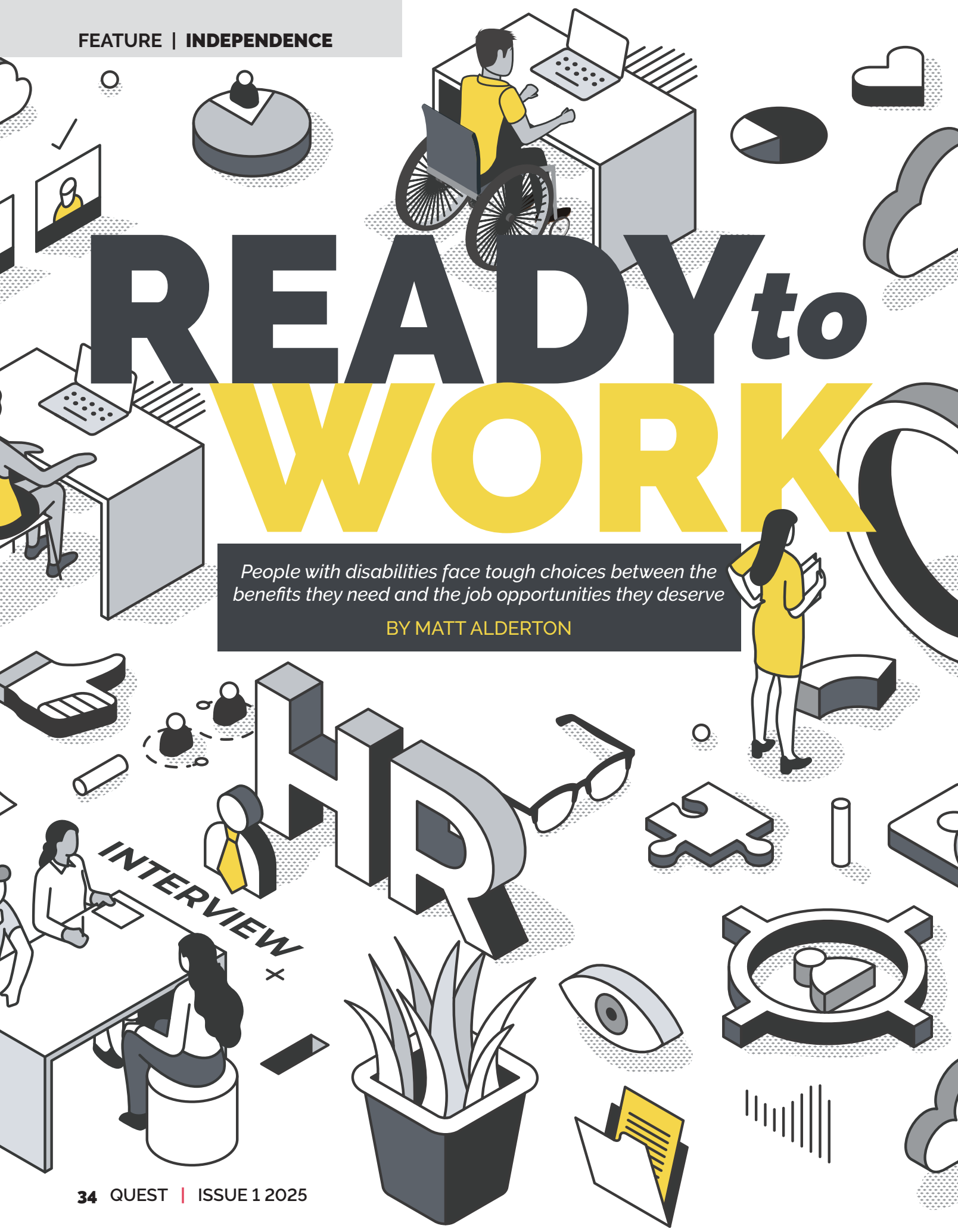

READY to WORK

People with disabilities face tough choices between the benefits they need and the job opportunities they deserve

BY MATT ALDERTON

Justin Moy excelled in science and technology in high school. Like many bright kids, he decided to use his talents to pursue a career in medical research. Along with his innate gifts, however, he had a personal motivation — to find a cure for the neuromuscular disease he lives with: LAMA2 congenital muscular dystrophy (CMD).

The first step toward his professional dream was to pursue a bachelor's degree in bioinformatics and computational biology at Worcester Polytechnic Institute in Massachusetts. Because LAMA2 CMD causes severe muscle weakness and contractures, Justin uses a power wheelchair and needs help with daily living activities.

"I can't transfer from my wheelchair, change my clothes, or go to the bathroom by myself," says Justin. "To function independently at college without my parents, I had to hire a personal care attendant (PCA)."

Justin needed Medicaid to afford the care he required, and to get Medicaid coverage, he first needed to qualify for Supplemental Security Income (SSI).

"I was on SSI for all four years of my undergraduate career," explains Justin, who graduated in 2022 and then enrolled in a doctoral program that provides him with a monthly stipend. Because SSI has an asset limit, receiving that stipend required him to surrender his SSI benefits.

"To go into a career that actually makes money, I needed to get off of SSI," says Justin, who is now a third-year PhD student at Boston University.

Though his stipend disqualifies him for SSI, it luckily does not exclude him from Medicaid in Massachusetts, whose state-run MassHealth plan has a Medicaid buy-in program that allows people with disabilities to earn wages while maintaining their Medicaid coverage.

Not everyone is so fortunate. In many cases, asset limits require people with disabilities to choose between the assistance they need and the self-actualization that comes from employment. If much-needed reforms to disability benefit rules and policies come to fruition, it might one day be possible to enjoy both.

Banking on benefits

Having a disability significantly increases the cost of living. People with disabilities often have higher costs related to food, shelter, transportation, and healthcare. In 2020, researchers working with the National Disability Institute estimated that a household where one adult has a disability that limits their ability to work requires, on average, 28% more income to maintain the same standard of living as a similar household without a disability.

Government-run benefits programs like SSI and Social Security Disability Income (SSDI) help cover some of the extra costs. SSI pays a modest monthly sum to people with limited income and resources who cannot work, including those with disabilities; for beneficiaries ages 18 to 64, the average monthly payment is $722.82, with a maximum of $943. SSDI, on the other hand, exists to help individuals who previously were employed but can no longer work due to a disability. For individuals who previously paid into Social Security through payroll taxes, the average monthly payment is $1,542.43, and the maximum is $3,822.

"These disability programs that the federal government provides are critical for meeting people's basic needs," explains MDA

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Director of Disability Policy Shannon Wood, who says benefits are especially precious for those in the neuromuscular disease community because they offer vital pathways to essential healthcare by way of Medicare and Medicaid — both of which cover many medical costs for individuals with low income or limited resources, including those with disabilities.

The rules for Medicare and Medicaid are complex to begin with but can be even more so for those receiving disability benefits. SSDI beneficiaries, for example, are automatically enrolled in Medicare — a federal program — after a waiting period of two years. If they have a qualifying condition, such as amyotrophic lateral sclerosis (ALS), they might be eligible sooner.

Medicaid is a joint federal-state program, so eligibility requirements and benefits vary from one state to another. In some states, SSI beneficiaries are automatically eligible for Medicaid, and there is one application process for both programs. In other states, individuals receiving SSI must apply for Medicaid separately or with an entirely different agency. (To learn about the rules in your state, contact your state Medicaid agency.)

"If you ask anyone who receives SSI or SSDI, the application process and reporting requirements to confirm that you're eligible for benefits are a nightmare. But many persevere because it unlocks access to medically necessary healthcare that in many cases is unavailable or unaffordable through private insurance," continues Shannon, pointing out that private insurers generally do not cover PCAs and home health aides — a critical service for Justin and many others like him. "At the end of the day, many people with neuromuscular diseases need long-term care services to live and fully participate in society. And they would not be able to get those services were it not for Medicaid, which many people get by qualifying for SSI. That's true no matter how much you make in the private sector. We know of attorneys who are living with spinal muscular atrophy (SMA), for example, who cannot afford home health aides or PCAs out of pocket even with six-figure salaries. The level of care that's required is just that expensive."

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Workforce worries

Clearly, government assistance can be a lifeline for people with disabilities. The same benefits that set them free, however, can sometimes hold them back.

That's because disability benefits have eligibility requirements, including limits on an individual's assets and income. For SSDI and SSI, federal guidelines require a monthly income of less than $1,620. SSI puts a $2,000 ceiling on an individual's total assets, including bank accounts, investments, insurance, and personal property other than a primary residence and one car. (SSDI does not have an asset limit.)

In theory, it makes sense: Benefits should go to those with financial need. In practice, however, it traps beneficiaries in a cycle of hardship and dependence, suggests Joel Cartner, Director of Access Policy at MDA.

Justin Moy (left) enrolled in a doctoral program that provides a **monthly stipend**. Receiving that stipend required him to surrender his SSI benefits.

Joel Cartner (left) has seen that **asset limits** often force people with disabilities to make hard choices between taking a job and potentially losing benefits.

"When you limit people's assets, you limit their ability to take care of themselves," explains Joel, who lives with cerebral palsy and was an SSI beneficiary in college and law school. "With the asset limit being only $2,000 for individuals, you have to make hard choices, like: Do I take a job that pays more than I'm allowed to make, and then potentially lose my Medicaid? Or do I avoid working so I can continue receiving the money I know is coming in and the health insurance that I know will cover my medical bills?"

Because they feel it's the safer thing to do, many people choose the latter, according to Stephanie Flynt McEben, a public policy analyst at the National Disability Rights Network (NDRN). "There are a lot of individuals with disabilities who are hesitant to start working out of fear that they might lose their benefits or insurance," Stephanie says. "That perpetual fear is something that keeps a disproportionate amount of the disabled community in poverty."

Were it not for that fear, many nonworking people with disabilities would jump at the chance to gain employment. Doing so would not only stabilize their bank accounts but also enhance their quality of life, suggests Julie Christensen, LMSW,

Employment Resources

These resources can help you navigate a transition to work and minimize its impact on your benefits.

AbilityOne: A federal program with a network of more than 600 community-based agencies that provide job training and opportunities for people with disabilities. **AbilityOne.gov**

Campaign for Disability Employment: A consortium of disability and business organizations that showcase supportive, inclusive workplaces. **WhatCanYouDoCampaign.org**

Centers for Independent Living: Local advocacy organizations run by and for people with disabilities that provide independent living services. **ncil.org/about/find-your-cil**

State Vocational Rehabilitation Agencies: State-supported agencies that help individuals with disabilities pursue employment. **csavr.org/stateagencydirectory**

Ticket to Work: A Social Security Administration program to support career development for people ages 18 through 64 who receive disability benefits. **ssa.gov/work**

PhD, Executive Director of the Association of People Supporting Employment First (APSE), a national organization that promotes the inclusion of people with disabilities in the workforce.

Individuals with disabilities want to participate in their communities and **contribute to the economy,** notes Julie Christensen (left).

"There are many different components of people's lives that contribute to overall good health, and there's ample research showing that employment is one of them," notes Julie, who says employment gives people with disabilities — just like people without disabilities — opportunities to learn new skills, interact with peers, and contribute to shared goals. This increases self-esteem, socialization, civic participation, independence, mood, and cognition, among other things.

"Your professional confidence impacts your personal confidence," Stephanie says. "Individuals with disabilities want to work. But when they're unable to work, or when the system assumes that they can't, that can lead to depression and anxiety, which becomes an additional barrier."

What's good for people with disabilities is also good for their communities. When more people work, it also means more people are paying taxes and buying goods and services from local businesses.

"Individuals with disabilities want to participate actively and personally in their communities, and contributing to the economy is a big part of that," Stephanie continues. "It's easy to take for granted, but something as simple as being a taxpayer can mean so much."

Real-world consequences

To stay within income and asset limits, employees receiving disability benefits typically can accept only the lowest-paying positions while working minimal hours and turning down raises, promotions, and bonuses — trade-offs their peers without disabilities don't have to make.

Caeser Chacon-Carro of Tampa, Florida, who lives with limb-girdle muscular dystrophy (LGMD), walks that tightrope daily. He spent years looking for employment before landing a job at a local amusement park in 2020. He currently works there as a park ambassador.

"I'm just trying to live the most independent and fulfilling life that I possibly can, and for me, part of that is being employed," says Caeser, 34, who gave up his SSI benefits when he started working but still receives a combination of Medicaid and Medicare — most of the time. If he's not careful about his hours and wages, his income can easily exceed what the programs allow, in which case he loses his healthcare benefits until his assets fall enough to be reinstated.

That happened in September 2024. "It was almost two months where I went without physical therapy or doctor's appointments. My caregiver is my cousin, and he came anyway because he loves me, but I couldn't pay him. It was really difficult," says Caeser, who persists despite the challenges.

SSI Update

Do you know the latest changes to Supplemental Security Income (SSI) benefits? Read about them on the Quest Blog at **MDAQuest.org/SSI-changes**.

Image: iStock.com/Rassco

"I'm here to represent people who cannot speak for themselves and to keep my position warm for all the disabled kids who come after me."

Progress through policy

Eligibility and income restrictions can only be changed with new legislation and policies at the federal and state levels. Fortunately, there is growing awareness of the challenges, and several programs help people with disabilities access meaningful employment while retaining critical benefits.

Some states, like Massachusetts, offer Medicaid buy-in programs that allow former SSI beneficiaries to retain Medicaid coverage by paying for it — just as they would with a traditional insurance premium. Section 1619(b) of the Social Security Act likewise allows qualifying individuals to retain Medicaid coverage if their income is too high to qualify for SSI but not high enough to compensate for the loss of Medicaid.

Other notable opportunities include the Social Security Administration's Plan to Achieve Self-Support (PASS) (**ssa.gov/disabilityresearch/wi/pass.htm**) and Trial Work Period (**ssa.gov/disability/work**). PASS allows SSI beneficiaries to set aside money that will help them gain employment or start a business without it counting toward income and asset limits. Trial Work Period allows SSDI beneficiaries to receive their full disability benefits, regardless of income, for nine months after returning to work. They can continue receiving benefits for another 36 months as long as their income does not exceed $1,620 per month.

"There are success stories, but the application process for these programs is difficult to navigate," Shannon says. "A lot of people end up just giving up."

New within the last decade are Achieving a Better Life Experience (ABLE) accounts (**ablenrc.org**), which are tax-free savings accounts that allow people with disabilities and their family members to save up to $100,000 to cover disability-related expenses. Only savings above $100,000 count as assets for the purpose of determining benefit eligibility.

"ABLE accounts are a really innovative policy solution," Julie says. "The problem is that they're not well known, they're not well utilized, and

For Caeser Chacon-Carro (left), **being employed** is an important part of how he lives an independent and fulfilling life.

Our community members can help **make programs better** by sharing their stories and advocating for legislation, according to Shannon Wood (left).

they're a little bit restrictive in terms of what you can save money for."

There is also an age restriction: ABLE accounts are available only to individuals whose disabling condition occurred before the age of 26. (That will increase to before age 46 in 2026.)

Although programs like PASS and offerings like ABLE accounts are helpful, more reforms are needed to strengthen benefits and workforce participation among people with disabilities.

"There needs to be a complete overhaul of Social Security law," Julie says. "But that is a huge undertaking, and Congress is unlikely to do it in what has become a very divided political climate."

Still, progress is possible, with lawmakers already considering numerous changes to disability benefits, according to Shannon. In 2017, for example, President Donald Trump signed the Tax Cuts and Jobs Act, which contained several provisions strengthening ABLE accounts — including letting employed persons make additional annual contributions to their ABLE accounts, allowing a tax credit for ABLE account contributions, and allowing funds from a 529 college savings plan to be rolled over into an ABLE account without tax penalty.

"All of these will expire at the end of 2025 without congressional action, so getting them renewed is a huge priority," Shannon says.

An even bigger priority is the SSI Savings Penalty Elimination Act, which would raise the asset limits for SSI beneficiaries from $2,000 to $10,000 for individuals and from $3,000 to $20,000 for married couples while providing annual increases tied to inflation.

"The SSI Savings Penalty Elimination Act is a straightforward bipartisan bill that makes important upgrades to SSI," Shannon says. "Asset limits haven't been updated in almost 40 years and have never been indexed for inflation. That's why they're so low. This bill would modernize benefits so people with disabilities aren't living at poverty levels to receive the care they need."

Along with other reforms, raising the SSI individual asset limit to $10,000 would pull an estimated 3.3 million Americans out of poverty, according to the Urban Institute.

MDA is doing its part to champion reform with advocacy efforts like MDA on the Hill, an annual event that brings more than 100 people living with neuromuscular diseases face-to-face with members of Congress for dialogue about disability benefits and other issues.

"If we want to make these programs better, we need members of our community to share their stories and advocate for bills that improve the lives of people living with neuromuscular diseases," Shannon says.

People like Justin and Caeser are determined to do their part — for themselves and the whole neuromuscular disease community.

"I feel like I'm stuck right now, but I don't intend to be in this position my whole life," Caeser says. "I'm going to break out of this." Q

Matt Alderton is a Chicago-based freelance writer who frequently covers health topics.