



Good afternoon. My name is Steve Beck. I am the father of 9 and 11 year old daughters. My 9 year old daughter Natalie has Down Syndrome. I am a Board Member of The Down Syndrome Association of Northern Virginia (DSANV) and Chairman of our Advocacy and Awareness and Governmental Affairs Committees. It is an honor to speak to you today on behalf of DSANV, the other Affiliates, our National organizations and the 400,000 individuals with Down Syndrome and their families. We would like to thank the Caucus for its leadership on these important issues and for allowing us the opportunity provide input.

Today, individuals with Down Syndrome, including my daughter, are active members and participants in their schools and communities. There are more opportunities for them to develop their individual abilities, continue their education after high school, find employment, and live independently. However, the system of supports and services, particularly for adults with ID was created decades ago and does not reflect the advances in education, healthcare and inclusive community environments.

The following national statistics regarding people with intellectual disabilities are disturbing and we need to begin reversing them. According to the PCPID Report of 2004: A Road Map to Personal and Economic Freedom for Persons with Intellectual Disabilities in the 21st Century; around 90% of adults with ID were not employed. Less than 1% owned their own home. Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) were the major source of income for the 1.1 million people receiving SSI and 600,000 receiving SSDI. Over 700,000 people with ID were living at home with parents that where 60 years old or older.

The focus of my committee work centers on employment, asset development, and self determination. The ability to save, grow and distribute assets without jeopardizing critical support services is essential in expanding these opportunities and extending them into adulthood. The costs of supporting a person with disabilities in our society far exceed the amounts received in public benefits. For example, the national average for a one-bedroom apartment is \$715 and a studio/efficiency is \$633, and both are higher than the entire monthly income of many people with disabilities who rely on the SSI program.

Given this economic reality, parents and persons with disabilities face a stark dilemma: either set aside 3-5 million dollars necessary to provide care and support for a person with a disability during that individual's entire lifetime or rely exclusively on public benefits. The only other option is to establish a trust fund which is typically very expensive to establish, maintain and control and is taxed at the highest individual tax rate.

When a choice is made to rely on public benefits, the person with a disability is not permitted under Social Security regulations to accumulate more than \$2,000 in assets. As a result, parents are not able to direct resources to the family member with a disability as they can to another child. The government has established numerous tax advantaged accounts such as: 529 College Savings accounts, IRA's, HSA's, and 401K's that allow people to save for education, medical needs and retirement. Individuals with disabilities and their families cannot utilize these tools because each would jeopardize their access to benefits.

Bill did a wonderful job explaining how SSI, SSDI and other programs affect people's ability to earn income and the same applies to asset development. Our Government Affairs Committee (GAC) has been working closely with NDSS, NDSC and number of other national organizations at the federal level to pass a bill that establishes a Savings Instrument for individuals with disabilities. Congressman Ander Crenshaw has led the effort on the House side introducing the FSAID Act in the 109th and 110th Congresses. At the close of the 110th Congress the House bill had 105 co-sponsors including all four co-chairs of the DS Caucus. There where two bills introduced in the Senate by Senators Casey, Hatch and Dodd last March. Members of the disability community, along with staff from all four offices have crafted a compromise that will be introduced perhaps as early as this week.

The FSAID bill establishes a savings instrument for individuals with disabilities and their families that provides them with the same flexibility, portability, tax advantages and low

costs that are available to all other Americans and their families. The legislation is built on the premise that persons with disabilities should be encouraged and supported in their efforts to save in order to create an independent life just as other Americans strive to do. The premise upon which the legislation is built is especially valid in our time of economic travail which may be of significant duration.

The Financial Security Accounts for Individuals with Disabilities helps bridge this gap by focusing on these fundamentals:

- **Allowable Expenses:** Educational expenses, Medical and dental care, Community-based support services, Employment training and support, Moving, Assistive technology, and Housing and Transportation
- **Flexibility:** Setting up an account is as simple and inexpensive as opening a savings account. Rollover provisions are provided for families that currently have other types of accounts set up. FSAID accounts are created and regulated at the federal level so they operate under the same rules in every state.
- **Control:** Allows individuals with disabilities and their parents to choose to manage the accounts and take responsibility for meeting reporting requirements. It also allows for the parents or individual to name a 3rd party to act as trustee.
- **Benefit Protection:** Prohibits any federally funded program from considering amounts held or distributed from the account as income or assets when determining eligibility for benefits.
- **Tax Advantages:** Like college savings accounts (529 accounts) and Roth IRAs, funds held in FSAID accounts grow tax free. Withdrawals are not taxed as long as they are used to pay for qualified expenses.

Conclusion:

Individuals with disabilities have all of the same financial needs as everyone else and in many cases the costs and barriers that need to be overcome are much higher for them. That is why we have the system of support services that you have heard so much about

from my colleagues this afternoon and why we focus so much effort on trying to strengthen and improve them. Allowing and encouraging individuals and families to develop assets to meet these needs is one very important step forward.

Thank you all very much for your time, your hard work, and your continued support.

