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Written Testimony before the Senate Finance Committee

July 23rd, 2014

Good morning, it is a pleasure to be here today and to testify before the Senate Finance Committee on Taxation and IRS Oversight. I am testifying today on behalf of the National Down Syndrome Society in this effort to pass the Achieving a Better Life Experience Act, better known as the "ABLE Act". This piece of legislation will afford millions of individuals with disabilities the opportunity to experience the "American Dream" and to achieve the highest reaches of success that this country has to offer, opportunities that should rightly be available to ALL of its citizens.

My name is Chase Phillips, and I have lived with the neurological birth defect, Spina Bifida, for all 29 years of my life. As a disabled individual I have been fortunate to partake in many of the same life events as my "able bodied" peers. My determination to thrive has led me to excel in many areas of life, despite my physical limitations. I was a coxswain on the United States National Rowing team because I had a competitive hunger to represent my country and compete at the highest level that my sport had to offer. I earned a Bachelor of Arts degree and graduated from the University of Wisconsin. Being able to go away to school enabled me to learn the life lessons that are unique to living on one's own while attending college. I chose a profession in finance that is very competitive and extremely challenging because I want to build a successful business and help people along the way. I married a wonderful woman because I wanted to experience the joy of connecting with a lifelong partner and starting a family. I volunteer with Children's National Medical Center because I have a desire to connect with kids who aren't much different from me. All of this, while living with a disability that has its daily challenges. My story is not unlike that of many other disabled Americans. However, stories of success are the exception, not the norm. There are many people living with disabilities who struggle to live independently, who desire to hold well paying jobs so that they can support themselves. Under the current system these individuals will survive, but few are able to thrive.

I am in a unique position because my personal experience living with a disability has intersected with my professional expertise as a special needs financial advisor. I currently run a practice at Bank of America Merrill Lynch that specializes in developing and implementing financial strategies focused on improving the financial well being of individuals living with special needs, regardless of their age or disability. In total, the four financial advisors within our practice have over eight decades of combined experience dealing with persons with disabilities. Three of our team members have disabilities themselves or have a family member living with a disability. We are fighting on the front lines of this battle both personally and professionally.

On a daily basis we see the challenges that families and individuals face as they strive to provide for themselves and their loved ones. Many of our clients are currently enrolled in Supplemental Security and Medicaid programs and thus must live within the programs' \$2,000 asset ceiling limit in order to remain program-eligible. These are people who seek to learn independent living skills so that they can hold a job and contribute to society. But because of these asset restrictions many individuals will never live on their own. For example, within these program restrictions, many people would not be able to save enough money for a first and last month's rent on a new apartment. This rule also limits the abilities of individuals to save for the down payment required to purchase a home. As a financial advisor, we recommend that our clients keep three to six months worth of expenses in

cash reserves in preparation for life's unexpected turns. This kind of planning becomes impossible with a \$2,000 asset ceiling. Asset restrictions chain individuals to levels of poverty and provide no real incentive to hold a higher paying job. Currently, over 70% of adults with disabilities are still living at home with their parents or caretakers. Four in ten individuals aged 21 to 64 with a disability were employed (41.1 percent), as compared to eight in ten adults without disabilities.¹

There are currently tools available to help those with disabilities preserve their benefits while keeping assets held in trust for their benefit. By using a properly drafted and administered Special Needs Trust, the disabled individual will continue to qualify for means tested programs such as SSI and Medicaid. The special needs trust may not distribute money to pay for basic items such as food or shelter or other goods and services that the Social Security Administration categorizes as "support and maintenance." As such, the beneficiary's SSI benefits may be reduced or eliminated if the trust pays for these basic needs. The theory is that since SSI benefits are specifically intended to pay for a person's food and shelter, if those goods and services can be funded by another source, the less SSI benefits are needed.

To magnify this issue, disabled individuals are not permitted to save in other tax advantaged savings vehicles such as Roth IRAs, 529 accounts, and 401ks because these assets are counted as part of the \$2,000 asset ceiling as per SSI guidelines. In essence, Warren Buffett can gift \$14,000 per year into a 529 college savings account and receive the benefits of those assets growing free of taxes (assuming they are used for qualified education expenses). Yet, a disabled American receiving SSI is not afforded this right, and thus is not only denied the right to utilize such a tax vehicle, but is essentially unable to save for their own retirement. If this is not considered discrimination then I don't know what is. It is not only unfair, it makes no sense.

The ABLE Act will allow individuals with disabilities to save money in a tax-sheltered savings account in order to pay for qualified expenses such as education, housing, transportation, employment support, and assistive technology. These assets would not be counted against the disabled individual for purposes of qualifying for SSI, Medicaid and other means tested programs. This account will serve as a self-sufficient booster for disabled individuals to live independently, go to college, get married, and start a family. No longer would an individual have to decline a higher paying salary for fear that their assets would eclipse the \$2,000 asset limit. The ABLE account is not designed to replace SSI, Medicaid, or the Special Needs Trust, but rather to supplement these current programs, thereby enabling individuals with disabilities to reasonably plan for the future. The ABLE account will be more transactional and also easier to administer for day to day spending needs. This account serves as the perfect complement to a special needs trust because it fills the gap between the short term funding needs covered by SSI and the longer term investments held within a special needs trust.

This piece of legislation is eight years in the making. Let's make it happen this year.

¹ Matthew W. Brault, *Americans with Disabilities: 2010: Household Economic Studies* (US Department of Commerce, Economics and Statistics Administration, US Census Bureau, July 2012).