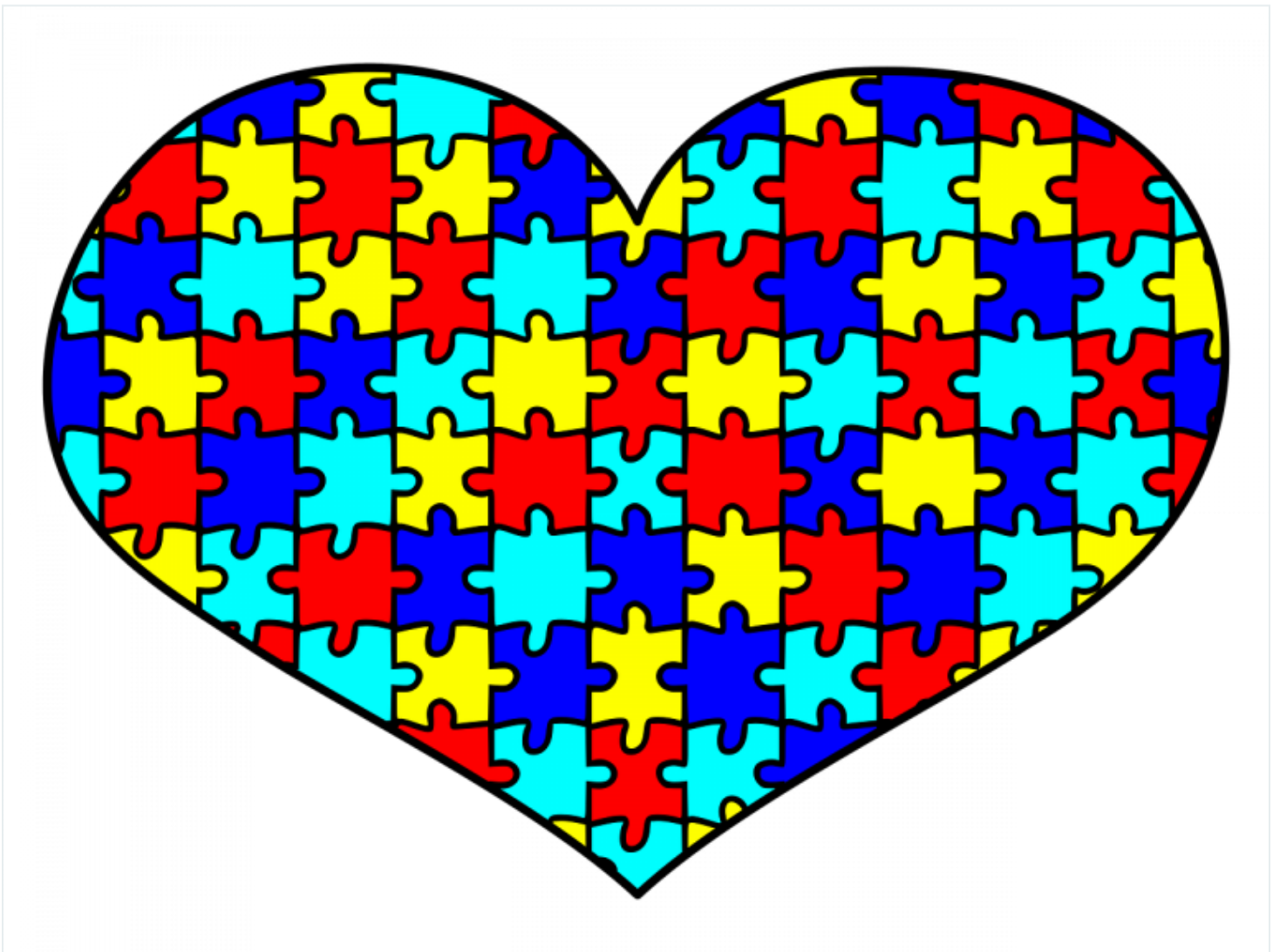


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and employment when they reach adulthood.

Nov. 23, 2022



*There are more of them than ever, and they need specific guidance to plan for the future in which they aren't there to care for their child.*

**By Mary Anne Ehlert, CFP®**

Imagine having to scrape together enough money to put your child through Harvard,

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autism spectrum.

Parents of special-needs children are so wrapped up in the day-to-day management of their child's education and treatment that they have little time to think about the future. And when they do think about it, it's with a sense of dread. *"Who will take care of my child when I'm gone?"*

As financial professionals, we need to help them not only think about the future, but plan for it as well. My firm, [Protected Tomorrows](#) in Lincolnshire, Illinois, specializes in helping such families, and it's part of my mission to share our knowledge and expertise with other financial professionals.

Families may have a million questions about their child's care, education, residence and employment when they reach adulthood. How does one qualify for government benefits? Evaluate the right school systems? Find the right residential program? Create an appropriate financial plan? Structure an estate plan?

I saw first-hand the difficulties my parents had in making sure my sister, Marcia, who had cerebral palsy, would be cared for when they could no longer do so. I and my staff — many who have family members with a disability — guide parents through this stressful, complex and heart-wrenching process one step at a time.

Since 1990, when I founded my firm, I've developed an eight-step process we use for future care planning that addresses all aspects of life including legal considerations, potential government benefits, transition planning, residential options, employment opportunities, recreational choices, investment solutions and family communication. At every step, we focus on a client's abilities, not their disabilities.

**Steps to helping a special-needs family plan their financial future**

## 1. Make the family feel comfortable with telling their story. Many special-needs

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**2. Identify the potential life needs of the special-needs individual.** Just like the disabilities themselves, these life needs can vary widely from residential care to community support, even to a life of independent living and employment for those with mild disabilities. This step helps quantify medical expense deductions, identify tax returns to be filed and clarify other expenses not yet accounted for.

**3. Discuss legal implications.** We're not attorneys, so we're not going to provide legal advice. We will, however, ask whether there are wills, powers-of-attorney, trusts and guardianships. The family may say, "Yes, we have wills," but the wills may not be adequate for this family. You can't determine that, but you can advise them to work with an attorney who is knowledgeable in estate planning for special-needs families. You should also coordinate or participate in the discussions with attorneys.

I've found that families want to delay this step because, until their child is 18, they receive in-school services. But the unexpected does happen, and if one or both parents die or become incapacitated, having these documents in place will only benefit the children, special-needs or not.

**4. Outline all the benefits the special-needs individual will be eligible for.** You have a role to play in ensuring the individual maintains their eligibility for such programs as Supplemental Security Income and Medicaid. Questions to be asked here include whether the special-needs individual has health insurance through an employer or parent employer; whether the individual holds assets in their name; and whether there's a possibility of an inheritance.

Often, clients proudly tell us that they're setting money aside in their child's name, sometimes working two jobs. Unfortunately, what they're doing will disqualify their child for government benefits. Families may be horrified when you recommend that they do not leave money directly to their child, until you explain a child over 18 may

not have more than \$2,000 in his or her name. Rather, families should establish an

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and to put this plan in a visual format to help the family see it clearly. If a sibling or other family member has agreed to be in charge, bring them into the discussion but don't leave them with all the work.

**6. Help the family plan for what happens when the special-needs individual ages out of state-supported education.** What will happen when that child (perhaps by then an adult) has to have a place to live, work and play? Again, you may not be an expert in these types of programs, but you can help a family by providing a network of professionals who can help them.

**7. Fund the future.** As financial professionals, we can help a client make wise decisions today that will be beneficial in the future. For example, If the plan dictates that a certain amount of money is needed for the lifetime of the individual, will the government provide all the necessary funding? Can the family fund the special needs trust with a large enough inheritance? Should life insurance be purchased, and who should be the policy owner?

**8. Review and revise as needed.** New legislation may be enacted that impacts a family's plans, a new program may be created, or one may be discontinued. Families require regular reviews to understand any changes that may occur, both within their own circumstances and the wider environment.

If you give your client only one piece of advice, make it this: Don't wait until the special-needs child is 18 to start planning. That's the toughest time, when a child ages out of the school system. There's no communication between schools and government agencies — all of a sudden, it's all up to the parent. Just that little bit of guidance may set a special-needs family on the right financial path.

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