### Proxy Parent Foundation Newsletter

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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 or brain disorder.

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.

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#### What's going on...

Proxy Parent Foundation provides both financial oversight and social support so that those who are disabled can thrive in society and experience a real quality of life. For many families, it also answers the question: Who will care when I'm not there? As always we have been busy, spreading the word.

In May, our Director of Legal Affairs, Gary Chang, Esq. represented Proxy Parent Foundation at the Meeting of the Minds Conference in Garden Grove, hosted by the Orange County Mental Health Association.

June was a particularly active month. In Sacramento, three of our Board Members, Carla Jacobs, Randall Hagar and John Buck represented Proxy Parent Foundation at the Disability Capitol Action Day. This is an annual event organized by The Disability Action Coalition. A resource fair is held on the Capitol lawn for attendees to listen to speakers and learn about existing services. Word of how our trust services are open to all disabilities, not only the mentally disabled, was met with great interest and enthusiasm.

Shortly after, Board members Randall Hagar and John Buck then made a very well-received presentation at the California Commission on Aging in Sacramento on the subject of how pooled trusts, such as ours, can protect the public benefits of those over age 65 (please see the article in this month's issue).

Also that month, Gary Chang represented Proxy Parent Foundation at the highly anticipated and well-attended "Pathways to Wellness" Mental Health Conference hosted by NAMI Westside Los Angeles held in Bel Air.

Finally, in August, Proxy Parent Foundation was very well-represented by board members, Carla Jacobs, Ann Eldridge, Randall Hagar, and our Directors of Legal Affairs and Social Services, Gary Chang and Bruce Lewitt at the annual NAMI California Conference in Burlingame.

#### Third Party and Self-Settled Special Needs Trusts and the Importance of the Pooled Trust for those over age 65

By Gary M. Chang, Esq.\*

Special Needs Trusts protect disabled persons receiving means tested government benefits such as SSI or Medicaid from losing those benefits should they receive assets in excess of \$2,000. The more traditional special needs trusts are called Third-Party special needs trusts because they are created for the disabled person with someone else's money, in most cases a family inheritance. Self-settled special needs trusts, which were created by federal statute and also known as First-Party special needs trusts, are called such because they are created with the beneficiary's own money.

What many persons do not know is that people with disabilities who are over the age of 65 that receive a cash windfall such as an inheritance, a settlement or award (for example as a result of a successful action for nursing home abuse) can establish a self-settled Pooled special needs trust that shelters their Medicaid benefits. If they did not put this money in a pooled special needs trust, they would very likely lose their benefits until this cash windfall was "spent down" to below \$2,000, leaving them back where they started. Instead, by putting that money in a pooled trust, those assets in this trust can then be used for their special needs while Medicaid can augment the expense, with Medicare, of their assisted living residence. There is also the possibility that if the individual who currently requires or may require assisted living has a disabled child, the remainder of their pooled trust after their death can rollover into a special needs trust for that child.



For those persons over age 65, it is important to note that there are two types of self-settled special needs trusts, both created by Federal Statute, and that only one provides Medicaid protection. The statute that governs the first type of self-settled trust, an individual special needs trust has language that restricts it to those under age 65, while the statutory language for the second type of self-settled trust, the pooled special needs trust has no age limit.

The PLAN of California Master Pooled Trust accepts third party and self-settled individual and pooled special needs trusts, so if you know of a person over age 65 who you believe may need the benefits of a pooled trust, or want to learn more about special needs trusts in general, please contact Gary Chang at Proxy Parent Foundation by phone 213.925.5526 or e-mail planofca\_ed@ yahoo.com for more information.

# Impact of Health Care Reform on Disabled Persons, Medicaid, and Special Needs Trusts

By Gary M. Chang, Esq.\*

The new health care reform law, now commonly called the "Affordable Care Act", is made up of two separate acts of Congress – the Patient Protection and Affordable Care Act (PPACA, H.R. 3590) signed into law by President Obama on March 23, 2010, and the Health Care & Education Reconciliation Act, signed one week later, which provided procedural enhancements to the PPACA.

Because the full provisions of the Affordable Care Act (the Act) are to be implemented over the course of almost ten years and the reality that the rollout of its provisions will be impacted by the

formidable vagaries of the sociological, political and financial climates over that period, it is very hard to predict the actual effects both ongoing and long term of the new law. However, it will unarguably bring a sea change to the nation's health care system and the treatment and protections provided for persons with disabilities.

Most discussions of the Act's impact concern its expansion of access to private medical insurance and such issues as prohibiting insurers from denying coverage for pre-existing conditions, or its requirement that individuals are now required to purchase insurance coverage and how the laws may penalize any who fail to do so, or even its establishment of an essential benefits package that includes coverage for mental health and substance abuse disorder services. It would be impossible for this newsletter and it is not this issue's intent to address the complexities of these issues, however, we recommend that our readers seek-out the following websites for additional information: www.chcf.org and www.healthcare.gov.

One thing that can be said with certainty is that the Act will not affect the necessity of providing for the financial well being of an individual and/or family member receiving government benefits with a special needs trust. If anything, the importance of the special needs trust to the family or individual estate plan will likely increase, because under the Act, as of April 1, 2010 all states may begin expanding Medicaid coverage to individuals with incomes at or below 133% of the Federal Poverty Level (\$29,400 for a family of 4, or \$14,400 for an individual) and by January 2014, all states must expand Medicaid coverage to all such individuals, including childless adults who meet these income guidelines.

What this means is that non-elderly, non-pregnant adults without children will qualify for Medicaid based solely on economic factors, without their being tied to eligibility for other benefits, primarily SSI. This untethering of Medicaid from SSI will open the door to thousands more disabled individuals

in need of this vital benefit. Additionally, as provided under the Act, state Medicaid programs will be able to offer additional services to assist those who need long-term care at home and in the community, there will be broadened and improved prescription drug coverage, and increased and enhanced services for individuals eligible for and receiving both Medicaid and Medicare.

Furthermore, in anticipation of expanding enrollment in Medicaid, states must develop processes to improve and increase outreach to disabled persons and to streamline the application and enrollment process which currently can be particularly challenging to those suffering from severe mental illness.

As we all know, due to the high cost of medications for the seriously mentally ill, it is the Medicaid benefit that is the most important of all "means tested" benefits. And, as more and more persons are receiving this benefit and other Medicaid benefits grow as mandated under the Act, the use of the special needs trust will be ever more vital in protecting these benefits from inheritances, court or insurance awards, or other cash windfalls.

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

## Timely Funding of a Special Needs Trust

By Baron L. Miller\*

If you have a loved one with a mental illness for whom you are providing care, you likely need to set up a special needs trust to continue to provide care after your death, and to protect public assistance benefits such as SSI. In this special needs trust you will provide for Proxy Parent Foundation or another responsible organization or individual to serve as the trustee i.e. the operator and administrator of the trust. How will that



trustee get the money you have left to fund the trust, and how long will this take? The answer to this question depends on the mechanism you have used to fund the special needs trust you have established.

The most common mechanism is a revocable living trust. A revocable living trust is an entity you establish to hold your assets while you are living and to distribute your assets to designated beneficiaries after you die. It generally takes the place of a will, and the advantage of it is that it enables your assets to be distributed without the trouble, time, and expense of probate court supervision.

When you establish a revocable living trust you transfer your assets to this trust, and typically you will designate yourself as its trustee, thereby keeping the assets solely within your complete control. You are able to continue to freely use those assets, to remove them from the trust if you want, and even to terminate the trust entirely. On your death a successor trustee designated by you will take over control of the assets and distribute them according to your written direction, including distribution to a special needs trust. A properly drawn revocable living trust will empower its successor trustee to at least partially fund the special needs trust immediately.

If you don't have a revocable living trust which is holding your assets, then chances are that even a partial distribution of your assets to a special needs trust will need to wait until a probate case has been opened in the court of the county where you resided, and a court order of preliminary distribution has been obtained. This normally takes at least several months, so if the special needs trust needs to go into operation sooner than that then you will need to make other arrangements now. Likewise if the special needs trust is to be funded with life insurance, or an annuity, or a retirement plan, all of which require some passage of time before benefits will be paid. A revocable living trust is often the best method for immediate funding, but there are other ways.

One way to get the special needs trust into operation without delay after your death is to create it and make it operational while you are living. As with a revocable living trust, you can be the trustee of this special needs trust and you can designate Proxy Parent Foundation or another responsible organization or individual to serve as the successor trustee. You can then keep enough money in this trust for the successor trustee to use for the benefit of your loved one until its full funding occurs through probate court order and/or receipt of insurance or retirement benefits.

Another method of getting money to a special needs trust sooner is to make the special needs trust the payable-on-death beneficiary of an account at a financial institution. Or, if Proxy Parent Foundation is to be the trustee of the special needs trust, then to avoid the passage of any time between your death and the ability of the trustee of the special needs trust to provide for your loved one, you can make a deposit with Proxy Parent Foundation while you're living, specifically for this purpose.

If you have established a special needs trust with Proxy Parent Foundation or other responsible trustee, then you have put the mechanism in place to provide care for your loved one after your death. You must make sure that you have also provided a way for the trustee of the special needs trust to timely provide that care.



\*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 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.

#### **Book Review**

By Joseph DeCarlo\*



Joe DeCarlo has been reviewing a book for each newsletter relating to mental illness.

This issue's review is on a book titled The Mind and the Brain by Jeffrey Schwartz, MD and Sharon Begley. Jeffery Schwartz is a research professor at the UCLA Department of Psychiatry and Biobehavioral Sciences. He makes a case for the power of the mind to make physical changes in the brain. People can be trained to re-wire their brains to relieve pain and depression. Even mature adults can remap to overcome compulsive behaviors. He uses examples of his patients with Obsessive Compulsive Disorder (OCD) such as excessive and ritualized hand washing. He was able to, through PET Scans, pinpoint brain structures that seem to be consistent with OCD. Schwartz argues that directed attention mental force can alter brain circuitry processing and that this is not a byproduct of the brain itself. A newborn brain contains 100 billion nerve cells (neurons) which connect up to anywhere from 2,000 to 100,000 other neurons. A conservative estimate is that an adult brain has 100 trillion synapse. This complexity is a challenge to understanding and dealing with brain disorders. There is little hope that the puzzle will be solved in our lifetime.

The author has a tendency of referring to many quotes from Abraham Maslow, William James and others which makes the reading this book very difficult to follow. My goal is to learn more about the brain and its workings. I would not recommend this book for parents seeking an easy to read book, as it is too technical and not easily understood.

\*Joseph DeCarlo is the father of a 34 year old autistic son "Joey" who also has epilepsy. Joey lives at home with his parents 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.

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