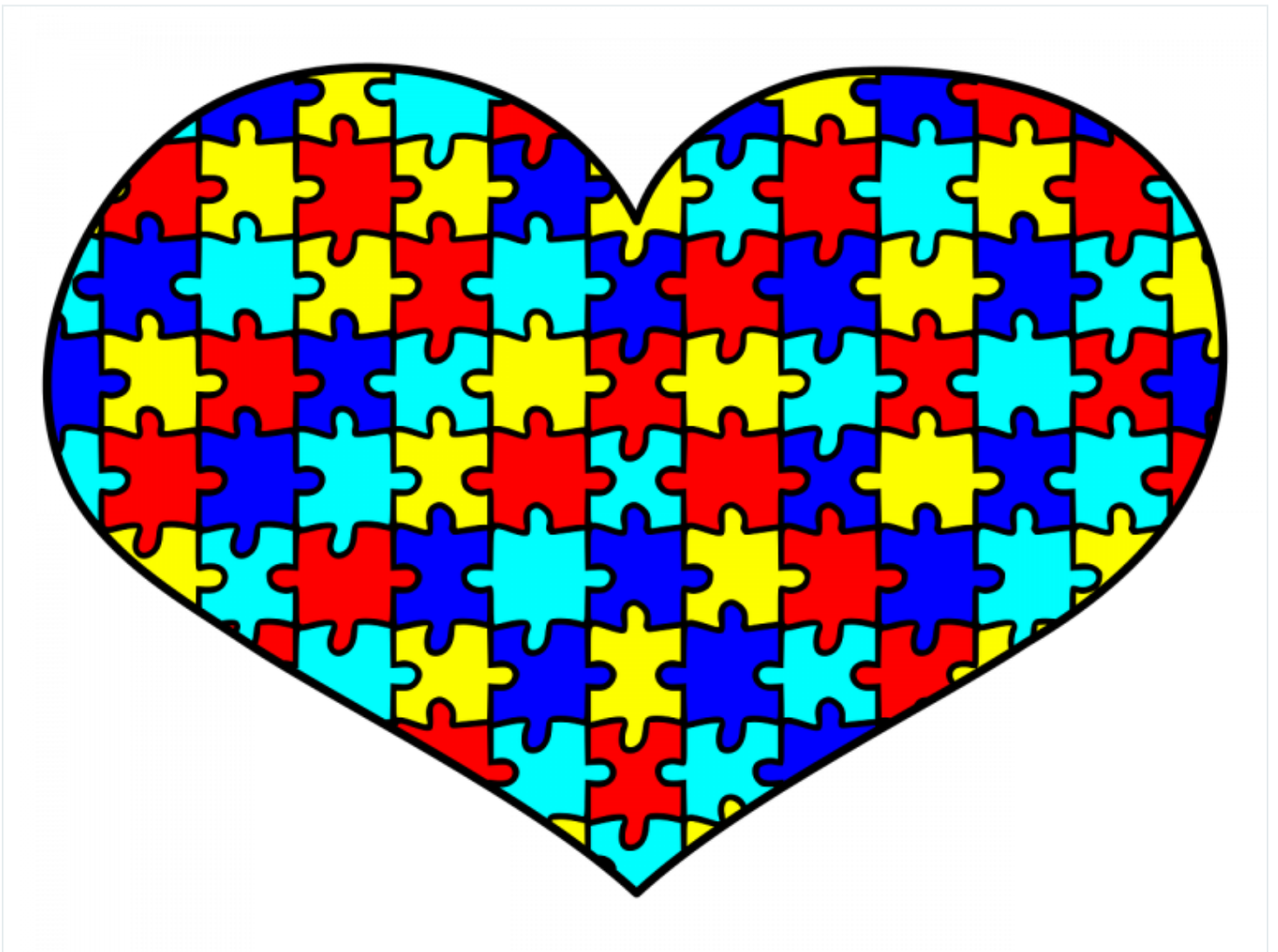


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cerebral palsy to reach 50 years in age.

Nov. 29, 2023



By Mary Anne Ehlert, CFP.

Improved medical care, educational interventions and community services have given individuals with disabilities a better quality of life and longer lifespans. It's not

unusual for people with Down syndrome to live into their 60s and those with

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aging parents to even think about it, let alone plan for it. As parents approach retirement age, they have so many questions:

- Will my child be able to live independently or will they require supportive housing?
- Can they find employment?
- What about their social lives and potential romantic relationships?
- Can I even afford to retire?

Parents may be counting on their other children to help care for a sibling with disabilities, but that may not be the best idea. Caring for a person with disabilities costs thousands of dollars a year, potentially jeopardizing the financial futures of those brothers and sisters. Some siblings may willingly take on the responsibility. Others may do so only grudgingly, or refuse outright.

If your clients find themselves in this situation, it is essential that you consult with an attorney and/or another financial colleague who is up on the latest legal and financial implications regarding care for disabled individuals. And, though there are a lot of things to sort out, they can be put into a few broad categories:

Assets and income

It's likely that an important share of the child's future support may come from government assistance programs, such as Supplemental Security Income (SSI), which guarantees a minimum income and is available to children with disabilities, and Medicaid, which covers a broad range of health care and caregiver costs. There are income limitations to these programs, though, so it's important to protect their access by not letting them inherit the estate.

Rather, set up a special-needs trust. You can set aside any amount of money, and the

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A child whose disabling condition was diagnosed before the age of 26, even if they're older now, is also eligible for an ABLE (Achieving a Better Life Experience) account, a tax-advantaged savings plan similar to 529 accounts for college. In Illinois, taxpayers who contribute to an ABLE account can take as much as a \$10,000 deduction if filing individually (\$20,000 jointly, limited by the ABLE contributions of \$17,000/year in 2023).

Congress is considering passage of the ABLE Age Adjustment Act, which would protect people who become disabled later in life – for example, a veteran who is permanently disabled in defense of their country – up to the age of 46. As of this writing, supporters are hoping for its passage before Congress adjourns for the year.

Trusteeships and guardianships

It's not all about the money. The parents – and the child as much as they can – need to designate a team that will provide different aspects of care. Who will be in charge of education and housing? Who will disburse funds from the trusts? Who can help with medical care and physical therapy? Clearly, this is a job too big for just one person, such as a sibling.

Rather, designate a person to coordinate these activities, which can be an attorney, sibling or other trusted agent such as yourself, then give them the support they need to carry out these important roles. Write these plans down – even put them in a visual format like a flow chart so that everyone has an understanding of their responsibilities.

Most importantly, this document needs to be revisited every few years and updated in case, say, a sibling passes away, an agency changes its operations or new legislation creates new opportunities or limitations.

Document, document, document

Some of the most important documents are a durable power of attorney for health

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In an ideal situation, all of this planning has taken place while the child and parents are still relatively young. But even if the parents are now in their 50s and 60s, it's not too late to put a plan in place to ensure a bright future for a child with disabilities.

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Mary Anne Ehlert, CFP®, specializes in financial planning for families with a disabled family member. She is the founder of [Protected Tomorrows](#) in Lincolnshire, Ill., and is a partner in [Forum Financial](#). For information, contact her at 847-522-8086.

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