



Proxy Parent Foundation newsletter

SPRING 2023 ISSUE 28

INSIDE THIS ISSUE

- 1 Message from our Managing Director
Bruce Lewitt
 - A Grateful Parent
Mary Walker
 - 2 Who to Designate as Trustee?
Baron L. Miller
 - 3 The Positive Impact of Personal Support Services
John Reynolds
- Review of *Demystifying Disability*, by Emily Ladau
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.

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



Many of you considering setting up a Special Needs Trust with Proxy Parent Foundation may be asking yourselves exactly who is responsible for overseeing our Special Needs Trusts. As

Managing Director of Proxy Parent Foundation, I manage both our personal support services program and our trust administration services. To fulfill that responsibility to our beneficiaries, I rely on the day-to-day coordination of all the elements that make up our operation. Our professional Investment Managers at Lindbrook Capital oversee our very conservative portfolios of investments. Our Trust Agents at Binder & Company issue daily disbursements from individual trusts. Our Board of Directors provide oversight and strategic direction. Our Proxy Parents provide personalized support directly to our beneficiaries. Our Director of Administration Karen Clark keeps track of the flow of communication within the organization and Assistant Managing Director Carol Larkin is responsible for outreach activities with other disabled organizations.

Baron Miller is a San Francisco based attorney, longtime NAMI member and Proxy Parent Foundation board member. Baron's article, *Who to Designate as Trustee?* weighs various options in choosing a trustee. Personal Support Specialist John Reynolds' article gives insight into the positive impact of Proxy Parent's unique Personal Support Services. Judge Timothy Taylor of the Superior Court in San Diego reviews many books for our newsletters. As the parent of a disabled son, Judge Taylor consistently

examines a wide range of approaches that aim to reveal the humanity in disability. Mary Walker's article presents the point-of-view of a mother whose need for our personal support services for her son may be relatable to you.

A Grateful Parent

Mary Walker

My son has schizophrenia and addiction issues and has been in a state-approved board and care for over 10 years. My husband and I had always visited him once or twice a week as much as we were able. But a couple years ago my husband was diagnosed with Alzheimer's, and I just couldn't take care of them both anymore. I remembered there was a Pay-As-You-Go option with Proxy Parent, contacted Bruce, and he easily set it up for me.

Pay-As-You-Go has been such a gift to me. His care person, John, is wonderful, kind, and caring. My son loves going out with him, and John has been so very helpful to him and to me. Besides helping him with housekeeping tasks (i.e., renewing state ID, taking him to Social Security to address issues, disabled bus pass ID, setting up bank accounts), he spends time with him doing enjoyable things. John has taken him to the beach, played pool, bought him take-out meals, and coordinated other outings that my son enjoys.

John through Pay-As-You-Go has given me such relief. I no longer have to do everything by myself for my son. I have help. I am so very grateful for this program and what they have done for both my son, me, and my other children. It has helped the whole family. I say a big "thank you!" to Proxy Parent, Bruce, and John!



Who will care when I'm not there?

Who to Designate as Trustee?

This is an updated version of an article published in 2017, reprinted due to the importance of the topic.



Clients of mine who want to establish a special needs trust for someone with a mental illness frequently share a common challenge: who to designate as the

trustee? It is a daunting problem, since the trustee often is expected to try to fill the shoes of the person establishing the trust, a person who likely has long been dealing with the formidable job of caring for a person with mental illness. How is someone else going to do what we do, with our knowledge gained from experience, with our devotion forged by love, compassion, responsibility and duty?

Clients ask me what do I think, who do I recommend. There are numerous options — family members and friends, private fiduciaries, financial institutions, non-profit organizations, financial advisors, attorneys and accountants. Depending on the situation, each has something to offer as a potential trustee. Each has drawbacks too.

I usually advise against attorneys and accountants due to the size of their fees — if they are affordable, then there is enough money to pay for an institutional trustee which would have the added advantage of being an experienced investor. Attorneys and accountants, I think, can make good trust protectors — those who would appoint and terminate trustees, who would receive financial and personal reports from trustees, who would serve as overseers but not day-to-day operators of a trust.

Financial advisors might have conflicts of interest and might lack knowledge about mental illness, and they generally don't want to expand their job duties beyond investment advice.

Family members and friends can be a good option, depending on their willingness, their interpersonal and financial skills, and whether their relationship with the trust beneficiary would be put in jeopardy by their control of assets and distributions.

Private fiduciaries — those persons who are licensed by the State to hold others' assets, and who are recognized by the courts as professional trustees — can be an excellent choice. But they too can be expensive, and as individuals they present the risk of not outliving the beneficiary.

The option with likely the best combination of advantages and slightest of disadvantages are non-profit organizations that specialize in special needs trusts. They know the subject matter, and are set up for it. I tell my clients to investigate them, starting with an internet search, but that they shouldn't expect to find a better one than PLAN. (Proxy Parent Foundation is a dba of Planned Lifetime Assistance Network (PLAN) of California.)

You could say I'm biased since I serve on PLAN's Board of Directors, but it's the other way around. I serve on the Board as an uncompensated volunteer because I believe in the organization.

PLAN is all about helping people who need help — those persons with mental illness and those persons who care for them. PLAN is not about making money. As PLAN is a non-profit organization, maybe that should be obvious, but we see plenty of non-profits who use an inordinate amount of their revenue to pay salaries and expenses of their principals. PLAN's staff is modestly compensated; none are overcompensated.

PLAN's rules require that a majority of board members be family members of persons with mental illness, and/or persons with mental illness. That is what qualifies me to sit on the Board, and it is an important requirement, tending to ensure that the organization's focus will always be the care of people who need it, and not the monetary enrichment of people who possibly don't. Most significantly, PLAN is staffed by people who care, people who are doing the work for the right reasons.

My endorsement is not unconditional. What happens in the future? What will be the quality of PLAN's staff and services then? Right now, e.g., the Managing Director is Bruce Lewitt, whose personal attention to trust beneficiaries is the stuff of legend. He seems eternally youthful, yet presumably is mortal. Who does his job and the jobs of others in the future will be key in the continued excellence of the organization. Because of the way PLAN is set up, and because of its history and its present, we have good reason to expect smooth successions, and that the continual skill and eminence of PLAN as a trustee will continue. As will my endorsement (or since I too possess mortality, the endorsement of my successor).

There are other effective trustees of special needs trusts out there. None in my opinion are superior to PLAN.

*Baron Miller is a board member of PLAN of California. He 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.*



Proxy Parent Foundation

The Positive Impact of Personal Support Services

John Reynolds, Personal Support Specialist

I have been a Personal Support Specialist for Proxy Parent Foundation since 2016, working to improve the lives of three beneficiaries. Mitchell lives in a board and care in Orange County. I meet with him on a regular basis and he's always glad to see me. He's an avid billiards player, so we go to a nearby community hall and play on most of our visits. He's a great player and usually beats me. You can imagine how this kind of outing improves his self-esteem! Also, with my support he's been able to stay off alcohol and cigarettes for the past six years. This is a huge improvement to his energy and overall health.

Another of my charges in Orange County, Donald, had been homeless. He is now living in a Board and Care. I took him to the SSA office to make sure his benefits were still good. I was able to get him a bank account and his OCTA bus reduction passes. He's been able to get a job and earn some extra money. My support has changed his life, making him much more confident. I am proud and happy when he tells me our visits are the highlight of his week.

Another beneficiary, Richard, lives in assisted living in Los Angeles. I make sure he's getting the care he needs there and keep his sister posted on his progress. I also keep in contact with his County Conservator with updates about Richard. Richard enjoys my visits and I am immensely proud to improve the quality of his life.

You can understand how gratifying my work is. I am grateful to have this job because I can see the kind of positive impact I can make on the lives of those I have served.

BOOK REVIEW:

Etiquette for the Ally in the Battle Against Ableism

Review of *Demystifying Disability*,
by Emily Ladau (Ten Speed Press, 2021,
187 pp.)

*by Timothy B. Taylor**

The descriptive subtitle of Emily Ladau's interesting book *Demystifying Disability* is "What to Know, What to Say, and How to be an Ally." But the author is no mere Emily Post. Indeed, one approaches reviewing her book with more than a little fear of transgressing her cardinal rules of "disability etiquette." A wheelchair user herself, she was born with Larsen Syndrome, an inherited and lifelong joint and muscle disorder. As you might expect, the mental toughness required to overcome the challenges she has faced yields someone unafraid of blunt talk. "What to say" is really "what not to say," and she can be preachy and militant in alternating paragraphs. The provocations even include an unapologetic frontal attack on the classic Charles Dickens holiday chestnut, *A Christmas Carol!*

Paradoxically, Ladau asserts she "is not one to sugarcoat things," but then immediately goes on to mince words. She claims we should all just say "disabled," but shy away from "differently able." Similarly, she urges relegation of the terms "high functioning" and "low functioning" to the ash heap (as if the folks on one end of those descriptors were going to take umbrage). Come on! I can tell you as the father of a profoundly disabled adult son: I always preferred when his teachers, aides and other service providers just said what was obvious and then designed the curriculum or program accordingly.

But a commitment to lifelong learning sometimes requires a reader to look past

trivial distractions like these, and keep plowing ahead in search of deeper lessons lying hidden underneath. And so it was here. The volume contains helpful tables about types of disabilities and disability models, and overviews of the sordid history of disability awareness and the often unflattering depiction of disability in the media. While handy for further reference, these elements pale in comparison to the central teaching moment of the book (at least for me).

Several years ago, a candidate for high office publicly mocked a disabled member of the news media who had tried to ask him a question at a press conference. (The candidate later denied doing so, though video confirmed the incident.) Ladau's book taught me something I had never been exposed to before despite advocating for a disabled person for more than 30 years: there is a term for this sort of conduct (beyond the obvious "boorish"). The author defines ableism as "attitudes, actions and circumstances that devalue people because they are disabled or perceived as having a disability." And the balance of the book is really a series of examples of ableism; first and second hand descriptions of the toll that it takes on both the disabled person and the uninformed ableist; a cry for its eradication; and an acknowledgment that the road to this goal will be long and slow.

If teaching just one reader about the pervasive presence of ableism in our society is all Ladau has accomplished, this is at least the first step in the journey she advocates. An author is successful if she provides new information, and even more so if she alters, even a little, how the reader looks at the world. That's the chief virtue of this slim volume, and that's what made it worth the effort.

**Judge of the California Superior Court, County of San Diego. The views expressed in this, his eighth 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
Pacific Palisades, CA 90272

ADDRESS CORRECTION REQUESTED



Please let us know if you would prefer receiving our newsletter by email. Thank you.
info@proxyparentfoundation.org

BOARD OF DIRECTORS

Officers

Joe DeCarlo, MBA, *President (Managing Partner, JD Property Management)*
Tom Stevens, *1st Vice President (Chairman, Los Angeles Capital Management)*
Marvin Southard, D.S.W., *2nd Vice President (Director, LA Dept. of Mental Health, Retired)*
Deborah Starkey, MBA, *Treasurer (CFO, Turning Point Community Programs)*
Bruce Lewitt, *Secretary (Managing Director, Proxy Parent Foundation)*

Members at Large

Randall Hagar, *Member at Large (Policy Consultant, Psychiatric Physicians Alliance of California)*
Steve Pitman, *Member at Large (Board President, National Alliance on Mental Illness (NAMI))*

Board Members

John Buck, *Past CEO, Turning Point Community Programs*
Gary M. Chang, Esq., *Attorney at Law*
Armida Colmenares-Stafford, *1st V.P./Sr. Relationship Manager, Pacific Premier Bank*
Elizabeth Galton, M.D., *Psychiatry*
Kerry Dean Kravitz, M.D., Ph.D., *Psychiatry*
Naomi Levi, *Senior Clinical Director, The People Concern*
Sheree Lowe, *V.P. of Behavioral Health at California Hospital Assoc.*
Baron Miller, Esq., *Attorney at Law*
Jennifer Wellenstein, MA, LMFT, *Deputy Chief Operations Officer, Turning Pt. Community Program*

Emeritus

Michael Antonovich, *former Los Angeles County Supervisor*
Bob Brooks, *Retired Businessman*
Ann Eldridge, *Retired Nurse*
Carla Jacobs, *CEO, Roy W. Smith Foundation*

I wish to help support Proxy Parent Foundation

A DBA of Planned Lifetime Assistance Network of California

Enclosed is my Tax-deductible donation of

\$ _____

Please use this donation to provide Proxy Parent Foundation's help to those who need it in the "here and now".

Please use this donation as our Proxy Parent Foundation enrollment donation. (Enrollment donations must be \$1000 or more and can be made in payments.)

Name of donor: _____

Address: _____

City: _____

State: _____ Zip: _____

Phone: _____ Email: _____

Please make your check payable to:

Proxy Parent Foundation
15243 La Cruz Drive, #889
Pacific Palisades, CA 90272



Or by credit card, go to our website at www.proxyparentfoundation.org