

Biz/Money

Providing special care

BY ELIZABETH LAZAROWITZ
DAILY NEWS BUSINESS WRITER
June 20, 2006

At 5 years old, Henry Brennan is just starting to walk on his own and speak a few words. His mother, Kim, revels in his achievements, but knows her youngest child will "probably always need some extra help."

When Henry was 4 months old, doctors discovered he was missing the proper connective tissue between the lobes of his brain, leaving him developmentally delayed.

Brennan and her husband, Brian, have put the same kind of care that they put into helping him develop physically and mentally into planning for his financial future - drafting a will, making decisions about guardianship for Henry and their two other kids, Claire, 12, and Hannah, 9, and creating a "special needs" trust.

Estate planning is vital for parents of children with special needs, but it often falls low on their "to-do" lists given daily struggles, experts said.

"A parent with a child with special needs wishes, 'Let my child live a long, healthy life, but let me live one moment longer,'" said Brian Rubin, an Illinois attorney who specializes in special needs estate planning. Rubin's 25-year-old son has autism and functions at about the level of a 5-year-old.

The reality, however, is that many mentally and physically disabled people are living near-average lifespans, making planning for their future critical, he said.

"The scary thing is that somebody else will be taking care of your baby - and they're always your baby," he added.

Most disabled adults and some children are eligible for government benefits, such as Supplemental Security Income and health care coverage under Medicaid.

Qualifying for these can also be key to getting into group residences, and recreation and work programs.

Those with more than \$2,000 in assets in their name, however, won't qualify, meaning that a direct inheritance can be dangerous for a person with special needs.

To prevent that, parents need to keep any money meant for the child in a special needs trust, experts said.

"A little a bit of planning can prevent a lot of trauma," said Michael Byrne, a financial planner with Lincoln Financial Advisors in Cherry Hill, N.J. His daughter and two brothers all have special needs.

For parents with limited assets, financial planners suggest funding a special needs trust with a life insurance policy, both for the family's main breadwinner and the main caregiver - often the mother - of the child with special needs.

Families, though, should consider paying for insurance premiums within the scope of their broader budget, being careful not to put their own health, or the welfare of their other children, at risk.

Parents frequently grapple with how to divide their estate amongst their disabled child and their other children, said Bernard Krooks, a partner at New York law firm Littman Krooks, which specializes in special needs planning and is helping the Brennans with their estate planning.

"Equal isn't always fair, and fair isn't always equal," Krooks said.

There are even more issues to deal with when a child reaches 18, such as whether the child can make his or her own medical or financial decisions or if the caregivers need to apply for guardianship.

In addition to making detailed legal and financial plans, experts also advocate writing a "Letter of Intent."

While it's not legally binding, it documents a child's routines, habits, likes and dislikes.

This can be invaluable when a new caregiver takes over, particularly for a nonverbal child whose parents have learned over the years to interpret something as subtle as a blink or a shrug.

A one-page summary of key points of the document is also helpful, Rubin said. The one he made for his son Mitchell, who lives in a group home, says that Mitchell will pull fire alarms given the chance and that he hates fish.

Kim Brennan said she tries not to think too far ahead in terms of Henry's progress, taking every day as it comes, but she's comforted by the idea that she's setting the stage for him to have a full and financially secure life.

"Wherever he nets out is just fine with me, but I need to know that I've done everything in my power to make him be the best man he can be," she said.