

Life Care and Estate Planning for a Special Needs Child

A life care plan should be an essential element of a family's estate plan if they have a special needs child regardless of the age of the child. The goal of the life care plan is to provide a comprehensive assessment and outline current and future needs (and associated costs) for an intellectually challenged or physically disabled child. The intent is to foster as much independence as possible while providing a safe and appropriate environment for them. During the estate planning process, families use the plan as a guide to locate necessary services and additional resources which may be needed in the care of the child.

WHY IS A LIFE CARE PLAN IMPORTANT?

There are several important considerations through the planning process. Typically, these children are receiving some services which are government funded. Parents should consider, however, that public benefits are often lacking and usually need to be supplemented to cover the cost of care. Additionally, benefits and the individual's needs will likely change over time.

To protect the disabled child's (or adult) benefits, it is helpful to use the life care plan to incorporate a special needs trust or a supplemental needs trust. Such a trust serves two primary functions – managing the funds for someone unable to do so due to a disability; and preserving the individual's eligibility for public benefits, whether

that is Medicaid, food stamps, Supplemental Security Income, public housing, CAP Services, etc.

Throughout this process, it is also important to budget for a case management service to effectively implement the plan. Typically, the case manager would have a rehabilitation or nursing background who could serve as a liaison to the estate attorney or financial planner who is managing the funds. The case manager could also assist with coordination of care, evaluating additional therapy or equipment needs, a change in medical condition, additional support needs or to respond to a crisis.

DESIGNING THE ESTATE PLAN

What typically happens in the estate planning process is I will work in collaboration with the family and attorney to provide a life care plan which outlines all the necessary services which may be required. Many times, these plans will look very similar to ones developed in other litigated settings (such as personal injury, medical malpractice, etc.) An example of some critical components (and costs) which need to be considered and addressed include:

- Case management services.
- Home placement versus facility, group home placement, or retirement housing.
- Respite care.
- Support care needs (nurse, nurse assistant, companion).
- Equipment needs.
- Transportation.

Once the life care plan is completed, it is reviewed with the client and the attorney but ultimately, the parent or the guardians use the plan as a guide in decision making.

CASE STUDY

I had the opportunity to consult on a case involving a young adult with a diagnosis of bipolar disorder and substance abuse. At the time of our meeting, she continued to reside with her parents in a highly structured setting. Because she continued to demonstrate poor judgment and decision-making skills, the parents asked for me to consult with and develop a plan.

Throughout the process, I completed a comprehensive assessment of their daughter, considered her current resources, and her desires, along with her parent's wishes and concerns. It was important for the daughter to have input during the process and for me to evaluate and provide options for consideration. We discussed the possibility of supported apartment living, group home, and independent living. Several scenarios and cost were then submitted with ultimately the family made decisions in consultation with their attorney.

The goal in this case, as with most estate plans for special needs children was to allow her as much independence as possible while protecting resources and the estate.

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