

February 1, 2016 RE: HB188 and SB104 Autism Speaks Letter of Support

To Whom It May Concern:

Autism Speaks is the world's leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Autism Speaks works to ensure that people with autism have the opportunity to lead fulfilling and independent lives.

We are writing to support HB188 and SB104 as the enabling legislation for the federal ABLE Act. The federal law was the culmination of an almost decade-long effort to create a new way for people with disabilities and their families to save for future disability expenses without losing eligibility for means-tested federal programs like Supplemental Security Income (SSI) and Medicaid. In testimony before the Senate Finance Committee Subcommittee on Taxation and IRS Oversight, Bob D'Amelio, a volunteer advocate for Autism Speaks and the father of three children, two of whom are on the autism spectrum, offered this support for the ABLE Act:

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.

Although Bob D'Amelio lives in North Carolina, he spoke for families in Alaska and around the country. Autism affects 1 in 68 children. ABLE programs offer a new opportunity to meet the future needs of people with disabilities. We are grateful that Alaska is poised to act on this opportunity.

Yours truly,

Stuart Spielman

Stuart Spielman Senior Policy Advisor and Counsel