

Brain-Injured in Nursing Homes Without Care Giffords Had

Don't Miss Out —

Follow us on: Facebook Twitter Instagram Youtube

by David Armstrong

12:01 AM EST

December 28, 2012

Share on FacebookShare on Twitter

Brain-Injured Languish in Nursing Homes

An ambulance enters the Texas Institute of Rehabilitation and Research (TIRR) in Houston, Texas where U.S. Representative Gabriel Giffords underwent rehabilitation. Giffords had music, speech, physical and aquatic therapy. TIRR Memorial Hermann brain injury teams include a rehabilitation physician, a neuropsychologist, a dietitian and a pharmacist. Photographer: Eric Kayne/Getty Images

Dec. 28 (Bloomberg) -- Larry Boswell sat slumped in a wheelchair. His sweatpants were soiled, his T-shirt soaked in saliva. Flies buzzed around his head.

He was able to walk when he arrived at Illinois' Cobden Rehabilitation and Nursing Center in 2008, government records show, something he can't manage now. Speech therapy for the 57-year-old ended shortly after he was admitted, according to a lawyer trying to persuade Medicaid to transfer him.

While much of what Boswell says is incomprehensible, he managed a clear "no" when asked if he wanted to stay where he was. Cobden officials didn't respond to telephone calls.

Boswell is one of nearly 244,000 brain-injured people consigned to nursing homes, according to data compiled by Bloomberg from U.S. Medicare and Medicaid statistics. He's also on the front line in a national battle to get people like him out of facilities that aren't equipped to care for them.

"People used to be put away in state hospitals and state developmental centers," said Steven Schwartz, a lawyer who filed a class-action lawsuit to force Massachusetts to provide alternatives to nursing homes for the brain-injured, and won a settlement that's still being implemented. "Now people with brain injuries are warehoused and put away in nursing homes."

Over 4 million brain-injured Americans -- including victims of car accidents, assaults, strokes and falls -- suffer from long-term disabilities that require specialized therapies. They are sometimes neglected in institutions designed for geriatric care, not for the treatment they need. In some cases, they're in



7

facilities with low scores from a U.S. agency that grades nursing homes on quality, cleanliness and other measures.

'Inhumane' Treatment

"The minute you step behind the curtain and look at what is going on with these people, it is nauseating," said Geoffrey T. Manley, a neurosurgeon and co-director of the Brain and Spinal Injury Center at the University of California, San Francisco. "What we are doing to them is inhumane and wrong."

Most Americans don't have insurance that will cover brain injury rehabilitation facilities, which handle about 40,000 patients. Insurers generally put sharp limits on the type and duration of long-term care they'll fund. That means the most severely brain-injured often end up on Medicaid, the federally-and state-funded insurer for the poor and disabled.

While U.S. law requires Medicaid to pay for nursing homes, the program has no such mandate for long-term care in a specialized brain-injury rehabilitation center, a person's home or a group residence. There are some Medicaid-paid slots --about 19,000 nationwide -- for the brain-injured outside nursing homes. Waiting lists for these exceed five years in some states, and officials say there isn't enough money to expand them.

'Treatment Gap'

Few receive the care former U.S. Representative Gabrielle Giffords had after she was shot in the head last year outside a Tucson supermarket. Citing the disparity highlighted by her case, her staff has called for an end to "the treatment gap."

Giffords, 42, spent five months at the TIRR Memorial Hermann rehabilitation center in Houston, Texas, with the bill paid by federal workers' compensation insurance. Her assailant, firing a handgun, killed six others in the attack.

In Houston, Giffords had music, speech, physical and aquatic therapy. TIRR Memorial Hermann brain injury teams include a rehabilitation physician, a neuropsychologist, a dietitian and a pharmacist.

That's hard to match in a nursing home. Fewer than one in 10 can care for a clientele with such extensive needs, said Scott Schuster, president of Wingate Healthcare, which owns 18 nursing homes in Massachusetts and New York.

"The system is not designed to care for brain-injury patients," Schuster said.

Less Restrictive

Wingate this month closed a 125-bed center in Middleboro, Massachusetts, that specialized in treating brain injuries because the Medicaid rate of \$320 didn't come close to covering the services patients needed, Schuster said.

More than a quarter of the brain-injured in nursing homes are capable of living in less-restrictive environments, said Susan Connors, president of the Brain Injury Association of America. University of Wisconsin researchers found that 19 to 22 percent of patients wanted community-based care in a 2009 study funded by the U.S. Centers for Disease Control and Prevention.

Bloomberg found 243,892 brain-injured patients in Medicaid-or Medicare-certified nursing homes using admissions data the homes are required to file to the government. They were culled from the 1.3 million total patients in the database by searching it for files containing the codes for brain injuries.

No License

The Boswell case illustrates the byzantine snarls in brain-injury care. He wants to live in one of the apartments or group homes in Carbondale, 15 miles away, that offer tailored brain-injury therapies and are operated by NeuroRestorative Inc. But the Illinois Medicaid program will only cover long-term care in a licensed nursing home -- and NeuroRestorative doesn't have a nursing home license.

Boswell's lawyer, Stacey Aschemann, said she's petitioning the Medicaid program to consider transferring her client to NeuroRestorative anyway.

While Medicaid pays \$118 a day for Boswell to live at Cobden, and NeuroRestorative would charge \$390 a day for someone in his condition, money doesn't seem to be the issue. Illinois Medicaid pays \$666 a day to send some state residents to a brain injury treatment center in Omaha, Nebraska, that has a nursing home license. Boswell doesn't want to leave Illinois and his family, Aschemann said.

Olmstead Decision

In Massachusetts, a 2008 promise by the state to help nearly 2,000 brain-injured live outside nursing homes has led to only a few hundred placements, according to Schwartz, a lawyer for the nonprofit Center for Public Representation. The promise was made in the settlement to the suit Schwartz filed on behalf of 9,400 brain-injured patients in the state.

The suit cited the U.S. Supreme Court's 1999 Olmstead decision that the disabled have the right to live in their communities if they aren't opposed and their placement "can be reasonably accommodated."

After the settlement, one plan to move about 1,600 patients out of nursing homes was shelved, Schwartz said, and he and state officials are still working on finding a way to meet the terms of their agreement. Paulette Song, a spokeswoman for the Massachusetts Medicaid agency, declined to comment on the case.

There's no question nursing homes are sometimes the best option, especially for people on ventilators or requiring feeding tubes. But the majority need therapeutic attention nursing homes can rarely provide.

Expanding Possibilities

And nursing homes don't necessarily want to take these patients on, said Greg Crist, a spokesman for the American Health Care Association, a Washington-based trade group.

"Our guiding principle, particularly with young people, is that we want them in the least restrictive care setting possible," Crist said. "We don't want them if they don't belong in our center."

In 24 states, U.S. Medicaid officials have granted waivers that expand the possibilities for people disabled by brain injuries. These include paying for rehabilitation therapy and for living at home or in community settings such as staffed apartments and small group houses.

Funding for the waiver programs is modest; most states limit how many people can participate, creating long waiting lists for those services.

In Connecticut, Jean Ferrier's request to live in the community under the waiver program has been pending for more than three years, according to her sister, Patty Van Etten. Since June 2011, the 50-year-old Ferrier has been at Aurora Senior Living of East Hartford. Her income is \$1,126 a month in Social Security disability, all but \$60 of which goes to Aurora.

Disjointed Thoughts

Ferrier had just turned 17 when she was thrown from a Jeep her boyfriend was driving, sustaining injuries so extensive doctors doubted she would walk or talk again, according to Van Etten. She proved them wrong.

With a brace on her right leg, Ferrier limped to a booth for lunch at a Denny's near Aurora and spoke haltingly. She suffers from aphasia, a common effect of brain trauma that results in disjointed thoughts and broken sentences.

"I would like to live somewhere else," she said. When asked where, she struggled and sighed before changing subjects.

After rehabilitation, Ferrier lived by herself for nearly a decade with family helping with laundry and shopping. After she was assaulted by a man who stole her car, she moved in with her mother. Her sister hired caretakers when their mother turned too frail to help, until that became too expensive.

One Star

Van Etten said the only place that would take Ferrier was Aurora. She eats meals in her bed and goes outside only when her sister comes to visit or during four scheduled smoking breaks. Her sister said she's not getting needed vocational and occupational therapy.

Officials at Aurora didn't respond to telephone calls. It has just one star in the rankings by the Centers for U.S. Centers for Medicare & Medicaid Services, with three times the state's average number of health deficiencies since 2011.

No nursing home in the state offers specialized care for patients like Ferrier, according to Melinda Montovani, of the Brain Injury Alliance of Connecticut. Most facilities “simply will not take someone with a brain injury, as it is not cost effective” at rates paid by Medicaid, Montovani said.

In New York, Medicaid pays for 173 brain-injured patients at Northeast Center for Special Care in Lake Katrine, a nursing home that specializes in the condition. The cost is between \$287 to \$491 a day per patient.

‘Cruel Allen’

Northeast Center has a rating of two stars in the federal ranking system. The most recent state inspection in November 2011 found strong urine odors in the dining room and hallways, and broken, stained furniture.

Two men, one an ex-employee, told police in 2009 that the facility wasn’t taking seriously a complaint they made about patient abuse. Northeast Center officials denied that was the case when contacted by law enforcement.

The two men said a worker, Allen Dinga, sent them videos of himself abusing a 66-year-old, wheelchair-bound man with a traumatic brain injury, according to a police report. Detectives discovered a dozen videos, taken over a six-week period.

The videos, with titles like “cruel allen ha ha” and “cruel allen smack,” show Dinga verbally abusing and swearing at patient James Jackson, slapping him in the head and asking if he can urinate in his bed. In one scene, Dinga flicks a lighter and says, “I will light you on fire.”

Burn Marks

The victim’s stepson, Jimmie Singleton, said a family member found burn marks on Jackson’s arm the next day. The family didn’t learn of the video until weeks later.

Dinga pleaded guilty to endangering an incompetent person and received three years probation. He couldn’t be reached for comment. Officials at Northeast Center didn’t respond to calls.

New York disclosed last year that 700 Medicaid recipients were living in out-of-state nursing homes. A majority suffered from neurobehavioral disorders, including brain injuries, and a “significant percentage” were in other states because of New York providers’ inability to hire and train “competent staff,” according to a state Medicaid report.

Marek Ross, one of the New York outplacements, is fighting in court to come home. Ross, 41, lives in a locked unit at Holyoke Rehabilitation Center, a nursing home in Massachusetts.

New York Medicaid sent him there in 2009, claiming there were no other options, Ross says in a lawsuit filed in federal court in Syracuse in June. He has been “warehoused in a locked facility out of state, out of sight, and out of mind,” his lawsuit alleges.

Telephone Privileges

At Holyoke, which has four stars in the federal rankings, Ross shares a room with another patient and claims many of his belongings have been stolen. He's allowed outside twice a day, his mail is monitored and his telephone privileges are restricted, the lawsuit claims. He must earn the right to attend church. New York Medicaid is paying \$412 a day for his care.

Holyoke "takes very seriously the personal needs and rights of its patients" and its "obligations to and responsibility for them," according to an e-mailed statement. Officials declined to comment specifically on Ross's case.

His placement in the nursing home violates the Americans with Disabilities Act by subjecting him to unjustified segregation, his lawsuit claims. He wants the court to force New York to transfer him. The state has denied violating Ross's rights, and requested a dismissal of the complaint.

In Illinois, Larry Boswell is also looking for a way out. He was in a coma for nearly two months after a car crash three decades ago. He was 24, and a long-haul truck driver.

Easily Agitated

The accident left him with physical injuries that made walking difficult. He was easily agitated and prone to outbursts. He would make inappropriate remarks to women.

With help from family and attendants paid by Medicaid, Boswell lived in apartments and other community settings for much of the last 30 years. He ended up in the Cobden nursing home in 2008 after two caretakers with whom he lived said they could no longer look after him.

"This program is the end of the line," said Bonnie Vaughn, executive director of the Southern Illinois Center for Independent Living, a nonprofit that helps disabled people live in community settings.

When Boswell was admitted, a physical therapist indicated he was able to walk 25 feet and follow commands. The therapist noted it was difficult to understand him, according to a report that doesn't identify him but contains details such as date of admission that make clear Boswell is the resident described.

'Relatively Young'

Vaughn, who has known Boswell for nine years, said the nursing home won't allow him to walk, even after a doctor wrote an order for a special walker that reduces the chances of him falling. "Walking has always been the most important thing to him," she said. "He is relatively young. If walking is a major component, why can't we make that happen?"

When two visitors recently saw him at Cobden, Boswell beseeched them to take him to a local park. He began to rise out of his wheelchair, saying he could walk and get into a car without assistance.

Aschemann, his lawyer, said he rarely leaves the nursing home, and usually only for medical appointments.

The state agency that licenses nursing homes in Illinois identifies Cobden's owner as Steven Blisko, and lists him as having interests in eight other nursing homes in the state. Blisko didn't respond to telephone calls.

Stale Air

At Cobden, the floor of Boswell's shared room was layered in grime. There were two plastic chairs, a broken television and a white sheet covering the window. Flies dotted his bed pillow.

The stale air smelled of urine. Patients in common areas appeared to have little to do. Several walked the halls asking visitors for cigarettes or money.

A 2008 inspection during the month Boswell arrived cited the home for failing to keep it free of pests. The state inspector reported flies landing on patients incapable of swatting them away and indicated staff did nothing about it.

While the federal rankings give Cobden the highest grade of five stars, state inspectors in May noted "a strong pervasive urine odor upon entrance to the facility's dining room." They described "dirty debris" on the floor of a resident's room, missing floor tiles and the entire length of a hallway marked with a "dark smeared substance."

Aschemann said Boswell deserves a chance to live in another environment. "He has made it pretty clear he doesn't want to be there anymore," she said. "He had once lived out in the community, and he wants to get back."

To contact the reporter responsible for this story: David Armstrong in Boston at darmstrong16@bloomberg.net

To contact the editor responsible for this story: Gary Putka at gputka@bloomberg.net