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Special Needs, Special Knowledge

Estate planning for families with special needs takes expertise and life insurance can help.

by Kate Smith

Brian Rubin had worked as an estate planner with the IRS, as an agent and as an estate tax attorney by the time his son, Mitchell, was born in the early 1980s. But when Mitchell was diagnosed with autism, Rubin realized he needed an expert to help with his own estate plan.

"I joke now about how I said to one of my mentors, 'I need to do something with my estate plan. I need to get some expertise,'" Rubin said. "He sent me to a school special-ed lawyer, because this was uncharted waters back then."

Rubin has spent the last three decades charting the waters of special needs estate planning and his Illinois law practice now focuses exclusively on special needs issues.

And there's no shortage of work.

The 2010 U.S. Census showed 56.7 million people—19% of the population—have a disability, including 8% of children under the age of 15. The prevalence of disabilities, particularly among children, is growing. According to the Centers for Disease Control, autism has increased 119% since 2000, making it the fastest-growing disability in the country. One in 68 children now has an autism spectrum disorder, up from 1 in 150 in 2000.

With disability numbers rising, chances are a client with special needs will walk through the door at some point. And when they do, Rubin and fellow experts advise seeking help. Special needs estate planning, they say, is not an area to dabble in. It requires expertise and a team approach in order to protect and provide for the affected individual.

"This would be the most important thing to know: Do not try to go this alone without the support and help of a very experienced estate planner who has experience in providing planning for clients with special needs," said Brett Berg, a vice president in Advanced Marketing in Prudential's Individual Life Insurance business. "It's always important to work with an attorney and CPA in estate planning, and here it is critical for making sure the individual's rights are protected and the resources are structured in the right way."

Estate planners who don't understand the complexities of this niche can jeopardize an individual's access to government benefits.

> **Key Points**
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> ▶ **Expert Advice:** Special needs estate planning should be a team effort that includes specialists in this niche.
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> ▶ **Starting Point:** Establishing a special needs trust is the first step in protecting a disabled individual's access to government benefits.
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> ▶ **Predicting the Future:** Because the government's assistance is not guaranteed, families should consider funding the future with a life insurance policy that guarantees an inheritance for their loved ones.

"This type of planning isn't about tax savings," said Beth Manes, a New Jersey-based attorney whose practice focuses on planning and advocacy for families with special needs. "It's about getting somebody qualified for and keeping them eligible for public benefits such as Social Security, Medicaid and adult services."

Because government rules vary by state and change over time, staying up to date on laws and understanding

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—Beth Manes, Attorney

how to navigate systems is crucial.

"You're dealing not only with federal and state laws, but you're also dealing with Social Security, which is federal, and then Medicaid, which is state specific," Rubin said. "In most cases, the special needs planning attorney is the quarterback because they know how to navigate the state's system of programs before age 18—what's available and how to get into them—and adult programs when they're done with school and the special-ed law no longer applies. The adult programs are usually controlled by the state and most of them are paid for by Medicaid, so you need to know how to navigate that, which depends on the state you're in.

"So the attorney needs to know not only estate planning and estate tax planning, but he also needs to know special needs laws and how to navigate that system."

Assets and Liabilities

Government programs are means-tested, and having assets in excess of $2,000 will disqualify an individual from receiving government assistance. In practical terms, that means even a small inheritance from a well-meaning relative could jeopardize eligibility if left directly to the disabled individual.

Protecting access to government benefits—be it housing, day programs, health care or Social Security—begins with a special needs trust. The most common of these is a third-party trust, which supplements government assistance and typically is funded by family.

"The name 'third-party special needs trust' comes from it not being the child's money," Rubin said. "There is no paper trail of it ever being the child's money. So they can have unlimited dollars in the third-party special needs trust and it's not counted as a resource or asset for purposes of eligibility for benefits."

There are limitations, however, on how that money can be used.

"Whatever the benefits are, whether it's Social Security or Medicaid, the trust can't allow payment for things those programs would otherwise be providing," Manes said. "It needs to supplement not supplant government benefits. Any properly drafted special needs trust is going to have that language peppered throughout—supplement not supplant."

The trust also must make clear that the disabled individual is not entitled to the money. "If the person can make demands on the money, then Medicaid and Social Security aren't so interested in supporting them anymore," Manes said.

Estate planners need to review boilerplate documents carefully to ensure the language doesn't inadvertently give the disabled individual financial control at any point.

"Most boilerplate documents name the trustees or executors who will act, and if everybody refuses to act and you run out of people, most state statutes say the beneficiary can appoint a replacement trustee," Rubin said. "Well, that means they can appoint themselves, which would give them control. So you need to be aware of the types of things buried in boilerplate language that could mess things up."

Planners also need to make sure the family's wills, pensions, insurance policies and other documents are properly worded to avoid what Berg calls "the three costly mistakes in estate planning," which are 1) leaving assets to a special needs child directly; 2) naming the child directly as beneficiary on a retirement plan, annuity or life insurance plan; and 3) directing the child's inheritance to another family member to administer on behalf of the child rather than directing it into a special needs trust.

"A special needs trust is the optimal tool," Berg said. "It is often the most effective way to help with security and quality of life."

Listing the disabled individual by category is a typical mistake in wills. For instance, a parent may leave the disabled child's portion of an inheritance to a special needs trust, but later in the document might state that if one of the children dies, that share goes back to "the other children."

"They fail to say, 'It goes back to the other children, but this particular child's share goes to the special needs trust,'" Rubin said. "We provide parents with instruction letters to give to family and friends. It tells them that if they're going to leave anything to little Johnny, they need to leave it to his special needs trust and this is how they do it. We'll give them a paragraph to insert into their will or their existing living trust that simply says, 'Notwithstanding to the contrary, anything that might go to

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—Brett Berg, Prudential

this person will now go to their special needs trust.'"

Monies incorrectly left to the child can be redirected into a first-party special needs trust to preserve benefits. These trusts, also known as self-settled or payback trusts, are for assets belonging to the individual, whether it be from an inheritance, lawsuit or child support payments, which are considered the child's asset rather than the custodian's.

Monies in a first-party trust must be used for the sole benefit of the individual. Upon death, any remaining money is used to reimburse the government for services rendered during the individual's lifetime.

"There's much more scrutiny with those because Social Security is looking over your shoulder," Manes said. "Any expenses that are paid above $5,000 need to be approved first by Social Security."

Manes recommends appointing an institutional trustee for first-party trusts. "There's so much to know and so much you have to do," she said. "If the family member does something wrong and it messes up the person's benefits and ends up disqualifying them, that's a lot of liability."

Funding the Future

Determining the right amount of funding is tricky. And often daunting.

"We're not talking about just providing enough money for your kid to go to college; we're talking about potentially supporting somebody for 40 years beyond your death," Manes said.

"I often have people say, 'Social Security and [the Division of Developmental Disabilities] will provide housing for him and Medicaid will provide health care, so I don't really need to leave anything for him. I'll just leave it to my other kids.' But what if in 40 years or 20 years the whole system collapses? Then what happens?

"I don't want to make these families more nervous than they already are, but it's my job to tell them all the terrible things that could possibly happen."

That's where life insurance offers a solution.

"When you talk about special needs, you have a permanent need and need a permanent product," Rubin said.

The most popular product for funding trusts is a permanent life insurance policy with a guaranteed death benefit. "What we tend to see is the clients with special needs children will look for ways to put the maximum amount of coverage into the trust that they can afford," Berg said. "The amount varies, but what you see is that the clients who qualify from an underwriting perspective and are eligible to be insured and understand the power of insurance in these trusts, will look for the maximum amount of coverage they qualify for and can afford."

Paying a high insurance premium isn't an option for all families. If cash flow is an issue, Berg suggested starting with term life coverage that can be converted to permanent coverage.

"The agents and brokers with whom the customer works need to investigate what the term coverage allows for within the contract as far as a conversion right, and then they need to help the consumer understand that they're going to start off with term coverage and likely will want to convert it later," he said. "And they need to explain the contractual provisions that allow for that, not only to the consumer—the mother, father or caregiver of the person with special needs—but also to the lawyer and CPA so they understand what the purpose of that strategy is.

"They need to understand we're starting with term because we want the most coverage for the least amount of premium and our plan is to convert it later. They need to know the rights under the specific contract chosen and the plan for converting. And they need to understand that if they don't convert the policy, the coverage may expire and they may not be able to secure more coverage."

Buying life insurance sooner rather than later is important. "Sometimes that's counterintuitive for clients," Berg said. "They often say, 'I have so many bills right now. How can I afford the life insurance?' That's a common objection agents and brokers face, especially with younger clients. But it's so essential for clients to understand, especially in this marketplace, that they have an opportunity to secure more coverage at a more affordable price over the long term when they investigate coverage at an earlier age." BR

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Three Costly Mistakes in Estate Planning

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2. Naming the child directly as beneficiary on a retirement plan, annuity or life insurance plan.
3. Directing the child's inheritance to another family member to administer on behalf of the child rather than directing it into a special needs trust.

Source: Brett Berg, Prudential

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