

the world. This identity comes from a community of those like us. This community is CODA, Children of Deaf Adults. I am hearing-deaf-coda, always on the edge of Deaf Culture."

- Introduction

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DISABLED COUPLE WANT TO TAKE MIDDLEMAN OUT OF HOME CARE....

Disabled couple want to take middleman out of home care They say they could

save money, pay staff more if they controlled resources

By Jennie Tunkieicz of the Milwaukee Journal Sentinel staff

Last Updated: Sept. 4, 1999

Waterford - Kathy Stone and Tom Kojis know they are exceptions to the rule.

They are "married spiritually, but not legally," as Kojis describes it, and live together in a lovely house teeming outside with summer flowers along the village's Main St.

He raises 12,000 seedlings in the basement each spring and runs a flower

and vegetable business in their driveway.

She has written a book, loves to do research on the Internet, paints and

enjoys bowling and swimming.

They both have spastic cerebral palsy.

Their condition causes slurred speech, and people who haven't known them

for long need an interpreter to understand what they are saying.

Nonetheless, they are articulate and know what they want.

They want to have complete control over their own care.

It's not for the power.

It's because they think they can reduce the overhead and pay their attendants more money, and, ultimately, reduce staff turnover.

"I want to make a better life for Kathy and me and for our help," Kojis said.

Kojis says it costs a total of \$125,000 - a combination of Medical Assistance and Community Integration Program funds which come from the state and federal governments - to provide home care for both of them annually.

The money goes to Racine County, which contracts with Society's Assets, a nonprofit agency that serves people with disabilities like Kojis and Stone.

Because Kojis and Stone are clearly able, the agency allows them to advertise for their attendants, interview them, do the necessary background checks, hire and schedule them.

"We are doing everything, basically, except writing the paychecks," the 46-year-old Kojis said.

"And," said Stone, 44, "that's what our goal is to do someday." Kojis and Stone know that taking care of them is difficult; their severe disabilities make it necessary for their attendants to help them with all basic living tasks. What they want is for their caregivers to make a better living doing it.

"We are asking to take out the middleman so the people who wipe our butts get what they deserve, not the people who sit on their butts,"

Kojis said.

While Society's Assets receives a rate of \$11.50 an hour to provide services for Kojis and Stone, the attendants receive a little more than half that - \$6.25 according to Kojis' figures, \$7 or better according to the agency's figures. Either way, Kojis thinks he can do better - that he could take the difference and pay some of it to the caregivers. Kojis said his frustration over the situation turned into depression when he saw a sign on a fast food chain restaurant offering \$7 an hour starting pay.

"We are desperate for help, and yet I sat an aide down recently and said, 'Go get another job. You can't make it and support your little girl by working here.' It was a big hurt, but it's better for her," Kojis said, tears welling in his eyes. "I'm just so frustrated because the answer seems so easy."

But officials say the issue is much more complicated than it sounds. "It's up to Racine County, but when it comes right down to it, it's legal liability," said Bruce Nelsen, executive director of Society's Assets in Racine.

Nelsen said he would not oppose the county granting the duties to Kojis and Stone.

"We are not going to stand in their way," Nelsen said. Keeping staff has been a problem for the agency in a very tight labor market, Nelsen said, and his agency is working to get rates increased for care. The medical assistance rate, for example, had been frozen for eight years and then was increased 1% a year for the last two years. Nelsen said the agency is simply not making any money; it just barely breaks even.

"It's a common misconception that (the difference) between \$7 and \$11.50 is profit. That's a very inaccurate perception," he said. Nelsen said 85% of the rate, or \$9.79, goes into direct care, which includes benefits and wages for attendants, in-home supplies, registered nurse visits and supervision. The remaining amount, \$1.71, goes for things like liability insurance, personnel management and billing for the federal funds.

While Kojis and Stone do handle many of the duties that normally are the responsibility of the agency, Nelsen said it is because they want to do those things.

"We bend over backwards and have worked with Tom and Kathy to make sure they are getting what they want and what they need within the bounds of what is legal and proper," Nelsen said.

Nelsen said there is tremendous liability in providing home care services. The legal questions involve things like who is responsible if a client or worker is injured, he said.

Robert Barbee, manager of adult services and long-term care support program for Racine County, said liability is the issue.

"We are perfectly willing to do it if Tom can come up with someone to serve as the fiscal agent who meets the criteria defined by law," Barbee said. "He could not do it himself unless he wants to be responsible as the employer."

As the employer, Kojis would have to take responsibility for social security taxes, workers compensation, unemployment compensation and related issues, Barbee said.

"We will consider it if someone is able to meet the rules and regulations, but to this date, we haven't seen anything (to prove that)," Barbee said.

Tom Hlavacek, director of the Milwaukee office of the Wisconsin Coalition for Advocacy, knows Kojis and Stone and thinks they should be given the opportunity to show they are up to the tasks.

"They are competent individuals," Hlavacek said. "They are not under protective placement or guardianship. If they want to assume that risk, there should be nothing to prohibit that."

"The burden of proof on whether they could do it should not be on them;

it should be on the county," he said.

Allowing people with disabilities to be in charge of the finances associated with their care is unusual, but not unique. Hlavacek said that as more people opted for independent community living in the 1980s and '90s, rather than institutional care, many counties hired agencies to serve as the fiscal agents.

"There is the concept of the dignity of risk, of letting people try things," Hlavacek said. "That's an important concept for independent living for all of us, not just people with disabilities."

Hlavacek said he would encourage a test period allowing Kojis and Stone to administer their own funds. "If they can't, they can go back to system and it shouldn't be that disruptive to system to let them try it," he said.

When he's feeling down about the situation, Kojis said he recalls the words of a friend.

"He said, 'Do you know why God put you in a wheelchair?' I was depressed at the time and I said, 'No.' His answer was, 'So that you won't take over the world - to slow you down.'"

"I can't take over the world, but maybe I can make it better for other people with disabilities," Kojis said. "Maybe or maybe not. We'll see."

SOURCE: Advocacy List <owner-advocacy@MAELSTROM.STJOHNS.EDU>

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CLIMBING BACK....

Climbing Back

by M. Wellman & J. Flinn (1992)

The inspiring story of Mark Wellman, Yosemite's incredible paraplegic ranger, who climbed El Capitan and Half Dome.

Forward by Senator Bob Dole.

SOURCE: The Disability Resource - http://www.disabilityresource.com