

Waiting Lists and High Costs Test Parents' Ability to Find Housing for Disabled Children

By Chris Maul Rice

Imagine putting a child through Harvard for the rest of that child's life. Could your bank account weather the punishment?

That's just one dilemma faced by parents of developmentally and physically disabled children. Depending on the level of care needed, residential housing for a special-needs child or adult could cost \$40,000 to \$60,000 a year.

Attorney Brian Rubin, former Internal Revenue Service agent and IRS estate tax attorney, now concentrates on "appropriate future planning for parents of special-needs children and adults. His middle son, Mitchell, is autistic and mentally disabled. He knows that, on top of all of the other issues parents must face with the birth of a special-needs child, future residential planning can be difficult.

According to Rubin, "In the nation, Illinois ranks 37th to 47th [depending on the service] in funding for special-needs kids with developmental disabilities. Parents don't realize that waiting lists for residential are so long."

Because Illinois funds few new residential facilities, there are three ways, Rubin said, for a disabled adult to get in a facility without prior arrangements.

"First, the parents have died and it's an emergency. Second, a disabled child is a danger to [himself] or third parties. Third, the parents know the right politician."

Many parents simply don't know or believe that, after their special-needs child turns 21, government programs end.

"Parents I've worked with are in shock when they find out that the needs of their child won't be automatically met," Rubin said.

Many families simply avoid planning for their special-needs child's future. In 1986, two Chicago researchers at the

University of Illinois Rehabilitation Research and Training Center on Aging with developmental Disabilities wanted to learn how many families made future living arrangements for their special-needs child.

Tamar Heller, director of the center, and Alan Factor, associate director for training and dissemination at the center, interviewed 100 older families throughout Illinois whose developmentally disabled son or daughter lived at home. Funded by the Illinois Planning Council on Developmental Disabilities, their study, one of the first of its kind, found that only 27 percent had made future living arrangements for their adult child.

That meant that less than half had confirmed their child's acceptance into a residential facility or made specific arrangements with another family member to assume care in the home.

Factor said, "Slightly more than half of those people wanted their son or daughter to live with another relative instead of going into a community residence.

"Many families don't make future plans because of emotional and practical issues. First, families feel, and rightly so, that no one will give their son or daughter the love and support that they do. Second, they know there are long waiting lists for residential services. And, third, oftentimes the residential services available aren't satisfactory to families."

Factor believes that parents' unease with residential facilities is understandable.

"Staff turnover is a big issue. There is a lack of continuity. Who will advocate for my son or daughter when I'm gone? Also consider that for some families, the child's government benefits may be necessary for the household."

Carl M. LaMell, president of Clearbrook, an Illinois not-for-profit residential center for developmentally disabled children and adults, knows the challenge of keeping qualified staff.

"We've been fighting for two years to get a dollar an hour more for our staff and trainers. If our [political] leaders would

make us a priority, this wouldn't be a problem. But we're not a priority for legislators. So we lobby with our hearts. We lobby with people. But money wins elections. We're at a very big disadvantage."

Even though Clearbrook's programs serve more than 500 special-needs children and adults, they have more than 800 people on their waiting list.

LaMell said, "The Illinois Department of Human Services has only 100 new openings for emergency cases each year. Even if there were 1,000 openings in the Chicago area, it wouldn't make a difference."

Mary Anne Ehlert, a financial planner and president of Ehlert Financial Group Inc., specializes in financial planning for families with special-needs children. Her sister, now deceased, had cerebral palsy. Her biggest challenge is helping place disabled adults after the death of a parent.

"People come in and say, 'The parent died and he had this child who is an adult. Help us.' It's real tough. We're not going to find the perfect solution like we would have if we had started planning when the child was younger."

Jennifer Twombly, research director for the National Low Income Housing Coalition in Washington, D.C., said that nationally, there are only 30,000 privately owned and operated multifamily assisted housing units available for the disabled, yet more than 4.3 million Section 8 vouchers are used nationwide.

Section 8, a Housing and Urban Development program was designed to give low-income families, senior citizens and physically or mentally disabled individuals the opportunity to live in "safe and decent rental housing at an affordable cost" by paying a portion of their rent.

The special-needs community's demand for affordable housing has changed the size and creation of residential facilities. Instead of larger community residences, they are demanding smaller homes.

Factor's research shows that the trend "has been to downsize to make a more homelike environment. This is the result of the self-advocacy movement by people

with developmental disabilities. Another outgrowth of self-advocacy is to purchase a home of their own. An adult with a disability may want to buy a home so that the property is under their control rather than a community service agency.”

In 1999, The Supreme Court issued a landmark ruling for people with disabilities. In *Olmstead vs. L.C.*, the court ruled that “unnecessary segregation and institutionalization of people with disabilities constitutes discrimination and violates the American with Disabilities Act.”

The court went on to say that “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life” and “confinement in an institution severely diminishes the everyday life activities of individuals.”

This ruling has bolstered the special-needs population’s self-advocacy push that began in the 1980s. A growing number of organizations, including Chicago’s Association for Retarded Citizens, has a program through which groups of five to eight clients share the cost of renting a home. Each client pays approximately \$225 for rent each month.

William Schneider, Chicago chapter president and CEO of the association, said, “We have a certain advantage. Because we serve the South Side of Chicago, homes are much cheaper than suburban homes. We can usually find a bank or foundation to provide enough money to buy a home. But the problem isn’t buying a home. The problem is that Illinois pays an inadequate amount for

providing services for people in these homes. It’s not the price of the home that’s the problem. It’s the price of paying service providers.

“When I think of what we’re asking the staff to do for \$7.50 an hour... I sometimes feel guilty paying them so little. The state has never provided adequate funding for services. Ever.”

One year ago, Jane Doyle and Kay Branz, both mothers of 22-year-old special-needs daughters, started the Center for Independent Futures. They found that, once their education ended at 18, opportunities for special-needs people ended too. Jane Doyle asked herself “Why aren’t our daughters reaping the benefits of their education?”

When their daughters turned 18 and left school, there were few employment, recreational or social opportunities.

“Kay and I had hopes and dreams for our own daughters that weren’t realized. So we came together to work with other families who shared our hopes and dreams to make something happen. Something different than what’s happening now,” said Doyle, who serves as chairman of the center.

The two mothers’ goal is to pull together networks of families to create new economic models for residential living through state as well as private funds. One of their goals is to expand the current housing options available to disabled adults.

Doyle said, “We want to see a continuum of options driven by the preferences of individuals and their families instead of current limited options driven by funding and program requirements.”

But their young company faces many struggles. Prejudice and misunderstanding often surface when disabled citizens move into a neighborhood.

Because of negative stereotypes, misinformation and ignorance about people with disabilities, it is difficult to create alternative housing. Just last year, Branz’s daughter, who is developmentally disabled, was forced to move out of a Deerfield townhouse she shared with two housemates. A neighbor harassed Branz’s daughter and her roommates by videotaping them when they walked outside, slashing caregivers’ tires and, finally, building a six-foot-high fence down the middle of the common driveway he shared with the disabled residents.

Ehlert has seen both sides of the future-planning issue. When her sister died, her parents “lost their purpose,” Ehlert said. “She was my parents’ life. Younger couples say, ‘we’ve got our child situated, we’ve got our child independent and we want a life to.’”

Rubin said, “With the birth of a child with disabilities, some friends fall away. You’ve heard the expression, ‘Broken dreams?’ Well, when your child is born you expect the child to be healthy, to go to school, to college, get married, get a good job, have their own children.

“Then, all of a sudden, someone throws a monkey wrench into your plans. It’s not going to be. Mitchell is a child who will be a child for the rest of our lives. We have this responsibility for the rest of our lives. Our dreams sure have been rearranged.

“Not broken but rearranged.”