

TRIBUNE WATCHDOG

SUFFERING IN SECRET:

Illinois hides abuse and neglect of adults with disabilities

Barbara Chyette holds up a picture of her late brother, Loren Braun, a group home resident who choked to death during a supervised outing. *(John J. Kim / Chicago Tribune)*

By Michael J. Berens and Patricia Callahan

The house had no address; the dead man had no name.

Illinois officials blacked out those details from their investigative report. Nobody else was supposed to learn the man's identity or the location of the state-funded facility where his body was found.

The investigation was closed as it began, with no public disclosure, and the report was filed away, one of thousands that portray a hidden world of misery and harm.

No one would know that Thomas Powers died at 3300 Essington Road in unincorporated Joliet, in a group home managed for adults with developmental and intellectual disabilities.

Or that his caregivers forced a 50-year-old man with the intellect of a small child to sleep on a soiled mattress on the floor in a room used for storage.

Or that the front door bore a building inspection sticker that warned, "Not approved for occupancy."

Not even Powers' grieving family knew the state had looked into his death and found evidence of neglect.

As Illinois steers thousands of low-income adults with disabilities into private group homes, a Tribune investigation found Powers was but one of many casualties in a botched strategy to save money and give some of the state's poorest and most vulnerable residents a better life.

In the first comprehensive accounting of mistreatment inside Illinois' taxpayer-funded group homes and their day programs, the Tribune uncovered a system where caregivers often failed to provide basic care while regulators cloaked harm and death with secrecy and silence.

The Tribune identified 1,311 cases of documented harm since July 2011 — hundreds more cases than publicly reported by the Illinois Department of Human Services.

Confronted with those findings, Human Services officials retracted five years of erroneous reports and said the department had launched reforms to ensure accurate reporting.

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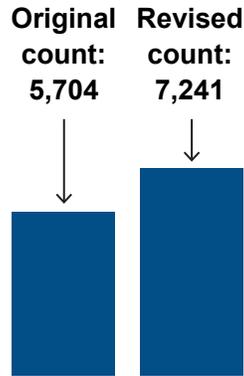
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A changing story

State officials retracted five years of erroneous reports on allegations of abuse and neglect after questions from the Tribune. [MORE »](#)



To circumvent state secrecy, the Tribune filed more than 100 public records requests with government agencies. But state files were so heavily redacted and unreliable that the newspaper had to build its own databases by mining state investigative files, court records, law enforcement cases, industry reports, federal audits, grant awards and Medicaid data.

The Tribune found at least 42 deaths linked to abuse or neglect in group homes or their day programs over the last seven years. Residents fatally choked on improperly prepared food, succumbed to untreated bed sores and languished in pain from undiagnosed ailments.

Other residents suffered forced indignities and loss of freedom, state records show. Some were mocked for their intellectual limitations, barricaded in rooms, abandoned in soiled clothing and deprived of food.

A male group home resident, accused of stealing cookies, was beaten to death by his caregiver. Employees at one home bound a woman's hands and ankles with duct tape, covered her head with a blanket and left her for several hours on the kitchen floor. For their own amusement, employees at another home repeatedly ridiculed residents to provoke outbursts, a game the caregivers called "breaking them."

And, all too often, vulnerable residents' health and safety has been left to unlicensed, scanty trained employees. Front-line caregivers failed to promptly call 911, perform CPR or respond to medical emergencies that resulted in death.

In hundreds of cases, the department allowed employees of group homes to investigate allegations of neglect and mental abuse in their own workplaces, the Tribune discovered. That alliance between group homes and Human Services' investigative arm, the Office of the Inspector General, is not specifically disclosed in state investigative reports.

Citing patient privacy laws, state officials maintain that the addresses of the more than 3,000 state-licensed group homes are secret. Illinois officials refuse to disclose the enforcement history of any home, even in cases of fatal abuse and neglect.

In contrast, Illinois nursing homes must maintain copies of investigative reports and surveys for public inspection. Additionally, state health officials publish a quarterly report detailing violations accompanied by nursing home names and addresses. There are no similar disclosure requirements for group homes.

In this culture of secrecy, even seemingly benign records get shielded from sight. For example, the Tribune requested a state-funded PowerPoint presentation that included a list of needed improvements to community care programs, including group homes.

The state responded. Except for the word "Recommendations," the entire slide was blacked out.

Citing the Tribune investigation, Human Services Secretary James Dimas has ordered widespread reforms to improve public accountability and streamline investigations.

"My concern is that too often agencies hide behind their confidentiality statutes, which makes it harder for the public to know what is going on," said Dimas, who was appointed last year.

Dimas said he will push for legislative changes, if necessary, to allow public disclosure of group home enforcement histories.

The shift in Illinois from large institutional facilities to less costly residential homes reflects the philosophy that these individuals, if supported, will lead fuller lives in the community, and more than 11,400 now live in group homes statewide.

Known as Community Integrated Living Arrangements, or CILAs, these homes accommodate eight or fewer adults in ordinary apartment buildings or houses.

The Arc of Illinois, a statewide advocacy group, reports that hundreds of people with disabilities have successfully transitioned into group homes in recent years. In 2011, a lawsuit brought by individuals who wanted to leave state-funded facilities resulted in a court decree that has forced Illinois to move more people into community settings.

State officials have touted group homes as a preferred option, citing cost savings that can be used to fund more community care. The annual cost of care for an institutionalized resident is about \$219,000 compared with \$84,000 at a group home, according to state records.

But Illinois has not increased reimbursement rates for group home staff wages in nearly nine years, leading to what industry leaders say are catastrophic conditions in which even the best operators are struggling to provide basic care. Illinois ranks among the five worst states for adequately funding community options, according to federal reports and studies by advocacy groups.

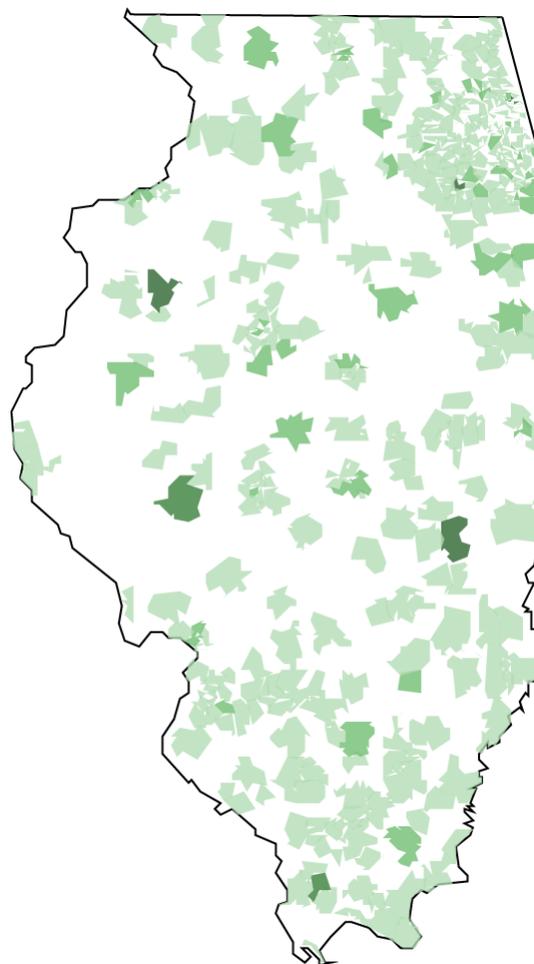
Where are the homes?

More than 3,000 group homes are scattered across Illinois, housing thousands of adults.

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Group home residents by ZIP code

Darker green means more residents



Shirley Perez, who directs a family advocacy program for the Arc of Illinois, said: "Some of the phone calls I get from families are that they are afraid."

Powers, born with a condition that led to brain damage, spent decades inside state institutions, unable to talk, unpredictable in behavior. When state officials promised him a better life in a real home and told his family he'd gain independence, Powers said yes the only way he knew how. He giggled.

But this was not the life that Powers found. Nor did thousands of other adults with developmental and intellectual disabilities, left to the mercy of a system designed to be invisible.

Joe Powers talks about his late son, Thomas, at his daughter Kathy's home in Aurora. (*John J. Kim / Chicago Tribune*)

Failures of care

In one Will County group home, state records show, a caregiver left a frail woman alone in the bathroom after filling the bathtub with water, unaware that it was scalding because a maintenance worker forgot to install a temperature-control valve. The woman tumbled into the tub and was severely burned. The Trinity Services caregiver put the woman to bed, later pulled socks over her peeling, bleeding skin and didn't seek medical help for more than an hour. The woman died days later.

At a Springfield home owned by Sparc, a caregiver forgot to give a man his anti-seizure medication before sending him to a day program in 2013. Rather than deliver the pills, investigators found, the caregiver told a colleague to throw them into the trash. The man suffered a major seizure, turned blue and was treated at a hospital.

A caregiver at a Macomb group home managed by Mosaic allowed a man to sleep with a stuffed snowman even though he had been diagnosed with pica — a disorder that compels people to eat nonfood items — and had a history of consuming stuffing, according to inspector general records. In 2012 the man tore open the snowman, ate the filling and choked to death.

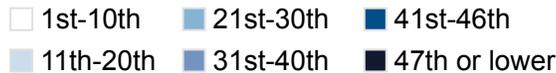
In case after case, group home businesses have delegated frontline care to inexperienced caregivers with negligible training, a cost-cutting combination that has led to harm, the Tribune investigation found.

Indeed, when the newspaper reviewed more than 200 substantiated cases of abuse and neglect, it found the vast majority of injuries and deaths are linked to inadequate staffing levels and failure to closely monitor fragile residents. Records show caregivers trying to cover up mistakes, failing to understand dangers of missed medications and underestimating the complex nature of disabilities.

Ranking the states on disability services

Illinois ranks among the five worst states for adequately funding group homes and other community care options, according to federal reports and studies by advocacy groups.

Ranking



Top 5

1. Arizona
2. Vermont
3. New Hampshire
4. Michigan
5. Hawaii

Bottom 5

47. Illinois
48. Montana
49. Arkansas
50. Texas
51. Mississippi

Source: The Case for Inclusion @ChiTribGraphics

Sparc's chief operating officer, Ryan Dowd, said his company fired the caregiver who directed a colleague to throw out anti-convulsant medicine, added more surveillance cameras in its group homes and switched from paper to electronic medication records so a nurse can better catch mistakes.

Nancy Davis, a Mosaic vice president, said her organization dismissed the caregiver who allowed the man to sleep with a stuffed snowman, hired outside behavioral experts to address the needs of residents with pica and retrained caregivers on how to protect those individuals.

Caring for adults with profound intellectual and developmental disabilities can be challenging. Some have the strength of a weightlifter with the impulsiveness of a child. In the blink of an eye, they can find themselves in crisis.

Yet caregivers in group homes earn an average of \$9.35 an hour, according to the Illinois Association of Rehabilitation Facilities. That wage is below the federal poverty level for a family of three. Low pay is a contributing factor in high staff turnover — more than 40 percent annually in some homes.

"Staff turnover — it's like a cancer that affects care," said UCP Seguin of Greater Chicago CEO John Voit, who has worked in the industry since the 1970s.

Group home executives complain that inadequate state funding has not allowed the industry to increase entry-level pay or raise existing salaries to retain skilled supervisors. They say caregivers can earn more money in many other industries, citing the experienced employees who recently resigned to take higher-paying jobs at Amazon warehouses.

To fill vacancies, business operators said they have turned to workers whose backgrounds would have disqualified them from jobs in the past.

"You're scraping the barrel," said Little City Executive Director Shawn Jeffers, whose agency's services include group homes for adults with disabilities in the Chicago area. "I have some folks who do some really dumb stuff."

Responding to what group home owners call a staffing crisis, state lawmakers in both houses this summer overwhelmingly approved \$330 million in funding to boost pay for caregivers. But Gov. Bruce Rauner vetoed the measure in August, citing a lack of state funds.

The Tribune also found that the group home industry is exempt from basic staffing standards required elsewhere in the state's long-term care system.

Nursing homes, state institutions and other extended-care facilities are required by law to employ on-site registered nurses who can detect and react to sudden changes in patient conditions. Even low-level employees must be state-certified aides who update skills through continuing education.

Group homes are not bound by these requirements. Many group home residents are not examined by a licensed nurse for weeks at a time, sometimes for many months, state enforcement records show. Instead, registered nurses often work from remote locations and supervise dozens of residents over the telephone.

Some unlicensed workers also are allowed to pass out prescription medications — a practice prohibited by law at nursing homes and state-owned facilities.

These and many other relaxed policies place group home residents at greater risk of undetected complications.

Few daily activities underscore the dangers of thin staff or the critical role of competent caregivers like the simple act of eating.

In 2014, a UCP Seguin group home resident attending the company's day program in Cicero choked to death on a marshmallow that a caregiver handed out as a treat. The victim had dysphagia, putting him at high risk of choking, and staff were supposed to give him only pureed or finely chopped foods, the inspector general found. UCP Seguin CEO Voit said his organization, one of the state's largest group home providers, has retrained staff on choking risks and revised safety protocols.

That same year, a man at a Trinity Services group home in Peoria fatally choked on a cheeseburger, carrots and applesauce when a caregiver stepped away. The victim's medical files warned he often swallowed food too fast and needed close supervision, but staff members were not properly trained about his special needs, state records show.

In response, Trinity Service officials said, they created a training manual for each group home that details how to monitor residents with diet restrictions and choking risks, including pictures that illustrate how to chop or puree food properly.

For Loren Braun, death came from a McDonald's hamburger and an inattentive caregiver who had been hired specifically to watch him.

At 61, Braun had no teeth and couldn't wear dentures. Born with developmental disabilities and diagnosed with schizophrenia, he had lived since 1997 in a North Side group home managed by Anixter Center.

Braun had a history of choking. His food had to be soft and cut into tiny pieces, and someone had to coach him at every meal to eat slowly and drink water between bites.

Braun's sister, Barbara Chyette, tried to protect her younger brother as best she could.

Loren Braun, who had no teeth and couldn't wear dentures, choked to death on food during an outing away from his group home. *(Family photo)*

As a former social worker at an Ohio psychiatric hospital, she saw the advantages of a small group home but feared that staffing levels were often inadequate for high-risk residents.

Tapping a family foundation set up by her late father, a postal worker, she donated money to pay Anixter for an extra caregiver to shadow her brother three days a week. She also donated a van to the home for community outings.

In November 2014, caregivers loaded Braun and four other residents into that van for grocery shopping, haircuts and lunch at a McDonald's. After returning to the group home, a caregiver discovered Braun unconscious in the back seat.

A Chicago Fire Department paramedic reported that he removed "almost an entire hamburger" from Braun's mouth and airway but was unable to revive him. He had choked to death.

State investigators cited his personal caregiver for egregious neglect. In a wrongful death suit, Chyette alleges that Anixter failed to address his choking risk, served her brother unsafe food and didn't protect him from neglect. Anixter executives declined to comment.

"Loren was like a baby," Chyette said. "Like you would have to be with a 2-year-old or 3-year-old — that's the kind of supervision that clients like Loren need. And the system does not provide that kind of supervision."

The attacker next door

Illinois group homes were first licensed in the 1970s as state-funded community options for adults with intellectual and developmental disabilities, the beginning of a civil rights movement to empty large institutions and nursing facilities.

This shift offered freedom and independence to scores of people with disabilities who were inappropriately consigned to institutional care. But as state downsizing continues, group homes are also destinations for individuals with a history of profound problems, often compounded by mental illness, requiring round-the-clock supervision for their safety and the safety of other residents.

A majority of group home businesses report that they cannot afford to provide that level of protection, according to industry trade groups.

Fragile individuals with disabilities sometimes live alongside those who have a history of violence or sexual aggression, a risky mix that has led to injury and death, state records show.

Group home owners are not required to report resident-on-resident assaults to the inspector general's office unless someone suspects that neglect was a factor, according to state law.

But law enforcement and state investigative reports reveal a troubling pattern of violence at group homes since 2010, including three homicides.

At a Trinity Services group home in Peoria in 2010, John Vogel, 45, was fatally beaten by a resident whose acts of violence had sent two employees and two housemates to the emergency room months earlier, according to inspector general and coroner records.

At a Bolingbrook group home managed by Individual Advocacy Group, Eduardo Formanski, 30, suffocated after another resident, who weighed nearly twice as much as he did, lay on top of him during a fight in 2011, according to police, court and medical examiner records.

That same year, Tramayne Yarbrough, 35, died of head injuries after a housemate pushed him down the stairs of a Palos Park group home operated by St. Coletta's of Illinois, according to medical examiner and inspector general records. The assailant had a history of physical aggression and had pushed someone else down the stairs about two months earlier, the inspector general's office found.

Responding to questions about the Vogel homicide, Trinity Service officials said they had provided extensive behavioral therapy to the resident responsible for the attack. Afterward, they said, group home employees received enhanced training to better deal with aggressive residents.

Addressing the death at the Bolingbrook home, an official for Advocacy Group said it was the only fatal incident in the group home's 17-year history. Attempts to reach St. Coletta's of Illinois for comment were unsuccessful.

Residents have also been victimized sexually by other residents, records show.

At a West Side day program operated by group home provider Habilitative Systems, a 33-year-old man had a behavior plan that addressed his history of sexually inappropriate behavior, including "engaging in sexual activity without consent." The staff was supposed to make sure he remained at least 3 feet away from program participants, and his care plan called for employees to accompany him even to the restroom.

But in July 2010, the man wandered away unnoticed and entered an unlocked restroom where he allegedly persuaded a 27-year-old man to perform oral sex, according to a state report that cited a witness account by a third man who entered the restroom and discovered the pair.

An investigator with the inspector general's office termed the sexual act consensual, even though the younger man had profound disabilities, wasn't able to speak and "could not provide any information for this investigation." The office did cite the business for neglect. An official for Habilitative Systems declined to comment about the case.

State law allows group home providers to mix defenseless residents with those who have histories of violence as long as businesses maintain adequate supervision and staffing.

It's hard to imagine anyone more vulnerable than 36-year-old Aaron Stanley.

Born with cerebral palsy and excess fluid in his brain, Stanley has the cognitive capacity of a 2-year-old, his mother said. Spastic quadriplegia restricts movement of his arms and legs, so he can't propel his own wheelchair. At a Berwyn group home managed by UCP Seguin, he was fully dependent on the staff.

Colleen Stanley didn't know that her son's bedroom was next to that of a man who not only had an intellectual disability but also was diagnosed with intermittent explosive disorder. A UCP Seguin employee later told police that Stanley's housemate was prone to episodes of unprovoked explosive violence and had "insurmountable strength."

In October last year the housemate walked into Stanley's room during the pre-dawn hours and nearly pummeled him to death while he lay in bed — beating him repeatedly in the head with a fire extinguisher, a television and a picture frame before stabbing his face with glass from the broken frame, police records show. Stanley's swollen face was so covered with blood that first responders could not see his eyes.

The sole UCP Seguin caregiver on duty that night — a woman alone in the house with seven disabled men — told police she tried to intervene but Stanley's housemate became more violent, and she was afraid he would attack her.

No charges were filed against Stanley's housemate, whose psychiatrist told police the man could not comprehend his actions. Instead, Human Services admitted him to a state-run institution for individuals with developmental disabilities, police records show.

Stanley, who had to undergo multiple reconstructive surgeries on his face, no longer lives at the UCP Seguin group home. His family is suing the provider for failing to protect him.

Citing the lawsuit, UCP Seguin's Voit declined to comment on the specifics of the case. In a written statement he said that, in general, when a person is harmed, his organization figures out the causes, retrains staff, revises safety protocols and disciplines employees to reduce the likelihood of recurrence.

"Ultimately, however," the statement said, "there are some occurrences or encounters that can neither be predicted nor prevented, even with the best of training, protocols and processes."

In an interview before her death from breast cancer in August, Stanley's mother said the system has to change.

"You can't put someone that's violent in the same house as someone that can't even get out of his way," she said.

A suspicious death

Even as a toddler, it was clear Thomas Powers would need a lifetime of care.

He never learned to speak, use a toilet or hold a spoon. He could walk, even run, but he was awkward and crashed into walls and furniture. He couldn't comprehend simple gestures or words, and at times he had trouble recognizing

his own family.

But he loved to have his hand stroked and his back patted. And he seemed most happy when traveling in a vehicle and staring out the window, family members said.

Thomas Powers as a child, front row, second from right, and as an adult with his sister Kathy at her home.
(Family photos)

Powers, one of nine children, had a rare inherited disorder – phenylketonuria, which can cause severe intellectual disability and medical problems. The condition is readily detected and treated today, but the test did not exist when he was born in 1960, and his disease went untreated as a child.

His father, Joe Powers, 83, said the family made the agonizing decision to institutionalize Thomas at age 6, when he had become an oblivious danger to himself and others. In one of many frightening incidents, he held an infant sibling above his head and made a throwing motion.

Thomas Powers spent four decades in state institutions, but in 2008 state officials pressured the family to move him because of planned downsizing at his facility, according to one of his sisters, Kathy Powers.

She said they promised he would receive more individualized care. A state contractor then steered them to Trinity Services, the state's largest operator of group homes for adults with disabilities.

Two years later, however, Trinity Services officials reported that Thomas Powers had become too much to handle. Caregivers complained that he was a whirlwind of motion and mayhem, running from kitchen to bedroom, tossing pans from the stove, breaking lamps, drinking water from the toilet, sometimes stripping naked to express displeasure.

"He was just out of control," a Trinity Services supervisor later said in a court deposition. "He was like an animal."

To better control Powers' behaviors, Trinity Services officials transferred him in May 2010 to another home, a 2,100-square-foot ranch house on Essington Road in unincorporated Joliet. Following the move, most of his daily activities would take place inside.

Thomas Powers, born with a condition that led to brain damage, was found dead in 2010 in a group home in unincorporated Joliet, three days after being transferred from another group home. He was 50. (*John J. Kim, Chicago Tribune*)

Canceled were Powers' weekday trips to a community day program where he had participated in arts and crafts projects with dozens of other people with disabilities. There would be no more of his favorite activity, riding in a transport van.

When Powers arrived, three other men were living in the house, state records show. None of them should have been there.

Two months earlier, a Will County building inspector had posted a "not approved for occupancy" sticker on the door after determining that Trinity Services had converted a residential property into a group home without proper permits and safety improvements. County officials charged that Trinity Services ignored that order to vacate the home.

While Powers' bedroom was being renovated, he slept in a cramped room jammed with boxes of other people's belongings, according to state records. He should have never been left unsupervised with loose objects, medical records show, because he suffered from pica and indiscriminately stuffed items in his mouth.

On his third day in the home, he was found dead.

His caregiver told state investigators that Powers, wearing pajamas, had rested through the night on a fully assembled bed, according to police and court records.

But sheriff's deputies found Powers dressed in blue jeans and belt, lying on the floor next to a mattress so stained that it was hauled away as garbage. The room was cluttered with ripped-open storage boxes, and a box spring with built-in bed

frame leaned against a wall.

Thomas Powers was living in a group home in unincorporated Joliet in 2010 when he was found dead lying next to a stained mattress in a cluttered room used for storage. (*John J. Kim / Chicago Tribune; Will County sheriff's office*)

The caregiver first told deputies that she found Powers with a plastic bag "laying over his face, covering it." She later changed her description, saying "it was like a sheet of paper."

Dr. J. Scott Denton, who conducted the autopsy for the Will County medical examiner's office, ruled the cause of death undetermined.

But later, in a deposition, Denton testified that "it's more likely than not that something unnatural happened," citing Powers' suspicious bruises and cuts, the plastic bag or sheet, the room in disarray and other unusual circumstances.

Powers' family, who maintained close contact with group home employees, filed a wrongful death suit and reached a confidential settlement last year.

"We will never know what happened for sure," said Kathy Powers. "But something wrong happened."

Trinity Services Executive Director Art Dykstra, a former state director for mental health and disability programs, said Powers thrived for years without incident but experienced sudden and unexplained weight loss and health complications in the months before his death.

Caregivers transferred Powers to the Joliet home because it had fewer residents than the home where he lived and might offer a calmer environment to counter his increasingly disruptive behaviors, he said.

Most of the building code violations in the Joliet home represented renovations that were underway or completed without proper permits, Dykstra said.

"Everyone at Trinity Services feels terrible about this death," he said. "We've tried our hardest to help people with complex needs like Thomas."

Records show that the Office of the Inspector General took five years to close the case, issuing its report after the Powers family settled its civil suit with Trinity Services.

Investigators cited the business and the caregiver for neglect, noting that residents were placed in a home with code violations and that Powers was forced to sleep on a mattress placed on the floor in a room full of debris. But the state took no further action against Trinity Services.

Under Illinois law, the inspector general's office is required to send a notification letter to families or guardians if neglect or abuse is found.

But members of Powers' family said they were unaware of the state's investigation until contacted by the Tribune. Inspector General Michael McCotter acknowledged that his office had failed to notify them.

Last summer, the Powers family received an apology from McCotter in the mail.

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Illinois' transition to group homes

Illinois has been moving toward a group home model for decades. Here are some major factors behind that transition:

- Beginning in the 1970s, Illinois downsized state-funded institutions because scores of people were inappropriately confined there.
- In the late 1980s, state officials created a special license for group homes that provide care for eight or fewer adults with intellectual and developmental disabilities. These homes were designated Community Integrated Living Arrangements, or CILAs. There are more than 3,000 such homes today.
- The U.S. Supreme Court ruled in 1999 that people with disabilities have the right to live in the least restrictive setting possible. Known as the Olmstead decision, the ruling also stated that unnecessary institutionalization violated the Americans with Disabilities Act. The decision forced states to fund more community services.
- In 2007, Illinois launched the Pathways to Community Living program, a federally funded initiative to transfer thousands of people with disabilities into group homes or other community placements from state institutions or nursing facilities providing long-term care.
- In a federal settlement known as the Ligas consent decree, Illinois agreed in 2011 to fund community access for adults with disabilities who lived in private intermediate-care facilities with nine or more beds, and those who lived at home but had sought community services or placement.

- Also in 2011, a federal court approved a sweeping agreement — the Colbert consent decree — that required Illinois to fund more community options for Medicaid-eligible nursing home residents with disabilities.
- In late 2011, then-Gov. Pat Quinn announced a cost-saving plan to close multiple state institutions and move hundreds of adults with disabilities into group homes. The Jacksonville Developmental Center was closed, but state officials shelved plans to shutter the Murray Developmental Center following a court fight with parents of residents.

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TRIBUNE WATCHDOG

SUFFERING IN SECRET:

Flawed
investigations
ignore victims
of neglect

JoAnna Mullis sits next to the grave of her mother, Tina Marie Douglas, who was fatally struck in traffic after fleeing her Lockport group home in 2013. *(John J. Kim / Chicago Tribune)*

By Michael J. Berens and Patricia Callahan

On her last night at a Lockport group home, Tina Marie Douglas tossed her few possessions in the trash and warned caregivers that she planned to run away in the morning.

It was not an idle threat. In the last three months, the 48-year-old state ward diagnosed with psychiatric and intellectual disabilities had slipped out of the home eight times and repeatedly run into the street. Her caregivers were considering moving her to a different home, one on a block with less traffic.

But that never happened. Shortly before dawn in October 2013, she broke away again, sprinted down a four-lane state road and was fatally struck by a car.

The Illinois Department of Human Services, which licensed the group home, assigned its inspector general's office to conduct a comprehensive review.

But a Tribune investigation found the inspector general's staffers never interviewed a witness, never visited the group home, never left their desks. Instead, they relied on group home employees to help investigate their own business and, based on those findings, determined the home was not at fault.

The Douglas investigation is one of hundreds in which self-policing played a role in determining whether neglect had occurred, including many where group home employees played an even more significant role — not only gathering evidence but drafting the state's final investigative reports.

These group home employees — dubbed "buddy investigators" by the Office of the Inspector General — handled at least 550 cases, the Tribune determined. And in the vast majority of instances, employees helped clear their own group homes of wrongdoing.

No other state has bestowed full-fledged investigative powers on caregivers at group homes serving people with intellectual and developmental disabilities, according to federal regulators.

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In the rush to close institutions, Illinois glossed over serious problems in group homes

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JoAnna Mullis talks about her mother, Tina Marie Douglas, who was killed by a car after fleeing a group home. She needed a court order to get the state's report on Douglas' death. (*John J. Kim / Chicago Tribune*)

The Tribune investigation, the first comprehensive examination of the state's secretive network of 3,000 group homes, also found that Human Services officials routinely obscured evidence of harm from the public.

The inspector general's office sealed 3,239 cases in which they found some evidence of abuse or neglect, a Tribune analysis of previously undisclosed state records from the last six years found.

Neither the public nor family members — not even group home residents — are allowed to know the nature of those investigations, the strength of the evidence or what reforms, if any, were mandated or made.

It's a flawed system that conceals the silent victims of abuse and neglect — some, literally voiceless — while allowing investigators to close as many cases as possible with the fewest consequences.

In one such case, the Tribune found, the inspector general's own investigators overlooked obvious clues pointing to neglect and were easily misled by a group home employee who later admitted she made up her story about what had transpired.

As a result of the Tribune's investigation, Human Services Secretary James Dimas said this month that he will seek to make public the records of all unsubstantiated cases. "We're working hard to push the envelope to become more transparent," he said. "And we're prepared to seek a change to the legislation if we decide that becomes necessary."

Additionally, Human Services Inspector General Michael McCotter has reopened both the investigation of Douglas' death and the neglect case involving the employee who gave false information.

Michael McCotter, inspector general for the Illinois Department of Human Services, said group home employees are no longer spearheading state investigations. (*John J. Kim / Chicago Tribune*)

McCotter credited the Tribune for sparking an agencywide audit and reform of investigative practices.

Human Services' oversight of group homes is fragmented, and McCotter acknowledged that his staff routinely didn't send its case reports to the division that licenses the homes — even when his investigators cited a business or its employees for abuse or neglect. He vowed to change that.

McCotter also said group home employees are no longer leading state investigations. In a policy change from the beginning of the year, McCotter began ordering his staff to visit group homes, conduct their own interviews and write all final reports.

As for state practices that have prohibited the public from knowing where abuse and neglect have occurred, he said, "It doesn't seem right, does it?"

Sealed away

Joanna Mullis needed a court order to pry loose the state report on the death of her mother, Tina Marie Douglas. She was stunned to learn that her mother had tried to run away so many times.

"Why would the state try to hide this?" Mullis said. "Why are they allowed to hide this?"

When the inspector general substantiates an allegation of abuse or neglect, the investigative report is a public record. If the office concludes there's no evidence to support an allegation, the staff rules the case "unfounded" and seals it.

But there's a third, more ambiguous category the office uses that also obscures files from the public. In cases the office labels "unsubstantiated," investigators uncovered some evidence of abuse or neglect but judged that it wasn't enough to issue a formal finding. Every detail is deemed confidential, and only a court order can unseal the file.

The Tribune tracked thousands of cases sealed under this category, including those involving the deaths of Douglas and hundreds of other group home residents.

Unlike most group home residents, who are disabled from a young age, Douglas suffered a traumatic brain injury in her 30s after two traffic accidents, leaving her with an intellectual disability, partial deafness, seizures and mental illness.

Family photos show Tina Marie Douglas in her 20s, left, and months before her death at age 48, right. *(John J. Kim / Chicago Tribune)*

Beginning in 2010, she lived in group homes owned by the state's largest provider, Trinity Services. During her three years at a Lockport ranch house where she lived with three women, Douglas ran away or attempted to flee dozens of times, driven by delusions that her real home was located elsewhere.

Trinity Services Executive Director Art Dykstra said the Douglas case highlights the dilemma of balancing residents' independence against their intermittent need for round-the-clock monitoring during times of crisis. The New Lenox-based provider manages more than 100 group homes.

He declined to discuss specifics about the death because Trinity faces a wrongful death suit filed by Mullis.

In Douglas' case, the investigative records show, Trinity operators were aware that her pattern of running away put her at greater risk of injury, especially given the proximity of a busy street, and they had talked about moving her to a safer location. Why that never happened is not directly addressed in the report.

Instead, the state's investigative report praised Trinity Services officials for taking in Douglas and commended caregivers for how they "clearly documented" her daily care.

But in a sworn deposition, a Trinity Services administrator acknowledged that caregivers had lost or inadvertently destroyed daily care notes detailing Douglas' last week of life in the group home.

The most perplexing aspect of the state's investigative report, according to Mullis, was a list of deficiencies in the home, along with recommended remedies. However, the report never mentions what specific evidence uncovered in the Douglas case prompted those concerns.

For instance, the report admonished caregivers to "ensure all seizures are documented" but didn't address whether Douglas had received proper medications and care for her seizures.

The biggest omission in the report may have been its most significant: Nowhere is it stated that investigators relied entirely on group home employees to gather evidence. Though Trinity Services employees didn't write the final report, they were the ones to conduct witness interviews and compile the records related to Douglas' care.

Tina Marie Douglas, a 48-year-old woman who had a history of running away from a group home in Lockport, right, was fatally struck by a vehicle in 2013 when she fled the facility. (*John J. Kim / Chicago Tribune*)

Not only did this system create an inherent conflict of interest, but it also put important investigative tasks into the hands of people with little training. These surrogate investigators — some with no more than a high school degree or equivalency — were given just two days of classroom training consisting mostly of PowerPoint presentations, state records show.

The inspector general's practice of relying on so-called buddy investigators goes back more than a decade, but by the time of Douglas' death their use was growing, mostly out of desperation by the state.

By 2013, staffing levels had fallen to historic lows at the inspector general's office. With just 18 investigators statewide, some carried up to 90 open cases, leaving just minutes a day to spend on each, state files show. Some cases languished without action for up to five years.

In addition to relying on group home employees, the inspector general's office also hired private nurses from employment agencies to fill gaps. The contract nurse who oversaw the Douglas case testified in a deposition that she received only two weeks of investigative training that included online and video courses.

McCotter, who was appointed in late 2012, in the last year has expanded the number of investigators in his office to 31 and is working to clear a backlog of cases. His office, he said, had to spend too much time redoing the work of the group home employees conducting investigations.

"These investigators, quite frankly, weren't as good as our investigators," he said.

A bungled case

As Deron Hardge lay in a coma, a machine helping him breathe, his mother phoned a state hotline for the inspector general's office.

Tara Wandick suspected her son had suffered neglect at the Harvey group home where he lived. At 23 years old, he had autism and a profound intellectual disability. He couldn't speak and was on seven medications, including one that controlled his epilepsy.

On the day paramedics rushed Hardge to the hospital, Wandick said, workers at the home gave conflicting accounts of why her son was gravely ill — first saying he had inhaled carbon monoxide, and then that it really was a seizure. She begged state investigators to uncover what had happened.

Deron Hardge, who has autism and a profound intellectual disability, was moved out of a group home by his mother after he suffered a medical crisis that put him into a coma. He now lives at a home in Chicago.
(John J. Kim / Chicago Tribune)

This time, the inspector general's staff didn't rely on buddy investigators to look into the case. Instead, they bungled it on their own.

In their report, which Wandick obtained by court order after suing Southwest Disabilities Services & Supports, investigators focused solely on the question of whether Hardge had suffered from carbon monoxide poisoning. Medical records proved he did not.

Therefore, the 19-month investigation concluded, the home had done nothing seriously wrong and ruled the complaint unsubstantiated. There was not enough evidence, an investigator wrote, to believe that anybody at Hardge's group home had "caused him pain, injury or emotional distress, or caused a deterioration of his physical or mental condition or placed his health and safety at substantial risk of harm."

But the Tribune found the inspector general's staff ignored multiple clues that pointed to neglect and relied on a caregiver who later testified she gave a false account.

Hospital records show that Hardge was suffering from severe hypothermia when paramedics rushed his unconscious body to Ingalls Memorial Hospital in March 2012. It took five hours of being cocooned in heating wraps and flushed with warm IV fluids before his temperature would register on the hospital's thermometer.

"It felt like he had been put in the freezer," Wandick recalled. "When the nurse came in, I asked her, 'Are you sure he's not dead?' "

Tara Wandick, top left, sued the operator of a group home in Harvey after her son, Deron Hardge, suffered a serious medical crisis there because of what Wandick believes was neglect. Hardge, 28, currently lives at a group home on the West Side of Chicago. (*John J. Kim / Chicago Tribune*)

Why was Hardge's body so cold if he was found inside a heated group home, as the inspector general's staff said he was? There is no indication in the state report that investigators ever tried to find out.

The state-mandated treatment plan that Southwest Disabilities drew up for Hardge promised he would be "supervised for 24-hours a day." But paramedics, who wrote that they found Hardge on the "ground ... cold to the touch," also noted that people at the home hadn't seen Hardge for several hours.

The inspector general's staff checked Hardge's medical records for carbon monoxide exposure but overlooked the more illuminating test result: Hardge barely had any of his anti-seizure medicine in his system when he arrived at the hospital. And nurses reported finding new and old wounds on Hardge's legs and pelvis, as well as a possible human bite mark on his upper chest.

Though Hardge survived his medical crisis, he can't communicate what happened. Nobody from Southwest Disabilities went to the hospital to watch over him or give emergency room doctors insight on what occurred. In their report, investigators relied on an eyewitness account from a woman identified by Southwest Disabilities as the caregiver on duty that day.

The caregiver, Christine Moore, told an investigator she called 911 after finding Hardge unresponsive on the group home floor.

But when Wandick's attorney deposed Moore this year, she said she had made up a story to save her job.

In fact, Moore had not shown up for her 7 a.m. shift, she said; Hardge's body was discovered around noon. Moore said she didn't know whether he was found inside or outside, or what had happened to him.

"I was out cheating," Moore testified. "And I was supposed to have been at work, but I wasn't there."

Moore said a co-worker covered for her that morning. But that colleague told the Tribune she wasn't there and didn't know what happened to Hardge. The city of Harvey didn't retain a recording or transcript of the 911 call.

Moore declined to comment.

Tara Wandick laughs with her son, Deron Hardge, 28, during a visit at his group home on the West Side of Chicago. *(John J. Kim / Chicago Tribune)*

Southwest Disabilities Executive Director Reuben Goodwin Sr. told the Tribune that Hardge was not left outside, nor was he left unsupervised for hours or neglected. Goodwin said he knows this because another Southwest Disabilities employee was present when paramedics were at the home. He would not reveal her name and said she has since died.

Goodwin said he plans to show in court that Hardge's "medical conditions and the medications he was on" caused the hypothermia, that the sores on Hardge's body were self-inflicted and that the bite mark was a scar that predated Hardge's time at Southwest Disabilities.

"I think we do a good job to make sure people are safe and that the staff is trained," Goodwin said.

Trouble has shadowed Goodwin as he operated a small network of state-funded group homes under different business names.

Carol Adams, secretary of Human Services in the early 2000s, tried three times to terminate state contracts with Goodwin's businesses after Illinois' federally empowered disability-rights watchdog called out deplorable conditions and financial mismanagement there. Goodwin disputed those findings. And, Adams recalled in an interview, Gov. Rod Blagojevich's office intervened to keep Goodwin's group home network open.

Since 2010, the inspector general's office has cited Southwest Disabilities employees for neglect linked to two deaths.

In addition, during the time Hardge was in the hospital, inspectors from Human Services visited Southwest Disabilities homes and found rampant problems with the dispensing of medications. And in 2012 and 2013, two other Southwest Disabilities residents were hospitalized for seizures and falls when staff failed to give them the proper doses of their epilepsy drugs, the inspector general's office found.

Before Hardge wound up in a coma, his epilepsy medicines had been so effective that Southwest Disabilities' nursing assessments stated that he hadn't suffered a seizure in at least three years. For someone with well-controlled epilepsy, one of the most common causes of severe seizures is missed doses of medicine.

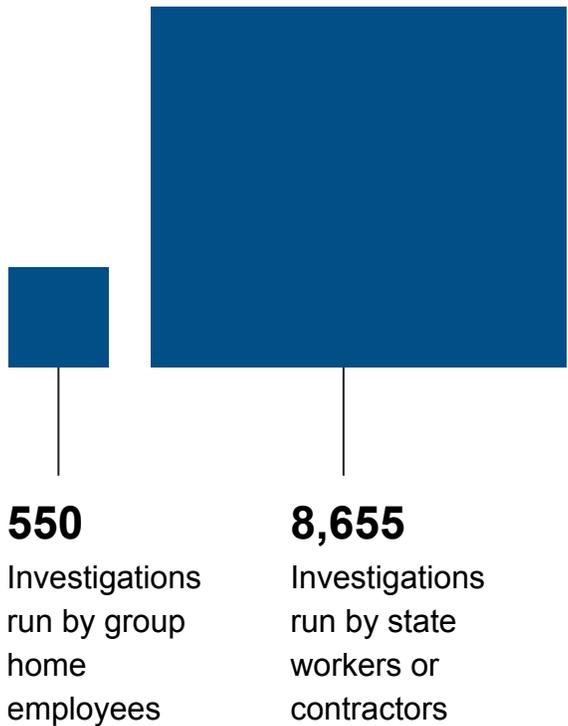
Allegations kept from public

In the first comprehensive examination of Illinois group homes for adults with developmental and intellectual disabilities, the Tribune found that the Department of Human Services routinely obscured evidence of harm from the public and relied on group home employees to help investigate allegations of abuse and neglect.

9,205

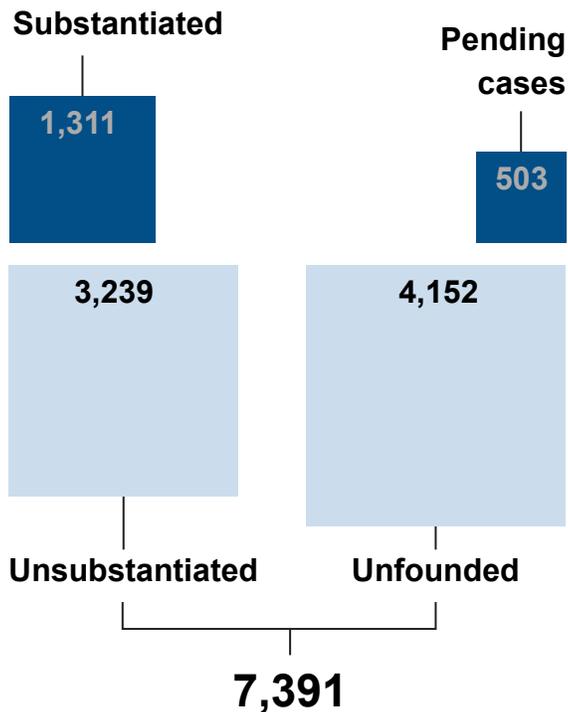
Allegations of abuse
and neglect, 2011-2016





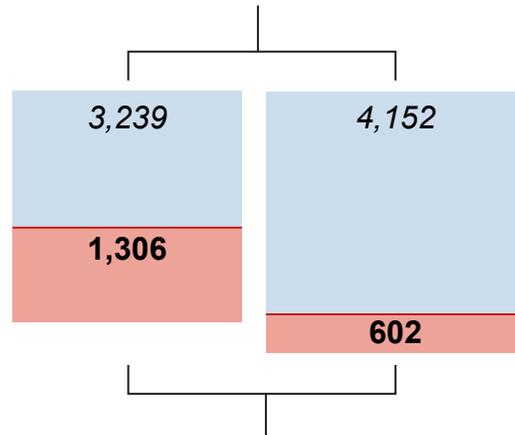
Outcomes

9,205 allegations



Only substantiated cases are available to the public. That means thousands of cases are hidden from view. An unfounded case means investigators didn't find evidence to support the allegation. "Unsubstantiated" means some evidence of abuse or neglect was found, but it was not enough to

was found, but it was not enough to support a formal finding.



Recommendations

Sometimes these cases include **recommendations** for changes at the group homes. But because the cases are sealed, the public cannot know the nature and severity of the problems to be addressed.

Source: State of Illinois

@ChiTribGraphics

Once Hardge received proper doses in the hospital, the level of the anti-seizure drug in his blood bounced back to normal, records show.

Did Southwest Disabilities fail to give Hardge his medicine? That remains a mystery. Although medication forms state that Moore gave Hardge his anti-seizure pills the morning he was rushed to the hospital and during her prior shifts, Moore testified that someone else had signed her initials.

Those records, she said under oath, were falsified. "It's not my handwriting," she said.

McCotter said he had not read his staff's investigative report on Hardge's case until the Tribune brought it to his attention. He immediately reopened the case and said he planned to discipline "the people that let this go through and not get to my level."

Said McCotter: "I thought there were questions screaming to be investigated."

A lack of oversight

More than a decade ago, Illinois lawmakers established a seven-member board to independently oversee the Office of the Inspector General and protect the rights of individuals with disabilities.

But the Tribune found that even this public safeguard has failed.

State records show that gubernatorial appointees of the Quality Care Board have frequently missed meetings and, in the last five years, never adopted a significant reform to improve the investigative system.

A March 2015 teleconference, for instance, lasted just 22 minutes, according to a recording of the meeting obtained by the Tribune. Members discussed board vacancies, when to schedule the next meeting and joked about the weather and the opening day of baseball. They didn't discuss a single group home case.

To track the board's meetings the Tribune obtained five years of state-produced recordings and meeting minutes.

Those records show that board members allowed McCotter and his staff to dominate most meetings. The board reviewed only those investigations hand-picked by the office.

"I know you are picking the best of the best," board Chairwoman Susan Keegan, a Chicago attorney, told state officials at one meeting.

Undermining the board's effectiveness, Gov. Bruce Rauner has failed to appoint members, as did his predecessor, Pat Quinn. Only four of seven positions are filled.

Two of the seats, vacant for the last four years, are supposed to be held by a person with a disability or the parent of such a person.

The group is supposed to meet quarterly, but because of board member absences the gaps between meetings sometimes stretched as long as eight months, state records show.

The longest-serving member, appointed by Quinn in 2005, is Thane Dykstra, who works for his father as chief operating officer for Trinity Services. Thane Dykstra testified on behalf of Trinity Services in the Douglas wrongful death suit.

Board guidelines permit one member to be an industry representative. But in a February 2013 meeting, a supervisor in the inspector general's office voiced discomfort about Dykstra's role on the board.

"Not to put Thane on the spot," then-Deputy Inspector General Robert Furniss said, "but the other thing that makes this a little more awkward is to what extent can Thane, as a provider and board member and by statute, oversee and monitor an agency that is sometimes investigating his staff."

Dykstra told the Tribune he works hard to stay neutral during discussions. His decades of experience caring for people with disabilities provide a valuable perspective to the board, he said.

Reacting to Tribune findings, Keegan and Dykstra, as well as board member Neil Posner, a Chicago attorney, said they are now scrutinizing all investigations, including all death reviews. The fourth board member, private attorney Untress Quinn, declined to comment.

Keegan, a former executive director of the Center for Disability & Elder Law in Chicago, said: "We've done our best with what we had."

The board also has asked to review sealed cases involving allegations that were unsubstantiated, like the cases of Douglas and Hardge.

The inspector general's office agreed to provide the records — as long as board members keep the details to themselves.

All agreed to sign state confidentiality agreements.

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Part Three - In the rush to close institutions, Illinois glossed over serious problems in group homes
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TRIBUNE WATCHDOG

A TROUBLED TRANSITION

In the rush to close institutions,
Illinois ignored serious
problems in group homes

Mark Winkeler needs 24-hour care and has lived his entire adult life at Murray Developmental Center. His mother, Rita, and others sued when the Quinn administration sought to close Murray and move residents into group homes. *(John J. Kim / Chicago Tribune)*

By Michael J. Berens and Patricia Callahan

Adults with mild disabilities were the most coveted. In April 2012, as Illinois moved to close several state institutions and relocate adults with disabilities into the community, representatives from group home businesses gathered inside the Jacksonville Developmental Center for a hastily organized auction.

A state official read aloud medical histories of residents with intellectual and developmental disabilities, prompting group home officials to raise their hands for desired picks.

Group home operators knew that then-Gov. Pat Quinn wanted to empty Jacksonville quickly — before any serious union or community opposition could be mounted — but some were taken aback by what they saw as a dehumanizing approach. "We were appalled by the auction," said Art Dykstra, executive director of Trinity Services, the state's largest group home provider.

The problems with Quinn's rapid-deployment plan, however, went beyond mere awkwardness.

Officials from the Illinois Department of Human Services promised residents that group homes offered a new beginning — one that would bring them more independence, safe and compassionate care, even a private bedroom.

But those promises obscured evidence found in the state's own investigative files that revealed many group homes were underfunded, understaffed and dangerously unprepared for new arrivals with complex needs, a Chicago Tribune investigation found.

In the five years preceding the auction, Human Services' inspector general substantiated more than 600 cases of abuse and neglect in group homes, an analysis of state data shows. State investigators tracked an additional 1,420 cases that uncovered evidence of harm or deficiencies but did not result in formal findings.

The Tribune's "Suffering in Secret" investigation (<http://www.chicagotribune.com/news/watchdog/ct-group-home-investigations-cila-met-20161117-htmllstory.html>), first published in November, uncovered a system where caregivers often failed to provide basic care while regulators cloaked harm and death with secrecy and silence.

Some cases of neglect found by the Tribune involved individuals who had been relocated to group homes from state institutions. Among the most startling: A man transferred from a state developmental center to a series of group homes died under suspicious circumstances in 2010 after he was forced to sleep on a soiled mattress on the floor of a cluttered room used for storage.

With adequate funding and social supports, adults with disabilities fare best when mainstreamed into the community, widely accepted research studies show. Spurred by court decrees and a growing disability-rights movement, most states have closed some or all of their institutions and shifted funding to community-based residences like group homes. But in Illinois, not enough money has followed the people, the Tribune found.

Group homes have gone nearly nine years without an increase in reimbursement rates for staff wages. Overall, Illinois consistently ranks among the lowest five states for financial commitment to community care, federal records show.

"We've said all along the community system is grossly underfunded," said Zena Naiditch, CEO of Equip for Equality, Illinois' federally empowered disability-rights watchdog. "It's been grossly underfunded for decades."

Instead of opening doors to independence, dozens of financially strapped group home businesses reduced or eliminated community activities as too expensive or time-consuming, according to investigative files from multiple state agencies.

Complaints of food rationing were common. One home budgeted \$1.22 per meal, limited servings to 4 ounces of protein and prohibited second helpings.

Even the state's promise of a private bedroom proved illusory. Though group home operators agreed not to admit more than four residents per home, hundreds of providers have routinely bunked up to eight people with disabilities into tight quarters, an analysis of state licensing files and advocacy group reports shows.

At the time of the Jacksonville closing, Human Services characterized the state's aging institutions as an antiquated and costly system with a long history of harm and inadequate care. By contrast, state officials described group homes as adequately funded and staffed.

But when group home providers were surveyed in 2012 to gauge support for Quinn's plan, they complained of pervasive problems, according to records obtained by the Tribune.

Several providers charged that Illinois routinely failed to fully disclose behavioral histories of state developmental center residents who represented a threat to themselves or others. Without that information, group homes can't take the steps necessary to keep all residents safe.

Providers also said state funding was inadequate to cover staffing costs, diminishing the quality of care inside group homes and decreasing residents' independence. Other group homes railed against the state's inability to fund necessary levels of nursing care, with one provider writing: "Typically, an individual is funded for approximately one hour per month for nursing oversight."

Instead of boosting funding overall or slowing down relocations, however, Human Services officials adopted an extraordinary tactic to obscure problems. They required group home executives accepting transfers to sign a pledge of loyalty, extracting a vow to "not do anything to inhibit, diminish, or undermine" the state's closure plans, the Tribune found.

Failure to sign, Human Service officials warned, would restrict access to the Jacksonville auction and result in no referrals of developmental center residents to fill empty beds.

To avoid being shut out, at least 67 businesses signed the one-page pledge, state records show.

But one group refused to be silent about the state's plans: parents of individuals in institutions who worried their children would not get the care they need in a group home. And in the town of Centralia, about an hour east of St. Louis, a battle was brewing.

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Rita Winkeler ties her son Mark's shoelace at Murray Developmental Center. Murray parents were apprehensive about a transition to group homes because they feared many did not offer adequate skilled nursing care. *(John J. Kim / Chicago Tribune)*

Parents fight back

ita Winkeler's 32-year-old son Mark has lived his entire adult life at Murray Developmental Center. His modest private room, equipped with a television and DVD player, is covered with family pictures and Chicago Cubs and St. Louis Cardinals memorabilia.

Because of severe developmental and intellectual disabilities, he requires 24-hour care; he needs to be fed, diapered and bathed. Winkeler believes her son is happy and well cared for at the center.

But after emptying Jacksonville and moving most of its 180 residents to group homes, the Quinn administration set its sights on Murray.

This time, though, parents and guardians of the residents banded together and orchestrated public events to rally support from the community, state labor unions and lawmakers.

Soon "Save Murray" signs blanketed Centralia. In a city of just 13,000 people, nearly everyone knew someone who had a connection to the center through a resident, employee or contractor. The potential closure represented a cataclysmic event for the rural community, located about 275 miles south of Chicago.

Beyond the economic impact, the battle for Murray centered on choice. For many parents and guardians, Murray was a haven — a place where the staff outnumbered residents, where a registered nurse was never more than a few steps away.

In early 2013, 11 parents and guardians of adult children who lived at state institutions, including Winkeler, filed a federal lawsuit to halt the state's plan.

Murray's cinder-block buildings border a 120-acre grassy oval crisscrossed by walkways that lead to an outdoor shelter with picnic benches and gardens, a gymnasium and outdoor pool. Built in 1964, Murray resembles an aging community college. But inside it has the look of a nursing home. Its six residential buildings, sheltering about 40 residents each, are dominated by a central desk with hallways branching out to rooms.

At the time of the lawsuit, there were 274 residents and 547 staff members, an enviable ratio made possible by a \$41 million annual operating budget.

Winkeler, a former third-grade teacher and head of the decades-old Murray Parents Association, said Murray families were not opposed to the group home concept. Indeed, Winkeler serves as guardian for her 58-year-old brother, who she said thrives in a group home setting.

"Group homes are great for some people like my brother," she said. "But the state wants to fit everyone into the same-size shoe."

Rita Winkeler talks about her son, Mark, who lives at Murray Developmental Center, an institution downstate. Mark, 32, has profound developmental disabilities and has lived at the center for his entire adult life. *(John J. Kim / Chicago Tribune)*

Following the lawsuit, the battle lines hardened.

Murray supporters alleged the state had used deceitful tactics to steer vulnerable adults into substandard group homes as a way to save money. In 2012, state officials calculated the annual cost of care for an institutionalized resident was about \$219,000, compared with \$84,000 at a group home.

The Arc of Illinois, a nonprofit advocacy group, emerged as a chief proponent for closure, referring to parents as misguided, describing residents as "incarcerated" and exhorting the public in a web blog: "Free our people!"

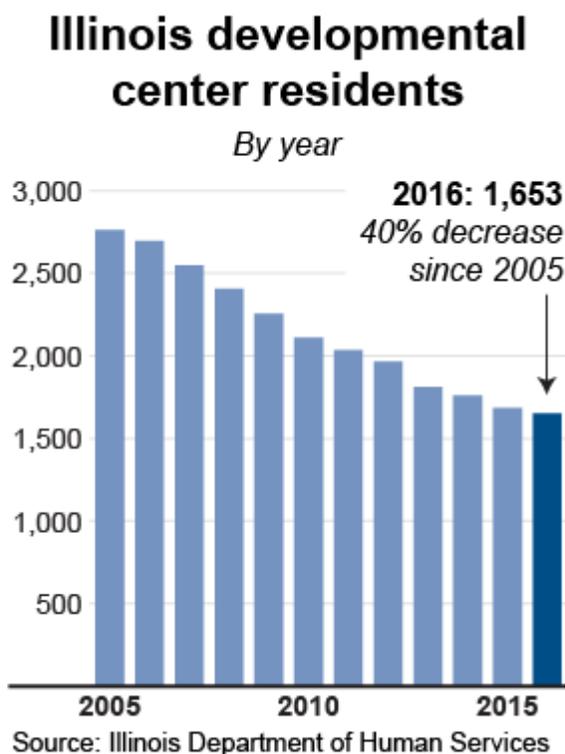
"There's no doubt that the state institutional model is a relic that should have been closed down in Illinois and other states long ago," Tony Paulauski, the group's director, told the Tribune.

As part of the court case, Human Services officials said most of the guardians of Jacksonville residents who responded to a state-funded survey were satisfied with the new homes. But Murray parents noted that nearly two-thirds of the guardians didn't answer the survey, which was conducted by the University of Illinois at Chicago.

Meanwhile, Human Services tracking records from April 2012 through March 2013 show a total of 84 admissions to hospitals or emergency rooms, 18 psychiatric admissions and 29 police encounters involving transferred Jacksonville residents.

All sides understood that the outcome of the court case could dictate the near-term future for how Illinois cared for people with severe disabilities.

For the last decade, prodded by a U.S. Supreme Court decision and federal consent decrees, Illinois has worked to transfer hundreds of people with disabilities who had been inappropriately institutionalized.



Many of Illinois' now-closed institutions had a long history of horrific conditions. At Murray, a staff member was accused last year of forcing a resident to take a shower as a punishment. The resident, who was deaf and blind, choked in the shower and later died at the hospital.

But Murray families argued that residents with severe disabilities who moved into group homes were unlikely to receive the 24-hour assistance they needed. Instead of funding that help, the state has used a cumbersome approval process to authorize extra staffing, typically for a limited number of hours each day. Group home owners said they were forced to guess in advance when the resident might be in the most need of care and oversight.

Families who toured prospective group homes said they observed thinly staffed shifts of inexperienced caregivers who acknowledged that they didn't know how to deal with aggressive behaviors or a medical crisis except to call 911, according to court records.

Murray parents also expressed fears that many group homes did not offer adequate skilled nursing care — fears that were warranted, a Tribune analysis of state investigative records shows.

At one group home business — United Cerebral Palsy Land of Lincoln — the Human Services inspector general cited four nurses for neglect involving three unrelated deaths between 2012 and 2015. Records from one of those cases reveal that two nurses were responsible for 52 residents from Springfield to Bloomington.

Since the deaths, CEO Brenda Yarnell said the group home business has hired a director of nursing to oversee two nurses to improve supervision of resident care. Salaries of two nurses are paid through private fundraising efforts, she said, because Human Services won't pay for additional nursing care.

Echoing written complaints to Human Services by many providers over the years, Yarnell said state reimbursement rates for nursing are inadequate, often covering costs of just one nurse.

"It's been really hard," she said. "The expectation is impossible."

New home a bad fit

Despite the pending lawsuit and known problems in the group home industry, Human Services officials in mid-2013 began to move out Murray residents whose state guardians did not oppose the closure.

A longtime Murray resident named Carl was among the first to be relocated, but he didn't go far. His new private group home, a 1,300-square-foot ranch house, was across a county road from Murray. In his wheelchair, he could stare out the window at his old life.

A Murray resident named Carl was moved across the street to this group home. Murray caregivers complained to officials that Carl's challenges made a group home the wrong fit. He was moved back after multiple hospitalizations. *(John J. Kim / Chicago Tribune)*

Murray caregivers complained to their supervisors and to the governor's office that Carl's severe medical, intellectual and physical challenges did not make him a good candidate for a group home where he would be limited in movement and have less contact with other people, according to court records.

Carl has poor vision and must use a wheelchair, though he can walk a few steps with a walker or staff assistance. He understands the concept of yes or no and has a small vocabulary — he can say "cookie" or "food," for instance — but he

wears diapers and requires help for the most basic activities, such as bathing, dressing or using the restroom.

At his new group home, run by Support Systems & Services, his wheelchair barely fit down the narrow hallway, according to witness accounts in court and state records. A Murray staffer who visited him described Carl as being "like a giant in a dollhouse."

According to a written report by a court-appointed guardian, Carl suffered his first seizure in three years after his anti-convulsant medication ran out and he received none for three days.

In addition to complaining about the home's size, Murray staffer Lorre Winter wrote a series of emails in July 2013 to Richard Starr, then director of Murray, stating that she was "seeing problems that weren't being addressed."

"There is more involved than just placing them in a house and feeding them," she wrote in the emails, which surfaced in the lawsuit against the state.

Starr wrote that Winter should "stick to objective concerns rather than subjective."

Winter, who had worked with Carl when he was at Murray, responded: "Someone has to speak up for these people and if that is what I have to do then I will and deal with the consequences later."

The Tribune verified Carl's identity and the home's location through government records and state emails. After months of discussions, the Illinois Office of State Guardian confirmed that Carl was a state ward. The Tribune is not using Carl's full name, as he is not capable of giving consent.

David Jaques, chief executive of Support Systems & Services, told the Tribune that Carl thrived at the home and improved his mobility after a physical therapist trained the home's staff to help him. Jaques attributed the initial lack of anti-convulsant medication for Carl to a billing problem at the pharmacy related to the transition from Murray.

While Carl was living in the group home, a federal district judge ruled in July 2014 that guardians of Murray residents could not stop the state from closing the facility. A three-judge appellate court panel later affirmed that decision and called Illinois a "laggard outlier" in the national movement to transition residents from institutions into the community.

Illinois facilities

State officials closed two institutions in recent years and seven large developmental centers remain.

Developmental centers, with number of residents in 2016 and change since 2005

Center, city	2016 (Change)
Choate, Anna	172 (-1)
Fox, Dwight	105 (-53)
Howe, Tinley Park	Closed 2010 (-420)
Jacksonville	Closed 2012 (-258)
Kiley, Waukegan	191 (-66)
Ludeman, Park Forest	392 (-28)
Mabley, Dixon	106 (4)
Murray, Centralia	208 (-134)
Shapiro, Kankakee	479 (-153)

Source: Illinois Department of Human Services

But the Murray parents found an unexpected supporter in Republican gubernatorial nominee Bruce Rauner, who won the November 2014 election and kept his vow not to close Murray. The parents had held off the state, at least temporarily.

Jerry Stermer, who served as a senior adviser to Quinn, defended the former governor's handling of the closure process.

The Jacksonville auction, Stermer said, was designed to match residents with group home providers who could meet their needs. Following complaints from businesses, state officials relied on a silent auction process in which group home officials marked preferred resident selections on paper, he said.

Quinn's goal, Stermer said, was to shift money from supporting a few hundred people in an expensive state facility to helping a far greater number of individuals receive community-based care.

The Rauner administration has stated there will be no institutional closures this fiscal year, which ends in June. About 1,650 residents remain in seven developmental centers, and the Arc of Illinois continues to lobby vigorously for

closing at least six of them. In 2012, Quinn targeted four developmental centers for closure but succeeded only with Jacksonville.

State records show that Carl was returned to Murray earlier this year, after multiple hospitalizations and new medical complications that caused severe weight loss. Winter now helps provide Carl's care.

For now, the state acknowledged, the institution is where Carl needs to be.

The Misericordia question

Hundreds of miles away on the campus of Misericordia Heart of Mercy, the most formidable opponent of the big-is-bad philosophy is gently rallying 200 women at a fundraising luncheon to take on what she calls "the injustice of the system of service for people with disabilities."

For nearly half a century, Sister Rosemary Connelly, the Roman Catholic nun who leads Misericordia, has defied convention as she built a community for 600 people with developmental disabilities on the site of an abandoned orphanage in Chicago's West Rogers Park neighborhood.

"The bureaucrats have held since the '70s that anything that is big is bad," Connelly tells the crowd at the Christmas luncheon. "They hate Misericordia because of the fact that we're big and we're not bad. We're good. And we're good because so many people believe in us enough to get involved."

If Murray resembles an aging community college, then Misericordia's 31 acres look more like an elite liberal arts campus, the antithesis of institutions that confine rather than care for people with intellectual disabilities.

Misericordia Heart of Mercy in Chicago serves 600 people with developmental disabilities. Its continuum of care, the size of its staff and the varied programming attract 300 families to Misericordia's waiting list.

(John J. Kim / Chicago Tribune)

Though the front-porch appeal of the buildings impresses visitors, it's the continuum of care, the size of the staff (about 1,000) and the varied programming (commercial bakery, greenhouse, restaurant, art studio, aquatic center) that attracts 300 families to Misericordia's waiting list.

Executives of some group homes pride themselves on taking in residents whom others won't — people with severe behavioral issues and mental illness. Misericordia doesn't do that because, Connelly says, her organization couldn't meet their needs.

On-campus housing options range from a village of homes for more independent residents to a skilled-nursing facility for medically fragile children and adults. As medical advances have extended the lives of people with disabilities,

Misericordia this year tapped private donations to open four 15-unit homes to cater to the needs of aging residents and those with dementia.

But to advocates who push for closing state institutions, any large facility that segregates residents from people without disabilities is a barrier to the ideal of community living and represents an outdated approach.

Paulauski, of The Arc, has been engaged in a philosophical tussle with Connelly for four decades as both pursue their vision of working with people with developmental disabilities.

"People with disabilities must be able to live in the community, work in the community, and participate in all aspects of community life together with their peers without disabilities," he wrote to supporters in an "action alert" last spring when a bill granting Misericordia special licensing status came up in Springfield.

Sister Rosemary Connelly, executive director of Misericordia, works in her office. The Roman Catholic Sister of Mercy for decades has tussled with activists who say all big settings are bad. (*John J. Kim / Chicago Tribune*)

Connelly sees Misericordia as a vibrant community. She doesn't oppose group homes; Misericordia operates 10 of them in Chicago and Lincolnwood.

Yet she calls them "isolated houses in the community" and says the 65 residents who live there, most of whom have off-campus jobs, have richer lives because they can come back to campus for activities. After-work social gatherings at Misericordia include clubs geared toward various sports, music, science, technology, sewing, theater and dance.

Her view: Big can be bad. Small can be bad, too. Both can be good. The danger comes when policymakers who control the funding insist that one size fits all.

"I don't think we're the only way," Connelly said. "All I say is we're a legitimate way."

The divide over institutional care threatens the government support of Misericordia and more than 200 of Illinois' other private intermediate-care facilities — settings that serve nine or more people with disabilities under one roof. Statewide, these private facilities care for twice the number of people that state developmental centers do and at a fraction of the cost. Misericordia, for instance, receives about \$65,000 annually for each of the 360 residents in its 21 intermediate-care facilities.

In his first year in office, Rauner proposed a 12 percent cut to the funding for this type of care, a reduction forestalled only by the state's inability to pass a budget. More broadly, federal and state officials are wrestling with which settings are too "isolated" to merit funding.

For example, federal and state regulators have put Misericordia's developmental training program under "heightened scrutiny" because when group home residents bake brownies, package ground coffee or fold clean laundry, they are doing so on Misericordia's campus, the type of setting that the federal government presumes has the "the qualities of an institution." To retain funding for this programming, Connelly and her staff have to prove that the people holding these jobs also have meaningful lives in the larger community.

As part of its programming, Misericordia runs the Hearts & Flour Bakery, which helps some residents develop job skills. (*John J. Kim / Chicago Tribune*)

For policymakers, the challenge is that for too long bigger settings were the only option. Stanley Ligas, a man with Down syndrome, could read and balance his checkbook and held a job at a Popeyes chicken restaurant, but the state repeatedly turned him down when he asked to move from a 96-bed intermediate care facility in Woodstock to a smaller home.

A federal lawsuit filed on behalf of Ligas and thousands of other people with disabilities led in 2011 to the Ligas consent decree, which requires Illinois to fund community living options for people who want to leave intermediate care facilities and those who are living at home but seek community services or placement.

Connelly knows what can happen if government loses faith in a model of care. Misericordia's campus sits on the grounds of the former Angel Guardian Orphanage, which closed in the 1970s when it lost government funding as the state shifted from orphanages to foster homes.

Misericordia can provide the care it does because Connelly, her staff and thousands of volunteers raise more than \$20 million in private money each year to supplement the government support.

But Connelly turned 85 this year. A goal of the Christmas luncheon was not just to raise money but also to build a next generation to take on the big-is-bad activists when she's gone. Connelly wrote to supporters this year that the state can learn a lesson from the shuttered orphanage.

"When I see the middle-aged homeless people on the streets of Chicago," she wrote, "I wonder how many are the so-called 'success stories' of the '70s when the government allowed institutions to close without providing adequate support for all involved."

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