

Fed-up families say N.J. ignores abuse in group homes. But that may change soon.

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Jennifer readily admits her 24-year-old son, incontinent and diagnosed with autism and psychiatric disorders, is "not easy."

But she says it's outrageous that he was assaulted and neglected in each of three group homes in which he has lived. One day last year, he took off his clothes, slipped out a first-story window and fled from the group home in Burlington County without staff noticing, according to a police report of the incident.

"I call the (state) hotline and they know me by name. But they do nothing," said Jennifer, who requested anonymity to protect her son from retaliation. "They are not creating a safe environment, where they have medical and behavioral care. It's glorified babysitting."

Jennifer represents a growing chorus of parents in New Jersey who are disgusted with what they see as the lack of accountability from group home operators, as well as the state regulators that oversees them.

This week, a pair of longtime disability advocates released their own blueprint for how the state should make group homes safer. It lands at the same time a prominent lawmaker and officials from Gov. Phil Murphy's administration officials confirm they are close to introducing proposals to improve scrutiny of the group home industry.

New Jersey regulators should be given the legal authority to fine group homes that have abused and neglected people with developmental disabilities "in violation of the civil and human rights," according to the report by Donna Icovino of Bucks County, PA. and Cyndy Hayes of Burlington County, parents with disabled sons who now live in safe group homes after difficult experiences.

They also urged the state to transfer the internal investigative responsibilities of group homes, psychiatric facilities, state-run developmental centers — any place where people with developmental disabilities live — to the Attorney General's Office.

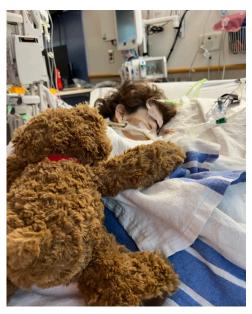
Involving the Attorney General's Office would remove what they see as a conflict of interest between group home providers and the state departments of Human Services and Children and Families, which license group homes but are also dependent on the industry to house nearly 10,000 people with developmental disabilities.

With this conflict, "Even the most well-intentioned efforts to resolve the issues related to abuse and neglect continue to fall further out of reach, putting the well-being of children and adults with intellectual and developmental disabilities in dire jeopardy," Icovino said.

There are many obstacles to reporting abuse and neglect, according to the report. The residents themselves may not understand what is happening or be able to speak up for themselves. Staff members who witness mistreatment want to help fear retaliation.

"Even when individuals or their staff do report incidences of Abuse and Neglect, these allegations are not given the same level of criminal or legal justice as neurotypical people are afforded," according to the report. "Individuals with complex severe behavioral health conditions are at greater risk of being abused, because of the acute nature of the challenges they experience. These are just a few of the many reasons why we need to be extra vigilant and provide specific training and supervision when it comes to overseeing all aspects of an individual's care and staff support."

Their work began after NJ Advance Media published "Alone, Autistic and Afraid" on Feb. 1, a report about Leah, a non-verbal young woman with a rare genetic disorder and autism spectrum disorder who endured extreme medical neglect and maltreatment while under the care of a group home in Ocean County, according to doctors who treated her. Leah needed to have all of her teeth removed because of extensive dental neglect, and she nearly died from complications from oral surgery, according to medical records.



Suffering from dental surgery complications, Leah was transported to Children's Hospital of Philadelphia in June 2022. Her family, from Middlesex County, is suing the Special Children's Center in Lakewood for medical neglect and abuse.

State officials investigated but did not substantiate her mother's complaint of medical neglect the group home, the Special Children's Center in Lakewood. The center has declined to respond to NJ Advance Media's requests for comment.

Paul Aronsohn, the New Jersey Ombudsman for Individuals with Intellectual and Developmental Disabilities, called on lawmakers to pass a law that would give the agencies that regulate group homes the authority to impose fines on the most egregious or repeat offenders. If the Health Department is permitted fines habitually bad nursing homes, he said, why can't disabled people deserve the same protections?

After the NJ Advance Media story published, state Sen. Joseph Vitale, D-Middlesex, who chairs the Senate health committee, and Senate Majority Leader Teresa Ruiz, D-Essex, said they would pursue the matter.

"We will look at those (fines) and work with the industry and the advocates. We will listen to what they have to say," Vitale said in February. "When someone is put in danger, there has to be some level of punishment that gets their attention."

Last week, Vitale said he expects to introduce legislation next month that would propose financial penalties for the worst offenders.

"Money motivates people to do the right thing," Vitale said. He declined to discuss the proposal until it was introduced.

The parent-activists' proposals earned the backing of Javier Robles, co-founder and chairman of the NJ Disability Action Committee, and a professor and co-chair of the Rutgers University Disability Studies committee.

"Why should these organizations where there are multiple events happening where people have been abused, why should they retain their license, and why shouldn't be these people be fined so it hurts them when they do it?"

"People with intellectual and developmental disabilities are some of the most vulnerable citizen and our mechanisms for protecting them are horrible," Robles said.

In his latest annual report released in July, Aronsohn renewed his call for fines. He said families contact his office on a daily basis to share the "heartbreaking stories and horrifying pictures" of abuse and neglect in group homes.

Icovino, who co-authored "The Family Crisis Handbook" and has served as support counselor for the Rutgers University Behavioral Health Care Mom2Mom Helpline, said she and Hayes were motivated to study the issue after the NJ Advance Media story and the Ombudsman's findings.

Hayes, a psychologist, said her son suffered in group homes and a state developmental center for years. It wasn't until she requested public funding to design a housing program and hire staff seven years ago did conditions improve. She said she wants other families to have the same opportunity.

"The results were clear - finally my son was able to live with the safety, health and respect he deserved," Hayes said.

The spokesmen for the state Commissioner of Human Services Sarah Adelman and Department of Children and Families Commissioner Christine Norbut Beyer also confirmed work on a bill is underway.

"The Department appreciates and welcomes input from families and guardians. We had not received the referenced white paper from advocates but are confident that we have shared goals," Human Services spokesman Tom Hester said.

"Over recent months, the Department and Senator Vitale have partnered to create a bill package that will strengthen the already-robust system of provider oversight," Hester said. "We look forward to sharing more soon. Our goal, as always, is to support individuals with intellectual and developmental disabilities to thrive in our communities."

The Department of Children and Families "is coordinating with the Department of Human Services to explore and support a remedy that speaks to many of the same concerns, and further develops accountability and transparency in our system," spokesman Jason Butkowski said.

Representatives from the group home industry agreed they were working together on a solution.

Cathy Chin of the Alliance for the Betterment of Citizens with Disabilities said her members "will remain extra vigilant in our efforts to provide individuals with intellectual and developmental disabilities the safety and security they require and the dignity and independence they rightly deserve."

But some pushed back on the notion that problems were widespread or that state oversight is weak.

"There are multiple investigation units within the Department of Human Services, all of which conduct comprehensive reviews of all reported cases of abuse, neglect, or exploitation," said Valerie Sellers, CEO for the New Jersey Association of Community Providers.

"In fact, New Jersey has more oversight of abuse, neglect and exploitation than any other state," Sellers said.

Celine Fortin of The Arc of New Jersey, stressed there is a push right now to improve training for direct care workers who take care of people with challenging behaviors.

"Any case of abuse and neglect is deeply concerning," she said. "But there is so much going on right now on the prevention side."

"We also need to keep in mind there are thousands of people who are served in the community and they are served well," Fortin said.

Leah's mother, who requested anonymity to protect her daughter's privacy, said she was "happy to hear this is moving ahead."

Leah, 21, is in a new group home in Middlesex County that welcomes the family's close involvement and is transparent about her care, her mother said. But she remains incensed that no one has taken responsibility for her daughter's suffering. She filed a lawsuit against the group home in Lakewood last year that is still pending.

Leah's mother and other parents have formed their own advocacy organization called "Also Human," so named, she said, because it seems society does not see people with developmental disabilities as worthy of life and dignity like everyone else.

"I want to get to the point where you don't need special laws for people with disabilities. All laws should apply to all residents of New Jersey."

The parent advocates' hope their blueprint can unite everyone involved to improve safety and dignity for people with intellectual and developmental disabilities.

"It will require the collaboration of all stakeholders, including self-advocates, families, advocacy groups, state-leadership, human service departments and divisions, service providers, outreach organizations, law enforcement, the IDD Ombudsman's office and the community at large," the report said.

"This mandate represents a major systemic change," the report said.