

The following materials are from the Achieving Independence Guide used by the Dale Law Firm for its clients. While these materials do focus on the needs of persons with disabilities in California, in the presentation we will explore how deinstitutionalization has affected development of services across the country and in Texas.

Defining the Challenge

When someone is asked to explain the purpose of a special needs trust, the typical answer is “to protect entitlement to public benefits.” That fails to address the big picture. The true objective of a special needs trust should be to optimize quality of life for the beneficiary. Most of the families we work with are dedicated advocates for their loved ones. Their overall goal is to provide the best quality of life possible, and maintaining benefits eligibility is merely one tool available for pursuing that broader goal.

My first task when counseling families on special needs issues is to help them understand the challenges that need to be addressed when developing a plan that potentially has a long time horizon.

An Introduction to Kathy



Kathy's Story

Imagine that you have a 17 year old daughter named Kathy

- Kathy has a disability and is going to need assistance for the rest of her life
- Kathy is likely to have a normal life span and could live 70 years or longer



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Imagine for a moment that you have a 17-year-old daughter named Kathy. Imagine that she has a severe disability and is going to need assistance for the rest of her life.

If, for instance, Kathy has autism but is otherwise healthy, she may live to be 87 years old. If you visit my office to create a special needs trust for her, we need to prepare a plan that, in the event something

happens to you, will provide for her needs for the next 70 years. Think of the enormity of that task. How are we going to provide for Kathy for 70 years in a world where there will almost certainly be many changes in public benefits, programs and services?

Many special needs trusts fail to take such changes into consideration. We, on the other hand, want to ensure that the plan we create for Kathy adapts as benefits and services change over the course of her life.

Public Services Will Change Over the Next 70 Years

One of the functions of a special needs trust is to supplement services provided by programs in the community. The next challenge that many parents grapple with is determining how much to set aside for that purpose. There are countless variables that may have profound consequences when making this determination. For instance, if Kathy is diagnosed with a developmental disability and is receiving regional center benefits in California, she is entitled to

appropriate services under what is called the Lanterman Act, which is funded primarily by the state and federal governments. The Lanterman Act, under today's rules, entitles all persons with developmental disabilities to appropriate housing and supports paid for by the regional center system. If it became necessary for her to move to Texas, there are currently long waiting lists for services, including residential services, and her trust would need to be funded with much more in order to achieve the same level of support.

In addition, even if Kathy remains in California, there is no guarantee that the programs she is currently entitled to will be there for the next 70 years or that the quality of the services will be maintained. Community programs for persons with developmental disabilities in California have been subject to many freezes and cuts over the years, and the providers of those services have not had a cost-of-living increase in more than a decade.

If Kathy has a psychiatric disability such as schizophrenia, in all likelihood, her community provides much less in support than if she has a developmental disability. All too many communities have few, if any, residential programs serving those with mental illness. Mental health services in California are currently undergoing an expansion, but huge improvements are still needed to provide supports that come close to those provided by California's regional center system for persons with developmental disabilities.

If Kathy has a physical disability and needs attendant services to assist her with basic activities such as dressing, transfers or bathing, she is likely to qualify for In-Home Support Services or IHSS. IHSS is a Medi-Cal-based program that is essential for many persons with disabilities and seniors, and allows many recipients to live in the community, rather than in nursing homes.



Our Quest

How do you provide for Kathy for 70 years when:

- We don't know what benefits will be available or the eligibility rules
- We don't know if the agencies out there will be available over the beneficiary's lifetime
- We don't know the best choice for who should serve as trustee

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