

Financial planning

**You need to
start saving
at early age to
help support
children with
disabilities**

By **CHERYL WADE**

for the Daily News

Paul and Kim White are making sure their son, who has a disability, will have more financial wiggle room in his life than what government programs can provide.

The White's 11-year-old son, Adam, has Down syndrome. Through careful financial planning, Adam's parents intend to provide him with money to secure amenities beyond food, clothes and shelter and to keep his life decisions out of the hands of probate judges and in the hands of family members or people the family chooses.

"You try to set up a trust so that there would be something there besides government assistance," Paul said.

Paul's parents used trusts before Adam was born as a way to protect their finances. So placing money in a trust for Adam was an obvious move, he said.

Jan Lampman, executive director of the Arc of Midland, said parents shouldn't wait until their disabled children are adults to set aside money for the future. Having a significant disability doesn't keep a person from wanting to work, live in his/her own home, have relationships and make a life. Some of that freedom comes because Supplemental Security Income or Medicaid pays for staff members to cook, perhaps groom and help the person with a disability to find a job. The problem comes when the disabled person

earns too much money to qualify for 'the help that makes independence possible,' Lampman said.

"I have the job, so now I've lost the support that helps me get the job," she said of the disabled person.

Sometimes, well-meaning relatives complicate matters by leaving the disabled person a substantial gift, Lampman added.

"I put that money in my bank account," she said, referring to the disabled person. "I do my Medicaid review and now I'm not eligible for Medicaid." So that gift of several thousand dollars doesn't go for a special trip, for example, but to pay staff, and those costs can burn through a sizable gift in a few months, Lampman said.

A person with a disability still might take that vacation, buy an amenity such as cable TV or get some special big-ticket item. But there needs to be a clear distinction between the person's assets and those held in trust for him or her, said Joseph Weiler, an attorney with Currie Kendall PLC in Midland. To make that distinction, the person administering the trust - the trustee - must be the one to decide how the money is distributed, he said.

"Essentially, that money is locked up and never goes (directly) to (a) son with special needs," he said. "But it can go for things for his benefit and the trustee can make that decision. The trustee makes that payment directly to the cable company, not to the son."

Weiler explained two types of "settled

trusts." One is a Medicaid payback. The trustee spends the money on behalf of the disabled person. If there's money left when the disabled person dies, the state will receive money from the trust to repay what the state spent in Medicaid benefits to the person. Under a pooled income trust, the money becomes part of a pool of money from a number of disabled people.

Lampman said the Arc oversees a pooled trust with subaccounts created for about 70 people the organization serves. "It's in a bank," she said. "The bank invests it. People have a choice between having the money go into a regular savings account or an investing account."

Uses for the money include buying furniture for a person who moves into his/her own home, paying for classes or buying dental implants or crowns, she said.

Lampman said families of disabled people should give them an estate planning kit for their 18th birthday. Estate planning is not just for the wealthy, and it's more than putting money into a trust. It also should be about finding someone to help the disabled person make financial decisions, she said.

For the Whites, planning isn't simply a set of figures on paper, Paul said. It also assumes lifelong love among the siblings.

"We try to provide ways for our other two children to want to stay here, so they will all work together as a family," he said.