April 12, 2013

The Honorable Diane Black
United States House of Representatives
Washington, DC 20515

The Honorable Danny K. Davis
United States House of Representatives
Washington, DC 20515

re: Tax Reform Working Group on Education and Family Benefits

via electronic submission: tax.reform@mail.house.gov

Dear Representative Black and Representative Davis:

On behalf of the National Down Syndrome Society (NDSS), thank you for your leadership of the Ways & Means Committee Tax Reform Working Group on Education and Family Benefits. We are deeply grateful for the opportunity to provide tax code reform comments. I am writing to draw your attention to the importance of **Achieving a Better Life Experience (ABLE) Act (S. 313/H.R. 647).** The ABLE Act will utilize the 529 college education saving account program to allow individuals with disabilities and their families the ability to save for their child's future just like every other American family.

To date, the ABLE Act has earned 28 cosponsors in the US Senate and 125 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). For the last seven years, NDSS has been working with 50 other national disability, nonprofit, religious, and other key stakeholder organizations to pass the ABLE Act. 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 wouldn't find another piece of tax legislation in the US Congress today that has as much bipartisan, bicameral support as the ABLE Act.

One of the major goals of any tax reform is to make the system simpler and fairer for all Americans. The ABLE Act ties directly into this goal by addressing one of the biggest inequities that currently exists in our system today. All Americans are encouraged to save for future and the future needs of their families and children through the use of tax free and tax advantage savings instruments. The only segment of our society that is effectively barred from using these savings tools are individuals with disabilities. If they or their family attempts to use any of these tools and save over $2,000 in cumulative assets, the individual with a disability will lose access to the critical support system provided by Medicaid and other federal benefits. Medicaid is often the only healthcare coverage option that most individuals with disabilities will have access to, especially as adults, and in order to maintain eligibility for the program, individuals with disabilities can never have more than $2,000 in their name.

The ABLE Act of 2013 would create a tax free savings instrument under the current 529 law for people with disabilities. It will allow them and their families to save money to pay for education, housing, transportation, medical and dental care, job training and supports and other critical needs not covered by public or private benefits or insurance. It also protects their eligibility for critical federal benefits such as Medicaid and SSI. The legislation also contains Medicaid fraud protection against abuse and a Medicaid pay-back provision when the beneficiary passes away. It will eliminate barriers to work and saving by preventing dollars saved through ABLE accounts from counting against an individual's eligibility for any federal benefits program.

Below are two real life examples of how this affects the Down syndrome and broader disability community.

Steve Beck, NDSS Board Member & Parent (Burke, Virginia)

I have two teenage daughters; Mariae Rose (age 15) and Natalie Elaine (age 13). Natalie was born with Down syndrome. Both are (A) students at Lake Braddock Secondary School, play sports, are Girl Scouts, have been in theatre or choral productions, share housework, and like to hang out with friends. Both also want to go to college, get a good job, have a place of their own to live, and eventually get married. They both have the personal drive and abilities to accomplish all of that and more. But it takes more than ambition and ability to reach those goals and it will take a combination of us and them working together to help them reach their full potential. The main difference is that many of the critical tools we need are in place for Mariae and not available for Natalie.

Shortly after Mariae was born, we opened a 529 account for her. There was no cost involved in setting it up and no annual out of pocket costs to maintain the account. Everything from $25 birthday gifts and inheritances to money she earns from walking dogs can be put away tax free to save for college. Once she graduates from college and gets a job, she will have access to private health insurance, 401ks, IRAs, Flexible Spending Accounts, Health Savings Accounts and many other tax advantaged and taxable accounts to save for her needs.

When Natalie was born, we again started the process of setting up a 529 account for her. We quickly found out that if we had done that it could have had a catastrophic effect on her future. The only option we had to save money for her was to create a 3rd party trust fund. It would cost between $3,000 and $5,000 just to create the trust and is taxed annually at the highest individual tax rate, and is so complicated that we would have to pay a tax attorney each year to do the taxes. Additionally, she could never control any of the money or contribute any of her own money to the trust. Any earnings, gifts or inheritances she received would have to be immediately liquidated or risk putting her access to benefits at risk. When she gets through school and begins searching for employment again the barriers come into play. She will either have to take a subminimum wage job or work a very limited number of hours to remain eligible for benefits. Even if she does manage to save some of those earnings she can never breech the $2,000 limit without losing her benefits.

How are we as parents or Natalie ever supposed to save for her education, housing, healthcare, job training, personal supports, and other items Medicaid does not fully cover, much less retirement? Given the right set of savings tools not only are we as parents but she as an individual capable of planning and saving for her future. Natalie is also capable of becoming a more independent tax paying member of her community. The ABLE Act of 2013 will not solve all of the challenges that Natalie will face in her lifetime, but it will at least help level the playing field and give her a chance of reaching her full potential.

Angie Cain, Self-Advocate (Indianapolis, Indiana)

Angie Cain lives in Indianapolis, Indiana with her family. Angie is 28 years old and has Down syndrome. Angie has five different jobs and works five days a week. Angie works a paid position at Kohl's on Mondays, volunteers at an assisted living care facility in the Alzheimer's unit on Tuesdays, volunteers at the Down Syndrome Indiana (DSI) on Wednesdays, volunteers at a hospital in the morning and at Best Buddies in the afternoon on Thursdays, and she works a paid position at the YMCA on Fridays.

Under the current law, Angie can't have more than $2,000 in assets and must maintain a very low monthly income. Angie is forced to limit the amount of money that she earns, so that's why she works a combination of volunteer and paid positions throughout the week. These limitations place a huge burden on Angie and her family to save for her future, retirement, transportation, and housing. If Angie had an ABLE account, she could work one, full-time paid position, and likely receive benefits from her employer and not rely on federal entitlements like Medicaid for her health coverage. Angie would also like to live independently, on her own, rather than with her family. If she had an ABLE account, she could pay her own rent rather than rely on state funding and waivers for housing options. Angie's family also worries about her living and financial situation, when they are no longer around. If Angie had an ABLE account, she and her family could save for future financial circumstances like long-term care, housing, and other necessary medical costs.

For Angie, the passage of the ABLE Act will offer comfort to her family in knowing that she will be financially secure, and receive the health and housing benefits she needs to reach her full potential. Angie deserves to have the same types of flexible savings tools that other Americans have through college savings accounts, health savings account and individual retirement accounts.

Passing this landmark legislation will go a long way to help people with Down syndrome and other disabilities realize and achieve their own hopes, dreams, and aspirations. Thank you for your leadership and your outreach to us on these vital policy considerations. We look forward to working with your Work Group and the House Ways & Means Committee as we move forward to address the significant challenges facing individuals with Down syndrome and their families as well as other disabilities in the tax reform process and enacting this landmark legislation.

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.

Sincerely,

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cc: Sara Hart Weir, Vice President of Advocacy & Affiliate Relations, NDSS (sweir@ndss.org)