

Commemorating 40 Years Of Disability Advocacy 1973-2013

July 26, 2013

The Honorable Max Baucus United States Senate Washington, DC 20510

The Honorable Orrin Hatch United States Senate Washington, DC 20510

RE: Achieving a Better Life Experience (ABLE) Act of 2013 (H.R. 647/S. 313)

Dear Senator Baucus and Senator Hatch:

As organizations that represent millions of Americans with disabilities, we write in support of the Achieving a Better Life Experience (ABLE) Act of 2013 (H.R. 647/S. 313). This measure, which continues to have broad bipartisan support, will help individuals with disabilities enjoy a better quality of life. To date, the ABLE Act has earned 38 cosponsors in the US Senate and 219 cosponsors in the US House and is being led by a bipartisan, bicameral set of Congressional champions, including Senator Robert Casey, Jr. (D-PA) and Senator Richard Burr (R-NC); and Congressman Ander Crenshaw (R-FL), Congressman Chris Van Hollen (D-MD), Congresswoman Cathy McMorris Rodgers (R-WA), and Congressman Pete Sessions (R-TX). At the conclusion of the 112th Congress, the ABLE Act earned the support of over half the entire Congress, with 41 cosponsors in the Senate and 236 cosponsors in the House. We feel strongly that you will not find another piece of tax legislation in the US Congress today that has as much bipartisan, bicameral support as the ABLE Act.

The Need for ABLE Accounts

A 529 plan is a plan operated by a state or educational institution, with tax advantages and potentially other incentives to make it easier to save for college and other post-secondary training. Earnings are not subject to federal tax and generally not subject to state tax when used for the qualified education expenses of the designated beneficiary, such as tuition, fees, books, and room and board. Current 529 plans serve a major life need, but these plans can fall short for the many individuals with severe disabilities who cannot or choose not to pursue post-secondary education.¹ The ABLE Act would amend section 529 of the Internal Revenue Code to encourage savings for the needs of an individual with a disability, whether or not those needs include savings for higher education.

ABLE accounts would supplement but not supplant benefits provided through private insurance, a beneficiary's employment, the supplemental security income (SSI) program, the Medicaid program, or other sources. Many individuals with disabilities rely on SSI and Medicaid to live independently. The

¹ E.g., only a third of young adults with autism attend college within six years of completing high school. Shattuck P, Carter Narendorf S, Cooper B, Sterzing P, Wagner M, Lounds Taylor J. <u>Postsecondary Education and</u> <u>Employment Among Youth With an Autism Spectrum Disorder</u>. *Pediatrics*. 2012; 129 (6): 1-8.

means tests for those programs², however, discourage individuals with disabilities from participating in the workforce and discourage their families from providing financial support. ABLE accounts will help people with disabilities enjoy greater financial security.³

How ABLE Accounts Could Be Used

ABLE accounts could be used for a variety of purposes, including the following:

- Education, including tuition for preschool through post-secondary study, tutors, and special education services;
- Housing, including expenses for acquiring, modifying, and maintaining a primary residence;
- Transportation, including expenses for using mass transit, purchasing and modifying vehicles, and moving;
- Employment support, including expenses for obtaining and maintaining a job, such as jobrelated training, assistive technology, and personal assistance supports
- Health and wellness, including premiums for health insurance, mental health, medical, vision, and dental expenses, habilitation and rehabilitation services, durable medical equipment, therapy, respite care, long term services and supports, nutritional management, communication services and devices, adaptive equipment, assistive technology, and personal assistance; and
- Miscellaneous expenses such as funeral and burial expenses.

ABLE Accounts are not intended to replace special needs trusts (individual or pooled) as an option for financial planning. ABLE Accounts provide an alternative to special needs trusts and could be used by lower-income individuals who lack access to individualized financial planning.

Eligibility for ABLE Accounts

ABLE accounts would be available for individuals who receive supplemental security income benefits or disability benefits. They would also be available under stringent conditions for individuals who are not receiving these benefits but who have a medically determined physical or mental impairment that results in marked and severe functional limitations.

ABLE Accounts, Medicaid, and SSI

As a safeguard against abuse, assets remaining in an ABLE account after a beneficiary dies are first distributed to any state Medicaid plan that provided medical assistance to the beneficiary. A key feature of ABLE accounts is their treatment under means-tested federal programs such as SSI and Medicaid. When the assets in an ABLE account reach \$100,000, any monthly SSI benefits are suspended but not terminated; benefits resume once the assets in the account drop below the threshold. Suspension of SSI benefits has no impact on an individual's Medicaid eligibility.

 $^{^{2}}$ To be eligible for disability benefits, a person generally may not have more than \$2,000 in countable resources and must be unable to engage in substantial gainful activity (SGA). A person who is earning more than a certain monthly amount is ordinarily considered to be engaging in SGA. For non-blind individuals, the monthly SGA amount for 2013 is \$1,040.

³ The poverty rate among non-elderly adults with a disability is 28.8 percent; those with a disability represented 16.3 percent of people in poverty, compared with 7.7 percent of all people aged 18 to 64. DeNavas-Walt C, Proctor B, Smith J, U.S. Census Bureau, *Income, Poverty, and Health Insurance Coverage in the United States: 2011*

A Case Study for ABLE



Aaron and Julia both have Down syndrome. They are engaged and live in Santa Rosa, California, in an apartment building.

Aaron and Julia have worked in a variety of job sites, including a local coffee shop, a recycling plant, and a factory for assembling American flags.

Medicaid and SSI provide Aaron and Julia with in-home care support assistants who help them get to work, go to the doctor, cook and clean, and attend educational and social activities. If they had an ABLE account, Aaron and Julia could do the following:

- Go to the dentist. California's Medicaid program covers one dental cleaning a year, but dentists recommend getting two cleanings. California's Medicaid program also doesn't pay for dental crowns.
- Get a hearing aid. California's Medicaid program doesn't cover hearing aids for the partially hearing impaired.
- Replace a pair of lost glasses. Vision benefits under California's Medicaid program are very limited.

Aaron and Julia represent just two of the individuals who could benefit from ABLE Accounts. The ABLE Act creates a tool for individuals with disabilities and their families that could lead to a more independent and fulfilling life.

If you have any questions or need any additional information, please contact NDSS' Vice President of Advocacy & Affiliate Relations, Sara Hart Weir, at 202-680-8867 or sweir@ndss.org and/or Autism Speaks' Senior Policy Advisor and Counsel, Stuart Spielman, at 301-518-3327 or spielman@autismspeaks.org.

As tax reform progresses, we ask that you strongly consider the benefits of these accounts for the individuals and families our organizations support.

Sincerely,

ACCSES

American Association on Health and Disability American Association on Intellectual and Developmental Disabilities American Association of People with Disabilities American Speech-Language-Hearing Association Association of Assistive Technology Act Programs Association of University Centers on Disabilities Autism National Committee Autism Society of America **Autism Speaks Bazelon Center for Mental Health Law** Brain Injury Association of America Collaboration to Promote Self-Determination Community Services for Autistic Adults and Children **Daniel Jordan Fiddle Foundation Easter Seals Family Voices** Lutheran Services in America Disability Network National Alliance on Mental Illness National Association of County Behavioral Health & Developmental Disability Directors National Association of Councils on Developmental Disabilities National Association of State Directors of Developmental Disabilities Services National Association of State Head Injury Administrators National Center for Learning Disabilities National Disability Institute National Down Syndrome Congress National Down Syndrome Society National Federation of the Blind National Fragile X Foundation Union of Orthodox Jewish Congregations of America TASH The Advocacy Institute The Arc The Disability Opportunity Fund The Jewish Federations of North America

UJA-Federation of New York Union for Reformed Judaism United Cerebral Palsy United Spinal Association