

When the Caregiver Can No Longer Provide Care

Summarized by Thomas T. Thomas

One of the greatest challenges that trustees of special needs trusts face when providing for a beneficiary with mental illness is the lack of appropriate case management services. **Stephen Dale** discussed how to create a special needs trust that incorporates case management for the beneficiary in order to ensure the best possible quality of life. **Christine Grabowski** will discuss the advantages of coordination between the trustee and [East Bay Innovations](#) (EBI) Case Management Services.

Stephen Dale is an attorney who focuses on special needs trusts and is the trustee of the [Golden State Pooled Trust](#) (GSPT). His interest in mental health began early in his life, because his family worked for three generations in California's state hospitals. He himself worked for 17 years as a psychiatric technician, later becoming a civil rights attorney, and eventually focusing entirely on estate planning for persons with disabilities, with a major focus on special needs trusts.



STEPHEN DALE

When the hospitals were shut down in the 1960s, Dale said, the intention was to move patients into the community, where they would be served by programs and halfway houses—but none of those services were adequately funded and none are left. “A return to the hospitals just won’t work in today’s world,” he said, “but neither does community treatment and the promise of making these patients part of the community with no programs.”

He pointed out that special needs trusts (SNTs), which provide for a beneficiary’s care, don’t generally work when a sibling or family member is named as the trustee, especially in cases where the beneficiary has mental health issues. The better course is to hire a professional fiduciary to manage the trust and have a family member as “trust protector,” overseeing the fiduciary. But neither family members nor fiduciaries are experts in the local programs and resources needed to provide quality of life for a person with mental illness.

What EBI and GSPT propose is a new combination of services: both fiduciary and case management, to provide quality care from existing programs and community agencies with the resources you have in a changing environment.

Dale and Grabowski are looking for support in their quest to spread this model as a better way to serve SNTs outside of Alameda County and across California. They call this program the “Life Passage Planning Project.” It is a non-profit effort funded by the May and Stanley Smith Trust and Poses Family Foundation and

overseen by Stetson University's College of Law.

Although East Bay Innovations is working with Golden State Pooled Trust on this project, they are available to work with other SNTs and programs.

Christine Grabowski is Director of the Life Planning Program with EBI, which has been offering case management services for 25 years, mostly for people with intellectual and developmental disabilities (IDD). She started out as an Independent Living Skills instructor in 2008. She began working part-time as an instructor in independent living services, and over the course of three years worked her way through several positions, including Assistant Director of Independent Living Services and Director of Supportive Living Services. In November, she entered her new role providing case management and advocacy support.



CHRISTINE GRABOWSKI

EBI currently serves about 250 people in Alameda and Contra Costa counties, most of them with developmental disabilities who are served by the Regional Centers of the California Department of Developmental Services.¹ EBI is already delivering services to about 50 people with mental health issues.

The organization has a “person-centered” approach, forming a long-term relationship with the beneficiary in order to understand his or her needs. Although EBI has no control over funds in the special needs trust and does not authorize spending, they can provide benefits management, including MediCal and Medicare, Supplemental Security Income (SSI), State Disability Insurance (SDI), and manage housing support; supported living services (SLS); and in-home support (IHS). They also help plan for independent living, including training for budgeting, shopping, nutrition, and meal planning.

EBI is not itself a caretaker organization but will work with local caretakers and agencies. Dale pointed out that most professional care managers, social workers, and registered nurses have more experience with seniors and their needs than with the mentally ill. Grabowski admitted that EBI is new to working with fiduciaries and SNTs, and its services are currently more aligned with independent living than with supported living situations.

The program's services are offered through a three-step process:

1. Assessment of the beneficiary's needs, including an assessment form, interviews, and a background check in support of housing requirements.
2. Creation of a delivery plan based on those assessed needs.
3. Periodic re-evaluation and modification of the delivery plan.

EBI's case managers will maximize the use of publicly funded services and generic resources; locate affordable housing; access health care and assist clients in following treatment plans, including taking them to appointments; advocate for and maintain public benefits; assist with recruiting, hiring, and training in-home workers

¹ Patients with mental illness do not qualify for Regional Center programs.

but not hire them directly; address safety at home and in the community; promote activities and opportunities for enhancing quality of life; and maintain case records and document expenditures for monthly reports to fiduciaries.

The last point about documenting expenditures is important, Dale said, because Social Security intends to review every expense made by the beneficiary. EBI can teach participants in independent living how to keep track of their receipts.

“We want the beneficiary to be as independent as possible,” Grabowski said, “and we will go all-in to teach them the skills they need.”

At the same time, EBI’s goal is to extend the life of the trust. As part of the re-evaluation process, they will phase out services as needed to achieve this.

Q. How much should you put into a special needs trust? And what happens when the funds are used up?

The funding depends on the age and situation of the beneficiary, so there is no rule. Many bank trust departments expect to manage amounts of \$250,000 and up. When the funds run out, services end, but EBI is conscious of costs, seeking the best quality of service for the lowest cost. And as funds begin to run out, they can focus on vocational training.

Q. What do these services cost?

An attorney may charge \$1,500 to \$2,500 to draw up a special needs trust. A professional fiduciary trustee may charge 1.5% of trust assets or about \$1,500 per year. Beneficiary case management can cost about \$180 per hour, but EBI seeks programs that can easily adapt to deliver these services and can usually find better quality at a lower rate.

Dale warned against thinking of the SNT as a “magic document.” The trust is only as good as the people administering it, and you are buying their experience in dealing with the mentally ill and in case management.

Q. Does EBI have the resources needed to deal with mental health issues?

The program has staff with degrees in both psychology and social work, as well as registered nurses. Most are in training for advanced degrees. Everyone in the program gets training in mental health issues, benefits, and substance abuse. Some have experience with homelessness. However, based on the personal assessment, they won’t work with patients who present a serious safety issue.

Q. If the beneficiary dies early, is money left in the trust be collected by SSI? And if the beneficiary is found at fault in an accident, is the trust money forfeited?

No, the trust money is protected. At the end of the beneficiary’s life or need, the amount left goes wherever the trust document directs it.

Q. Can the attorney who draws up the SNT become the trustee?

Some do. Golden State Pooled Trusts doesn’t, because that has the appearance of self-serving.

Q. Do I have to be part of GSPT to get case management services from East Bay Innovations?

EBI can work with other pooled trusts or private fiduciaries, based on individual assessment. The SNT does not need any special language to delegate duties to an agency like EBI.