NATIONAL DOWN SYNDROME SOCIETY
The National Advocate for People with Down Syndrome
Since 1979
“Nobody can do it alone. Having consumers, parents and other advocates working together with a key legislator or two is the only way to pass a bill. Legislators help with the process, and the stakeholders provide the passion.”

— The Honorable State Representative Judy Ann Buffmire from Salt Lake City
Utah
State Legislature since 1992
MISSION
The mission of the National Down Syndrome Society is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome.

VISION
The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities.
A historical nine year journey... What took us from here to there!

A kitchen table idea

President’s Desk
The "ABLE Act" Story

85% of the entire US Congress supported the ABLE Act

- 381 out of 435 in the US House of Representatives
- 78 out of 100 in the US Senate

Most significant disability legislation since the Americans with Disabilities Act (ADA) was passed 25 years ago.

T.O. family celebrates ADA at White House

7-year-old, parents share in anniversary

By Bartholomew Sullvan
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WASHINGTON — Little Brianna Pitzela followed up shaking hands with President Barack Obama on Monday by giving a kiss to Vice President Joe Biden. Brianna, who has Down syndrome, turned 7 this week and went with her parents, Brad and Juliane Pitzela, of Thousand Oaks, to the White House to celebrate the 25th anniversary of the passage of the Americans with Disabilities Act.

The Pitzelas heard the president say that "days like today are a celebration of our history. But they're also a chance to rededicate ourselves to the future — to address the injustices that still linger, to remove the barriers that remain."

While listening to Obama, Brad Pitzela, 38, said he was struck by the "amazing" message the president imparted. "What he said that I found really touching was that, for the next 16 months, he was going to continue to push forward an agenda that's friendly to the disability community — and even beyond. So he seemed to say that his legacy beyond his presidency might be tied to helping folks with disabilities," he said. "We need champions in this," he said. "We definitely need champions."

The Pitzelas were invited to represent the National Down Syndrome Society in the East Room ceremony for their long-time efforts at getting the Achieving a Better Life Experience Act passed at the national and state levels. Brianna helped cast a vote for the federal House bill in December at the invitation of Rep. Julia Brownley, D-Wentlake Village. That measure has since been signed into law.

"The ABLE Act allows folks with disabilities to earn money without losing access to Social Security and Medicaid benefits," Pitzela explained. When he's not working in e-commerce marketing, collecting comic books and action figures, Pitzela said he's lobbying for passage of the California version of the ABLE Act, which is pending in Sacramento.

The California bills — AB 449 and SB 324 — would conform with current federal law and encourage individuals and families to save private funds "for the purpose of supporting persons with disabilities to maintain their health, independence, and quality of life."

The bills are co-sponsored by the Pitzela's state representatives, Sen. Fran Pavley, D-Agoura Hills, and Assemblywoman Jacqui Irwin, D-Thousand Oaks.
What it took to get the ABLE Act passed...

This week, the House will vote on the #ABLEAct to help people with disabilities save for the future. #passtheABLEAct

https://t.co/1HVT1MK

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Saving a Future for Those With Disabilities

Back in the old days, when Congress did crazy things like pass legislation, a wonder bill like the ABLE Act might have a decent shot of passing.

But today, even with a long list of priorities — it's a good list, unless you're growing food or have lots of weapon support — it's not a slam dunk, because there's a way in Washington to swamp good ideas, especially those that involve reading the tea leaves and spending little money.

Making a Better Life Opportunities Act would be a huge win for people with disabilities, and their parents and other caregivers. It would allow them to put money into tax-deferred savings plans, like 529 plans that parents can use for their kids, to cover expenses like education, housing, transportation, health and rehabilitation, among other things. Advocates say the accounts, called 529-ABLE plans, would be easier and less expensive to set up and maintain than the current funds often used for beneficiaries with disabilities.
The Stephen Beck, Jr. ABLE Act
Becomes the Law of the Land
– December 19, 2014
WHAT is ABLE?

A federal law which amends the federal tax code to add Section 529A in order to:

create a new option for eligible people with disabilities
to save money in a tax-exempt account
that may be used for qualified disability expenses
while still keeping their eligibility for federal public benefits.

This law AUTHORIZES states to create their own ABLE programs but does not require them to do so. A state may create its own ABLE program, or residents of that state may open an ABLE account in another state.
Landscape

- 54 million people with be eligible for an ABLE account
- Accounts can be used across the lifespan of individual – more transactions but more ability to acquire assets in an ABLE account
  - People with disabilities are living longer/life expectancy is at a all time high
- The Disability Community are loyal customers – “Gap Factor” – One Stop Shopping for all 529 Plans
- Estimated cost just to raise a child with Down syndrome or Autism is around $1 million out of pocket
<table>
<thead>
<tr>
<th>Challenges in US System</th>
<th>Opportunities for PWD</th>
<th>Intent of ABLE</th>
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<tbody>
<tr>
<td>People with disabilities can only have $2,000 in assets at any given time to remain eligible for Medicaid (our national healthcare system for people with disabilities) and Social Security Insurance (SSI)</td>
<td>People with disabilities are going to college – we have 250 postsecondary programs in the US now</td>
<td>To encourage and assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities to maintain health, independence, and quality of life</td>
</tr>
<tr>
<td>Medicaid &amp; SSI do not provide all the necessary supports and services</td>
<td>People with disabilities are pursuing employment opportunities, especially in competitive and integrated settings, like no other time</td>
<td>The legislative intent of ABLE Accounts is to provide secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities</td>
</tr>
<tr>
<td>We disincentivize “employment” in the US</td>
<td>People with disabilities want to work and can work</td>
<td>To supplement, but not supplant, benefits provided through private insurances, the Medicaid program, the supplemental security income program, the beneficiary’s employment, and other sources</td>
</tr>
<tr>
<td>Sheltered Workshops and sub-minimum wage is legal, unemployment rates are very high in the US</td>
<td>People with disabilities are living longer and have so much to contribute to society</td>
<td></td>
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ABLE ACCOUNT MECHANICS

- Each eligible individual may have **only one** ABLE account
- THE “Designated beneficiary” is the account owner
- Total annual contributions may not exceed the federal gift tax limit, which is currently $14,000
- Multiple individuals may make contributions to the one ABLE account
- Aggregate contributions may not exceed the state limit for 529 savings accounts
- Beneficiary can remain on Medicaid at all times but Social Security benefits can be suspended at $100,000
- Funds can only been spent on qualified disability expenses
- Medicaid Payback
Our Mission

To advance the effective implementation of policies and initiatives that promote full economic inclusion for individuals with disabilities through both traditional and innovative tools, like the newly created ABLE accounts, work initiatives, and financial literacy programs.

Key Objectives

- Promote and market the widespread availability and diverse utilization of ABLE accounts to eligible individuals and their families
- Advocate for legislative and regulatory policies, at both the federal and state levels, to ensure effective implementation and full participation
- Promote policy initiatives that advance financial literacy tools for all persons with disabilities
- Educate eligible beneficiaries, as well as family members and caretakers on ABLE accounts, on the use of ABLE accounts as a savings vehicle for the use for designated distributions, how ABLE accounts will interact with public assistance/means tested programs and protection beneficiaries from financial abuse
- Explore and engage stakeholders in advocating for a comprehensive federal and state legislation agenda to break down barriers to employment while creating meaningful employment opportunities for individuals with disabilities through all employment
Join the Conversation

The National Down Syndrome Society has a strong online presence & would like you to be a part of it!

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Instagram: http://www.instagram.com/ndssorg

You Tube: http://www.youtube.com/ndssorg

Pinterest: http://www.pinterest.com/ndssorg
Questions?

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