



**TESTIMONY PRESENTED TO THE SENATE FINANCE COMMITTEE  
SUBCOMMITTEE ON TAXATION AND IRS OVERSIGHT**

**BY ROBERT D'AMELIO, VOLUNTEER ADVOCATE FOR AUTISM SPEAKS**

Chairman Casey, Ranking Member Enzi, Senator Burr, and members of the subcommittee, thank you for the opportunity to speak today on behalf of Autism Speaks, the world's leading autism science and advocacy organization, for the ABLE Act. My name is Bob D'Amelio, and I am the father of three wonderful kids, Nicholas, Christopher, and Lindsey. My wife, Christi, is here with me today.

My story is about a middle class family from the city of Charlotte in the great state of North Carolina. I am a data center manager for FIS and Christi is a realtor. We have lived in North Carolina for 17 years and some of our biggest and saddest moments have happened there. Like many families across the nation, our family is an autism family – both of my sons are affected, Christopher more severely than his brother.

I have been advocating for better autism services since 2001. I am the volunteer vice-chair of the Autism Speaks chapter board in Charlotte, and have chaired Walk Now for Autism Speaks Greater Charlotte six times. This year's walk will be held at the zMAX Dragway on Saturday, September 27<sup>th</sup>. We expect seven to eight thousand people to walk on behalf of those affected by autism.

That's a large number of people, but no one should be surprised by our turnout. According to the Centers for Disease Control and Prevention, in North Carolina 1 in 58 children – 1 in 35 boys – have an autism spectrum disorder. These numbers are higher than the national averages. Children like Nicholas and Christopher live in Charlotte, elsewhere in North Carolina, and in towns, cities, and states across the country. These children need access to proven behavioral therapies and good school programs. Many need medicines to manage their most disabling symptoms.

None of this care will come cheap. According to research funded by Autism Speaks, the lifetime cost of care for an individual with autism averages \$2.4 million when autism involves intellectual disability and \$1.4 million when it does not. Families who have a child on the spectrum need to be able to save for the future.

This is where the ABLE Act would help. An ABLE account would enable families like mine to save for housing, job supports, education, and other services without the fear of losing Social Security or Medicaid benefits. The current section 529 plans fall short for the many individuals with autism and other disabilities who cannot or choose not to go on to college. As

much as anything else, the ABLE Act is about fairness. If Christi and I can use a college savings account to provide for our daughter Lindsey's future, why can't we use something similar to take care of Nicholas and Christopher?

I would love to sleep at night knowing that I was doing everything I could to secure the future of my children. My son Christopher is a very smart young man, but he will need a job coach and at some point a residential program. Saddling my daughter Lindsey with a big financial burden is not fair when Christi and I can provide for Christopher. Lindsey is already mature beyond her ten years of age. She knows that she will be looking after Christopher and keeping tabs on Nicholas for her entire life.

Autism teaches you to be strong, to persevere when others tell you to give up, to celebrate the small steps in life, and to appreciate what you have. But autism demands your time and energy and changes how you live as a family. Parents like Christi and I want to do everything we can for our kids – for all of our kids, disabled or not. The ABLE Act would allow families to make the future more secure for children with disabilities, taking the burden off siblings, other family members, and government. Please take the simple step of passing ABLE. We all will sleep better when it becomes law.

Thanks again for letting me testify before you.