



# Proxy Parent Foundation newsletter

SPRING 2013

ISSUE 11

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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  
 17602 Seventeenth St., #102-240  
 Tustin, CA 92780  
 714.997.3310  
 toll free 888.574.1258  
[www.proxyparentfoundation.org](http://www.proxyparentfoundation.org)

## Nevertheless...

By Gary M. Chang\*

As we have all noticed, the news has been permeated in the last several years by events that have either the stamp of or the association with mental illness. Even in stories where mental illness does not take center stage or is not mentioned at all, those of us who have family members or friends who are suffering from mental illness read between the lines or the sound bites looking for signs of the underlying symptoms that would explain the actions making the headlines. And all too often, as the pages of the story are turned and the underlying facts revealed, we nod as what we quietly predicted to each other turns to be true. Mental illness has left its scar on the face of the map once again and we wince.

It is so disturbing when mental illness takes the headlines for all the wrong reasons. It's certainly a huge public scar on the public's consciousness in these extreme cases, but there are so many gentler far more common aspects of the mental illness experience that same public is not made aware of. The quieter stories rarely surface. As we all know, while mental illness can certainly be the reason for some spectacularly uncomfortable and emotionally challenging moments – chaotic outbursts, cries and screams and exhortations by both the afflicted and their loved ones toward each other, although there can be lingering psychic wounds, moments of truly irreparable physical destruction and violence in any large scale are very rare, or do not happen at all. Not only do we in the mental health community share tears of pain and anguish from wounds felt upon us or inflicted on others, there really are moments of happiness, laughter, peace and acceptance (at least momentary).

Whether it's having your child who has been isolated and quietly angry for several days suddenly

strike up a conversation, totally in the moment, with a passing insight that comes from some place you weren't sure still existed; or something as simple as looking at an old photo or hearing an old song and spontaneously laughing out loud together at the happy memory. Yes, there's a flip side and so often these pleasures are bittersweet, but let's seize these moments wherever we can find it. Although it's easy to fall into the trap, being bound together by negativity is poisonous.

In dealing with an illness where 1) there is yet no cure, 2) treatment options are difficult to access and when found are generally inadequate, 3) hopes are constantly dashed until the only one left is maintenance, 4) stigma is pervasive and insidious, 5) we are fortunate to know if our loved ones have a roof over their head and where that is, and 6) statistics say that there is a good chance our children with mental illness will not survive us due to the toll of their symptoms and medications – despite all, whenever it's possible we must still try to hang tight to the good times and release the bad.

Enough of this. We cover a lot of ground in this issue - from Board Members, Baron Miller writing on when a special needs trust should take effect (answer being, the same as all legal answers, "it depends"); to Randall Hagar of the California Psychiatric Association, our Sacramento correspondent, with his update on possible changes to health and mental health care in California under the Affordable Care Act (there's no one whose finger is more on the pulse of what's going on in the Capitol); to Joe DeCarlo and his film review of *Silver Linings Playbook* - we have a little something for everyone.

Please enjoy.

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



# When Should a Special Needs Trust Go Into Effect?

By Baron Miller\*



As discussed in articles in previous editions of this newsletter, establishing a special needs trust in an estate plan is mandatory

for virtually everyone who wants to provide future assistance for a disabled person. One of the first questions that often arises when one is ready to establish a special needs trust is whether the trust needs to be made effective immediately, or whether it should become operative only after the death of the person creating it. The answer depends on several factors.

Sometimes parents reach a point where they are no longer able to devote the necessary time and energy to caring for their ill child. They need someone else to step into their shoes and deal with the ups and downs and the often perpetually tragic drama that comes with the responsibility of watching out for someone suffering from a serious mental illness. A solution for them is the immediate creation and funding of a special needs trust which can then be administered by a third party.

Sometimes the parents' need is to accomplish some kind of financial separation from their ill child. Providing ongoing care may be taking up a disproportionate share of

their lives, and it may be creating conflicts with their child which negatively impacts their ability to have meaningful interaction with the child. These parents may find that establishing and funding a special needs trust now and having a third party administer it now can remedy this situation.

Sometimes there are a number of persons who want to make present or after-death gifts to a disabled person, such as different sets of parents and grandparents and siblings. Establishing a special needs trust now enables each potential gift-giving person to make their gifts without each of them needing to create a separate special needs trust in their own estate planning documents, i.e. instead of drafting a new special needs trust in their own estate plan, they can instead make a gift to an already existing special needs trust.

Another instance where the immediate creation of a special needs trust might be necessary or even required is where a disabled person receives a windfall such as an individual inheritance (where a gift is not to a special needs trust), or obtains a recovery in a legal claim. If the disabled person is receiving public assistance, then the windfall will likely disqualify him or her from the public assistance benefits unless the newly received funds are transferred to a (particular kind of) special needs trust.

Most of the time it will be sufficient for one who wants to make a gift to a disabled person to draft a special needs trust inside a will or living trust and provide for the establishment of this special needs trust only after death. (The options available to

accomplish this will be the subject of an article in the next newsletter.)

Occasionally, however, as outlined above, it is absolutely necessary to establish a special needs trust that is effective right now, and not one that is effective only after someone's future death. The decision of when to make the trust effective must be made by the person(s) who wants to make a gift to a disabled person, usually after consultation with their attorney who can more fully explain their choices. It is an important decision with serious consequences.

*\*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 is available for telephone consultations and will not charge for consultations concerning the propriety of making payments for the benefit of an SSI recipient. He can be reached at 415.522.0500 ext. 03.*

## Capitol Insight

By Randall Hagar\*



Vast changes are directly ahead in the delivery of health and mental health care in California due to the Affordable Care Act.

In California, the health benefit insurance exchange (called Covered California) which



acts as a marketplace to offer access to health benefits to those who work in small businesses that don't offer insurance or whose income is low enough that they cannot pay for individual health insurance policies is now certifying health plans to offer their products. Enrollment will begin in October 2013 and the benefits will be in use January 1, 2014.

Part of the process in the exchange will be the offering of expanded Medi-Cal benefits to hitherto ineligible persons i.e. single adults, as well as those who make some income but more than Medi-cal usually allows i.e. incomes up to 138% of the federal poverty level.

Those individuals who have incomes between 138% and 400% of the FPL will be eligible for subsidies of their premiums. Tax credits will be available to small employers who offer health insurance to their employees as well.

There are requirements to integrate the treatment of health, mental health and substance use conditions – which are very important because all of these services are often critical and much needed by persons with severe mental illness and their delivery in an integrated fashion is much more effective at reducing a number of bad outcomes.

Benefits in the exchange must include a robust mix of mental health and substance use services that comply with federal mental health parity rules. This means that a full array of services, and a full array of medications must be available for mental health and substance use treatment. The federal parity law states that mental health and substance services may also not be limited in a way that is more limited than for health services. This

provision is necessary to remedy historical discrimination by insurers and health service plans in the offering of health benefits to enrollees who need those kinds of services.

To find out more about Covered California there is more information at: <http://www.coveredca.com/>.

*\*Randall Hagar is the Director of Government Affairs at California Psychiatric Association (CPA). Mr. Hagar is immediate past president of California Coalition for Mental Health, is a Board Member of the California Public Protection and Physician Health, Inc., the Roy W. Smith Foundation, and Proxy Parent Foundation.*

## MOVIE REVIEW

By Joseph DeCarlo\*

This month we will be deviating from a book to a movie due to the timing of its release. The



*Silver Linings Playbook* movie is based on a 2008 novel by Matthew Quick. It involves a period in the life and

struggles of a bipolar man, played by Bradley Cooper, who was recently released from a mental facility into the care of his parents (played by Robert DeNiro & Jacki Weaver). The movie deals with Cooper's outbursts and radical behavior when he doesn't take his medication. He goes into the reasons he doesn't like to take his medication so there's a better understanding why something that

seems so simple is a major problem that most outsiders don't understand.

He meets a bipolar widow (played by Jennifer Lawrence) who talks him into a dance contest. For football fans, especially of the Philadelphia Eagles, fans of tailgating parties, this movie hits home. For those of us who have loved ones, including the screenwriter and director David Russell, who has a bipolar son, this is an excellent presentation of how personal relationships are affected and the problems a family faces and their attempts to cope and adjust. With all the negative publicity on shootings involving mentally ill people, this is a positive story and shows why treatment is so important and necessary.

This is an emotional, troubling, funny and romantic movie that is a good learning tool for families to view together and discuss afterwards. When you leave the movie theater, you will feel happy even though this is a serious movie that offers help and encouragement for those trying to cope with loved ones who are struggling with mental illness. I give it 5 stars out of 5 for outstanding acting and this movie was nominated for 8 Academy Awards.

*\*Joseph DeCarlo is the father of an adult 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](mailto:joe@jdproperty.com).*

Proxy Parent Foundation  
17602 Seventeenth Street, #102-240  
Tustin, CA 92780

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*a dba of Planned Lifetime Assistance Network of California*

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