



Proxy Parent Foundation newsletter

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ISSUE 15

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PROXY PARENT FOUNDATION

Proxy Parent Foundation offers two services.

We are Trustee of the PLAN of California Master Pooled Trust, which is open as a trust vehicle for any disabled person in California.

We provide Personal Support Services for beneficiaries of our Special Needs Trusts who have a mental illness or brain disorder.

Just like a loving family, we coordinate public and private social services and medical care while providing family-like attention to help the person improve his or her quality of life.

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

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In This Issue

By the time these words are read, this most painful election will have ended and we will have elected a new president. And for all the rhetoric from both sides, as usual, we all will carry on. So let's all take a deep breath and do so. With that in mind, I am proud to introduce our three articles. There has been much discussion in our past newsletter issues of our PLAN of California Master Pooled Trust, whereby parents can set up a special needs trust and after they are gone, the inheritance they leave will begin providing for Proxy Parent Foundation Personal Support Services for their disabled child or children.

However, there is also a means for those services to commence for the beneficiary in the here and now, well prior to the passing of the grantors. That is the subject of our first article by Nancy Nigrosh, the wife of Bruce Lewitt, our Director of Social Services, and it describes not only how such services can be started but also provides examples of what those services may entail. The second article is a Legislative Update by Board Member Randall Hagar, on how the wheels keep turning in Sacramento and what to look out for in the coming months. His position as Director of Government Affairs for the California Psychiatric Association (CPA), leaves him especially equipped to grabble with and explain these issues and bills that will have effect on the mental health community, in one way or another, whether they pass or not. Last but not least is another book review by Board President, Joe DeCarlo, on the "The Mind-Gut Connection" and what it may have to do with mental illness. I hope you will enjoy reading them as much as I did.

How Can a PLAN Special Needs Trust Work Before It's Funded? What is a PAYG?

*By Nancy Nigrosh
Director, School of Writing for Film, Television
& Digital Media, Academy of Art University*

Parents, siblings and other close relatives seek out Proxy Parent Foundation (aka PLAN of California), because they've arrived at the need for a plan that can serve as a means to sustain the same kind of personal support they've been giving all along to a family member with severe and chronic mental health issues. Joining Proxy Parent Foundation's PLAN of California Master Pooled Trust can become part of a family's estate plan. Once a family joins, their beneficiary's Special Needs Trust can be funded at any time before, or, upon the grantor's passing. This streamlined process of joining the Master Pooled Trust includes a detailed assessment of a beneficiary's unique needs and resources. The assessment is an evergreen document that can be adjusted over time as a beneficiary's needs change while the resources of their trust essentially decrease, to be recalibrated to last as long as possible, ideally over the beneficiary's lifetime.

Often families who join Proxy Parent Foundation's Master Pooled Trust will need immediate assistance with their beneficiary's care. In that case, Proxy Parent Foundation offers a Pay As You Go program (PAYG). PAYG can offer Proxy Parent Support Services before a beneficiary's trust is funded. Proxy Parents



are persons who are familiar with the care of individuals with a mental illness, and who perform the same kind of care family members do – such as oversight of supplemental needs for food, clothing, medical treatment, and other personalized needs, as well as help the beneficiary interact with the public mental healthcare system.

PAYG is only available to families who have joined the Master Pooled Trust. Under the PAYG program, a grantor deposits funds that are calculated to last over a six-month period to Proxy Parent Foundation. The funds pay for the services of a Proxy Parent/Personal Support Specialist, as well as some limited supplemental expenses for the beneficiary.

Alan (not his real name), whose parents live out of state, became involved in a series of negative living situations, refused to take prescribed medication, and was prone to go homeless after bouts of drug use. His parents contacted PPF, established a SNT and funded a PAYG for the here and now. The Personal Support Specialist established a rapport with Alan, but Alan still refused to take medication. Alan's symptoms escalated to the point where his acting out was frightening and threatening to his neighbors, which led to a hospitalization. The family sought a Conservatorship, and the PSS put them in touch with the necessary legal services. The court established the Conservatorship and Alan was then placed in a locked Facility. Still, it was a struggle to get Alan to take his medication. His compliance was erratic, despite the best efforts of the nursing staff. The Personal Support Specialist assured Alan he would continue to bring him cigarettes and other supplemental needs but ONLY

IF Alan agreed to take an injectable form of his medication that he'd taken before and that had proven effective. Alan understood that this quid pro quo of no meds, no cigarettes was no bluff. Alan agreed to these terms and his doctor prescribed the injectable form of the medication. Today Alan is stable and living in a licensed but unlocked setting in the community where Alan's Proxy Parent Foundation Personal Support Specialist visits with him regularly and continues to act in Alan's best interests in the same ways a caring parent would. Please contact Proxy Parent Foundation for more information about its PAYG program.

Legislative Report

by *Randall Hagar*
Director of Government Relations
California Psychiatric Association



The 2015-2016 Legislative Session finished on August 31, 2016 and the period for the Governor to sign bills concluded on September 30th, 2016. A mindboggling total of 5,103 bills were introduced in the two-year session. At press time 2,156 bills were signed by the Governor, 245 were vetoed and the remainder failed to make it through the legislative process for one reason or another. The two-year session will be remembered for a number of widely heralded issues: adopting death with dignity legislation; removing the personal belief exemption for vaccines; spending priorities for cap and trade revenues; and, others.

Closer to home, 2016 legislative action approved \$2 billion in bonds to provide housing for people with severe mental illness, to be paid back through revenue from the 1% tax on the income of millionaire's (Proposition 63 also known as the Mental Health Services Act). Some controversy attached to passage of this legislation: if income for the Act were ever to drop precipitously, the bond debt payment could require money allocated to mental health programs to be reallocated for debt service meaning potential losses in currently available services. For the foreseeable future, though, this is not likely since the income from the tax has doubled in the last five years; most counties have significant amounts of unallocated MHSA funds; the number of millionaires has grown by 10,000 over the same period (meaning the taxable base has expanded); and, the bi-partisan Legislative Analyst indicates that the rate of revenues into the state MHSA account will continue to increase at least incrementally until at least 2020. Stay tuned!!

Another major event which played out in 2015-2016 was the establishment of 17 new county Laura's Law programs all approved after a 2014 law clarified that MHSA funds could be used for the services in these programs. Laura's Law requires court-supervised treatment for people who have a history of repeated failure to engage in treatment resulting in multiple hospitalizations, arrests, or threats or acts of grave bodily harm. For a small group of people this kind of treatment structure is the only pathway to stability. Counties must individually adopt these programs, and while the 18 extant programs make



these services available to just over 50% of the state's population, 40 counties lack them. There is more work to be done, but an extension of the authorizing legislation isn't one of them: AB 59 (Waldron) extends the Laura's Law program until 2022 and was signed by the Governor.

The California Psychiatric Association was very pleased that the Governor signed its signature piece of legislation for 2016 on September 23 – a measure, AB 38 (Eggman) - which establishes an early psychosis intervention pilot program for privately insured families. Research has shown that it is possible to intervene either before, or just after, a first psychotic break and significantly reduce the often severe and lifelong disability associated with illnesses like schizophrenia. The gamut of wrap around services required to achieve these outcomes are readily paid for by public programs, but private health insurance does not cover the full scope of services necessary. AB 38 would require a report to the legislature on 100 enrollees in the pilot who have private insurance — a study to be conducted by the long established and successful Early Detection and Preventive Treatment program at UC Davis. The expectation is that the pilot will demonstrate outcomes such as returning to and staying in school or employment as well as reduced psychiatric inpatient and outpatient psychiatric costs — so that private insurers will have an incentive to cover the full gamut of necessary services. Privately insured families now have to subsidize many of these services out of their own pocketbooks.

In addition the following are other mental health bills in the session with their disposition shown:

- Additional Requirements Foster Child Medication Orders, SB 253 (D-Monning) (Vetoed by the Governor)
- Restrictions on Psychotropics used for Dementia in Patients with Probate Conservatorships, SB 938 – (D-Jackson) (Failed passage on the Assembly Floor)
- Physician Health and Wellness Program for Substance Abusing Physicians, SB 1177 (D-Galgiani) (Signed by the Governor)
- Clarification that MHSA Funds can be used for Mental Health Crisis Services, SB-1273 (R-Morlach) (Dead: Administration All-County Letter Clarifying this as an appropriate use of MHSA funds made this bill moot)
- Augmented Loan Repayment Program for Psychiatrists, SB 1471 (D-Hernandez)
- (Dead: the Governor used funds targeted for this purpose, for other purposes)

Neurobiology of Stress. He describes the “brain-gut microbiome axis analgen’s to a super computer – one that can perfectly adjust to our ongoing changes in our internal and external work, and that has intricate connections to our immune system in our body”. In other words, the gut is like the second or little brain. Our nervous system in our gut has between 50 to 100 million nerve cells. The vagus nerve is nerve is a pathway for communications between the gut and the brain.

The intention when purchasing the book was to see if there is any relationship between bipolar, depression, autism and other mental illness and the gut. If so, we can develop treatments from these findings. Mayer’s findings were inconclusive and he says there are a lot of experiments underway, but most of the evidence is really speculative, however “in five years we should have better answers”.

The book, however, does have some good ideas on stress reduction, nutritional choices to reduce inflammatory potentials of your gut microbiota.

**Joseph DeCarlo is the father of a 42-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 the Proxy Parent Foundation and can be reached at joe@jdproperty.com.*

Book Review

By *Joseph DeCarlo**

The Mind-Gut Connection

by Emeran Mayer, M.D.



This issue we will focus on the book “The Mind-Gut Connection” by Emeran Mayer,

M.D. Dr. Mayer is the Medical Director at UCLA Oppenheimer Family Center for

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