



# Proxy Parent Foundation newsletter

SPRING 2022 ISSUE 26

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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, an email landed in my inbox from John Buck, former CEO of Turning Point Community Programs.

John is also a long-time

member of Proxy Parent Foundation's Board of Directors and himself a Proxy Parent. Turning Point Community Programs (TPCP) is a provider of integrated mental health services, employment, and housing options for a Northern California region, including Sacramento, and is the local provider there for Proxy Parents to our beneficiaries of our Special Needs Trust throughout our foundation's history.

John's email describes a cautionary tale of what can happen when a parent passes away before completing the process of setting up a Special Needs Trust with us. A parent hadn't signed the Joinder Agreement while she was still able. After she passed away, her ex-husband, the son's father, ignored her wishes for her Living Trust to be joined to PLAN's Master Pooled Trust. As a result, her son received no Proxy Parent services for many years. John's email made me reflect on an important decision I know many of you are facing. This decision for the future benefit of your disabled family member is more than financial, it's

also about designing and implementing responsible care. For this reason, I have spoken to many of you about joining our PLAN of California Master Pooled Trust. A Trustor's sudden passing can wipe out the best of intentions. For the beneficiary John was telling me about, the mother's signature would have changed everything. For the full story, see John's email published in this newsletter.

We also touch upon a different meaning of the word trust in this issue---from Proxy Parent Foundation Board Member and estate-planning attorney Baron Miller. Baron addresses a question from a parent about her son's refusal to let them talk to his psychiatrist. Also in this issue, Los Angeles-based Proxy Parent Lourdes Andrade focuses on how the strategies of time, patience and persistence helped her gain the trust of a mistrusting beneficiary.

### Email from Board Member, Proxy Parent, and former Turning Point CEO *John Buck*

*Bruce,*

*Some 30 years ago a committee of five parents of adult children interviewed me to determine whether Turning Point Community Programs (TPCP) would be the best local agency to provide Proxy Parent Foundation (PPF) services in a five-county region including Sacramento. All five committee members have since passed away including Tom Hoeffel (a former PPF Board Member who brought me onto the Board). One of the committee members, Delores, wanted*



# Who will care when I'm not there?

someone to look after her son David. I met David and started some personal services. One week before Delores's passing, she indicated that her trust was set up to fund PPF services but had not been formally linked to PPF with a Joinder Agreement. In a surprising deathbed reversal, Delores's trust came under the control of David's father, Delores's ex, who essentially shut me out of David's life for two decades. With his health failing David's father sought to bring me back into the picture. I began providing direct services a couple of years ago under a pay-as-you-go setup. David was especially fond of taking trips to the various lakes and rivers in the Sacramento area and he often expressed concern for his father's health. I was with David through his father's passing and his own inoperable cancer diagnosis some twelve months ago. Last Tuesday we took an hour and a half drive to Folsom Lake and the old town of Folsom. We had a good time. On Saturday, David fell quite ill and passed yesterday peacefully. It was an honor to fulfill the commitment I made to his mother some 30 years ago and a pleasure to have spent so much time with David.

One of the other family members on the interview committee was June F. She was very challenging and her advocacy and love for her son intimidated many. Two TPCP workers, separately, broke down in tears and requested reassignment so I provided the direct service for most of the last 30 years myself. June passed seven or eight years ago, and I continue to stay in touch with her son Mike by phone as he has been in Napa State

hospital for the last 17 years. He is my last PPF original client. Direct service for PPF has been gratifying to me and you and your support have amplified everything I have experienced. I want to thank you for being there with me over these many years! I plan to continue my support and efforts to spread the word about the wonderful work we do!

MY SINCERE APPRECIATION,

John Buck

## Q and A Time, Part 2

PLAN Board member and attorney Baron Miller has agreed to share answers to questions he receives concerning laws affecting those with mental illness. Readers are encouraged to submit their questions.

### Question:

My adult son is being treated for schizophrenia by the County Mental Health Department. I have been helping him for years and would like to be able to discuss things with his psychiatrist, but she won't talk to me, and won't even return my calls. Her receptionist says my son needs to sign an authorization, and he is refusing to do that. When I try to discuss this with him, he won't say anything except that he doesn't want me talking to his doctor. I realize I could make my assistance to him conditioned on him authorizing me to get information from his doctor, but there already are conditions

I have imposed – such as regularly seeing the doctor and taking prescribed medication – and I don't want to make him feel I am completely running his life, nor would I want to stop helping him if he still refused to sign an authorization. Is there any way I can get the doctor to just give me basic information so I can better assist my son?

### Answer:

This general situation is actually quite common. I don't know your specific history with your son and his doctors, but I will assume that you are every bit as well-meaning as you sound, that you have done nothing to justify the doctor ignoring you, that keeping you out of the loop is not being done for some kind of therapeutic reason, and that your son would benefit from the doctor sharing information with you.

It sounds like your son might be deriving some sense of autonomy by refusing to authorize the doctor to communicate with you. And possibly the doctor believes that is good and could even be promoting it. No one will talk to you, so you can only guess. An absurd situation for you to be in, and one I would think the doctor should be able to handle more effectively, although she is likely doing what she feels is best for your son.

There is no way to force the issue other than to threaten the elimination of something you are doing for your son as a lever to gain his cooperation, and it appears



# Proxy Parent Foundation

you are wisely refraining from doing that. We have to pick and choose our battles, and you are intelligently concluding that the overriding issue here is that your son see the doctor and take his meds.

The doctor is not violating any law, albeit she may not be providing optimal care to your son by excluding you, given that you may have information that would help her treat him. As she works for the county, she has superiors, and there is no reason I am hearing not to report her conduct to them, although that would not necessarily result in the situation changing.

There are exceptions to the rule that disclosure of information can be made to you only with an authorization. One is that the doctor could listen to you communicate to her – a one way conversation that could provide her with needed facts affecting your son's treatment. And you could propose that to her in a letter or email, or even send her periodic letters or emails giving her information you think is relevant and that she may not be getting. She might ignore it, but she might not.

Another exception is where a patient's cognition is impaired to the point where his refusal to sign an authorization is irrational and self-destructive, e.g., if your son had delusions that you were trying to harm him. Then the doctor could legally disclose things to you, but I don't think that is your situation. If it is, then that should be

reported by you to the doctor's superiors.

While my sympathies are with you, what you need more than that is a change in the law preventing medical providers from disclosing needed information to care providers without an authorization. A more workable and useful rule would be to allow medical providers to make disclosures when they believe that they would more likely than not be beneficial to their patient. Maybe check with your local NAMI on what efforts if any are being made to change the law, and possibly get involved in that worthwhile cause.

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**Article by Proxy Parent/Personal Support Specialist** *Lourdes Andrade*

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## Thanks for Listening

For decades, mental health issues were stigmatized and those experiencing them were often ostracized, neglected, and forgotten. Johnny is a 40-year-old with a history of homelessness, drug addiction, arrests, and hospitalizations, who was part of that demographic. He had become a part of the system where many feel alone, hopeless and confused. When I first met Johnny, he kept to himself and was distrustful. As a Proxy Parent/Personal Support Specialist working with him, he didn't trust me. I

knew I had to build that trust and relationship. Johnny was someone who didn't care about his upkeep, hygiene, or attire. I gave him space and time and encouraged him to share his thoughts with me. With time, patience and persistence, Johnny opened up to me. I found common ground with him in sports and music. I understood his needs and worked around him by providing support. We worked together in improving his personal appearance and I took him shopping for the first time. At first, Johnny was nervous and anxious. He expressed to me how he gets paranoid being around people and doesn't like it. He hated the malls. I listened to him and didn't want to overwhelm him. We took small steps and purchased a few clothing items and ate lunch together. Three years later, Johnny schedules shopping trips with me, asks the store staff for help, picks out his own clothes and freely orders his lunch and has improved his personal appearance. He likes to sing along to rap music from the 90s, which I do too. We have the best time singing karaoke. It takes him down memory lane which he loves to visit. He smiles ear to ear and it's impossible to hide his excitement. During our visits, Johnny always thanks me for listening and for being there for him. It's been amazing to see Johnny's journey and his growth and to remind him that he's not alone.

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ADDRESS CORRECTION REQUESTED



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receiving our newsletter by email. Thank you.  
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Enclosed is my Tax-deductible donation of

\$ \_\_\_\_\_

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