



**House Energy & Commerce Committee
Subcommittee on Health
Title: Improving the Medicaid Program for Beneficiaries
Date: September 18, 2015**

**Statement for the Record
By the National Academy of Elder Law Attorneys**

Dear Chairman Pitts, Ranking Member Green, and Members of the Subcommittee:

Thank you for the opportunity to submit this statement for the record on H.R. 670, the Special Needs Trust Fairness Act, introduced by Representatives Glenn “GT” Thompson (R-PA) and Frank Pallone (D-NJ).

The Special Needs Trust Fairness Act of 2015 corrects a problem in current law that presumes all individuals with disabilities lack the mental capacity to establish their own special needs trusts. This false and unfair presumption imposes unnecessary legal fees and costs, court delays, and uncertainty on people who can little afford it.

The fix is simple: H.R. 670 would add the words “the individual” to 42 U.S.C. § 1396(d)(4)(A) to allow people with disabilities to establish their own individual special needs trusts.

The Senate passed a companion version of this bill (S. 349) by unanimous consent on September 9, 2015. We look forward to working with this Subcommittee to ensure swift passage in the House of Representatives.

Background

People with disabilities who want to live active lives face daunting costs to pay for what others do as a matter of course – from getting out of bed, taking a bath, or feeding or clothing oneself – to more complicated tasks – travel, reading and writing, or working productively. Medicaid may cover the medical and remedial costs for many, but of course there are many more expenses incurred during everyday living. Congress has long recognized the limits of Medicaid; in 1993, it authorized two types of special needs trusts that allow people to set aside funds to pay for supplemental care and meet their non-medical needs while retaining Medicaid. And, just last year, Congress added ABLE Accounts, which provide tax incentives for individuals with disabilities to save funds for their non-medical disability needs without loss of Medicaid.

The Problem: “*The Individual*” is Missing from the Statute

In 1993, Congress authorized two kinds of trusts – individual and pooled non-profit trusts. The law, as drafted, allowed individuals with disabilities to place their funds in a pooled non-profit trust, but in another section left out the words “the individual” thereby failing to allow individuals to establish their own special needs trust:

- Individual trusts “must be established by a parent, grandparent, legal guardian of the individual, or a court.” 42 USC §(d)(4)(A).
- Pooled Trusts accounts “must be established by a parent, grandparent, legal guardian of such individual, *the individual*, or a court.” 42 USC (d)(4)(C)(emphasis added).

More recently, in the related ABLE Act, Congress permitted these accounts to be “established by an eligible individual.” P.L. 113-295

There is no valid public policy reason for prohibiting competent individuals with disabilities from establishing their own individual special needs trusts where all of the other, much more significant requirements are met. These requirements are plainly more important than who signed the document; they are, briefly, that the trust or trust account be:

- Irrevocable.
- Provide payback to Medicaid following the death of the beneficiary for all of its expenditures for the beneficiary.
- Managed by a trustee for the “sole benefit” of the disabled individual.

This legislation would, of course, keep all of these requirements in place.

Why This Common Sense Legislation Should Pass

Current Law Violates the Dignity of People with Disabilities

The presumption in the current statute that all people with disabilities lack mental capacity is false, offensive, and denies a constitutional right to disabled Americans. NAELA Treasurer Michael Amoruso, Esq., a disabled attorney who is both legally blind and has substantial bilateral hearing loss, has drafted hundreds of these trusts as part of his practice for other individuals, and yet the current law does not allow him to sign such a trust for himself.

Ends Unnecessary Judicial Red-Tape

For individuals without parents or grandparents to set up their trust, the law requires court approval. Three examples illustrate this burden:

In Orleans County, New York, a NAELA attorney explained that to get a trust approved, he must draft a petition with all the particular facts about the beneficiary and the trustee, obtain the consent of the attorney for the local department of social services, which can take several weeks in rural counties where the attorney is new to special needs trusts and is part-time, document the consent of each proposed trustee, submit an affidavit for approval of the fees, with a proposed court order, and pay (with client funds) the \$210 court filing fee. This normally takes about two months as opposed to two weeks where there is a parent or grandparent willing to establish the trust. In one case, it took from early July to the following April.

A Florida NAELA member says the practice there is to establish a “voluntary” guardianship, starting with a physician’s statement that the individual is disabled but competent, then filing a petition for the “voluntary” guardianship. The judge appoints the guardian, at which hearing the

attorney files a separate petition authorizing the special needs trust, which the judge signs. Once the special needs trust is signed, the attorney petitions to dismiss the guardianship.

In Montgomery County, Maryland, a judge denied a petition to establish a special needs trust, notwithstanding the state Attorney General's consent, due to lack of familiarity with these trusts. It was approved at a later hearing, but at additional cost and delay.

Authorizing individuals to establish their own trusts will eliminate reams of such unnecessary complications.

About NAELA

The National Academy of Elder Law Attorneys (NAELA) is a national, non-profit association comprised of 4,500 attorneys who concentrate on legal issues affecting the elderly, people with disabilities, and their families. NAELA members provide advocacy, guidance, and services to enhance the lives of their clients. It is the oldest and largest such association in the United States.

Conclusion

H.R. 670, the Special Needs Trust Fairness Act is a commonsense fix that is sorely needed. We look forward to working with Chairman Pitts, Ranking Member Green, Ranking Member Pallone, and Rep. Thompson on a bipartisan basis to ensure this legislation passes the House of Representatives swiftly.