



# Proxy Parent Foundation newsletter

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## INSIDE THIS ISSUE

- 1 Happy families are all alike; every unhappy family is unhappy in its own way . . .
- 2 Will or Trust or . . .
- 3 New Scientific Test for Mental Illness

### PROXY PARENT FOUNDATION

Proxy Parent Foundation offers two services.

We are Trustee of the PLAN of California Master Pooled Trust, which is open to California residents of all disabilities.

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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## Happy families are all alike; every unhappy family is unhappy in its own way. . . —LEO TOLSTOY

By Gary M. Chang\*

So wrote Leo Tolstoy, one of the many venerated artists and/or geniuses through history who have been retrospectively diagnosed as suffering from mental illness. Now we have the tragic death of Robin Williams, another in that long line, this time diagnosed under the analysis and diagnosis of modern psychiatry. For some of us, knowing that many with genius are touched or even consumed by mental illness, it is a comfort, perhaps because we hope it will lessen the stigma upon our owned loved one, or maybe we recall how brilliant or creative our own loved ones were before illness overcame them and we mourn what if. Yet, while it is true that many geniuses throughout history have suffered from mental illness and their particular form of such may have been the fire for their creativity, it is sad to realize that, in a way, humankind is also a great enabler, taking enjoyment and entertainment from their brilliance, unaware or worse romanticizing the pain and need that inspired and/or fed it.

This opening line to Anna Karenina has always been with me since I first read it years ago. While it generally lies deep under still water, it keeps coming to the surface when ripples cross the pond. Was Mr. Tolstoy unhappy when he wrote it (some modern experts say he suffered from clinical depression)? If he

were not, would he have reversed it, so that all unhappy families were alike and vice versa? We know the fate of his Anna is an unhappy one. In either case, reversed, the words would still resonate; because no matter what family we belong to we are all different yet all the same. When we are happy we enjoy everything around us almost indistinguishably, but when we are unhappy we each view the world through our own discontent and resentments.

Recently, I went to the store with my dear daughter. She was having a bad day. Even though it was extremely hot outside, she did not want to enter with me. Instead paced anxiously back and forth across the storefront, her eyes tight and forehead furrowed under a woolen cap pulled low, so that it half covered her pretty face, lost in her own world, and mumbling softly at no one anyone else could see. Inside the store, I was feeling protective and self-conscious of the societal stigma imposed by what I knew to be her symptoms, when I noticed several customers staring out the front window pointing. Suddenly furious, I was about to angrily ask them what the heck they found so upsetting when I heard one tell an employee to call the police while several others rushed outside and surrounded a car parked in front with all its windows rolled up. Inside was a large black dog, drooling and desperately panting. The customer was paged and rushed out to tend to her pet just as the small crowd circling the car seemed about to break a window. Now calm, I was watching bemusedly through the glass as the dog owner was being berated, when suddenly my daughter appeared at my side, seemingly oblivious to all that had been going on, and impatiently asked me if I had found what I needed and if we



could please go home. “Yes,” I said, and she gave me that smile that lights up the world. We can both be so easy to please.

It is always important to attempt to remind ourselves that things are never all that they seem and to try not to allow our own discontent to cause us to understand others too quickly. After all, as has also been said, everyone has their reasons, even, I pray, those that I may never understand.

In any case, I hope you enjoy this issue of our newsletter. In it you'll find two excellent articles, one by Board Member, Baron Miller, which is an astute overview on the pros and cons of whether to use a will or trust for both your estate plan and to fund a special needs trust and another by Board Member, Joe DeCarlo, concerning an exciting new scientific testing software, still under development, that may help determine the effectiveness of psychotropic medications far more accurately than the current hit and miss method and correspondingly could greatly reduce the cost of treatment.

Finally, it is always nice to meet many of our readers in person as Bruce Lewitt, our Director of Social Services, and I did at the NAMI California Conference in August down here in Southern California. So for those of you up North, Board Members, John Buck and Randall Hagar will be appearing at the 34th Annual Mental Health and Aging Conference on Thursday, October 30 at the Red Lion Hotel in Sacramento. If you can attend, please stop by and say, Hello. Here's a link to learn more about the event: <http://sacmhac.tpcp.org/>

*\*Gary M. Chang, Esq. is Director of Legal Affairs for Proxy Parent Foundation.*

## Will or Trust or . . .

By Baron L. Miller\*



In my article published in the last edition of this newsletter I discussed the issue of when to make a special needs trust effective, either now or after one's death. I set out reasons why it might be best to establish a special needs trust which is effective now, and reasons why it might be unnecessary to make it effective now. And I said that in the next newsletter I would write on the options available to create a special needs trust which would not go into effect until after death. This is it. The most common and traditional way of providing for the distribution of assets after one's death is by will. A will is a good way to accomplish after-death gifts, as its terms have no effect whatsoever until one dies, and a will can be changed or revoked up until that eventual moment. A will makes no change in the ownership of one's assets until after death, and it is usually relatively uncomplicated and inexpensive to draft.

One can make a gift in a will to a special needs trust, either one that is already in existence or one that is established by the will and goes into effect after death. Because the will is changeable until death, provisions for use of trust money and the identities of the trustees and ultimate beneficiaries can be kept current without too much trouble or expense.

The downside to a will is that it might require a probate court administration after

death to put its provisions into effect. In California if one dies with assets titled in his/her name which exceed \$150,000.00 in value, the only way to effect a distribution of those assets is to administer a probate estate in court. There is nothing essentially wrong with doing this; the problem is that it can be expensive, due to court and other procedural costs, administration fees, and attorney fees.

The way to avoid probate court for estates worth \$150,000.00 or more is to make sure that one's assets are not titled in his or her name at death. This can be done by making gifts before death, by designating after-death beneficiaries on specific accounts, and/or by establishing and using a living trust to hold title to assets. If one's individual assets are worth more than \$150,000.00 and s/he wants to leave some or all of them to a special needs trust while avoiding probate, then either that special needs trust will need to be established now along with a non-will method of providing for distribution of them to that special needs trust, or else the living trust mechanism will be required to establish the special needs trust.

An expedient and inexpensive way of avoiding probate is to designate beneficiaries of specific assets on the title documents that pertain to those assets – making them what are known as payable-on-death (POD) assets. But if there is no special needs trust in existence, and no will or trust which provides for the establishment of a special needs trust, then there would be no special needs trust that could be named as a beneficiary of any specific asset.



Depending on the size of one's individual estate i.e. the value of the assets which are titled in his or her own name or which are not in POD accounts, one can use a simple will to create a special needs trust. For example, if one's assets consist primarily of something like a retirement account or life insurance where one can readily designate a POD beneficiary, then a will can be used to establish the special needs trust, and the special needs trust can be designated the POD beneficiary, and probate would be unnecessary.

In most situations what will be needed to avoid probate is a living trust. One creates this trust and transfers his or her own assets to it, and provides in the document establishing the living trust that a special needs trust is to be established after death in order to take distribution of a gift made for the benefit of a disabled person. Because the living trust is the title holder (owner) of the assets on death, replacing the individual who set up the trust as the owner, the assets owned by the trust do not count toward the \$150,000.00 limit. There are some additional procedures in setting up a living trust, and so a living trust will cost more than a will to create, but the overall cost savings by avoiding probate can be enormous. And like wills, living trusts are amendable until death.

That which will make life easiest and least expensive is frequently desirable, and so a determination needs to be made of just what legal mechanisms will accomplish this and can be used. One warning: due to differences in asset values and personal situations, what will work for one person won't

necessarily work for another, so caution is in order when hearing others say to you what you might need. The main point is that you have options, and they should be fully explored before you make your decision.

*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, 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.*

## New Scientific Test For Mental Illness

By Joseph DeCarlo\*



In lieu of a book report, this issue we will focus on a new scientific test which is a

cloud-based software known as PEER Interactive that allows psychiatrists to prescribe psychotropic drugs rather than the current trial and error method. The software tool compares a measurement of patient brain waves (EEG) with those of past patients and how these patients responded to multi medications. This self-learning software treats mental health conditions that in the past have relied on observations and not comparable indicators. PEER Interactive uses

brain waves of a patient to identify drugs for relief from mental disorders such as depression, anxiety and post-traumatic stress disorders. It also identifies drugs least likely to be effective and a drug's side effects.

The US Army at the Walter Reed National Military Medical Center in Bethesda, MD is presently funding a 2,000 patient study. This study uses the PEER Interactive software. The database has brain waves from more than 9,000 former patients.

The National Alliance on Mental Illness estimates that 58 million Americans suffer from mental health disorders. The cost is about \$800 for EEG and PEER reports.

The company that has developed this software is CNS Response, which is located in Aliso Viejo, California.

The cost for insurance companies, Medicare and Medicaid, are billions per year. If clinical tests verify effectiveness, PEER Interactive software could reduce doctor visits and hospital stays by getting the correct medications the first time rather than the present trial and error method, which is more costly and may have adverse side effects on the patient. PEER Interactive software shows promise for faster and more effective diagnosis and treatment for mental health consumers in the future.

*\*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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