WSJ.com THE WALL STREET JOURNAL. ONLINE

When Crisis Hits the Disabled

Limited Options for Support and Housing Exist for Aging Caregivers and Their Children

By CLARE ANSBERRY
April 29, 2008; Page A8

Seventy-nine year old Anna Dromgoole arrived at the Plano Specialty Hospital a month ago with severe wounds on her legs. Her 41-year-old son, Kent, who has Downs Syndrome, was at her side.

Ms. Dromgoole refused to be admitted unless Mr. Dromgoole could stay with her. She, like thousands of other aging caregivers across the country, had no place for her developmentally disabled child to go. When crisis hits, they find themselves at the mercy of strangers.

In their case, the stranger was Beth Lambdin, Plano Specialty's clinical liaison, who found a semi private room for the Dromgooles, thinking they would be back home in a few weeks.

Richard W. Rodriguez

Kent Dromgoole may end up living with Beth Lambdin, who works for the hospital, if she can't find a better alternative for him.

That scenario fell apart when Ms. Dromgoole went into respiratory arrest. That leaves her son, who himself has since been hospitalized, with no one other than Ms. Lambdin to turn to and nowhere to go once he is released from Plano Specialty later this week.

"I'm his one constant," she says. "I'm really no one, just a stranger who met them three weeks ago."

That Ms. Lambdin, an acquaintance of less than a month, may end up housing Mr. Dromgoole speaks to her character. But it also underscores the limitations of the nation's programs to assist those with developmental disabilities, especially in emergencies, which promise to hit more often as the nation's caregivers grow increasingly frail. "We have not addressed the needs of aging caregivers," says Susan Murphree of Advocacy Inc., a federally funded protection and advocacy system for

Texans with disabilities. "One of the things we don't have is help for people in crisis situations."

An estimated 2.9 million people with intellectual or developmental disabilities or some significant functional limitation live with caregivers -- mainly parents -- who are 55 years or older.

As they age beyond their caregiving capacities, as Ms. Dromgoole apparently has, their children need a formal and supported living arrangement. Unfortunately, there aren't enough of those arrangements.

About 80,000 people with developmental disabilities nationwide are on waiting lists for various services to help them live in the community. Texas, alone, has about 35,000 people waiting for home and community services, in spite of funding last year to serve additional people.

Spending for such programs continues to increase annually, although levels vary by state. It reached $2 billion last year, which represented a 10% increase, says Charlie Lakin, who researches residential programs at the University of Minnesota. "But the reality is, it's not growing enough to meet the demand."

Moreover, options may narrow further as budget-strapped states try to hold down spending and the federal government looks for ways to control spending for Medicaid -- the main source of funding such programs -- the concern is that options will further narrow.

Mr. Dromgoole's parents divorced when he was five and he has been alone with his mother since, most recently sharing a condominium.

His mother kept him close to her, taking him with her when she cleaned houses, played bingo and bowled. He took out the trash, got the mail and once had a job bagging groceries. "I help my mother plant some flowers and cut the yard," he says.

Many people in Ms. Dromgoole's generation didn't expect their children with various developmental problems to outlive them and didn't explore options for them to live on their own. In some cases, they were afraid that something bad would happen to their children without their attentive eye or they were frustrated by lack of options when they did look.

As she got older, Ms. Dromgoole had a harder time getting around. Her circulation was bad. Cuts on her legs wouldn't heal and became severe wounds. Several weeks ago, when his mother couldn't get up from the couch and he couldn't lift her, Mr. Dromgoole called 911. "She's real sick right now," he says.

At that point, although she didn't realize it at the time, Ms. Lambdin became his defacto caregiver. That first week, when both mother and son were at the hospital, Ms. Lambdin tried to keep Mr. Dromgoole, a likeable outgoing man, engaged. She brought him coloring books and paints and took him to Firehouse Subs, where he ordered an oversized sandwich dubbed the "Wreck."

"He's verbal and independent. He just can't live alone," she says. "He was never taught those life skills."

When his mother's condition worsened, Ms. Lambdin realized that the short term stay she envisioned wasn't going to happen and that Mr. Dromgoole might not be able to return home.

She called every number in Ms. Dromgoole's little phone book and found one living relative -- a first cousin in Louisiana, herself elderly and with a disabled child. Neighbors and friends voiced concern but are likewise older.

Various social service agencies offered untenable solutions. One said Mr. Dromgoole could get emergency help if he was left at a homeless shelter. Groups that work with the developmentally disabled had an opening in a supervised residential program nine hours away in San Antonio, but nothing closer. Ms. Lambdin doesn't want to move him that far from his mother.

She called her friend, Travis Fogle, at Silverado Senior Living, a well-regarded private pay home for those with Alzheimer's and dementia. Silverado, she knew, would take people for three days in an emergency situation. Mr. Fogle extended that stay for a week and a half, at no cost.

Mr. Dromgoole flourished there, putting vases with daisies and carnations on dining room tables, and helping to feed residents, who couldn't feed themselves. He went ballroom dancing, to his first hockey game and saw an Elvis impersonator. Staff trimmed his dark hair and cut his long nails, washed his clothes and his mother's, too. Mr. Dromgoole requested and received simple meals he was accustomed to -- corndogs, macaroni and cheese and skillet fried potatoes and onions.

"We just wanted it to be a positive experience for him," says Mr. Fogle. It was, but it was also unsustainable. It would cost more than $80,000 a year for him to live there and Mr. Dromgoole receives only $1,200 a month in Social Security.

"They did as much as they could," says Ms. Lambdin. Some Silverado families are trying to raise money for him to return.

With Mr. Dromgoole leaving Silverado, Ms. Lambdin asked Dr. John Lavery, Plano Specialty's medical director, if he could return as a patient. She had noticed swelling on Mr. Dromgoole's legs and suspected cellulites. After an examination, he was admitted. "He had a medical condition," says Dr. Lavery, declining to elaborate. Medicare is paying for his stay, although Mr. Dromgoole will be responsible for his $996 deductible.

He is responding well to treatment and will likely be released in a few days.

In the meantime, he watches wrestling on TV and calls Ms. Lambdin several times a day. He asked for a birthday cake for his mother, who turned 80 Monday. Ms. Dromgoole remains on a ventilator. When Mr. Dromgoole visits her, he sings "Peaks and Valleys," kisses her on the forehead, and says "Momma, you need to get better."

Ms. Lambdin continues to search for an appropriate local residence for Kent. If nothing materializes, she will bring Mr. Dromgoole home to live with her husband and three young daughters, ages 11, 9 and 5. The stairs on their split-level home would be hard for Kent, who weighs about 260 pounds, but not impossible.

"I've got feelers out everywhere," says Ms. Lambdin. "Unless by some miracle, someone comes in and says they have him covered, he'll come home with me."

Write to Clare Ansberry at clare.ansberry@wsj.com[1]

URL for this article:
http://online.wsj.com/article/SB120943103924651427.html

Copyright 2008 Dow Jones & Company, Inc. All Rights Reserved