AJCCLASSIFIEDS SUBSCRIBE TO THE

ajc.com
The Atlanta Journal-Constitution

HOME NEWS METRO SPORTS BRAVES BUSINESS LIVING OPINION TRAVEL SPECIAL S

Top **local headlines**
- Dorsey had five people on 'hit list,' authorities
- McKinney, dad cited for conduct at polls.
- What role did Turner play in Levin departure?
- Rosalynn Carter likes adventurous life,
- Bogus money a part of scam.
- Ex-Fulton jail official collapses on stand at her bribery trial.
- Fulton commission delays salary vote.

AP headlines this **hour**

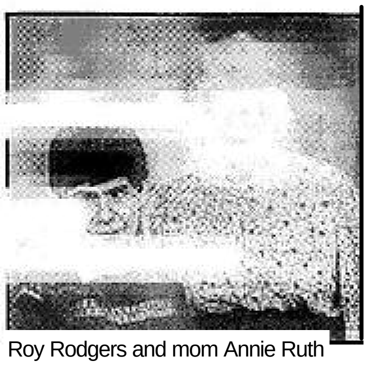
- Daschle Anthrax Letters Same
- Up to 35 People Shot at Indiana Factory
- U.S. Gives Afghan Rebels Air Cover
- Columbine Diary Prompts

[The Atlanta Journal-Constitution: 12.02.2001]

Georgia broke its promise of good home for beloved son

By ANN HARDIE

Atlanta Journal-Constitution Staff Writer



Roy Rodgers and mom Annie Ruth Rodgers.

Roy Irbie Rodgers Jr., born Oct. 3, 1946, was a treasure.

The chubby infant couldn't roll over or parrot words like other children, but that didn't matter to parents who had long prayed for a family. Roy and Annie Ruth Rodgers embraced their son's retardation as a sign of God's confidence in their ability to raise this special child.

They cared for him as long as they could. But they violated the golden rule for parents of children like Roy: They didn't outlive him.

Once they were gone, Roy was promised a safe, fulfilling life in a good home. Instead, in both life and death, the government safety net responsible for his well-being failed to keep that promise.

His mother would not have been surprised. "She said, 'My son will not make it out there,'" said Rose Marie Newell, a friend. "You could do anything to him and he wouldn't protect himself."

For many years in the Rodgers home, nothing came before the black-haired boy with the crossed eyes, shuffling gait and hooked right hand. Young Roy loved collards and sweet corn and tomatoes, so his mother planted a huge garden. Father and son tooled around Palmetto in a red pickup truck searching for the perfect orange soda.

MORE ON
BROOK RUN

Photo album
» Georgia broke its promise of good home for beloved son.

Day 3
» State to evaluate care for 3,600 in group home or residential care.

Day 2
» Georgia broke its promise of good home for beloved son?
» Privacy laws shield details from families.

Day 1
» Group home deaths reveal ugly picture of state care.
» Who let Stephen Bennett die?
» System has too few safeguards.
» Critics warned state was moving too fast

About this series

About the reporters

Roy's parents celebrated his accomplishments -- his first steps at 6, his first trip to the toilet even later. He was a happy child, tapping for| hours on a Crisco can to the sounds of the radio, shrieking in delight at the crashes and booms of thunderstorms.

He couldn't speak in sentences, but he learned words to express the things important to him: momma, rain, home, tea. Roy loved sweet tea, the sweeter the better.

But as his body matured, Roy threw violent tantrums, pummeling his head with his fists. His mother had his hands tied, then cried as he squirmed for freedom. Doctors prescribed sedatives that sapped the life from him.

By 1973, Roy and Annie Ruth, older parents to begin with, were just old. They took a step they once thought unthinkable. They turned their 26-year-old only child over to the care of a state institution.

The Georgia Retardation Center in Dunwoody was home for hundreds of others with retardation. Many residents couldn't see or speak or hear. Others had severe emotional problems: self-abuse, sexual aggressiveness, suicidal tendencies.

Roy's father, who died of cancer several years later, never got over institutionalizing his son, friends and family say. Annie Ruth pushed her guilt aside. She became a fixture at the facility, often driving the 100-mile round trip from Palmetto. She called every day, sometimes twice, to check on her boy.

Roy's progress encouraged her. Doctors weaned him off the harsh medication, and the staff handled his self-abuse with behavior modification tricks. He even learned to feed himself, spooning food with his good hand.

With his behavior in check, Annie Ruth brought her son home every other weekend for the next 20 years. At 87, as she lay dying in the hospital, she cried, "It's my weekend to get Roy."

Roy showed his heartache the only way he knew. He took the portrait of the two of them - the one with his mother's proud smile and protective arm around him — and turned it face down on the dresser.

"That baby liked to grieve himself to death," his cousin, Bernie Blair, said.

The good provider |

Annie Ruth had taken comfort that after her death, her son would be safe with his other family - the staff who had cared for him for half his life.

She had weathered rumors that the facility's residents would be moved to small group homes. She had been dead three years when Gov. Zell Miller revived the effort.

The facility, renamed Brook Run, shut its doors in 1997, despite concerns of parents, advocates and lawmakers that the system was not yet in place to care for its residents.

The decision about where Roy would live fell to a second cousin, Diane Clark. The state's Division of Mental Health, Mental Retardation and Substance Abuse offered her a choice: another institution, most likely elsewhere in the state, or a two-story home around the corner in Palmetto. "The state said they were a real good provider," Clark said. "Roy was coming home."

Roy's new home was run by Mi Casa, Spanish for "my house," one of 17 smaller providers that teamed up and bid to care for residents displaced by the Brook Run closure. By 2000, Mi Casa was taking in more than $1.6 million in taxpayer dollars to care for 46 residents.

Mi Casa accepted some of the most difficult residents. Owner Martha Mahan, a registered nurse, said she trained her staff to handle them. But state investigators later found the staff lacked the training and experience to care for these people.

Mahan hired her son's cleaning lady, Johnnie Mae Sales, and Sales' husband, a Circuit City custodian, to run the home where Roy lived with three others.

"They didn't tell us anything about these mens," Sales said. She and her husband were fired after five months, she said, for leaving residents unattended, which she denies.

The residents could be a handful. None was verbal. One was so anxious he slept with his head beneath the muslin sheets. Another had to be moved to a different bedroom on a different floor, Sales said, after she caught him trying to fondle Roy. "He was so strong," she said. "You really had to watch him."

There were signs Roy was having trouble adjusting to his new life. He was dressed in disposable diapers, after years of not needing them at Brook Run. "If I didn't accomplish nothing else," Sales said, "Roy was in Hanes when I left."

In the spring of 2000, reports of abuse surfaced when a Mi Casa resident complained that staffers, including Mahan, her husband and son, hit him in the face and head, according to a letter from a state-paid monitor. Another resident said he ran away because he didn't want to bemistreated anymore, the monitor wrote.

A state official saw several residents paving a parking lot, raising concerns of exploitation, and standing at attention when addressing Mahan's husband. In May, the division's Office of Consumer Protection opened an investigation.

Eighteen residents, monitors and former staffers described abuse by Mi Casa staff, according to state investigative files. They told of fat lips, bloody noses, a broken finger and a dislocated shoulder.

Nineteen Mi Casa employees - including six members of Mahan's family who allegedly hit residents - told state investigators they never saw any abuse.

Mahan, reached recently at her Fairbum home, denied the allegations. "There were never any beatings anywhere," she said. She dismissed former staffers as disgruntled employees and residents as unreliable.

"Racism all the way" is how Mahan characterized the state's investigation. "If they thought we had done all this, then why didn't they move people right away?" she said.

Mahan and her family have their supporters, including families of more unmanageable residents who have struggled over the years to find willing caretakers.

"I thought they did a great job," said Fred Williams, whose son has been bounced from group home to group home. "I don't see how anybody can do what they do."

The office never informed law enforcement about the allegations of abuse. In August 2000, it concluded Mi Casa staff probably abused residents, but "there is insufficient evidence . . . to substantiate beyond a reasonable doubt." It recommended that Mi Casa remain open if it corrected its problems, including training staff on how to handle difficult residents.

But within weeks, the state terminated its contracts with Mi Casa in light of a separate investigation into its use of medications. Mi Casa challenged the action in court, but a judge refused to intervene.

The division found that 26 residents had been prescribed "old generation" anti-psychotics - most highly sedating - that can cause tics and other involuntary movements. Almost all the residents also had been prescribed other sedating medications.

Some residents, the state found, were showing signs of possible side effects, including unsteadiness and falls. Others were constipated and having trouble urinating.

One resident taking up to 28 pills a day appeared so overmedicated, a state official reported, that he was "drooling to such a degree that the towel placed around his neck was saturated."

Only a few residents' medical charts, the state found, specified symptoms or diagnoses justifying the medication. Residents were not being properly monitored for potential harm to their liver and blood cells. .

Roy, who had taken only medication to treat a reflux condition when he left Brook Run, was getting anti-psychotics and sedatives. "Roy was no trouble so I don't know why he would need it," Sales said.

Later, state investigators reported Roy had fallen a number of times, but they could find no evidence the falls were ever checked out to determine if he was over-sedated. The division concluded the medications were being used to "chemically restrain" residents.

The state found the drugs all were prescribed by Dr. D.-Ann Travis, a Fairburn family physician. On Sept. 18, 2000, the division sent a complaint to the state Medical Board; the board will not discuss the case.

Mahan denied that residents were being overmedicated.

Travis, reached recently, said the Medical Board has cleared her of wrongdoing, although its findings are confidential. "I was simply practicing medicine the way medicine is practiced," Travis said.

She said she "merely refilled" prescriptions written by another doctor. However, the state found that Travis had placed Roy on the anti-psychotics and sedatives.

In September, the state moved residents from Mi Casa, after first identifying 11 who would need close supervision as they were weaned off their medications.

A lost treasure

On June 1, 2000, three weeks after the state's investigation began, Roy was dancing around his living room. His cousin had called that day to invite him to a family picnic.

Dressed in a T-shirt and shorts, he went to bed in the usual position: propped on his side because of his reflux problem.

In the morning, he lay on his stomach, naked from the waist down, dead.

Palmetto police found no apparent explanation for why Roy, 53, was fine one day, dead the next. His body was taken to the morgue.

The search for what killed him essentially stopped there. The Fulton County medical examiner's office, overwhelmed with bodies that day, concluded Roy died of natural causes and decided against an autopsy.

It did so largely on the word of Dr. Travis, according to an investigator in the medical examiner's office. Travis said she would sign a death certificate noting congestive heart failure as the primary cause, the investigator said in a statement in DHR's files.

Roy's family said they knew of no heart problems, and his medical records do not mention the condition. Travis said the medical examiner's office, not she, identified the cause and she agreed to sign the death certificate out of "professional courtesy."

In light of the state's investigations, she never did. The medical examiner signed off on the death five months later, attributing it to "natural causes not otherwise specified."

Martha Mahan said Roy's death definitely was unexpected. "If you asked if he had to die, I don't know," she said. "I was not there."

A 23-year-old staffer who had worked for Mi Casa less than a month was there that night. She had no previous experience caring for people with mental retardation, but she alone was responsible that evening for the welfare of four men.

The young woman told police that she last checked on Roy at 9 p.m., then found him dead at 7 a.m. She later changed her story, telling state investigators she looked in on him throughout the night. She could not explain how he died.

Neither can the Office of Consumer Protection. In fact, the office didn't know for more than three weeks that Roy had died, even though it was investigating Mi Casa at that time. The reason, state officials say, is Mi Casa's failure to properly report the death, preventing a timely and adequate review.

The only thing that was clear, the state concluded, was that Roy received inadequate care at Mi Casa. Without an autopsy, the exact cause of Roy's death may never be known.

"If I had to guess, I'd still say he died of natural causes," said Dr. Michael Heninger, the medical examiner who eventually signed off on Roy's death. "Looking back, sometimes we wish we had done an autopsy."

The state's report on Roy's death recommended that the state educate the medical examiner's office on the importance of conducting inquiries and autopsies on people with mental retardation. A year later, that has yet to happen.

If there is an answer, it lies buried in a sunny spot at Holly Hill cemetery in Fairburn. Roy is buried there, alongside his parents, in the plot Annie Ruth bought for him before her own death. He was laid to rest in the blue casket she picked out.

"I don't know if it happened right or not - her going first," said Blair, Roy's cousin. "She couldn't have stood what happened to her baby."

If you have a question or complaint, call:

«¦ **Division of Mental Health, Mental Retardation and Substance Abuse,** Office of Consumer Protection, 404-657-5737 **On the Web:** www2.state.ga.us/departments/dhr/mhmrsa.html

Georgia Advocacy Office, 404-885-1234 (outside Atlanta, 800-537-2329)
On the Web: www.thegao.org

Back to top | **ajc.com home**

home | news | metro | sports | business | living | opinion

ajc.com
The Atlanta Journal-Constitution

HOME NEWS METRO SPORTS BRAVES BUSINESS LIVING OPINION TRAVEL SPECIAL S

[The Atlanta Journal Constitution: 12.02.2001]

Laws to shield privacy keep details from families

By KEN FOSKETT and ANN HARDIE Atlanta Journal-Constitution Staff Writers

The very laws written to protect the privacy of people with mental retardation keep the public -- including families - from knowing how they died.

Under the interpretation of state attorneys, these laws have prevented families from knowing the details of their loved ones' records, whether they are alive or dead — even if those records contain notes on abuse or neglect.

A year ago, state officials told more than 35 families that their relatives, all with mental retardation and under the state's protection, were being moved to new private group homes. The letter alluded to a state investigation into allegations of abuse.

But the letter didn't explain that state investigators had documented allegations that many residents had been physically abused and heavily sedated to control their behavior.

Members of several families said state officials never told them of allegations that their loved ones were abused or overmedicated. Even the family of a man who died in one of the homes couldn't find out about circumstances.

"They never gave me one iota of anything," said Diane Clark, who said she called state officials four times to ask how her cousin Roy Rodgers died.

Georgia officials maintain that state laws and federal regulations concerning Medicaid beneficiaries keep them from disclosing details about a person's diagnosis or medical care, often even to family members.

The Department of Human Resources cited the confidentiality of its records when it refused the Journal-Constitution's request for the names of people who died

Top local headlines
- Dorsey had five people on 'hit list,' authorities
- McKinney, dad cited for conduct at polls.
- What role did Turner play in Levin departure?
- Rosalynn Carter likes adventurous life,
- Bogus money a part of scam.
- Ex-Fulton jail official collapses on stand at her bribery trial.
- Fulton commission delays salary vote.

AP headlines this hour
- Leahy, Daschle Anthrax Letters Same
- Up to 35 People Shot at Indiana Factory
- U.S. Gives Afghan Rebels Air Cover
- Columbine Diary Promt

MORE ON BROOK RUN

Photo album
Georgia broke its promise of good home for beloved son.

Day 3
»State to evaluate care for 3,600 in group home or residential care.

Day 2
? Georgia broke its promise of good home for beloved son?
*Privacy Laws

* Group home deaths reveal ugly picture of state care.
» Who let Stephen Bennett die?
* System has too few safeguards.
» Critics warned state was moving too fast

About this series

About the reporters

Rehearing Call
- Striking Teachers Trade Class for Jail
- Incentives for Postal Service Managers
- Militants Defy Arafat Crackdown
- Hamas Backers, Palestinian Cops Clash
- Palestinian Cops, Hamas Backers Clash
- Palestine Cops Battle Hamas Backers.
- Syria Leader, Wife Have First Child
- .Saudi Man Denies bin Laden Link
- Arafat Moves Against Islamic Militants
- Palestine Cops Clash With Protesters
- Palestine Cops Clash With Hamas

while under the care of one of its mental retardation programs.

DHR officials contended that the people had a right to medical privacy even after they died, it eventually released initial reports on 146 deaths to the newspaper, but deleted virtually every fact from the files, including the names and all medical details.

After lengthy negotiations, DHR officials agreed to provide the newspaper with more files on four deaths after releases were signed by family members. But even then, access to the files was delayed for weeks when the agency insisted that a mother or siblings prove they were involved in making medical decisions.

DHR has yet to follow through on a pledge to release files on three others for whom DHR's Division of Children and Family Services was legal guardian.

Of four suspicious deaths investigated by the state in the past two years, no family members were told the results of the inquiries. Two families said they didn't know the state had even investigated the death.

The state has no policy requiring it to turn over the findings to family members, said Joann Coiwell, DHR's deputy director for mental health, mental retardation and substance abuse.

"I don't know why," Coiwell said. "There just isn't one."

Back to top | ajc.com home

home | news | metro | sports | business | living | opinion

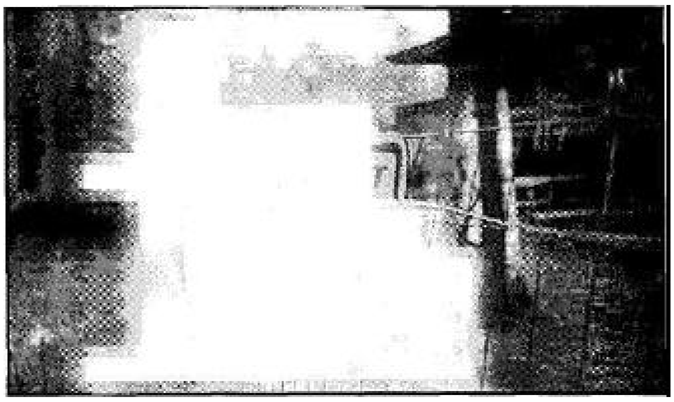
AJCCLASSIFIEDS SUBSCRIBE TO THE

ajc.com
The Atlanta Journal-Constitution

HOME NEWS METRO SPORTS BRAVES BUSINESS LIVING OPINION TRAVEL SPECIAL S

Top local headlines
- Dorsey had five people on 'hit list.' authorities say,
- McKinney, dad cited for conduct at polls,
- What role did Turner play in Levin departure?
- Rosalynn Carter likes adventurous life
- Bogus money a part of scam.
- Ex-Fulton jail official collapses on stand at her bribery trial.
- Fulton commission delays salary vote.

AP headlines this hour
- Leahy, Daschle Anthrax Letters Same
- Up to 35 People Shot at Indiana Factory
- U.S. Gives Afghan. Rebels Air Cover
- Columbine Diary Prompts



Much of Brook Run, the onetime retardation center in Dunwoody, has been locked away behind fencing since it closed in 1997 and many residents were sent to community settings around the state.

Group home deaths reveal ugly picture of state care

By ANN_HARDIE and KEN FOSKETT Atlanta Journal-Constitution Staff Writers

Georgia now houses thousands of people with mental retardation in privately managed group homes instead of state-run institutions. Officials say most are living fuller, more rewarding lives.

It is the dead they cannot account for.

At least 163 of Georgia's most vulnerable residents have died under the state's watch in the last four years, in circumstances largely shrouded in secrecy. Some who died were malnourished, bruised, scalded, dehydrated.

The Department of Human Resources, the state agency responsible for their care, would not say how these people died or even who they are, and it concedes that the toll undercounts the actual number of deaths.

The Atlanta Journal-Constitution - which inquired after parents complained about abuse and neglect - found the names of 117 of the dead, most of them by

MORE ON BROOK RUN

Photo album
» Georgia broke its promise of good home for beloved son.

Day 3
» State to evaluate care for 3,600 in group home or residential care.

Day 2
^Georgia broke its promise of good home for beloved son? » Privacy laws shield details from families.

Day 1
* Group home deaths reveal ugly picture of state care. » Who let Stephen Bennett die?
» System has too few safeguards.
» Critics warned state was moving too fast

About this series

About the reporters

comparing heavily censored state records with a database of death certificates. The circumstances of those deaths, while a partial sample, paint a troubling picture of the community-based safety net.

» Almost half died before their 40th birthday, despite the state's expectation that people with these disabilities . live to old age.

> Thirteen died as a result of choking or food aspiration, which often is considered preventable.

Death was unexpected for two of every three people. But no autopsy was done to look for abuse or neglect in 75 percent of those cases.

Among the deaths was a 22-year-old covered in bed sores who weighed only 46 pounds. Jerald Jones, born with cerebral palsy, died helpless on a worn mattress on a hot July day. The sweltering heat of his Clayton County bedroom caused the dehydration that contributed to his death.

A 27-year-old woman living in another Clayton County group home died two days after she was found face down in a tub of water. Teasha Nichols, prone to seizures, had been drawing her bath by herself, even though the staff was required to be with her.

The deaths also included three people found to be severely malnourished, a man who fell and broke his neck and two men who choked eating lunch at their day centers.

Three others were killed in traffic accidents, one hit by a drunken driver while crossing a busy six-lane highway. Three died over a 16-month span in the same Douglasville home.

Knowing how these people are dying can save lives. Case in point: Robbie Green.

The Douglasville woman was meticulous about her hygiene and always bathed herself. She apparently forgot to add cold water to her bath, was hospitalized with third-degree burns and died from complications of surgery. The accident never would have happened if the water heater had been set to 110 degrees, as state regulations require.

No one had ever tested the water because the home in which a social service agency had placed her did not even have a license to care for her. Green's death prompted the state to order the agency to install hot water regulators on all homes where disabled residents live.

Such preventative action was precisely what the state envisioned when it created a special office in May 1999 to investigate suspicious deaths. But 2 1/2 years later, the state has completed investigations in only four deaths of people with mental retardation.

The Department of Human Resources cites federal and state privacy rules in refusing to disclose details of the deaths. Even parents and siblings never learn how their loved ones died.

"They have not written me. They have not called me. Nothing," said Patricia Wirrick, Green's sister.

State officials maintain that the number of deaths is not inordinately high or alarming. At the same time, they cannot say how many people actually have died. Flaws in the way deaths are reported and tracked make it impossible to determine whether people living under DHR's care in community settings are dying at the same rate as those in institutions.

Officials concede some deaths go unreported and never receive state scrutiny. But they insist they are improving oversight of Georgians with mental retardation under their care.

"Any death of any consumer is important," said Dr. Karl Schwarzkopf, DHR's acting director of mental health, mental retardation and substance abuse. "And if it's due to a system's failure, we want to know about it and try change what the failure was."

Fewer autopsies done

Over the past several decades, states around the country have aggressively sought to care for people with mental retardation in the community, rather than state institutions.

Life on the outside is more humane, state officials argue, and carries the promise of a cozy home, possibly a job with a paycheck and the opportunity of belonging to the larger world. And taxpayer dollars for the disabled go further in community settings.

Georgia joined the movement in earnest in 1997 when it closed the Brook Run retardation center in Dunwoody and transferred 326 people into privately managed group homes and apartments. (About 3,600 people with mental retardation live in community settings today, twice the number of just five years ago, according to the DHR.)

Many can be challenging. They often had been institutionalized for decades and came with an array of medical problems, including seizures, blindness and paralysis. Some couldn't speak or hear.

Many residents also suffered from mental illnesses and had major behavior problems, including self-abusive tendencies.

When Brook Run closed, critics warned the state was unprepared to assure these residents' well-being. Their fears were realized when 27-year-old William Lee Barrett, who had lived in Brook Run half his life, died in December 1997 — just six days after moving into a Marietta group home. An independent investigation found Barrett's caretakers hadn't attended a two-week training program and questioned the speed with which he had been placed in his new home.

"Lee was a very fragile person, but with the proper care he could have lived a long time," said David Truran, a former official with the Georgia Advocacy Office, which investigated Barrett's death.

The Cobb County medical examiner, who said he didn't know Barrett's condition made him susceptible to choking, decided not to autopsy the body and ruled he died of complications of cerebral palsy.

But the precise cause of death remains unknown. In a wrongful death lawsuit, Barrett's family charged caretakers were not properly trained and did not take proper precautions to reduce his chances of choking. His caretaker, United Cerebral Palsy of Greater Atlanta, denied wrongdoing but settled the suit.

State law requires medical examiners to investigate the death of anyone living in a prison or other state institution. Barrett and the thousands of other patients who were moved into community settings no longer fell under that protection.

After Barrett's death, the Georgia Advocacy Office, a federally mandated watchdog group for the disabled, urged every Georgia coroner and medical examiner to scrutinize the deaths of people with mental retardation for signs of neglect, abuse, suffocation and choking. The advocacy office asked them to autopsy those bodies with the same vigilance they would anyone else.

The problem, however, persists. Four of every five deaths reviewed by the newspaper were not autopsied.

Delinquent reporting

Despite concern over Barrett's death, Georgia officials did not establish a statewide policy for reporting deaths of people with mental retardation until 15 months later.

The policy, effective in March 1999, required companies and agencies providing residential care to report a death within 24 hours of learning about it so an investigation, if necessary, could begin promptly.

But records show 40 percent of these deaths were reported at least three business days later, often after the dead had been buried or cremated. One in four was at least a week late, and several came in months late. A care provider can lose its state contract for late reporting, but officials concede that penalty never has been imposed.

The state policy also requires that follow-up reports must be submitted a week and a month after a person's death. State officials could produce those reports for about only one in four deaths.

The policies are designed to evaluate the deaths and make sure that other residents are not at risk.

The death of Sue Quillian, 55, should have been a clear sign of trouble.

Sue never spoke, despite the hours her mother spent reading children's books to her. She never learned to walk or feed herself. "I never resented having Sue," Virginia Quillian, 82, said. "She taught me patience. She taught me not to feel sorry for myself." It took 26 years for Virginia Quillian to wear herself out and place Sue at Brook Run.

At her healthiest, Sue weighed 88 pounds. The Brook Run staff counted her calories to ensure she got enough to eat and closely observed her feedings because of her tendency to choke.

Quillian didn't get the same attention at her DeKalb County group home, her mother maintains. At times, Virginia Quillian said, one staffer had to tend to four residents, all in wheelchairs.

Sue's meals often cooled as she waited to be fed, her mother said, and Sue refused to eat the cold food. Quillian's doctor, concerned about her weight loss, inserted a feeding tube so the staff could give her boost her diet with nutritional supplements.

Sue was hospitalized on March 1, 1999, with a rattling cough. The doctor took one look at her and told her mother she was malnourished and dehydrated. "The doctor told me that night he would not want to see her go back to that home," Virginia Quillian said. "That tore me to pieces."

Sue Quillian never went back. She died three weeks later in a nursing home of aspiration pneumonia, an inflammation of the lungs commonly caused by inhaling food.

Nothing in Quillian's file at DHR indicates that anyone attempted to learn about her death or find out why she was malnourished. Virginia Quillian said no one from the state ever contacted her after Sue's death.

But a year later, state inspectors visiting the same group home were so concerned about four residents that they recommended they see nutritionists. One resident, under doctor's orders to be weighed monthly, hadn't been weighed in many months, the inspectors found. The reason: The home didn't have a scale.

Proof of commitment?

Since Brook Run closed in 1997, state officials have added layers of supervision to better monitor a vulnerable population spread out over more than 1,000 private homes. Inspectors make unannounced visits, and monitors are required to check on these people twice a month.

The state's efforts, officials say, have focused primarily on the living. "When a person dies . . . it is important that you learn what you can learn from that," said Charles Hopkins, who oversees mental retardation services for DHR's Division of Mental Health, Mental Retardation and Substance Abuse. "There is a lot more to be done to try to have people be in a safe environment where they grow and have some quality of life."

DHR created the Office of Consumer Protection in May 1999 after a scandal in Elberton underscored the need. Disabled citizens there were scammed by the very officials charged with supervising their care. Nine employees of a state-created community care network had been fired in the previous year amid allegations of insurance fraud, abuse and neglect.

The new office was charged with tracking and reviewing all death reports for people with mental retardation, mental illness and substance abuse problems and investigating complaints of shoddy care and suspicious deaths. Its four employees work with 13 state consumer protection advocates around Georgia.

From the beginning, advocates of the disabled were skeptical. "It was more or less just another layer," said Bruce Roberts, an attorney with the Georgia Advocacy Office. "It sounded good, but it wasn't going to do anything."

In interviews, state officials pointed to the office as proof of DHR's commitment to the safety of people in its care. But in practice, the office has fulfilled critics' expectations.

Most deaths receive only cursory review, especially if they don't meet criteria the office has identified as possibly suspicious, including suicides and deaths of people under younger than 35. years old. Most never receive the follow-up reviews mandated by DHR's policies.

Nor has DHR ever analyzed the deaths for trends — although its own policies require it -- so it cannot say how many might have been prevented, much less take steps to avoid similar deaths in the future.

The death of Stephen Bennett (see article) was one of the worst. An autopsy found he was malnourished and dehydrated, and bruises suggested he had been placed in physical restraints for prolonged periods. DHR investigators concluded he had been neglected.

But the investigation was closed without action 20 months later, after no action had been documented for more than a year.

Doris Clanton, the office's director, conceded the Bennett investigation dragged on too long and acknowledged other problems, including lapses in the death reporting system. She said some care providers
- may deliberately avoid reporting a death, but other incidents are the result of ignorance.

"It was a new system," Clanton said of the 1999 reporting policy. "You want to give them time to learn it."

DHR does not expect that every death will be reported anyway, Clanton said, although its policy clearly states otherwise. The important thing, she said, is to have enough reports to identify weaknesses in the system.

"The system of making sure that your state knows who dies is a reporting system, it is not knowing each and every [death]," Clanton said.

Yet even reported deaths don't get scrutiny that could pinpoint systemic problems. Aspiration pneumonia -which develops after choking - is a major cause of death among people with mental retardation and often can be prevented if staff is properly trained. However, the state has not analyzed where people have died from it or whether increased training or education is needed.

Clanton said her office doesn't have the expertise and manpower to do such a trend analysis.

The division, Clanton said, plans to train all its consumer advocates on how to conduct death reviews and investigations. "The division and all of us are looking for ways to ensure that we are being more effective and efficient," she said.

While Clanton declined to blame others at DHR for the problems in her office, one former DHR employee said the Office of Consumer Protection received little support and encouragement from senior management.

Crystal M. James, a former consumer rights advocate in the office, said senior DHR officials never gave the office enough staff or resources to do its job.

"The Office of Consumer Protection was not truly set up to protect consumers," said James, who left last year.

"All the bad stuff was like the big purple elephant in the room," James said. "Don't look because if you have a problem, you have to do something about it. But we didn't have the resources to do anything."

If you have a question or complaint, call:

Division of Mental Health, Mental Retardation and Substance Abuse, Office of Consumer Protection, 404-657-5737 **On the Web:** www2.state.ga.us/departments/dhr/mhmrsa.html

Georgia Advocacy Office, 404-885-1234 (outside Atlanta, 800-537-2329)
On the Web: www.thegao.org

Back to top | **ajc.com home**

home | news | metro | sports | business | living | opinion

ajc.com
The Atlanta Journal-Constitution

Stephen Bennett and Lois Curtis, living in a group home after being in institutions, shared a moment at dinner.

Who let Stephen die?
DHR found neglect, but no culprit

By KEN FOSKETT
Atlanta Journal-Constitution Staff Writer

Stephen Bennett devoured candy. Even in his 20s, he looked forward to Halloween and Easter with the abandon of a 5-year-old.

One Halloween, Stephen gobbled down all his candy and then all his nieces' and nephews' treats, giving himself a bellyache that lasted all day.

Mildly retarded, Stephen also was prone to violent outbursts. His older siblings recall his temperament, sweet and mild as a child, worsened at age 7 after his mother, a heavy drinker, died suddenly. Stephen hit or bit himself, sometimes both. As a teenager, he once threw a brick through a neighbor's window.

Stephen at age 6

Stephen lived much of his life in mental hospitals until he landed at Brook Run, a state-owned retardation center in Dunwoody, in 1996. A year later, Stephen became one of the first people to leave Brook Run before the state closed it.

His new caregivers - Loving Hands Inc., owners of a group home in DeKalb County - promised to feed, clothe and care for Stephen for $118 a day. He had his own room. He attended classes to learn how to count money, develop his speech and adapt to life outside an institution.

Then, less than three years later, he was dead at age 24. To this day no one knows exactly what happened.

Loving Hands told Stephen's family he died of natural causes.

But autopsy results found nothing natural about his death.

Stephen's dehydrated body, once a chunky 185 pounds, weighed a mere 145. Both lungs were infected with pneumonia, and his blood was toxic with streptococcus bacteria. The medical examiner, Dr. Gerald Gowitt, concluded Stephen either had nothing to eat or drink for three or four days, or very little over a period of two weeks.

Bruises and lesions covering Stephen's body, some only days old, were "too numerous to discuss individually," Gowitt said, adding that some marks suggested Stephen had been restrained for long periods.

Gowitt ruled Stephen died of a blood infection, but the manner of death was undetermined. There was clearly neglect, he wrote in his autopsy report, but "I am less certain that it is deliberate or intentional."

What's worse, Stephen died even after people told authorities he was in medical crisis, Department of Human Resources files show.

Neighbors saw him flailing around half-naked in subfreezing weather.

• A van driver reported "he looked like he could die."

¦ A state caseworker saw bruising and noted he looked seriously ill.

"It's absolutely incredible that someone could go from reasonable health to being dead from all these different things in the span of a month," said Bruce Roberts, an attorney who investigated the case for an independent watchdog group.

At first, Stephen's death was treated as a possible crime. But the outrage faded as Stephen's case was shunted from one agency to the next.

» The medical examiner said he couldn't prove abuse.

* Police said they couldn't charge anyone unless the medical examiner ruled there was a crime.

* And DHR's investigative report - completed 20 months after his death - found Stephen was neglected but could not identify a culprit. Investigators "didn't feel like that they had the answer," said Doris Clanton, DHR's head of consumer protection for people with retardation. Loving Hands was not punished.

"Every [agency] was waiting for somebody else to take action," said Dr. Karl Schwarzkopf, DHR's top official over mental retardation programs.

DHR's lead investigator on the case, Crystal M. James, said she expected her findings would shut down Loving Hands.

But the case never moved forward because no one pushed it, James said. She said the environment at DHR discouraged investigators from moving aggressively against bad care providers, an allegation Clanton denied.

"The culture is to avoid lawsuits . . . to try not to bring that type of negative attention to the system," said James, who left the Office of Consumer Protection a year ago.

Loving Hands' attorney, Robert Kenner, rejected any suggestion Loving Hands contributed to Stephen's death. "They have actually gone beyond their duties in terms of care that they administered to him," he said.

Nightmares replaced answers for Paul Miller, Stephen's half-brother. For months, the Carrollton resident said, he woke up in a cold sweat with an image of Stephen lying in his room alone.

"How could they just let him lay there and die?" Miller said.

On Friday, Miller sued Loving Hands and other agencies involved in Stephen's care for the wrongful death of his brother, alleging that he had been bound, beaten and left to die.

"Someone needs to be held accountable," he said.

Prognosis: Death

Loss and neglect dogged Stephen's life for more than a decade. After his mother died, he was shuttled between grandparents and foster homes for four years, then was sent to a mental hospital in Florida. Schooling ended after seventh grade.

Stephen's half-sister kept him for two years but couldn't cope and turned him over to the Georgia Mental Health Institute in Atlanta in 1995.

There, Stephen often was put in restraints. Other times he lay for hours curled in a fetal position. A Decatur disability rights lawyer pushed for Stephen's transfer to Brook Run, then to a home with Loving Hands. The Loving Hands home was monitored by KenMarc/Georgia Providers Collaborative, one of five private agencies selected by the state to care for former Brook Run residents.

Stephen enjoyed his new freedom outside Brook Run. He liked watching movies and socializing with his housemates.

State workers had emphasized Stephen needed stability, but Loving Hands transferred him to four homes in 1999 alone, ultimately placing him in a townhouse in south DeKalb with a single caretaker and a housemate. Over Thanksgiving that year, Stephen went home with his half-brother, but he was returned after one day when he lit matches in Miller's home.

Christmas was no better. Stephen's half-sister, Traci Blackstock, returned him Christmas Eve after he went to the bathroom on himself. "I just couldn't take care of him and my children," she said.

Stephen's last weeks are chronicled in 300 pages of documents in DHR files that portray starkly different pictures of his health and behavior.

At the day center where he attended classes, director Sandra Fields repeatedly noted Stephen seemed lethargic and complained of being "overmedicated."

But Loving Hands caretakers described him as violent and uncontrollably. They said he beat himself continually and was faking symptoms of illness to gain attention.

Stephen pointed to "old bruises" and said, "Wait till I show all these bruises and say you did this," Loving Hands owner Diane Cobb wrote in notes dated Jan. 8, 2000.

On Jan. 12, a doctor said Stephen had the flu and ordered five to seven days' bed rest, according to Loving Hands' notes. But three days later, Stephen was taken shopping at a mall, the notes said.

The home was required to keep daily notes on residents' health and behavior. But 11 days of Loving Hands' notes on Stephen are missing - Jan. 18-28.

There are harrowing reports on Stephen from other sources during that period. On Jan. 25, a neighbor said she saw Stephen outside, half-clothed, in subfreezing weather. "He was out there crawling around with his pants down, with his naked bare behind in the snow on the ground," Jennifer Moore said. "It brought tears to my eyes."

On Jan. 27, Loving Hands said Stephen was having "problems walking," according to his DFCS caseworker's files. That night, another DFCS worker noted Stephen appeared "drugged" and very sick, she later told investigators.

On Jan, 28, the van driver said he saw Stephen lying on the floor of the home, "naked with bruises from head to toe, and he looked like he could die." He told Stephen's day center director, who said she immediately telephoned DFCS and KenMarc, the private agency that contracted with Loving Hands.

That night, Cobb took Stephen to a hospital emergency room, where nurses observed "multiple bruises all over body" and signs of dehydration. Stephen told a KenMarc employee there he bruised himself by running into the refrigerator and crawling on the ground.

The emergency room doctor, in the discharge papers, said Stephen needed to be supervised more closely for seif-abusive behavior. But the doctor's verbal warning was even more blunt.

"He just told me that if [Stephen] kept it up he was going to be dead soon," KenMarc's Myrtle Mitchell said.

KenMarc called for one-on-one supervision the next day to prevent Stephen from hurting himself, but Loving Hands staff told police the supervision didn't start for five days. During that time, the home's notes said, Stephen beat himself, stopped eating and "showed very little interest in moving body parts."

The end came Feb. 8, the same day KenMarc had called a meeting at Stephen's home to discuss his "behavior."

Willie Ingram, a behavior specialist with Georgia Regional Hospital, arrived to find Stephen lying in bed, alive but barely responsive. He urged Cobb to get Stephen to an emergency room.

In a later interview, Ingram said Cobb insisted Stephen was faking his symptoms.

Before he left, Ingram checked on Stephen once more. "If he's faking, he's doing a good job of it," Ingram said as he left.

Stephen never made it to an emergency room. Cobb said she found him sitting in a chair, head cocked and staring into space. She said she attempted CPR, but it was too late. Stephen was dead.

Police have doubts

Two days after Stephen's death, DeKalb police obtained a warrant to search Stephen's townhouse, listing "murder" as the reason.

Acting on Gowitt's suspicions about Stephen's bruising, police searched for restraining devices. They found none.

DHR's Office of Consumer Protection launched its own inquiry. Several red flags popped up, recalled James, the lead investigator.

* Loving Hands staff gave conflicting accounts of Stephen's activities on the day he died. The home's notes said he had been eating. The medical examiner found he hadn't. And why had no one noticed Stephen had lost 40 pounds?

* Stephen's house parent was a former fast food restaurant manager with no experience in the mental retardation field. Loving Hands said it trained her, but the house parent said she never received formal training and her only duties were cooking and cleaning.

*The "one-on-one behavior specialist" assigned to Stephen for the last five days of his life had been removed from caring for him a year earlier after hitting Stephen on the **head** with a broom.

By coincidence, another **DHR** division was turning up more problems with Loving Hands. Inspectors found lapses in the storage and distribution of medications, sloppy record-keeping and out-of-date fire inspections. Loving Hands was given four months to fix the problems.

On Feb. 17, officials moved three patients out of another Loving Hands home because of concern for their safety.

But five days **later,** yet another division of the DHR placed an emotionally troubled young woman in the home where Stephen died. DHR officials could not explain how that placement was made while a homicide investigation was underway.

DHR's investigation officially ended Oct. 16, 2001. No actions were documented after March 2000. The report concluded Loving Hands failed to heed signs of Stephen's deteriorating health, but recommended no action because it had corrected the unrelated problems outlined by the other DHR division.

One of DHR's regional placement boards stuck with Loving Hands, too, reasoning other small home providers would have the same set of problems.

"They are not much different than your average provider," said Earnestine Pittman, director of the Fulton County Regional Board.

Finally, just a few weeks ago, the Fulton board canceled its contract with Loving Hands after a resident was found wandering on the shoulder of I-285 with cuts and bruises. The man likely injured himself while trying to escape from the home, the board determined. He said he never wanted to go back.

Stephen's housemate, Lois Curtis, now lives in a new home, having asked to leave Loving Hands' care three months after Stephen died. Curtis believed he went straight to heaven and, for a while, she wrote Stephen letters there.

"He went to heaven, and then I missed him," Curtis said recently. "I miss him. I miss him."

Back to top | ajc.com home

home | news | metro | sports | business | living | opinion

ajc.com
The Atlanta Journal-Constitution

A Brook Run resident waited in December 1997 to be carried to a group home when the center closed down.

Safeguards not sufficient, advocates say

By ANN H_ARD[E **and** KEN FOSKETT
Atlanta Journal-Constitution Staff Writers

Georgia's safety net for residents with mental retardation still lacks adequate safeguards, resources and leadership, say advocates for the disabled.

"The accountability within the system now is not working," said Joyce Ringer, director of the Georgia Advocacy Office, an independent watchdog. "I think we all agree on that."

* **Lax oversight:** People with profound retardation are as vulnerable as children, yet the system to investigate their deaths is weak and ineffective by comparison. When a child dies under unusual circumstances, a state investigative unit is supposed to kick into action. Committees at the state and local levels also are charged with reviewing those deaths, and the state Legislature recently created a child advocate office that can also step in.

State officials are considering whether similar procedures could help them in investigating mental retardation deaths, said Andy Boisseau, spokesman for the Georgia Department of Human Resources. Under Georgia law, the deaths of children and people living in state institutions must be reported to coroners and medical examiners for review. But the law does not apply to people who move from institutions to group homes, even though they are equally likely to be victims of abuse or neglect. "Mental retardation, in and of itself, doesn't kill people, but it can be a contributor," said Dr. Michael Heninger, a Fulton County medical examiner. "At the same time, people with mental retardation are extremely easy to abuse."

People who die prematurely in group homes and apartments also have not captured the attention of state officials, law enforcement and the public because of a perception that these people are more likely to die anyway. "These are human beings," said Eric Jacobson, director of the Governor's Council on Developmental Disabilities. "If there are suspicious circumstances, that needs to be investigated."

» **Questionable quality, too few resources:** The state insists that people with mental retardation are better off in the community than institutions. At the same time, the state is desperate to identify qualified providers of residential care. Many of the deaths identified by the newspaper pointed to unqualified, underpaid or overworked caregivers.

Georgia ranks near the bottom in spending on community-based care for people with developmental disabilities. Unlike some states, Georgia also lumps programs for mental retardation in with those for mental illness and substance abuse, even though the problems are vastly different.

"There has been a lack of vision and leadership . . . to get us to a point to where there are quality providers and services," Jacobson said.

Last year, the Legislature created a state ombudsman for people with mental retardation, mental illness or substance abuse problems. That office still has not been funded.

• **Too little accountability:** While advocates see a need for privacy, they argue the strict interpretation of confidentiality laws reduces accountability. "You have have a system . . . that invites investigation and is open to review," said David Truran, an advocate for the disabled.

Some states that track deaths publish numbers and causes. Georgia has no system to do that.

The secrecy is pervasive. Parents of disabled Georgians even have difficulty learning the identities of other parents in the system.

"Confidentiality is the biggest barrier," said Beth Tumlin, chairwoman of Georgia's Unlock the Waiting Lists Campaign, which lobbies for more money to place developmentally disabled residents in community homes. "It's their way of keeping us in the dark."

Back to top | ajc.com home

home | news | metro | sports | business | living | opinion

The Atlanta Journal-Constitution: 12.02.20011

Critics: Brook Run closed before homes were ready

Amid much fanfare, the state opened the Georgia Retardation Center, later known as Brook Run, in 1969 as a state-of-the-art residential facility for people with mental retardation, autism, cerebral palsy and other developmental disabilities.

It closed the 98-acre Dunwoody facility in 1997 amid much hand-wringing and controversy.

Gov. Zell Miller led the efforts to put Brook Run out of business, saying people with mental retardation would have a better guality of life in community settings.

Miller had the support of advocates for the disabled, as well as the editorial boards of The Atlanta Journal and The Atlanta Constitution, arguing money spent on the facility could be used to expand services for needy people already living in the community.

Many Brook Run residents had lived at the facility for two decades or more, and their families likened the closure to a potential death sentence.

They worried about unsafe homes and untrained staff. They were concerned their relatives would not receive the same medical and psychological attention they got at Brook Run.

To quiet the controversy, the state gave the families options: Their loved ones could move to another institution of the state's choosing or to a private residence of their own choosing. The state moved residents of other institutions into community settings to make room for Brook Run residents.

A total of 326 people moved from institutions into private residences supervised by the state.

Some of the very advocates who supported the closing of Brook Run believed the state was moving too hastily.

Photo album
» Georgia broke its promise of good home for beloved son.

Day 3
»State to evaluate care for 3,600 in group home or residential care.

Day 2
^Georgia broke its promise of good home for beloved son?
» Privacy laws shield details from families.

Day 1
» Group home deaths reveal ugly picture of state care.
» Who let Stephen Bennett die? »
System has too few safeguards. »
Critics warned state was moving too fast

About this series

About the reporters

Sean

Rehearing Call
- Striking Teachers Trade Class for Jail
- Incentives for Postal Service Managers
- Militants Defy Arafat Crackdown
- Hamas Backers, Palestinian Cops Clash
- Palestinian Cops, Hamas Backers Clash
- Palestine Cops Battle .Hamas Backers
- Syria Leader, Wife Have First Child
- Saudi Man Denies bin Laden Link
- Arafat Moves Against Islamic Militants
- Palestine Cops Clash With Protesters
- Palestine Cops Clash With Hamas

In June 1997, an independent panel assembled by the Georgia Advocacy Office concluded the state's efforts to close Brook Run should be delayed by at least a year. Miller's administration disagreed.

The last residents were moved out on Dec. 20, 1997.

-- *Ann Hardie*

Back to top | ajc.com home

home | news | metro | sports | business | living | opinion

ctnow.com produced by The Hartford Courant

Don't

▶ HOME ▶ NEWS ▶ BUSINESS ▶ SPORTS ▶ ENTERTAINMENT ▶ CARS ▶ JOBS ▶ HOMES SEARCH

MARKETPLACE
Cars | Jobs | Homes
Ads & Coupons
Business Directory
Classifieds Special
Sections

? NEWS
Columnists
Connecticut
Education
Health Lottery
Nation/World
News(g>3 Politics
Special Reports
Towns Traffic
Weather

» BUSINESS
Columnists
Real Estate
Technology

V SPORTS
Baseball
Basketball
College Sports
Columnists
Football
High School Sports
Hockey
Husky Hardcores
Skiing

* ENTERTAINMENT
Arts & Theater
Attractions
Columnists Dining
Events Movies Music
TV & Radio TV
Listings

LIFESTYLE Books
Columnists Food
Northeast Style &
Shopping Travel

OPINION
Columnists
Commentary
Editorials
Letters Other
Opinion

? SERVICES
Business Directory
Find a Person
Search By Phone #

CONNECTICUT

Lawmakers Call For Inquiry Into DMR

¦ Question Practices, Use Of Privacy Laws In Group Home Deaths

December 4, 2001

By DAVE ALTIMARI, And ELIZABETH HAMILTON Courant Staff Writers

Concerned lawmakers vowed Monday to launch an immediate, bipartisan investigation into the deaths of disabled people living in group homes funded and licensed by the state Department of Mental Retardation.

Calls for an inquiry came from both Republicans and Democrats in response to a Courant investigation that found evidence of neglect, staff error or other questionable circumstances in one in every 10 deaths that occurred in group homes over the past decade.

"I want a thorough investigation so that people won't die like this anymore and so that people, especially families, can get the information they need when a loved one dies," said Sen. Judith Freedman, R-Westport, the co-chairwoman of the Program Review and Investigations Committee.

On Monday, Sen. Toni Harp, D-New Haven - co-chairwoman of the public health committee, which oversees DMR - called for a joint public hearing with Freedman's committee as early as this month, to examine issues raised by the newspaper's stories. The unusual call for an immediate hearing was an indication of the seriousness of the issues to lawmakers, whose regular legislative session does not begin until February.

Particularly troubling, Freedman and other legislators said, was the revelation that DMR investigates itself when clients die and then refuses to release its written findings, even to next of kin. The stories also detailed how autopsies of DMR patients are sometimes done at teaching hospitals and not the state medical examiner's office.

"I was shocked to see someone's body was sent to UConn for an autopsy. I can't imagine a family not knowing what happened to their son or daughter," Freedman said. "When you find one questionable case, you don't turn your head. You dig deeper to see if there's a problem."

Freedman was referring to the case of Lisa Barry, who died in a DMR respite care facility in 1998. Her parents questioned whether the 21-year-old had been given the medications to control her seizures, but that question was never answered because the pathologist who conducted the autopsy at the University of Connecticut Medical Center failed to draw enough blood.

State Senate President Pro Tern Kevin B. Sullivan, D-West

Fatal Enors. Secret Deaths (Elizabeth Hamilton And Dave Altimari)

Add your **comments on this** story.

I applaud the Hartford Courant for bringing this story to light- this is a population that is easily overlooked. Our governor and the legislature need to STOP cutting the budget for group home development. Too much is at stake!
Submitted by: Janice Favreau
12:55 PM EST, Dec 6, 2001

There should be more focus on providing training to employees and more positive incentives, so we can be succesful at our jobs.
Submitted by: Caring worker at Harc
12:46 PM EST, Dec 6, 2001

Read more comments or **post your own**

Police Question Man In Fatal Shooting

Hartford's New May Gets To Work

or Officer Acquitted Of Sex Assault

Courant Archives
Internet Directory
Maps/Directions
Newsletters
Obituaries Site Map

* *AFFILIATES*

Hartford, and House Speaker Moira K. Lyons, D-Stamford, expressed similar concerns Monday and said the legislature would react swiftly.

"We're able and willing to bring this to any level of scrutiny we need to," Sullivan said. "I think it's a very serious problem."

A spokesman for Gov. John G. Rowland said Monday the governor would "support" a review of group home deaths by the Program Review and Investigations Committee, but stopped short of calling for one himself.

"The stories raised several issues. Most importantly, the need for DMR to be more open with the review of these deaths," the governor's spokesman Dean Pagani said. "The commissioner has said he will take action to ensure that occurs and the governor expects that to happen."

Over the past month DMR Commissioner Peter O'Meara has written two letters to group home providers and parents of clients warning them about The Courant's investigation and assuring them that DMR "has undertaken an extensive review of our systems and policies."

O'Meara goes on to say that based on that review, "I am very comfortable that Connecticut has one of the most comprehensive and effective oversight systems in the country."

DMR has assigned a person in each of the agency's six regions to answer questions from parents about deaths or abuse complaints. The agency also recently hired an ombudsman, more than a year after legislators approved the position.

Some lawmakers suggested Monday that the state appoint an advocate for the mentally retarded who would have the same subpoena powers as the state's child advocate. That person would be responsible for conducting investigations into deaths and allegations of neglect, and the findings would be available to the public.

Others said state agencies such as DMR simply should not be allowed to claim confidentiality in death investigations by citing state statutes intended to protect the privacy of clients.

"The right to privacy is the client's right, not the commissioner's or the agency's," said William Curry, a Democratic gubernatorial candidate, who called on the state to investigate DMR. "They should not be hiding their shortcomings behind these laws. This report describes one of the saddest violations of the public's trust we've ever seen in Connecticut."

Sullivan agreed, and said the legislature will review its confidentiality laws if this is how they're being used.

"It makes no sense to me that mortality review records are confidential," Sullivan said. "I think we've made a mistake historically if that's the case."

Other lawmakers said they want to see more than just an investigation of deaths or public disclosure laws. Issues such as funding, staffing levels and training must also take priority, according to Sen. Edith Prague, D-Columbia , a ranking member of the legislature's Public Health

Yale Puts Distance On Car Contest

Rivals Accuse Rowland Of Backing Off Pledge

Committee.

"Who is minding the store here? We need to make sure there is enough oversight of DMR and of the private corporations so that these deaths don't keep occurring."

HOME | NEWS | BUSINESS | SPORTS | ENTERTAINMENT | CARS | JOBS | HOMES
Contact Us | Advertise_0nJine | Privacy Policy | Terms of Service

ctnow.com
produced by The Hartford Courant

▶ HOME ▶ NEWS ▶ BUSINESS ▶ SPORTS ▶ ENTERTAINMENT ▶ CARS ▶ JOBS ▶ HOMES SEARCH

* MARKETPLACE
Cars | Jobs | Homes
Ads & Coupons
Business Directory
Classifieds Special
Sections

Columnists
Connecticut
Education
Health
Lottery
Nation/World
News@3
Politics
Special Reports
Towns
Traffic
Weather

Columnists
Real Estate
Technology

* SPORTS
Baseball
Basketball
College Sports
Columnists
Football
High School Sports
Hockey
Husky Hardcores
Skiing

ENTERTAINMENT
Arts & Theater
Attractions
Columnists
Dining
Events
Movies
Music
TV & Radio
TV Listings

* LIFESTYLE
Books
Columnists
Food
Northeast
Style & Shopping
Travel

* OPINION
Columnists
Commentary
Editorials
Letters Other
Opinion

* SERVICES
Business Directory
Find a Person
Search By Phone #

CONNECTICUT

At One Home: Cold Showers, Wet Hair, Dark Rooms

December 3, 2001

By DAVE ALTIMARI, Courant Staff Writer

Mary Truman doesn't believe Charles Mather should have died.

Six months before the 39-year-old Mather succumbed to pneumonia, Truman had filed a complaint with the state, alleging that other employees in the state-run group home where she worked in Lebanon were neglecting the mentally retarded residents. She said residents were being subjected to cold showers, put to bed with wet hair and left unsupervised in dark rooms.

The next business day after she filed the complaint, the Department of Mental Retardation suspended Truman -and eventually fired her - claiming she had been accused of racial discrimination. She recently filed a $5 million federal lawsuit against the state, charging that her civil rights were violated.

"If this is the way the state treats its whistle-blowers, then you've got big problems," said David Aboulafia, a New York attorney representing Truman.

A review of death records by The Courant found that more residents died in the Lebanon group home than any other in the state over the past 10 years. Five of the six mentally retarded people who died suffered some sort of respiratory failure, and all but two were less than 50 years old.

It is not possible to tell whether the deaths were directly related to the neglect alleged in Truman's lawsuit, in part because records of any investigations DMR may have done are not public.

In her lawsuit, Truman said that less than four months after she lost her job, Mather died. She said that when she helped care for Mather, he was a perfectly healthy man who had no history of pneumonia or respiratory failure.

DMR said it reviewed every death in the Lebanon home after The Courant made inquiries over the summer, and found no correlation between any deaths and the allegations raised by Truman.

"The clients in that home are some of the most complex individuals in our system and, in fact, their lives were lengthened by the treatment they received," DMR Commissioner Peter O'Meara said.

As far as the fact that nearly all of them died of respiratory problems, O'Meara said, "that's what people with those severe illnesses die from."

Courant Archives
Internet Directory
Maps/Directions
Newsletters
Obituaries Site
Map

* *AFFILIATES*

Most residents of the home were among the last transferred from the state-run Mansfield Training School, an institution that closed in the early 1990s. Many have a problem swallowing that leaves them prone to bronchial infections caused by inhaled food particles - a condition common to severely retarded people.

It is a risk of infection that would be worsened by the cold, wet conditions described by Truman.

The state Office of Protection and Advocacy investigated Truman's complaint, but would not comment on its findings.

Sources familiar with the case said the office has substantiated some of Truman's allegations, specifically about cold showers, and has asked DMR to change some of its procedures.

Attorney General Richard Blumenthal has opened an investigation into the deaths. But the remains of all but one of the deceased residents have been cremated, and some of the deaths occurred as many as eight years ago, making any inquiry difficult.

At least one relative of one of those who died recalled seeing conditions similar to those alleged by Truman. Leah Clark said she visited the group home not long before her brother, Malcolm Renshaw, died of pneumonia in 1997.

"Malcolm had his own room," Clark said. "His door was closed and the lights were off, and when I asked why, they said he was sleeping.

"But when I went in, he was banging his fists against the bed flailing around."

Clark said that when Renshaw died, DMR recommended having his remains cremated because it was cheaper than a burial. The state held a memorial service at the group home and, Clark says, planted a tree in his memory.

HOME | NEWS | BUSINESS | SPORTS | ENTERTAINMENT | CARS | JOBS | HOMES
Contact Us | Advertise Online | Privacy Policy | Terms of Service

ctnow.com produced by The Hartford Courant

CONNECTICUT

How Did They Die? The State Won't Say

¦ Answers Lie Buried With The Dead

December 3, 2001

By DAVE ALTIMARI and ELIZABETH HAMILTON MCOURANT STAFF WRITERS

The corpse-of-the-day in Dr. Jack Hasson's pathology class was the alabaster cadaver of a young mentally retarded woman, ready to be dissected for the benefit of University of Connecticut medical students.

Lisa Barry's body was a welcome training tool.

Hasson needed human remains for classroom training, and he was always eager to accept the occasional deceased group home resident sent his way for autopsy by the Department of Mental Retardation. He wasn't sure how that informal practice got started and he didn't question why the state medical examiner wasn't doing the autopsies - in his view, "the more the better."

As the pathology students gathered around for a lesson in human anatomy, Lisa's grieving parents back home in Niantic were awaiting answers to their own questions:

Why were so many of Lisa's anti-seizure pills still sitting in a bag by her bed at the state's Seaside Regional Center in Waterford the morning she suffered a fatal seizure? Did group home staff fail to give their 21-year-old daughter her life-sustaining medication?

Michael and Kathy Barry hoped an official autopsy by forensic experts at the state medical examiner's office, which investigates suspicious deaths, would reveal the truth about why Lisa died. But that autopsy was never done.

Instead, Lisa's body was shipped to Hasson's classroom, where the 72-year-old assistant professor of pathology, unschooled in forensic science, never took the steps necessary to determine if Lisa had been given her medication. The answer to that question went with Lisa to her grave.

Deprived of an adequate explanation for why she died, the Barrys would then have to file a lawsuit and wait many months - finally obtaining a court order - to learn how Lisa's death had been investigated. They came to realize that their efforts had been stymied by a heavy veil of secrecy that cloaks the deaths of group home residents in Connecticut.

The veil is nearly impenetrable, a Courant investigation found. It hides a system in which DMR investigates itself when clients die, and then refuses to release its written findings, even to families; where the mortality review process - and its conclusions - are kept secret; and where


Staff members at a group home

Michael McAndrews/Hartford Courant)


Michael and Kathy Barry
Michael McAndrews/Hartford Courant)


Lisa Barry

CHARLIE LAKIN

There is no excuse for hiding his information. I can't see how anyone can justify it. I think the

the most reliable way to uncover neglect or abuse - through an official autopsy - is sometimes thwarted by state officials looking to save time and money.

Advocates for the mentally retarded say state laws invoked by DMR as a rationale for keeping a tight lid on death information should not be used to shield the state or its private group home providers from public scrutiny when clients die.

"There is no excuse for hiding this information. I can't see how anyone can justify it," said Charlie Lakin, a University of Minnesota researcher specializing in issues affecting the disabled. "I think the public's right to know that information is a trust."

public's right to know that information is a trust." - *Charlie Lakin, University of Minnesota researcher*

Even those who lobby for the nonprofit companies that run most of the state's group homes say there is no reason not to inform the public about deaths that occur under state-sponsored care.

Ron Cretaro, who heads the Connecticut Community Providers Association, said he was surprised to learn that details of deaths in group homes are not released by the state.

"I'm actually astounded **that** none of [DMR's] investigations are public," he said.

State Secret

When a group home resident dies, the results of DMR's investigation are literally a state secret.

If the death is accompanied by an allegation of abuse or neglect, DMR investigators typically interview group home staff, review the client's medical history and present their findings internally. As a rule, there is no public disclosure, although sometimes the findings might be revealed in the course of a wrongful death lawsuit or criminal prosecution.

Occasionally, an independent state agency, the Office of Protection and Advocacy, will perform its own review of a DMR death. But the office does not have the authority to enforce corrective actions, and it can report its findings only to DMR - not even to next of kin.

What's more, the office isn't always notified when people die, which further hampers its watchdog role, according to its executive director, James McGaughey.

"We don't get notified as much as I'd like about deaths in group homes," McGaughey said.

In addition to investigating allegations itself, DMR also conducts separate medical reviews of certain deaths. Its Medical Quality Assurance Board last year investigated 53 of 197 deaths referred to it by regional DMR officials around the state, according to DMR statistics.

Some state agencies, like Connecticut's Office of Child Advocate, make public the results of death investigations. DMR, however, denied Freedom of Information Act requests for the results of investigations into 20 group home deaths, including Lisa Barry's, as well as the results of the 53 mortality reviews it conducted last year.

The agency cited two state laws, one of which prohibits the release of information that would violate the privacy of group home clients. In invoking that law, the agency chose not to apply an exception that allows disclosure in cases when the information being sought pertains to matters of public concern.

DMR also invoked a law that prohibits the release of a broad range of information collected by public health agencies "for the purpose of reducing morbidity or mortality from any cause or condition ..." Legal precedents have dealt almost exclusively with cases involving the state health department - not DMR - but DMR said the law also applies to it.

In addition to dismissing requests from the media, DMR has not hesitated to lower the legal curtain on families seeking answers about the deaths of loved ones in group homes.

After asking for autopsy reports or copies of investigations, relatives of several deceased group home residents said, they were often put off by officials or their phone calls were not returned. Ultimately, they never received any of the information sought, and most gave up asking because the topic was too painful.

DMR officials acknowledged that they do not provide investigative reports to families unless forced to during litigation, but they insist the agency shares all pertinent information about deaths and reviews investigation findings with families.

But in a recent letter DMR sent to families of group home residents - in which the agency warned them of The Courant's investigation - the agency pledged to take steps to communicate better with next of kin. DMR is assigning "a contact person" in each of its regions to handle inquiries by family members, the letter said.

DMR's initiative comes too late for some families. The Courant found several cases in which next of kin said they were unaware of evidence of neglect or errors in a death, or unable to obtain basic information.

Kathleen Sniadecki knew her 25-year-old son, Michael, died in 1998 after his head became trapped between the mattress and rail of his bed. In an interview, she said that she assumed it was just a tragic accident and that she had no concerns about how DMR handled the case.

Sniadecki didn't know, however, that DMR officials investigated her son's death and determined that the staff in the Naugatuck group home had improperly installed the rails, which didn't fit her son's bed. Nor did she know that questions had been raised about how long Michael had been dead before he was found.

The Passariello family says they were thwarted in their attempts to find out more about why their son, Lawrence, died in a Hamden group home last year.

Lawrence had a propensity to quickly gulp large quantities of food or to place inappropriate items in his mouth, requiring the group home staff to monitor him almost constantly. But one day last year, he was able to get his hands on a hot dog, swallow it and choke to death before being discovered by staff, according to a lawsuit filed by his estate.

When Lawrence's family sought information on how he died, DMR "basically just ignored us," said the family's lawyer, Christopher Licari of New Haven.

"We asked for any reports on Larry's death and got stonewalled," Licari said. "They allowed us to go through his prior medical records, but nothing since the incident, which seemed kind of an odd way of doing things."

Few group home deaths illustrate the frustration experienced by family members more than that of Lisa Barry.

Unsolved Riddle

Lisa's parents had resolved early on to take care of her themselves, after learning she suffered cerebral palsy from having the umbilical cord wrapped around her neck during birth.

They had her undergo an operation at Johns Hopkins Hospital so her feet would be flat against the floor and she could learn to use a walker. They took her everywhere, whether it was on their boat or to one of the stock car races Michael and Kathy loved to attend, rarely asking for any assistance.

But in the fall of 1997, Kathy Barry broke her foot, and caring for Lisa became more difficult. They started leaving Lisa for short stays, no more than a few days at a time, at the Seaside respite care home in Waterford.

During her eighth stay at Seaside, 10 days before Christmas in 1997, Lisa died of a seizure.

When Michael Barry arrived at the home the morning Lisa died, he noticed a state police detective carrying bottles of medications out of Lisa's room. He heard pills rattling in the bottles and told the detective there shouldn't be many pills left - a check of the bottle revealed eight Depakote tablets, when, the Barrys said, there should have been two.

The Barrys filed a lawsuit against DMR and began requesting information about the agency's review of Lisa's death. DMR said it found no evidence of neglect, but it refused to release the findings of its internal investigation.

Unknown to the Barrys, the Office of Protection and Advocacy had performed its own inquiry, which concluded that the staff had failed to document what medications they gave Lisa and also may have altered medication records by whiting out dates and signatures. The office suggested "appropriate" disciplinary action for all the nursing staff Involved, but because its recommendations are nonbinding it is not known whether any action was ever taken.

The office reports its findings only to DMR, so families usually don't know about them. The Barrys eventually learned of the report on Lisa's case after someone mailed it, anonymously, to their Old Lyme attorney, Michael Quinn.

"I think someone there must have felt sorry for the family, or realized they didn't want a court fight over the document," Quinn said.

As they pressed their lawsuit, the Barrys were in for another surprise: Hasson, the doctor who had autopsied

Lisa's body, had not drawn enough blood to determine if she had been given her medication.

That came as a shock, because early on the Barrys had pinned their hopes for solving the riddle of the medication on the autopsy they were told was being done. But the results came back without any finding of an official cause of death.

Questioned by the Barrys' lawyer, Hasson acknowledged that he wasn't trained in the forensic procedures normally used to look for evidence of a crime, and he didn't know why Lisa's body - or those of other DMR clients over the years - had been sent to him and not to state forensic experts. His task, he said, was to establish a cause of death, while also using the autopsy as a teaching tool.

"I don't know how it happened. It just was a fact of life," Hasson testified. "I didn't argue with that at that time, because I wanted autopsies for teaching, so I said, the more the better."

Had the autopsy been done by the state medical examiner's office, things might have turned out differently.

The medical examiner, who employs forensic pathologists, has the authority to investigate any suspicious death in the state, but because of limited resources, his office does not always conduct an autopsy. Chief State Medical Examiner H. Wayne Carver said his office reviews all cases of DMR clients who die, but performs autopsies only if there is possible evidence of unnatural circumstances.

"A lot of them are natural deaths and we simply record the basic facts and have them reviewed by one of the doctors here," Carver said.

In Lisa's case, he said, an assistant medical examiner on the scene determined that she died of complications from her medical condition, and therefore did not recommend an autopsy. But in a small number of cases - less than 20 percent of the time - DMR seeks an autopsy on its own, and it did so in Lisa's case.

But, as it turned out, because DMR had sent the body to Hasson, neither DMR nor the Barrys would ever find out for sure why Lisa died.

Marcia Noll, DMR's director of health and clinical services, said the agency farms out the autopsies to whatever hospital can do them. She said DMR had no idea Hasson wasn't a forensic pathologist, and she said the agency has no way of knowing what hospitals have qualified pathologists.

"We have to trust the hospitals that we deal with," Noll said, adding that her office is reviewing its autopsy policies. "Perhaps what we should be looking into is contracting with one particular hospital."

As for Michael Barry, admissions, years later, that DMR is reviewing its policies does nothing to appease his anger. He and his wife recently settled their lawsuit against DMR for $750,000 and have moved out of the state.

"The state killed my daughter," Barry said. "Then they wouldn't take responsibility for it or tell us how it happened."

ctnow.com produced by The Hartford Courant

▶ HOME ▶ NEWS ▶ BUSINESS ▶ SPORTS ▶ ENTERTAINMENT ▶ CARS ▶ JOBS ▶ HOMES SEARCH

CONNECTICUT

Gratitude First, Then Shock And Regret

December 2, 2001

By ELIZABETH HAMILTON And DAVE ALTIMARI, The Hartford Courant

Like many parents with mentally retarded children, Robert Benson felt a sweet rush of gratitude every time he thought about the group home where his brain-damaged son was so happily ensconced.

The feeling was especially strong, given that Benson had fought for so many years to get Stevie out of Mansfield Training School. He'd even been one of the first parents to sign on to a class-action lawsuit that forced the state institution to close in 1993.

The father's relief would be short-lived, however.

Four years later, Stevie, at age 38, put his hand in another resident's Easter basket at the group home in Westport, popped what he thought was a chocolate into his mouth and choked. A coroner would later pull a child's pink paddle ball from his throat.

Benson, whose wife and other disabled son were already dead, had now lost his entire family. In shock, he didn't ask a lot of questions about Stevie's death. He simply buried his oldest son and tried to move on.

But then something happened that, years later, would cause him to wonder if the owners of the group home that he bestowed so much faith in had privately feared that Stevie's death could cause them legal troubles. The operators deny it, but the possibility haunts Benson to this day.

"I was still shocked about Stevie's death, and didn't really think about it," Benson said in a recent interview. "I hate to think they took advantage of me, but now I wonder."

Benson's suspicions are rooted in a rather mundane event: Three months before Stevie died, Benson had made the nonprofit group home operator, Clasp Homes Inc., the beneficiary of a modest life insurance policy on his son.

Benson figured that long after he died, Clasp would still be caring for Stevie, and he wanted to do something to help the people who would take on that burden - he even lobbied other parents to do the same.

But Benson never thought he would outlive his son. So when Stevie died, Benson, facing funeral bills and other financial difficulties, asked Clasp if it would consider giving him the $12,000 it reaped from his son's life insurance policy.

Clasp President Martin Horan told Benson he'd turn the

MORE HEADLINES

A Sister's Pain

MORE

To read the details of six deaths under questionable circumstances, click here.

To view a video produced by Hartford Courant TV reporter Ellen Burns and Videographer Alan Chaniewski, click here.

To view a WNPR.org audio interview with Hartford Courant reporter Elizabeth Hamilton, Click here.

COMMENTS

Add your comments on this story.

I applaud the Hartford Courant for bringing this story to light- this is a population that is easily overlooked. Our governor and the legislature need to STOP cutting the budget for group home development. Too much is at stake!
Submitted by: Janice Favreau
12:55 PM EST, Dec 6, 2001

There should be more focus on providing training to employees and more positive incentives, so we can be succesful at our jobs.
Submitted by: Caring worker at Harc
12:46 PM EST, Dec 6, 2001

Read more comments or post your own

request over to his board members for review. A short time later, Clasp's board had an answer: Benson could have the money, but there was a catch - he would have to first sign a release pledging never to sue Clasp in connection with Stevie's death.

Benson, who says he had never considered suing Clasp, signed the release. It was June 17, 1997, a month and a half after his son died.

Benson now says he wonders whether staff neglect was a factor, and he regrets not asking more questions at the time. Since his son's death, a staff member in another Clasp home in nearby Easton was charged with negligent homicide, after a resident there drowned in a bathtub last year.

Horan, however, said Stevie's death was simply an unfortunate accident.

Stevie didn't have a history of sneaking food, Horan said, and the home was "fully staffed" at the time he died. DMR officials declined to comment about the case, citing confidentiality laws, except to agree with Horan that Stevie did not have a history of stealing or bolting food.

Choking is a common cause of accidental death among mentally retarded people, many of whom have limited swallowing functions.

In an interview, Horan wouldn't explain why Clasp tied the transfer of the life insurance payment to a promise from Benson not to sue the agency in connection with his son's death. But after the interview, Horan wrote a letter to Benson saying he was "concerned that the Hartford Courant may attempt to make Clasp's cooperation with your request to turn over the proceeds of Steve's life insurance policy appear to somehow be a negative or unscrupulous thing."

"We both know that this is not the case," Horan wrote. "I felt then, as I do now, that we processed your request openly, honestly, efficiently, and with a great deal of sensitivity and concern."

Stevie's death was painfully ironic.

As one of the lead plaintiffs in the class-action lawsuit against the state, he could have been a poster boy for deinstutionalization of the mentally retarded. He spent his childhood in institutions from Connecticut to Texas, where his behavior problems led straight to isolation rooms and strait jackets, which in turn led to more behavior problems.

In 1974 - the same year his family moved to Westport and his younger brother, Michael, died of encephalitis - Stevie was sent to live at Mansfield Training School. His father recalls that time as a "nightmare."

"He was a zombie," Benson said. "I visited every two weeks and he'd be in bed or locked in his room every time I went."

Stevie's mother, Adrienne, was so distressed about her son's condition that she stopped visiting, Benson said. Soon afterward, she developed cancer and died a few months before he left Mansfield.

Benson, who still cries when he speaks of his wife's death, said former Gov. Ella Grasso personally arranged for Stevie to be moved into a special program at Mansfield. That put him at the head of the line for placement in the group home setting his parents had always wanted..

"It was based on the dying wishes of a parent," Benson said, covering his tear-filled eyes.

It is just as difficult for Benson to contemplate the death of his older son, who blossomed in the group home. By the time he died, Stevie had a girlfriend, played basketball in the Special Olympics, had a job and attended dances.

In some ways, too, Stevie seemed invincible to his father - despite his disability. He was a wiry, 6-foot charmer with a shock of black hair, a big grin and an even bigger appetite, who rarely got sick, his father said. He'd even bounced back from a 60-foot fall off a carnival ride at Bushnell Park one summer.

"Anyone who could survive everything he went through," Benson said, his voice trailing off, "I figured he'd be here forever."

ctnow.com produced by The Hartford Courant

▶ HOME ▶ NEWS ▶ BUSINESS ▶ SPORTS ▶ ENTERTAINMENT ▶ CARS ▶ JOBS

CONNECTICUT

The Toll: Suffocation, Drowning, Choking, Burns

December 2, 2001

By ELIZABETH HAMILTON And DAVE ALTIMARI, The Hartford Courant

Joseph Rodriguez could have been a peerless pickpocket, so swift were his hands, but money didn't interest him in the slightest.

All he desired was food.

Joe wasn't discriminating. He'd eat anything, even if he had to fish it, rotted, from the garbage or sneak it half-eaten off someone's plate when heads were turned at the table.

Every staff member at Joe's group home in Danbury knew, and feared, his talent for filching food. After all, when you're responsible for a profoundly mentally retarded man with no teeth, food-stealing is not just a question of bad manners - it's life or death.

But over the written objections of Joe's guardian, the group home eliminated one-on-one supervision for Joe. On April 10, 1999, that money-saving decision bore tragic consequences.

While the three staff members on duty that afternoon were busy changing adult diapers and showering the other four mentally retarded residents, Joe was left alone for roughly 15 minutes. He walked into the kitchen, pulled an uncovered pan of raw pork chops from the refrigerator, stuffed large chunks of the meat in his mouth, and choked.

Joe was declared brain dead and taken off life support after three days of seizures so severe that the staff at Danbury Hospital was afraid to strap him to his bed for fear he'd break a bone. He was 48.

The death of Joseph Rodriguez - as unfortunate and avoidable as it was - was hardly the first of its kind, nor would it be the last.

Despite a history of official insistence that untimely deaths are virtually nonexistent in Connecticut's 774 group homes for the mentally retarded, a Courant investigation found evidence of neglect, staff error or other questionable circumstances in one out of every 10 deaths over the past decade.

Among the 36 cases identified by The Courant, more than a dozen involved residents who swallowed food or objects they shouldn't have had. Two suffocated in their beds. Two overdosed on medication; another wasn't given her medicine. Five died of pneumonia in a home where residents allegedly were given cold showers and put to bed with wet hair. Others died of falls, burns or drowning.

A Sister's Pain

To read the details of six deaths under questionable circumstances, click here.

To view a video produced by Hartford Courant TV reporter Ellen Burns and Videographer Alan Chaniewski, click here.

To view a WNPR.org audio interview with Hartford Courant reporter Elizabeth Hamilton, Click here.

Add your comments on this story.

I applaud the Hartford Courant for bringing this story to light- this is a population that is easily overlooked. Our governor and the legislature need to STOP cutting the budget for group home development. Too much is at stake!
Submitted by: Janice Favreau
12:55 PM EST, Dec 6, 2001

There should be more focus on providing training to employees and more positive incentives, so we can be succesful at our jobs.
Submitted by: Caring worker at Harc
12:46 PM EST, Dec 6, 2001

Read more comments or post your own

In addition, dozens more fell victim to potentially treatable viruses and infections. Still other deaths are shrouded in mystery, the explanations unavailable even to grieving families.

Because the state Department of Mental Retardation refuses to release details of most group home deaths, it is impossible to determine precisely how many of the 364 deaths DMR says occurred over the last 10 years were avoidable, or were the inevitable result of medical conditions common to a fragile population.

With rare exceptions, most of the mentally retarded men and women found during The Courant's investigation died in almost total obscurity. That is because virtually all death records kept by the state Department of Mental Retardation are secret - making it difficult even for next-of-kin to obtain detailed information when a loved one dies.

The Courant uncovered the deaths by analyzing hundreds of public death certificates, court files and DMR documents, and by interviewing families of victims and group home employees. Among the findings:

The overall rate of deaths in group homes has dramatically outpaced the growth in the group home population over the last 10 years. DMR attributes the rising death rate to an aging clientele, but an analysis of those who died shows their average age rose only slightly over that time.

When it comes to deaths, there is little public accountability in a $260-million, taxpayer-funded group home system that essentially regulates itself. Police are not always called for untimely deaths. Many families say they don't receive reports of autopsies or death investigations unless they sue the state. Some questionable deaths, like Rodriguez's, don't even show up on DMR's official list of deceased clients - an oversight the department could not explain.

When the state does acknowledge an untimely death, it often fails to take meaningful action against group home operators, even when the case is clearly linked to staff neglect or a blatant error. In one case, DMR took no action against a private operator after its failure to fix the water temperature in its home led to the scalding death of a resident.

Some of the deaths identified by The Courant were linked to apparent staffing shortages in the homes. Private group home operators, who serve more than 60 percent of the people living in group homes, complain they are underfunded and are seeking another $200 million from the state.

Arch Of Oversight

The extent to which even advocates for the disabled have been kept in the dark about deaths was apparent in comments last December by Peg Dignoti, executive director of the Association of Retarded Citizens of Connecticut. Reacting to news of bathtub drownings in two homes, Dignoti defended the system, saying she had "probably heard of one death like this" in 40 years. Dignoti said in a subsequent interview that she was referring specifically to drownings.

In an interview over the summer, however, Dignoti was stunned when told of The Courant's findings of many more questionable deaths than were previously known. She said changes had to be made - particularly in the department's lack of accountability to families and guardians.

"I'm shocked," she said. "I really am. I had no idea."

To be sure, Dignoti and some other advocates say, group homes are still preferable to the large, impersonal settings of institutions. This is why, they say, there has been a nationwide push toward deinstitutionalization for the last 30 years, and why in 1999 the U.S. Supreme Court ruled that states are in violation of the Americans with Disabilities Act if they deny community placements to the mentally retarded.

The first class-action lawsuit on behalf of Connecticut's mentally retarded was brought in 1978, and eventually forced the closure of Mansfield Training School, an institution that held 1,870 people. Group home advocates are still fighting to have more than 600 people living at Southbury Training School, Connecticut's last large institution, moved into the community.

The balance between giving someone the "dignity of risk" -which involves letting them live in the least restrictive environment possible - and keeping them from harm's way is a delicate one, experts say.

Part of that balance is making sure the growth in community-based services is accompanied by adequate funding and oversight, said James Gardner, president of the Maryland-based Council on Quality and Leadership in Supports for People with Disabilities.

Charlie Lakin, the director of a national research center at the University of Minnesota that tracks issues related to the disabled and provides staff training to nonprofits, said privatization of the group home system has also eroded the quality of care. States like Connecticut save money by contracting with private agencies to run the homes.

"[States] need to stop pretending it's enough to buy services and visit the facility once a year," Lakin said. "The state doesn't buy highways from people who don't demonstrate an ability to build safe roads."

The annual, per-resident cost at a DMR-run group home is $183,773; at a private group home it is $87,550. State officials say DMR-home residents tend to be more needy, but they also acknowledge that private-home operators spend less on staff salaries, benefits and some other costs.

Compared to other states, Connecticut has a mixed record when it comes to spending on the mentally retarded. It ranked fifth in the nation in total spending, in terms of spending per $1,000 of personal income, according to a 1998 study by the nonprofit Institute for the Study of Developmental Disabilities.

But while DMR's spending on institutional services - like Southbury Training School - went up from 1993 to 1998, spending on group homes and other community services remained flat during the same period, the study found.

DMR Commissioner Peter O'Meara strongly defended what he calls the "arch of oversight" his agency uses to monitor its group home system, a system that includes extensive hiring and training policies, a special investigations unit for abuse and neglect claims, and a two-tiered mortality review process. He said that in such a large operation, with hundreds of homes and thousands of residents, some problems are unavoidable.

O'Meara, who said DMR spent the summer conducting its own review of deaths after it learned of The Courant's investigation, acknowledged that there have been some untimely deaths. But he said the agency's review did not turn up evidence of widespread, systemic problems, such as lack of funding or staffing.

DMR's analysis went back to 1997 and did not cover the 10-year period examined by The Courant. The agency also did not offer any numbers of its own for untimely deaths in group homes.

No federal agency or research group collects data on deaths in group homes, national experts said, making it impossible to compare Connecticut's record to other states. Furthermore, there is no uniformity in the way states track their own data, experts said, which makes it difficult to conduct even small, regional studies.

Connecticut officials said their analysis of the state's overall death rate for mentally retarded people in all DMR settings - including thousands who live in apartments, long-term care facilities and Southbury Training School - showed no significant trends in death rates or causes.

The only recurring theme among group home deaths, said O'Meara, was human error by staff members.

"We do hundreds of thousands of things for our people, from taking them to McDonald's to getting them dressed to caring for their sniffles," O'Meara said. "There are some people in the system who don't necessarily follow the rules or exercise good judgment. But our workforce, by and large, is caring, competent and committed."

Clues To Deaths

In some ways, Christopher Soulard, 26, didn't stand a chance.

Not only did Newington group home workers make him a peanut butter sandwich for lunch without cutting it up, they refrigerated it overnight so it was as hard as clay by the time he left for his day program the next morning.

Then, when Christopher was transferred to the van belonging to the day program's operator, the staff turned their backs long enough for him to open his lunchbox, stuff the sandwich into his mouth and choke to death.

If it hadn't been the sandwich that killed him, it could have just as easily been one of the other things in his lunch that day - a whole apple and animal crackers. It could have even been some of the stuff investigators later found rattling around on the floor of the two vans Christopher sat in that morning: a fishhook, hard candies, a watermelon rind, cigarette butts and stale french fries.

It was all potentially lethal for someone with a long history of sneaking and bolting his food - a history so well-documented that DMR regulated the size and texture of foods he could eat. No meat or raw vegetables larger than a quarter-inch thick. No whole foods, like apples or pieces of bread.

Choking is a common hazard among severely mentally retarded people. In fact, most of the questionable deaths found by The Courant stemmed from residents swallowing things they were not supposed to have: forbidden food, a rubber ball - one woman died of intestinal blockage after swallowing a latex glove.

Yet in Christopher's case, an investigation by DMR later concluded, group home staff failed to heed DMR-imposed restrictions on the size of the food Christopher was allowed to eat. DMR divulged the report of its internal investigation during a lawsuit by Christopher's mother that the agency settled this year.

DMR dismisses the majority of abuse and neglect complaints it receives. Last year, it concluded that 54 percent of the 1,313 allegations made agencywide were unsubstantiated; in 1999, the figure was 63 percent.

Not long after Christopher's case, DMR sent a notice to its regional directors ordering them to review their vehicle safety procedures. It has not been uncommon for DMR to react to client deaths by issuing internal medical advisories or safety alerts - a practice that can provide a roadmap to certain deaths that the agency may recognize were avoidable.

For instance, DMR issued an advisory on the dangers of bed rails following the 1998 death of Michael Sniadecki, 25, whose head became caught between the mattress and rail and went unnoticed until he suffocated. The advisory makes no mention of Sniadecki, but instructs group home operators to adopt policies on the "potential safety hazards" of bed rails.

Other advisories have included warnings about infection control, aspiration pneumonia - a respiratory illness caused by inhalation of food and liquids into the lungs - and epileptic seizures. Many were sent out following deaths involving those problems.

In addition to the 36 untimely deaths, The Courant's investigation found 33 residents ranging in age from 25 to 80 - most were under 50 - who died of infections related to inhalation of food into the lungs and retention of fluids inside body cavities.

Severely mentally retarded people are susceptible to both conditions, which are manageable but require close monitoring by caregivers, according to DMR's own advisories. Because the medical histories of DMR clients are not public, it was not possible to determine what kind of care the 33 residents received.

Critics give DMR credit for taking steps, albeit sometimes after the fact, to prevent future untimely deaths. But among the various ways a group home resident might fall into danger, there are two that have never been the subject of a DMR advisory: lack of money and staff.

Staffing Shortages

Karen Robinson was the only person caring for the five residents of the group home in Easton that Sunday afternoon, so it is perhaps understandable that she was a little distracted when it came time to bathe 36-year-old

Belynda Brown.

It was Dec. 17, 2000, and growing dark by the time Robinson helped Belynda undress and lower herself into the tub. She had to get dinner soon, a resident named Emma was screaming downstairs, and there were no towels in the bathroom - a fact Robinson realized too late.

She called for Susan, another resident, to fetch a towel. When Susan never returned, Robinson went looking herself. By the time she got back to the bathroom five minutes later, Belynda - who was not supposed to bathe unattended - had slid beneath the water. She was pronounced dead at Bridgeport Hospital a short time later.

Robinson, who told police she knew the risk of leaving Belynda alone in a bathtub, was charged with criminal negligent homicide. She pleaded not guilty and her case is pending. Robinson declined through her lawyer to be interviewed for this story, as did Belynda Brown's parents.

Belynda wasn't the only DMR client to drown last year-11-year-old Samuel Hadden, who was living in a Bloomfield group home run by the Greater Hartford Association for Retarded Citizens, died less than a month earlier while left unattended in a bathtub. A group home worker who had only been on the job four months was arrested in that case as well, and has pleaded not guilty.

No action was brought against the executives of Clasp Homes, operator of the Easton home, or the Greater Hartford Association for Retarded Citizens, which operated the home in Bloomfield, although both cases seemed to raise questions about staffing levels and training in nonprofit group homes.

Staffing levels are predicated on the medical complexity of the people living in each home and the activities planned for a given day, DMR officials said.

Martin Horan, the director of Clasp Homes, insisted that having only one person on duty when Belynda died was appropriate - although he said others might come to a different conclusion.

"I can really understand how a lay person would look at it that way," Horan said. "But these things are thought through with a great deal of effort and care."

Clasp and Greater Hartford ARC are among the private nonprofit companies that care for 62 percent of Connecticut's mentally retarded residents. DMR directly cares for the rest, as well as provides oversight, licensing and funding for the nonprofit providers.

The annual cost of keeping one person in a state-run group home increased by 58 percent between 1992-2000, according to estimates provided by Connecticut officials, while the annual per-client cost of caring for someone in a nonprofit home dropped 4 percent during the same time period.

The state saves more than $130 million a year by privatizing such a large portion of its group home system, according to private group home operators who complain they are chronically under-funded. Gail Ford, executive director of the ARC of Southington Inc., said lack of money has made it difficult to attract qualified people.

"During one two-year period, I could not hire anyone," Ford says. "No one was suitable. One person had 14 criminal arrests. Others failed drug tests."

The funding shortfall is blamed for a host of problems.

Homes are frequently short-staffed, which means everyone has to take extra shifts and workers are shuffled from home to home in an effort to fill gaps. This, and employee turnover rates as high as 50 percent, means staff aren't always familiar with the individual needs of residents and creates a lack of stability for the residents themselves.

Although several group home operators interviewed spoke privately about the potential for disaster caused by the lack of funding, none wanted to admit it publicly for fear of alarming their residents' families or demoralizing workers. They said they also worried about retaliation by DMR.

"How loud do we have to scream before we're heard? We're scared," said one group home director. "I'll tell you, there are times you pray nothing goes wrong. You've just got your fingers crossed."

Lakin, the University of Minnesota expert, says there is no question that financial strains can translate into quality-of-care problems.

"Who told that poor staff person, who is making seven bucks an hour and working two part-time jobs, that the person they're feeding has very limited swallowing mechanisms? Nobody." Lakin says.

"Or they may be out of the room because they're chasing someone down the hall who messed their pants and there's no one else to take over where they left off."

Errors in Judgment

DMR officials, and some group home operators, disputed the idea that a lack of funds has put any clients at risk.

O'Meara said his agency's review this summer turned up no evidence of systemic problems, such as inadequate salaries or staffing shortages in the private sector.

"Are these deaths associated with a stressed system?" said O'Meara. "I would say no."

And although O'Meara acknowledged that there have been deaths due to "errors of commission and omission" by group home staff, he declined to say how many of these deaths his staff had identified during its review.

In subsequent interviews, top DMR officials gave varying accounts of how their research was conducted, but all said the agency did not review all group home deaths.

Steven Staugaitis, director of strategic leadership for DMR, said that "in 90 percent of the cases, the staff was trained and they just didn't follow the proper procedures."

"The most constant theme was individual judgments or lack thereof to follow prescribed rules," he said. "Sometimes individuals make judgments that aren't based on negligent intentions, but are errors in judgment."

But the death of Joseph Rodriguez shows how staffing decisions can have a potentially significant impact on the well-being of group home residents.

According to a DMR investigation, the nonprofit operator of Joe's group home, the Connecticut Institute of the Blind, failed to assign a staff person to watch him, even though his caretakers knew he needed to be in their sight at all times. Sheryl Lam, a nurse on duty the day Joe died, says CIB had eliminated one-on-one supervision for Joe when it got the DMR contract to run the home in 1998.

"CIB came and they took away the one-on-one with Joey," said Lam, who was suspended along with other employees who were on duty the day Joe died. "They cut our staff down. They took a lot of the people off full time and made them part time."

DMR eventually cited CIB for neglect, but the action had no punitive effect on the company, nor on the state officials who signed off on CIB's staffing decisions.

Stephen Earl, vice president of administration at CIB, said it is the company's policy not to comment on clients' deaths because it would "violate their privacy" and could be insensitive to their families. But he defended CIB's record, saying it conducts internal investigations of any death, abuse or neglect case, is heavily regulated and monitored by DMR, and has a system of "progressive discipline" that discourages staff error or neglect.

"This organization is proud of its elf, maybe to the point of being cocky," Earl said.

Maria Welter, Joe's sister, had repeatedly begged DMR and CIB to assign more staff to the home so someone could watch Joe at all times. Today, she can't stop thinking about - and regretting - the painful day in 1989 when she turned her only brother over to the state.

Welter was exhausted: She was newly divorced and working two part-time jobs at McDonald's to support her four children and Joe. One morning, when her brother had a serious diabetic reaction, she panicked.

"It scared me. Did I give him too much insulin? Did I forget to give him his nightly snack when I got home from work the day before?" Welter said in a recent interview at her home. "I said, That's it. I'm scared.[1]"

Because the waiting list to get into a DMR group home was so long, however, Welter took the advice of a local advocate, who told her the state couldn't turn people away if they were homeless. So she sent Joseph to a DMR day program, carrying a bag and a note saying he was no longer welcome in her house.

She put her head down and began to cry.

"That's what I had to do to my own brother," she said. "And then they killed him."