



Proxy Parent Foundation newsletter

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INSIDE THIS ISSUE

- 1 Message from Our Managing Director, *Bruce Lewitt*
- 1 How One Small Step Became a Giant Step *Nancy Nigrosb*
- 2 “Q and A” Time *Baron Miller, Esq.*
- 3 Book Review *Our Family’s Struggle* *Judge Timothy B. Taylor*

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

Bruce Lewitt



Our Foundation was created by families like you. They were familiar with the same challenges you have in dodging the threat of homelessness, in securing safe,

affordable housing, in navigating mental health bureaucracies, and in dealing with judicial inaction at the very moment when timely action could productively interrupt revolving door hospitalizations and give treatment a chance. Proxy Parent Foundation understands your dedication and perseverance. Our mission is to step in when you no longer can.

What impresses me most about the stories in this issue is the grit and determination shown by families who face the complex mechanics of orchestrating public and private care for a loved one who is disabled.

Attorney and Proxy Parent Foundation Board Member Baron Miller’s article portrays a family in crisis when their daughter is brought to the ER by police responding to her psychotic episode.

Judge Taylor’s review of Robert Kolker’s book, *Hidden Valley Road*, describes the lifelong impact on a family when six of their ten children are diagnosed with schizophrenia.

Nancy Nigrosb’s article spotlights how an elderly parent solves the problem of housing for her son with severe mental illness. It turns out she didn’t have to look far for an answer.

How One Small Step Became a Giant Step

*By Nancy Nigrosb**

Through my husband Bruce Lewitt, Proxy Parent Foundation’s Managing Director, I became aware of the kinds of everyday issues PPF’s families face in the challenge to keep their loved ones who are disabled, out of harm’s way. Treatment is, of course, the brass ring, but another critical need is how to solve the problem to find, safe, affordable housing.

My friend Janet (not her real name) told me how her family was confronted with this same situation. “My brother Phil (not his real name) moved only once in his life – and it was only just across the street”. I’d met her unforgettable brother years before. When we shook hands, he nodded and smiled as though he just heard a joke in his mind even though we hadn’t said a word yet. He was unkempt and unshaven, and I suspected he might be wearing pajamas under his coat and scarf. He was sweet and funny, and made us laugh. But I could sense his frustration, sadness, and loss.

He’d been living with his mother all his life until she became too elderly to cope with his heavy tobacco use, junk food diet and recreational drug use. “You need to move out,” she told him. But where was he to go? He was brimming with classic negative symptoms of schizophrenia. Nevertheless, he was sometimes able to perform at a local comedy club. He was used to staying up at all hours, loudly composing songs and comedy routines. But, the time had finally come for Phil to give his mother a little peace and quiet.

Very motivated, Janet’s mom was not only able to find a place nearby for Phil, but one that was directly across the street. She could actually see him out in front on the sidewalk in front of his place, sometimes panhandling, and wave. He made quite an impression on passersby, in his old bathrobe and beret.



Who will care when I'm not there?



Within a few months, his mom died peacefully. Phil passed away about a year later. At his memorial, Janet was stunned by the tribute from the comedy club community Phil had been part of, that had accepted and embraced all his challenging behaviors. I thought about that one time I'd met him. To sum up what it was like to be around Phil, I'd say he had an uncanny ability to take any space he was in, and turn it into his living room. His great gift was, how much he was able to make *you* feel at home.

**Nancy Nigrosb is a Performance Coach for Writers, a Consulting Editor and Instructor at UCLA Extension's Writers' Program.*

"Q and A" Time

Proxy Parent Foundation Board member and attorney Baron Miller has agreed to share answers to questions he receives concerning laws affecting those with mental illness. Readers are encouraged to submit their questions. This is the first of them.

I have a client ("Bill") for whom I have much respect due to the decency and attentiveness he displays toward his adult daughter ("Irene") who suffers from schizophrenia. A few years ago Irene was picked up by the police at a time she had gone off of her meds, as she is prone to do. One of the officers told Bill she was expressing delusional ideas and was not responding to the officers' attempts to engage her.

Recognizing her psychotic state, they took Irene to the county hospital Emergency Department where mental health services are provided.

Irene was placed on a 72 hour hold by the psychiatrist on duty, and after a hearing a couple of days later the hold was extended for a period of up to 14 more days. Bill was pleased, hopeful she would receive the care she needed.

With the assistance of a patient's rights advocate Irene then petitioned the court for release and another hearing was set. Confirming her still delusional state, Irene called Bill and urged him to attend the hearing so he could tell the judge she should be released.

At the hearing, a psychiatrist from the unit treating Irene testified she was responding well to the meds she was getting there, and that with the assistance of the woman who shares the apartment Bill provides for her – a woman who suffers from borderline personality disorder – Irene could safely resume her life outside of the hospital. Bill countered with some of Irene's history which included repetitive times of going off of her meds and ending up in jail or a hospital; he added some of the ways her symptoms are ignored by the roommate who would help her. He encouraged the hearing officer to deny her release, and to let Irene continue to improve in a therapeutic setting where she could possibly gain insight into her need for meds.

The hearing officer ordered Irene's release. Bill said the hearing officer seemed perturbed by his proposal and wondered if it might have been due to false accusations against him made by Irene decades before when she was in a psychotic state (which might have been in records reviewed prior to the hearing). Before ending the proceeding the hearing officer told Bill if he wanted to hospitalize Irene, he should petition the probate court for conservatorship over her.

Bill asked me if he could do this. Many legal issues are not clear-cut, and often turn on specific facts or on interpretations of

words and intent. With this one though, I didn't tell Bill, "maybe," or "it depends," or "possibly if all goes well;" I told him no. Whether the hearing officer was misunderstood (doubtful, knowing Bill), or confused, or reckless, the unasked-for advice she gave Bill was erroneous.

Other than an involuntary hospitalization that can occur when one is accused or convicted of committing a crime, the only way for one to be placed in a locked psychiatric facility against her will is through the process that began when the police took Irene to the hospital (the process that was terminated when her release was ordered).

A probate conservatorship could give Bill the authority to obtain private psychiatric care for Irene, and the ability to communicate with her therapists. But neither a probate court, nor a probate conservator appointed by the court, has the power or authority to involuntarily place someone in a locked psychiatric facility. Only what is known as an "LPS" conservatorship could result in that. And only a county, not a parent, can petition for an LPS conservatorship (and then only at the conclusion of the process Irene had been going through before her release).

Bill had a second question: what is a parent to do when he can't get help from a county or the court system. For that I do not have a definitive answer, just a suggestion. There are people who can help, people like Bruce Lewitt, Managing Director of Proxy Parent Foundation, and his slew of Personal Support Specialists ("PSS"). They will work with persons with Irene's symptoms and try to get them to understand their need for meds. They provide care unaffected by being part of the history of the illness and all of the emotions that accompany it. I've seen what case managers and a Proxy Parent Foundation PSS can do, and what so often we parents, through absolutely no fault of our own, cannot do.

Bill's efforts to get help from the county failed, but he learned a couple of things which could help in the future. He won't



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be quitting now, that's for sure, because that's not what we do.

**Baron Miller has an adult child with schizophrenia. His law practice is focused on assisting families of persons with mental illness. He has written a book, Laws We Need to Know: Understanding Rules and Programs for Persons with Mental Illness, which is available from online booksellers in print and digital formats, or at www.baronmillerlaw.com.*

BOOK REVIEW:

One Family's Struggle

Hidden Valley Road, by Robert Kolker (Doubleday, 2020)

by Timothy B. Taylor*

"A happy family is but an earlier heaven."
—GEORGE BERNARD SHAW (1856-1950)

Readers of this newsletter will acutely understand the impact on a family with just one member having severe mental illness. What if you had six? Robert Kolker's second book, subtitled "Inside the Mind of an American Family," seeks to address that daunting proposition (and much more).

Kolker's subject is the Galvin clan of Colorado: World War II veteran dad, focused on his military career but in many ways not what he seemed; traditional mom, outwardly cheerful but perhaps using that façade to maintain her own sanity; ten sons and two daughters, baby boomers all. As their parents sought to raise them to be patriotic, church-going all-Americans, six of the boys would ultimately be diagnosed with schizophrenia. It was, the author writes, possibly "the most mentally ill family in America." Through their struggles, they became a "monumental case study in humanity's most perplexing disease."

Early segments of the book alternate between the family's history and the history

of the study of what was first referred to as dementia praecox and only later came to be called schizophrenia. It was, Kolker notes, an unfortunate naming decision. Schizophrenia, he writes, is not about split personalities but rather a split between a sufferer's internal and external lives. Unlike other brain conditions like autism, which tend to "dilute and dissipate a person's most identifiable personality traits," schizophrenia "muffles nothing and amplifies everything," rendering almost all emotions dreadful and frightening for the patient (and overpowering for his family). And there was plenty of fear in the Galvin family: sequences of violence, clergy sexual abuse and even murder-suicide and incestuous rape are littered through the narrative.

Kolker uses novel-like pacing, but plenty of cold, hard facts emerge. He recounts early suspicion about the heritability of the disease, and professional debate about other potential explanations. As autism had proponents of the now debunked "refrigerator mother" theory, so it was in the study of schizophrenia: supposed experts who blamed the parenting. Families endured decades of controversy between supporters of talk therapy, advocates for complete removal from the family environment, electroshock therapy, and the shifting "cocktails" of drug interdiction that were advanced over the years (particularly after institutionalization was de-emphasized in the Community Mental Health Act of 1963). Today, Kolker reports, more than three million Americans suffer from schizophrenia, and it accounts for sizeable percentages of both suicides and psychiatric hospital beds.

Advances in science, initially in the area of imaging technology, allowed researchers to peer into the structures of the brain, and this in turn led to a sea change in how scientists came to view schizophrenia. Two such inquiring minds were those of Robert Freedman and Lynn DeLisi, who approached the mysteries of the disease from different directions but came into the lives of the Galvin family at about the same time. In

the anything but quiet home on Hidden Valley Road near Colorado Springs, the two researchers found "the perfect sample" for an inquiry into the existence of a genetic propensity for severe mental illness. And the advent of human genome mapping took the DNA of this family in directions they never could have imagined. In their quest for answers to the elusive question of why one family could be so beset, they learned that the experts theorize that the same mutations on the SHANK2 gene may cause epilepsy in one person, autism in another, schizophrenia in another, cause one person to be bipolar, and yet have no impact at all on another person with the same mutation.

A fascinating aspect of the book deals with the challenges – and frequent reversals – faced by researchers Freedman and DeLisi. They faced not only the dead ends and brick walls that scientists regularly encounter with experimentation, but also loss of funding caused by corporate mergers and lack of interest in their work by the marketing arms of drug companies. Their patience and willingness to carry on is a story unto itself.

As the dysfunctional family grew older, afflicted members died from complications from the medications they had endured for decades. The matriarch, physically failing but mentally aware into her 90's, continued to deflect criticism for her decision years before to focus on the many needs of her profoundly ill sons to the profound exclusion of her daughters. And those daughters reckoned with their difficult childhoods in very different ways: one mostly withdrawing, the other assuming responsibility for her brothers' care and treatment. It is a story which will resonate with all who have family members afflicted with serious mental illness, and all who care about those who do.

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

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