Proxy Parent Foundation newsletter

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PROXY PARENT FOUNDATION

As the Trustee of the PLAN of California Master Pooled Trust, we are open to serving any disabled person in California.

We offer Personal Support Services for our beneficiaries with mental illness or other brain disorder who have joined our Master Pooled Trust.

We coordinate public and private social services as well as provide access to healthcare. Working directly with beneficiaries is how we create a family-like atmosphere that maintains a better quality of life for them.

Proxy Parent Foundation is a dba of Planned Lifetime Assistance Network (PLAN) of California, a 501(c)(3) nonprofit corporation.

Proxy Parent Foundation
15243 La Cruz Drive, #889
Pacific Palisades, CA 90272
714.997.3310
www.proxyparentfoundation.org

Message from our Managing Director

Bruce Lewitt



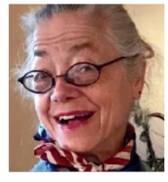
Towards the end of a recent introductory conversation with an estate lawyer and his client, the lawyer asked me, "How do we know funds in your Pooled Trust won't be mismanaged -- or worse?" A frank question deserved a frank answer. I told him day-to-day aspects of the pooled trust are managed by four separate organizations that have no affiliation or mutual ownership. Proxy Parent Foundation is a 501(c)(3) nonprofit and solely serves as the Trustee of the PLAN of California Master Pooled Trust. Each beneficiary has their own personal trust account at Fidelity. Fidelity holds the funds and issues monthly trust account statements. As a privately-owned custodian, Fidelity provides protection guarantees to reimburse for losses from unauthorized activity. CPA firm Binder & Company acts as our Trust Agent to handle administrative duties related to beneficiary distributions, bill pay, and tax prep. Lindbrook Capital, an SEC Registered Investment Advisor, manages the investments of the pooled trust accounts and does so as a fiduciary. Lindbrook makes decisions that always put the best interests of our beneficiary accounts first. The separation of duties being performed on behalf of our Pooled Trust administration results in multiple layers of oversight and is key to avoiding fraudulent or criminal behavior.

In this issue we have three authors who write about how the special needs of disabled individuals are met — or about how the special needs of a disabled individual go unmet. Kristy Williams is one of our Personal Support Specialists. Her article is a tender report for you about her work with three of our beneficiaries.

Proxy Parent Foundation board member, Steve Pitman contributes a story about the lack of personalized oversight for his disabled brother from a blithely unaware bank trustee. We are also fortunate to feature Judge Timothy Taylor's beautifully written review of Jonathan Rosen's recently published book, *The Best Minds, A Story of Friendship, Madness, and the Tragedy of Good Intentions.* Author Rosen intimately shares the many multi-faceted breaks his lifelong disabled friend suffers... none of which were orthopedic.

My Work with Three Beneficiaries

Kristy Williams, PSS



I am a Proxy Parent Foundation Personal Support Specialist. My understanding of the population we work with comes first through my education. I received a B.A. in Recreation Therapy from California State University at Long Beach in 1980, an M.A. in Clinical Psychology from Pepperdine University in 1987, plus earning my MFCC through clinical internships at Metropolitan State Hospital in Norwalk and at a private locked psychiatric facility. Besides those credentials I've gotten to use my athleticism — as an aerobics instructor, yoga teacher and personal trainer, as well as positions as a Recreational Therapist for the YMCA and as an Activities Director in various nursing homes. I also apply my creative skills teaching art, music, dance, and drama. Aside from those educational, life and professional experiences, the secret to my success has always been that I'm super social, task oriented, and have lots of patience.

I met Bruce Lewitt while working as the Activities Director and Social Worker for the Brentwood Manor, a 144-bed Board & Care. We had residents with dementia, and/or a range of



Who will care when I'm not there?

medical issues, and a mixed smorgasbord of mental health issues that presented all kinds of challenges. When Bruce would come visit a Proxy Parent Foundation beneficiary who lived at the Manor, he and I would always compare notes. When Bruce (finally!) went on his honeymoon, I kept an eye on the beneficiary for him. In July 2016 when Brentwood Manor was closing, Bruce recruited me to work with Proxy Parent Foundation beneficiaries. My very first beneficiary was a hoarder, who was secretive, and had a cat. She'd previously been a cat hoarder as well. She lived 28 days at a time, in motels. So, every 28 days I'd pack up her stuff and relocate her and the cat to a different motel. She had a reputation of not being a very good guest which meant many motels wouldn't accept her back. It was a very challenging situation. Today, the beneficiary has a private room at a Room and Board and is on a tight budget that is carefully managed by Proxy Parent Foundation, that also includes a Geriatric Care Manager.

Currently, I have three beneficiaries I've been seeing for a number of years. Each one is unique. One beneficiary and I like to take walks and do yoga, then go shopping at CVS. She's poised and intelligent. And like me, she is into fashion. Sometimes I'll share some of the designs of outfits I've drawn and have her critique them. We're both avid readers. We enjoy sharing ideas about the books we're reading. We also talk about intrusive thoughts. This helps her to keep up a positive routine for her mental health.

Another beneficiary is also a hoarder, but since her mobility is very limited by her excess weight, her stuff mostly consists of magazines and clothes. She dresses nicely but rarely wears the same thing twice because her incontinence spoils most of her clothing. She has lots of odd beliefs, so our conversations are sometimes very out there.

My third beneficiary initially didn't trust me. He constantly questioned my intelligence. He'd try to intimidate me with angry behavior. He'd ask me all kinds of questions about the law, something he's quite knowledgeable about. But I held my own with him since I also have a paralegal certificate. We've been working together for over 5 years, and I really enjoy my work with him. He was once a stand up comedian, so humor is always a part of our time. On the phone or on days we get together, we talk about all kinds of subjects — politics, science, spirituality, music, family, and current events. We also talk about anger management and stress reduction. Lately, we've been studying botany together and take nature walks. To add to the mix, I'll bring my dog with me. He loves dogs and my dog loves him. Though he's also a hoarder of found objects, he uses them to build clever inventions. The housekeeping rules at the motel he lives in year-round are just lenient enough that he's able to abide them. Sometimes I realize, in some respects, I'm a hoarder too since art teachers can never have too many art supplies. Well, I guess the truth is, yes, they can. Namaste.

A Cautionary Tale

Steve Pitman, PPF Board Member and President of NAMI-OC

Many caregivers express concern for the future, yet only half have made plans for their loved one's future care. 8.4 million Americans care for an adult with a serious emotional or mental health issue and 45% of those caregivers are parents caring for adult children. Almost half are living in the same household and 33% have been providing care for 10 or more years, according to "On Pins and Needles: Caregivers of Adults with Mental Illness," a talk that was presented at the NAMI Convention 2016.

I know of families that have bought homes and then staffed them with professional caregivers for their disabled family members. For most of us that is not an option. Some families leave funds in a Special Needs Trust at a bank to pay bills for the disabled family member. The problem is, more often than not, the Bank Manager is not going to be in direct communication with the disabled beneficiary — so how could they know anything? For instance, how could they know if the beneficiary is taking meds or seeing a clinician — or if they're even taking basic care of themselves? How could they know if the beneficiary of the trust has had others move into their housing with them - like my brother did? How could the Bank Manager know the roommate was buying things with the beneficiary's credit? When someone else is paying all the bills, credit ratings get better, and there is no way to turn it off. In one episode my brother bought five cars...two of them from the same salesman on the same day! There's another solution you can consider: Proxy Parent Foundation. One decisive advantage is that Proxy Parent Foundation's Personal Support Specialists are hired to "lay eyes" consistently on your family member. They might socialize, talk, problem solve together, or meet for coffee or a meal but decidedly it's more than just a "hello." These Proxy Parents keep in touch with the Managing Director. The Managing Director shares the Proxy Parents' reports with the Board and adjusts services when necessary. This is an organization started by a group of NAMI parents who were faced with the same situation as yours and mine, who asked themselves, "What happens to my family member when I'm gone?" I speak from informed experience and recommend you put Proxy Parent Foundation on your list of people to speak with about your future Special Needs Trust plans. Like they say, the future will be here before you know it!

A Friendship Through Flames

Review of *The Best Minds*, by Jonathan Rosen (Penguin Press, 2023)

*by Timothy B. Taylor**

As the lapsed Catholic and late storyteller Jimmy Buffett once reminded us, "there's a thin line between Saturday night and Sunday morning." Just so, the border between genius and severe mental illness can be equally narrow, complicated, and indistinct. History holds many examples: Ernest Hemingway. Vincent Van Gogh. Sir Isaac Newton. Sylvia Plath. Brian Wilson. Jonathan Rosen's book tells the story of Michael Laudor, a Jewish kid from suburban New Rochelle on the Long Island Sound whose descent into (and emergence from) profound schizophrenia is the focus of the narrative. It is a compelling story.

The book begins as the tale of a friendship. Think about the dozens or even hundreds of people you have known over the arc of your lifetime. Now consider this with regard to those on the list you consider your closest or longest friendships: do you remember the exact moment you met him or her? That list will be much shorter, perhaps only a handful. The author recalls every aspect of his first encounter with Laudor the summer before fifth grade, and goes on to chronicle their youth together and their friendly rivalries in high school. Both are received into Telluride, a prestigious summer program for rising high school seniors. Both are later admitted to Yale University. Rosen begins noticing changes in his friend as the pair become sophomores, and they drift apart (but never completely). Laudor graduates in only 3 years, and lands a high paying job at a well known business consulting firm with equally high demands. Rosen continues at Yale, then pursues graduate studies in California.

Laudor's psychotic break comes at age 25, soon after Rosen returns to New York, and not long after Laudor successfully applies to Yale Law School. He defers the start of his legal education and spends 8 months in treatment in a locked ward at a psychiatric hospital in New York City. Before his medication is calibrated, he tells his fifth grade friend he is in "prison." He believes his "parents had been replaced by murderous counterfeits." His halfway house counselors tell him he is fit only to become a cashier at Macy's.

What happens next is remarkable. Laudor discloses his diagnosis and delusions to the beloved dean of the Yale Law School, Guido Calabresi (later a Judge on the US Court of Appeals). In response, Calabresi welcomes Laudor into the first year class. With the support of the faculty and many others, he manages to overcome both his frightening hallucinations and the debilitating effects of the anti-psychotic medication he must take just to get through the day. He finishes the course of study, and dubs Yale Law School "the most supportive mental health care facility that exists in America."

The wider world initially proves less accommodating. Although Yale provides a post-graduate fellowship which Laudor uses to expose the shortcomings of the Americans with Disabilities Act when it comes to mental illness, his search for a law professor job doesn't go well. He answers one interviewer "yes, I'm hallucinating right now," and describes a fiery scene worthy of Dante's Inferno. His coping mechanism is equally compelling (and perhaps eerily familiar to anyone who runs several monitors on their computer): he was able to "treat his mind like a giant television set, assigning images to different channels," the screens "arranged in a hierarchy of terror from greatest to least."

The tide appears to turn when Laudor's struggle and seeming conquest becomes the subject of a long profile in the Metro section of the New York Times. Overnight he becomes a role model for those suffering from schizophrenia. A book deal and a movie script soon follow. A director is hired, and a well-known actor is cast for the lead role. But Laudor loses his supportive father and, despite long-standing literary ambition, struggles to write the promised autobiography. His return to full-blown psychosis inexorably leads to a multi-layered tragedy. A later chapter contains observations from Proxy Parent's own Carla Jacobs.

Rosen's writing is exquisitely researched and displays an impressive breadth of knowledge. He exposes (as have several authors reviewed in these pages) the embarrassing shortcomings of mental health treatment in America. Among the culprits: the Kennedy Administration's well-intentioned shift toward deinstitutionalization of the Community Mental Health Act of 1963, and the Reagan Administration's 1981 decision to defund the 1980 Mental Health Systems Act. Blame enough to go around, as any visit to the Skid Row of any major city will confirm.

Without adequate support, Laudor, like Icarus, flew too close to the sun. His story will resonate with readers of this newsletter, and all who care for someone battling the demons of schizophrenia.

**Judge of the California Superior Court, County of San Diego. The views expressed in this, his tenth review for the Proxy Parent Newsletter, are not intended as a commercial endorsement, and are Judge Taylor's opinions alone.*

Proxy Parent Foundation
15243 La Cruz Drive, #889
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