

Caregivers of Adult Children Are Getting Fresh Assistance

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Carol Carr was trying to end the suffering of her sons, who were 42 and 41 years old, when she shot and killed them at a Georgia nursing home last month. Both were in the advanced stages of Huntington's disease, a degenerative nerve disorder that slowly cripples the body and brain. "She had gone from nursing home to nursing home trying to find someone who could care for them adequately," says Eric Hearn, her attorney in Zebulon, Ga. "Both of these boys were virtually helpless."

Her desperation has put the spotlight on an oft-forgotten group: parents whose children return to the nest after they are struck by a dread disease, or who have developmental disabilities that prevent them from ever leaving in the first place. The group is so little noticed that in November 2000, when Congress created the National Family Caregiver Support Program, it offered virtually no aid to parents caring for adult children.

Still, an estimated 2.7 million adult children with developmental disabilities live at home with a family caregiver. One in four live with a caregiver who is 60 or older. No one has even tried to count parents caring for older children with cancer, AIDS, and terminal illnesses like Huntington's. But the numbers are growing as medical advances extend the lives of the ill and disabled.

Children with Down syndrome, for example, plagued by heart and respiratory problems, once rarely lived to adulthood, says Marsha Seltzer, a professor of social work at the University of Wisconsin in Madison. "Now, people with Down syndrome are living into their 60s." In response, lawmakers and businesses are starting to help. Several state and local governments are jumping into the "respite" business -- assembling pools of temporary caregivers who can give parents a much-needed break and, in some cases, helping to pay for such services. At the same time, groups such as the National Respite Coalition, based in Annandale, Va., are pushing more states to offer similar help.

At the local level, lawyers and financial planners are starting to develop counseling services for parents who care for adult children. Parents themselves -- recognizing that their disabled sons and daughters might well outlive them -- are fighting for public aid to build more permanent homes for such children.

Oregon has led the way in respite care. In 1995, a grass-roots program to provide relief for caregivers with young children was expanded after organizers received calls from parents

caring for adult children. In 1997, the state government agreed to fund the program, which now receives \$650,000 a year, along with matching grants.

Even though there isn't much money involved, such support can make a difference in the lives of people like Charleen Braunbeck, a 61-year-old widow with osteoarthritis caring for her 32-year-old son. She receives two stipends each year for a few hundred dollars each, one from the state and another from a nonprofit group. That enables her to take a break three times a year from the round-the-clock care she provides her son, Ken, who has been disabled since he was stricken with viral encephalitis at the age of six months. Among other tasks, he needs help brushing his teeth and walking; if he pushes himself too hard, he has severe seizures.

Ms. Braunbeck checks Ken into a group home about 12 miles from her house that offers respite care for \$20 a day, then heads to the Oregon coast for a few days with her golden retriever to take long walks and sleep in late. "Nobody can take care of my child the way I can," she says. "But I know that it's important for me to go away for awhile, because it nurtures me. I need that."

Nebraska and Wisconsin have followed Oregon's lead with their own programs. Maryland has hired a statewide respite coordinator, and respite services in Oklahoma are getting off the ground. An additional 25 states have formed respite coalitions to push for similar funding, says Jill Kagan, chairman of the National Respite Coalition. Meanwhile, a national effort is afoot: Sen. Hillary Clinton (D., N.Y.) introduced a bill in May to take "lifespan respite" movement nationwide with \$91 million in funding and a national center to coordinate relief.

Beyond the demands of daily care, parents also must come to grips with the question of who will watch over their children when they are gone. "You pray that your child lives a long life, but you live one day longer," says Brian Rubin, a Chicago-area estate-planning attorney. His 21-year-old son, Mitch, is autistic. Mr. Rubin decided a few years after Mitch was born to open his own firm close to home and specialize in helping other parents plan for their children's future. Each day, he counsels three to four families on legal and financial obligations most parents never have to consider, such as creating a special-needs trust to protect a child's government benefits.

One of the toughest decisions such parents have to make is whether, and when, to move an adult child out of their home -- and how to pay for it. To that end, parents have started pressing state governments to provide services. Mary Lou Blair, a 72-year-old resident of East Falmouth, Mass., spent a decade lobbying Massachusetts officials along with a handful of other parents to build and staff a home for their disabled adult children.

"We decided that we didn't want to wait until we were on our deathbed to find care for our son, but it was still the hardest thing I ever did," Ms. Blair recalls. Her son, who is legally blind and developmentally disabled, moved into the home full-time when he was 28. Since then, says Ms. Blair, "other parents have followed in our footsteps and lobbied to have residences for their children."

Requests for publicly supported residential services have climbed 18% nationwide since 1994, notes David Braddock, executive director of the Coleman Institute for Cognitive Disabilities in Boulder, Colo. Since the mid-1990s, parents have filed lawsuits in 18 states in an attempt to force states to expand residential care to people on waiting lists to receive it. So far, decisions or settlements in at least seven of those states have called for expansion.

But even when a place to live is available, the transition can prove tough. Advent Christian Village, a nonprofit retirement community in Dowling Park, Fla., started a program in 1994 to accommodate parents and siblings caring for an adult family member with disabilities. To date, the participants have experienced more failures than successes, says James Humbles, the community's president and chief executive. One mother refused to let the staff help her grown son learn to live independently. Some disabled residents had a tough time understanding the need to respect the privacy of other residents.

"It's very complex for both the family and the organization that wants to help," says Mr. Humbles. "Regretfully, we're much more cautious about the families we bring in now."

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