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U.S. special-needs families face complex retirement planning



Children take part in goal ball at Camp Abilities in Brockport, New York, in a file photo. REUTERS/Mark Blinch



By **Mark Miller** | CHICAGO

Mary Anne Ehlert came by her expertise in financial planning for special-needs families the hard way: she has lived through the challenge herself.

Ehlert, a certified financial planner based in Lincolnshire, Illinois, has a sister who was born with cerebral palsy, and a son who suffers from blindness and mental illness. Both of her parents developed disabilities later in life.

"I started out by asking my parents about planning they had done for my sister, and found out what they had done really was wrong."

When she left behind a career in corporate finance and launched her own planning firm in 1989, she focused on serving families with disabilities. Today more than half of her clients have a special-needs family member.

The financial planning challenges for parents of special-needs children are complex. One of the toughest for these parents is planning for their own retirement, and balancing that with the long-term needs of a disabled child, who may outlive them.

Key challenges, according to Ehlert, include creating a plan for the family member's care, projecting cash flow needs well into the future, and making decisions about investment allocations for assets dedicated to the family member.

"We always have a line item in our cash flow models showing what the cost will be to support a child when they are grown, but usually our clients can't think about that while they are working - they are focused on education, doctors and many other immediate needs," she said.

"Suddenly the child is done with school, the parents are getting older - and they are trained to think that government will pay for it all - but it won't."

GOVERNMENT ASSISTANCE

Government assistance typically begins with Supplemental Security Income (SSI) benefits from Social Security. Disabled children from birth up to age 18 can receive SSI if their parents meet the program's low-income and asset requirements. At age 18, they can qualify for SSI on their own; the maximum benefit in 2016 is \$733 per month.

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In most states, SSI recipients automatically qualify for Medicaid, which provides a range of services for disabled people. But Medicaid funding is facing severe financial strains in many states, with services being cut back.

Social Security Disability Insurance (SSDI) is an important benefit for special-needs families. SSDI pays benefits to adults with disabilities that began before they turned 22 years old.

It is considered a "child's" benefit because it is paid on the parent's Social Security earnings record.

The benefit is 50 percent of the parent's Primary Insurance Amount (PIA) - the amount he or she would receive at full retirement age. If the parent is deceased, the benefit is increased to 75 percent of PIA.

But the decision to file for SSDI needs to be considered in a broader family claiming context.

That is because SSDI is available for the child only if one of the parents is receiving Social Security retirement or disability benefits, or if a parent is deceased. That brings into play a number of complex computations about optimizing a family's overall Social Security income.

Families with special-needs children also should take a more conservative approach to allocation of their retirement portfolios, Ehlert said, with a higher level of cash than usual.

"You still want growth and a nice, diversified portfolio, but there needs to be enough cash there that if the market plunges, there are resources to meet immediate needs, and for the portfolio to recover."

Congress created a new saving opportunity for disabled people in 2014 with passage of the Achieving a Better Life Experience (ABLE) Act.

The law permits creation of ABLE tax-advantaged savings accounts that allow people with special needs to save up to \$100,000; higher amounts can lead to suspension of SSI benefits.

A number of states have created ABLE accounts.

(More information is available from the ABLE National Resource Center: (bit.ly/1VWp8Dd))

Another key step is creation of a Special Needs Trust to receive assets on behalf of the disabled family member, managed by an appointed trustee. The trust can hold a mix of assets, including cash, an investment portfolio and life insurance.

Ehlert advises clients to buy “second to die” policies that provide benefits to heirs after the last surviving spouse dies. “It’s really the cheapest way to fund living expenses for a child,” she said.

Once a retirement plan is in place, be sure to share it with extended family. Anyone with a specific future role needs to be informed, and agree to it.

“It’s important to educate the family on what the parents have set up, and to make sure everyone knows where the important documents can be found,” she said.

(Editing by Matthew Lewis)