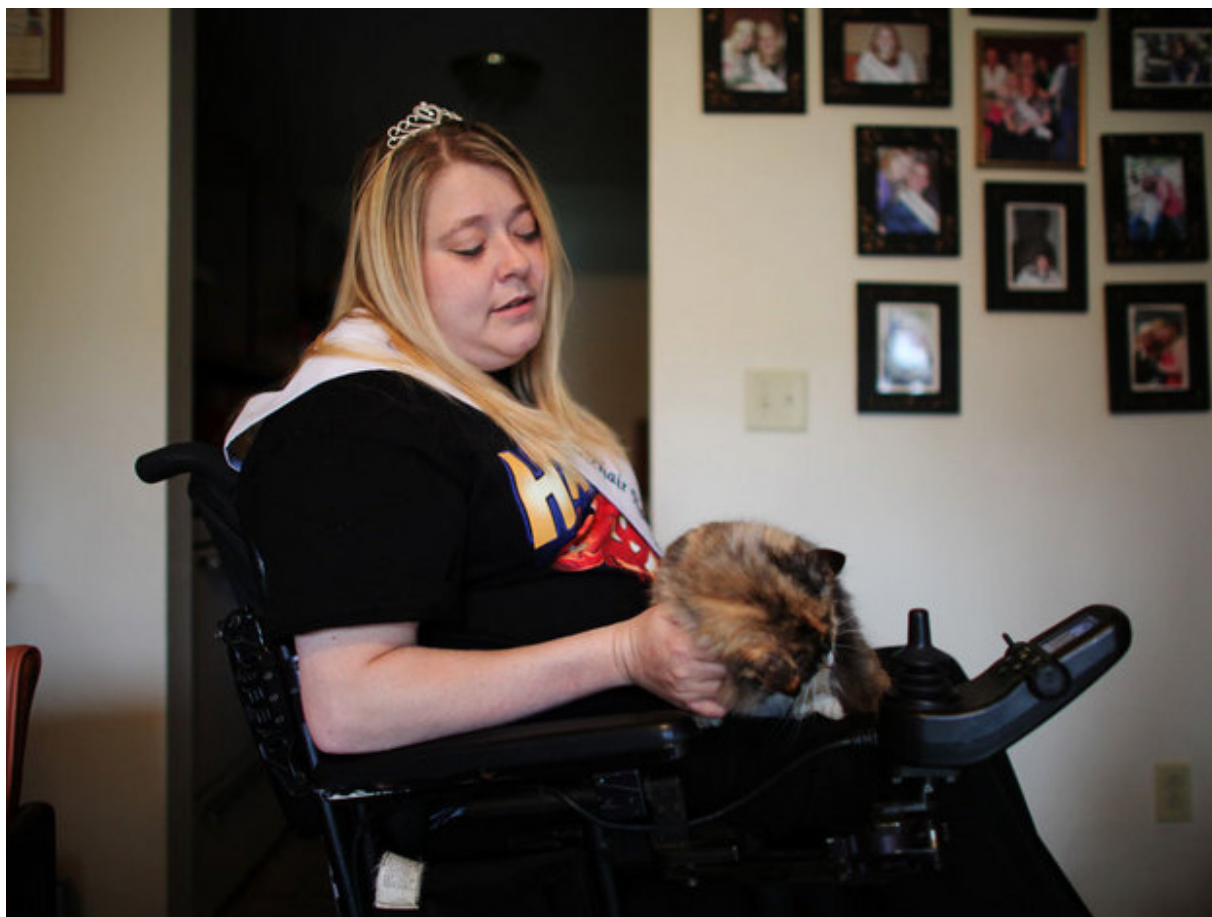


A New Nursing Home Population: The Young

by JOSEPH SHAPIRO



John Poole/NPR

Michelle Fridley, 33, with her cat in her apartment in Canadaigua, N.Y. Ten years ago, on the way to her baby shower, Fridley, then 23, was in a car accident that left her a quadriplegic. This year, she was crowned Miss Wheelchair New York.

December 9, 2010

text size **A A A**

There's one age group that's going into nursing homes at a higher rate. And it's not the elderly.

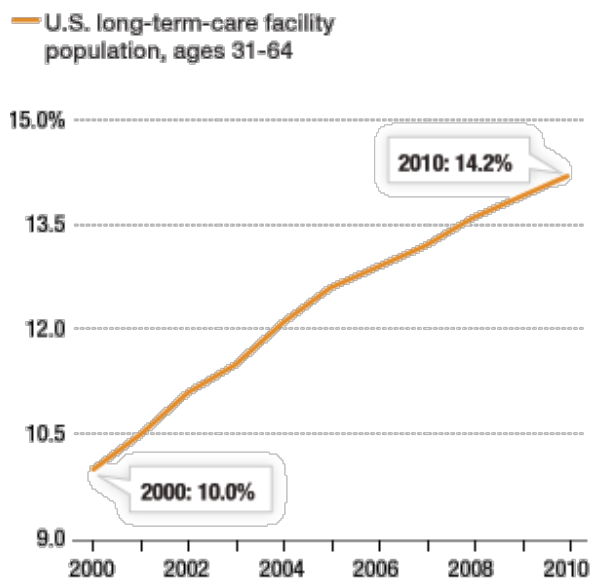
Young people ages 31 to 64 now make up 14 percent of the nursing home population, an analysis of federal data from the Department of Health and Human Services by NPR's Investigative Unit found. That's up from 10 percent just 10 years ago.

The data do not show why this age group is entering nursing homes in such higher numbers, but Michelle Fridley's fight to stay out of a nursing home may provide a clue.

Working-Age Nursing Home Residents

In the past 10 years, adults ages 31 to 64 have been the fastest-growing population in nursing homes.

Ten years ago, Fridley was nine months pregnant and 23 when, driving on a rural road in upstate New York's Amish country, she came over a blind hill and swerved to miss a horse and buggy. Her car hit a tree; she was left a quadriplegic.



Source: U.S. Centers for Medicare and Medicaid Services
 Credit: Robert Benincasa and Stephanie d'Otreppe/NPR

At the time, Fridley was driving home to decorate for her baby shower. Her daughter, Felicia, was born nine days later. Ever since, Fridley, who is now 33, has fought to stay out of a nursing facility and continue living in her own home.

Fridley and her daughter now live in their own apartment — but only because a New York state program pays for Fridley's personal care attendants.

"Attendants are my arms and legs. I wouldn't be able to do anything without my attendants. They help me to get bathed in the morning. They get me dressed. They attend to my, both my, you know, urinary and bowels; my personal needs. They help me to cook. They drive me from doctors' appointments to wherever I need to go, and I like to get out," Fridley said.

Since her injury, there have been three times when she almost went into a nursing home. One came earlier this year when officials in New York proposed cutting the attendant care program. After Fridley and others protested — and she told her story to New York Gov. David Paterson — the decision was reversed. However, more state cuts are expected next year.

According to a study by the AARP Public Policy Institute, the cost of attendant care is about a third the cost of providing care in a nursing home or institution. But there's an upfront cost to states to hire the case managers and aides, find the housing, and pay for other things that make this home-based care work. And states worry that more people — who now depend upon family to provide the care to keep them out of nursing homes — will start demanding this care at home.

So as states face record budget gaps, the programs that help people live at home are cut.

From Colorado Public Radio

Laura Frank of the Rocky Mountain Investigative News Network reports on the struggle to receive long-term care at home.

Colorado Public Radio:
 Independent Living Part 1
 Colorado Public Radio:
 Independent Living Part 2

Nancy Miller, at the University of Maryland, Baltimore County, thinks that may be one reason the percentage of 31- to 64-year-olds is growing in nursing homes. Miller, an associate professor in the school's department of public policy, has been studying why young people enter nursing homes and published several reports documenting these data. She has found that it's also this same group going into nursing homes at higher rates. It's a trend she has found in almost every state over the past 10 years.

"They were much more likely, relative to their older counterparts, to have a diagnosis of diabetes and renal failure," Miller said. "And then I also found that a substantial share came in with a mental health problem."

Miller says that shows states lack programs to help these people receive care at home. And when such support exists, it's hard to find.

Pat McMurry, who runs a nursing home outside Atlanta, agrees that it's the availability and funding of state programs that has caused the growth of working-age people in nursing homes.

"I've been in this business for almost 50 years now," McMurry said. "And traditionally, nursing homes were the little old men or the little old ladies that either outlived their relatives or had some kind of a fall or a fracture. Now we're seeing a transition to a younger population, either for psychiatric issues, which once upon a time were addressed in psychiatric state hospitals, which a lot of those have closed. So this is really the only means available that are financially reimbursed."

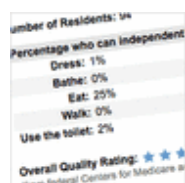
Fighting 'Institutional Bias'

Over the past 20 years, federal laws and policies have established a civil right to get long-term care at home. But NPR's investigation found [that is only sporadically enforced](#).

More than 60 percent of what states spend on long-term care for the elderly and disabled goes to pay for people — like Michelle Fridley — to live in a nursing home. The amount spent on home-based care has grown steadily, but not nearly enough to meet the need. Nationwide, there are some 400,000 people on state waiting lists for home-based care, double the number 10 years ago.

Home Or Nursing Home: America's Empty Promise To Give Elderly, Disabled A Choice

About This Series: There's been a quiet revolution in the way the elderly and young people with disabilities get long-term health care. A new legal right has emerged for people in the Medicaid program to get that care at home, not in a nursing home.



SEARCH: Independence Rates At Nursing Homes

Interactive database: The independence level of residents at nursing homes around the country.



Youth In Nursing Homes Seek Alternative Care

Despite alternatives for long-term care, many disabled young people remain in nursing facilities.



Care At Home: A New Civil Right

New federal policies are giving people who need long-term care the right to receive it at home.

At a protest in Washington last spring organized by [ADAPT](#), a disability civil rights group, Fridley and her daughter, then 9 years old, participated. The group wants Congress to make it mandatory that states pay for people with disabilities — young and old — to live in their own homes. That means expanding state programs that pay for in-home attendants.

The protesters blocked federal office buildings and ones that house groups representing state lobbyists and the private nursing home industry. On the back of Fridley's power wheelchair, a hand-lettered sign said: "I'd Rather Go To Jail, Than Die In a Nursing Home."

She had also stuck a round sticker on her coat that said "Defending Our Freedom." That freedom is the [civil right to get their long-term care at home](#). It was established by a 1999 Supreme Court decision in what's known as the *Olmstead* case. The court cited the Americans with Disabilities Act, the sweeping anti-discrimination law that is mostly thought of as something that puts wheelchair ramps on buildings and tells employers they can't discriminate in hiring decisions against the disabled.



Families Fight To Care For Disabled Kids At Home

NPR INVESTIGATION: States are caught between helping families and dealing with Medicaid costs.



A New Civil Right Looks For Stronger Enforcement

Officials are slow to respond to nursing home residents fighting to receive care in their own homes.



Milestones In Long-Term-Care Policies

Changes in policies and funding have made home- and community-based care a more viable option.

NPR News Investigation: Home Or Nursing Home
Dec. 9, 2010

But the Supreme Court justices said the provisions of the ADA also make the unnecessary institutionalization of people with disabilities a form of discrimination.

Since then, federal policies have said states need to do more to meet the obligation that resulted to create more community-based care. The recent health care overhaul has several provisions to create financial incentives for states to expand these attendant-care programs.

But there is a contradiction in federal law. Policymakers call it the "institutional bias." Federal law requires states to pay for nursing homes, while community-based care is optional.

Fridley and the other members of ADAPT demanded that lawmakers pass the Community Choice Act, which would end the "institutional bias" in Medicaid and make it mandatory for states

to pay for home-based care, just like it is a requirement to pay for nursing home care now.

A pilot program was included in the recent health care overhaul, but it's voluntary for states. The larger bill has languished in Congress. One reason: The Congressional Budget Office estimates it would cost \$5 billion a year. Some academic studies have said much of that money would be offset by the cost savings of caring for people at home.

Janice Zalen, with the American Health Care Association, the largest association of long-term care providers, says that nursing homes play an important role filling a gap for people who don't have other choices or who can't easily put together in-home services.

She also notes that who lives long-term in nursing homes is changing.

One reason is the rise in assisted living, a more homelike alternative. Residents get their own, private apartment, but there are nurses and aides to help, too. Nearly 1 million Americans reside in assisted living; more than 1.5 million live in nursing homes.

Zalen says people who are less disabled — and who can afford to pay for expensive assisted living — are leaving nursing homes. The people who stay in nursing homes are poorer and sicker.

"If you go into assisted living, you'll often see people that used to be in nursing facilities. And what they say about the nursing-level people, they used to be in hospitals," she said.

And for people who are poorer and sicker, there's a big advantage to being in a nursing home: You don't have to pull together all kinds of services. All the care is under one roof.

"It's automatic, it's just there," Zalen said. "You have your physician ... there. The nurses are there; the nurse aides are there; the dietitians are there. Everybody that needs to be there is there."

By federal law, people who face going into a nursing home must be told about alternatives. But in Miller's study in one state, nearly 30 percent of younger people in nursing homes said they weren't told about options. Often doctors and other health care providers just don't know what's available — and recommend a nursing home instead.

Moving From Family Care To Independence

Those who don't go into a nursing home often rely on care from family members — who provide it at no charge to the state, but at a cost that can be their health, time and stress.



Enlarge

John Poole/NPR

Michelle Fridley helps her daughter, Felicia, get dressed up to go to a Halloween party.

That's what happened to Michelle Fridley's mother, who cared for Michelle and Felicia for several years after the accident.

The first time Fridley almost went into a nursing home was right after her accident. She said discharge planners at the rehab hospital waited for a moment when her mother wasn't around.

"I was pulled into a meeting at the hospital," Fridley recalls. "And they recommended that I not put the burden on my family: 'Think of what you're doing to your mom.' And they recommended that I go in the nursing home. I said, 'Oh, if my mom hears this she's going to hit the roof.' She was working so hard so I didn't go into a nursing

home."

Fridley's mother, Pat Plyter, moved to a house that could be made wheelchair accessible. When Fridley finished her rehabilitation at the hospital, she and her daughter moved in with Plyter.

Plyter found herself waking up at night to care for both her adult daughter and for her newborn grandchild. A state program paid for attendants, but mostly just three hours a day. Fridley's two nieces also helped.

"When she was in her accident, I just prayed to God to give me the strength to do it," said Plyter. "It was extremely hard. I cried a lot."

Fridley needs someone to turn her body in bed when she's in pain. So her mother stayed up all night, and then went to her job — as a hospital nurse — in the morning. The late hours took a toll on Plyter, mother and daughter agree. And in recent years, as Fridley needed more help, while her mother got less sleep.

The constant caregiving created friction in the household: Plyter noted there was relief for her daughter,

but not much for her.

"She would have a lady come in during the day and give her a shower, a pedicure and a manicure and put her makeup on," Plyter says. "I couldn't even do that and she'd sleep during the day and I didn't have sleep."

"It was to the point where she wasn't even showering," says Fridley. "And it was because she really didn't have time. I was really depressed and I really hated what I was doing to my mom."

Fridley worried, too, that as Felicia got older, she would feel forced to take on more of the care. So a little over a year ago, Fridley made a desperate decision: It was time to go into a nursing home.

But after discovering the Center for Disability Rights, a disability advocacy group in Rochester, she was able to move to a new apartment. The group, along with her local state senator, helped her move to a nearby county, where she could receive funding to live independently.

The money paid for a small apartment where she now lives with Felicia, and attendants who are there 20 hours a day. She even hired her two young nieces, who used to do a lot of the work free.

Fridley says this has been the difference between going into a nursing home and living what she considers a normal life. She's raising her daughter, she volunteers at Felicia's school and she's getting a degree in health care management through an online university. She works as a volunteer advocate at the disability group that helped her. And this year she was named Miss Wheelchair New York.

"I've never been happier," Fridley says. "I have never been healthier. And I'll say that again: I've never been healthier. I've never been more excited. I'm living my life to the fullest."

She has also become a volunteer advocate, working at the disability center that helped her. Earlier this year, when the state of New York proposed cuts in the hours of attendant care that people like Fridley could get, she was one of a group that went to the state capitol and met with Paterson. Fridley told him her story of trying to stay out of the nursing home. The program was saved.

But more cuts are expected next year. So Fridley keeps up her advocacy. Because, if the cuts go through next time, Fridley fears she'll be forced to leave behind her normal life — and give up Felicia — joining the growing number of working age adults who are going into nursing homes.

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- Michelle Fridley

comments

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