



Special needs require special attorneys.

Statement of Richard A. Courtney, CELA* CAP**

President of the Special Needs Alliance

“Improving the Medicaid Program for Beneficiaries”

**A hearing by the
Committee on Energy and Commerce
Subcommittee on Health**

United States House of Representatives

Friday, September 18, 2015

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Good morning. Chairman Pitts, Ranking Member Green, and members of the subcommittee, I congratulate you on holding this hearing to examine ways that the Medicaid program can be strengthened to better serve its beneficiaries. I appreciate the opportunity to come to Washington, DC, to testify in strong support of the Special Needs Trust Fairness Act, H.R.670, introduced by Representative Glenn Thompson and Energy and Commerce Ranking Member Frank Pallone, and in the Senate, S. 349, introduced by Senators Grassley and Nelson. This legislation has been one of the top public policy priorities of the Special Needs Alliance and the National Academy of Elder Law Attorneys. I am honored to serve as the current President of the Special Needs Alliance and I am a past member of the NAELA Board of Directors and former chair of their Special Needs Law Section. Both organizations wholeheartedly support the Special Needs Trust Fairness Act.

The Special Needs Alliance (SNA) is a national, non-profit organization committed to helping individuals with disabilities, their families, and the professionals who serve them. Many of our member attorneys have family members with special needs; all of them work regularly with public benefit programs, guardianship/conservatorships, planning for disabilities, and special education issues. We volunteer significant time to the special needs community and advocate for legislative and regulatory change to improve the quality of life for individuals with disabilities. The majority of our members are also certified as elder law attorneys (CELAs) by the National Elder Law Foundation and are members of the National Academy of Elder Law Attorneys (NAELA), which has devoted substantial resources to meeting the needs of the special needs community.

As you know, the Special Needs Trust Fairness Act was passed unanimously by the Senate on September 9, 2015, making this hearing and your consideration of the bill very timely. We greatly appreciate your work toward passage.

Personal Background

I have become an “expert” in special needs issues from both personal and professional experience. In 1979, I became the father of identical twin daughters. My wife and I love both our daughters and are very proud parents, but they have led quite different lives. Melissa was in “gifted and talented” education and sports through college and is now a young wife and mother to two elementary school-age boys. Melanie, her twin sister, was genetically the same, but different. She is a wheelchair user with cerebral palsy and learning disabilities. But through her determination and hard work, she completed high school and community college, earning an

Associate of Arts degree in three and a half years. She found a job with our state ARC chapter as coordinator of a project called “My Voice, My Choice” teaching self-advocacy skills to young adults with developmental disabilities. Suffice it to say, she has taught us a great deal as well. She has never wanted help with things she could capably do. She does not easily accept that she cannot do something because she is physically disabled. She does, however, need and is receiving care under a Medicaid waiver benefit. The cost of paying for her care and supportive services is high, and she must rely, as do many persons with disabilities, on programs like Medicaid.

The Problem

For now, my wife and I are here to be supportive of Melanie, but that won’t always be the case, and her needs may grow as she gets older. If someday she were to receive some money or property through inheritance or an insurance or litigation settlement, she could lose her Medicaid waiver benefits that pay her attendant to assist her for a few hours each day with certain activities of daily living. In order to keep those benefits, she would need to have those funds placed in a “self-settled” special needs trust (also known as a Supplemental Needs Trusts or (d)(4)(A) trust). That is what Congress intended when it created this and other trust options for those with disabilities in the Omnibus Budget Reconciliation Act of 1993.

Unfortunately, that law included a drafting oversight that seems to assume that a person with disabilities lacks the requisite mental capacity to enter into a contract and therefore is not legally allowed to create her or his own special needs trust (SNT).

These trusts are not complicated. They have a trustee to ensure that funds are used for the sole benefit of the disabled individual. Funds that are placed in such a trust would allow Melanie to pay for additional health care not covered by Medicaid as well as pay for basic daily living items such as clothing, going to the hairdresser, furniture for her home, or a computer. These are things that many of us take for granted, yet many individuals with disabilities don’t have the necessary resources to make such purchases without funds from a special needs trust. These are often funded by a family member or secured through a legal settlement.

So, Melanie would not be allowed to create her own SNT, and - believe me - she would question why. She would not understand why, unlike her sister, she could not create such a trust and appoint an independent trustee to manage those funds. She would question why, if her mother and father were deceased, she may be unable to have a judge establish such a trust for her. This has been the result for many under current law, which requires that a trust created with the assets of a person with a disability be established by that person’s parent, grandparent, legal guardian or a court, but not by her or himself. Unfortunately, some courts have been unwilling to establish trusts on behalf of an individual with disabilities. So, Melanie’s situation is not unique; many others in every state face similar obstacles to creating simple SNTs that will enable them to supplement their care needs beyond what Medicaid provides.

In some states, another trust option called a “pooled trust” run by a non-profit would be available. There is no such trust available within our state, so without the correction of the statute sought in H.R. 670, individuals in many states may be forced to send their inheritance or settlement funds out-of-state to be managed by organizations and entities they know nothing

about. In my practice during the last year, I have informed several clients that this was their only option under current law. While reluctant to do so and confused as to why they could not fund a trust in their home state, they were forced to use the pooled trust to retain essential medical and health care benefits.

Under current law, an individual with a disability and without surviving or cooperative parents or grandparents would be forced to resort to the court for assistance in creating the trust. We have assisted hundreds of persons with court-created trusts over the years. This places an enormous burden on already strained court resources to help a competent (but physically disabled) adult establish a trust while no such burden is placed on the court where a non-disabled adult wishes to do the same. Beyond the degrading presumption of mental incompetence, the effect of the law means that persons with disabilities who have no close family must petition the court and undergo unnecessary legal fees, court delays, and even potential guardianship. In some cases, if the individual does not have the funds to hire a lawyer, then she or he loses access to necessary government benefits.

The Solution: Special Needs Trust Fairness Act

The disparity in the law creates an equality and fairness issue. One should have the right to contract if one has the requisite legal capacity. There seems to be no record of or reason for this disparity in OBRA '93. We believe it was a legislative drafting oversight and not the intent of Congress to deny a basic right to individuals with disabilities.

A statutory change – the Special Needs Trust Fairness Act – would fix this problem with two-words. Simply by adding “the individual” to the current law that describes who can create a SNT would permit Melanie and other mentally-capable adults with disabilities to create a trust. In contrast, the words “the individual” were included in the pooled trusts provisions of OBRA '93. The new ABLE Act program recognized that accounts created under that law are “an account established by an eligible individual, owned by such eligible individual, and maintained under a qualified ABLE program.”

We ask that you support and pass the Special Needs Trust Fairness Act thereby removing the misplaced presumption that individuals with disabilities lack mental capacity. This change will save disabled individuals, including veterans, thousands of dollars that can be spent on necessary care, services, and personal items for these individuals to have the best chance for a quality life.

Many disability and aging advocacy organizations have shown support for the Special Needs Trust Fairness Act, including: the American Association of People with Disabilities, Easter Seals, United Spinal Association, National MS Society, National Association of State Directors of Developmental Disabilities Services, Mental Health America, Lutheran Services in America Disability Network, the American Network of Community Options and Resources, Christopher & Dana Reeve Foundation, Pennsylvania Special Olympics, Academy of Special Needs Planners, Iowa Office of the State Long-Term Care Ombudsman, State of New Jersey Office of the Ombudsman for the Institutionalized Elderly, The Florida Bar Elder Law Section, and the Academy of Florida Elder Law Attorneys. I believe it is safe to say that these groups and numerous others believe that many persons with disabilities are quite capable of handling their own affairs and that to presume otherwise is unfair and degrading.

In closing, let me quote a friend and colleague Michael Amoruso, who has worked so hard to correct this inequity in the law. Michael is a leader in the elder and special needs law communities. He is also legally blind and moderately deaf. Under current law, he would not be able to sign (create) his own special needs trust if he ever needed one, even though he has drafted thousands of trusts for clients over the years. In calling us to action to fix this injustice, he wrote “Yet, even to this day, those of us with disabilities must continue to erase the historic, age-old stereotype that a person with a disability is a lesser individual than her or his able-bodied neighbor.” The Special Needs Alliance and NAELA ask that you correct this drafting oversight in the law as Michael put it “so that those of us who have disabilities can regain the dignity we deserve and remove the misplaced presumption that we lack capacity due to our disabilities.”

On behalf of Melanie, my family, and so many others, I thank you for allowing me the opportunity to testify before you today. I look forward to taking your questions.

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