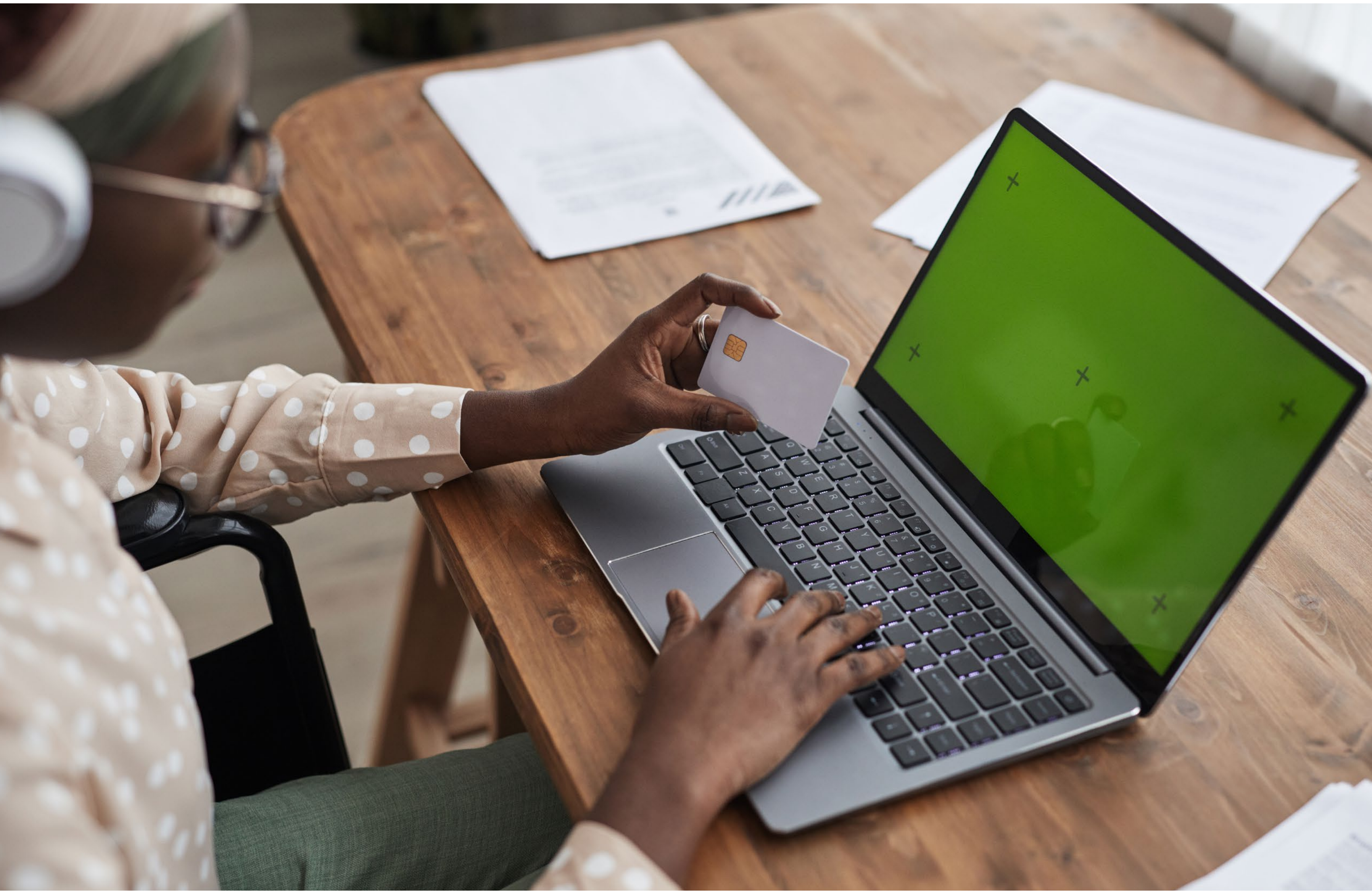

Photo: By Seventyfour via AdobeStock

Access to credit is an additional concern for disabled women — particularly disabled women of color.

The U.S. credit system perpetuates racial and economic inequity, limiting opportunities for economic growth for those most in need and fueling the cycle of poverty. While credit scores might appear to be neutral, they are anything but. Despite laws that prohibit discrimination in lending based on race, gender and other factors, credit scores nonetheless perpetuate disparities and reinforce generations of oppression.[107] This is because the factors that contribute to credit score and history — such as length of credit history, the types of payments and debt considered, utilizations, mix of credit types and more — were themselves shaped by generations of systemic racial, gender and other forms of oppression.[108] Credit scores thus leave women, people of color and disabled people at a disadvantage. The weight placed on one's credit history and score does not just impact borrowing opportunities; it also limits access to housing, employment opportunities and more.

For disabled women, particularly disabled women of color, compounding factors based on race, gender and disability increase the risk of lower credit standing and barriers to credit access. Historically, women were not guaranteed the right to open their own credit cards without a cosigner until the passage of the Equal Credit Opportunity Act (ECOA) in 1974. Without prior credit history, women were inherently disadvantaged. Even today, there is evidence of a gender gap, likely due to factors including differing economic circumstances and experiences in the labor market. For example, women pay more for credit cards — on average, interest is half a point higher for women than men[109] — and for mortgages, despite being less likely to default than men with similar credit scores.[110]

A history of deliberate and discriminatory policy choices — which continues to this day — plays a role in access to credit and credit history.

Compared to the average rate of subprime credit scores in majority-white counties, about 1.7 times more people in majority-Hispanic counties, 2.5 times more in majority-Black counties, and 2.6 times more in majority-Native American counties have subprime credit scores.[111] A lack of generational wealth, which is more common for families of color, undermines the ability to build a positive credit history and increases the likelihood of negative markers.[112] Black and Hispanic consumers, for example, may have a shorter or no credit history due to lack of access to credit.[113] Immigrants — including immigrant women — also experience this barrier.[114] Without an established credit history in the United States,[115] immigrants may have difficulty accessing common services (such as a credit card or bank account) or even renting an apartment. When consumers do not have access to better-regulated financial services, they may be pushed to rely on more costly and even predatory services such as payday lending, and risky products such as cryptocurrency.[116]

A long history of redlining and mortgage discrimination, among other factors, plagues the U.S. credit system with continued racial discrimination.[117] The term "redlining" originated in practices by government officials in the 1930s who created criteria for mortgage lending; they used red ink to mark areas on maps where there were higher concentrations of Black residents to warn mortgage lenders of an "investment risk."[118] As a result, Black people faced significant barriers to building and maintaining generational wealth.[119] Black adults are more likely than white adults to have a disability: One in four Black adults has a disability.[120] A number of factors contribute to this disparity, including a history of experiencing violence, discrimination and exclusion.[121]

Disabled people have less access to credit and are more likely to have lower credit standing than those without disabilities.[122]

Households with at least one disabled member are more likely to have unmet credit needs than those without a disabled member, regardless of race.[123] As discussed, people with disabilities are more likely to work in low-wage jobs. People with low incomes are more likely than those with higher incomes to have negative information, such as debt in collections, on their credit histories.[124] High interest rates and late fees add to the challenge of paying off such debt. This negative information impacts credit history and score. Medical debt, which is rampant among disabled people, may also appear on a credit report or in collections — despite the inevitable and necessary nature of medical costs. While the three major credit bureaus — Experian, TransUnion and Equifax — have voluntarily agreed to ensure all paid medical debts and all unpaid medical debts of less than $500 are removed from credit reports[125] (In 2022, credit bureaus anticipated this change would erase up nearly 70 percent of all reported medical debt on credit reports[126]), errors do occur and unpaid medical debt greater than $500 may still appear. The CFPB is considering a rule to prohibit the use of medical debt in credit determinations and to prohibit the inclusion of unpaid medical debt in credit reports, though no rule has been finalized.[127] Negative information may also appear when a disabled (or even nondisabled at the time) person takes out a loan prior to a medical emergency or disability onset.[128] After the event, the person may be unable to pay off the loan, resulting in missed payments and possible collections.[129]

Not only does credit history impact credit access but it also impacts access to housing and employment opportunities. Many landlords rely on tenant background checks, which include credit history, to determine whether to approve a tenant application.[130] For disabled people, particularly disabled women of color, in need of the nation's limited affordable and accessible housing, tenant background checks can lead to precarious housing situations. In many states, prospective employers can also conduct a credit check.[131] These employer credit checks can fuel the cycle of poverty by allowing employers to deny applicants who already face financial hardship or insecurity.[132]

Reforms to the credit system are needed, including, but not limited to, the following actions:

- **Office of the Comptroller of the Currency (OCC) and Federal Deposit Insurance Corporation (FDIC) Community Reinvestment Act (CRA) regulations must explicitly address disability and servicing disabled borrowers**, who are disproportionately likely to live in low- and moderate-income neighborhoods contemplated by the act.[133]
- **Congress should establish a public credit registry under the control of the CFPB** to replace the major three private, for-profit credit bureaus — Equifax, Experian, and TransUnion.
- **Congress should pass the Comprehensive CREDIT Act**, which would reduce the amount of time that negative information can remain on a credit report, remove medically necessary medical debt from credit reports, provide for free credit score access and more.
- **Congress should limit the use of credit history** in the housing and employment context.
- **The CFPB should continue to work toward finalizing a rule prohibiting the inclusion of medical debt on credit reports.** This step would ensure that unpaid medical debt of more than $500 is removed from credit reports, as well as mandate that credit bureaus do not report unpaid medical debt of less than $500 — which is currently voluntary on the part of the major three credit bureaus.

Discrimination by lenders also plays a role in access to credit, particularly for disabled women. In a focus group conducted by the National Disability Institute, a Blind woman recalled bank staff treating her as though it were not possible that she could be eligible for a mortgage on her own.[134] Paternalism, or making decisions for someone else based on the stereotypical assumption that they cannot, is particularly pronounced when ableism, sexism and racism intersect.

Since disability is not a protected class covered by ECOA,[135] disability discrimination in lending or by banks is only covered under the Americans with Disabilities Act (ADA) or the Rehabilitation Act of 1973 (for lenders in receipt of federal funds).[136]

ECOA does prohibit source-of-income discrimination[137] — such as discriminating against a borrower based on their receipt of Social Security Disability Insurance, Supplemental Security Income and other disability-related benefits. However, source-of-income discrimination ultimately is not equivalent to disability discrimination. While the ADA and Section 504 of the Rehabilitation Act of 1973 largely cover the types of discrimination in lending that ECOA might cover, the potential for disability discrimination by digital financial services and financial technology (fintech), for example, are of concern. Federal agencies play a critical role in enforcement of these anti-discrimination laws. Agencies such as the FTC and the CFPB have also begun critical enforcement of discrimination claims under their authority to pursue unfair and deceptive acts or practices.[138]

- **The CFPB and the Department of Justice must collaborate** to strengthen enforcement under ECOA, the Fair Housing Act (FHA), the ADA and other anti-discrimination laws.
- **The CFPB, the FTC and other agencies must continue their efforts to combat discrimination** under their authority to pursue unfair and deceptive acts or practices.
- **Congress must add disability as a protected class under ECOA** to close any loopholes in protections for digital financial services and financial technology under the FHA or the ADA.

Subprime Lenders

Predatory lenders (including those who make short-term loans, predatory mortgage lenders and others) specifically target consumers struggling to pay their bills,[139] as well as disabled consumers and women, particularly women of color.[140] These types of lenders are considered predatory when loan terms or practices are unfair, deceptive or abusive.[141] These types of alternative financial services can worsen credit and increase debt.[142] Because disabled people are less likely to have access to affordable credit, they are more likely to turn to pawn shops, payday lenders, rent-to-own stores or auto title loans compared with nondisabled people.[143] People of color, who are more likely to live in banking deserts than white people, may also be targeted by and turn to these types of lenders.[144] Women are more likely than men to have subprime mortgages,[145] which generally carry higher interest rates. For disabled women, particularly disabled women of color, the risk of being targeted by subprime lenders is likely compounded. We recommend the following:

- **Congress should pass an interest rate cap on all consumer loans** that would help protect consumers targeted by predatory lenders. While the 36 percent cap proposed in the Veterans and Consumers Fair Credit Act was a good start, more protection is needed.
- **The CFPB and FTC must both continue and increase enforcement actions against predatory lenders.**
- **States should pass anti-predatory lending laws**, and those that have passed these laws should both continue and increase enforcement of them.

Inaccessible and Unaffordable Banking Options

Even when people with disabilities have assets to save or invest, financial institutions are not always accessible. Disabled households are more likely to be unbanked and underbanked.[146] According to a 2019 National Disability Institute report, in focus groups of underbanked participants, some expressed feeling unwelcome by their bank due to their disability.[147] According to one participant, "I've had bad experiences because sometimes banks don't want to deal with people with learning disabilities so they push you aside."[148] Additionally, focus group members who were Blind, Deaf or had mobility disabilities cited accessibility concerns at their local branches, including communication challenges and physical barriers.[149] Similar accessibility concerns were raised about bank websites and technologies.[150] Banks also have a history of denying disabled people access to accounts or services when they have a guardian or conservator or when they want support from an agent-in-fact (under a power of attorney) or a trusted person in a supported decision-making arrangement.[151] When people cannot access bank accounts or credit because of their disability or choice to receive support, the Americans with Disabilities Act, the Fair Housing Act,[152] the Rehabilitation Act of 1973[153] and other laws may come into play to prohibit this discrimination. For example, the Department of Justice reached a settlement with Bank of America for denying mortgage loans to any person under a guardianship or conservatorship, which it claimed was in violation of the FHA.[154]

Accessibility includes concerns related not only to disability accommodations and access but also to the expense of maintaining an account.

One of the other major reasons disabled people are unbanked and underbanked is because they do not have enough money to keep in an account.[155] Many banks have minimum balance and/or deposit requirements that result in a monthly fee if not met. Because disabled women, particularly disabled women of color, have less income, these barriers are of particular concern.

Additionally, while the Community Reinvestment Act is an important statute that incentivizes banks and financial institutions to provide services to low- and moderate-income (LMI) neighborhoods, factors such as disability, race and gender have generally not been as explicitly considered in determining whether a household or geographical area meets the definition of LMI,[156] despite the fact that disabled people, women and people of color are more likely to live in poverty. This is particularly true for people living at the intersections of these identities. Without incentives to serve these communities, financial services remain inaccessible to many disabled people.

When money in an account is limited, an account holder may also be at risk of overdraft. According to the National Disability Institute, many disabled focus-group respondents were underbanked to avoid overdraft fees.[157] These fees may compound if an individual continues to use the account and incurs additional overdraft fees or if there are other fees assessed, such as non-sufficient fund fees. Banks essentially punish those who do not have adequate funds by assessing additional charges. After some time, banks may close the account, or even send the balance owed to collections. Bank tellers in largely nonwhite locations are more likely to report higher overdraft fees than bank tellers in largely white locations.[158] For disabled women of color, this combination is devastating. While a proposed CFPB regulation would limit overdraft fees by large banks,[159] permitted fees would still greatly impact the economic health of disabled women.

Failure to provide or invest in financial education opportunities for disabled women also plays a role in credit access, banking options and financial equity. While financial literacy alone does not and cannot lift someone out of poverty, for disabled people in particular, assumptions about people's capacity and abilities often lead to a lack of financial education or choice. Disabled people therefore are not always empowered to make their own decisions and handle their own finances. Capacity is fluid and can change over time,[160] particularly with additional support. When disabled people are not provided with information or education, it is difficult to grow or develop financial capacity. Disabled people therefore may not learn about critical financial tools, services and options.

When disabled women cannot access bank accounts or credit, their economic health may suffer. Changes are needed to ensure that disabled women have access to financial services. We recommend the following:

- **Congress should create a large-scale public banking system** to provide affordable, low-interest loans and accounts.
- **The Department of Justice, CFPB and other agencies should prioritize enforcement of the ADA, the FHA and the Rehabilitation Act** to ensure that disabled people have access to banking and financial services.
- **OCC and FDIC CRA regulations must incentivize serving disabled people**, particularly disabled people of color, who are more likely to have low incomes.[161]

Financial Abuse and Exploitation

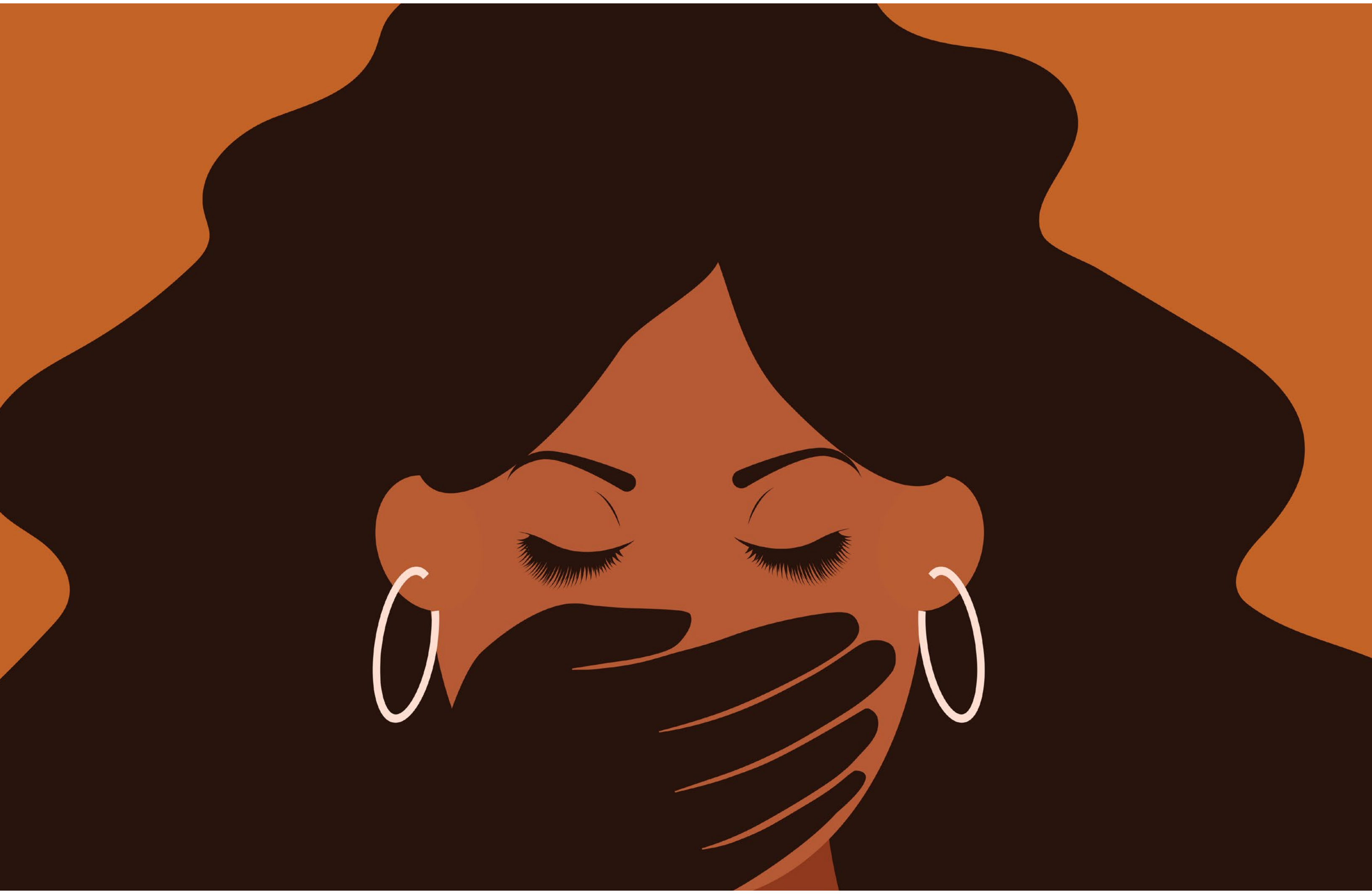

Photo: iStock.com/salim hanzaz

Disabled women may face financial abuse and exploitation by family, friends, neighbors or even career guardians or conservators.

Disabled adults may be placed under overly restrictive guardianships, which may prevent them from being able to make their own reproductive,[162] health care, financial and other choices. A guardian is "an individual or entity, whether a private party, family member, or state employee, appointed by a court to make some or all decisions on behalf of an adult whom the court finds to have a diminished decision-making ability."[163] While guardianships were intended to provide disabled people with additional protection, guardianships often lead to abuse and exploitation; they are also often granted unnecessarily and without proper procedural safeguards in place.[164] A guardianship may be granted to make all decisions or limited to make only certain types of decisions.[165] However, limited guardianships are underutilized.[166]

Guardianships are of particular concern for women given the history of oppression and stigma that has led women to be called "hysterical" or "insane" for exhibiting average human emotions.[167]

One recent high-profile example of exploitative guardianship illustrates this concern: Britney Spears' conservatorship case. During this case, Spears testified about how she was forced to work against her will and had no control over her own finances.[168] Her father, who was her conservator, took more than $6 million from her earnings over the course of the conservatorship.[169] When under guardianship, disabled adults are unable to make their own decisions pertaining to whether to work, where to work and how money may be spent, impacting the economic health of disabled people. Disabled adults under guardianships may also face sexual and economic exploitation, neglect, and abuse.[170]

There are less restrictive alternatives to guardianship. A disabled person may decide to pursue a power of attorney. In that case, the disabled person assigns certain powers to an agent and can revoke these powers at any time. Supported decision-making is another option,[171] which "involves the formalization of a network of trusted individuals who would assist the individual in making decisions; however, the decision would ultimately be left to the individual."[172] That ensures the individual retains the right to make their own financial choices. We recommend that Congress do the following:

- **Pass the Guardianship Bill of Rights Act**, which is an important step in establishing 1) standards for when guardianship and less restrictive alternatives to guardianship are appropriate; 2) due process protections; and 3) standards pertaining to fundamental rights that cannot be restricted, among other standards.

- **Invest in services and resources for disabled people who require financial resources and assistance** with handling cases of abuse and exploitation.

States must do the following:

- **Improve enforcement throughout the guardianship decision-making process** to ensure that procedural and substantive due process are guaranteed.
- **Provide transition services** for people with disabilities.
- **Reduce guardianship usage and appointments** in favor of less restrictive alternatives, such as supported decision-making.
- **Adopt a supported decision-making framework.**
- **Improve guardianship oversight.**

In addition to these recommendations, we need better data on guardianships, including who is under guardianship, who guardians are, what powers guardians have and guardianship oversight. These data will help us better understand the impact of guardianship on disabled women, particularly disabled women of color.

> The financial abuse and exploitation of disabled people more broadly is a concern. It is not only guardians or conservatives who engage in financial abuse and exploitation of disabled women.

The best way to protect disabled women is to empower and educate them to control their own economic futures. However, protective services and enforcement may still be necessary:

- **States must establish and invest in more extensive programs** through Adult Protective Services and/or Offices of Attorneys General to ensure that disabled adults can pursue claims related to financial abuse and exploitation.

Conclusion

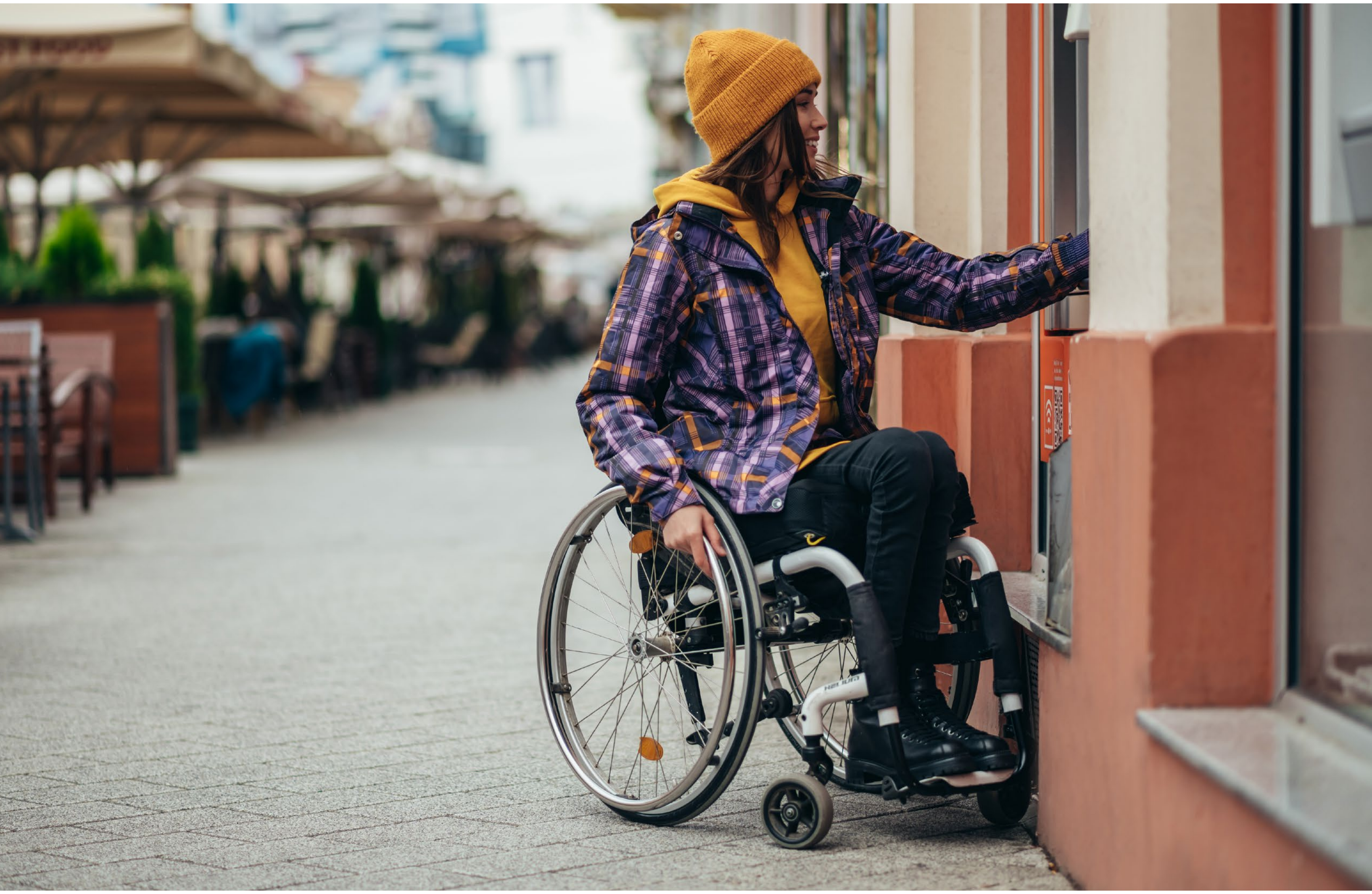

Photo: By Zamrznuti tonovi via AdobeStock

While building wealth is critical for the economic, physical and mental health of disabled women, there are myriad barriers to doing so.

Disabled women rely on public benefits such as SSI and Medicaid, but asset limits, income limits, work disincentives, overpayments and modest benefit amounts stunt financial growth. Disabled women are forced into debt, whether it is credit card or commercial debt, student debt, medical debt or other forms of debt. The cost of being disabled simply is not addressed in current policy. The way the U.S. credit system functions — effectively reinforcing a history of discriminatory barriers to credit — makes it impossible to access safe credit options, leading disabled women to rely on exploitative payday lenders.

Disabled women struggle to access bank accounts and services due to discrimination, minimum requirements to keep accounts open that cannot be met and more.

These barriers to building wealth are deliberate policy choices made to keep disabled women, particularly disabled women of color, in poverty. However, this report has charted a path to address these systemic barriers. By addressing the inequities that target disabled and multi-marginalized women and centering their perspectives, policymakers will uplift everyone.

Acknowledgments

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