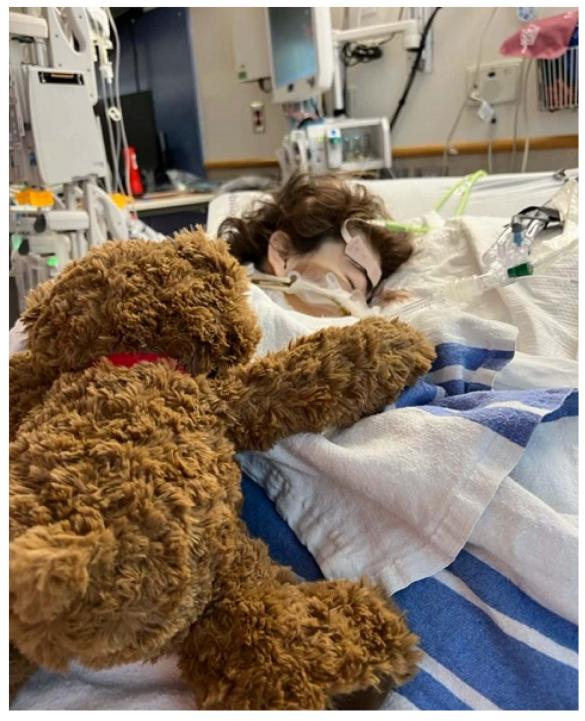


N.J. leaders vow to toughen group home oversight after NJ.com report

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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.

By Susan K. Livio | NJ Advance Media for NJ.com

When hospitals and nursing homes make mistakes that jeopardize patient safety, the state Health Department wields the authority to demand improvements by imposing fines. But state agencies that oversee group homes and other services for people with intellectual and developmental disabilities don't have that legal power.

Two prominent state lawmakers say they are considering ending this inequity by drafting legislation that empowers the state departments of Human Services and Children and Families to fine group home operators with serious deficiencies that put vulnerable residents in harm's way. They also vowed to look into how the state investigates complaints about group homes.

The proposal emerged from a Feb. 1 special report by Advance Media, "Alone, Autistic and Afraid," which examined what doctors called medical neglect and maltreatment of a non-verbal young woman with Cornelia de Lange syndrome, a rare genetic disorder and autism spectrum disorder while under the care and supervision of a group home in Ocean County, until her eviction two years ago.

At age 18, Leah needed to have all of her teeth removed and undergo treatment for malnutrition after she went for a prolonged period of time in pain without receiving acid-reflux medication, basic dental hygiene and medical evaluations, according to medical records and internal communications with staffers shared by her mother. The state Department of Human Services investigated and concluded that the group home provider, Special Children's Center in Lakewood, did not neglect her, despite concerns, "including (her) low weight and the fact that none of (her) teeth could be saved."

"Whether this was a systematic failure, a leadership failure or a staff failure or all three, any reasonable person would conclude she was recklessly and severely neglected," said state Sen. Joseph Vitale, D-Middlesex, the chairman of the Senate Health, Human Services and Senior Citizens Committee. "If it were my kid, my head would explode."

In the report, the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families noted that aside from revoking a license, the law does not allow state regulators to levy fines against group home providers to demand improvements and punish blatantly harmful behavior.

Vitale said he and Senate Majority Leader Teresa Ruiz, D-Essex, are considering legislation that would give the state the authority to impose fines — a remedy available to the Health Department, which licenses and inspects hospitals, surgery centers and nursing homes.

Vitale also said he would examine the rigor with which the state investigates abuse and neglect complaints, a longtime concern for many parents and advocates.

"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. "When someone is put in danger, there has to be some level of punishment that gets their attention."

"You can't excuse what happened here and say we should not have more accountability," Vitale added.

Ruiz agreed. "Either they are meeting the guidelines for treatment, and if they are not meeting them, there should be an infrastructure that holds the agency accountable."

"As a parent, this is devastating," Ruiz added. "We have to look into this."

State Senate Minority Leader <u>Anthony Bucco</u>, R-Morris, called ordering fines when group home providers harm the vulnerable people under their care "a no-brainer." He said he would look to introduce the legislation or work across the aisle with Democrats, who control the 120-member state Legislature, to see this happen.

"It's also the parents and relatives of these people group homes. They have to be able to sleep at night knowing their loved ones are safe," Bucco said.

Paul Aronsohn, the Ombudsman, welcomed support for the proposal, writing in an email, "There need to be real consequences for substantiated claims of abuse and neglect, including significant financial penalties against culpable provider agencies."

Aronsohn also pledged to convene a working group for a "meaningful dialogue concerning abuse and neglect in state-licensed congregate settings."

<u>In previous annual reports</u>, the Ombudsman's office has identified the safety of residents and the quality of the state's investigations into mistreatment as serious issues needing more attention.

Aronsohn said Gov. <u>Phil Murphy</u>'s administration "should lead an open and frank discussion about abuse and neglect — a discussion that includes individuals, families, advocates, providers and legislators," Aronsohn said.

Representatives for the group home and other service providers said they are ready for this conversation.

Cathy Chin, executive director for the Alliance for the Betterment of Citizens with Disabilities, noted that she called for an advisory panel after the last Ombudsman's annual report.

"ABCD would be happy to participate," Chin replied in an email. "Regarding fines, I don't know enough to comment. Perhaps that should be a consideration of the advisory group."

Tom Baffuto from The Arc of New Jersey, a nonprofit organization that represents the interests of providers and families, said, he too would participate and keep an open mind. "The Arc of NJ would be willing to participate and consider all options available at this point," he said.

The co-founder and executive director for the Special Children's Center Chaya Bender and the nonprofit's attorney Thomas Madden did not respond to a request seeking comment this week. They also did not respond to calls, a certified letter and emails seeking comment before the report ran last week.

The state Department of Children and Families pays to board two children with disabilities at the Special Children's Center, department spokesman Jason Butkowski said. The department halted admissions in 2020 after the center declined to consider additional children for placement.

NJ Advance Media is not identifying Leah by her true name at her family's request, fearing that speaking out so forcefully against community housing providers would lead to retaliation as Leah is able to enter the adult system of services when she turns 21 this year.

Leah's mother, who is suing the Special Children's Center for gross negligence, said she is gratified that after seeking justice for her daughter for more than two years, there is a path forward.

Leah was placed in a medically induced coma in June 2022 stemming from complications from the oral surgery required to remove her "unsalvageable" teeth, according to medical records. The Ocean County Prosecutor's Office has declined to bring criminal charges but says the case remains open.

"Victims suffer in stages, first by direct actions of their abusers and then through inaction of those who are tasked with protecting them," said Leah's mother, a mother of four from Central Jersey.

"In my daughter's case the abuse was perpetuated by all who failed to help Leah despite the obvious signs of abuse, evidence, testimony — (state officials), law enforcement, medical professionals - the exception were the very few who saw my daughter as also

human, deserving of rights, justice and protection. The entire system must be overhauled if people with (intellectual or developmental disabilities) continue to be hurt without any consequences for those who harm them."