



Proxy Parent Foundation newsletter

SPRING 2021 ISSUE 24

INSIDE THIS ISSUE

- 1 Message from Our Managing Director, *Bruce Lewitt*
- 1 Taking Time to Plan for the Future *Nancy Nigrosh*
- 2 Mediating Needs *Marie Stein*
- 3 Book Review Harmful to Nobody a review of *Caught in the Web of the Criminal Justice System* *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



As Trustee of Proxy Parent Foundation's PLAN of California Master Pooled Trust, we must conform to the rules and regulations of SSI. Our Personal Support

Specialists, Contact Advisors, and Primary Authorized Representatives work with me to perform a crucial role in this regard to determine the specific supplemental needs of individual beneficiaries in order to disburse allowable funds from their trusts. Some beneficiaries have no public system case manager, family member, or trusted friend in their life, while some trusts are simply too small to afford Personal Support Services. One such beneficiary came to us through the foster care system. She felt alone in this world, was homeless, and also, understandably, anxious and angry. Marie Stein, our Trust Services Coordinator, and, most recent staff member, was able to engage with this young woman, and offer her caring direction. Marie's article, "Mediating Needs", appears in this newsletter. Also in this publication, Judge Timothy B. Taylor provides personal insights as the parent of an autistic son in his review of "Caught in the Web of the Criminal Justice System". This compelling book gives a firsthand account about the defense of an autistic young man, who is prosecuted for gaining access to pornography through the internet. Nancy Nigrosh's article, "Taking Time to Plan for the Future", describes the profound impact that proper planning and active engagement with our foundation can have on the beneficiary of a special needs trust.

Taking Time to Plan for the Future

*By Nancy Nigrosh**



They have a saying at Proxy Parent Foundation, wishing all their Grantors who have set up a trust with them, to live to be 100+ years old. Paul, the

dad of one of our trust beneficiaries, must have been listening. He recently passed away at the age of 101.

Ten or so years ago, after hearing about Proxy Parent Foundation from his estate planning attorney, Paul first contacted Proxy Parent Foundation about his son, Lucas. This became the first of many conversations about Proxy Parent Foundation's Master Pooled Trust administration and also about its unique Personal Support services. Lucas was in his late 50's, and had never lived independently. In fact, he was still living in the family home in self-imposed isolation in his room. Given this situation, Paul was very motivated to make a succession plan for his son's care. Proxy Parent Foundation was created by families facing the same quandary for their children — or, in some cases, another disabled family member. In every case, every family must first make an assessment about their potential beneficiary's needs for the future, and design a budget to gauge what level of resources a special needs trust would need to have to be able to meet their supplemental needs. Paul's assessment addressed Lucas's medical history, extended family member dynamics, past and current health providers, educational background, personal skills and interests. Most importantly, there was clarity about the



Who will care when I'm not there?



evergreen nature of this assessment, able to be adjusted at any time, with the added goal that the resources to be placed in the trust should last as long as

possible, ideally for Lucas's lifetime.

Next, Paul signed a joinder agreement to set up a trust for Lucas with Proxy Parent Foundation. Each beneficiary's special needs trust is part of its Master Pooled Trust, but each beneficiary's sub-account remains independent, with its own resources. Paul expressed interest in also setting up a Proxy Parent's Pay-As-You-Go account. Each "PAYG" account has its own service plan to fund Personal Support services for a Personal Support Specialist, whom they call a "PSS", as a proxy family member. Paul was keen to establish a PSS to work with Lucas in the here and now, even before his trust was funded. Proxy Parent Foundation provided a PSS for Lucas and introduced him into the family home for regular visits. Now Paul had peace of mind and the understanding that it would be a years-long journey they would all be taking together, with plans to check in regularly with Proxy Parent Foundation to refresh the needs and resources assessments. It took about three years of consistent and determined effort for Lucas to fully appreciate how his father had introduced a reliable and caring proxy family member who understood the complexities of Lucas's illness. Now Paul had someone who was capable of advocating on his son's behalf in a wide range of instances — in the same way families like yours must do in watching out for their

children or stepchildren, siblings, in-laws, or nieces, nephews, cousins, or close family friends, who struggle with disability.

**Nancy Nigrosh is a Performance Coach for Writers, a Consulting Editor and Instructor at UCLA Extension's Writers' Program. Nancy is married to Bruce Lewitt, Managing Director of Proxy Parent Foundation.*

Mediating Needs

By Marie Stein*



As someone with a close relative with chronic mental health issues, I know the stress of having to manage day-to-day challenges and the pain that lingers over unresolved or unaddressed conflicts. Over time, I've learned there are skills that make all the difference in establishing and building trust to create the foundation to resolving disputes to provide effective and caring support.

These are the same skills I use as a professional mediator — for small claims courts disputes of all kinds, from broken hearts and wounded pride to broken windows and wasteful employees. In Juvenile Dependency Court, I meet families to help them arrive at a parenting plan, and coach them on better communication skills to be able to exit the dependency system. I've also mediated disputes between artists and between co-workers who can't seem to work together but want to be able to retain rights and credit in their work. By asking thoughtful, non-confrontational questions to help

identify interests, I encourage all parties to take agency and responsibility for their choices. Mediators do not judge or determine a resolution for a dispute, but are trained to help parties identify their concerns, interests and emotions, to explore possible resolutions, and to encourage and facilitate the best agreement possible for all stakeholders.

As Trust Services Coordinator at Proxy Parent Foundation, I listen to first-party trust beneficiaries who have no primary authorized representative. Understandably, these individuals want to have agency over their lives, and express concerns about accessing their trusts. I consider listening to be an important part of my role, but, as trustee, our foundation has total discretion over what disbursements are made. My job is to weigh disbursement requests against the tight regulations of Social Security and to work with our Managing Director in arriving at decisions that protect the beneficiary's best interest, which is to responsibly follow the rules. Explaining those rules to each beneficiary, I find myself using tools very similarly described by Dr. Xavier Amador, founder of the LEAP Institute and author of "I Am Not Sick, I Don't Need Help! How to Help Someone with Mental Illness Accept Treatment". Dr. Amador presents a four-part method using the acronym "LEAP": Listening, Empathize, Agree, Partner. This formula is also the heart of the services that Proxy Parent Foundation provides.

**Marie Stein is the Trust Services Coordinator at Proxy Parent Foundation. She is a professional mediator, arbitrator and facilitator, and provides audit, risk and regulatory compliance consulting services for financial services companies.*



Proxy Parent Foundation

BOOK REVIEW:

Harmful to Nobody

Review of *Caught in the Web of the Criminal Justice System* (Dubin and Horowitz, Eds.) (Jessica Kingsley Publishers, 2017, paperback, 350 pp.)

by Timothy B. Taylor*

Readers of this newsletter have previously been introduced to my 32 year old autistic son, John. He has never spoken, cannot otherwise communicate in any conventional sense, and is almost completely socially isolated except for immediate family. He is, functionally, stuck at the age of three, and is profoundly disabled in almost every sense of the word. Yet we know for certain he is, deep within, a confirmed heterosexual. How? Every time a magazine or catalogue comes in the mail, he silently searches for the swimsuit ads! Tame stuff to be sure, but it bespeaks a larger problem the contributors to *Caught in the Web of the Criminal Justice System* seek to address: the hesitancy of those who care about the severely disabled to think of them as sexual beings, and the consequent lack of attention paid to educating them about the pitfalls waiting for them in the wider world. Nowhere is this problem more acute than in the lives of high-functioning autistic people when they intersect with the unforgiving body of law governing possession of child pornography.

An earlier review in these pages traced the difficult road traveled over the last 80 years by doctors and mental health professionals in understanding autism. Only relatively recently have researchers come to understand that the syndrome is actually a spectrum. Persons on the high functioning end may graduate from college and even obtain employment, yet still suffer from huge deficits in social interaction, in understanding the feelings and motivations of other

people, and in forming relationships. At the same time, co-existing problems of obsessive/compulsive disorder — combined with natural curiosity and the focused attention necessary to master the computer and the internet — have led high functioning adult autistic males to discover pornography as their only sexual outlet. As the contributors to this volume make clear, the internet is full of nominally “free” sites where a few mouse clicks can take a person unable to understand the gravity of what is transpiring to a dangerous place within minutes. Because many of these individuals are child-like in their own emotional development and often lack a “theory of mind” which would enable them to understand the agony of the victims portrayed in the materials they are unwittingly accessing (and due to the lack of attention paid to educating them in these areas), many such individuals have been unwittingly caught possessing hundreds of images of children being abused.

Statutes at both the federal and state level are unforgiving. Many mandate prison sentences even for persons with no criminal history, and all require imposition of the modern day Scarlet Letter: registration as a sex offender for many years if not for life. Needless to say, for persons who have overcome huge roadblocks to attain some level of independence, these legal sanctions can represent permanent and devastating reversals. In a sad irony, the more “functional” and independent an autistic person is in a real world setting, the more apt he is to transgress and face prosecution and a loss of that independence. For families of the autistic person, the laws run counter to the theory underlying the “least restrictive alternative” approach that underlies so much of special education placement and other programming.

The book is set up as a series of chapters by contributors from varying backgrounds.

Some are schooled in the law; others are psychologists, special education experts and social workers who may be tapped by defense lawyers as expert witnesses. Early chapters tell, from two perspectives, the first hand story of defending an autistic adult man in such a prosecution. Chapters 5-11 question the validity of the registration requirements and the assumptions underlying same (the notion that mere possessors of pornography are likely to “graduate” to “hands on” offenses). But the most poignant chapter of all is the one by the autistic man, Nick Dubin, who became a felon for something he did only in the privacy of his own bedroom.

Clearly, one way to approach the problems outlined in this volume would be for legislatures to relax the laws for mere possession, to provide treatment options rather than mandated incarceration, and to acknowledge that the one-size fits all approach of the current statutes may not apply to those with an autism diagnosis. But in the present weaponized political environment, who will lobby for reducing penalties for possession of child porn? What sane legislator would carry such a bill? The answer seems obvious. In all likelihood, it will fall to individual lawyers and judges in particular cases to effect change — change that the contributors to this book amply demonstrate is sorely needed. This volume will serve as a resource in which all the thinking necessary to undertake this Sisyphean task is collected in one place. In this, the authors and editors have done a great service.

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

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