

Can Ailing Illinois Afford In-Home Care Program For Seniors?

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On a recent afternoon, 80-year-old John Earl Johnson watched television from the sofa in his Edgewater neighborhood apartment as Reginald Griffin prepared a quick meal of pork and beans with extra sausage — a staple from both their childhoods.

Johnson, a former chef, still loves to cook, but emphysema, diabetes, high-blood pressure and other chronic ailments make caring for himself difficult. He doesn't want to go into a nursing home, and has been able to forestall that with help from Griffin, who is paid by the state through the \$1 billion-a-year Community Care Program.

But the program, created in 1979 under then Republican Gov. Jim Thompson, may be on the verge of a significant overhaul that could reduce in-home help for many, another consequence of the state's deepening budget crisis. It currently provides in-home help to 84,000 seniors, most of them women.

Most of the seniors served by the program across the state are white, though in the Chicago area most are African-American, according to a 2009 study, the most recent available, prepared for the state Department on Aging.

For more than three decades, Illinois has viewed the program as both a cost-saving and more comforting alternative to nursing home care for low-income residents as they coped with the infirmities of age. But demand for the program has soared as Baby Boomers swell the ranks of the elderly, and the cost-saving initiative itself has become quite costly.

Without changes, Gov. Bruce Rauner's administration expects program costs to grow an additional \$391 million over the next five years. Rauner now wants to scale back services for about 40 percent of those currently assisted by the program, a proposal that is projected to save taxpayers \$120 million but is also causing anxiety for largely housebound seniors like Johnson.

The effort comes as elected officials have feuded for nearly two years over passing a budget, an ideological war with plenty of collateral casualties. Among them are agencies hired by the Department on Aging to deliver services under the Community Care Program.

The budget impasse has so far led to a \$13 billion backlog in paying bills to state vendors. Of that amount, \$230 million is owed to agencies providing home care help for the elderly. The plight of those agencies and the elderly clients they serve will likely be front and center at public hearings on the overhaul proposal hosted by the Department on Aging on Monday in Springfield and Thursday in Chicago.

"This is a mess," said Robert Thieman, executive director of the Illinois Association of Community Care Program Homecare Providers. "Those that can hold on are holding on the best they can."

At present, the program serves seniors both enrolled in the federal Medicaid program as well as those with modest incomes that make them ineligible for Medicaid. The Rauner proposal would continue a full range of services for those on Medicaid but transition some 33,000 participants who are not into a separate program with reduced supports. Those impacted are mostly spread out across the state's south and northwest region and the Chicago area.

Where seniors most affected by program changes live

The map shows the concentration of seniors by Illinois House District who receive services through the Community Care Program and are not enrolled in Medicaid, the public health insurance for low-income people. These are the seniors the state is proposing to transition to a new program in an effort to save \$120 million.

Data from Illinois Department on Aging (JARED RUTECKI/BGA)

Among them is Johnson, who lives in a one-bedroom apartment decorated with photos of days gone by when he stood his full five foot seven inches and didn't need a cane for support.

Johnson lives on a \$1,500 monthly disability pension, enough to keep him technically above the poverty line though he struggles to make ends meet. About a third of his income covers rent and utilities. The rest pays for additional bills, out-of-pocket medical expenses and food.

Griffin, Johnson's home care aide, now does Johnson's grocery shopping and laundry, but it's likely the revised program will no longer pay for such tasks. Instead, the state is proposing to supplant home helpers with vouchers for participants to go out for meals at local restaurants and Uber rides to get there.

And instead of paying Griffin to do the wash, the state would pay a company to do it for Johnson. For some others who live in multi-floor homes, the department said it would pay to move a washer and dryer so it is easier for seniors to do their own laundry.

Such changes have drawn fierce opposition from advocates for seniors who argue that the program works precisely because of its human component. Without assistance, the advocates contend, seniors who otherwise could stay in their homes might end up prematurely in a nursing home—the same costly outcome the state hoped to avoid in setting up the program in the first place.

Lori Hendren, associate director of advocacy and outreach at AARP Illinois, said the state is being shortsighted. She said the Community Care Program costs a monthly average of \$859 per senior while nursing home care is more than triple

that amount.

The Department on Aging does not believe that the state will see an increase in nursing home admissions because of the new program. It argues that a quarter of the seniors it wants to move to the new program will see no changes in services. The rest will see changes, but under the new program they or their family members will be able to purchase additional benefits.

Jennifer Reif, deputy director of the Department on Aging, said she understands the anxiety and the perception that the new program will cut services. Even so, she said the department was trying to think outside the box to address the growth of the state's aging population.

"We don't want anyone to be admitted in a nursing home because resources aren't in place," Reif said. But, she added, the state is also trying to be financially responsible.



Homecare worker Reginald Griffin (right) assists John Earl Johnson with his finances. (Photo/Jose More)

The Republican administration first unveiled its plan in 2016, but implementation has been slow in the face of strong resistance from Democrats lawmakers as well as interest groups representing seniors. Earlier this year, the Aging department published a proposed framework for the overhaul, but the rules governing it must still be approved by a legislative panel that governs such administrative rulemaking.

Meanwhile, state Sen. Daniel Biss, a Democrat from Evanston who is seeking his party's nomination for governor in the 2018 elections, recently introduced legislation aimed at blocking Rauner's plan. Lawmakers passed similar legislation in 2016, but it was vetoed by Rauner.

"We have a moral obligation to provide care for those who have been here the longest; to provide care for people who want to live in their homes" Biss said at a recent press conference in Springfield.

Other Democrats in Springfield acknowledge the gravity of the state's budget crisis, but argue that the solution should not be to make cuts at the expense of vulnerable seniors.

"If we make changes and they result in more seniors going to the nursing home, then we are doing the opposite of what we were supposed to do," said Anna Moeller, a Democrat from Elgin and chair of the House Aging committee.

State Sen. Dale Righter, a Republican from Mattoon, said the bottom line is that while the Community Care Program provides good services, it is "inefficient in the way it operates." The difference, he said, is that the new program will target services to better tailor seniors' needs. "And that's how we save the projected \$120 million."

Budget fights to fund the program aren't new. Over the years, advocates for seniors have pushed to expand the program's reach and increase services for seniors who need it the most. Elected officials have balanced those wishes with the program's increasing cost.

Under Thompson's administration, the Aging department managed to obtain federal financial assistance to underwrite a portion of services offered to Medicaid recipients. Currently, that federal money covers \$200 million of the overall cost.

Jean Blaser, a former Department on Aging official who long oversaw the program, said its launch years ago placed Illinois at the forefront of a nationwide shift away from the institutionalization of older adults. At the time, Blaser recalled, the state decided not to make a distinction between low income seniors on Medicaid and those who were not because older adults often cycled on and off the federal health insurance program.

“At some point you have to say: Look, this is the decent thing to do,” Blaser said.

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