

Proxy Parent Foundation newsletter

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INSIDE THIS ISSUE

- 1 All Things Must Pass
Gary M. Chang

Saying Yes
Bruce Lewitt
- 2 The Show Goes On
Baron Miller
- 3 Book Review
History of a Jigsaw Puzzle
Judge Timothy B. Taylor

PROXY PARENT FOUNDATION

We are Trustee of the PLAN of California Master Pooled Trust, which is 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 provide access to healthcare, all the while maintaining a family-like atmosphere that promotes a better quality of life for the beneficiary.

Proxy Parent Foundation is a dba of Planned Lifetime Assistance Network (PLAN) of California, a 501(c)(3) nonprofit corporation.

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All Things Must Pass

For those of you who are not already aware, although I will continue to serve on the Board of Directors, by the time you read this I will have retired from Proxy Parent Foundation, as Director of Legal Affairs. So, although I customarily write the introductions to this newsletter, this issue is my farewell. Suffice to say, interacting with so many of you over the last 11 years has made them among the most rewarding of my life. I will miss everyone with whom I have shared our mutual concerns, but many of you (too many, in fact, to name), will forever hold a special place in my heart. For you, even if we have only communicated over the phone or email or post, I nevertheless hold a picture of you in my mind's eye.

Although, this move on my part is bittersweet, it is made far easier in my knowing that leadership will continue under Bruce Lewitt, our Managing Director, who most of you are even more familiar with than myself through his working with you as Director of Social Services. He has been with Proxy Parent Foundation even longer than me and we have collaborated on virtually all levels of the Foundation's operations for years. As you who have dealt with him know, he is a true champion of our cause, our families and beneficiaries and I am certain you will find the transition seamless.

To close, it has also been a great pleasure and honor to work with everyone of the Board of Directors and Staff through the years, but I must give a special thanks to Carla Jacobs, who brought me into the fold those many years ago to join the Board and help her serve, through Proxy Parent Foundation, our mission of serving the disabled community, particularly those with mental illness. I know each of us will continue the fight in our own ways, and so too will Proxy Parent Foundation.

Fondly,

GARY M. CHANG
Director of Legal Affairs, Retired

Saying Yes



In 2018, when Gary Chang, our Director of Legal Affairs, announced his intention to retire, Proxy Parent Foundation's Board of Directors asked me to step in as the Foundation's Managing

Director. I didn't hesitate to say yes. My decision was rooted in the commitment the Board, Gary, Carla Jacobs and I have made to the families and individuals who have joined our PLAN of California Master Pooled Trust over the years.

Proxy Parent Foundation is governed by its Board of Directors, almost all of whom have disabled family members themselves and truly understand the complex needs of the unique individuals we all serve. We seriously value the consistency of service in our trust administration and personal support services. Maintaining our continuity of leadership fundamentally supports Proxy Parent Foundation's dedication to keep its promise of long-range care to those families and individuals. Since 1992, this promise has continued to guide us today, and will continue tomorrow, and in the years ahead.

Though I serve, as the saying goes, at the Board's pleasure, the pleasure from my work essentially comes through my daily contact with families and our first and third party beneficiaries. From my 25 years of experience serving this community, I can tell you these relationships deepen considerably over time, and I look forward to adding new families to our fold.

Onward,

BRUCE LEWITT
Managing Director



The Show Goes On

By Baron Miller*



When I am advising clients, and when I talk to NAMI groups about

planning estates, an important issue is who should serve as the trustee of a special needs trust. I recommend PLAN as an option.

I explain the way PLAN is set up, and about the people who operate the organization. I mention Gary Chang, (formerly) Director of Legal Affairs, and how his personality and disposition are part of his skill set, how he understands the effect of his actions on those who contract for and receive PLAN services. I tend to say that while Gary and others who I speak of won't be working forever, I believe effective people will take over for them as needed. Easy for me to say, and now it will be put to the test, as Gary has retired.

The immediate plan is for Bruce Lewitt, whose title has been changed to Managing Director, to take over Gary's administrative and supervisory duties, and for PLAN to hire an attorney trained by Gary to take over his legal duties on an as-needed basis. Also to make up for Gary's absence, Karen Clark, the Director of Administration, will see an increase in her job duties. Board member and visionary Carla Jacobs will continue to do every last thing necessary. And Gary will serve on the Board of Directors, and will be available for consultations.

The transition will work because there is a sensibility at PLAN that ensures it will work. No one involved is simply "doing a job." All understand the need for the

job they are doing, and for the patience and compassion and knowledge they bring to it. That's why they're there.

As for Gary, well, when Board President Joe DeCarlo informed the Board last August of Gary's intent to retire, here is a sampling of what he and other Board members wrote to each other.

"It is with sadness, however great appreciation for all that he has done, that I announce the retirement of Gary Chang. He has ably served for twelve years as Proxy Parent Foundation's Director of Legal Affairs and before that as a Board Member....Gary, thank you for your excellent and steady guidance to help us achieve the success we are today. Your dedication to our beneficiaries and their families exemplifies what PPF is all about." Joe DeCarlo

"I certainly hope this will be a happy event for Gary. Obviously it is not now for PLAN, or personally for me. I have relied so much on him, all of us have. Yes, Gary's work and attitude and graciousness and wisdom does exemplify the best of PLAN. We will find a good person to replace him but he will be missed. I am already missing him." Me, seconded by Marv Southard

"I'm sorry to lose you, Gary. It has been a pleasure working with you!" Elizabeth Galton

"In my 12 years of working nearly every day, shoulder-to-shoulder with Gary, I could not have wished for a better colleague or friend. Having Gary in our lives is like having an attorney in the family, someone we've always been able to turn to not only for trust expertise, but for sound judgment regarding every imaginable need our unique beneficiaries can generate." Bruce Lewitt

"Gary brought an interesting combination of competence, commitment and empathy to the task. Although 'everyone can be replaced,'

replacing Gary will put that old adage to the test! We will miss him!" Steve Pitman

"Hard to know exactly what to say, except that our world/work shifted in a good way when Gary came on board, and will shift again when he leaves." Randall Hagar

"Gary called us once as a civilian for his daughter. We chatted. I invited him to a board meeting and the rest is history. His steadiness, dedication, and thoroughness was seen from the start....I know Gary. He will stick through for us until we find a plan that will take us to the next step with all the bases he covered....He is like that: the most loyal, gentle, steady person I have ever had the honor of knowing. Thank you, Gary, from the bottom of my heart to the stars." Carla Jacobs

"Good to know you will never leave.... Gary, I respect your decision...." Tom Stevens

This is from those who regularly work with Gary. I expect we will soon be hearing similar sentiments from persons who have established trusts with PLAN and their lawyers.

Goodbye, sort of, my beloved friend. See you at a ball game, a board meeting, a restaurant, a NAMI conference, maybe a court hearing, maybe a golf course. We'll talk the next time I have a question, or sooner. Thank you, Gary, and be assured that because of you and those like you PLAN will continue to expertly perform its undertaking of serving the mental illness community.

**Baron L. Miller is an attorney in private practice in San Francisco who specializes in estate planning for California families of the mentally ill. He is a long-time NAMI family member, an advocate for the rights and interests of families of the mentally ill, and a board member of Proxy Parent Foundation. He does not charge for telephone consultations on the propriety of making payments for the benefit of an SSI recipient. He can be reached at 415.522.0500.*



Book Review: History of a Jigsaw Puzzle

By Judge Timothy B. Taylor*

Review of *In A Different Key – The Story of Autism*, by John Donvan and Caren Zucker (Broadway Books, 2016, paperback, 670 pp.)

Autism is a challenging set of jigsaw puzzles, and this book tells the fascinating story of how doctors, psychologists, researchers and parents started assembling the complex pieces beginning in 1942. In that year, Leo Kanner first identified autism as a syndrome separate from what was then called “childhood schizophrenia” (although Kanner, a child psychologist at Johns Hopkins, was the first to acknowledge autism “was there before,” undiscovered throughout history). The book was initially published several years ago, and was a Pulitzer finalist in 2017. Despite my nearly 30 years of involvement in the separate universe that is autism, I had not come across the book until I was browsing in a local bookstore in late 2018. As I often do, I ignored the “blurbs” and just started reading Part 1, entitled “Autism’s First Child.” Within the first 10 pages, I learned that Kanner’s “Case No. 1,” a boy named Donald Triplett, had “an astounding capacity for recall” but that his parents had to “cajole him to eat.” These phrases also describe my own autistic son John, so I was immediately hooked.

Becoming the parent of an autistic two year old in the late 1980’s meant doing a good deal of reading and research. I learned about the early (and now discredited theory,

popularized by largely self-taught Chicago psychologist Bruno Bettelheim, that autism, was caused by mothers who didn’t bond lovingly with the children. I learned about efforts with widely divergent tactics to educate autistic children, led by Ivar Lovaas and Edward Ritvo at UCLA and Eric Schopler and Gary Mesibov at UNC-Chapel Hill. (We ended up taking John to see both Ritvo and Mesibov.) I read several books by autistic authors Temple Grandin and Donna Williams, and parent Catherine Maurice.

This cast of characters is prominent in the early chapters of the book, but most interesting for me were the segments involving the late Bernard J. Rimland, father of the autistic man who became one of the models for the character portrayed by Dustin Hoffman in the 1988 movie *Rain Man*. Dr. Rimland wrote a seminal book, published in 1964, which eviscerated Bettelheim’s “refrigerator mother” theory. I had the great good fortune of representing Dr. Rimland in litigation in 2002, before becoming a judge. He was known as the father of modern autism research, and was an intensely colorful man with very definite (and sometimes controversial) opinions. His story alone would be worth reading; its intersection with the work of the other players, and their interaction with parents of autistic children desperately seeking answers, makes for a fascinating history.

Mid-volume, the book turns to the work done, chiefly in London, by English researchers. They sought not only to help autistic children, but discover the true nature of the affliction. Next up: the advent, and subsequent debunking, of “facilitated communica-

tion,” one of several interventions would lead to disagreement among those seeking to solve the autism puzzle. Indeed, conflict and competition, often bitter and acerbic, has marked the paths of autism treatment, research and fundraising for decades. The book dissects this infighting, which in recent years witnessed an ultimately fruitless debate over whether the MMR vaccine causes autism (it does not). Even more recently, another group unexpectedly elbowed its way to the table: high functioning autistic people, some of whom question the validity of the search for a “cure” for autism. Donvan and Zucker make clear that the story of autism is far from over. But they end where they began, with “Case No. 1,” Donald Triplett. Finding out what became of him makes the book all the more worthwhile.

As for my son John: he is 30 years old now, has never spoken, and still lives at home in the same bedroom he has slept in for over 25 years. He needs assistance with most activities of daily living. Several autism advocacy groups use logos incorporating puzzle pieces, and in a happy irony, John’s hobby is completing large difficult jigsaw puzzles. He had some miserable early years, but today leads a quiet, happy (albeit constrained) existence today. His success is due in part to the work of the people whose story is told by Donvan and Zucker. Their book is masterful, and should be required reading for any parent beginning (or in the middle of) the “long strange trip” that a diagnosis of autism portends for a family.

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

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