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Providing Trustee and Support Trust Services to Beneficiaries Nationwide

FINANCIAL PLANNING FOR CHILDREN WITH SPECIAL NEEDS

There are many resources for families and caregivers for children with special needs. However, the spiraling costs of care and rising numbers of children with diagnosed disabilities, planning for the long term care and enrichment needs of special needs children warrants serious consideration. An important tool for financial and wealth planners in working with client with juvenile or adult disabled children is the Pooled Special Needs Trust, sometimes referred to in places – by its location the 1993 Budget Reconciliation Act – as (d)(4)(c) Trusts.

While it is possible for the very wealthiest to self-insure and manage all health care related expenses in their lifetime, the case for children born with a diagnosed disability or who have a diagnosis early in their lifetime, the management of costs of care can be simply overwhelming. The advocacy and research organization Autism Speaks recently calculated the costs for providing lifetime care for an individual impacted with intellectual disability from autism can reach \$2.3 million¹. This figure is especially staggering when one considers the recent finding from The Centers for Disease Control and Prevention which estimated that 1 in 88 children born in the U.S. will be diagnosed with autism or an autism related disorder².

While the cost of lifetime care may appear overwhelming or problematic, cost data that is available on the continuum of care for loved ones provides more insight into the financial picture. Genworth Financial's "Cost of Care" study looked at consumers' care costs were in 437 regions across all 50 states³. As an example, Genworth's study revealed the annual cost of a home health care aide in Washington state is \$51,366 and in Arizona \$45,760, while semi-private nursing home care was \$88,633 and \$72,635 respectively. Other organization's data on cost of care reveals similar trends and rising costs across the continuum of care⁴.

Pooled Special Needs Trusts with professional administration relieve much of the emotional and financial burden from families and loved ones for caring for a disabled child. Professionally administered trusts, with a focus on the preservation of public benefits, work to protect inherited familial assets for enhancements of a child's care or lifestyle beyond their public assistance support. The financial drain, even for wealthier families, often means resources will not stretch through a child's lifetime needs.

Another value of Pooled Special Needs Trusts for financial and wealth planners is that they can be set up as First Party settled (e.g. self-funded) or Third Party settled (e.g. outside grantor providing funding). Working with a single governing trust document and consistent disbursement and funding management procedures provides for a consistent administrative experience for beneficiaries and their families / caregivers.

An excellent informational article looking at the issue of special needs trusts from a generational wealth and familial care perspective can be found in the December 1, 2012 issue of *Barron's* magazine⁵.

¹ "New Research Finds Annual Cost of Autism Has More Than Tripled to \$126 Billion in the U.S. and Reached £34 Billion in the U.K." Report online at <http://www.autismspeaks.org/about-us/press-releases/annual-cost-of-autism-triples>

² "Key Findings: Trends in the Prevalence of Developmental Disabilities in U. S. Children, 1997–2008" Report online at <http://www.cdc.gov/ncbddd/features/birthdefects-dd-keyfindings.html>

³ Genworth Financial "Cost of Care Study" interactive website can be found <https://www.genworth.com/corporate/about-genworth/industry-expertise/cost-of-care.html>

⁴ "John Hancock Announces Results of 2011 National Long-Term Care (LTC) Cost Study" found online at http://www.johnhancock.com/about/news_details.php?fn=apr2011-text&yr=2011

⁵ Tatiana Serafin, December 1, 2012, "Creating Special Trusts for Challenged Kids," *Barron's*.