“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
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.
FOUR AREAS OF PROGRAMMING

National Advocacy & Policy Center creates systemic change through legislative advocacy

The National Buddy Walk® program honors and celebrates individuals in their communities

Public Awareness initiatives bring new and positive presentations of Down syndrome to the public

Community outreach programs provide comprehensive and accurate information and resources on Down syndrome
NDSS LEGISLATIVE AGENDA

The legislative and policy priorities span the life experience of individuals with Down syndrome from birth through adulthood and range in issue from healthcare to asset development.

These priorities have been shaped by self-advocates, families, affiliate leaders and others under the direction of the NDSS Board of Directors and the National Governmental Affairs Committee (NGAC).

- Improving Health Outcomes and Quality of Life for People with Ds
- Improving Education Opportunities for People with Ds
- Increasing Opportunities for Adults with Ds
- Creating and Economic Future for Individuals with Ds
PURPOSE OF THE ABLE ACT

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

The legislative intent of ABLE Accounts is to provide secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities

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
THE “ABLE ACT” STORY – A LONG, OPEN ROAD!
A HISTORICAL NINE YEAR JOURNEY... WHAT TOOK US FROM HERE TO THERE!

A KITCHEN TABLE IDEA

PRESIDENT’S DESK

Pass me, please!
WHY NDSS BUILT AND INVESTED IN THE FIRST-EVER DOWN SYNDROME GRASSROOTS NETWORK
BUDDY WALK ON WASHINGTON(S)!!!
A FIREPLACE CHAT & A BALCONY SUMMIT...

September 2013

October 2013
My mom was my advocate, she and I had many conversations about the ABLE Act. She said to me, “Sara, we have to get this bill passed.” She promised me that she will be at the signing of this bill into law. I would like to keep this promise alive for her, for me, and for the thousands of people with Down syndrome and other disabilities. We deserved to be heard, THANK YOU!
STRANGE AND EVEN STRANGER BEDFELLOWS

Thank you to our newest

#ABLEact cosponsors!

Senator Harry Reid (D-NV) - Majority Leader of US Senate and Senator Mitch McConnell (R-KY) – Minority Leader of the US Senate are the newest cosponsors of the Achieving a Better Life Experience Act. Thank you for your support!


#passtheABLEact
Saving a Future for Those With Disabilities

By THE EDITORIAL BOARD  MARCH 13, 2014

Back in the old days, when Congress did crazy things like pass legislation, a sensible bill like the ABLE Act might have sailed to the president’s desk. But today, even with a long list of positives — it’s a good idea, solves a pressing problem and has lots of bipartisan support — it’s not a slam dunk, because there’s always a way in Washington to squelch good ideas, especially those that involve tweaking the tax code and spending a little money.

The Achieving a Better Life Experience Act would be a boon for people with disabilities, and for their parents and other caregivers. It would allow them to put money into tax-deferred savings plans, like the 529 plans that parents use to save for college, to cover expenses like education, housing, transportation, therapy, rehabilitation and assistive technology. Advocates say the accounts, called 529-ABLE plans, would be easier and less expensive to set up and maintain than the trust funds often used for beneficiaries with disabilities.
#PASSTHEABLEACT – AN AMAZING SOCIAL MEDIA CAMPAIGN

This week, the House will vote on the #ABLEAct to help people with disabilities save for the future.
j.mp/1HVTtMK

12/2/14, 1:48 PM

6 RETWEETS 3 FAVORITES
HOUSE OF CARDS – ABLE STYLE

- Getting Congress to prioritize disability
- 112th Congress Push – Fly-in
- Tax Reform – An Up Hill Battle!
- Identifying a consistent bipartisan message – D’s & R’s
- “The CBO Score” heard around the world - $20 BILLION!
- Pulling Everything Off the Shelf
- The “ABLE Legislative DREAM Team”
## NET INCREASE IN THE DEFICIT FROM CHANGES IN DIRECT SPENDING AND REVENUES

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<th>1.8</th>
<th>2.4</th>
<th>3.2</th>
<th>4.0</th>
<th>4.7</th>
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</thead>
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**SOURCES:** Congressional Budget Office and the staff of the Joint Committee on Taxation.

**Notes:** Components may not sum to totals because of rounding.

*Estimates are relative to CBO’s April 2014 baseline.*

* = between -$50 million and $50 million.
SENATE FINANCE COMMITTEE HEARING

#passtheABLEact

IT’S TIME TO PASS THE ABLE ACT!
Achieving a Better Life Experience Act (S. 313/H.R. 647)

#passtheABLEact

ABLE HEARING
ONE WEEK FROM TODAY!

NDSS Board Member and Self-Advocate, Sara Wolff to testify

July 23rd at 10 EST
Senate Finance Committee
Subcommittee on Taxation & IRS

national down syndrome society ndss
A WEEK LATER, LET’S MARK-UP THE ABLE ACT
WHY CONSTITUENTS MATTER!

Boehner Buddies

Portland Pressure

McCarthey Mania

McConnel I Meeting

Reid Response

Camp’n Out with Camp

Leaning on Levin

Scranton Duo

Crenshaw Cares
BRI HITS THE 218 VOTE – HOUSE GALLERY GOES WILD!

Thousand Oaks girl casts vote for legislation

BY: Rachel McGrath
POSTED: 4:25 PM, Dec 14, 2014
UPDATED: 4:46 PM, Dec 14, 2014
TAG: thousand-oaks/news/local/comejo-valley

Six-year-old Brianna Pitzele, of Thousand Oaks, recently helped pass the ABLE Act in the House of Representatives that aims to give people like her a better chance in life.

Brianna accompanied Rep. Julia Brownley, D-Westlake Village, onto the floor of the House on Dec. 3 and pressed the button signaling Brownley’s “Yea” vote in support of the legislation.

The Achieving a Better Life Experience Act received bipartisan support, passing by a vote of 404 to 17.

Brianna and her parents Brad and Julianne Pitzele traveled to D.C. on Dec. 1 at the invitation of the National Down Syndrome Society and said they were on tenterhooks until the news came that the bill was headed for a vote.


Brad Pitzele watched from the gallery as his daughter played a historic role in getting the legislation passed.

“Julia had her push the button for her vote and then another congresswoman asked Brianna to make her vote for her and that was the one that made the light turn green to show it has passed,” said Pitzele. “It was a pretty amazing experience.”

The Senate did not take up the legislation before the end of the 113th Congress.

“It’s a really, really important bill, and there’s overwhelming support for it,” Brownley said from Washington on Tuesday. “If it doesn’t happen in the 113th Congress, it will be introduced again.”
HOUSE VICTORY – ABLE PASSES AS A STAND ALONE BILL!
HOW THE TAX EXTENDERS PACKAGE HELPED US PASS THE ABLE ACT (WITH 18 MINUTES NOTICE)
CELEBRATING AT THE WHITE HOUSE
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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