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SUN., AUG 16, 2009 - 9:11 AM

## State program helps keep elderly, disabled in their homes

By JASON STEIN

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A car crash in September 1998 scorched A.J. Nickel's body, shattered his spine and severely injured his brain, wiping out his short-term memory.

In the following years, his parents have shouldered an enormous task — caring for their 6-foot-2-inch, 240-pound son every second of the day.

To do it, the Dodge County couple are leaning on a little-known new state program that helps vulnerable, low-income residents live independently outside of institutions. The IRIS program (which stands for "Include, Respect, I Self-Direct") allows participants or their families to oversee, within limits, a budget for their own care.

### LINKS

• [To learn more about IRIS](#)

year-old son at home. "We have nothing left except (this) program."

The Medicaid long-term care initiative, similar to other programs in Dane County, has given new freedom to severely challenged state residents since its start just over a year ago. In at least several cases, however, IRIS appears to be paying higher benefits than similar programs in other states, including a case in which a family member of a participant is being paid \$26 an hour to care for the participant.

The IRIS program, created because of a federal requirement, is similar to the state's better-known Family Care program. Both operate in 47 counties, providing



DAN BAULCH -- BEAVER DAM DAILY CITIZEN

Jane Nickel assists her son A.J. Nickel as he gets some exercise outside their Mayville home Friday afternoon. Nickel says she and her husband, Darwin, try to find as many different ways as possible for A.J. to get exercise.

### OTHER STORIES

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long-term care to elderly and mentally or physically disabled people outside of nursing homes.

"It's really for people who are independent who want to have more hands-on involvement in their care plan," said Fredi Bove, interim administrator of the state's Division of Long-Term Care. "There are a lot of people who have gotten really excited about the program."

That certainly includes Nickel, who in March became an independent consultant helping participants navigate the program.

Nickel said the program gives savvy participants more flexibility than earlier systems. A previous Medicaid program, for example, paid one worker \$32 an hour to care for A.J. 20 hours a day every day, for a total of \$640 a day. Now Nickel and another family member each work six hours a day for \$11 an hour each, or \$132 a day.

More flexible IRIS rules also saved \$3,000 on a special bathtub for A.J., Nickel said.

"We actually saved money by doing it this way," Nickel said. "I love this program."

Lynn Breedlove, executive director of Disability Rights Wisconsin, said on the whole IRIS seems to be improving the lives of many participants.

"It can be pretty liberating and empowering to think, 'Wow, I really have some say here,'" Breedlove said.

### High pay for some

But the State Journal also found cases that raised questions about the program. In one, a family member is being paid \$26 an hour for up to 17 hours a week to provide personal care and other services for an IRIS participant. Department of Health Services spokeswoman Stephanie Marquis said the payments — the highest paid to family members under IRIS — are justified because the participant is eligible for more expensive private duty nursing care that costs \$33 an hour.

"The IRIS participant can be aggressive and have outbursts related to personal care (and) there are some tasks that the individual will only permit the family member to complete," Marquis said.

Marquis said there are "about five" family members receiving more than \$20 an hour to care for IRIS participants due to the participants' "complex medical or behavioral needs."

In Florida, a program similar to IRIS called Consumer Directed Care Plus has paid no more than \$23.50 an hour to any worker — both family members and others workers — providing care for elders, disabled adults, or adults with brain or spinal cord injuries, said Sherry Jackson, community waivers unit manager at the Florida Department of Elder Affairs.

Steve Verriden, a Madison activist for the disabled who sits on an IRIS program committee that examines requests by participants to receive more money, said he believes the program is well run and careful about expenses. But he said paying \$26 an hour to a family member would need to be justified by "pretty serious or substantial care."

The program also spent \$15,850 to help a participant modify a cargo van to make it handicapped accessible by installing a ramp, hydraulics, special driver controls and other items. Marquis justified the spending, saying the individual spent \$15,800 the previous year to pay for outside transportation to medical appointments and other trips and is expected to need even more transportation in the future.

### Vehicles covered

David Sievert, operations director for The Management Group of Madison, which helps run IRIS, said the program also helped lease a vehicle for a participant for a limited time and was considering helping a participant make loan payments on another vehicle.

Both Sievert and Verriden said helping a participant obtain a vehicle can occasionally save taxpayers from costly payments to the private companies that transport some participants regularly.

"That's fairly exceptional," Sievert said of the payments related to vehicles. "I don't think it's going to be by any means the

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rule.”

New Mexico's similar Mi Via program, on which IRIS is partly based, won't pay for vehicles, only adaptations to vehicles, said Cathy Stevenson, deputy director of that state's Developmental Disabilities Supports Division.

Jackson said Florida's CDC Plus program will also only pay for vehicle modifications. Even then, the participant must save money within a 12-month period out of that person's regular monthly budget, with most saving only a few hundred dollars per year.

“Because of these factors, the typical vehicle modification is very modest,” Jackson said.

### PROGRAM SAID TO COST LESS THAN ALTERNATIVE

Participants in the IRIS program receive a budget to hire their own workers and pay for long-term care. The similar, better-known Family Care program uses HMO-like managed-care organizations to provide the care.

Frail elderly or disabled participants who meet the income limits can choose between Family Care and IRIS in the 47 counties where the two programs have been rolled out, including Jefferson, Richland, Sauk and Columbia counties but not Dane.

In IRIS, participants' monthly budget is determined by figuring what services, such as nursing attention or help with bathing or eating, the users need and how much they cost. The participant or a responsible family member can then direct the money to pay for services approved in a care plan.

IRIS last year cost \$3.8 million in state and federal money and more than 700 people participated in it or registered for it, receiving some \$3,400 a month on average, according to the state Department of Health Services. A 2005 study done on the Family Care program in four pilot counties found caring for the elderly and disabled outside of institutions saved \$452 per person per month.

To learn more about IRIS, go to [www.wisconsin-iris.com](http://www.wisconsin-iris.com) or call  888-515-4747 .

3 comments : <a href="#">add a comment</a>	
TCOK Forumite Joined: 08/15/2009 Total posts: 1	BRAVO to the Feds and the state :) for designing a program like IRIS! Persons who self-direct their long term supports and services will be healthier, happier and more efficient in meeting their self identified outcomes. The impressive savings of programs like IRIS will speak for themselves. I cannot wait until IRIS comes to Dane County. :D Thank you for sharing your story Jane and AJ.
randy r Forumite Joined: 12/22/2006 Total posts: 146	Why wouldn't this be a major concern for all Americans. It is the right thing to do. If any person would oppose this they should be strapped to a wheel chair for a couple of months.
djcbuffum Forumite Joined: 07/13/2009 Total posts: 9	I thought the article was about confining people in their houses. I'm glad that it's not.

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