-SPEAKER NOTES

Explanation of Special Needs Trusts

Summarized by Thomas T. Thomas

The presenter at our August 28 speaker meeting, attorney **Stephen Dale,** is an expert on Special Needs Trusts (SNTs). His website, https://dalelawfirm.com, contains several educational videos which will be helpful as you consider and/or initiate this process, so crucial in planning for the future of your ill relative.

"Nobody volunteers for this," Dale said in opening his presentation. "We're all drafted one way or another."

He has dealt with developmental and behavioral health disabilities all his life. Dale is the third generation in a family of institutional workers at Agnews Insane Asylum in Santa Clara, where he grew up on the grounds. He said that the system of institutional care—which ended with community-based care programs starting in the Kennedy Administration—was not all bad but tended to degenerate toward abuses. But community care without real community living and involvement is not much better.

Dale trained as a psychiatric technician and was a nurse for 17 years before getting his law degree. Once out of law school he interned with the Disability Rights Education and Defense Fund, where he worked to win lawsuits and get settlements for his clients—and learned that as soon as they won, they would lose their public benefits. He got involved in Special Needs Trusts and learned an appreciation for these benefits. He did note that Supplemental Security Income, which is one of the main benefits for those with disabilities, is a necessity for many people, but it's not a good program.

Dale's practice morphed into estate planning and planning for people with disabilities, especially with SNTs. He serves as a trustee for many of these plans, and he also established the Golden State Pooled Trust, which now is responsible for 213 beneficiaries. His law firm uses the WealthCounsel software for setting up trusts.

The biggest issue with these trusts, Dale said, is not the document itself but who will serve as trustee. The SNT should create a distribution plan that meets the beneficiary's needs and provide a check-and-balance situation of accountability to make sure the beneficiary's quality of life is maintained. He warned that changes were coming to various laws that would make maintaining benefits more complex.

He asked the audience to imagine that they had a 17-year-old daughter who had schizophrenia. She will need some level of assistance her whole life. You set up a third-party trust to provide for her needs in the death of your death or incapacity. But people are living longer, and she can expect to survive to age 70 or more. In that time, benefits laws like SSI and MediCal[1] will change. Local social services will change. Her condition may change. Her advocacy system—which might be subject to outside predators—may change. Attitudes about mental health—which are

[1] The California version of Medicaid.

subject to stigma and villainizing—may change. And the resources available to her may change.

In all of this you need to know how your child will be evaluated to take advantage of available public benefits. Dale then identified the main programs:

Supplemental Security Income (SSI) is a needs-based program of the Social Security Administration (SSA) that provides people with disabilities the money to pay for food and shelter, including utilities. Right now, SSI pays $1,182.94 per month. To qualify, the person must meet the criteria for disability, income, and resources, and parts of the law will change in October 2024.

Disability is not just a diagnosis, and it does not apply to SSI after age 65—where the person's status changes to "elderly." To be considered disabled, the person must be unable to engage in substantial gainful activity (SGA) for at least a year or more. As of 2020, the SGA for a non-blind person is earning more than $1,550 per month.

Under SSI, any cash gifts you give your ill relative must be reported as income. Any unearned income reduces the SSI benefit dollar for dollar after the first $20. Earned income reduces the benefit one dollar for every two dollars earned after $65.

In-kind support and maintenance under SSI, such as food and shelter, reduces one-third of the federal benefit plus $20. As of 2023, this was a dollar-for-dollar reduction up to $334.33. As of October 2024, in-kind gifts of food are not counted, and the reduction for shelter is limited to $334.33.

The resource test under SSI includes anything that can be converted to cash. If the person has more than $2,000 available on the first day of the calendar month, the SSI benefit is lost until that amount is reduced. A person can have ownership interest in a home provided it is their principal residence. The home can have any value, but maintenance on it is limited to the SSI income of $1,182.94. As of March 2005, the person may have household goods of any value, one automobile of any value, a life insurance policy with a cash surrender value of only $1,500, a term life insurance policy of any value, a burial plot of any value, but burial expenses limited to $1,500.

"Getting someone into a safe living situation," Dale said, "is most of the game."

MediCal/Medicaid is a needs-based program using SSA funding which is administered at the state level. The individual must have limited resources, but the program does not count income. If the beneficiary gets at least $1 in SSI income, then they automatically get the full scope of Medicaid coverage for free.

Social Security Disability Income (SSDI) is not needs-based. To qualify, the person must have worked the required number of quarters and paid into Social Security. There are no income or resource limits, but the person must have a disability.

Childhood Disability Benefits is an SSA program for children who are disabled before age 22. The benefits become available when the parent dies or is disabled, and the child is not earning above the level of SGA. The child gets one-half of the parent's benefits when the parent becomes disabled and three-quarters when the parent dies. At that point, the child's SSI income is eliminated, and their SSI-based MediCal is reviewed.

"The problem," Dale said, "is determining exactly when a disability based on mental illness begins."

The elements of a Special Needs Trust are that it is a contract to control property to meet some objective of the beneficiary. The trust document is drafted so that the assets are not considered "available resources" in determining the beneficiary's eligibility for needs-based benefits. Third-party trusts and estate planning can be established by anyone other than the beneficiary or their spouse. The trust can be revocable and amended by the grantor. At the end of the beneficiary's life, there is no requirement to pay back MediCal benefits from the trust, and the remainder can be paid to the further-named beneficiary. The SNT may be a testamentary trust within the grantor's living trust, or it can be a standalone trust with pour-over provisions in the grantors living trust or will. The trust allows the grantor to customize the administration of the assets.

"The big issue," he said, "is planning for expenses with a home left in the trust."

Pooled trusts are like a cross between a 401(k) and an SNT. The grantor signs a joiner agreement to the master trust with information about the beneficiary and what the grantor wants to do. The pooled trust cannot accept all types of assets, such as real property, vehicles, or business interests. And it cannot provide customized investment options or opportunities. The benefits of a pooled trust are that it is good for smaller trusts; it maintains the beneficiary's MediCal qualification for client's over age 65; and the annual fees are lower than for a private trustee.

Choosing the right trustee, the trust's management team, is essential. It is common to name a family member, but the position requires a lot of work and responsibility. And sometimes the beneficiary does not always get along with other family members. "Getting the right personality mix between trustee and beneficiary is a lot like setting up a blind date," Dale said.

One approach is to set up the trust with a private professional person, a pooled trust, or a bank but with oversight by a family member. That oversight can be an individual or an advisory committee, who can amend the trust and replace the trustee as necessary. The beneficiary of an SNT cannot do this. Dale noted that a pooled trust like Golden State is essentially a call center, and the grantor needs to set up a beneficiary advocate as well.

When doing your planning, he said, your primary focus should be who will manage the trust, which may be more important than what the document does. "You are setting up a care plan," he said. When interviewing firms to prepare the SNT, ask what experience they have in finding people to administer their trusts.

Q. What are the costs of setting up a Special Needs Trust?

A. The Dale Law Firm charges $3,500 for an SNT alone and $5,500 for the full package of a living trust and an SNT. But the firm currently has a backlog of clients. If you want to contact Dale himself, send an email to steve@dalelawfirm.com.

Q. What do professional trustees generally cost?

A. A usual billing would be $150 to $200 per hour—but not everything is done by the trustee him- or herself. Professional trustees charge by the hour, while a corporate trustee like a bank usually charges by a percentage of assets, which usually includes the cost of money management.

Q. Would you advise setting up a professional trustee before you die?

A. That would be a great approach. Death is a traumatic time, especially for your child. Getting a trustee ahead of time lets you see how they get along and assures your child that they will be taken care of. A good care manager is worth his or her weight in gold.