



## **How to Get Started with Special Needs Planning**

**By Kelly A. Thompson, Esq.**

Given packed schedules, fragmented services and lack of information, how can families get started with special needs planning? A University of Illinois study found that fewer than half its respondents had done long-term planning for their children with developmental disabilities.

### **Getting Started**

While the challenges are significant, the reality is that, due to healthcare advances, individuals with disabilities are increasingly outliving their caregiver parents. While that may seem a distant concern to some families, it's important to start planning as early as possible. Depending on the child's needs, ensuring their long-term quality of life can be expensive and complicated. But how to begin?

You might begin by talking to other parents who are facing similar situations. How did they get started with special needs planning and what advice can they offer? The transition counselor at your child's high school should also be able to help. Be on the lookout for presentations on special needs planning offered by nonprofits, such as chapters of The Arc or local pooled trust programs.

### **Approaching Milestones**

Consulting a special needs attorney is also a good place to begin, since they can provide a framework for comprehensive planning. Families frequently have their first contact with a special needs attorney as a child approaches their 18th birthday. That's because, in most states, 18 marks legal adulthood, at which point parents may no longer have access to the individual's health, educational, legal and financial records unless they take prior action.

It's a time to consider whether or not establishing a power of attorney, health care proxy or guardianship might be appropriate. Given a loved one's circumstances, what would provide the right foundation for independence, while ensuring their security and enabling parents to assist with important decisions? This is also when most individuals with qualifying disabilities may become eligible for Supplemental Security Income (SSI), so understanding the ins and outs of public programs becomes critical.

In addition to mapping out the benefits landscape—which could also include SSDI (Social Security Disability Insurance), Medicaid, Medicare, food stamps and more—a special

needs attorney can guide families through the considerations that will determine which services their child will need throughout life and what costs will be involved.

Will their child be able to work? Will they require full-time care? Where will they live? What sort of social life are they likely to want? Based on those answers, they can determine what will be covered by public programs and what must be paid for with private funds. An attorney can explain how a [special needs trust \(SNT\)](#) and/or [ABLE account](#) can be used to pay expenses without jeopardizing eligibility for important means-tested government programs. They can begin discussing [funding sources—insurance, investments, bequests](#)—and the possibility of involving a financial planner in order to determine the best way to accumulate the necessary assets.

A special needs attorney can also help families think through the “circle of support” that will be available to the child when parents can no longer act as caregivers. Will siblings be able to help out? Who should be trustee for a special needs trust, a highly responsible role with sole discretion to disburse its funds? What about successor trustees when the original trustee is no longer willing or able to perform their demanding duties?

A good special needs attorney will also have developed deep ties with care managers, therapists and many other service providers within the community. As a result, they can be an invaluable guide to other resources needed by the individual and family.

Taking that first step towards long-term special needs planning may seem daunting. But it’s the best way to ensure that a loved one with disabilities can remain financially and socially secure.

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