February 2023

New Housing That Supports Independence



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Freedom Village at Hamilton Woods

By Michelle Diament / reprinted from Disability Scoop January 9, 2023

IRS Increases Limit For ABLE Accounts

People with disabilities can save more money without jeopardizing eligibility for government benefits thanks to a change in tax rules for the new year.

Starting this month, the federal gift tax exclusion increases from \$16,000 to \$17,000 annually, according to the Internal Revenue Service.



The deposit limit for ABLE accounts — a savings vehicle for people with disabilities — is tied to that metric, so it will grow as well.

The rise is the result of inflation and follows a similar uptick in the maximum allowable ABLE account contribution last year.

Created under a 2014 federal law, ABLE accounts allow people with disabilities to save up to \$100,000 without forgoing eligibility for Social Security and other government benefits. Medicaid can be retained no matter how much is in the accounts.

Funds saved in the special accounts can be used to pay for qualified disability expenses including education, health care, transportation and housing. Interest earned is tax-free.

Annual ABLE account deposits are generally capped at the value of the IRS' gift tax exclusion. But, people with disabilities who are employed can save some of their earnings in addition to the gift tax amount of \$17,000.

For this year, workers with disabilities in the 48 contiguous states will be able to save \$13,590 more that the gift tax exclusion while Alaska residents can accrue an additional \$16,990 in compensation and \$15,630 for those in Hawaii, according to the Autism Society.

ABLE accounts are offered through programs in 47 states, many of which are open to individuals nationwide if they have a disability that onset before age 26. Starting in 2026, that age limit will rise to 46 under a recently passed law.

As of September, there were more than 131,000 ABLE accounts open with \$1.133 billion in assets, according to ISS Market Intelligence.

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^{Page 2} 'I can no longer be an executive at a high level': Workers with disabilities, including long COVID, are finding their place as companies become more flexible

By Zoe Han Reprinted from 1/8/23 2:12 PM ET (Market Watch) Dow Jones Newswires (c) 2023 Dow Jones & Company, Inc.

Why 2023 could be the year that more workers with disabilities find jobs

Dana Pollard started a new job at the end of 2022, after spending three years recovering from a 2019 stroke. Pollard, 56, lives in Fort Worth, Texas, with his wife. After the stroke, he could not recognize her. He couldn't remember things, and one side of his body was partially paralyzed.

After months of physical and speech therapy, and with the help of medication, Pollard's condition stabilized. His doctors told him that severe stress could still cause seizures, but Pollard has been managing well. Before the stroke, Pollard managed about 6,000 employees as a director of canvassing. In his new position as a canvassing manager at Tarrant Windows and Siding, he oversees 10 to 15 people who go door to door to advertise and sell the company's products and services. His day-to-day responsibilities include hiring and training canvassers, as well as a bit of walking now and then.

The responsibility and physical work required are far less than what his old job demanded, but Pollard said that his new position is suitable given his condition and will be good for his recovery. "I can no longer be an executive at a high level. I just can't think that fast anymore," Pollard said. "I'm just not that person anymore, not yet."

His experience and reputation in the industry helped him land the job, but Pollard said getting hired was still a lengthy process. "A lot of places, they don't have the facility to help people with disabilities go back to work, and they don't have the educational tools. They don't have the capabilities for disabled people to actually work in their facilities," Pollard told MarketWatch. "I just happen to be qualified for this job because of my background, but I couldn't be hired for the job that I used to have," he added.

Unemployment is high for workers with a disability. Many people with disabilities face serious difficulties finding work. The unemployment rate for people with a disability was 6% in November -- down from 10.8% in 2021, but still higher than the rate of 3.3% for those who do not have a disability, according to government data. The COVID -19 pandemic was itself a disabling event. An estimated one in five people infected with COVID-19 experience long-term effects, known as long COVID, experts from the Federal Reserve Bank of New York said, citing data analysis from the Centers for Disease Control and Prevention. Estimates of long COVID's prevalence vary, the CDC notes; symptoms also vary in severity and can include difficulty breathing, fatigue that interferes with daily life and brain fog. Around 15 million Americans of working age will deal with the effects of long COVID at some point, and 1.8 million of those will be unable to work, according to estimates from the University of North Carolina's Kenan Institute of Private Enterprise. Among COVID long-haulers, 26% said their condition had negatively affected their employment or the number of hours they were able to work, according to a separate report from the Federal Reserve Bank of Minneapolis in July.

But the pandemic has also made employers more flexible and more inclusive, pushing them to better adapt to the needs of workers who have long COVID or other disabilities, experts said.

So could 2023 be the year that more people with disabilities land jobs? It's a myth that workers with disabilities, in particular those enrolled in the Social Security Disability Insurance (SSDI) program, don't want to be in the work-force, said Diane Winiarski, director of Allsup Employment Services. "They absolutely do want to return to work. They want to be given the opportunity," she told MarketWatch. Inflation squeezes people with chronic conditions SSDI and Supplemental Security Income (SSI) are two Social Security programs that provide financial support to people with health conditions that prevent them from being able to work. SSDI is for those who have worked before, with monthly benefits based on a person's previous income, whereas SSI doesn't require previous work experience.

Such health conditions include chronic illnesses, including long COVID. The Social Security Administration's annual cost-of-living adjustments track changes in consumer prices from year to year. For those who receive SSDI or SSI benefits, an 8.7% increase was applied to monthly benefits starting Jan 1. This increase means the average monthly SSDI benefit for a worker with a disability will increase by \$119 to \$1,483, according to the Social Security Administration.

Page 3

But for many people, that support barely covers living expenses. That's especially true for those who need to pay for medications, caregivers and transportation to doctor visits, said Terry Wilcox, CEO of Patients Rising, a group that advocates on behalf of people with chronic illnesses. Many people with chronic conditions cannot take on side hustles or extra hours due to physical strength limitations, Wilcox added. As a result, they have limited disposable income to cover price increases on necessities like groceries and gas. "Anyone who knows anything about SSDI knows it's not what most of us would consider a livable wage," Wilcox said.

Inflation in the U.S. reached a 40-year high last June and has squeezed Americans' budgets. The year-over-year increase in the cost of living has shown some signs of cooling, but it was still 7.1% in November compared with the previous year. In October, several low-income families told MarketWatch that they could not afford to buy meat, while others said they had to juggle utility payments and grocery bills.

Remote work has helped make workplaces more inclusive As a result of the pandemic, workplaces have become more flexible and, in some ways, more inclusive of workers who were not able to work in an office before the pandemic, according to recent research by the Kessler Foundation, a research and charitable organization for people with disabilities. "The COVID-19 pandemic positively impacted the use of disability-related employment practices by focusing greater attention on accommodation processes and increasing the use of remote work, flexible work schedules and job sharing," said survey co-author Andrew Houtenville, an economics professor and research director at the University of New Hampshire Institute on Disability.

While all workers benefited from the expansion of flexible work arrangements, many of those changes have been especially important to employees with disabilities, he said. In 2023, the labor market will remain tight, according to the recent Hiring and Workplace Trends report by Indeed and Glassdoor. Employers have been turning to sometimes-overlooked pools of workers, including people with disabilities or people with criminal records, and will need to do more to accommodate these workers by adopting flexible work policies, the report said. Winiarski recommends that employers test the waters, perhaps reassigning workers to different duties or dividing up nonessential roles. "We encourage part-time work -- and then gradually increasing the hours," she said. Support for finding a job makes all the difference

When it comes to finding jobs, workers with disabilities face a variety of challenges, Winiarski said. But for those on SSDI, the first challenge is often in overcoming fear and helplessness, she added.

Two years after his stroke, Pollard wanted to go back to work, but he didn't know how. At the time, he was still using a cane and his cognitive abilities, although slowly improving, were not back to normal, so he wanted to take "baby steps." Pollard signed up to work with a company that helps people like him find jobs. Yet for a year and a half, he didn't get the support he was looking for. "They had no idea of how to help me," Pollard said about the company. They would propose "the most ridiculous jobs that I could never have done -- general labor where I would have to wear a hard hat and [carry a] welder and I'm, like, really? There's no way I could do any of these jobs," he said.

He eventually landed his current job after working with Allsup Employment Services, which specializes in helping people with disabilities return to work. Allsup works through Social Security's Ticket to Work, a free program for people who are receiving disability benefits. At Allsup, Pollard was assigned to a case manager who provided guidance and helped him prepare for interviews. The manager also worked with him to identify roles that suited him. He and his case manager, Pollard said, were a "dynamic duo." Pollard said that when it came to finding a job, it made all the difference to have people who seemed to understand what he was going through. "They actually listen," he said. "They listen to your story."

Postsecondary Student With Autism Spurs NCAA Rule Change

By Susan Snyder, reprinted from The Philadelphia Inquirer/TNS | January 4, 2023

Sebastian DeSimone was born with "a little bit of autism," as he tells it. The 20-year-old, who wants to become a teacher's assistant, enrolled at Gwynedd Mercy University, a small, private Catholic school in Montgomery County. As part of his collegiate experience, he was determined to run for the Division III school — and last fall he completed his first season on the cross-country team, where he placed third of six on the team at the Atlantic East Conference Championship — not bad for a freshman.

But DeSimone, who is from West Orange, N.J., might not have had the chance to compete if it hadn't been for his determination and that of his mother, Joanne. NCAA rules generally require athletes to be full-time students in degree-bearing programs. DeSimone is enrolled in Gwynedd Mercy's Integrated Studies program for students with intellectual disabilities; they earn certificates, not degrees.

Joanne DeSimone researched the issue and asked Gwynedd Mercy to request a waiver from the NCAA. DeSimone got his waiver, and in August, the NCAA's subcommittee for legislative relief approved a change that will make it easier for students with intellectual disabilities at Gwynedd Mercy (and nationwide) to compete in Division III athletics — if they have the athletic ability.

Massillon Myers, an NCAA spokesperson, said the subcommittee decided to take up the issue early last summer after receiving a request from another Division III school to make the process easier. "Future Integrated Studies students will not need to submit a waiver request to staff," said Myers.

Under what's known as a "previously approved waiver," students with intellectual disabilities will be eligible as long as their programs are approved by the U.S. Department of Education. The programs need to require students to make academic progress toward a goal or outcome and have them enrolled full time. They also need to allow students to participate in clubs and events on campus, according to the new rule.

It all makes Sebastian DeSimone and his mother smile. "He told me he feels good because he's helping to change the community," said DeSimone, who, like her son, wore a Gwynedd Mercy cross-country team sweatshirt during a recent interview on campus.

More than 350 universities nationwide have programs for students with intellectual disabilities. In 2004, there were just 25, according to Think College, a federally funded center that tracks, supports, and advocates for such programs. In Pennsylvania, there are 19, including at Temple, Drexel, Pennsylvania State University, West Chester, Widener, Arcadia, Villanova and St. Joseph's, according to Think College. Most of these programs don't award degrees, although some, like Gwynedd Mercy, offer certificates. Students audit university classes — DeSimone enrolled in five during the fall semester, including education and psychology — and sit with other students and get support from peer mentors and university advisers. At some colleges, like Gwynedd Mercy, they live on campus, like DeSimone, and experience college life.

The new NCAA rule for integrated studies' students only applies to Division III schools. Among those in Pennsylvania with programs, other than Gwynedd Mercy, are Arcadia and Widener.

Joanne DeSimone said her son liked to run from the time he was a small child, and he was fast. "He was my flight risk," she said.

DeSimone said he began running for sport when he was in seventh grade and wanted to make friends outside of his selfcontained special education classroom. He joined the team at West Orange High School in Essex County and worked very hard to make varsity, his mother said. "He said, 'I want to be with everybody," his mother recalled.

He improved his time in the 5K by six minutes from freshman to senior year, when he ran it in 18 minutes, 9 seconds. "It was beautiful as a parent to watch," she said. "You see your child struggling academically, and even when they are making gains, it's not like big kind of gains that they can appreciate themselves. In running, it's very easy to see. It's all numbers." As he runs, Sebastian DeSimone said he plays music in his head — the B-52's is one of his favorite groups — and he also enjoys staying fit.

When her son was in high school, DeSimone got an NJSIAA (New Jersey State Interscholastic Athletic Association) waiver for him to participate in a fifth year of running. So she knew waivers were possible. "I did a deep dive to learn the division rules, and talked to coaches locally that I knew," she said. "I also hired a consultant who specialized in eligibility."

She gave everything she learned to Gwynedd Mercy. "Our campus was very much not if, but how — how can we make this happen?" said Amaya, the Integrated Studies director.

From Norman's Desk

My readers know that I'm a big advocate for voting rights for people with disabilities, and I believe strongly that voting is the sole most powerful tool that we have for change. That tool is being endangered by political forces trying to limit voting in the name of "election security" but, in reality, to gain political advantage.

Everyone wants our elections to be secured from tampering and fraud, but before people with disabilities lose our voting rights, there should be substantial factual evidence of a security issue that actually impacts an election.

Take the state of Wisconsin, for example. According to published accounts, a state judge ruled in January 2022 that there were just two ways someone in the state could return a mail-in ballot: they could either place it in the mail or return it to their local clerk in person.

That was a big problem for Wisconsin citizen Martha Chambers. She has been paralyzed from the neck down after a horse-riding accident. Chambers can write and paint using a stick she holds in her mouth. But when it comes to voting, she needs help with her ballot.

"I can fill out my ballot. I can sign it. I can fill in the little dots," she said to <u>The Guardian</u> for an article. "But I can't hand it, I can't fold it, I can't put it in the envelope. I could not put it in the mailbox. I can't get out my door to put it in the mailbox."

<u>The Guardian</u> further reported that when Wisconsin' primary came around las year, Chambers voted absentee because of health concerns, so. She took a risk by having someone else return her ballot for her despite court rulings saying that was illegal.

"Like a rebel," she said. "We should be able to vote without any concern, just like anybody else."

Wisconsin is not alone in making it harder for people with disabilities to vote. Alabama banned curbside voting; this option enabled people with disabilities to vote when they could not enter the polling place due to barriers. A Texas law limited what assistance voters could get at the polls and required those who provided assistance to swear an oath. In Florida, a new law makes it harder to request a mail ballot.

Disability advocates are taking note of the trend and are fighting back. "Any of the restrictions that have been proposed, if they have an impact on access for voters as a whole, then they tend to impact access voters with disabilities exponentially," said Michelle Bishop to <u>The Guardian</u>. Bishop is the voter access and engagement manager with the National Disability Rights Network.

The fighting back happens state by state. There were many court rulings in Wisconsin last year fine-tuning what is allowed under state law. In July, the state Supreme Court said ballot drop boxes were not legal, but the court did not rule directly on whether third parties could help voters with disabilities place their ballots in the mail.

After Chambers and a handful of other voters filed a lawsuit, however, a federal judge ruled in August that voters with disabilities can have someone else assist them with returning their ballots as required under the Voting Rights Act.

The right to vote is precious. A secure election without the suspicion of fraud is also the standard that everyone wants. These two goals should not be conflicting concepts if common sense is used.

Norman A. Smith, Follow us on Twitter @TheFreedomGuys "Like" us on Facebook.com/ProjectFreedomInc



To Attract In-Home Caregivers, State Offers Paid Training — And Self-Care

By Laurie Udesky, reprinted from Kaiser Health News | January 10, 2023

One November afternoon, Chris Espedal asked a group of caregivers — all of whom work with people who have cognitive impairments, behavioral health issues, or complex physical needs — to describe what happens when their work becomes too much to bear. The participants, 13 caregivers from all over California, who had gathered in a Zoom room, said they experienced nausea, anxiety, shortness of breath, elevated heart rates, and other telltale signs of stress.

"I want to scream!" one called out. "I feel exhausted," said another.

Espedal, who has been training caregivers for 18 years, guided the class through a self-soothing exercise: "Breathe in for four counts, hold the breath for four, exhale for four." She taught them to carve out time for themselves, such as setting the goal of reading a book from beginning to end, and reminded everyone to eat, sleep, and exercise. "Do not be afraid to ask for help," Espedal said. She added that one of the best ways they can care for their clients — often a loved one — was to care for themselves.

The class is a little touchy-feely. But it's one of many offerings from the California Department of Social Services that the agency says is necessary for attracting and retaining caregivers in a state-funded assistance program that helps 650,000 low-income people who are older or who have disabilities age in place, usually at home. As part of the \$295 million initiative, officials said, thousands of classes, both online and in-person, will begin rolling out in January, focused on dozens of topics, including dementia care, first-aid training, medication management, fall prevention, and self-care. Caregivers will be paid for the time they spend developing skills.

Whether it will help the program's labor shortage remains to be seen. According to a 2021 state audit of the In-Home Supportive Services program, 32 out of 51 counties that responded to a survey reported a shortage of caregivers. Separately, auditors found that clients waited an average of 72 days to be approved for the program, although the department said most application delays were due to missing information from the applicants.

The in-home assistance program, which has been around for nearly 50 years, is plagued by high turnover. About 1 in 3 caregivers leave the program each year, according to University of California-Davis researcher Heather Young, who worked on a 2019 government report on California's health care workforce needs.

It doesn't help that the pay is low. According to the state, the average hourly rate for caregivers in the in-home assistance program is \$15.83. Rates vary because the program is administered locally, with each county setting its own.

"Training is very helpful," said Doug Moore, executive director of the United Domestic Workers of America AFSCME Local 3930, which represents roughly 150,000 caregivers in California. "But when the wages are low — and you can make more at Target or McDonald's and get a signing bonus — then you're going to go and do that work versus harder work, which is taking care of someone with a disability or a person that's aging."

The training initiative came out of Gov. Gavin Newsom's Master Plan for Aging to improve the quality of caregiving careers. Theresa Mier, a spokesperson for the Department of Social Services, said the state hopes financial incentives will help attract new workers and keep them caring for people with specialized needs longer. In addition to their hourly pay for taking classes, in-home caregivers will receive incentive payments that start at \$500 for 15 hours of training. They can earn up to \$3,500 if they go on to work at least 40 hours a month with a qualified client for at least six months. Previously, counties offered some training but did not pay workers for their time.

The state issued grants, including \$16 million to Homebridge, a San Francisco-based caregiving organization, to coordinate training. Classes will be offered in Spanish, Cantonese, Mandarin, and Armenian, in addition to English, to reach more workers. And state officials are planning a social media campaign to recruit new caregivers.

But the incentives are committed only through the end of 2023.

Greg Thompson, executive director of the Personal Assistance Services Council, the public authority that manages Los Angeles County's in-home program, would like to see paid training become permanent. "There needs to be, in my opinion, some kind of accountability, structure, supervision, and ongoing training," he said.

Many caregivers who attended early courses care for family members with a mix of physical and behavioral needs. In fact, 3 out of 4 caregivers in the in-home assistance program are relatives of clients. But the state needs to prepare for a workforce shift, one that requires people to look outside their families. The number of California seniors is expected to be nearly 8.5 million by 2030, an increase of more than 40% from 2019. Many of them will be single.

The state will need more caregivers like Luz Maria Muñoz, who has worked in the in-home assistance program for six years. The Bakersfield resident has navigated challenging situations on the job. One older client was on 30 medications. Another had bedsores, which can be life-threatening if not properly treated. Muñoz peppered the client's nurse with questions about dressing the wounds and felt responsible for the client's well-being.

"Those wounds needed to be cleaned daily," she said.

Muñoz said she's interested in the training. The department said it sent notices about classes to all participating caregivers and will follow up with updates. Counties also helped spread the word online, in newsletters, and via posted flyers.

Early sessions have filled up as soon as they're set up. Leslie Kerns, the in-home assistance registry manager for Connecting Point, the public authority for the program in Nevada, Plumas, and Sierra counties, said some classes were full after three hours.

Angelina Williamson cares for her mother, who has a disability, in San Diego and took a course on mobility and transferring patients. She said she learned how to use her body to break a fall and that if her mother falls, it's better to bring her a chair than pick her up because her mother has enough upper body strength to pull herself up, with Williamson's help.

Recent surveys suggest that caregivers are likely to be interested in self-care. In a review of nonprofit caregiver resource centers in California, 35% of caregivers reported that their health had worsened while providing care, and 20% had experienced symptoms of depression. Some caregivers also reported being lonely, which could include lacking companionship, feeling left out, or feeling isolated from others. And a 2020 report by the National Alliance for Caregiving and AARP found that 26% of caregivers had difficulty managing their stress.

Robbie Glenn, a single father in Anaheim, attended Espedal's self-care class and learned to take time for himself. By day, Glenn cares for his 11-year-old son, Edin, who has birth defects from alcohol exposure and has nonverbal autism. Edin needs help going to the toilet and bathing. He has epilepsy and sometimes walks in his sleep. By night, Glenn freelances, doing post-production work, such as film editing and color grading.

Glenn now uses a timer to remind himself to take a break. "And," he said, "I've been doing those breathing exercises a lot."



February is American Heart Month! Join CDC and Project Freedom this month in raising awareness about cardiovascular disease (CVD) prevention. There's work to be done across all age groups, not just among older adults. cdc.gov/heartmonth

The ABCS of Heart Health

Every year, Americans suffer more than 1.5 million heart attacks and strokes. The good news is that you can help reduce your risk and improve your heart health by following the ABCS!

A: Take aspirin as directed by your health care professional.

Ask your health care professional if aspirin can reduce your risk of having a <u>heart attack</u> or <u>stroke</u>. Be sure to tell your health care professional if you have a family history of heart disease or stroke, and mention your own medical history.

B: Control your blood pressure.

Blood pressure measures the force of blood pushing against the walls of the arteries. If your blood pressure stays high for a long time, you may suffer from high blood pressure (also called hypertension). High blood pressure increases your risk for heart attack or stroke more than any other risk factor. Find out what your blood pressure numbers are, and ask your health care professional what those numbers mean for your health. If you have high blood pressure, work with your health care professional to lower it.

C: Manage your cholesterol.

Cholesterol is a waxy substance produced by the liver and found in certain foods. Your body needs cholesterol, but when you have too much, it can build up in your arteries and cause heart disease. There are different types of cholesterol: One type is "good" and can protect you from heart disease, but another type is "bad" and can increase your risk. Talk to your health care professional about cholesterol and how to lower your bad cholesterol if it's too high.

S: Don't **s**moke.

Smoking raises your blood pressure, which increases your risk for heart attack and stroke. If you smoke, quit. Talk with your health care professional about ways to help you stick with your decision. It's never too late to quit smoking. Visit smokefree.gov or call 1-800-QUIT-NOW today.