

Proxy Parent Foundation newsletter

FALL 2018

ISSUE 19

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Book Review
*The Curious Incident of the
Dog in the Night-Time*

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

WELCOME FRIENDS AND READERS – It is with great pleasure that I introduce this Fall 2018 newsletter. Not only is there a book review by our Board President, Joe DeCarlo, of the intriguing best seller, *The Curious Incident of the Dog in the Night-Time*, a mystery novel whose protagonist is a 15 year old boy with Asperger's Syndrome, but there are also two very personal and deeply felt articles that will touch and inform all of us who have family or friends afflicted by seriously debilitating mental illness who are unable to help themselves. The first is by Board Member, Baron Miller, on the importance of obtaining financial powers of attorney and medical directives while your disabled loved one has capacity. The second is by Nancy Nigrosh, wife of our Director of Social Services, Bruce Lewitt, with her touching and enlightening story of Bruce and his long history with, and deep commitment to, one of our longest served trust beneficiaries. It is a testament to the resilience and perseverance of both that beneficiary and Bruce. The commitment and bond as described in their story exemplifies Proxy Parent Foundation's core mission.

GARY M. CHANG
Director of Legal Affairs

Get Empowered

*By Baron Miller**



My daughter suffers from schizophrenia, and about 20 years ago when she was considerably more functional than now she was helping out in my office a few days a month. Her condition is unstable, but with some attentive supervision at that time she was able to accomplish tasks, which helped everyone else, lightening our loads.

One day as she was filing a financial power

of attorney and a medical directive she asked me what they were. I explained that they give another person the authority to make financial and medical decisions if the person signing them becomes incapacitated. She seemed impressed by this, and I asked her if she wanted them for herself, making me her legal agent. She did.

She had minimal assets and no need for financial decision-making, and surely no medical practitioner would allow me to contradict her choices simply because she had made me her agent. But both of us knew the future was uncertain, and so she executed the documents and I became her legally authorized agent to make financial and medical decisions. She would need to be in dire straits before my authority would mean anything; regrettably that didn't take long, and I was soon using the powers she gave me. With the financial power Social Security accepted my signature on a required document my daughter wouldn't sign because she was too impaired to understand it. Then, the County of Marin certified her birth certificate, and San Mateo High School gave me her transcript, and medical records came from a former psychiatrist, all of which were crucially needed, and all because I showed them my authority to act.

The most significant use of the financial power came a few years ago when Social Security notified me as my daughter's payee that she was disqualified from SSI for having \$200,000 in a bank account. Eventually Social Security told me this information came from a bank's report, but no one at Social Security or the bank was interested in my authority, and they would not give me any information, which might enable me to understand and correct the situation. Have your daughter contact us was the uniform refrain.

I told my daughter her SSI had been cut off and asked for her help. She said she was never on SSI. I told her of the account in her name with \$200,000 in it. She said oh yes that's mine. I named a number of banks for her and asked if she also had accounts at any of them, and she answered yes, her stated balances totaling millions. It was obviously bring-



ing her pleasure to imagine herself wealthy. But she was penurious, and without vital SSI and Medi-Cal the intoxication of her grandiose thought disturbance was self-defeating.

I kept at it until I encountered a real live decent employee at a branch of the bank involved, a recent immigrant who in his words was living the American dream. For him consequences of mental illness did not seem foreign. He explained how the fraudulent scheme worked and said to provide him with the power of attorney and he would then provide me with all needed information.

It was then that I learned the bank report to Social Security neglected to mention that the address of the depositor was not my daughter's, that the account was opened online (something way beyond the ability of my daughter to do) and as it happened on the same day that her purse and wallet had been stolen, that the source of the \$200,000 deposit was a bounced check from another state, and that in the banking world this type of identity theft and attempted fraud is not uncommon. And I received enough documentation to prove this to Social Security, to prove she had no money. It took many months but her SSI was reinstated and back benefits were paid too. The alternative would have been a Probate Conservatorship, an arduous and expensive process.

If we keep at it we will eventually encounter someone sensitive to our needs who will help. So if your loved one is willing to make you her financial and/or medical agent now, whether you need it now or not, get it done. There might be a future day when it will make all the difference.

**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 propri-*

ety of making payments for the benefit of an SSI recipient. He can be reached at 415.522.0500.

Continuity of Care

By Nancy Nigrosh*



Bruce Lewitt, the Director of Social Services for Proxy Parent Foundation, is my husband. This means I have a front row seat to see exactly how he and other Personal

Support Specialists serve the foundation's beneficiaries and their families.

Recently Bruce came home after visiting Fred, a beneficiary who was in the hospital. He told me that he met Fred many years ago when his mom first set up a trust at Proxy Parent Foundation. She was feeling overwhelmed. Fred had gone through a revolving door of Board and Care facilities because he was prone to wander out of each one and end up in the state hospital. The state hospital recently closed, and Fred had returned to the family home to live. His mom needed help with finding a new living situation for her son for him to hopefully become more stable. Fred became a beneficiary under Proxy Parent Foundation's Pay-As-You-Go Program, and Bruce started to work with Fred as his Personal Support Specialist (PSS). Bruce became familiar with Fred's and his mom's particular needs and then paired Fred with another very qualified PSS.

For many years the PSS worked with Fred, but when his mom passed away, Fred wandered off and went missing. The Board and Care filed a missing person's report with the police, but it was the PSS, who scoured the streets for Fred and found him. Keeping Fred stable required constant oversight by his PSS. Like so many beneficiaries, in addition to his severe, chronic schizophrenia, Fred continued to experience multiple medical issues for which he is treated by the public health system. Like so many others

who suffer from schizophrenia, Fred was a heavy smoker, unable to quit. He'd made it through a series of serious lung infections, a hip fracture and survived cancer. These conditions, combined with behavioral problems of his sometimes physically acting out, to the extent of even striking staff and other residents, have caused Fred's psychiatric medications to be changed frequently. This pattern sometimes contributed to new medical issues, or unwanted new side effects. The PSS was there to care for Fred for many years, until the he finally retired. Because of the value that Proxy Parent Foundation places on continuity of care, Bruce stepped back into the role of Fred's PSS just as Fred's health began a serious and steady decline.

There was great urgency because Fred's cancer was spreading, and his Deputy Public Guardian had been reassigned to another department and no replacement had been named. Bruce visited Fred in the hospital frequently. He stayed in a constant dialogue with Fred's medical treatment team. They relied on Bruce to keep Fred's spirits up and to gain Fred's consent for medical procedures. Life-saving cancer surgeries were performed. Fred pulled through after a long, trying recovery. A new Deputy Public Guardian was finally assigned. Bruce pleaded with her to find a quality locked Skilled Nursing Facility that would be able to simultaneously handle Fred's fragile medical and volatile psychiatric needs.

Then Bruce learned that each new team of successive caregivers in the public system had no sense of Fred's history. Bruce discovered that his charts weren't digitized or otherwise shared. The hospital where Fred had his recent cancer surgery had also closed and none of the hospital's records were available to be distributed.

Despite the fact that Fred was conserved, Bruce thought there must be files, but if there were, it appeared they weren't coordinated to follow Fred to facilities he may be treated in or transferred to. When a beneficiary is conserved, Proxy Parent Foundation doesn't



have access to the records. Bruce made several calls and spoke to a number of staff but could only get anecdotal documentation.

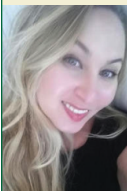
Bruce knew he needed to request whatever records there were from the Public Guardian's Office. He asked if the Public Guardian's office had Fred's mental health and medical records, and if they did, Bruce was requesting access. He learned the Public Guardian doesn't keep medical or psychiatric records, and that there is no central repository for treatment history. All Bruce could do was to continuously update Fred's treatment providers and address needs he knew were important to Fred - access to an outdoor space so he could feel the warmth of the sun, and if that time out included smoking a cigarette on the hospital's scheduled smoke breaks, so be it.

When I'm asked about Bruce's work, I explain that what Bruce and Proxy Parent Foundation's Personal Support Specialists do is no different than what so many mothers and fathers, brothers and sisters, relatives and friends do in caring for their loved ones who are disabled by severe and chronic mental illness. That's why the foundation offers this unique service.

** Nancy Nigrosh is a writing coach and consulting editor. She is a frequent contributor to Indiewire's 'Thompson on Hollywood' blog and serves as a judge, consultant and panelist for multiple writing competitions and conferences. She teaches at UCLA Extension's Writers' Program.*

Recent and Upcoming Events

by Kimberly A. Alsabery, Communications & Client Relations Officer



On September 5th Proxy Parent Foundation had the pleasure of joining NAMI Long Beach at the College Medical Center to speak about trust planning and Personal Support Services.

Proxy Parent Foundation was an exhibitor at the 31st annual CPA (California Psychiatric Association) Conference at the Laguna Cliffs Marriott Hotel, Dana Point on September 21st and 22nd. Board member, Randall Hagar, the CPA's Director of Government Relations spoke on legal and legislative updates in psychiatry. Seminars covered diverse topics such as suicide prevention and psychopharmacology.

Proxy Parent Foundation participated in NAMIWalks Los Angeles County on October 6th to raise awareness for Mental Health.



(Some of the Proxy Parent Foundation Team at NAMI Walks Los Angeles 2017)

Annual Giving Day, November 27th is coming up. We ask that you keep Proxy Parent Foundation in mind. Proxy Parent Foundation is a 501(c)(3) organization, which has provided trust and Personal Support Services to those with disabilities for more than 25 years. Your tax-deductible gifts help to ensure that we continue to provide assistance to our growing beneficiary base. You can make a donation by mail or via our website by visiting www.proxyparentfoundation.org and selecting.

Donate Now

Book Review

*By Joseph DeCarlo**

The Curious Incident of the Dog in the Night-Time

By Mark Haddon



The Curious Incident is a best-selling novel about a 15-year-old boy with Asperger's Syndrome (top of

the Autistic Spectrum) who is also a savant. He sets out to solve the murder of a neighborhood dog. The boy, Christopher, can name every country and their capital and knows every prime number up to 7,057. We learn that he does not like to be touched, will not eat brown or yellow foods and likes to curl up in the corner and groans. He has a memory like a camera and can rewind to scenes with no keys or buttons. We see how this 15-year-old who narrates this book, processes information and thinks differently than normal. We see how his father and mother must adapt and adjust to his nuances, fears and idiotic cries to keep things under control. The motive of the book was not to discuss mental health or emotional disabilities but to create an interesting story. The first third of the book, which is a total of only 211 pages, is slow, but it piques your interest thereafter. This book puts you inside the head of this developmentally challenged boy as he solves the murder of a neighborhood dog. This leads him to discover his mother was not dead and how Christopher has to deal with this and other events that changed his previous world, as he does not like change.

**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*

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\$ _____

- ☐ 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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