



National Alliance on Mental Illness

Special Needs Trusts Basics




Special needs require special attorneys.

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Brian Rubin Buffalo Grove, Illinois

- Attorney Brian Rubin is the father of a thirty-four year old son, Mitch, who is dually diagnosed with both mental illness and developmental disabilities (Bi Polar, OCD & Autism). Brian's law practice is LIMITED to appropriate "Special Needs Legal & Future Planning" for his fellow Illinois parents and families of children and adults with special needs.
- He is a frequent lecturer to NAMI Chapters in Illinois, and has spoken previously, numerous times, at NAMI National Conventions.
- Brian is an Officer and Director of the Special Needs Alliance.
- Among Brian's many "hats", he is a Commissioner on the State of Illinois Guardianship & Advocacy Commission.



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Robert Fleming

- Robert Fleming is a member of the Special Needs Alliance, the premier national organization of lawyers working with "special needs" trusts. Robert is the author of The Elder Law Answer Book, now available from Aspen Publishers. He is a Fellow of both the American College of Trust and Estate Counsel and the National Academy of Elder Law Attorneys. He has been certified as a Specialist in Estate and Trust Law by the State Bar of Arizona's Board of Legal Specialization, and he is also a Certified Elder Law Attorney by the National Elder Law Foundation. Robert is a member of the State Bar of Arizona (he was President of the Young Lawyers Section in 1978, Chair of the Probate and Trust Section in 1992, and chair of the Mental Health and Elder Law Section in 1999), and the Pima County Bar Association (he was President in 1986).



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Member of Special Needs Alliance
 Family worked three generations in California State Hospitals
 Worked 17 years as a Psychiatric Technician

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The Voice

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The Voice Newsletter

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This installment of the Voice was written by Special Needs Alliance member Evan J. Krame who focuses his practice on estate planning, probate, special needs planning and elder law. Evan is a past president of Shared Horizons, operating a pooled trust serving the Mid-Atlantic region. Evan also served as co-chair of the Estates, Trusts and Probate Section of the DC Bar. He has been honored as a Top Attorney and Best Lawyer in Washington and Maryland. Evan is a candidate for rabbinic ordination, seeking to blend his work in the law with pastoral care and spiritual direction skills. You may visit his website at Law Offices of [Evan J. Krame](#).

Special Needs Trusts And Home Ownership: A Trustee's Concerns

One of the most challenging responsibilities of a trustee of a special needs trust is balancing the benefits of purchasing a handicap-modified house for a beneficiary with the financial pressures of a steadily decreasing trust balance and steadily increasing household expenses.

I am the trustee of a special needs trust established for an adult woman named Sasha. Although Sasha faces

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Free Trustee Handbook

Free Trustee Handbook

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Free Trustee Handbook

Get Your Complimentary Copy of the Handbook for Trustees

A special needs trust can be a very powerful aid in managing care for a family member with a disability. It can provide supplemental items like therapy, respite care, dental work, companions, entertainment, education — all without interfering with the beneficiary's SSI, Medicaid or other government programs. The special needs trust can be a flexible tool. It can also be very difficult and confusing to administer.

Have you been named as trustee of a special needs trust? Have you created a special needs trust, and wonder what the job of trustee is actually like? Are you a trust beneficiary, trying to figure out what the trustee is permitted — and required — to do? The Special Needs Alliance is pleased to offer its free booklet on administering special needs trusts. In plain English, it can help you understand the choices and obligations.

You can download a PDF of the Handbook for Trustees. If you'd prefer, we will send you a printed copy — at no cost — with an obligation to read it and then return it to us with your feedback.

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Lastly

- If you have an attorney in your region that you feel is leader in your community and an advocate for persons with please give us their name and contact information.
- We are always looking for the best to join the Special Needs Alliance team so we can better serve persons with disabilities and their families

Stephen W. Dale

DEFINING THE CHALLENGE

Defining the Challenge

- When someone is asked to describe the purpose of a special needs trust, the typical answer given is to protect entitlement to public benefits.
- Focusing only on preservation of public benefits fails to address the big picture.
- The true objective should be to maximize the quality of life for the beneficiary with a disability.

Defining the Challenge

- The objective of most families we work with is to provide their loved one with the best quality of life possible; a life that promotes independence and is free from abuse and neglect.
- Maintaining benefits eligibility is merely one tool available for pursuing that broader goal.

Imagine



- You have a daughter named Kathy who has schizophrenia.
- Kathy is likely to need some level of assistance for the rest of her life.
- You come to the estate planning attorney to provide for her needs in the event of your incapacity or death.
- Kathy is otherwise healthy and is likely to live 70 years or longer.

The Challenge

- ▶ Benefit laws may will change
- ▶ Social service systems will change
- ▶ Her condition may change
- ▶ Her advocacy system may change
- ▶ Attitudes may change
- ▶ The amount of resources she needs may change
- ▶ Trustee options will change



**The Special Needs
Trust as an Advocacy Tool**

- Disability tends to be a life-changing experience.
- Part of the experience in caring for someone with a disability is advocating and securing resources.
- In all too many cases, that level of care is not intuitive; it is a skill that has to be learned, practiced, and perfected over time through practical experience.
- By necessity, family members can become quite adept at navigating disability service and benefits systems.

**The Special Needs
Trust as an Advocacy Tool**

- Focusing only on the preservation of public benefits also ignores what may be a greater issue
- Persons with disabilities are often subject of abuse and neglect and require a great amount of vigilance.
- It is often essential to be vigilant for signs that their loved one is not being abused or neglected.

**The Special Needs
Trust as an Advocacy Tool**

- In many cases it is possible for a parent to detect evidence of abuse of their child even if the child is nonverbal through changes in behaviors or other cues.
- For example, if a child begins holding their hands over their head as if to protect themselves from being hit, there is a great possibility that the child is being abused.

Ed Roberts

“Anyone can join our group at any point in life. In this way, the Disability Rights Movement doesn't discriminate.”



Definition of Estate Planning

I want to provide for myself and my loved ones during my lifetime, and upon my incapacity or death give what I have to who I want, the way I want, when I want, and if I can save every last fee, tax or court cost possible.

From Loving Trust



The Big Question



Does my disabled loved one need Special Needs Planning?

- Assistance in managing funds
- Build flexibility to deal with changed circumstances
- Focus on advocacy and asset protection
- Could maintaining qualification for SSI or Medicaid be a tool to assist my disabled loved one?
