

## The Voice, *The Official Newsletter of SNA*

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### Welcome!

You are reading *The Voice*, a newsletter published by The Special Needs Alliance. Our purpose is to provide information--and answers--about special needs planning for family members and professionals. We hope this newsletter helps you. We would love to hear your questions, suggestions and comments; please feel free to e-mail us. We also encourage you to forward our newsletter to others who might benefit from the information here, or who might have similar questions.

### Non-Profit Organizations as Trustees of Special Needs Trusts



**Question:** A reader of *The Voice* writes to ask: "Can you suggest some non-profit organizations that act as trustees and have a knowledge of special needs trusts?"

**Our Response (from Alliance member Brian Rubin, an Illinois attorney):** First, before you decide to use a non-profit as trustee, I urge you to consult with an [Alliance attorney in your area](#) to review the advantages and disadvantages of using family or close friends, or possibly a traditional corporate fiduciary (Trust Company).

When relatives or close friends are not a viable alternative to serve as trustees of a Special Needs Trust (and the demands and specialized knowledge can make the job a challenging one), the choice of a competent and caring trustee becomes very difficult. Non-profit organizations in many states and some nationally, have attempted to resolve this very serious problem by accepting the role of trustee of "private" or "individual" 3rd party special needs trusts, even relatively small trusts--where "small" is an obviously variable concept.

Many non-profits have established Master "Pooled" Trusts. The individual special needs trusts are actually "sub-accounts", managed under the umbrella of a "master" or large trust fund. The non-profit trustee also often serves as

an advocate for the beneficiary with special needs. These may be pooled 3rd party trust accounts (that is, funded by contributions or inheritances from someone other than the beneficiary himself or herself), or self settled “pay-back” trust accounts as authorized by federal law (that is, trusts funded by assets of the individual with disabilities, whether those funds existed before the disability, were inherited without proper advance planning, or were received from personal injury settlements).

The typical non-profit master trust is established by a local charity or nonprofit agency to serve persons with special needs. Sometimes, several charitable organizations serving different populations will pool their resources to establish a community pooled trust. Their services as trustee, however, are usually not free. The family of a prospective trust beneficiary will normally have to pay a “set-up” charge, as well as an annual fee. The family generally is required by the non-profit to engage an attorney, at the family’s expense, to represent them in the process.

There are some non-profits that have operated successfully for many years. It is essential that families perform due diligence investigating the stability and history of the non-profit, of the Master or Pooled Trust, before making the decision to participate in the Trust.

In my state (Illinois), I often recommend the use of such a non-profit, a chapter of the Arc of Illinois. I suggest that you contact an Alliance Attorney in your state for similarly individualized recommendations. Another suggestion is that you contact your [state Arc chapter](#) for a recommendation. In some states, the state Arc actually serves as trustee.

Some things to consider in selecting a non-profit trustee:

- Will the organization be responsive and attentive to the needs of the beneficiary?

- Who will be managing the investments?

- What is the initial and what is the ongoing cost?

- What are the provisions when the beneficiary passes on?

- What provisions are there for family involvement in decisions?

**Conclusion:** Non-profit trustees are an excellent option in some cases, but with much local variation. Before giving

blanket advice about the non-profit alternatives, an attorney will need to know more about the beneficiary's condition, the size and source of the trust, and the expectations of family members and caretakers.

**About the Author:** [Brian Rubin](#) is a Special Needs Alliance member in Illinois, and he is also the father of a son with autism (among other special needs). Brian is very active in the disability community, serving as a member of the Board of Directors of The Arc of Illinois and as a former chairman of the Illinois Department of Human Services Statewide Advisory Council on Developmental Disabilities.

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