



**Testimony before New York City Council Committee on Mental Health, Developmental
Disability, Alcoholism, Drug Abuse and Disability Services**

**Proposed Res. No. 1314-A
Achieving a Better Life Experience (ABLE) Act of 2013 (S. 313/H.R. 647)**

**September 17, 2013
National Down Syndrome Society
Julie Cevallos, Mother of Nina Cevallos; Vice President of Marketing for
National Down Syndrome Society**

Re: The ABLE Act

Hello. My name is Julie Cevallos. I am the VP of Marketing for the National Down Syndrome Society. I am the proud mother of Nina Cevallos. Nina is four years old, and happens to have Down syndrome. Our organization commends the New York City Council Committee on Mental Health, Developmental Disability, Alcoholism, Drug Abuse and Disability Services to holding today's hearing, and joining along side NDSS' efforts to call upon the United States Congress to enact and the President to sign Achieving a Better Life Experience (ABLE) Act of 2013.

My dream for my daughter Nina is that when she transitions from school to working, she will do something she excels at, that gives back to the community, and that she is paid for her work. That she can go to the bank and deposit her check into an account without fearing that she will lose much needed benefits that support her health and well being. Everyone wants to earn a living and be independent, and every parent wants to help his or her child to do so.

Nina is in kindergarten, and I have absolutely no doubt she'll graduate from high school with a typical diploma and attend some kind of post-secondary education program to help her learn more and get a job. But, because she can lose necessary and valuable Medicaid and Social Security support she'll need at various stages of her life for many reasons, I am scared to even open a bank account with birthday gift money in it. She can't have more than \$2,000 to her name or she will lose benefits. Our family can't save in her name, which is demeaning, and heart breaking, not to mention bad financial policy. We have no tax-free method of saving for her education, or other expenses (including housing, transportation and health expenses), even though we have a 529 for her brother. If I had to choose, we need it more for her!

It's a strange situation because while she's really healthy now, and she's included in school and doing well, she still needs support and special programs, and will need various types throughout her life. It doesn't mean she can't do things, it means she needs help and help costs money. It's only fair that as a family we can save for her, in her name, for her expenses and have the same tax advantages other families have, for more typical kids. She might be fine all the way until later adulthood health wise, but 80% of adults with Down syndrome get dementia along with other health issues, so I would not be comfortable not having Medicaid help and Social Security help available to me. It shouldn't be a choice between being totally reliant on government benefits, vs. being totally independent and paying the whole way for very costly assistance needed during the lifespan. As a family, we need a way to save for her needs under her name, without losing benefits. We need and have the right to be as independent as possible, by saving and paying for things we need, while still having support.

The ABLE act makes it fair that like I do for my son I can save for her expenses tax free without being penalized by losing support. There is no reason she needs to be poverty stricken to get support. This is my story, but we have stories from all over the country where individuals with disabilities and their families could secure more financial independence and individuals with disabilities could have more options for employment.

There is no another piece of legislation before the US Congress today that has this much bipartisan, bicameral support. As you likely know, the ABLE Act has 256 cosponsors in the US House and 44 cosponsors in the US Senate; these cosponsors amount to over 50% of the entire US Congress.

The ABLE Act is a sound piece of policy that will positively impact all people with disabilities in the US. Our organization is committed to seeing the ABLE Act enacted into law this year.

Again, thank you for convening today's hearing. NDSS praises the Committee for its leadership on behalf of people with Down syndrome and other disabilities.

**THE COUNCIL
THE CITY OF NEW YORK**

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. 1314-A

in favor in opposition

Date: 9/17/13

(PLEASE PRINT)

Name: Julie Cevallos

Address: 37 Valleywood Rd. Castle CT 06807

I represent: National Dawn Syndrome Society

Address: 606 Broadway NY NY 10012

◆ Please complete this card and return to the Sergeant-at-Arms ◆