

The New York Times

‘I Want to Live Like a Human Being’: Where N.Y. Fails Its Mentally Ill

A cutting-edge program to help severely mentally ill people live on their own has endangered people who were not ready, a new investigation shows.

By Joaquin Sapien and Tom Jennings

Dec. 6, 2018



Abraham Clemente, who is schizophrenic, moved out of an adult home into his own Brooklyn apartment last year. “I don’t want to live like this,” he said in August.

The stench from Abraham Clemente’s apartment in Flatbush, Brooklyn, this summer was overwhelming. Maggot-infested scrambled eggs were strewn across the floor; a cantaloupe was so spoiled, it seemed to be melting. Feces were ground into the carpet.

Mr. Clemente, who is 69 and has schizophrenia, kept the shower and sink running for the “oxygen.” He blamed a kitchen fire on a doll nailed to a cabinet. He believed he could crush and smoke his antipsychotic medication to achieve its intended effect.

Yet the state of New York determined Mr. Clemente was capable of living on his own.

He is one of hundreds of severely mentally ill New York City residents who have been moved out of institutions into private apartments over the past four years under a landmark 2014 settlement. The approach is meant to be a national model for the rights of the mentally ill to live independently.

It begins with the assumption that most people in adult homes — group facilities that often house hundreds of residents — can live on their own with the right help. Adult home residents are given a subsidized apartment, called scattered site supported housing, and assigned a team of social workers and others to help navigate bureaucracies, housing problems and everyday tasks.

But more than 200 interviews and thousands of pages of medical, social work and housing records reviewed by ProPublica and the PBS series Frontline, in collaboration with The New York Times, show that for some residents, the sudden shift from an institution to independence has proved perilous, and even deadly.

One man drank himself to death. Another suffered a fatal heart attack in the foyer of his building, during a blizzard, naked. One woman was choked and left dead in a bathtub last year; three people of interest in the murder are fellow supported housing residents. The family of another woman believes her mental health declined when she moved into supported housing, contributing to her suicide.

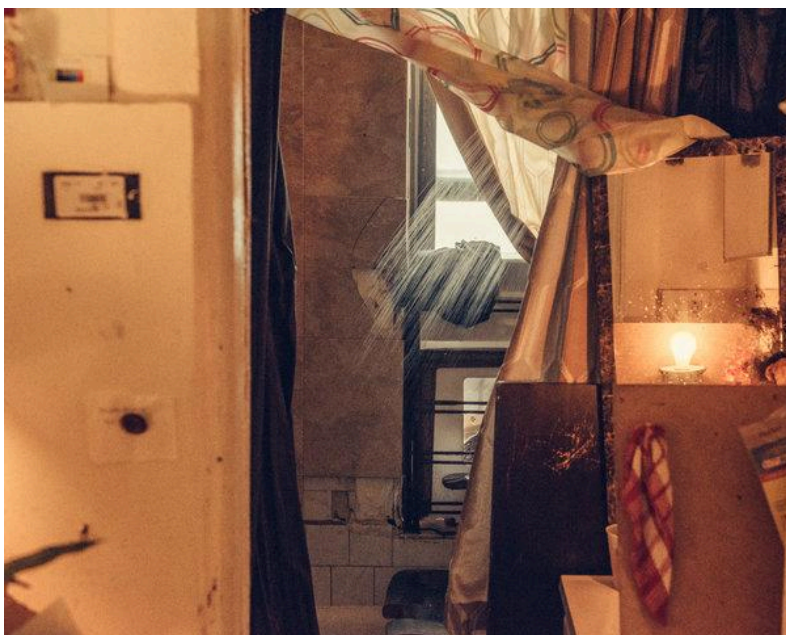
Certainly, many people flourish when given the chance to live independently. A court-appointed monitor has interviewed more than 300 people who have moved out of adult homes and has said that for the most part, they are satisfied with the change.

“I’m sure some of them have their rough days because if you have serious mental illness, you have rough days,” said Cliff Zucker, a disability rights lawyer who led the court case that ended in the 2014 settlement. “But better to have it in your own home and live in freedom.”

David Lazarowitz, 45, said he takes his medication routine seriously and loves to shop and cook for himself, keep his apartment tidy and learn about gardening or auto mechanics on YouTube.

“This is a chance that otherwise, I would never have,” Mr. Lazarowitz said.

But in addition to the deaths, ProPublica and Frontline identified more than two dozen cases in which people in supported housing were not able to care for themselves, leaving them in unsafe or inhumane living conditions. Most of those people moved back to an adult home, but others ended up in a nursing home or a psychiatric ward. One resident landed in jail. One is missing, according to the police.



Mr. Clemente kept the shower and sink running for “oxygen.”

More than 20 people who have worked on the transition, from social workers to nonprofit executives, said the ideology behind the lawsuit endangered scores of people who were not ready to live alone with only minimal support.

“We put the cart before the horse. We committed to the housing before we knew what the needs were,” said James Introne, the New York deputy secretary of health from 2011 to 2013 and a principal negotiator of the settlement.

Front-line social workers and others estimated in interviews that anywhere from a quarter to half of their former adult home clients either have failed — meaning they died in preventable ways or shifted into a higher level of care — or currently lack the help they need to live safely.

Until recently, the state agencies that have overseen adult homes and some related care — the Department of Health and the Office of Mental Health — did not have a system to track serious problems among people who entered supported housing.

After months of questions from ProPublica and Frontline, the state released some numbers in mid-November: Of the 764 people who have moved so far, 32 have died and 39 have returned to adult homes.

But the state did not provide details on the deaths or any investigations into them. Nor did officials provide information on other outcomes for former adult home residents, such as becoming homeless, landing in a psychiatric hospital or suffering dangerous incidents.

Officials with the Office of Mental Health acknowledged that there had been some serious incidents among those who moved. Still, the office said, only a “small percentage” of the group could not overcome the challenges of living alone.

“I truly believe that stigma and discrimination have historically left too many individuals with serious mental illness living in institutions,” Ann Marie Sullivan, the commissioner of the state Office of Mental Health, said in an interview.

State officials also said they have a new reporting system that better captures incidents. The office declined to answer questions about individual cases, citing privacy concerns.

The stakes for the program’s success are high. United States District Judge Nicholas G. Garaufis, who presided over the case, [has expressed frustration](#) with what he believes is a slow transition. About 1,700 more people have said they are interested in moving.

The Department of Justice, which joined the New York lawsuit that ended in the settlement, has filed similar suits in North Carolina, Illinois, Delaware, New Hampshire and Mississippi with the goal of expanding independence for the mentally ill nationwide.

On a 95-degree afternoon in August, Mr. Clemente would not answer the door for a reporter, which was unusual. A caseworker called 911.

Officers pushed on the door and broke its rotted jamb. They gasped as flies swarmed them. Mr. Clemente stumbled out, half-naked and sweating. When paramedics arrived, one greeted Mr. Clemente by name, remembering him from previous hospitalizations. His blood sugar levels called for a visit to the emergency room.

“I don’t want to live like this,” Mr. Clemente said, before agreeing to get in an ambulance. “I want to live like a human being.”



Bugs crawled over the remnants of an angel food cake at Mr. Clemente’s apartment in Brooklyn this summer.

A history of abuse and neglect

The settlement has its roots in a lawsuit initiated in 2003, a year after The New York Times published a Pulitzer Prize-winning investigation into adult homes.

Once considered a humane alternative to psychiatric hospitals, adult homes abused and neglected residents and churned them through unnecessary medical appointments to rack up Medicaid

payments. People died of preventable illnesses. Mental health treatment was poor or nonexistent.

The lawsuit aimed to prove that New York had violated the federal Americans with Disabilities Act by allowing the homes to warehouse residents while neglecting their psychiatric needs. Mr. Zucker and other advocates argued that many did not need to live under 24-hour watch.

The state fought the lawsuit, asserting that conditions at the adult homes had improved, and that moving residents into supported housing would cost too much and suit only those who needed minimal supervision.

In 2009, their arguments unfolded before Judge Garaufis in a five-week trial.

One witness was Dr. Jeffrey Geller, a medical director of a large state hospital in Massachusetts who had been involved in overseeing community programs for patients who left psychiatric hospitals in the 1970s and 1980s.

He testified that advocates had underestimated how much help people would need. After reviewing case histories and interviewing more than 100 residents of New York City adult homes, he warned that a quick shift to independent living “may actually physically harm individuals and in some cases cause death.”

“I thought adult homes were abominations,” Dr. Geller said in a recent interview. “But I also thought the plaintiff’s remedies were preposterous.”

Experts on the plaintiff side testified that adult home operators had encouraged a “learned helplessness” in their residents that could be overcome with proper care in their own apartments. Dennis Jones, a former top mental health official for both Texas and Indiana, said he thought virtually everyone living in adult homes could be moved to supported housing.

Advocates made another compelling argument: Because adult homes abused Medicaid, the state would save money by moving people out.

Judge Garaufis sided with the plaintiffs and determined that supported housing would be cheaper than housing people in adult homes.

After a successful appeal, the state opted to settle the lawsuit rather than retry the case. It began the process of moving people out of nearly two dozen adult homes in the city.

Six nonprofits were chosen to act as intermediaries with landlords and help residents with housing problems.

Others opted out. The \$15,043 that New York was spending on each resident annually on rent, utilities and a monthly visit from a nonprofit worker struck some housing experts as far too low, even with Medicaid and additional state funds covering therapy and other services. That figure has increased to \$17,375. People who live in supported housing also contribute 30 percent of their own income to rent.

“We were anticipating being genuinely involved,” said Steve Coe, the founder of Community Access, one of the first housing programs that took in psychiatric patients in the 1970s, “but then the system they set up just didn’t make sense.”



Steve Scher, who ran the nonprofit Staten Island Behavioral Network for 14 years, said he was shocked by the backgrounds of some patients allowed into his housing program after the settlement.

A push to move

From the beginning, the transition was problematic.

The independent monitor found that adult homes tried to stop people from leaving by scaring residents or making it difficult to obtain records that would help determine whether they were capable of living alone.

State officials and service providers held weekly calls to discuss the pace. Several people who participated told ProPublica and Frontline the pressure to move people out was like a “weekly firing squad.”

Residents had to be evaluated to determine if they were ready to move. Three clinicians who said in interviews that they were involved in dozens of evaluations said they believed their concerns about some residents were overruled or ignored. Three additional workers tasked with recruiting and preparing residents for the transition said it was obvious some were ill-equipped, but they were told to sell the move.

Dr. Sullivan, who has led the state Office of Mental Health since late 2013, said her office has not urged evaluators to move people who were not ready.

“The assessment should look at everybody’s potential. Sometimes people can disagree about that — there have been some disagreements on the call — but that is not our policy by any means,” Dr. Sullivan said.

Still, Steve Scher, who ran the nonprofit Staten Island Behavioral Network for 14 years, said he was shocked by the backgrounds of some patients allowed into his housing program after the settlement.

“If someone was actively using drugs, it didn’t matter,” he said. “If someone was currently drinking, it didn’t matter. If someone was a fire setter, it didn’t matter.”

The nonprofit Institute for Community Living, which now runs Mr. Scher’s program, did not respond to requests for comment on issues Mr. Scher raised.

Once people are in supported housing, they can be assigned a dizzying array of agencies and bureaucracies. Many clients see therapists. Some have home health aides or use food stamps. Others are assigned peers who have been through treatment and assist others.

Although often innovative and devoted, caseworkers could be overwhelmed, Clarence J. Sundram, the independent monitor, wrote in 2015. Some juggled as many as 100 cases. The state recognized that some residents would need a bigger safety net.

Under a program called Adult Home Plus, some residents were assigned a “care coordinator” with a caseload capped at 12 to meet with them four times a month and wrangle the myriad services and providers.

But coordination among the teams can be rocky, and turnover is high, Mr. Sundram has written and ProPublica and Frontline have found.

Cristal Irons, a former care coordinator with the nonprofit Federation of Organizations, said a communication breakdown put her in danger. She said she and a worker for Institute for Community Living were supposed to try to hospitalize a psychotic patient. She wound up going alone. The resident choked her, slammed her against a door knob and severely injured an arm that then needed multiple surgeries, she said.

Ms. Irons was eventually fired for what Federation told her was abuse of her paid family leave. She is suing I.C.L. for negligence, arguing that the organization knew the patient was a threat.

I.C.L. did not respond to questions about this incident.



Antonio McCoy, who has a master's degree in social work, said he earns more money driving for a ride-hailing service than he did as a caseworker.

Antonio McCoy, who has a master's degree in social work, said Federation discouraged him from spending too much time with his clients.

“It’s more about the numbers and the metrics, and raking in the insurance money versus actually providing quality care and services to the clients,” Mr. McCoy said.

He quit after three months. He said he earns more driving for a ride-hailing service.

Joseph Buzzell, a lawyer representing Federation, said the organization “has not found any indication that it has violated any of its duties to provide services.” He also said that former Federation employees may “harbor unmerited grudges.”

Slipping through the cracks

For four years, Mr. Sundram has urged the state to develop a more robust oversight system to track problems in supported housing.

“With the strong presumption in the settlement agreement that virtually all class members are qualified for supported housing, it is not unexpected that the presumption proves incorrect in some cases,” he wrote in his most recent report.

In his reports, Mr. Sundram has identified cases of people who have slipped through the cracks, including a 34-year-old woman who moved to supported housing in 2016 after four years in an adult home.

She stopped taking her antipsychotic drug and began trying to solicit sex from passing drivers and swap alcohol for drugs with neighborhood children. Case managers knew she needed more care, but no one seemed to know how to help her get it. Eventually, facing eviction, she became homeless.

Jorge Bulario, a social worker with the Staten Island Behavioral Network from 2014 through 2017, told ProPublica that when he or his colleagues tried to raise concerns about supported housing residents with state officials, they were shouted down.

More than a dozen people working in a similar capacity said the same.

“The Department of Health’s message was: These people want to move out. We have to give them the chance,” Mr. Bulario said.

Mr. Bulario said one man disappeared for several months shortly after moving out of an adult home. He said he and his team eventually learned that the man, who had stopped taking his antipsychotic medication, had taken a bus to San Diego and was later found in a psychiatric ward on Staten Island.

One woman drank herself into a stupor daily. Mr. Bulario said he saw her lying on a couch covered in broken glass and feces on several occasions. Another woman frequently wandered outside her apartment in nothing but a bra and diaper, he said.

All three moved back to their adult home in Staten Island, where Mr. Bulario now sometimes works for a managed long-term care contractor.

In March, Judge Garaufis signed a new order telling nonprofits to report to the state any incident, from deaths to unsanitary living conditions, that jeopardized someone in supported housing.

The state must investigate the incidents, but the court order covers only those enrolled in Adult Home Plus. And 42 percent of people who moved under the settlement are no longer enrolled in that program, according to the monitor’s most recent report.

Before agencies began reporting incidents, ProPublica and Frontline identified at least six deaths that raised questions.

Jagnanan Ramnanan, 67, died of complications related to liver failure last year after repeated warning signs about his drinking problem. Just days before he had a fatal heart attack, 54-year-old Bernard Walker was seen “practicing his karate” in his underwear in the snow. He died naked, in the cold, inside the foyer of his Queens apartment building in 2016.

Cindy Boyle, 45, was found strangled in the bathtub of her Queens apartment last year. The police said three persons of interest are former adult home residents.

At least two men died within a month after their move from the adult home. One of them, 63-year-old Peter Harris, could not follow a managed diet, his sister said. Six workers familiar with his case told ProPublica he had a kidney disorder, and harmful foods were found in his Staten Island apartment when he died in 2016.

“The intentions were good. They were trying to get him on his own, but he had become very, very dependent on other people taking care of him,” said his sister, Marianne Harris.

Mayorby Chimilio spent four years in an adult home, where she spoke so often of suicide that staff members swept her room regularly to ensure she was not hoarding pills. After she moved into supported housing, she was hospitalized repeatedly for depression and suicidal thoughts. Her sisters said it appeared she had stopped taking her medication.

Chimilio, 41, wound up living at the Creedmoor Psychiatric Center campus on Long Island. In February, she flung herself from a rooftop and died.

“There should have been more of a step-by-step process,” said Ms. Chimilio’s son, Davon Blanks, 25. “She needed a more collaborative effort, more coordination.”

Some families, working with ProPublica, have tried to obtain the results of state investigations into the deaths but were refused. Officials said these were internal documents shielded by state law.



Sam Tsemberis, a housing expert, testified for the plaintiffs in the landmark lawsuit but declined to participate in the program.

The right to fail

Antonia Lasicki, the executive director of a New York trade group that represents nonprofit housing providers, was initially skeptical of the settlement but now supports it. Ms. Lasicki said services have gotten better and members of her trade group have told her there was a high success rate, although she did not have data.

She said the state has not required extensive documentation of failures. “It would be like you or I reporting to the government if something happened in our apartment,” Ms. Lasicki said. “It would not be a normal thing to do.”

A psychologist who testified for the plaintiffs in the lawsuit, Sam Tsemberis, disagreed. In the early 1990s, Mr. Tsemberis created Pathways Housing First, which helped severely mentally ill homeless people live on their own with help. He ultimately declined to participate in the supported housing program.

“If they were just like anyone else, why would they be sending them an Adult Home Plus coordinator?” he asked. “Why would you send them a housing case manager? How did they trick themselves into absolving responsibility for care?”

The argument underlies the biggest debate in the transition from adult homes to supported housing. Mentally ill people, some advocates argue, deserve the “right to fail” and the “dignity of risk.”

The debate surfaces in cases like Mr. Clemente’s.

A few months before Mr. Clemente moved out of his adult home last year, the company that had been managing his health care warned the rest of his team that he was not interested in learning how to handle his medication.

“At this time,” the company said, “we cannot safely provide service to this member in a supported apartment.”

Mr. Clemente moved out anyway.

By January 2018, records show, he was hospitalized. His care coordinator told the police he tried to hit her after being off his medication for five days. Records show he had been violent in the past, admitting to evaluators that he spent time in prison after stabbing his wife and her lover.

In February, Mr. Clemente accidentally started a fire in his apartment. The agency overseeing his home health aide recommended he should move into a more supervised system, called Level II housing. Another agency disagreed. In March, he started another fire.

In May, an aide quit because she was “in fear of her life,” records show. By the end of July, the company that had been managing his health care said it would no longer work with him because he continuously refused its services.

In September, he turned down a bed in a Level II group home in Brooklyn — a fully staffed psychiatric facility — because it did not allow smoking inside, according to two staffers.

ProPublica and Frontline shared details of Mr. Clemente’s experience in supported housing with several experts, including Mr. Zucker, the advocate who launched the case.



Mr. Clemente inside his Brooklyn apartment.

Mr. Zucker offered to help Mr. Clemente directly and then asked a question: “Is he unhappy?”

Dr. Geller, the Massachusetts hospital medical director who testified at the trial, said that was the wrong question.

“We have a lot of people who we commit who are perfectly happy, but they otherwise cause problems for society, that endanger other people, endanger themselves,” he said.

Ms. Lasicki has found herself wondering if the pendulum has swung too far.

“I tend to take the position of: More freedom is better than less freedom,” Ms. Lasicki said. “But there are cases where you have to wonder, ‘What are we doing?’”

Mr. Clemente remained in supported housing until the fall, when one day he wandered into his former Brooklyn adult home, convinced he had a job as a security guard and people owed him money. An ambulance took him to an emergency room, where he got into an altercation. He was sent to a psychiatric ward.

On Nov. 1, Mr. Clemente moved back into an adult home.