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Proxy Parent Foundation

Proxy Parent Foundation offers two services.

We administer the PLAN of California Master Pooled Trust, which is open as a trust vehicle for any disabled person in California.

We provide Personal Support Services for beneficiaries of our Special Needs Trusts who have a mental illness.

Just like a loving family, we coordinate public and private social services and medical care while providing family-like attention to help the person improve his or her quality of life.

Proxy Parent Foundation is a dba of Planned Lifetime Assistance Network (PLAN) of California, a 501(c)(3) nonprofit corporation.

Proxy Parent Foundation

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Proxy Parent Foundation



This Issue Focuses on Special Needs Trusts

Message from the Executive Director

Proxy Parent Foundation provides solutions for people and their families who are coping with disabilities by combining expert financial, legal and social resources with compassionate concern.

In July, NAMI Contra Costa President Al Farmer invited volunteer and long time supporter Julie Hoffman to educate their members about the benefits of Proxy Parent Foundation. This was held at the Concord campus of John Muir Medical Center and over 50 members attended. After an informative 45 minute talk, there was an in-depth question and answer session.

NAMI Santa Barbara and Proxy Parent Foundation Board member Ann Eldridge hosted Gary Chang and me for another educational seminar held at the Mental Health Association building.

In August, we had a booth at the NAMI California Annual Conference held in



Torrance. Hundreds of attendees stopped by and more showed up at our workshop given by

Baron Miller, Esq. at the NAMI California Annual Conference.

Julie Hoffman, board members Gary Chang, Esq. and Baron Miller, Esq. (Estate Planning Attorney).

September saw Gary Chang speaking, at the invitation of Ratan Bhavnani, to approximately 70 members of NAMI Ventura County. At the invitation of Cindy Gill, I gave an educational talk at NAMI Bakersfield.

In October, we will have a booth at the California Psychiatric Association conference. The Board and staff of Proxy Parent Foundation enjoy the opportunity to host educational lectures and seminars whenever possible. To schedule a talk, please contact akastens@proxyparentfoundation.org.

Amy Kastens

Proxy Parent Foundation Presents

Personal Support Specialists and Special Needs Trusts *Who Will Care When You're Not There?*

January 16, 2010
Oakland, CA

Hosted by Mental Health Assn. of Alameda Co.

What is a Special Needs Trust? By Baron L. Miller*

Seemingly everyone you know is telling you that you need a special needs trust. You don't doubt it, necessarily, but you would like to know just what these trusts are and how they work. This column will attempt to explain that.

A special needs trust is a specific type of trust that can exist for disabled persons. A trust is a type of legal entity, similar to a small company or maybe a mom and pop store, owning

assets and earning income, with legally recognized rights and obligations.

The person or organization which is in charge of a trust is called the trustee. The trustee operates a trust by protecting and investing its assets, and using them and their income for the purposes of the trust.

Different types of trusts exist for different purposes. The sole purpose of a special needs trust is to maintain a fund for the needs of a disabled person. Its main distinction from other trusts is the restrictions that govern how the trust funds can be used. A properly drawn special needs trust will not affect a disabled person's right to public assistance benefits.

A special needs trust gives its trustee wide discretion in deciding how to distribute trust assets and income, while preventing a trustee from making distributions which would jeopardize eligibility for public assistance benefits. However, often a special needs trust will allow the trustee to make distributions which might reduce public assistance benefits, if the trustee determines that the value derived from those distributions would outweigh those reductions.

A trustee of a special needs trust is allowed to consult with the trust's beneficiary concerning distributions, but the document establishing the trust must deny the beneficiary the power to command any distributions. It is because of this absence of power that the assets of a special needs trust are, as a matter of law, deemed not to be owned by the beneficiary. It is what keeps the assets and income of the trust from being treated as those of the beneficiary, and what enables the beneficiary to remain eligible for public assistance benefits.

It is likely that right now we are assisting a loved one with personal care and financial support. We understand our loved ones' needs for public assistance benefits to pay for basic living and medical expenses, and how essential it is for us to supplement

these benefits. We also understand the necessity to be careful in what we spend money on and how we spend it, as some expenditures can reduce our loved one's public assistance benefits, or even extinguish them. When we are no longer able to render this assistance, a special needs trust will stand in for us and continue the process of assistance.

There are two very crucial aspects of a special needs trust. The first is to properly establish one so it meets the legal and practical requirements which will make it effective for its purpose. The second is to appoint a trustee who has the ability to do the job.

The job of a trustee of a special needs trust is unique. The trustee must have the financial sense to obtain a maximum amount of income by investing the trust's assets while at the same time protecting them from the risk of loss. At least as importantly, the trustee must understand the individual special needs of the beneficiary, and know how to deal effectively with the beneficiary. A trustee needs to make wise decisions on how to spend trust funds so that the real needs of the beneficiary are provided for and the trust funds will last for the beneficiary's expected lifetime.

Often a family member or a trusted friend is the best selection as a trustee. But there are pitfalls, such as potential conflict with the beneficiary and possibly placing an unwanted burden on the family member or friend. Sometimes an organization like Proxy Parent Foundation, with its experience and expertise, is the best choice to serve as trustee.

A special needs trust is a significant estate planning tool, and is something that should be established for the great majority of disabled persons. A good special needs trust will enable us to feel assured that our disabled loved ones are protected to the extent possible.

**Baron L. Miller is an attorney in private practice in San Francisco who specializes in estate planning for California families of the mentally ill. He is a long-time NAMI family*

member, and an advocate for the rights and interests of families of the mentally ill and is a board member of Proxy Parent Foundation. He does not charge for telephone consultations on the propriety of making payments for the benefit of an SSI recipient. He can be reached at 415.522.0500.

First Party and Pooled Special Needs Trusts

*By Gary M. Chang, Esq. **

From Baron Miller's article, you are now aware of what a special needs trust is and how it functions to protect a disabled person's means tested benefits such as SSI or Medi-Cal by providing a "safe harbor" for income and assets over the strict \$2,000 limit, an excess of which will cause a loss of eligibility for benefits. There are basically two types of special needs trusts. The first is the Third Party Special Needs Trust. This is the more common one as they are traditionally created by families to leave an inheritance to a disabled child, grandchild or relative.

The other special needs trust is a **First Party Special Needs Trust**, so called because the trust is *funded by the assets of the beneficiary of the trust*. For example, let's suppose that you are a disabled person and you find you are about to receive a gift, inheritance, or a litigation or insurance award and settlement. That "windfall" will likely put you over the \$2,000 asset and income limit and cause you to lose your benefits. However, if that money is put into a First Party Special Needs Trust, it will not be counted as assets or income and you can maintain your benefits.

There are two types of First Party Special Needs Trusts. The first is an individual stand-alone trust that can be set up by a parent, grandparent, guardian or court. A stand-alone trust must be drafted by an attorney and often then needs to be approved by a court. This can be a costly process. The individual First Party Special Needs Trust will also need a willing and qualified Trustee to manage the trust, and generally, a financial institution to do the money, investment, and



accounting management. And, if there is not an individual trustee willing to act, most institutional trustees will not accept trusts of less than several hundred thousand dollars in assets. Another thing to note is that individual stand-alone First Party Special Needs Trusts will not protect the benefits of a beneficiary over the age of 65.

The other type of First Party Trust is a **Pooled Special Needs Trust** that can be joined by parent, grandparent, guardian, or court, but also by the disabled person him or herself as long as he or she is competent to do so. It is also open to all ages, so there is no age limitation. A Pooled Special Needs Trust, must be created and maintained by a nonprofit organization such as Proxy Parent Foundation and is governed by a Master Special Needs Trust. This Master Trust serves as the governing trust document, and the disabled person's assets "join" it as a sub-trust, thus the drafting of an individual special needs trust is not required. The sub-trust assets receive all the protections of a special needs trust, so benefits are protected, but although your trust funds are never commingled with funds of the other sub-trusts, they are "pooled" for investment purposes to achieve lower management fees from the financial institution administering the trust.

Proxy Parent Foundation's PLAN of California Master Pooled Trust, accepts both Third Party and First Party Pooled Trusts. There is no minimum asset limit to fund the trust. Please contact us if you are interested in learning more.

**Gary M. Chang, Esq. is Proxy Parent Foundation's Director of Legal Affairs.*

Book Review By Joseph DeCarlo*

A Brother's Memoir

Boy Alone (2009) by Karl Taro Greenfeld, is a new book about how a brother and his parents, a Jewish father and Japanese mother, deal with Noah, their autistic son who is now 42 years old. The book describes their struggles,

trials, frustrations and challenges of dealing and discoveries with an autistic child and his progression to middle age.

The parents, Josh and Fumi, moved from New York to Los Angeles in hopes that a new program at UCLA would provide a cure. They encountered both good and bad doctors, difficulties getting placement for Noah when he became too difficult to handle. Housing ranged from group homes to institutions to live-in care takers or host homes.

One of the most disheartening aspects in the history and treatment of Autism has been the attitude of some of the medical professionals. For example, Bruno Bettelheim in his book *The Empty Fortress*, 1967, said that mothers of autistic children were to blame for their condition. Leon Kanner in *Autistic Disturbances* said, "In the whole group, there are very few really warm hearted fathers and mothers." The parents had to cope with the stigma of these "witch" doctors in the 1940's and 50's, even today neuroscience is not very parent friendly.

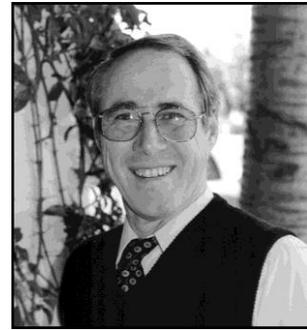
A disturbing fact is a follow up article in Time Magazine by Karl Taro Greenfeld, "when he, my father and mother are in their 80's and will go on as long as possible caring for Noah, Karl asks himself the question, "will I always be there for Noah, as my parents have been?" His answer, "I wish I could say, yes, definitely, I will be there. But I honestly don't know."

The question really is, who will take care of the developmentally disabled person after their parents pass away? Many siblings have life issues in administering a special needs trust for their disabled sibling. How can the parents provide for care needed before they pass away and thus achieve peace of mind?

There is hope and a solution. For more information, please visit the website www.proxyparentfoundation.org.

**Joseph DeCarlo is the father of a 34 year old Autistic son "Joey" who functions with the capacity of*

a 6 year old, who lives at home and goes to Project



Independence, a Regional Center of Orange County funded program. Mr. DeCarlo is President of the Proxy Parent Foundation and can be reached at joe@jdproperty.com.

New Family Education and Resource Center (FERC) Opens in Alameda County

FERC is a new and innovative family/caregiver-centered program that provides information, education and support services to family/caregivers of children, adolescents, transitional age youth, adults or older adults with serious emotional disturbance or mental illness in Alameda County. FERC is a component of Alameda County's MHSA Community Services & Supports plan and is operated by the Mental Health Association of Alameda County under contract with Alameda County Behavioral Health Care Services. FERC's toll-free number is 888.896.3372 and website is www.askferc.org.

Donations to
Proxy Parent Foundation
are gratefully accepted.

By Mail:
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Tustin, CA 92780

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*Proxy Parent Foundation is a dba of
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