

# Proxy Parent Foundation newsletter

SPRING 2020 ISSUE 22

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## PROXY PARENT FOUNDATION

We are Trustee of the PLAN of California Master Pooled Trust. We are open to any disabled person in California.

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

We coordinate public and private social services and we also provide access to healthcare. Our mandate in working directly with beneficiaries is to maintain a family-like atmosphere that promotes 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.

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## Message from Our Managing Director: Anticipating the Future



*Bruce Lewitt*

As we shelter in place to comply with our governor's executive order, we may

very well find ourselves looking back to all the times over the years we've had to anticipate the question of future care for our family members with special needs. As Proxy Parents, we've had a long experience with how families address this inevitable question since the question itself defines the very mission of our foundation.

A great example of how Proxy Parent Foundation's caring commitment is able to sustain over time, is a family who'd reached out to us a number of times over the years about their son Hank. Hank had once lived briefly in a Board and Care, but it wasn't a positive experience for him, and he'd moved back in with his folks. When Hank's mom passed away, his father's health began to deteriorate, and Hank's siblings assisted their father to put together the paperwork for a Special Needs Trust for their brother's benefit. Even though knowing that the only home Hank had ever known would have to be sold at some point, his father was very reluctant to impose any significant changes on Hank. Yet, his father realized it was time to prepare the whole family for the future. He signed the Joinder Agreement for Third Party Trusts with Personal Support Services Agreement, and also signed up for our

Pay-As-You-Go program for one of our Personal Support Specialists to start to work with Hank before such time as the trust was funded.

Once Hank and our Personal Support Specialist (PSS) met, they developed a very positive rapport. With Hank's particular needs in mind, the PSS began to look for a Board and Care arrangement. Together Hank and his father were able to acclimate toward accepting the reality of an impending move for Hank. They were now able to understand that this transition was in both their best interests.

The PSS introduced Hank to a promising Board and Care location. They visited the facility together a number of times, and surprisingly, Hank felt very comfortable with the prospect of having greater independence in this new arrangement and decided to move in. Even more surprisingly, Hank expressed how much he enjoyed his new housing, since it suited his needs in so many ways. His whole family paid frequent visits to Hank's new living situation, while Hank's father was finally able to move into an Assisted Living facility.

Shortly after the house was sold, Hank's father passed away. With the support of his siblings and the PSS, Hank was able to handle the loss as a part of a caring community at the Board and Care. The proceeds from the sale of the house not only funded Hank's Special Needs Trust, but also served to fund the father's estate plan for the whole family. Under the current COVID-19 stay at home orders, Hank and his PSS stay in touch through phone call check ins. This is a challenging time for everyone, but we will always maintain our caring support for our beneficiaries and stick to our mission. We will get through this together.



# Who will care when I'm not there?

## Found

By Carla Jacobs, PPF Board Member



Frankie at age 10

Vancouver's skid row is actually a beautiful place. Like many of the skid rows in the United States, it's gentrifying and transitioning into art districts and lofts. It always mingled with the tourist district close by on the port and has some of the most beautiful historic buildings in all of Canada. At night on its sidewalks, stories are woven as lost people find a place to live and die.

I didn't see my brother Frankie much after our hippie days were over. I moved to Southern California, married, had a baby and got a job. I only took quick trips back to Santa Rosa, usually for a celebration or a funeral. Frank became a wanderer, a traveling storyteller, who in-between journeys lived with our mother.

I'm sure my mom knew Frank had mental illness. My paternal grandmother had schizophrenia and mom cared for her in her older years. But like so many families then we didn't talk about it. Of my grandmother,

she only said, "She was jolly but different." Of mental illness, I knew nothing.

In 1986, Mom died unexpectedly. Frankie was wandering. I couldn't track him down until after she was buried, and her small rural property was sold. Frank didn't want me to wire him his money; he said he would come get it personally. When I picked him up at the airport, he said, "Quick, duck into the elevator. The CIA is following us." No one was there. As he pulled me through the closing of the door, I realized this was not a spoof. Frankie really believed he was being tailed. At the bank he regaled the manager with fantastical stories of his escapades during the Brazilian banking crisis while simultaneously stuffing \$25,000 cash into his pockets and crocodile boots.

*In 1993, OBRA overhauled a Medicaid law and authorized relatives and courts to place inheritances and settlements into a special needs trust to protect their benefits and cover their supplemental needs. Proxy Parent Foundation was formed to provide the added benefit of providing experienced personal support specialists to work directly with its beneficiaries with mental illness. In 1986, however, Mom only had me to answer her question "Who will care when I'm not there?"*

I received a few collect calls from Frankie after that and an occasional letter postmarked here or there. One included a hand-drawn map to a treasure he said he had buried should I ever need it. Then,

he called from Winnipeg, Manitoba. He said he had a lead on a good dump truck in Kitchener, Ontario. Would I lend him enough to get there? No calls came in for a couple of years. Then the silence was broken with a call from a private detective in Pennsylvania. A dump truck really was involved in Frank's story but not the one in Kitchener, Ont. He had been hit by one several years previously when he was in that state. The insurance company wanted to settle but Frank couldn't be found. I went to court and got an order to settle on his behalf. A few years later, when Frank made contact again, I sent him his money.

*In 2006, Proxy Parent Foundation formed the PLAN (Planned Lifetime Assistance Network) of California Master Pooled Trust. It can accept settlements and windfalls. Had it been available for the dump truck settlement when Frank got his settlement, its knowledgeable and professional management would have disbursed it for his special needs.*

His calls became fewer and fewer. I searched through the silence. This past year I located him. His cremated remains laid in Vancouver pauper's field, one of many who had died on the streets, unclaimed. I put a plaque on his grave. It says, "Frank Henry Rowlin, 1945-2008, Found".



# Proxy Parent Foundation

## BOOK REVIEW:

## A Guide for Those Who Serve

By Judge Timothy B. Taylor\*

Review of *Laws We Need to Know*, by Baron Miller (published through IngramSpark and will be available on Baron Miller's website: <https://www.baronmillerlaw.com>.)

Some book reviews reveal as much about the reviewer as they do about the book being reviewed. This is not necessarily thunder-stealing or conceit. Sometimes it's because of the impact of the work on the reviewer, or the personal connection the reviewer felt with the author's efforts. Such a book is Baron Miller's forthcoming *Laws We Need to Know*.

Mr. Miller, a long time Proxy Parent Foundation board member, has subtitled his work "Understanding Laws and Programs for Persons with Mental Illness." The Foreword makes the author's aims clear: Provide family members and other supporters "a resource which explains pertinent laws and legal procedures, and which is available at their fingertips." Miller more than delivers, in concise and clear prose which is well organized and aided greatly by a detailed table of contents.

After a chapter devoted to the tensions between our traditional notions of liberty and privacy on the one hand and the sometimes frustrating need of the person trying to support the consumer of mental health services to get and give information on the other, Miller launches into chapters dealing with hospitalization and the criminal justice system. In the latter, he took me back to

my days 15 years ago as a brand new judge, arraigning misdemeanor defendants and taking plea-bargained dispositions. As Miller astutely observes, then and now, many in the defendant pool would be better served with treatment options rather than fines and incarceration. And Miller yearns for the day when leaders have the courage to fund programs providing those options.

Miller's treatment of government programs and estate planning led me to think about my own struggles with my son John, about whom I wrote in this column last year. The same is true of a later chapter on obtaining a probate conservatorship. The conservatorship process was foreign to me even as a judge, and although I did have the good sense to retain counsel to lead me through it, I probably would have asked better questions and had a clearer overall picture of what to expect if I had been the beneficiary of Miller's guidance.

Subsequent efforts to obtain SSI for John fell prey to the same lack of experience (plus bureaucratic resistance by nameless, faceless representatives of the agency supposed to help). I found myself nodding my head when Miller suggested the retention of counsel for this task as well. Ultimately this was done, and John now receives what he was entitled to all along. And the trifecta was achieved when the same counsel was able to assist with a revision of an estate plan which incorporates a special needs trust. I rest easier knowing this is in place for John, and Miller emphasizes the attributes of this peace of mind.

Miller's chapter on LPS conservatorships also struck a responsive chord. Several years ago I had the duty to preside over a very interesting jury trial in such a case. Although Miller correctly notes the decision to undertake such a trial is expensive, time-consuming and otherwise fraught, the jury

in this case did not find the question presented difficult based on the evidence. After a two day trial, the jury was out less than an hour, returning a 12-0 verdict.

Miller ends the book with a section on strategies for dealing with the often frustrating need to discuss the disabled person's affairs with doctors and other authorities. This reminded me of a "shoe on the other foot" anecdote, humorous only in retrospect. In those days (and perhaps still), SSI eligibility required a doctor's note confirming disability. Although John has been the way he is since birth, and is entirely non-verbal, and all the paperwork reflected this, there were no exceptions to the regulations. So I dutifully took him to the appointment with the physician contracted to the government. They called him in, and I sent him back. About 5 minutes later, the doctor came out to the waiting area and said, "I can't get him to answer my questions." Welcome to my world, doc! I asked her for a piece of paper and wrote on it "I owe Doctor Smith \$100,000.00." I handed it to her and told her to hand it to John and have him sign it. She did, and he laboriously applied his childish scrawl. Needless to say, we got the certificate of disability.

As the foregoing makes clear, I only wish I had the benefit of Miller's book when John was on the cusp of adulthood, instead of now when he is 31. Baron Miller has been serving others since his distinguished legal career began when this reviewer was still in high school. With this volume, his legacy of service is sure to continue for many years to come.

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

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