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~Navigation Menu~

Go

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Self-Determination pits rights vs. safety

Parents say independence puts mentally disabled adult children in danger

BY LAURA HAFERD

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MEDINA: John and Jean Boehnlein don't care if the state of Ohio thinks they're overprotective.

The state wants to give their 37-year-old son, Scott, more control over his life.

But parents like the Boehnleins say the new Self-Determination Initiative for adults with mental retardation will put their sons and daughters in danger. One study published in 1999 backs them up, reporting an 88 percent increase in deaths among those who move out of an institutional setting to community housing.

"We know better than anyone what our special children can do and cannot do," said the Medina father.

The debate is this: Should Ohio's mentally retarded adults exercise their civil rights, or should they have more traditional, protective and expensive care?

Instead of providing a sheltered and segregated setting, the Ohio Department of Mental Retardation and Developmental Disabilities is testing the national Self-Determination Initiative in Medina and 30 other counties. The plan aims at bringing disabled clients out of MRDD institutions and into the normal life of their home communities.

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Under Self-Determination, each adult with impaired intelligence must choose and authorize a budget for his or her own government services. Some of these clients cannot learn to read, or even speak -- and have relied on their parents to handle their affairs.

Parents like Harlan and Mary Johnson of Medina think they are being pushed aside as the local MRDD board tries to make clients such as their son Warren, 48, become more independent.

Harlan Johnson calls Self-Determination "The Big Lie." He says it makes no sense to ask people with impaired reasoning to figure out for themselves what services they need.

"The lack of ability to make choices *is* the disability of individuals with mental retardation," Johnson said.

What bothers him most about this program, Johnson said, is that he suspects it is not really about retarded people's civil rights at all.

To him, and parents like him, it seems more like "a cynical political trick" aimed at elbowing parents aside.

Why?

"To save money," said Mary Johnson.

Ohio MRDD director Kenneth Ritchey argues that Self-Determination offers dignity to clients -- and saves money.

"There is a dignity for every individual to feel they are supporting themselves," Ritchey said. "... The theory of Self-Determination across the U.S. is that, if it works right, it's better quality (services) at less cost."

The Self-Determination program aims to tailor services to each disabled person's daily needs, instead of paying for institutional nursing, sheltered workshops, or supervised day-care centers.

By contracting providers for only those Medicaid-waiver services that each client's "Life Plan" specifically warrants, the program saves money for the state.

"Instead of a nursing home, what does this person really need?" asks Delaware County MRDD Superintendent Robert Morgan. He heads one of the first four Ohio counties that began trying Self-Determination under the original national project funded in 1997 by the Robert Wood Johnson Foundation.

"If it's just to have a person checking on you, we'll fund

\$5,000 or \$8,000 (a year) to have someone checking up on you."

The state's cost for MRDD clients' care has grown from \$280 million to \$340 million over the past decade.

An audit by one of the initial 1998 Ohio pilot programs, in Delaware County, showed a savings of \$106,764 in county funds for just 25 clients enrolled in the first year -- and an overall local cost savings of 13 percent over the annual average adult service costs of \$10,864 after three years.

In the New Hampshire pilot program by the Robert Wood Johnson Foundation, the National Program Office on Self-Determination reported the average service cost for Medicaid-eligible clients under the traditional system used to be \$44,425. Those costs declined to only \$22,314 per person under Self-Determination.

The Johnsons say they have tried their best to help their son, Warren, live a normal life despite his disabilities.

Warren Johnson has his own apartment at Ann Tubbs Estates, a 39-unit supported-living apartment complex for the handicapped. He drives his own car, even though he was not able to read the driving exam and had to have it read to him.

Now, the Johnsons say, they feel they must be constantly vigilant to make sure some MRDD administrator or case worker is not trying to get their son to sign away his program benefits. In the past year, they complain, their son's "Life Plan" documents have been submitted to Warren for authorizing, instead of to his parents.

"These plans are so complicated, they are difficult enough for Mary and I to understand," Harlan Johnson said. "And we have normal intelligence."

Under pilot programs such as one in Medina County, those retarded adults who cannot sign their names to individual budget plans can authorize the plans by making a mark on the paper, by verbal assent, or -- for those who cannot speak -- by nodding a head in approval.

Parents like the Boehnleins, who remain closely involved with their three adult MRDD children, feel threatened by Self-Determination.

"Some people say we (parents) are overprotective, but we have a right to be," Boehnlein said. "I have invested too much of my life in them to allow them to put themselves in danger."

The Boehnleins, now in their 60s, say the new approach in Medina has brought division in their family.

"I started getting literature from the (MRDD) Achievement Center, saying Jennifer and Scott wanted to be put on the residential list," Mrs. Boehnlein said. Jennifer, 33, told her mother that people at the Achievement Center had asked if she would like to get her own apartment.

The Boehnleins' son Scott, 37, said that he would like to get an apartment -- because, "Well, my friends are there."

His mother was appalled at the idea. Scott, who works in the Medina MRDD's sheltered workshop, cannot read or speak clearly. He has not learned to cook, shop or tell time.

But when his mother explained that he would have to move his bedroom furniture to the apartment, Scott said no -- he wanted an apartment, but he also wanted to leave his bed where it was, to sleep at home at night.

"He doesn't really understand," his mother said.

Introducing MRDD clients to the possibilities of independent living is the key to Self-Determination, according to Gary Tonks of The Arc of Ohio. His organization helps spread the word.

The Arc's CHOICES program holds parties for clients in the county MRDD centers. Volunteer mentors who themselves have disabilities tell the other clients how they have tried new kinds of housing and jobs away from the institution.

"Our program is one on one -- 'Let's go to the Dairy Queen,' or 'Let's go see what an apartment looks like,'" Tonks said. "If friendships develop, that's how we pair people up."

The Arc's volunteer friends may not be in a client's life for very long, Tonks said. "Team memberships ebb and flow . . . this week to next week."

Sonja Mawhorter of the Ohio League for the Mentally Retarded thinks Self-Determination is just a way to get parents out of the picture -- so retarded adults may be induced to accept cheaper programs and lower levels of services.

"It's manipulation of the worst kind and exploitation of people with disabilities," said Mawhorter.

Encouraging adults with disabilities to take jobs in the regular work force is another goal of Self-Determination.

But the state MRDD employees union and some parents' groups say they fear the state may eventually close off the choice of the traditional sheltered workshops.

Warren Johnson, son of Harlan and Mary Johnson, says he

does not want to leave his job at Medina's sheltered workshop, Medina Achievement Packaging Systems. But he thinks the staff there wants him to take a job out in the community.

"I know they talk about it," he said. "They would like to see all of them (MRDD clients) go out and work somewhere else. I'm going to stay there."

A few years ago, Warren tried a couple of jobs in local machine shops, but neither went well. His mother said he felt ostracized by his co-workers.

Besides setting up a trust for his financial interests after their death, the Johnsons asked their son to voluntarily sign a legal instruction that all contracts should be co-signed by them while they live.

Even with that authorization in hand, the Johnsons say, they have to keep alert.

"Two days ago, they (MRDD staff) brought to him something to sign at work," Mrs. Johnson said one day in January. "He told us the same night.

"We tried to get from him what it was," she said, "but he wasn't quite sure."

Ohio's Self-Determination project does not call for parental authorization of individual budgets or plans, according to Nancy Richards, Ohio MRDD manager of adult systems. If parents want to have that kind of authority, they must go to probate court and seek to be named legal guardians of their children.

Elaine Benchoff of Wadsworth did just that, she said, after she learned that her son was being asked to sign Life Plans.

"I don't want him to be taken advantage of," she said. "He would be asked to sign papers, and he can't even read."

Adults with Down Syndrome, like her son, she said, "can be talked into anything."

Even when parents do seek legal guardianship, they may be in for a fight when they disagree with MRDD administrators.

Although Chuck Winters and his wife obtained guardianship of their retarded daughter in Lucas County, that did not prevent the director of their daughter's development center from going to court to challenge their decision when they removed her from a program. A guardian ad litem was assigned by the probate court to investigate, Winters said; the parents' decision stood.

But a California court last year upheld the choice of a man with mental retardation who wanted to move out of his institution -- against advice of his guardian and doctors.

Danger documented

A 1999 study in the American Journal on Mental Retardation found that persons moved from institutional to community housing had an 88 percent greater chance of death in the following year -- compared with those who stayed.

The kind of thing that parents fear is what happened to Montgomery County MRDD client Russell Durst last year. After he was placed in a new job in the Dayton area, he was coming home one day in January 2000, on a new 90-minute bus route.

The 32-year-old Durst reportedly became lost and disoriented, the Dayton Daily News said. He was killed running across Interstate 70.

Ray Thomas, head of The Arc of Summit County, is an advocate of Self-Determination and deinstitutionalization. He also is a parent of a 19-year-old daughter with mental disabilities. He wants her to have a normal community life, Thomas said, but when it comes to safety, he is another cautious parent.

"I have seen instances where parents took guardianship because the service system was pushing for something the parents thought was dangerous," Thomas said. Some service providers, he said, "have an unrealistic crusade to liberate this child from their parents."

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- Parents say independence puts mentally disabled adult children in danger
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