



By Kim Lamb Gregory

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When Dr. Kerry Kravitz's uncle was alive, he didn't worry about a family member in Los Angeles who was living with schizophrenia. Kravitz's uncle took the relative to appointments, checked on him, and made sure he was on his medication.

But when his uncle died, there was no one nearby to look in on the family member. Kravitz, who has a psychiatric practice in the Bay Area, would fly to Los Angeles on weekends to check on his relative. Kravitz had devoted his life to helping others with mental illness, but felt powerless when it came to a member of his own family.

"After my uncle passed away, we were very concerned," Kravitz said. "He (the relative) would be too paranoid to answer his door or answer his phone. He would clearly be off his meds."

Kravitz, who protected the identity of his relative, then learned about an organization called the Proxy Parent Foundation.

PPF is a nonprofit organization that provides a two-pronged service: a master financial trust for everyone enrolled, and a support person to help each beneficiary with everyday responsibilities. The trust can be established for a person with any sort of disability, but the personal support specialists are only for those with mental illness.

Currently, there are more than 80 trusts — the majority for people with disabilities other than mental illness. Of those, 25 clients qualify for personal support specialists.

There are about 450 California families who have arranged for services in the event of the parent or guardian's death, but PPF board members say the group is not widely known in Ventura County.

Once Kravitz's relative was part of the PPF, there was a nonprofit trustee to manage his money, and a designated personal support specialist to look in on him and help him with everyday obstacles. Kravitz was delighted with the improvement in his relative. He got back on his medication and was able to hold down part-time work, Kravitz said.

"There is really a pretty miraculous turnaround in pretty much everything," Kravitz said.

Carla Jacobs, who is on the board of the Proxy Parent Foundation, said the

foundation was started by family members involved in the National Alliance on Mental Illness and the Los Angeles Mental Health Association.

"The families were recognizing there was a huge need of basically, who would care if they weren't there?" Jacobs said.

Jacobs said the mental health system is there to help, but each person with severe mental illness needs someone who is just a phone call away — usually a family member. Without a family member, people with severe mental illness risk falling through the cracks.

Her brother, Franky, who was diagnosed with schizophrenia, is an example.

When their mother died more than 20 years ago, Franky received his inheritance directly. He used the money to wander across the U.S. and Canada, or wherever his delusions drove him, she said. Jacobs believes if PPF had been available then, Franky would have received the help he needed.

"My mother had been his silver thread," Jacobs said. "The person who kept it all together. He's been missing for almost 20 years now."

A matter of trust

When parents or guardians of a person with a mental illness die, the one left behind is vulnerable on many fronts.

If they inherit money that causes assets to rise above \$2,000, the inheritance could disqualify the mentally ill person for California's Supplemental Security Income, according to Thousand Oaks certified financial planner Thomas Stevens, the chairman of PPF's business committee.

Stevens said families often try to set up what's known as a special needs trust to guard against this, but there are obstacles.

"Usually you're calling your family lawyer who typically has not done this kind of thing," Stevens said. "They're usually very expensive and then you have the problem of who is going to manage the trust. You then try to get a financial adviser who won't want to take on this small of an account."

If an account is set up through the PPF, any inheritance goes into a special needs pool, which includes all of the beneficiaries in California. Because it's in the pool trust, the money is not recognized as an asset, so the beneficiary can continue to receive SSI benefits. But the trustee still gets all of his inheritance.

Stevens said the account is individually tailored to meet each client's needs.

Jeffrey Marvan, 53, is relieved his 86-year-old mother, who lives in Camarillo, set up a trust for him through PPF.

Marvan was working as an attorney in Washington, D.C., when his father died.

Marvan, who had his own practice, said he ran out of money and began to isolate himself — something he later learned was part of his undiagnosed mental illness.

"I didn't tell my mother I was suffering," he said. "I fasted and had all my electricity and gas cut off."

Marvan said his weakened state eventually resulted in his being rushed to the hospital where he was diagnosed with schizophrenia.

With medication, Marvan is now in control of his mental illness, and he plans to tackle a part-time job soon. Not having to worry about money to survive is a burden off his shoulders, he said.

A phone call away

Once a family signs up with PPF, each beneficiary is assigned a personal support specialist.

Bruce Lewitt of Los Angeles serves as a personal support specialist for six PPF beneficiaries. He said their needs vary, but generally involve Lewitt coordinating public and private social services, making sure the beneficiary is following a doctor or psychiatrist's orders, and checking in to make sure all is going well.

"We don't provide treatment, we don't provide psychotherapy," said Lewitt, who also is director of social services for the PPF. "All of our proxy parents know about medication. They are in touch with treatment providers. We know what we don't know."

A support specialist might do anything from arranging transportation and housing to making sure a client has food in the house. Lewitt is the personal support specialist assigned to Kravitz's relative.

"Bruce was able to get him back on his SSI and back into treatment," Kravitz said. "He's been able to keep his appointments independently and take his medication independently."

If he's alive, Franky is 65 now, Jacobs said, and probably homeless. She wants to save other families from the grief and uncertainty her family has endured.

"We want to always be there," Jacobs said. "Just like a mother and father always wants to be there."

