

For Immediate Release

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SNA President Supports Special Needs Trust Fairness Act before Congress

September 18, 2015 (Tucson, Arizona)— Special Needs Alliance (SNA) President Richard A. Courtney, CELA, testified today before the U.S. House Energy and Commerce Committee Subcommittee on Health in favor of the Special Needs Trust Fairness Act (H.R. 670). Introduced in the House by Reps. Glenn Thompson (R-PA) and Frank Pallone (D-NJ), the bill would enable individuals with disabilities to establish, on their own behalf, financial instruments that can be critical to their economic security. SNTs are a means of protecting eligibility for such meanstested programs such as Medicaid and SSI (Supplemental Security Income), while setting aside funds for expenses that they fail to cover. The same measure was approved unanimously by the U.S. Senate on September 9.

Courtney noted that the legislation that originally created special needs trusts (SNTs), OBRA '93 (Omnibus Budget Reconciliation Act of 1993), "included a drafting oversight that seems to assume that a person with disabilities lacks the requisite mental capacity to enter into a contract.... We believe it was ... not the intent of Congress to deny a basic right to individuals with disabilities." At present, "first party SNTs" must be created for an individual with disabilities by a parent, grandparent, guardian or the court.

His remarks were grounded in both his professional background as a special needs and elder law attorney and his personal experience as the father of a daughter with cerebral palsy and learning disabilities. Speaking of daughter Melanie's determination to live as independently as possible, he noted, "She has never wanted help with things she could capably do. 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."

Current law would prevent her from creating her own trust if she were to receive an inheritance or settlement, and she could lose the Medicaid waiver benefits that pay her attendant to assist her for a few hours daily with certain activities of daily living. Having an SNT would allow Melanie to pay for additional health care not covered by Medicaid, as well as basic needs 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," Courtney continued.

"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."

SNA is a national, not-for-profit organization committed to helping individuals with disabilities, their families and the professionals who serve them. Membership is based on a combination of relevant legal experience in the disability and elder law fields, direct family

experience with disability, active participation with national, state and local disability advocacy organizations, and professional reputation.

Read Courtney's full testimony here.

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