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# Babes Among Elders: Nursing-Home Kids

## Parents Want Cheaper Home Care, but Medicaid Pays to Institutionalize; Ronnie's Journey

By CLARE ANSBERRY

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COMMERCE, Ga. -- Ronnie Rivera, a 15-year-old in braided pigtails, sits in a wheelchair in a narrow hallway of Hill Haven senior-citizen nursing home. A half-dozen other residents, many with dementia and most four to six decades older, sit nearby. Around them, a maintenance worker mops the linoleum floor.

Ronnie has lived in this single-story red-brick building since she was 10 years old, the only child among elders. Her mother, Iris Rivera-Smith, has tried unsuccessfully for years to get the financial help she would need to bring her daughter home.

Thousands of other children are growing up in nursing homes across the country, many for the same reason as Ronnie. Federal disability insurance guarantees nursing-home care for the disabled. But in many states, its coverage isn't enough to let those people, children included, live at home -- even when the cost to taxpayers, and the strain on families, is often much lower.

Born legally blind, with club feet and cerebral palsy, Ronnie can't walk or speak. She can't feed or dress herself. But she responds to touch, smells and sounds, pounding her chest with her right hand and laughing when happy. Latin music, the outdoors and her mother's voice make her happy.

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Clare Ansberry


Iris Rivera-Smith kisses her daughter Ronnie.

Until five years ago, Ronnie lived at home and went to school with other developmentally disabled children. Then she had severe respiratory problems. Her lungs filled with fluid and she almost died. Doctors told her parents that Ronnie should go to a nursing home to receive 24-hour care for the few weeks she was expected to live.

Ronnie outlived expectations and remains here, more than 100 miles from her home. She doesn't go to school. Her world consists largely of the home's long corridors, its atrium with a big-screen TV and her room, with its cinder-block walls painted blue.

About 4,000 children nationwide live in nursing homes, according to Medicaid -- a small, often hidden population that has wound up in these incongruous settings, often against their parents' wishes. While some of the homes cater to children, many are traditional facilities designed for the

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aged. Their staff may dote on young residents but are often more familiar with geriatrics and dementia. Visits to family may be limited: Nursing facilities often give away residents' beds if they spend more than 10 nights a year away from the home.

"Any child in a nursing home is so outrageous -- it offends the sensibilities," says Ruby Moore, executive director of the nonprofit Georgia Advocacy Office, a federally chartered group that supports the disabled.

But for these families, there is often no alternative. Parents may seek help after their disabled child suffers a life-threatening emergency, or a divorce leaves a single working parent without time or resources for child care. Depending on what institutions are located near the family, a child may be sent to a group home, a state or private school or, often in the case of the most severe disabilities, to a nursing home. A total of about 26,400 children are in out-of-home facilities across the country.

Home care isn't an option for many parents. Medicaid, the federal-state program that insures people with low income or disabilities, automatically pays for nursing homes. It's up to individual states to decide how much they will pay for in-home services. Few states fund the level of skilled care such patients require, leaving parents with a burden that can run tens of thousands of dollars annually. Nationwide, there also aren't enough home-care workers, nurses and therapists to serve these families. About 93,000 developmentally disabled Americans of all ages are on waiting lists for home and community-care services.

When home care is available, it typically costs taxpayers less. Georgia spends about \$81,000 a year for each resident in institutional care, which includes nursing homes. Home and community care, by comparison, costs about \$26,000 a year, according to the University of Minnesota's Research and Training Center on Community Living.

"We simply don't do enough to support families to care for their children with significant disabilities at home," says Eric Jacobson, executive director of the Georgia Governor's Council on Developmental Disabilities. To begin to address the issue, last year Georgia's state legislature committed \$48 million to programs for the disabled, including a plan to move more than 140 institutionalized children, including 87 in nursing homes, back to their families.

In the meantime, Ms. Rivera-Smith, 46 years old, makes the four-hour round trip to Hill Haven at least once a month, in between working and caring for a young grandson. She brings Elmo dolls, dollar-store hair ribbons and handmade bibs, embroidered with hearts. On Ronnie's birthday, Ms. Rivera-Smith brought her daughter home to eat chocolate cake with her cousins and four older siblings. Ronnie wore a new red dress.

The federal Centers for Disease Control and Prevention has called for all children with disabilities to be out of "congregate settings" -- four or more people with disabilities -- by 2010. Budgets for home care have grown. Federal and state spending for home- and community-based services, the bulk of it through Medicaid, increased to \$17.2 billion in fiscal 2005, nearly tripling the amount spent in 1997. Spending on institutional care over the same period was up 20%, to \$12.1 billion.

"The Bush administration has been very supportive of home-care," says Mary Kahn, a spokeswoman for the Centers for Medicare & Medicaid



Iris Rivera-Smith helps her daughter Ronnie into her wheelchair.

Services. "It is particularly poignant when a young child is involved."

Yet even as home-care spending has increased, the population of institutionalized children has remained steady in recent years.

In 1977, more than 90,000 developmentally disabled Americans under the age of 21 lived in congregate care facilities. After a national movement away from institutional care, the number dropped to 26,000 in 1997, only to edge up to the current 26,400, according to the University of Minnesota community living center.

The needs of these children vary. Some have survived a traumatic injury, such as a near-drowning, and live on a ventilator, responding with their eyes to touch and sound. Those with severe mental retardation often require help to dress and eat, but don't require involved medical care. Others have physical disabilities but a mind that leaves them aware of their setting and their singularity.

"Compared to the other residents, I was healthier, physically and mentally," says Danny Shirey, 26, who has muscular dystrophy and was sent to a Columbus, Ohio, geriatric nursing facility when he was nine.

In his six years there, he would roam the halls in his electric wheelchair, help older people play bingo and euchre, or guide disoriented patients to their rooms. He looked forward to monthly visits from his family, who lived in Pittsburgh. The facility's occupancy rules made going home for an overnight visit rare.

"There has to be a better alternative," says Mr. Shirey, who received some tutoring during his nursing-home stay and has attended school. He now consults with groups trying to improve options for children with developmental disabilities. "I was far away from my family. I remember crying myself to sleep many nights."

On nights when Judy Zifka, 52, is feeling particularly lonely, she will drive to Providence Child Center in Portland, Ore., and climb into bed with her 15-year-old daughter, Andrea. They listen to Billy Idol, Dave Matthews or jazz. Her daughter will sometimes hum, the only sound she makes.

Born seemingly healthy, Andrea Zifka had her first seizure at three months. Doctors performed an MRI and found her brain lacked the natural folds that control the ability to speak, chew, move or register emotion by crying or laughing.

Though profoundly disabled, Andrea wasn't eligible for Medicaid because she lived at home and her father, an electrician, was earning \$35,000 a year, putting them above Oregon's poverty line. Her father's private insurance covered hospital stays but wouldn't pay for in-home nursing care, therapists or all the medical equipment Andrea needed. For those with private insurance, out-of-pocket expenses for prescriptions, lifts, wheelchairs and other equipment can run more than \$50,000 a year.

By age 9, Andrea had lost all purposeful movement. Ms. Zifka dressed, bathed and turned her to prevent bed sores. As her energy and sympathy went to Andrea, her marriage suffered. After carrying her 70-pound daughter up and down steps, she developed rheumatoid arthritis in her spine.

Her husband, Lance Zifka, worked on construction projects, often out of town. "I just couldn't guarantee that I would be working close to home and I could tell she couldn't lift her anymore," he says. "It just wasn't going to work."

The closest residential option was Providence, three hours away from the family's home in Bend, Ore. The family had sent Andrea to the nonprofit facility, one of the nation's 40 pediatric nursing homes, for short-term care in the summer. When Mr. Zifka heard it had a long-term bed available, he requested it for Andrea.

"I felt like I totally failed my daughter," says Ms. Zifka. "I'd wake in the middle of the night, come out in the living room and cry." She visited Andrea every two weeks from Bend, making the six-hour trip in one day.

After several months, Andrea's seizures began intensifying. "I believe she was dying of loneliness over there," her mother says. Ms. Zifka rented a room in Portland so she could spend two weeks a month with her daughter. She spends the other two weeks with her husband and son. While she's away, Ms. Zifka asks Providence's staff to play her daughter CDs the Zifkas made. On them, Andrea can hear her parents reading fairy tales.

Andrea has been there two years. Ms. Zifka says she's glad her daughter is with her peers, not at a nursing home geared to older people. Andrea goes to school. Providence's pediatric facility hosts proms and takes the children to malls and horseback riding. In a recent production of "The Wizard of Oz," Andrea was Glinda the Good Witch, pushed across the stage in a chair.

Ms. Zifka says she knew they would eventually need someone to care for Andrea. She just didn't expect it so soon. "It was wrong that I had to make the choice that I did," she says. "It was wrong that the only way I could get help was to send her away."

Medicaid pays Providence Center about \$100,000 a year for each child, says administrator Pat Budo. Average home and community-based spending for someone such as Andrea, with developmental disabilities and extensive health-care needs, is about \$35,000. "It is crazy," Ms. Budo says. "This child could be kept at home at much lower costs."

Which services Medicaid covers, and whom it covers, vary by state. The Centers for Medicare & Medicaid Services pays a percentage of each state's total costs, often footing a higher share of needier states' bills. States determine who is eligible for the aid, with some covering only those below the poverty line and others paying for all residents with certain disabilities.

This year, Oregon passed legislation to allow all severely disabled children living at home to get Medicaid coverage, regardless of family income. It would also help the 83 children currently in the state's nursing homes, such as Andrea Zifka, to move home. The new policy begins Jan. 1.

It is an involved process. Agencies must line up nursing care, therapy and schooling. Homes may need wheelchair ramps or hoists to lift children out of bed. And there are other, more delicate issues. Parents may be reluctant to relinquish the safety net of 24-hour-paid care. Some argue that certain children are so medically fragile that there will always be a need for institutional care.

Laurie Faulk never wanted her son in a nursing home, but didn't know she had a choice.

Donald, 14 years old, is legally blind and has mental retardation. Cerebral palsy keeps him from walking. He is fed by a tube and can't dress or bathe himself.

Until he was 6, Donald lived with his parents in their rural Georgia home. Ms. Faulk took him to doctors, exercised his legs and taught him to say words like "love," "good" and "up." But that year, she and Donald's father divorced. With no job, Ms. Faulk moved with her son to a small trailer, where she washed clothes in the bathtub.

At one point, when her ex-husband was caring for Donald for a few days, Ms. Faulk was arrested for driving under the influence and ended up in jail, she says. Donald's father gained custody and, at age 6, the boy ended up in a geriatric nursing home, the only child among some 100 residents. A paper sign on his door, decorated with teddy bears, read "The Baby's Room." Donald's father didn't return calls seeking comment.

Ms. Faulk visited weekly, decorating his room with bunnies for Easter and Santa Claus for Christmas. She would take him outside to listen to the birds, wheeling him down the hallway past older residents who sat in their doorways, television sets blaring. "In there, all he heard was people moaning and groaning," Ms. Faulk says.

Donald spent most of his six years there in bed, his mother says, lying on his side and facing the wall. His spine curved and his hands grew stiff and curled. He developed blisters and bed sores and was hospitalized several times because of problems relating to his feeding tube, she says. "I was always sad and angry," she says. "He would stink and smell so bad I had to wash him so I could even kiss him."

Gillian Grable, project director for Georgia Advocacy Office, a nonprofit group that was helping track down children in the state's institutions, came across Donald. The office was working with other state agencies on the Children's Freedom Initiative, one element of Georgia's plan to provide new services for people with disabilities.

Ms. Grable called Ms. Faulk and asked if she wanted her son back home. With the agency's help, Ms. Faulk found an attorney who helped her gain custody of Donald. By then, she had a job, repainting walls and cleaning rental properties, and was sharing a house with a friend.

Donald came home in February 2006. Medicaid money, which once went to the nursing home, pays to have someone stay with Donald from 9:30 a.m. to 5 p.m., while Ms. Faulk works. It also paid for a bath chair, hospital bed and suction machine that keeps his breathing tube clear. Speech and occupational therapists, as well as a special-education teacher, come several times a week.

Donald's once-stiff hands can now hold a ball and rag doll. Their refrigerator displays his art, the latest being a cherry tree with blossoms of pink-tinted popcorn, which he made with the help of his teacher. Donald's dark curls, shorn at the nursing home to avoid matting, have grown in.

Having him home is comforting. "He wakes up and I hear him laugh and talk," Ms. Faulk says. "I don't have to worry about him."

Ms. Rivera-Smith is working with the state advocacy office to bring her daughter home as well.

For now, Ronnie spends a portion of her day in the doorway of her room, right across from the nurse's station. Staffers wheel her to the atrium for performances by local church choirs and activities like line dancing, musical chairs and a pirate party where able residents swung at a piñata. Ronnie can hear the music and laughter, which is all part of sensory stimulation, says Dana Carey, administrator of Hill Haven.

"There's not a lot you can do for Ronnie. We rub lotion on her, do her hair," says Ms. Carey. "We do a lot of passive participation, where she sits in the hallway with the radio on."

When she comes to visit, Ms. Rivera-Smith takes Ronnie for walks. On a recent outing to a shopping center, she pushed Ronnie's wheelchair and described a lace dress in a window. "Oh baby, I love this. That would look good on you," she said. They dropped into Bath & Body Works to smell Moonlight Path, their favorite fragrance.

Before leaving Ronnie at the nursing home, her mother climbed into bed next to her, whispered in her ear and gave her a kiss goodbye.

After, she walked down the hallway, past the atrium where a half dozen older residents were watching "The Price is Right." She stopped to rub the arm of a white-haired woman resting in a reclining chair. The woman had been Ronnie's first roommate until she became too frail. Ms. Rivera-Smith punched a code to open the locked doors, and stepped outside.

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