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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.

Proxy Parent Foundation

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Proxy Parent Foundation

This issue focuses on

Personal Support Services

What's going on....

Proxy Parent Foundation is a model of what dedicated community members, disability advocates and professional expertise can accomplish to help disabled people and benefit society.

Proxy Parent Foundation was proud to see Executive Board member Carla Jacobs honored on Dec. 9, 2009, when she was awarded the Nonprofit



Excellence Award by the Center for Nonprofit Management. Ms. Jacobs was described as an "innovator and collaborator responsible for moving her organization forward" by members of the nonprofit community in Southern California.

Whittier Law School & Proxy Parent Foundation hosted a Special Event on Pooled Special Needs Trusts – How They Can Protect Your Clients with Disabilities and How Trusts Established Under d(4)(C) Can Protect Medicaid of Those 65 and Older. The lecture was given by Thomas Beltran, Esq., General Counsel to Proxy Parent Foundation and Gary Chang, Director of Legal Affairs for Proxy Parent Foundation. Gary can be reached at 714.997.3310 or toll free at 888.574.1258 for more information regarding Proxy Parent Foundation Special Needs Trusts.

Proxy Parent Foundation is pleased to have joined forces with over 35 groups representing chronic conditions to become a member of the Chronic Care Coalition whose mission is to "improve the health care system where all Californians can access appropriate affordable quality healthcare."

Mental Health Association of Alameda County and Proxy Parent Foundation sponsored a



day-long conference "Caregivers Planning for the Future" on March 20, at Merritt College in Oakland. Board member Carla Jacobs was the Keynote Speaker.

Also in March, Proxy Parent Foundation was a sponsor and had an information table at the Gilfix Special Needs Trust Conference in Palo Alto.

Proxy Parent Foundation is a California nonprofit dedicated to assisting people with disabilities by safeguarding access to government benefits through the creation and administration of the Proxy Parent Foundation PLAN of California Special Needs Trust and providing "family like" Personal Support Services for people with mental illness and other brain disorders. We hope you enjoy this issue on how our Personal Support Services help answer the question, "Who will care when I'm not there?"

Highlight on Bruce Lewitt, Our Director of

Social Services



Proxy Parent Foundation prides itself on the work of their Personal Support Specialists who help bridge the gap between what the public

mental health system provides and what is really needed for a beneficiary with a psychiatric disability so that person can experience a better quality of life. Bruce Lewitt, Proxy Parent Foundation's Director of Social Services and a long time Personal Support Specialist is dedicated to providing flexible, customized Personal Support Services. Bruce loves the work and the population he works with. The personalities

involved, illnesses, symptoms, and sheer complexity enthrall Bruce.

Bruce believes of Proxy Parent Foundation that the most important thing Personal Support Specialists can provide is being there for the long haul providing flexible, customized "family like" services as the stories in this issue regarding beneficiaries of Proxy Parent Foundation's Personal Support Services exemplify. He believes it is important to loosen the boundaries between the Personal Support Specialist and beneficiaries to make it more humanized and to understand that other people can provide the clinical treatment but that Proxy Parent Foundation needs to provide the family relationship and closeness. It's a team effort of the beneficiary, family, physicians and the Personal Support Specialists of Proxy Parent Foundation working together to maximize the quality of life of the beneficiary. For more information as to how Proxy Parent Foundation's Personal Support Services program can benefit your loved one with mental illness or other brain disorders, please feel free to call Bruce at 714.997.3310 or toll free at 888.574.1258.

Highlight on Board Member John Buck and Personal Support Services

*By Jill H. Estroff**



Although John Buck is the CEO of a multi-million dollar nonprofit mental health agency and regularly meets with elected

leaders and government officials, there's nothing like a date to meet with a Proxy Parent Foundation (dba PLAN of California) beneficiary to inspire and remind him why he does this work.

John relates, "I'm not constrained within the role of a government employed therapist, or case manager when I act as a Proxy Parent Foundation Personal Support Specialist. I'm truly able to put my efforts into a buddy role, or a big brother-younger brother type of role. In the beginning I might see a client every week or two weeks and then over time, if you

do your job right, the person needs you less and less. You become more like the grandparent that, just checks in every once in a while."

John estimates that in the 16 years that he's worked with Proxy Parent Foundation, he has gotten to know about 25 different beneficiaries. John might take a client grocery shopping, or out to lunch, negotiate with a landlord or resolve conflicts with a neighbor—it just all depends on what is needed most at the time. Through John's work as a Personal Support Specialist, he has gotten to know some wonderful families who are committed to helping their loved ones to make sure they're cared for, maintaining the best quality of life possible.

Brad (different name) has been John's personal services client for 15 years. Brad's brother Stanley lives near Atlanta and John's help is a great relief to him. Stanley explains that his brother was in a California state hospital at age 18 and that he has been his conservator since their Mother died in 1984. Brad has had many diagnoses over the years including bipolar with schizophrenia and obsessive compulsive disorder. For more than 20 years, Stanley has lived near Atlanta, several thousand miles apart from Brad. John is Brad and Stanley's extended family. He has been able to intercede and be Stanley's eyes and ears of what is really going on. He knows the continuum of Brad's moods, the highs and lows. He's not only there to address a crisis, but he's there in the context of Brad's overall physical and mental well being. As Brad's Personal Support Specialist, John figures out what needs to be done whether it be finding an alternative home that's most appropriate or making sure that for Thanksgiving and Christmas, Brad has a holiday meal. Brad looks at John as a very good friend, someone he can confide in and trust. If there's a crisis, Stanley knows he can't get there from 2,500 miles away, but John can be with Brad in a matter of hours.

Tad's son Dale (different name) has been with Proxy Parent Foundation for about nine years, According to Tad, "We've found it works very well. Our son is very happy with it. John Buck was our first support specialist. Dale currently works with Lewis Tatum, the maintenance supervisor for Turning Point Community Programs. They try to get

together about once every other week and go out to lunch. In our will we've made provisions for Dale's continued care with Proxy Parent."

What would Tad say to parents considering the personal support services at Proxy Parent Foundation? "Give it a try, and see how it works for you depending on your family's needs. I like the normalization, so to speak, that it gives Dale a chance to meet and spend time with people who are not ill."

Lewis said, "Since I began working with Dale in December 2006, he's a lot less reserved. He was soft-spoken and very quiet at first, but now he voices his opinions a lot more and his work ethic is really strong. We work together every other week for a full day. He's helped with remodeling projects of a kitchen and bathroom, and a lot of other tenant improvements. He is now a Turning Point employee and does get paid for his work. All the staff truly loves him. He's intuitive and very enthusiastic and never complains. He's definitely one of our success stories."

** Jill H. Estroff is a contractor for Turning Point Community Programs and was the previous Communications Director. Previously, Jill directed communications for Sacramento County Public Health, Economic Development and the Crocker Art Museum.*

The Importance of the Trustee

*By Baron L. Miller**

As with most things in dealing with a disabled child, planning for his or her care after our demise is not a simple matter. For starters, it's a situation where we must face our own mortality and the reality that we won't always be there to provide and oversee desperately needed care and support.

Like it or not, we can't escape the fact that we must set up an estate plan. Which means: 1) the need to find an attorney to set it up - someone knowledgeable in this area of the law and familiar with and sensitive to our situation; 2) deciding how much in the way of cash or other assets will be set aside for future care and support; and 3) determining who to empower to take our place when we are gone.

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The mechanism usually needed to fund future care and support is a special needs trust, the mechanics of which were explained in the Fall 2009 Proxy Parent Foundation newsletter. Briefly, a special needs trust is a type of entity which holds and protects assets set aside for a disabled person, provides for care and support of the disabled person, and enables the disabled person to become or remain eligible for public assistance programs.

The individual or organization which operates a special needs trust is called the trustee, and the trustee's responsibilities are complex and immense. To the extent possible, the trustee must safeguard the trust assets and at the same time protect those assets so that they will maximize the benefits available for the best interest of the individual whom they are intended to help. The trustee must use the trust funds to supplement the disabled person's special needs while also ensuring that the use of funds will not jeopardize or reduce public assistance benefits. From an investment standpoint, both long-term and short-term investment strategies are required, as is maintaining a ready supply of cash to cover any unexpected urgencies.

Just as important as having financial savvy, or knowing how to hire someone who has it, a trustee of a special needs trust must be aware of and understand the needs of the disabled person who is the beneficiary of the trust. The trustee must figuratively stand in our shoes, and therefore must know and understand the nature of our loved one's disability.

Occasionally we see someone with seeming unlimited amounts of assets to set aside for the future care and support of a disabled loved one. For this person a bank trust department may suffice as a trustee, for there will be enough funds to pay trustee fees, beneficiary liaison fees, investment advisers fees, brokers fees, social workers fees, and attorneys fees, along with the actual expenditures that directly benefit the disabled person. For the vast majority of us, money is more finite and the process of care and support needs to be streamlined.

It is fortunate when one has a family member or friend who is able and willing to serve as trustee, for this is sometimes the best possible situation. It is also rare, as being

qualified to serve consists of, in addition to trustworthiness and desire, a comprehensive knowledge of finances, the disability, and our child. Also required is an ability to maintain strict relationship boundaries with our child over the course of a lifetime, something which can be especially difficult for close family or friends.

Frequently clients will ask me for a recommendation of a trustee. I always recommend Proxy Parent Foundation. This is not because I derive some kind of direct economic benefit. The benefit I derive from my association with Proxy Parent Foundation is being associated with Proxy Parent Foundation's unique and striking capability to serve as trustee of a special needs trust that I always recommend it.

Proxy Parent Foundation was predominantly established by family members of the mentally ill. Proxy Parent Foundation does not exist to pay salaries, bonuses, or dividends, and its operations do not make anyone wealthy. Its sole purpose is to be a parent by proxy when real parents have departed this world. To do this, Proxy Parent Foundation has family members of disabled persons overseeing its operations, an experienced social worker and attorney conducting its day to day operations, and professional personal support specialists and investment advisers who contract with it to provide needed services. It is not a business; it is a secular godparent, and a highly skilled one.

Planning for future needs can be a big source of anxiety for us. Once we establish the plan, and do it right, we remove one large worry. This is something we must do, sooner or later. It is all part of being a parent.



**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.

Book Review

*By Joseph DeCarlo**

In this issue I am reviewing ***Treating the Brain*** authored by Dr. Walter G. Bradley (Suggested Retail Cost \$25), Dana Press, Washington D.C. Dr. Bradley is a nationally leading Neurologist who has written an easy to understand book for those of us who want to know more about Epilepsy, Stroke, Alzheimer's and Parkinson's disease. Unfortunately it did not cover Autism, Bipolar disorders and Schizophrenia. The book describes each disorder, symptoms, diagnoses, probable causes, treatment options and care and long term prognosis.

My son is afflicted with Epilepsy and this book gave me clear answers on the multiple types of medication and side effects in an easy to understand format that I have been seeking for many years.

This is a very good reference book for those of us close to anyone with a neurological disorder. The human brain has approximately 100 billion neurons making it the most complex part of our body and we many never know its full interworkings. However, ***Treating the Brain*** will provide readers a very helpful and practical insight to enhance their knowledge.



**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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