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# CRAIN'S CLEVELAND BUSINESS

## ESTATE PLANNING

### Thinking ahead

*Parents of special needs children must plan for their futures — as well as their kids'*

By **EILEEN BEAL**

4:30 am, August 20, 2007

Even when her now-24-year-old son Seth was a baby, Debra Chwast thought he might have a developmental problem.

"His language didn't seem to be developing in an appropriate way," explained the 62-year-old former social worker of Cleveland Heights.

Still, she and her then-husband were shocked when a psychologist friend called — after observing Seth at a party — and told them that Seth was probably autistic.

The Chwasts took Seth to a series of specialists who diagnosed autism, and from that point forward, they became Seth's social services, education and health care advocates.

But it wasn't until Seth turned 18, and Ms. Chwast attended a Cuyahoga County Board of Mental Retardation and Developmental Disabilities workshop, that she realized she also needed to think about Seth's future.

"This was the first time that I really understood the magnitude of the problem," she said.

Within days of the workshop, Ms. Chwast contacted Janet Lowder, a Cleveland-based lawyer who specializes in disability law and estate planning.

"She didn't just walk me through estate planning, she helped me find out what benefits Seth was entitled to and helped me apply for them and understand the legal implications of all the decisions that we were going to be making," Ms. Chwast said.

When parents plan for the future of their special needs child they are doing two generations' worth of financial, estate and care planning, said Chagrin Falls-based elder law attorney Matt Lynch.

"The parents are planning for themselves and for the long-term welfare and care of their

child," he explained.

According to Mr. Lynch and Ms. Lowder, the critical areas that must be addressed in planning for a special needs child include:

- The protection of the child's eligibility for government benefits, such as Supplemental Security Income and Medicaid, which provide shelter, food, clothing and health care for developmentally delayed and catastrophically injured people.
- The extent of the adult child's self-determination role.
- Advocacy, guardianship and conservatorship issues.
- Creation and funding of a financial vehicle that will pay for long-term oversight and care of the adult child.

The most practical way to care for a special needs child is to create a trust with the child as the beneficiary, Mr. Lynch and Ms. Lowder said.

"Trusts allow parents to control how their funds will be used beyond the grave. There is no other device to accomplish that goal," said Mr. Lynch.

While trusts can be funded at any time, usually they are funded at the surviving parent's death through disbursements from a will, the sale of the parent's home, pension plans, stocks and bonds and life insurance. They also can be funded from settlements from court cases.

In Ohio, there are three common trusts for special needs children, according to Ms. Lowder.

- **Wholly Discretionary Trust:** This is the most flexible kind of trust because its resources can be used to provide for the "general well-being" — necessities as well as non-necessities — of the beneficiary.
- **Special Needs Trust-Medicaid Payback Trust:** This type of trust is specifically structured to supplement government benefits and preserve the flow of those benefits to the beneficiary. "When the beneficiary dies, the state has a Medicaid claim against (the trust)," explained Ms. Lowder, noting that very often the state's claim for Medicaid payback exceeds what's left in the trust.
- **Pooled Trust:** This type of trust is similar to a Special Needs Trust, but it is managed by a nonprofit. This type of trust — because it can be added to at any time — is useful to beneficiaries who are employed since all sources of income are directed into the pool for distribution. The Community Fund Management Foundation, for which Ms. Lowder is legal counsel, is one of the largest pooled trusts in Ohio.

It takes time and lots of questioning by a lawyer to set up a trust. "(Lawyers) need to get to know the client's financial and personal situation and the needs of their adult child," explained Mr. Lynch.

Most trusts cost between \$1,500 and \$2,500 to set up; those involving multiple consultations and significant assets may cost up to \$5,000. "If someone tells you they'll be able to set up a trust for you in a couple of hours, and that it will cost you \$300, go

someplace else," advised Mr. Lynch.

Once a trust is set up, deciding who should manage it for the child can be challenging. Siblings, good friends or a lawyer versed in disability law and financial planning can manage a small trust.

Ms. Lowder said it's probably best to have a financial institution manage large trusts with family input.

The key for choosing the person or institution to manage the trust? That's a no-brainer, said Mr. Lynch. "They must be trustworthy."



Debra Chwast worked with lawyer Janet Lowder, who specializes in disability law and estate planning, to establish a plan for her son Seth's future. Ms. Chwast is pictured with a portrait of Seth, who has autism, and some of his artwork.

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