

What's going to happen when we're gone?

By Chris Maul Rice

Even before a child's birth, parents begin imagining. When will my daughter say her first word? Walk? Will she play violin, soccer, or baseball? Will she become a great golfer, artist, teacher?

The possibilities are endless.

But what if your child is born with a severe disability? What if your child couldn't play in Little League, not because he didn't want to but because he physically could not? What if it was your responsibility to provide for your child's financial and residential needs for the rest of his or her life?

If you don't plan properly, what kind of future will that child have?

When Jim and Judy Jablonski's son, Jimmy, was born, his disabilities slowly began to materialize and doctors didn't know what to expect. Jim, a Chicago police officer, and Judy, a former teacher and full-time mother, think back to the first few weeks of their son's life.

"We didn't know what to anticipate for him," Judy Jablonski said. "We participated in early intervention programs to help Jimmy in his development, he attended a swimming program at the YMCA and participated in family vacations and activities.

"As time went by and he lost the little language he had acquired, school testing determined that Jimmy's Individualized Education Program needed to include physical, occupational and speech therapy," she said. "Although Jimmy is frustrated by his inability to talk and communicate his needs, he does understand simple phrases. Our goal is to make him as independent as possible, realizing that he will always need custodial care."

Jimmy has attended year-round school since he was 3. Now 18, he attends Gateway to Learning, a school where he receives individualized instruction, including a multisensory approach and materials.

On a recent day, he arrived home at

his usual time of 3:30 p.m. Warmly greeting his son, Jablonski's voice boomed through the tidy Northwest Side home before he ushered Jimmy into the kitchen for a snack.

Jimmy gently tapped his fingers to his mouth to communicate his wish for a snack. He uses other hand signals and colored cards to communicate his needs. Once the Jablonskis, who also have a younger daughter, realized how severe Jimmy's disabilities were, Jim Jablonski started working extra jobs to earn extra cash. He wanted to make sure that Jimmy's needs would be met long after he and his wife were gone.

Then, six years ago, the couple heard Mary Anne Ehlert speak at their son's school. Ehlert is a certified financial planner who specializes in working with families of special-needs children.

Jablonski shakes his head. "Anyone who has a special-needs child, the first thing they should do is sit down with someone like Mary Anne Ehlert."

Jablonski's instincts were correct: It is important to save for a special needs child's future. But it must be saved in a Special Needs Trust.

"Many times," Ehlert said, "Clients proudly tell us that they've been setting money aside for their child's future in the child's name--knowing that they won't always be around. Sometimes they even work extra jobs to have those additional funds available. What they're doing, in fact, is ensuring that their child will not qualify for benefits for which they might have been entitled. Parents can still save those dollars but the need to use the appropriate Special Needs Trust."

In fact, if funds are not properly managed, future government entitlements will be lost. For example, for a special-needs child to receive Social Security and Medicaid entitlements after turning 18, the child may not have more than \$2,000 their name.

Mary Jarrett, public affairs specialist for the Social Security Administration in the Chicago Metropolitan Area, says many parents call Social Security concerned about jeopardizing a child's Social

Security benefits. They want information about setting up a trust. "Since Social Security cannot tell parents how to set up a trust, the best approach," says Jarrett, "is to do your research."

How, then, can parents provide for their child's additional financial needs without jeopardizing government benefits?

Based on court decisions as well as statutes in most states, parents can set up special-needs trusts to provide supplemental funds for their child without jeopardizing government benefits.

These trusts, in the hands of an experienced attorney or investment adviser, can help parents pay for the extra expenses their child will need after the parents' deaths.

Mary Anne Ehlert's financial advice comes from years of certification and schooling, but she relates to her clients on a more personal level because her sister, now deceased, had cerebral palsy. Ehlert often asks parents where their child will get the money he or she needs.

"Their first response is, 'government benefits.' The rest from family, insurance and investments," Ehlert said. "But parents still really count on government benefits. Social Security may not be there forever. So the family really needs to think through that.

"Sometimes a family comes in and says, 'My child lives at XYZ facility and gets residential funding.' And I ask, 'What do you think you need to leave for your child?' and they'll say, 'Well my child's fine. I don't pay anything.' And I ask, 'Do you take them out to dinner Buy them birthday gifts? Take them on vacation with you? What if they need special drugs not covered by Medicaid? Dental care? Podiatry? Therapists? Do you want these things to continue?'"

"They start thinking about this and realize these things may cost 10 to 20 thousand a year. And that's with residential funding. Imagine if there's no residential funding. Then you're talking 50, 60, 70 thousand dollars a year. It's like putting your child through Harvard for the rest of her life." Attorney Brian Rubin,

former Internal Revenue Service agent and IRS estate tax attorney, concentrates in what he calls “appropriate future planning” for parents of special-needs children and adults. His middle son, Mitchell, is autistic and is mentally disabled. As a parent of a special-needs child, Rubin knows the incredible responsibility parents feel.

“We try not to use the ‘B-word’ [burden] when we refer to our son. As parents, we wish that Mitchell will have a long, healthy life. At the same time, we pray that we live one day longer than him. You know nobody is going to there for your child like the parent is.”

Of Harry Hinkle’s four children three are disabled. His 40-year-old daughter is schizophrenic, his 37-year-old son is retarded and his youngest son, 32, is autistic.

He realized that, through the years, he had been saving his money in “unprotected” accounts.

“There wasn’t that much money in the early years, of course. When you’re first starting out, you’re not saving as much, as any newlywed knows. Anybody who has children nowadays knows. If the money’s not protected, all the work and effort you put into it could be lost very easily.

“Find an attorney who is familiar with these particular trusts because there are only a few attorneys who actually

know how to draw these up. You can get an attorney who will draw up a special-needs trust for you, but if it’s not the right kind, it’s not going to do what you think it’s going to do.”

The U.S. Census Bureau estimates that about one in five Americans have some kind of disability. In 1993, the U.S. Department of education estimated that more than 100 million children ages 6 to 21 had some type of severe developmental disability that will require them to remain at home or to live in a residential facility for the rest of their lives.

The Department of Human Services Illinois Center for Rehabilitation and Education, a residential and educational facility just west of Chicago’s business district, includes financial management in its curriculum. Because most of the center’s students are physically, not cognitively, disabled, teachers and social workers must prepare their students for life after they leave the facility.

Marion L. May, occupational therapy administrator with the center, said that an important part of this training includes financial management.

“Some of our students have never had money to manage. Some students are wards of the state. They get maybe \$60 allowance a month. So when they get ready to live in our apartment program, we work in collaboration with DCFS and say, ‘this child needs some money to man-

age.’

“That child has to learn how to take out his own phone service, pay his grocery bill. We provide him with a roof over his head but the rest is up to him to manage,” May said.

When a young adult with special-needs turns 18, parents are faced with an additional hurdle: applying for Social Security and Medicaid benefits. As if negotiating the piles of forms wasn’t enough, a state-designated doctor must observe each applicant, report to the Social Security Administration on the nature of that person’s disabilities and recommend appropriate entitlements.

But the process can be demoralizing. Audrey N. Lewis, executive director of Families of SMA (Spinal Muscular Atrophy), recalls the day she took her son, Garrett, to be observed by the state-designated doctor.

“As a parent, you’re always trying to thing about all the things your child can do. Now the doctor asks me to focus on all the things my son can’t do. It’s not a self-esteem builder.”

After years of advocating for her son, Lewis has learned that “you don’t have to be afraid. Know your rights. Know there are people there to help you if you don’t have the time or the energy to do it by yourself. You’re never alone. There are people who truly understand from the human end. Not just the business end.”