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## WHEN CARE FALLS SHORT

*WORKERS OFTEN ILL-PREPARED FOR DISABLED*

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**Document Text**

Last April, Barbara Vaccaro called a local Italian restaurant and had a plate of ziti and meatballs delivered to her room at the Meridian Manor nursing home in Waterbury.

A nurse later found Vaccaro choking on the food. Staff performed CPR but the 58-year-old developmentally disabled woman had stuffed so much food into her mouth that emergency medical technicians couldn't intubate her. She died at a local hospital.

Just days before her death the staff was instructed to feed Vaccaro, who survived a similar choking incident a year earlier, a soft-food diet and supervise her while she ate. But, state records show, staff were unaware of the food delivery until the nurse entered her room to deliver her roommate's meal.

Advocates for the developmentally disabled say patients like Vacarro need constant supervision, whether it is because they fall a lot, need a significant amount of medications or have a history of choking.

Nursing homes, advocates say, are often not equipped to properly care for the developmentally disabled.

"Our position is that they shouldn't be there," said Leslie Simoes, executive director of The Arc Connecticut, the state's largest advocacy group for people with developmental disabilities.

But dozens of developmentally disabled state residents move into nursing homes each year. In 2011, 51 patients entered nursing homes, the same number as the previous year. In 2009, 65 state clients were moved into nursing homes.

Tracking their care is complicated by large caseloads and the fact that the state Department of Developmental Services, which is responsible for their care, has no regulatory control over nursing homes. In some cases, the homes fail to notify state agencies of changes in their patients' conditions in violation of state and federal regulations, state records indicate.

The agency that oversees nursing homes -- the state Department of Public Health -- cited facilities for health care errors involving the deaths of DDS clients in nine cases from 2004 to 2010, records show. In four other deaths involving suspected abuse or neglect, the health agency either declined to investigate or found no wrongdoing.

"While DPH administers and enforces state and federal regulations designed to protect all residents of Connecticut nursing homes, DPH is mindful of care issues that especially impact the developmentally disabled," department spokesman William Gerrish said.

Waterbury attorney Iaonnis Kaloidis said staff at Meridian Manor were aware that Vaccaro had a history of choking and had a habit of ordering takeout food, so much so that any food she ordered was supposed to be viewed by a nurse before she could eat.

"We are still investigating what happened to Barbara and exploring our options because we clearly have concerns about the way she died," Kaloidis said. "This shouldn't have happened,"

The state health department fined Meridian $510 for violating department policies. The home did not return calls for comment.

James McGaughey, executive director of the Office of Protection and Advocacy for Persons With Disabilities, which investigates the treatment of people with developmental disabilities, is among those who say DDS clients should not be in nursing homes.

In fact, even the commissioner of the department wants nursing homes out of the equation. He wants his agency's clients to "age in place" at home, or in licensed DDS programs devoted exclusively to the clients. But Commissioner Terrence Macy's plan for the "next generation" of group homes is still several years away.

Macy acknowledged putting the department's clients into nursing homes "is not a good model for our folks."

"Wherever we can we are trying not to put them in nursing homes but you have to have a policy that makes sense," Macy said.

Following Vaccaro's death and that of another DDS client, Charlotte Valdambrini, who choked on a marshmallow in a Cromwell nursing home in March, McGaughey sent a letter to both Macy and public health Commissioner Jewel Mullen calling for better training for nursing home staff in dealing with DDS clients.

Macy said he has assigned staff to meet with public health officials and discuss the choking incidents and to insure that protocols that DDS follows are passed along to nursing homes.

Simoes said the system is set up to fail because nursing home staff members "are not traditionally trained to support physically able people with cognitive disabilities."

"The system is a setup. The nursing home, the workers and the intellectually disabled individuals are all set up for negative consequences," Simoes said.

Many times when parents become too old to care for their intellectually disabled son or daughter any longer, they often look for an opening in a DDS facility. But just as often, there is a waiting list to get in, so the nursing home becomes the only remaining option or last resort.

Simoes and other advocates favor providing state aid and services to families, so they can continue to care for intellectually disabled loved ones at home.

She said it would be significantly less expensive than a nursing home.

LACK OF NOTIFICATION

Among the problems associated with the placement of the developmentally disabled in nursing homes is the lack of timely notification of patient deaths, records indicate.

On a June day in 2008, an executive with the state agency that cares for intellectually disabled people walked into the Trinity Hill Care Center in Hartford to check on a woman named Ava Siena.

Siena, 53, had Down syndrome and was placed in the nursing home six years earlier after both her parents died. As a client of the state Department of Developmental Services, Siena's care was of interest to DDS ombudsman Edward Manbruno. His job was to help make sure agency clients received proper treatment.

But Manbruno never got to see her. Ava Siena, he was told when he arrived, had died. Three months earlier.

The fact that no one from DDS was notified of Siena's death was a familiar scenario. The lack of timely death notifications -- a violation of state and federal laws -- has been a source of concern for years among patient advocates, a review of state records and interviews with social service officials reveals.

In those cases, state monitoring of the clients' care can suffer and their treatment needs can go unmet by facilities not equipped to handle the complex cases, patient advocates say.

McGaughey said his office sometimes doesn't learn about a case days or weeks after the fact. With DDS unable to exert day-to-day influence, the response to substandard care of its clients in nursing homes is often not immediate.

The vice president of the company that operates Trinity Hills where Siena lived and other nursing homes said that DDS, not the Office of Protection and Advocacy for Persons With Disabilities, has the authority to investigate these cases.

"It is important to clarify the types of investigations that are performed in the long-term care industry. While the Department of Public Health regulates and surveys nursing homes frequently, such is not the case for DDS or OPA," said Michael Landi, vice president of iCare Management.

Trinity Hills "did not undergo any investigation nor receive any communication from these agencies at any point," Landi said. "In fact, OPA is not even a state regulatory agency. Rather, it is an advocacy organization."

Concerns about delayed death reporting have swirled around state patient-care agencies for years ? even before the case of Ava Siena came to the attention of McGaughey's office.

Early in 2008, McGaughey had been involved in discussions with DDS aimed at convincing the agency it needed to take a stronger stance against nursing homes that don't report deaths of state clients in a timely manner.

Then Siena died from pneumonia at Hartford Hospital in March 2008.

"That case was the last straw," McGaughey said.

He fired off a letter to then-DDS Commissioner Peter O'Meara reminding him that nursing homes were required by law to report deaths of state clients "promptly." McGaughey's letter cited two cases where deaths weren't reported. One was Siena's.

McGaughey wanted to know why O'Meara had not followed through on the agency's promise to send a letter to nursing homes in February 2008, reminding them of their obligation. It referenced the state's Fatality Review Board, established in 2002 by then-Gov. John Rowland in response to a previous probe by The Courant into group home deaths.

But Landi said that it wasn't his agency's responsibility to notify next of kin in the Siena case. Landi said notification "should have been performed at the hospital level" because the patient was transferred there from Trinity Hills.

McGaughey said state regulations are clear the nursing home is supposed to notify DDS if one of its clients has a change of condition.

"It was the nursing home's responsibility to notify DDS of Ms. Siena's hospitalization, as this represented a significant change in her condition," McGaughey said. "It was also the nursing home's responsibility to notify DDS of her death, which occurred approximately two weeks after she was admitted to the hospital."

A Courant review of state records indicates that 20 nursing homes failed to report deaths in a timely manner a total 24 times from 2009-2011.

Danbury Health Care Center failed to promptly report deaths of DDS clients four times during that period. Bridgeport Health Care Center is cited in state documents as failing to report two cases.

In a statement, HealthBridge Management, which operates Danbury Health Care, said "the loved ones of patients, as well as the physicians responsible for their care, are immediately notified upon the death of a patient."

HealthBridge operates eight other nursing homes in Connecticut, including Newington Health Care Center, which was cited for a delayed death report to DDS in 2010.

"The requirement to notify DDS of the death is an additional requirement, one which we of course take quite seriously but is unique to DDS patients," Senior Vice President Lisa Crutchfield said. "Once DHCC was made aware of the failure to report the 2010 deaths, on its own initiative it instituted an internal 'double check' system that has avoided any further occurrences of this oversight."

Crutchfield said her company was not aware of any 2011 deaths that were not reported in a timely manner, even though state records show that twice in 2011 the Danbury facility failed to timely report a death.

"It is important to note that we take the reporting requirements very serious, and this was a reporting issue, not an issue of care," Crutchfield said.

But Ava Siena's brother said it was unsettling to learn that no one at the state agency responsible for his sister's care knew that she died.

"Ava did have a case worker who I would have expected to know if something happened to her," John Siena said. "Isn't that supposed to be their job?"

OPA officials said that since Siena's death wasn't reported until three months after she died very little investigation could have been conducted.

Noting that hundreds of DDS clients died in nursing homes for all reasons in recent years, DDS officials said the delayed reports accounted for 9 percent of the cases.

Macy said he didn't believe that anything sinister was behind the delayed death reports.

"Nine percent is not as alarming to me as it may be to you," Macy said. "Sometimes cases can get lost in the shuffle, it is not an indication of anything sinister occurring."

OFF THE RADAR

DDS case managers who oversee clients in group homes are responsible for about 85 people ? about twice the caseload of their counterparts who monitor clients in group homes and other DDS-licensed institutions.

Advocates and state investigators said DDS clients sometimes fall off the radar when they go into a nursing home. Too often, what was intended to be a short-term rehabilitation stint becomes a long-term stay, and the DDS case manager can lose track of the client.

"The hospital sends the patient to the first Medicaid bed [in a nursing home] that becomes available no matter where it may be, so they could end up on the other side of the state," McGaughey said.

DDS case managers have said in correspondence to OPA investigators that frequent contacts with DDS clients in nursing homes makes the nursing-home staff more attentive to that client. But it can be difficult for the case workers to maintain that contact once the client leaves the nursing home to go to a hospital.

DDS case managers assigned clients who end up in nursing homes are only required to make visits once a year. They must check in at least quarterly. Often that is a phone call to the nursing home.

Samuel Morales was dead for more than a month before DDS found out.

Morales, 70, died while living at the Chelsea Place Care Center in Hartford in January 2009.

Earlier that month, he fell at the nursing home, struck his head, and later died at Hartford Hospital. His death certificate listed his death as accidental and the cause as respiratory failure and an unspecified head injury.

The medical examiner's office declined to do an autopsy on Morales. Neither the DDS case manager nor protection and advocacy officials were notified of Morales' death until March, more than a month later.

When DDS officials did find out about Morales' death they sent a nurse consultant to Chelsea Place to check on other residents DDS had placed there, records show. DDS then referred the nursing home to the Department of Public Health.

Landi, whose company also owns Chelsea Place, disputed that Morales was even a DDS client, saying a review of their screening records determined he was not a DDS client and therefore no public notification of his death was necessary.

But McGaughey it is clear from DDS records that Morales was a client. A case manager had visited him at the nursing home six months before his death. Morales even participated in a day program away from the nursing home provided by DDS.

Fatality Review Board records show that the public health department cited the nursing home for discontinuing 15-minute bed checks on Morales without first performing a proper assessment. The department also cited Chelsea for inadequate clinical records keeping, important in Morales' case because nurses should have known that Morales had a history of seizure disorders that could cause falls.

But Landi said that is not an accurate analysis of the health department investigation and that the violation letter cited by the board was inaccurate in its conclusions.

"It is also important to note that the violation letter you are utilizing is not an accurate violation letter for this investigation as it includes many violations that were subsequently deleted or significantly altered after an appeal hearing was performed," Landi said.

McGaughey said Morales' medical records were obtained by DDS and also given to the fatality review board.

They showed no documentation of any seizure activity, no record of neurological consultation and no restrictions on his movements, despite a history of frequent falls.

Someone did raise questions about how Samuel Morales died.

Rosa Morales, Samuel's sister, said that the funeral home director in charge of preparing her brother's body for burial told her that she should be asking questions as to how and why her brother died.

But Rosa Morales said she chose not to do that.

"My brother used to fall down every day of his life," Rosa Morales said. "Now he doesn't fall down anymore and he is with our mother in heaven and that is all I need to know."

Credit: DAVE ALTIMARI, JOSH KOVNER and MATTHEW KAUFFMAN, daltimar@courant.com

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**Abstract** (Document Summary)

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