



# Proxy Parent Foundation newsletter

FALL 2012

ISSUE 10

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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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## Moving Forward

By Gary M. Chang\*

By now, the outcome of the presidential election has been determined. At this point, no matter how it may please or pain us one way or the other, the winner is not important. What is important is that we all take a deep collective breath and move forward and continue to advocate for the rights and benefits of the mentally disabled either for ourselves, our family members, or both.

Whether it is fighting to see that the small steps in the right direction that have been made in the last few years are not eroded, such as the Mental Health Parity bill, which forces insurance companies to give mental illness the same weight and coverage as any other illness; or the baby steps of progress made in fighting the ever ongoing battle to de-stigmatize mental illness, let's all unite and find our own way to express our feelings, presence and be heard.

At one time or another we have all felt and expressed the feeling and conviction that no one understands the condition of mental illness, whether it's the person afflicted or the family, unless forced to live it. It's as if there is some invisible wall separating us from the rest of society. But in order to tear down that wall, bit by bit, it could be as simple (or difficult) a thing as talking honestly and unashamedly to friends and family, writing a letter to our local congressperson and/or newspaper or working with and in support of an organization like NAMI, but every little and large contribution to the collective effort will help.

Don't leave it to our present leaders to guide us out of the wilderness of mental health care in America, let's try to find a way to take them by the

hand and show them the way. And above all, and in any case, don't count on them. Keep an open mind, learn all you can, and given the realities of the day, try and create a plan for your or your loved one's future.

This issue contains an article by Randall Hagar, a Proxy Parent Foundation Board Member, and Director of Government Affairs for the California Psychiatric Association, on how the Affordable Care Act may affect an individual with mental illness and another article by myself on a commonly asked question about special needs trusts. We also have a book review by Board Member, Joe DeCarlo, of JD Property Management, Inc. that I am sure you will find of interest. Please feel free to write, call, or e-mail us back with any questions or comments these articles may raise.

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

## Legislative Update – Health Care Reform

By Randall Hagar\*

With the coming changes to the health care



delivery system posed by the federal health care reform mandate in the Affordable Care Act (ACA), the question has been raised about whether

any of these changes would affect Proxy Parent Foundation beneficiaries. The answer is that there will be few if any changes for an individual with a mental illness who is receiving public benefits.



Those individuals with disabilities, including a mental illness, who receive Social Security Disability Insurance benefits or Social Security Supplemental Insurance benefits, both cash awards and health insurance coverage in either program will not be affected substantially by federal health reform. This means that the eligibility criteria for these programs will not change because of federal health reform. This also means that the ACA does not change the cash benefits structure, nor does it affect the basic entitlement to health care through Medicaid (called Medi-Cal in California). Medicare coverage should also not change substantially as the ACA is now currently written, with the exception that the so called “donut hole” for Part D Medicare prescription drug coverage will become smaller and out of pocket costs for medications will decrease fairly significantly in 2014 if a beneficiary has been a Part D enrollee.

Finally, there will be improvements in access to general health care brought about by the ACA for people with disabilities because the ACA incentivizes the integration of mental health, substance use, and primary care services into one physical location; or, into medical homes which offer a single point of responsibility for the coordination of all types of general and specialty health care, including substance use and mental health treatment. It will also support the formation of mental health homes that would integrate primary care services into mental health and substance use treatment services. These reforms will increase the quality of health care, and produce better health care outcomes for individuals. As well, a recent study of individuals with severe mental illness found that when these individuals received good quality health

care services it not only improved their health status but also created better mental health outcomes - such as fewer psychiatric hospitalizations, or fewer days in a psychiatric hospital!

*\*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.*

## Do We Really Need a Special Needs Trust?

By Gary M. Chang\*

As you have all been told many times a special needs trust is an essential part of an estate plan for a family leaving an inheritance to a disabled child. Money placed in a special needs trust will not be counted as assets in determining means tested public benefits such as SSI and Medi-Cal so the beneficiary of the special needs trust will be able to keep his SSI and most importantly, Medi-Cal benefits while the money in the special needs trust can be spent for their supplemental needs.

However, as Trustee of over 100 Stand-Alone and Pooled Special Needs Trusts, families often ask us at Proxy Parent Foundation if they really need a special needs trust. What if instead, they leave their disabled child's share of their estate plan to a sibling(s) who is willing and able to spend the funds for the disabled one's care and

needs? Problem solved, rather than going to the trouble, expense and complications of creating a special needs trust, the disabled child's money never goes directly to him or her so, just as with a special needs trust, the money will not be counted as an asset and his SSI and Medi-Cal benefits will not be affected. Theoretically, this could work. Ideally, it keeps the sibling(s) involved both financially and more directly as caregivers. But familial love aside, especially if the sibling has his or her own family, this may be too much to ask. With the rising cost of health care and education for his children, how do the funds stay separate? Let's say the family trust leaves a well-sibling responsible for his disabled sister's financial needs. If he runs into financial problems of his own, his debts could be subject to creditors that would draw no line between what was intended to be “his” and “his sister's”. Then suppose at some point he uses some of his sister's funds to stay afloat hoping to make good later, when times change, but times never do change? And what if he dies before his sister? After his estate plan provides for his wife and children, how much would be left for her? And who would care for her then? With all the vagaries of life, it's an unfair situation in which to put any sibling. Better to create a special needs trust.

Whether you have an attorney draft a stand-alone special needs trust and name a family member, friend, or financial institution as trustee, or create a special needs trust by joining a pooled trust such as our PLAN of California Master Pooled Trust with Proxy Parent Foundation as nonprofit trustee, and have the well-sibling(s) named as Primary Representatives, it's better to be safe than sorry. Except for very rare circumstances,



when the time comes, your disabled child will need his or her inheritance left to a special needs trust. If you have any questions at all about any of the above, please contact us by phone at 714.997.3310 or by e-mail at [info@proxyparentfoundation.org](mailto:info@proxyparentfoundation.org).

## SSI Electronic Payment Deadline

Most of you likely already know, but for those of our readers receiving Social Security or Supplemental Security Income benefits, if you are not already receiving your payments electronically, you must do so by March 1, 2013. If you don't, the U.S. Department of the Treasury may send your benefits via the Direct Express® card program to avoid an interruption in payment.

Don't be alarmed, the official Social Security Administration site says switching is safe, quick and convenient. And if you don't believe that from past experience, just remember you don't have a choice, and think of all the time you'll save not going to the bank to make your deposits once you have completed the process to go electronic. So if you are still receiving benefits by mail, you can obtain a password and start or change to Direct Deposit online. If you don't have access to a computer or an internet connection, you can also sign up at your bank, credit union or savings and loan.

Or, you can call Social Security at 1.800.772.1213 (TTY 1.800.325.0778). For more information and links to various pages that will help you through the process, use the following web address – <http://www.socialsecurity.gov/deposit/> to get started.

## BOOK REVIEW

By Joseph DeCarlo\*

### Father's Day: A Journey into the Mind and Heart of my Extraordinary Son

by Buzz Bissinger



Several people recommended this book to me as it is about a boy, Zach, and his relationship with his father, Buzz, who is also the author. Zach was born a premature baby, 13 weeks early and weighed 1 lb 13 oz. He has a twin brother Gerry, who is now a teacher and both are in their mid twenties. Zach however, has an IQ of 70 and functions at 8 or 9 years old. He is a savant (brain has overdeveloped in one area to offset the damage that has occurred in another area). I have an autistic son who has an IQ of 60 and functions at 6 years old and is now 37 years old.

Buzz took 10 years to accept his son Zach and realized he had to stop searching for miracles. He became tired of looking for answers that would never come and to "accept Zach for what he is". I am not sure that Buzz really accepts Zach for who he is. He didn't want Zach to bag groceries as that was unbecoming and wanted him to work in the mailroom of a law firm which was more becoming and made Buzz feel better. Yet, Zach was happy "bagging groceries".

From my perspective, the real focus of this book is how "the dysfunctional perfectionist" negative narcissist deals with a constant fear of failure. Buzz has had two divorces, broken engagements, and his current

wife is living overseas much of the time. Meanwhile, Zach seems to have adjusted like my son Joey, he is happy in his environment. Buzz however, is forever running from the moment he first saw Zach through the window at the hospital as a bloody quiver in the doctor's hands. When Buzz said to his current wife Lisa, in front of Zach, "all I do now is write shit", she told him "what really bothers me, is you suck the joy out of everything and then you die, and what's the point?"

The book was about Buzz traveling cross-country from Philadelphia to Los Angeles by car with his son, Zach. He used a tape recorder to keep a log. This trip was supposed to be a bonding experience between a father and his developmentally challenged son. Buzz is a classic example of what NOT TO DO, instead of helping a child adapt and grow into whatever he can accomplish and be happy, adjusted and adapted to their surroundings. Zach seems to have adapted very nicely however. I believe that Buzz needs to seek professional help so he can accept Zach as he is and not what he wants Zach to become. Buzz reveals all of these problems and that he is bi-polar and instead of this book being about how to deal with developmental problems, it turned out to be about how not to deal with these problems.

This reviewer felt sad that Buzz would not bring himself to admit that he is the problem, and not his son.

The past is history, the present is now and the future is tomorrow... so concentrate on the present and future.

*\*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).*

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*a dba of Planned Lifetime Assistance Network of California*

### Enclosed is my Tax-deductible donation of

\$ \_\_\_\_\_

- Please use this donation to provide Proxy Parent Foundation's help to those who need it in the "here and now".
- Please use this donation as our Proxy Parent Foundation enrollment donation. (Enrollment donations must be \$1000 or more and can be made in payments.)

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