



Ryan Platt Featured in article written by AARP.org

Securing a Future for Your Child With Disabilities

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Seven steps parents need to take before they die.

Six years ago, Jackie and Alan McDonald wondered how they would pay for their son Brendan's college education. Today they stay awake at night worrying about how they will afford to take care of him for the rest of his life.

Brendan was 16 years old when he was driving too fast to a friend's house near his Charlotte, N.C., home. The road curved and Brendan hydroplaned across the slick road, finally crashing into a tree. The impact left him with numerous broken bones, internal injuries and, most devastating of all, brain damage.

Now 22, Brendan has short-term memory problems. Multitasking is a huge challenge. While his mother hopes he will someday be able to live independently, doctors say complex tasks such as driving a car will forever remain outside his capabilities. This summer Brendan will start classes at the local community college, but the McDonalds have no guarantee that their son will ever be capable of finding gainful employment.

And so Jackie, 55, and Alan, 62, find themselves trying to plan, not just for their own later years, but for the rest of their son's life, an estimated 50 or so years.

They are not alone. The McDonalds are among the parents of an estimated 717,000 developmentally disabled adult Americans (including those with Down syndrome and autism) living with caregivers over the age of 60.

"We were told that we'd need \$1.8 million to [support him] for the rest of his life," Jackie McDonald says. "I don't know who has that kind of money. I remember when I heard that figure, I said, 'Who in the world prepares for something like that?'"

No one prepares for it, but once it's needed, planning is crucial. Government programs such as Medicaid and Supplemental Security Income (SSI) can help defray some of disabled adults' expenses. But SSI barely covers the rent in a group home; the federal monthly benefit is currently \$637, with some states providing additional funds. Money you set aside can help save your child from a life of poverty. On the most basic level, it can provide extra funds to live comfortably and participate in hobbies. Or, if you plan early and well, it can fund a more comfortable lifestyle in a private-pay assisted living facility, where fees can run \$3,000 a month.

No matter how old you are, it's never too late to start saving for your child's future. The first step is creating a financial and legal plan for the child.

"It is better to have your plan than what I call the government's plan," says Ryan Platt, a certified special care planner with Hinrichs Flanagan in Charlotte, N.C., and founder of A Special Needs Plan, Inc. "In that case the child becomes a ward of the state. The state will determine where they will live, who will take care of them and what type of lifestyle they will lead. It is usually not the situation that parents would like to leave their child in."

"One of the hardest stresses we've had to deal with is making sure he's taken care of once it's our time to go," says Jackie McDonald. "A year ago we set up a trust to help prepare for his future. Now we know Brendan is protected in case something happens to Alan or myself. That helps me sleep at night."