

Proxy Parent Foundation newsletter

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Bruce Lewitt

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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

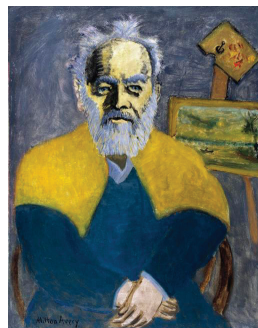
Bruce Lewitt



Recently I attended our annual Proxy Parent Foundation board meeting, my first as Managing Director. I've been to many board meetings over the years

when I served as Director of Social Services, but I'll never forget my very first one.

Our meetings were held at that time in a conference room at the LA County Board of Supervisors building on Temple Street in downtown LA. Walking down a hallway tastefully lined with paintings, one in particular caught my eye, so I stopped to take a closer look.



Portrait of Louis M. Eilshemius by Milton Avery, 1942, Smithsonian American Art Museum

I recognized the artist, Louis Michel Eilshemius. His talent to present an unearthly dreamlike world would strike anyone as singularly eccentric and unique.

For me, it was like running into an old friend because I grew up in my parents' New Jersey home looking at Eilshemius's artwork. My dad was a collector of New Jersey artists from the 1920s and 1930s, and he knew a lot about them. He told me Eilshemius had a mental illness and had lived with his older brother, when his unstable behavior and rage-filled tirades had isolated him from the art business community, and led him to withdraw from public view. This

conversation with my father always stuck in my mind, and years later as I began working with Proxy Parent Foundation's beneficiaries, I became immersed in the profound sense of isolation people with mental illness experience.

At Proxy Parent Foundation we assist beneficiaries of our Master Pooled Special Needs Trust to live a better quality of life than would otherwise be available to them by using the resources in ways to help encourage them to interact with the community-at-large and present their truest selves, and not just their illness. We've recently revamped our website to make it easier for families and individuals to learn about our Trust Administration and Personal Support Services. For a closer look please visit our website at www.proxyparentfoundation.org, or our Proxy Parent Foundation Facebook page. I can be reached at info@proxyparentfoundation.org.

Simple Ways to Reduce Stress and Anxiety for Caregivers

*By Tracy Shawn, M.A.**



It can be tough for caregivers to carve out time in which to take care of themselves. The physical and psychological demands that come along with caregiving especially when it entails looking after a loved one may exacerbate worry.

Reading self-help books about overcoming anxiety reminds you that you're not alone.



Knowing this is one of the first steps to dealing with it more effectively because it helps one feel less isolated and can increase hope. When you realize how many others suffer from anxiety and stress, as well as how many people have learned to utilize positive coping skills, you'll gain more confidence and energy in which to fight your own battle. Another way to deflate stress is to read fiction. Studies have shown that reading literature decreases anxiety because the reader becomes so involved with the protagonist that the brain reacts in such a way that whatever the character has overcome, in her own emotional way, so has the reader.

I also highly encourage caregivers who are dealing with anxiety, stress, and worry to engage in some kind of creative endeavor. It doesn't have to take hours out of your day, or even become an ongoing hobby. But think about what takes you out of yourself, even if it is for short bursts of time. Creativity comes in many forms. Be mindful of things that have allowed your brain to take a respite from ongoing stressors and then try to practice those activities on a daily basis.

Self-talk is the easiest, handiest, and I feel, oftentimes the most successful tool in which to decrease anxiety and stress. A simple but effective self-talk phrase for caregivers is this: "I am strong, caring, and resilient."

**Tracy Shawn, M.A. is an award-winning author of the novel, "The Grace of Crows," about how a woman with debilitating anxiety is able to transform her life.*

Granny Flats for the Disabled

By Joseph W. DeCarlo*



New laws, additional options and creative ideas have made it easier for parents to provide their disabled relative with a safe, dignified and affordable place to live. In October, Governor Newsom signed legislation that has made it easier for a homeowner to build a small free-standing home on their property or convert a garage, spare room or unused office into residential space.

Granny flats, in-law units, backyard cottages, or casitas are more formally known as Accessory Dwelling Units (ADUs). The new legislation removes many local government and homeowners' association requirements that previously blocked or slowed construction or forced a homeowner to pay onerous fees for utility hook ups or provide additional parking spots.

As the father of a severely disabled man, I know it will take more than construction of a separate unit for him to be safe and comfortable. Currently he lives with my wife and me in our house and we provide him substantial care. As we get older, we may not be able to provide our developmentally disabled son the physical and supportive care we now do. And that's where the creative thinking comes in.

At a recent meeting I attended with the Executive Director and Housing Directory of the Orange County Regional Center, facts were discussed that helped me understand

how a granny unit could work for my family. If our son is housed in a detached unit, the Regional Center will be able to provide him supportive services that have been unavailable while he lives in our family house. And, we will still be able to have him close.

In-Home Supportive Services (IHSS) are also available for people with other disabilities through your counties and range from assistance with household chores to personal care and paramedical services.

Costs on constructing an ADU or buying a prefab are moderate because you already own the land. The unit could be one or two bedrooms with the second bedroom also rented or used for a full-time caregiver. For families who need financing, their present home might be able to be refinanced.

Since the disabled person is living in their own apartment, the person could pay a reasonable rent to the parent/landlord without their SSI check being potentially penalized as in-kind support. If the parent wanted, the parent could put that income into an inter vivos special needs trust to pay for additional special needs the person may have.

This is not for all families and consumers, however it may be a viable housing option that includes supportive care services for many consumers and their families.

**Joseph DeCarlo is the father of a 44 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.*



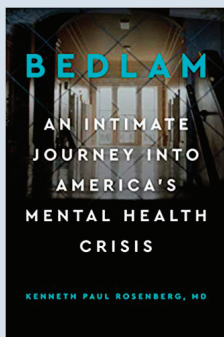
BOOK REVIEW:

An Elephant in the Room

By Judge Timothy B. Taylor*

Review of *Bedlam*, by Kenneth Paul Rosenberg, MD (Avery Books, 2019, hardcover, 240 pp.)

By Judge Timothy B. Taylor*



The title of this review, my second for the Proxy Parent Foundation, is not meant to evoke the delusions and hallucinations experienced

by many of those who suffer from serious mental illness (SMI). Rather, it is intended to focus on the fact that the greatest society in human history has, according to author Kenneth Rosenberg, “managed to make a very bad situation worse over the past one-hundred-plus years.” The premise of the book is that the United States has gravely mishandled its approach to SMI, and that we need to talk about it, change the way we think about it, legislate about it, and devote more money and human resources to dealing with it. Of particular interest to the Proxy Parent family, Rosenberg (a psychiatrist with his own poignant story) traces the descent of the American approach to SMI treatment from the vantage point of “the epicenter of the catastrophe: The State of California, Los Angeles in particular.”

What gave rise to perhaps the biggest public health policy debacle of all time? There is ample blame to go around. The Kennedy Administration, affected in no small part by JFK’s own experience with his sister, hastened the process of deinstitutionalization. Certainly the Reagan Administration’s 1981 decision to defund the 1980 Mental Health Systems Act contributed; this shortsighted effort to cut spending, which sounded the death knell for most state mental hospitals, is among the litany of missteps covered in the book. Taken together, these errors and many others have resulted in the situation we have today - one in which emergency rooms and jails take the place of the long shuttered treatment facilities; the streets of California’s cities become the dumping ground for people ill-equipped to navigate the out-patient treatment model that was supposed to replace the traditional approach; where cops have become the largest and most expensive psychiatric outreach team; and where mental illness crises are the only health emergencies in which the first responders are police officers or sheriff’s deputies.

Rosenberg traces developments (and the lack thereof) in drug therapies, and then turns to the public policy impacts and costs of deinstitutionalization; the consequences of shortened timeframes for inpatient care and the consequent lack of consistency and follow-up; and the prevalence of dual diagnoses (SMI with an overlay of serious drug abuse/addiction). He addresses the criminalization of mental illness and the ironic hesitancy to take away civil liberties from people who, when their illness is in full bloom, are unable to comprehend what their rights even are. Anyone driving in

one of California’s downtown areas sees the results, as individuals with SMI make up a sizable percentage of our large and growing homeless population. We see them in our courts, often as criminal defendants or recreational litigants but more recently (in a positive shift) in specially designed mental health tribunals substituting out punishment and incarceration in favor of pathways to treatment and stabilization. He gives some reason for hope, noting the 2018 decision of the Los Angeles County Board of Supervisors to build a mental health hospital instead of a new jail wing.

Helpfully, Rosenberg ends with a section giving specific recommendations for people with SMI and their families and caregivers. But the portions of the book that really move the narrative forward are the intensely personal ones: his own experience with his schizophrenic sister, and how her struggles throughout their shared lives shaped him, dictated his choice of profession, and led him ultimately to the journey of discovery which resulted in the writing of this important book. To his evident surprise, he finds a common thread: among the mental health professionals he contacts in his research, many came to their calling because of the presence of SMI in their own immediate families. We owe those who have taken up the cause of those who give little back in return and lack the ability or political power to speak for themselves a debt of gratitude, and this book is a good first step toward enhancing our collective understanding of a problem that will affect one in five families and imposes huge costs on our society.

**Judge of the California Superior Court, County of San Diego. The views expressed are his own.*

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