

Proxy Parent Foundation newsletter

SPRING 2018 ISSUE 18

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PROXY PARENT FOUNDATION

Proxy Parent Foundation offers two services.

We are Trustee of 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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Welcome

CONGRATULATIONS TO BOARD MEMBER

MARV SOUTHARD on being awarded NAMI California's 2018 Lifetime Achievement Award. As most of you know, Marv is former director of the Los Angeles County Department of Mental Health which is the largest public mental health system in the country and has been a longstanding Board Member of Proxy Parent Foundation for many years. The award is being presented to Marv at this year's NAMI California Conference in Monterey on June 1-2. Proxy Parent Foundation will be presenting a workshop there and we encourage any readers to attend both our workshop and to applaud Marv and his years of dedicated service to the mentally disabled community in our state.

As for this issue itself, I'm pleased to say that we've got several more informative articles for you. It begins with another very fine and concise article from Board Member, Baron Miller, with advice and suggestions on how to navigate the often murky waters when seeking safe harbor in supplementing the needs of a family member receiving SSI while attempting to follow the complex regulations of the Social Security Administration.

Baron's article is followed by a recounting by Bruce of the very special relationship he was able to establish and maintain over the years while providing personal support to, "Tolly" (name changed), one of our oldest and most endearing beneficiaries, even after he had passed on. As you will see, it was a relationship as important to Bruce as it was to "Tolly".

After Bruce's piece, we have the book review column by Joe DeCarlo, our Board President. This time he reviews a book studying brain and neurological disorders and their treatment.

To close we have some updates from Kimberly (who many of you have spoken to by now) introducing our new website, and also telling you what we've been up to and where we'll be appearing in both Northern and Southern California in the next several weeks. I encourage you to try and meet Bruce, Kimberly, and me at either of those upcoming events. You'll find further details on the website, or you can always contact Kimberly by phone or email. Also, please give us

any comments or suggestions on the new website, so it can continue to evolve and improve.

I am sure you will enjoy. As always, we welcome your thoughts and your loyalty as readers and friends.

GARY M. CHANG
Director of Legal Affairs

How to Supplement SSI

By Baron Miller*



I am asked frequently by parents how they can best give financial aid to a disabled child without it adversely affecting the child's SSI benefits. There is no single answer or formula, as good ways to supplement SSI are dependent on numerous factors such as the recipient's needs, the parents' ability, contributions from others, and even the parents' income tax bracket.

But there are some fundamentals that apply to all. The predominant purpose of SSI is to provide funds for food and shelter. There is an asset limitation – to qualify for SSI one cannot personally own liquid assets of more than \$2,000 - and there are income limitations too which if not met will reduce the amount of SSI each month and if income is high enough will terminate eligibility altogether. The evident idea behind this is that the more income one has to use for food and housing, the less SSI she will need to pay for food and housing.

Of course, even the maximum amount of SSI benefits can be insufficient to enable a recipient to actually buy food and housing and the other things she needs to survive physically and emotionally, unless some kind of expense pooling takes place (e.g. roommates) or someone else supplements the SSI. That the amount of SSI is often inadequate for its purpose is not the subject of this article. Instead, the focus here is on how to most effectively do what we need and want to do, which is supplement SSI.

Payments parents make for housing and food will reduce SSI, while literally everything else that a parent might pay for will not reduce SSI, so parents



likely want to spend the bulk of their financial assistance on expenses other than housing and food. Rent, mortgage, and real estate tax payments all constitute housing costs, as do utilities for the home – gas, electricity, water, garbage. Food is food, although sometimes a restaurant or group meal could be deemed an entertainment expense, which will not affect SSI. Cash is always a no-no; if an SSI recipient is given cash to pay for things every dollar given over \$20/month is going to reduce and eventually terminate her SSI benefits; our payments need to be made directly to providers of goods or services.

Despite our best efforts to spend elsewhere, there is a good chance that housing costs will still need to be subsidized by us. When parents pay for rent or a portion of rent the resulting reduction of the SSI stipend is limited to a percentage of SSI which would otherwise be paid, with the maximum reduction being approximately \$280/month. If this means the difference between substandard housing and comfortable, safe, healthy housing, then paying for rent or a portion of rent is obviously a good way to supplement SSI.

Sometimes an SSI recipient will be living with parents in their home which they either own or rent, possibly paying nothing for the privilege, or paying a specific amount for rent out of her SSI stipend, or paying for her actual fractional share of housing and food expenses out of her SSI stipend. How best to structure this situation can be challenging.

If rent is not charged, or if it is deemed less than reasonable in amount, then it will reduce SSI benefits, again by a maximum of approximately \$280/month. If rent is charged, and if it is deemed reasonable rent by Social Security, it will maximize the amount of the SSI stipend. However, the rent collected will also be income taxable to the parents collecting it.

Often the best way to handle a situation where an SSI recipient is residing with her parents in a rented home is to not charge her rent and instead have her pay for her fractional share of food and rent and other household expenses. Structured this way, the payments from the SSI recipient to her parents likely will not be deemed income to the parents as the arrangement would not provide a direct profit

to the parents, and Social Security should factor the payments into its calculations to determine the amount of the SSI stipend.

If the parents own their home, then they can't charge for a fractional share of rent, and if they were to charge for a fractional share of mortgage/tax/insurance expense it would likely be taxable income unless the child were receiving an ownership interest in the home. If the parents do charge rent it will convert their home into a business, which enables them to depreciate the home and deduct other expenses on their income tax return. This would be helpful, but likely there would still be tax to pay.

Parents and others who are supplementing SSI need to be careful so as not to reduce or terminate SSI when that can be avoided, and they also need to be careful not to create what the IRS calls a taxable event which will result in an income tax burden for them. And everyone needs to be consistent; payments cannot be called something such as rent for one purpose and something else such as a share of expenses for another purpose. When in doubt, get advice for the specific situation.

**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.*

Tolly's Business Card

By Bruce Lewitt*



Tolly was a long time beneficiary of a Special Needs Trust with Proxy Parent Foundation.

When he passed away, I reached out to contact Tolly's surviving relatives named in our trust

documents. Unfortunately, the family had distanced themselves from Tolly a number of years before, so it took some doing. I managed to track down his niece. She traveled to Los Angeles to participate in scattering Tolly's ashes. I showed her his business card, and she showed me some family pictures of him taken during from her childhood when Tolly had been once a surprisingly vibrant young man.

More than twenty years ago, when his mom was still living, I started to work with Tolly as a Pay-As-You-Go beneficiary. My first call of every day since that time was from Tolly. He'd sing the Kellogg's cereal song, "The Best To You Each Morning!" Or he'd say "Bonjour, comment ça va?" Over the course of the day he peppered our calls with French words perhaps because it reminded him of the time when he and his father collaborated in creating English subtitles for French films. Sometimes he'd speak in French, or some Italian or Russian phrase he'd learned from watching any of the multiple premium cable channels paid for by his Special Needs Trust.

In addition to the psychiatric symptoms of his mental illness, Tolly had multiple digestive health issues. He'd had most of his esophagus removed and a number of other surgeries, that Tolly and I handled through the public system. He always had to have a private room in his Board and Care because he needed an unusually high level of support. He chain-smoked cigarettes, which didn't help, medically speaking. One time when I visited him in the hospital, I asked what I could bring. I expected him to say "cigarettes", but he said, "Pastèque, I mean, watermelon...", he translated. The slices I brought from Ralphs that day might as well have been champagne and caviar because this was a gesture he never forgot.

He loved to paint, so his Special Needs Trust purchased an easel and kept Tolly in art supplies. He'd gotten his art appreciation from his mother, who'd been an art dealer. He liked to go to the library and read science journals or medical books and introduce himself around, giving out his card. He also had musical talent, so Proxy Parent Foundation purchased a saxophone. I arranged with a friend for a violin to be donated for Tolly's



use, as well as music lessons, something he very much enjoyed. He also loved to stroll around the UCLA campus from where he was a proud alumni with a degree in French. He always carried his translation business card as a way to introduce himself, and never stopped trying to drum up some business.

A few years ago, when I was spending my honeymoon in France, Tolly made a point to remind me to take his business card with me. During the trip, I used Google Voice to call him, to continue our daily check-ins as usual. "Let me know if you need anything translated", he offered, then added "and let them know I'm still here." I instantly knew what he meant, because it was on a trip to France while in college many decades ago that Tolly was hospitalized with what was perhaps his first break into mental illness. His father immediately got on a plane and brought Tolly home for what was to become a lifetime of treatment for paranoid schizophrenia.

Proxy Parent Foundation fulfilled its promise to Tolly's parents when they set up the Special Needs Trust with us so many years ago. We answered the question, "Who will care when we're not there?" Personal Support Services provided through a Special Needs Trust are our primary commitment to individuals with severe and chronic mental illness. We not only navigate the public system, but the true challenges of daily life, and relieve feelings of intense isolation. In all his interactions with me, Tolly carried a professional identity in the form of a business card that helped him get out of bed in the morning and step livelier through the day than would have been possible otherwise.



**Bruce Lewitt is Proxy Parent Foundation's Director of Social Services and has acted as a Personal Support Specialist for active PLAN*

beneficiaries (as well as Pay-As-You-Go) since the mid 90s. Bruce has over 25 years experience managing mental health programs and advising seriously mentally ill clients and their families.

Book Review

*By Joseph DeCarlo**

Treating the BRAIN: What the Best Doctors Know

By Dr. Walter G. Bradley



Dr. Bradley was one of the World's leading neurologists and Chairman Emeritus at the University of

Miami's Department of Neurology. He starts the book with basic brain anatomy and discusses various neurologic conditions such as strokes, epilepsy, head injury, Alzheimer's, Parkinson's and cancer. The book covers the complexities of dealing with nerve disorders and how the nervous system works. Case studies and examples of how neurologists and scientists approach treating various nervous system disorders, which is very helpful to understand. The brain is an important organ that determines how the body functions under normal and abnormal conditions and what happens when there is a malfunction. Dr. Bradley defines each disorder, describes the diagnosis, clinical features and treatment options. He uses illustrative cases to convey the complexities of the brain. The book examines the brain in layman's language covering medical and everyday aspects of neurological problems. It is an easy and informative book to read.

**Joseph DeCarlo is the father of a 43-year-old autistic son "Joey" who also suffers from epilepsy. Joey lives at home with his parents and attends Project Independence, a Regional Center of Orange County funded program. Mr. DeCarlo is President of Proxy Parent Foundation and can be reached at joe@jdproperty.com*

Announcements and Events

by Kimberly A. Alsabery, Communications & Client Relations Officer



Proxy Parent Foundation is proud to announce the launch of our refreshed website. The refreshed website is easier to navigate and highlights upcoming events, relevant

articles, programs, and makes it easier to get or stay in touch. Please visit our website at www.proxyparentfoundation.org to see the new layout. Featured on our website is the Amazon Smile program. Proxy Parent Foundation will receive a portion of all purchases made on www.smile.amazon.com and designated to "Planned Lifetime Assistance Network of California." A direct link can be found on our website.



Proxy Parent Foundation has been very active. The Los Angeles Abilities Expo in February and the Parent Caregiver Conference in March are among the events in which we have participated. Proxy Parent Foundation will have a booth and will be hosting a workshop at the NAMI California Conference 2018 in Monterey June 1-2. The following weekend, June 9-10 you can find Proxy Parent Foundation supporting the Southern California Special Olympics Summer Games (on whose Board, our own Board Member, Tom Stevens, also serves) in Long Beach where we will be in the Family Village. We hope to see or hear from you soon!



Pictured left to right are Kimberly Alsabery, Bruce Lewitt, and Gary Chang at the 2018 Los Angeles Abilities Expo.

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ADDRESS CORRECTION REQUESTED



Please let us know if you would prefer
receiving our newsletter by email. Thank you.
info@proxyparentfoundation.org

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I wish to help support Proxy Parent Foundation

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".
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