SPEAKER NOTES

Who Will Care When I'm Not There?

Summarized by Thomas T. Thomas

At the March 28 meeting, we heard from attorney **Baron Miller,** the father of a 37-year-old daughter with severe schizophrenia. "When she became ill, I learned how to set up my estate so that she would be taken care of when I died. Estate planning for parents with mentally ill children has become a specialty of my practice, and I've been doing it for about 20 years."

BARON MILLER

In the course of this work, Miller came into contact with the PLAN [Planned Lifetime Assistance Network] of California master trusts operated by the Proxy Parents Foundation.[1] The Los Angeles County Mental Health Association and NAMI of California jointly started the group about 30 years ago, but it is now an independent nonprofit corporation. Miller volunteers as a member of the board of directors, writes articles for their newsletter, and makes presentations about their trusts. A majority of the board members are family members with a mentally disabled child; so the organization remains focused on its mission and not on money or advocacy.

Proxy Parents administers Special Needs Trusts (SNTs), which answer the question "who will care for my child when I'm not there." Depending on the severity of the child's illness, Miller said, a parent is left with several options for future care.

Simply making a gift of assets through a will or other estate planning document is problematic, because people with mental illness don't always have good judgment about spending their money. And the assets will adversely affect any public assistance benefits. To be eligible for Supplemental Security Income (SSI) under the Social Security Administration, which includes benefits under Medi-Cal, a person must be disabled, unable to work, and own assets in his or her name of less than $2,000. A large inheritance would disqualify the child from receiving these public benefits.

Leaving assets to a sibling or other relative, called a "keeper," with instructions to care for the disabled child is also problematic. The gift then becomes taxable; the assets would be subject to the keeper's debts; and when the keeper dies, they would pass on to others through the keeper's estate planning. Also, Social Security would consider the assets as belonging to the disabled child and disqualify him or her from benefits.

---

[1] See www.proxyparentfoundation.org, or call 888-574-1258 for more information.

A third option is a formal arrangement with the keeper to set up a trust for the benefit of the disabled child. But again, Social Security would consider the trust among the child's assets.

The fourth option, and the best in Miller's opinion, is the Special Needs Trust. The trust is established for the disabled person and gives the trustee—the person operating the trust—absolute discretion over how to use the income and principal within certain guidelines. These include using the assets to supplement the public assistance benefits in a way that will not disqualify the beneficiary from receiving them, maintaining the assets for the beneficiary's expected lifetime, and investing them for maximum return while keeping the principal safe.

The big question then becomes, who will serve as trustee? "It's a big job requiring big skills," Miller said. The trustee must be an expert in mental illness, knowing the disease and how the loved one thinks and reacts. The trustee must also be expert at handling money, to preserve the fund and make it last. The best trustee might be a family member who knows the beneficiary. "This is not always a bad thing to do," he said, "but the problem is that a family member might not want to take on the job, and the situation might create conflicts and friction between the family member and the beneficiary."

Professional organizations and people exist to serve as trustees. Banks and other financial institutions might be good at handling money, but they may not understand mental illness or the needs of the disabled beneficiary.

Proxy Parents offers both financial expertise and personal support. Originally, they worked with two California banks to manage these trusts; now PLAN manages the trusts itself, holding and investing the money with the dual aims of preserving and protecting the assets, and dispensing them for the beneficiary. The support role is carried out by Proxy Parents' network of "personal support specialists," who work like case managers.

The specialist meets regularly with the child, takes him or her out to lunch or dinner and to medical and dental appointments, helps make purchases, intercedes in case of problems, and represents the child—in fact, does almost everything the living parent does now.

The specialists are professionals working under contract with Proxy Parents. Currently, while the organization holds trusts for hundreds of parents in the Bay Area, it is not actively administering any trusts to beneficiaries in Alameda County; so no personal support specialists are under contract here. In other counties, parents can contract with Proxy Parents to provide services on a "pay as you go" trial basis, while they're still alive, to make sure they and their disabled child are comfortable with the service.

"I'm personally sold on Proxy Parents," Miller said, "and I think they're the best people for this. But you have to feel that way—and you may not." He then opened the floor to questions.

Q. What is the ballpark figure for retaining a personal support specialist?

A. In Alameda County, such a professional case manager would charge about $100 an hour. Proxy Parents adds $15 to $20 on top of that.

Q. How much money needs to be in the SNT?

A. That depends on the age and life expectancy of the child, history of the illness, situation of other family members, and your financial condition. You might want to leave a disproportionate share of your estate to the disabled child in the SNT, for example, which could then name other siblings or relatives as beneficiaries after his or her death. (The child cannot pass on the SNT's assets through estate planning.) Generally, given the unpredictability of a mental illness, it is not possible to put too much into an SNT. PLAN used to recommend a minimum trust of $150,000, but they will take trusts with lower funding, depending on the options.

Q. What does PLAN charge to administer a trust?

A. It's a percentage of the assets. That percentage changed recently, but the cost is still less than other financial institutions in Miller's experience.

Q. What taxes does the SNT beneficiary pay?

A. The trustee does not pay the money out as cash but instead buys the beneficiary various goods and services, so there is no tax effect. If the beneficiary receives more than $20 a month in cash, the public benefit is reduced by that amount, up to $260 a month—although Medi-Cal benefits will continue.

Q. Are the trust assets pooled or separate under PLAN? And how are they managed? Are they protected from embezzlement?

A. The trusts are held in separate accounts. Generally, they are managed in money market accounts, which are federally insured, and in government bonds. As to safety, you never want to trust anyone too far, and even bank employees can embezzle. But the bank is liable to make its customers whole, and PLAN has insurance for this reason.

Q. Can a parent fund an SNT while he or she is still living?

A. The trust can be set up anytime. Sometimes, a parent wants to detach him- or herself from the child financially and let a trustee deal with the situation. Sometimes, there may be several people—grandparents, aunts and uncles—planning gifts for the disabled child, and then a single SNT can be set up to receive them. The trust does not have to be funded at the time it's established.

Q. Does PLAN operate outside California?

A. No, because they don't feel equipped to administer trusts under different state laws. But there are similar organizations in other states which offer other options.

Q. What does it cost to set up an SNT?

A. That depends on the situation, what's going into the trust, and how complicated it is. The cost can range from $1,500 and upwards. Simply drafting the trust documents costs about $1,000.

Q. Suppose I want to save on the cost of those support services and name my sister as a co-trustee?

A. PLAN only works under their master trust, which designates the personal support specialist as trustee. However, they do want an advisory person, either volunteer or paid, to be named as a contact in the trust documents. Ideally, this should be someone who knows and cares about your child. The specialist values the input and advice this person can give.