

Empowering People with Disabilities to Save, Invest and Achieve a Better Life

Past, Present & Future Policy Directions

The landmark, bipartisan Stephen Beck Jr. **Achieving a Better Life Experience (ABLE) Act of 2014** recently celebrated its 10-year anniversary. Hailed as the most significant disability reform legislation since the passage of the Americans with Disabilities Act (ADA) of 1990, the ABLE Act allowed states to establish and maintain tax-advantaged ABLE plans where contributions and investment earnings can be used to pay for the designated qualified disability expenses (QDEs) for the person with a disability.

The ABLE Act continues to give individuals with disabilities the opportunity to save for disability-related expenses in a tax-advantaged account without losing eligibility for certain public benefits programs, like Medicaid and Supplemental Security Income (SSI). Medicaid and SSI have income and asset limitations, which often prevent people with disabilities from saving money for the future or taking jobs that earn more than the limitations allow. Funded with after-tax dollars, similar to a Roth IRA, ABLE accounts grow tax-free, and withdrawals can be made at any time for a broad range of qualified disability expenses. Some states also offer state income tax deductions for contributions to ABLE Accounts specific in-state plans.

The reality is that many individuals with disabilities can only find health care coverage through Medicaid. According to a 2018 Congressional Revenue Service (CRS) report, the total Medicaid long-term service spending was \$154.4 billion in 2016, making Medicaid the largest single payer of long-term care.

Private insurance usually does not cover this kind of care, and individuals with existing disabilities cannot buy individual coverage for it. If available, it can run from \$50,000-\$200,000 per year in the private market. Thus, individuals with disabilities often find themselves reliant upon Medicaid as the only way to pay for the type of care they need. ABLE account holders are using their ABLE accounts to save money above the asset limitations in these programs in order to purchase homes, modify vehicles, pay for college, cover daily living expenses such as gym memberships, hire their own caregivers, personal care attendants, and job coaches, and pay for transportation services like Uber and Lyft.

According to the National Association of State Treasurers (NAST), to date, the disability community has saved \$2.46 billion in assets under management (AUM) across 204,000 ABLE accounts since the first program launched in June 2016. Currently, there are over 8 million individuals with disabilities eligible to open an ABLE account, and that figure will grow to 14 million people (including 1 million veterans) when the ABLE Age Adjustment Act goes into effect in January of 2026.

KEY TAKEAWAYS

- The ABLE Act of 2014 is one of the most significant pieces of disability reform legislation passed since the ADA. ABLE Accounts should now be expanded to provide people with disabilities financial security, the ability to work, and more choices in care.
- ABLE accounts should be integrated with federal and state benefits programs like State Medicaid enrollment, HCBS waivers, Vocational Rehabilitation, Social Security Benefits (i.e., SSI and SSDI), Ticket to Work programs, etc.
- There is more work for Congress to do, such as eliminating the Medicaid clawback, opening the use of ABLE accounts for lump sum payments or retirement vehicles.
- States have significant opportunities to align and expand access to existing benefits to work alongside ABLE Accounts.

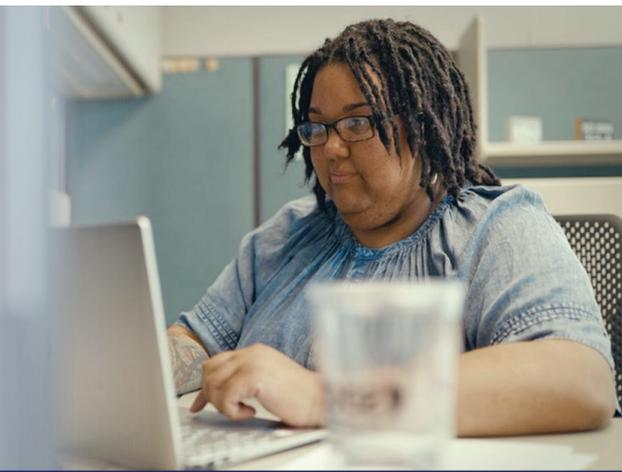
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FAST FACTS

for ABLÉ Account Enrollees



Who is currently eligible?

ABLE accounts are for individuals whose long-term disability began before age 26 (note: the age of eligibility will increase to 46 on January 1, 2026).

You must meet one of the following criteria:

- ✓ Eligible to receive SSI or SSDI benefits (note: you don't have to be receiving benefits just meet the SSA criteria)
- ✓ A doctor diagnosed you with a disability

How much can you contribute?

Annual contributions for an ABLÉ account holder can come from any source and amount to "Gift Tax Limit" each year (In 2025, the limit is \$19,000).

If the ABLÉ account holder is working, he or she could qualify for the "ABLE to Work" option, which means an individual can contribute up to the federal poverty level amount each year (In 2025, the limit is \$15,060 in the continental US, and at higher amounts for Alaska or Hawaii).

How can you use your ABLÉ account?

ABLE accounts are designed to help pay for the account owner's "Qualified Disability Expenses (QDEs)," which are designed to be broad. These could include but are not limited to: education, housing, transportation, employment training and support, assistive technology and related services, health, prevention and wellness, financial management and administrative services, legal fees, and basic living expenses.

What are SSI and Medicaid limits?

SSI: You can continue to receive your monthly SSI checks until your ABLÉ account balance goes over \$100,000 (note: if you use your ABLÉ funds for a housing expense, you must spend it in the same calendar month).

Medicaid: No matter how much money is in an ABLÉ account, you never lose eligibility for Medicaid benefits.

ABLE Success Stories Around the Country



Photo courtesy of Tim Carpenter, *Kansas Reflector*



Photo courtesy of NFB's *Braille Monitor*



Photo courtesy of *ColletteDivitto.com*

Pattie and Patti Garbeff Plan for the Future

Pattie is a young woman with Down syndrome. She has been on the Kansas' Home & Community Based Services (HCBS) IDD Waitlist for almost 8 years. She has been working part-time for over 20 years at her local Hen House Grocery Store. She was one of the early ABLE account holders in Kansas when the program launched in 2017. Pattie is focused on building her ABLE account as a savings tool for when her mother and primary caregiver is no longer here. She is taking advantage of the direct deposit feature from her paycheck, having family and friends contribute to her account for birthdays and holidays, as well as ensuring these funds are invested. Patti will often say, "I have a sense of peace of having this account for Pattie. And, she has a sense of security for her future with an ABLE account."

Daniel Garcia Becomes a Home Owner Using His ABLE Account

Daniel Garcia, an active member of the National Federation of the Blind (NFB) community, was frustrated when his landlord informed him that his lease wouldn't be renewed due to his entire apartment complex remodel. He knew it was time to start saving for his own home. After doing research on home financing options, he decided his best option was to open an ABLE account. With his full-time job at the IRS, Daniel began savings in his ABLE account as a financial mechanism to purchase a home, and saved up enough for a down payment in 50 short days.

Colletley's Cookies – Promoting ABLE in the Workplace

Collette Divitto, born in 1990 with Down syndrome, is the owner of Colletley's Cookies and Colletley's Leadership. After years of rejection for employment and always being told she was not a good fit, Divitto decided to not give up. She started her own company based on her love of baking so she could earn a fair living and live independently. Colletley's Cookies, based in the Boston area, has made millions of cookies. Collette is a proud ABLE account holder, and uses her account for daily living expenses, like housing, gym memberships, and travel. As a disabled business owner, she also ensures that ABLE account education is included in the HR onboarding process for her employees with and without disabilities.

Congressional History: Bipartisan Support for the ABLE Act

The idea behind the ABLE Act started around a kitchen table in Northern Virginia. After a local board meeting, several parents from the Board of the Down Syndrome Association of Northern Virginia (DSANV) were discussing the inequities and injustices that existed in the current system preventing individuals with disabilities and their families to save for the future.

These five parents sitting around that kitchen table developed the initial idea and successfully advocated for the introduction of the first ABLE bill, which at the time was called the Financial Savings Account for Individuals with Disabilities (FSAID) Act. This bill was introduced in 2006 by the first ABLE Act Champion, Congressman Ander Crenshaw (R-FL). In 2010, the bill was renamed the ABLE Act; and changed to amend Section 529 (the college and university savings program) in the IRS Tax Code to allow for the establishment of 529 ABLE accounts.

The ABLE Act continues to achieve wide bipartisan support and popularity among federal and state lawmakers, State Treasurers and, most importantly, the disability community at large. While it took eight years and four U.S. Congresses to enact the ABLE Act in 2014, the bill earned the support of 85% of the entire 113th U.S. Congress when it was signed into law by President Obama. Led originally by Congressional Champions including U.S. Senators Richard Burr (R-NC) and Bob Casey (D-PA) and U.S. Representatives Cathy McMorris Rodgers (R-WA), Ander Crenshaw (R-FL), Pete Sessions (R-TX), and now U.S. Senator Chris Van Hollen (D-MD).

46 states and D.C. have ABLÉ programs cemented in state law. However, unlike at the federal level, there has been less focus on improving and capitalizing on the existing state ABLÉ framework. There is a tremendous opportunity to advance state policies that improve and expand ABLÉ programs.

State Infrastructure Behind the National ABLÉ Program

Upon the federal authorization of the ABLÉ Act in 2014, disability organizations worked swiftly to enact ABLÉ laws in state legislatures. To date, 46 states and the District of Columbia (DC) have launched state-administered ABLÉ programs which are operated out of various state government entities. Currently, there is strong momentum underway in both Wisconsin and Idaho in launching new state ABLÉ programs.

These state-administered ABLÉ programs are housed in various government agencies:

- state treasury offices
- state departments of human services/public health
- departments of revenue/budget and finance
- state college savings plans
- departments of rehabilitation services
- developmental disabilities (DD) councils

Each state's ABLÉ program also has a designated program administrator (i.e., Vestwell State Savings, LLC, d/b/a Sunday Administration, Ascensus College Savings Recordkeeping Services, LLC, PNC, Bank of Bangor, etc.) which supports state governmental entities in managing their ABLÉ programs.

Federal ABLÉ Landscape: Legislative Challenges & Solutions

One of the biggest hurdles to the continued success of the ABLÉ Act is the uptake of ABLÉ accounts. With only 204,000 ABLÉ accounts and over 8 million people eligible, there is only 2% utilization in the nationwide market. The average ABLÉ account size is approximately \$12,000.

There are a few critical and key challenges that can be addressed with federal and state policy. Further education and outreach and better coordination with existing federal and state benefits programs for people with disabilities. These opportunities include:

- Identifying and deploying strategies to scale ABLÉ by integrating and aligning ABLÉ accounts with federal and state benefits programs like State Medicaid enrollment, HCBS waivers, Vocational Rehabilitation, Social Security Benefits (i.e., SSI and SSDI), Ticket to Work programs, etc.
- Increase competition in the ABLÉ marketplace by allowing more financial institutions, authorized private institutions, and advisor-sold options to be offered to people with disabilities.
- Leveraging opportunities to expand ABLÉ Accounts by providing choice in care and supports through demonstration projects that allocate funds directly to eligible recipients ABLÉ accounts.
- Eliminating the federal Medicaid clawback requirement, which allows state Medicaid agencies to request reimbursement for Medicaid expenses paid since the ABLÉ account was opened (note: ABLÉ account holders who never used Medicaid are not subject to the clawback).
- Engaging and collaborating with large and small-employers and their Employee Resource Groups (ERGs) to promote ABLÉ account education, direct deposit features and establish new matching programs.
- Enhancing national and regional media about the benefits of ABLÉ accounts, ABLÉ testimonials, and success stories.

Looking Back: What was in the ABLE 2.0 Framework?

Since the original passage of the ABLE Act in 2014, the landmark law has been improved eight times. This includes the following federal action:

Year	Federal ABLE Policy Improvement	Legislative Vehicle
2015	Congress eliminated the state residency requirement in the original ABLE Act	Protecting Americans from Tax Hikes Act of 2015 (as part of the Consolidated Appropriations Act of 2016)
2017	Congress included several important provisions in the Tax Cuts & Jobs Act (TCJA) including the enactment of the following time-limited tax provisions: <ul style="list-style-type: none"> The ABLE to Work Act which allowed for additional ABLE contributions from a working adult with a disability who is not contributing to a retirement vehicle; The ABLE Financial Planning Act which allows for an individual to rollover a 529 to an ABLE account (529A) without any tax consequence; and Allowed an ABLE account's designated beneficiary to claim the saver's credit for contributions to the account. 	Tax Cuts & Jobs Act (TCJA); Provisions are set to sunset and must be addressed
2022	Passage of the ABLE Age Adjustment Act, which increases the age of eligibility from 26 years old to 46 years old.	Secure 2.0 (section 124); Age of eligibility increase goes into effect on Jan. 1, 2026
2025	Passage of the ENABLE Act which makes permanent the following provisions: <ul style="list-style-type: none"> Increased Contributions to ABLE Accounts "ABLE to Work" — Individuals with disabilities who are employed can continue to make additional contributions to their ABLE accounts — equal to the lesser of their annual income or the federal poverty level for a one-person household. This provision is now permanent, and includes an additional year of inflation adjustment to the base contribution limit. Tax-Free Rollovers from 529 Plans to ABLE Accounts - Families and individuals can now permanently roll over funds from 529 college savings plans to ABLE accounts without tax penalties — offering even greater flexibility in planning for education and disability-related expenses. Saver's Credit for ABLE Contributions — Designated ABLE account beneficiaries who contribute to their own accounts can now permanently qualify for the Saver's Credit — a key tool in promoting long-term financial security. 	One Big Beautiful Bill (OBBA) which was signed into law on July 4, 2025

118th ABLE Act Congressional Legislation

In the 118th Congress, there were two significant Congressional efforts to expand the ABLE Act framework. These included:

The Ensuring Nationwide Access to Better Life Experience (ENABLE) Act

Newly elected U.S. Senator Eric Schmitt, formerly Missouri State Treasurer and founder of MO ABLE in 2018, introduced the bipartisan Ensuring Nationwide Access to Better Life Experience (ENABLE) Act, which aims to permanently extend the expiring TCJA provisions. The ENABLE Act passed unanimously in the U.S. Senate on September 20, 2024. Eventually included and passed in the One Big Beautiful Bill in the 119th Congress.

The ABLE Tomorrow Act

Retiring Congresswoman McMorris Rodgers unveiled her legacy ABLE plan entitled The ABLE Tomorrow Act in December 2024. The ABLE Tomorrow Act cemented the Congresswoman's Congressional leadership and legacy on the ABLE Act, while introducing several new ABLE 3.0 policy ideas to capitalize on the momentum behind the ABLE Act. These included:

- Extending the TCJA expiring provisions aligned with the ENABLE Act
- Eliminating the Medicaid clawback in the original ABLE Act of 2014
- Providing a two month grace period with enhanced notification for beneficiaries' prior to losing SSI should their accounts accrue past the \$100,000 threshold

- Encouraging SSA and the VA to offer ABLE education programs for families and military families when they open up an SSI or SSDI
- Reaffirming that qualified expenses in ABLE accounts aren't assets under Medicaid so they don't count towards resource limits
- Permitting ABLE-eligible workers to allow an employer to make contributions to a 529A account in lieu of contributions to the employer's defined contribution plan so that an employer could receive a tax deduction for the contribution
- Allowing for a one-time lump sum (i.e., for a life insurance or estate transfer, etc.) into an ABLE account beyond the federal gift tax contribution limit

What's Next? ABLE 3.0 Framework

As the 119th Congress begins and President Trump takes office, several new policy ideas have emerged that could expand, enhance, and build on the success of the original ABLE Act and ABLE 2.0. These are outlined across in three priority tiers:

Tier	Federal Legislative Concept	Legislative Vehicle/Strategy	Background
TIER 1	Eliminate the Medicaid clawback in the original <i>Stephen Beck Jr., ABLE Act of 2014</i> .	Language included in the ABLE Tomorrow Act/2024 bill	<p>A Medicaid Clawback can occur when an ABLE account holder passes away, the remaining funds in the account may be used to reimburse the account holder's state for Medicaid expenses paid after the ABLE account was established. The possibility of a State Medicaid agency clawing back ABLE funds remains a deterrent for self-advocates and families to opening up ABLE accounts.</p> <p>Currently, this is a federal requirement from the original ABLE Act. However, to date, 17 states have already eliminated the Medicaid Clawback by enacting state legislation.</p>
	Increase competition in the ABLE marketplace to expand the number of entities that can offer ABLE plans by allowing financial institutions, authorized private institutions and advisor-sold plans to be offered.	*NEW	<p>Amend language in Section 102 of the original ABLE Act to "allow qualified ABLE programs to be established and maintained by eligible financial institutions, authorized private entities and allow for advisor-sold plans to be offered for ABLE accounts", in addition to existing options for ABLE plans to be run by "states or state agencies".</p> <p>There is a great need for more competition in the ABLE marketplace. Allowing more financial institutions (i.e., national banks, financial institutions, etc.) to offer ABLE plans would increase and expand awareness of ABLE accounts to people with disabilities, family members and caregivers. Moreover, there is precedent in the 529 plans where advisor-sold plans have increased the uptake of 529s.</p>
	Allow State Vocational Rehabilitation (VR) Directors to utilize ABLE accounts as a mechanism to provide financial support to eligible consumers for training, transportation, education and other work-related expenses.	*NEW	<p>People with disabilities are limited to accessing job training, college programs, etc. based on where they live. VR is a program funded by federal and state taxpayer dollars to the tune of \$3 billion operated by the U.S. Department of Education's Rehabilitation Services Administration (RSA), and carried out by designated state VR agencies.</p> <p>Allowing VR financial support, scholarships and work-related expenses to work alongside ABLE Accounts would allow for PWDs to have more flexibility, increase access to job training programs/colleges and ensure more PWDs are career ready.</p>
	Increase the SSI threshold in the original ABLE Act from \$100,000 to \$150,000.	*NEW	<p>Many ABLE account holders and early adopters are now reaching the \$100,000 SSI threshold putting their SSI benefits in jeopardy.</p> <p>Amend Section 103 of the original ABLE act to increase the SSI payment suspension to \$150,000.</p>

Tier

Federal Legislative Concept

Legislative Vehicle/Strategy

Background

TIER 2

Establish a federal interagency ABLE task force to coordinate best practices, ABLE education and outreach, alignment with federal agencies and departments to promote ABLE accounts alongside similar disability benefits/programs like SSA, VA, Medicaid, HUD, Voc Rehab, etc.

***NEW**

There is low understanding of the benefits of ABLE accounts. An interagency task force should encourage ABLE education in case management of all programs.

Passage of the ABLE Employment Flexibility Act

Revised bipartisan bill introduced in July of 2025 in US House/US Senate

The bill aims to help workers with disabilities save money and build financial security without risking their essential federal benefits by allowing employers to make tax-exempt contributions to employees' ABLE accounts instead of traditional 401(k) accounts. This change ensures workers with disabilities can save for their future without jeopardizing the federal support they rely on to thrive in their communities. The bill was introduced by U.S. Senators Schmitt (R-MO) & Klobuchar (D-MN) and U.S. Representatives Fitzpatrick (R-PA) & Sharice Davids (D-KS) in July 2025.

ABLE to Retire Act/Provision: Allow individuals with disabilities (who don't currently access retirement accounts) to accept contributions from employers into ABLE accounts as retirement contributions — up until the annual IRA limit (= \$7,000); and exempt contributions by employers as income for SSA benefits.

***NEW**

This is a unique opportunity to engage employers and retirement community to elevate what "retirement with dignity" and future policy should look like for the disability community

Allow for one-time lump sum payments per beneficiary (i.e., for a life insurance or estate transfer, etc.) into an ABLE account beyond the \$19k/gift tax contribution limit.

Language included in the *ABLE Tomorrow Act/2024 bill*

Determine what cap is needed for allowable one-time lump sum payments such as life insurance payouts, larger 529 rollovers, and estate payments over the ABLE beneficiary's life

Require SSA and CMS to include information about ABLE accounts during the enrollment process for SSA benefits and HCBS waiver.

Language included in the *ABLE Tomorrow Act/2024 bill*

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Require the Federal Government to offer ABLE account direct deposit features to federal employer workforce, AbilityOne, SourceAmerica, etc.

***NEW**

State of Ohio has adopted; Kansas is working with its Dept. of Administration to adopt ABLE strategy

Provides a 2-month grace period with enhanced notification for beneficiaries' prior to losing SSI should their accounts accrue past the \$100,000 threshold.

Language included in the *ABLE Tomorrow Act/2024 bill*

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TIER 3

State ABLE Policy Solutions and Incentives

Much of the state advocacy around ABLE programs has centered around the early legislation to establish state ABLE programs. As mentioned above, 46 states and D.C. have ABLE programs cemented in state law. However, unlike at the federal level, there has been less focus on improving and capitalizing on the existing state ABLE framework. There is a tremendous opportunity to advance state policies that improve and expand ABLE programs.

State Policy & Educational Opportunities	Opportunity	Background	Action
Enhance & Promote ABLE State Tax Incentives	Many states offer state tax incentives related to contributions to ABLE accounts but several offer none. Many states could benefit by increasing state tax incentives and establishing new incentives for ABLE accounts.	Several states, like New Mexico, D.C., Florida, etc. have no tax incentive.	Conduct a landscape assessment of current ABLE state tax incentives and determine states that could benefit from enhancing their ABLE tax policy. Expand financial educational tools to educate parents and caregivers about contributions and incentives for ABLE accounts.
Create Medicaid Flexibility Pilot Demonstration	A state could apply for a 1915 Community Supports Waiver in Medicaid to create a demonstration project to allocate funds directly to eligible recipients' ABLE accounts to allow for individuals with disabilities to save, invest and spend funds on disability qualified expenses. By contributing directly to individuals with disabilities and their families, we lessen the need for federal and state government bureaucracy, and provide more choices for caregiving services.	No state has ever taken this approach. By providing choices to individuals with disabilities, this has the potential to give people with disabilities access to more flexible and less costly caregiving arrangements. It also may provide a bridge to state portability of Medicaid dollars if an individual needs to move across state lines.	State applies for a 1915 (c) Medicaid Home and Community-Based Services (HCBS) Community Supports waiver.
State-by-State Medicaid Clawback Elimination	While 17 states have eliminated Medicaid Clawback from their state ABLE plans, the Medicaid Clawback contained in the original ABLE Act remains a deterrent for individuals and families to open ABLE accounts. State Medicaid agencies do not have the staff, resources and infrastructure to track clawbacks; as a result, we are seeing only a minimal number of clawbacks occur when an ABLE account holder passes.	States like Florida, Virginia, Tennessee and Kansas to name a few, have eliminated Medicaid Clawbacks with state legislative action.	---
Adopt state legislation to align and expand ABLE with other state agency, departments and benefits	This is a low-cost way to deliver ABLE information to eligible account holders while also encouraging early financial planning and saving throughout a person with a disability's life. Each state approaches its disability infrastructure differently, but expanding ABLE education alongside state programs like Vocational Rehabilitation, Social Security Benefits, Medicaid/Home & Community Benefits (HCBS) could have a lasting impact.	Illinois and Maryland have enacted state bills that help coordinate information about ABLE accounts for students accessing special education services during I.E.P. meetings. Maryland is exploring awarding Vocational Rehabilitation scholarships directly into ABLE account to allow more flexibility.	Develop a state-by-state ABLE advocacy and enhancement assessment and road map. Identify opportunities to allow for states to have flexibility to grant federal/state benefits like Voc Rehab, various HCBS waivers and funds directly into ABLE accounts.

(Table continued...)

State Policy & Educational Opportunities	Opportunity	Background	Action
ABLE Roadshow Campaign/ Scholarship	The Kansas State Treasurer's Office, in collaboration with the Developmental Disabilities Council and the Department for Aging and Disability Services, embarked on a statewide initiative to bring ABLE account education to communities across Kansas. Over six months, the team visited 52 locations, offering in-person training sessions to individuals and families. As an added incentive, individuals on the IDD waitlist who attended received a \$100 scholarship, which was directly deposited into their newly created ABLE accounts.	Through this targeted grassroots approach, the Kansas ABLE program achieved a 25% increase in the number of accounts and grew assets under management by nearly \$8 million.	Expand the state ABLE Roadshow in additional states, connecting with individuals and families in-person to provide ABLE education and support.

How Employers Can Engage and Support ABLE Accounts in the Workplace

We have seen a rise in the number of national and state employers looking to improve support, accessibility, hiring and retention practices and reward disabled talent. Organizations like the Society for Human Resource Management (SHRM) and Employee Resource Groups (ERGs), at US Bank, ManTech and Autism Speaks, are offering regular sessions on ABLE accounts to their employees. In fact, some employers, SBR Resources, a mid-size disability provider to Intuition, are stepping up and providing ABLE matching programs for their employees.

As mentioned above, U.S. Congress enacted the ABLE to Work Act in 2017, which expanded the ABLE Act to allow adults who are working and not already contributing to a workplace retirement plan to save additional money each year in an ABLE account.

Companies around the country are finding that educating their workforces about ABLE accounts and offering incentives to match ABLE accounts are terrific strategies to promote disability inclusion and recruit new talent — not only to employees with disabilities, but also to those employees who are caring for a loved one with a disability.



Specifically, there are several ways employers can incorporate ABLE into the workplace:

- Include ABLE account education and materials as part of your HR department onboarding process
- Offer direct deposit information on ABLE accounts — both employees with disabilities as well as family members and caregivers can take advantage of direct depositing payroll earnings into an ABLE account
- Design and launch ABLE matching contribution programs, or even contribute a flat percentage to employees with an ABLE account

Conclusion

ABLE Accounts have already allowed the disability community to save more than \$2.46 billion assets under management (AUM) across 204,000 ABLE accounts since the first program launched in June 2016. Now there are big opportunities for Congress and the states to expand ABLE accounts and for employers to better implement them in benefits packages.

About the Authors

Sara Hart Weir

Executive Director, Kansas Council on Developmental Disabilities; Senior Fellow, Able Americans

Sara Hart Weir is a national disability leader, federal and state policy expert and proud Kansan. Weir has been working in the disability community for over two decades. Weir's passion was inspired by Kasey, her late best friend of twenty years from Kansas who had Down syndrome.

Early in her career, Sara quickly realized that the disability community did not have high-powered lobbyists, wealthy corporations or influential political action committees working for them, she went on to change that, and continues to dedicate her career and service to allow everyone to have a fair shot at the "American Dream" by promoting solutions that give all Americans with disabilities access to a better life.

Weir serves as the Executive Director of the Kansas Council on Developmental Disabilities (KCDD) where she leads the statewide organization dedicated to improving the lives of Kansans with intellectual and developmental disabilities (I/DD) throughout every corner of the sunflower state. Weir has transformed KCDD into the most well-respected disability organization in Kansas' State Capitol fighting to eliminate the state's historic 10-year IDD Home & Community based services (HCBS) waitlist. In just two state legislative sessions, KCDD helped lower its waitlist by at least 1,200 Kansans with IDD, and is leading a three-year plan to eliminate the waitlist.

Early in her career, Weir joined the National Down Syndrome Society (NDSS) as the Vice President of its National Advocacy & Policy Center and oversaw the Down syndrome community's advocacy and policy agenda in Washington, DC and in state capitals across the country.

In late 2014, Weir was named the President & CEO of NDSS where she served until 2019 when Sara stepped down to run for US' Congress. During her tenure at NDSS, Weir led the bipartisan national advocacy coalition and strategy on the passage of the landmark *Stephen Beck Jr., Achieving a Better Life Experience (ABLE) Act* of 2014. Weir secured over 85% of the entire US Congress as cosponsors of the ABLE Act — specifically 381 of 435 US Reps. and 78 of 100 US Sens. The ABLE Act is hailed as the most significant disability rights bill since the Americans with Disabilities Act (ADA). The ABLE Act established private sector, tax-free savings accounts that allow Americans with disabilities to save and invest their own money for the future. Subsequently, Weir led the advocacy effort to pass 47 state ABLE laws; and helped launch the majority of state ABLE programs across the country. Weir worked with Republican Leadership in 2017 to enact the two key disability provisions in the Tax Cuts & Jobs Act (specifically the ABLE to Work Act and ABLE Financial Planning Act). To date, 46 states and D.C. have launched ABLE programs and assets under management in ABLE accounts have grown over \$2.4 billion.

Weir was the Congressional Republican Primary Runner Up in Kansas Third District's (KS-3) 2020 five-way primary in 2020. Weir has a Bachelor of Arts in Psychology and Political Leadership from Westminster College and a Master of Science in Public Policy and Management from Carnegie Mellon University's Heinz College.



Rachel Barkley

Director, Able Americans at the National Center for Public Policy Research

Rachel K. Barkley, director of the National Center's Able Americans program, has a decade of experience connecting Members of Congress, state and national think tank leaders, corporate stakeholders, state legislators, governors, advocacy professionals, and media influencers around shared goals. She has overseen the strategy for multi-state issue campaigns, executed many communication plans, managed the development of policy agendas, and advanced federal legislation spanning a variety of issues and committees through coalition action.

Rachel was the External Relations Senior Advisor to Representative Cathy McMorris Rodgers (WA-05). Previously, she also worked as Director of Outreach for the U.S. House of Representatives Conference Chair and as Director of Coalitions and State Outreach for the Republican Study Committee, the largest caucus in Congress. Rachel got her start at a national non-profit for state policy think tanks, State Policy Network, where she worked as a liaison between state and national organizations.

She started RK Barkley Consulting in 2019 and has represented a diverse array of clients from the tech and innovation, financial services, and nonprofit think tank sectors. She serves clients in an external relations and strategic leadership capacity — executing coalition development, event strategies, marketing plans, speaking engagements, and organizational brand advising. Rachel also has led strategic planning and project management for her clients and coalitions. She is the Executive Director of the Alliance for Opportunity, a multi-state coalition to advance an anti-poverty and upward mobility agenda.

Just three weeks after having her first baby and turning 30, Rachel was diagnosed with a rare spinal cord tumor that threatened her life. The tumor and surgery to remove it left her as a quadriplegic. She and her husband, Taylor, survived months in hospitals, near death, rehabilitation, and their return home accompanied by work to regain their family life and movement in Rachel's body. This life-altering experience has changed how she approaches health care, disability, and safety net policy reform.

