

## Planning for Your Disabled Family Member's Financial Future

*Summarized by Thomas T. Thomas*

Caring for a family member with mental disability can be a full-time job: housing, treatments, prescriptions, finances. Many parents worry what will happen as they get older, and eventually when they are no longer available to provide the necessary direct support. At our September 22 meeting, we heard from attorney **Susan St. Amour**, who has a private practice in San Francisco, and then from **Akio “Joe” Shimizu**, Bay Area representative for PLAN of California, a CAMI-sponsored financial program.

Susan St. Amour specializes in disability law, estate planning, and conservatorships for families with disabled children. She herself has a disabled child, a daughter with quadriplegia, and has served on the governor's task force on disabled children.

“Estate planning for these families is different,” St. Amour said. “While they have the same opportunities as other families to use wills and trusts, they also can use the special needs trust [SNT], which is designed to preserve the means-tested public benefits available to a person with disability.”

She distinguished between public entitlements and means-tested benefits. The former—like Social Security retirement and Social Security Disability Income (SSDI), which also automatically entitles the person to Medicare benefits 24 months after filing—are independent of the disabled person's ability to pay. Medicare, however, does not provide for long-term care or for outpatient prescriptions, and only provides up to 100 days of psychiatric care per year.

Means-tested benefits—like Supplemental Security Income (SSI), which entitles the person to Medi-Cal—provide somewhat more complete coverage but are available only so long as the disabled person meets financial eligibility requirements.

One means-tested program is In-Home Support Services (IHSS), administered by the California Department of Social Services under Medi-Cal. IHSS provides for any kind of care required to meet the disabled person's needs, up to 9 hours per day or \$283 per month. There is separate disability screening for this benefit, and the agency is strict in adhering to its guidelines, but the means testing is covered under SSI.

Under means testing, a disabled person may:

- Own a house of any value, provided it is his or her primary residence.
- Own a car of any value, provided it is equipped for a disability. Otherwise, the maximum allowed value is \$4,500.
- Own household goods with a total value not exceeding \$2,000. “However,” St. Amour said, “that amount represents the fair value of the goods, not their purchase price or replacement value.”

- Own liquid assets—that is, stocks, bonds, or cash—worth no more than \$2,000.
- Own property which is not the primary residence provided it is worth no more than \$2,000. Such property will also be considered part of liquid assets.
- Receive income of no more than \$660 per month. “Every dollar above that,” she said, “must be available to pay medical costs. But the costs are only paid as services are used.” For example, if the person earned \$860 in one month and used \$50 in medical services, he or she would only be obligated to pay \$50 out of the \$200 excess. If the next month there was no excess income and the person had \$100 in medical expenses, Medi-Cal would reimburse the expenses in normal fashion.
- Receive no more than \$20 per month in non-earned income, such as gifts and trust distributions other than those from an SNT.

“Special needs trusts were developed about 20 years ago,” St. Amour said. “Before that, parents were advised to disinherit their disabled children in order to preserve their access to means-tested benefits. Instead, parents were supposed to give the disabled child some token of sentimental value, while leaving their money to siblings.

“Sometimes, parents leave a ‘morally obligated’ gift to the other children, with the understanding that they will care for the disabled child. But this approach has potential problems, because the siblings have their own lives and sometimes their own financial difficulties.”

A parent can set up what is called a classic support trust for a disabled child, but should do so only if the child can live independent of any means-tested benefits. “We urge our clients to be conservative in estimating the child’s future need for such benefits,” St. Amour said. Under this kind of trust, a trustee or professional trust manager holds the money for the beneficiary and pays him or her the income earned on the estate’s principal. The assets belong to a legal entity, the trust, and not to the beneficiary.

A special needs trust works much the same but, because the payments are directed to specially defined needs, they do not count toward the \$660 per month in income or \$20 per month in gifts. The trust can provide for food, shelter, and clothing of any actual value, which SSI reckons with a cap of \$184 per month and reduces the publicly paid benefit accordingly. The defined needs under the SNT typically include extra medical care, dental care, travel expenses to visit relatives, computers and video games for recreation, and so on. A professional fiduciary reviews the child’s requests for services and goods to supplement the standard of living, then arranges for payment to the provider or vendor.

Trusts can be established in a parent’s will so that they come into effect at the time of death and are funded by the child’s share of the estate. St. Amour has developed trust language to allow that, if a disabled child requires means-tested benefits, the trust functions as an SNT but otherwise is treated as a classic support trust. The parent’s will can also designate where the trust funds are to go at the disabled child’s death, or it can give the child power of appointment.

An estate plan typically costs \$1,500 to \$3,000 to set up. “It’s usually better to use a professional fiduciary to administer the trust,” St. Amour said, “rather

than try to train a family member in all the rules of running a trust.” She said a professional will either charge a percentage of the amount of money managed in the trust, or an hourly fee—usually \$45 to \$95 in California. Costs under the latter system can actually decline as the manager settles into the role and can delegate routine duties to lesser-paid staff.

Joe Shimizu then explained the program offered by the Planned Lifetime Assistance Network (PLAN) of California. The program has been in operation about ten years, is supported by the California Alliance for the Mentally Ill (CAMI), and has a representative of the Los Angeles Mental Health Association on its board. Funds are administered by Citizens Bank in Pasadena and by Westamerica Bank in Sacramento. PLAN is part of a national alliance, so its benefits are available if the family moves out of state.

After the parent pays a \$1,000 deposit, the program offers two types of service: pay-as-you-go, and a special needs trust.

Pay-as-you-go provides support to the disabled child when the parent is out of touch, such as on a business trip or vacation, or lives at a distance. The parent and PLAN’s service contractor prepare a services agreement based on the number of contact hours required. The contractor, who wears a beeper, will intervene in resolving a crisis, help the child build social networks, find housing, and obtain public benefits.

At the parent’s death, PLAN establishes an SNT for the lifetime of the disabled child. The service contractor prepares and implements an individual care plan and maintains the standards of service.

For administering the trust, Citizens Bank charges 1 percent of the trust balance per year; Westamerica charges 1 percent of assets over \$1,500. After the beneficiary’s death, the plan charges 2.5 percent times the number of years of service—up to 25 percent of the balance—as an endowment for continuation of the program. The trust document names any of the beneficiary’s surviving siblings as successors to PLAN for the balance in the account.

The fees and endowment may make PLAN less attractive for a large family with many siblings to share in the estate. But its feature of providing a service contractor who becomes familiar to the child during the parent’s lifetime may be attractive to those with an only child who is disabled.