



What financial plans required for special needs kids?



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Allie Burton, 11, of Brick, has Down syndrome and autism. She attends equestrian instruction at Celtic Charms in Howell. (Photo: DOUG HOOD/STAFF PHOTOGRAPHER) Buy Photo

Allie Burton turned 11 years old last Wednesday.

She enjoys horseback riding, cheerleading, swimming at the YMCA, doing track and field, and is the ambassador for the Brick Elks lodge.

It's safe to say that her schedule is packed with activities that might, under some circumstances, be expensive. But some, like the horseback riding at Celtic Charms in Howell, offer scholarships by way of discounted fees, for those who demonstrate need.

"(People ask) 'How do I get the state to pay for this?' or 'I've never heard of the (Division of Developmental Disabilities),' " said Sherry Burton, Allie's mother, of Brick.

Allie has autism and Down syndrome, and is in remission from leukemia.

The cost of the activities she participates in, coupled with the cost of health care and additional programs can quickly add up to a mountain of expenses without support.

Burton, who used to work at New Horizons in Autism, an organization that provides services for individuals with autism and their families, is familiar with the realm of special-needs financial planning.



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Parents of children with special needs have to plan financially to participate in many extracurricular activities. Allie Burton, 11, of Brick, has Down syndrome and autism. She attends equestrian instruction at Celtic Charms in Howell. Instructor Nancy Forsyth and volunteer Lorrie Scalia of Howell walk with Allie and her horse, Rocky. (Photo: DOUG HOOD/STAFF PHOTOGRAPHER)

Two major milestones

She said there are two major financial milestones that a family of a person with disabilities must prepare for: when that individual turns 21, and when the caregiver passes away.

Gary Weitzen, of Freehold, is just starting to face the issue of planning for his son, Christopher, now.

"My son's 20 with autism. He's the joy of my life – he's incredible, even with his challenges. Not a day goes by that I'm not thankful that he's in my life," he said. "One thing I struggle with every single day is what happens when I'm dead? How do I take care of him after I pass?"

The key is financial planning, said Lori Sackler, senior vice president of wealth management at Morgan Stanley in Paramus.

"Integrating a financial plan is critical," Sackler said. "It alleviates stress and anxiety that parents are experiencing, and also makes sure the child has a sense of security and some dignity and autonomy."

If a caregiver dies without first setting up a will, or instructions for the care of their child with special needs, the result could be "tragic," Weitzen said.

"Most likely the courts and local jurisdiction would have to appoint somebody to represent the needs of the heirs," Sackler said. "That's not a good thing."

Sackler said there are a wide range of government benefits available for a person with disabilities, depending on their needs and circumstances. Hiring a lawyer to help navigate the different types of benefits is ideal.

According to the Social Security Administration, Supplemental Security Income (SSI) is available to help the aged, blind or people with disabilities by providing cash to meet basic needs for food, clothing and shelter.

Last year people who qualified for Title XVI SSI benefits received an average payment between \$660 and \$662 every month, according to Social Security. Title XVI benefits encompass qualifying aged, blind or disabled individuals.

However, "resources" in the name of the person who is applying for SSI cannot exceed \$2,000 for an individual or \$3,000 for a couple, or else that person becomes ineligible to receive the SSI benefit, according to Social Security.

"Resources" include cash, bank accounts, stocks, U.S. savings bonds, land – excluding the home you live in or the land it is on – life insurance, personal property, vehicles, anything owned which could be changed to cash and used for food and shelter, and deemed resources.

Household goods, personal effects, one vehicle, grants, scholarships, fellowships and gifts – for a time after they're received – do not count as resources.

The value of resources poses a problem for parents of children with disabilities, because when the caregiver dies, almost nothing can be left to the child, because the increase in resources would halt SSI benefits.

Special needs trust

"Typically, what's considered is a special needs trust. It's a trust specifically designed for families and the needs of a (person) with special needs," Sackler said.

Weitzen said this is the route he's taking.

"This way, we can leave money through life insurance or through gifts to take care of Christopher after we're gone," he said. "Setting up the trust, probably the decision to set up the trust is the major hurdle."

According to Parents of Children with Disabilities, special needs trusts can be funded by life insurance, standard government benefits, gifts, assistance funds, inheritance, property and military benefits.

Funds from the trust can be used for transportation, home health aides, education, rehabilitation, computer equipment, and medical and dental care not provided by government benefits.

Funds from the trust cannot be used for food, housing, property taxes, home insurance utilities, or transferring cash to the benefactor.

Then, somebody needs to be chosen to look after the trust.

"You can set up agencies (to do it)," Weitzen said. "Personally, I'd like somebody who knows and loves my son to look after the trust."

In conjunction with setting up the trust, some caregivers struggle with is determining who will look after their child and his or her trust, Weitzen said.

"Your family should have discussions," Burton said. "In the plan, you want the family well informed to take care (of the child) and they should know their doctors."

In some cases, Sackler said, families don't want to burden siblings with the care of the individual with special needs. Depending on a family's financial state, Sackler said professional caregivers and advisers could be appointed to be responsible for an individual's care, if other family members are unable or unwilling.

Turning 21

The second milestone is the 21st birthday.

"At 21, the services stop," Weitzen said. "(The child) can stay in school until 21, and then they go to adult services. Everything changes."

Weitzen said Christopher will graduate from Brick Township High School this year, and now, Weitzen is in the process of deciding where his son can go.

"It's hard. There's no entitlements, and there's waiting lists," he said. "You really have to research and know what you're looking for. My son's needs are really different from another child's needs. Twenty-one is a huge issue."

Burton said that at 21, an individual's support from the state Department of Children and Families (DCF) ends, and they must apply for support from the State Division of Developmental Disabilities (DDD).

"You have to be on top of that, (the state) doesn't just do it," Burton said.

Furthermore, she said parents have to consider where their child will spend the day. It's likely that they'll have to register for a day program, if that individual isn't fully independent.

There are many resources to help parents navigate the spheres of benefits and services that available for families, however they must be sought out.

For example, DCF paid for Allie to attend summer camp for free at the YMCA, but that is a service that isn't widely known.

"Nobody is going to give you anything," Burton said. "The state's not going to call you and give free summer camp."

So Burton said she spends a lot of time networking, and helping other families.

Weitzen, who is the executive director of Parents of Autistic Children (POAC) headquartered in Brick, said his organization has constant year-long free activities and workshops for families.

Weitzen also said that although the financial issue is daunting, it needs to be tackled early.

Burton said the first step is finding an attorney who has knowledge of special needs financial planning. Many times, qualified attorneys will set up tables at support groups or networking events. Burton started financially planning for Allie when she was 4.

Weitzen has waited until now.

"It's something like facing your own mortality is a rough thing," he said. "People think they're going to live forever, but they're not. Getting a will done is very important if you have a child with special needs."

HELP AVAILABLE

Supplemental Security Income: This program is designed to help aged, blind, and the disabled who have little or no income. It provides cash to meet basic needs for food, clothing, and shelter. ssa.gov/ssi

Medicaid: This program provides health coverage to non-elderly individuals with disabilities, including those who are working or who want to work. Federal law provides for both mandatory and optional coverage for individuals with disabilities. medicaid.gov

Department of Children and Families (DCF): This state program is New Jersey's comprehensive agency dedicated to ensuring the safety, well-being and success of children, youth, families and communities. www.state.nj.us/dcf

Wrap Around Services (DCF): This program provides caregivers with vouchers to pay for necessities that are not available through existing programs. www.state.nj.us/dcf/families/support/kinship/

New Jersey Health Link: This program is the nation's most comprehensive healthcare consumer information website serving seniors, families, children and healthcare professionals. www.nj.gov/njhealthlink