
Special Report

Alone, autistic and afraid

Medical records and witnesses say Leah was severely neglected at her group home. The state disagreed.

Today 7:30 AM

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



Leah is an autistic young woman who cannot speak.

But through her tears, her desperate gestures in sign language and rapid weight loss, she had been pleading for help for months in 2021, her mother said.

In the fall of that year, Leah's teachers contacted her mother to report the 18-year-old's growing agitation and aggression in the classroom. Medical evaluations soon revealed her daughter, who resided at the **Special Children's Center**, a group home in Lakewood, had been living with searing mouth pain from advanced tooth decay that left her teeth "not salvageable," according to hospital records. Employees at Leah's group home privately told her no one was consistently administering her prescribed acid reflux medication and brushing her teeth.

When anti-psychotic meds failed to soothe her, group home workers who “needed a break” from her unruly behavior locked her in her room or took her to the local hospital’s psychiatric unit, according to records and text messages exchanged between group home employees and her mother that she shared with NJ Advance Media. Another text message included a photo of a rope tied from the doorknob of her daughter’s bedroom door to a banister, to prevent her from escaping.

The final showdown came one night in January 2022, when the teen’s mother and her oldest daughter paid a visit to the group home. A security guard blocked them from entering, saying they needed to make an appointment. Leah’s mother called the Lakewood Police Department for help entering the house, according to a police report and an audio recording made by Leah’s family.

What they saw shocked them. Giving her a bath, they could see her Leah’s ribs. Her bones seemed to be poking out from her papery skin, her mother said.

Shortly after that visit, on Feb. 2, 2022, a Center employee drove Leah to Monmouth Medical Center South in Lakewood and left her there.

(NJ Advance Media is identifying her as Leah at her mother’s request. Her mother also asked that she not be identified because she fears other group home operators may shun her daughter as the family searches for Leah’s next placement.)



Leah was transported to Children's Hospital of Philadelphia after suffering oral surgery complication in June 2022. Her family is suing the Special Children's Center in Lakewood for medical neglect and

The next day, the Center's Executive Director Chaya Bender emailed Leah's mother stating she would not be allowed to return. "Current circumstances have made it impossible for the program to continue to meet (Leah's) needs safely," according to the letter.

Leah's mother believes the Special Children's Center betrayed the family's trust — and also feels her daughter was abandoned by the state.

State Human Services officials declined to substantiate allegations of abuse or medical neglect against the Center in two investigations — even after seeing letters from doctors who examined and treated Leah stating there was no other way to explain her weight loss and unsalvageable tooth damage.

Families and some disability advocates and parents have long questioned the thoroughness and objectivity of state investigations into abuse and neglect — believing the bar is set too high to substantiate harm. Cases like Leah's reveal larger problems advocates say need to be addressed to protect residents of New Jersey group homes.

In its **latest annual report**, the New Jersey Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families described working with scores of families who are frustrated no one is held accountable when their loved ones are mistreated.

"What does it take for DHS to substantiate an allegation?" said Leah's mother, who is suing the Center. "I need people to be aware what happened to my daughter. I want to expose the system because there is no justice for her."

Bender, the Center's co-founder and executive director, and the nonprofit's attorney Thomas Madden did not return several calls and emails seeking comment for this story. They also did not respond to certified letters sent to their offices in Lakewood and Parsippany, respectively.

Eva Loayza-McBride, spokeswoman for the Department of Human Services, which investigated Leah's case, declined to discuss this case. But she stressed the department's Office of Investigations' 60-person team "conducts thorough, independent, objective and timely civil investigations."

"There may be instances when a burden of proof cannot be established, so a substantiation does not occur," she added.

"The Department demands the best from the providers and caregivers that support the individuals we serve, and our top priority is always the health and safety of individuals with intellectual and developmental disabilities," she added.



Leah lived at this group home in Lakewood until she was evicted by the Special Children's Center in 2022. Susan K. Livio

Group homes are intended as safe spaces allowing individuals with intellectual and developmental disabilities to live in home-like settings within their communities. The homes are regulated by the state and funded with public money but are privately operated and managed, offering 24-hour supervision, personal assistance, socialization and medical oversight. The state performs annual inspections as well as surprise checks.

The Special Children's Center describes itself as a full-service agency for people of all ages with developmental and intellectual disabilities — from group homes, daycare and preschool to after-school programs to summer camp and job training, according to its website. It provides a kosher living experience, a valued asset to the area's large Orthodox Jewish population.

According to the nonprofit's 2021 tax return, it is supported by 557 employees, just as many volunteers and \$30 million in assets.

The nonprofit was founded by Bender and Jenine Shwekey, and grew out of their willingness in their teens to provide respite care for families privately struggling to raise a child with physical and developmental disabilities, according to a YouTube interview last year.



Special Children's Center's founders Jenine Shwekey, left and Chaya Bender appeared on a Youtube show, Meaningful People last year. They discussed how and why they created the nonprofit, which they said assists more than 600 children with disabilities and their families. "You can't believe behind closed doors what is happening," Shwekey said, describing the pressures families face raising children with disabilities. YouTube

The Special Children's Center started out in a small apartment in Lakewood about 25 years ago and now includes two community facilities, a 30-acre farm, and a day camp in Deal, Bender and Shwekey explained in a 90-minute interview on the podcast **Meaningful People last year.**

They said they provide day care to nearly 100 infants and toddlers, and respite any day of the week when parents need help — maybe because they are sick or want to spend time focusing on a newborn or the needs of their other children. Records show it operates three group homes in Lakewood, including the one where Leah lived, with a combined capacity of 14 young people, according to the state **Department of Human Services' licensed provider report card.**

"We take with the hardest of the hard. We take everyone," including kids who can't sleep, Bender said. "Staff are up with them the entire night."

They are also prolific fundraisers to meet the needs of the community — which extends to families in Brooklyn. The amount the state pays the Center is not "a baseline as to what your child will get. We see the kid and we see the need" and spend accordingly, Shwekey said during the interview. Their goal was to raise \$20 million, she said.

New Jersey pays group homes like the Special Children's Center \$805.31 a day per child — nearly \$240,000 a year, state officials said. During the current fiscal year that began July 1, the Department of Children and Families has paid the Center \$541,168.32, and \$6.5 million to group homes statewide serving similar disabled children, department spokesman Jason Butkowski said.

In September 2020 — about a year before Leah’s mother discovered her deteriorating condition — the state stopped sending children to the Special Children’s Center. But it wasn’t because of accusations of mistreatment.

The Department of Children and Families, which licenses and inspects group homes for kids, objected to the Center’s refusal to consider five prospective children for placement in 2018 and 2019 even though “there have been multiple vacancies in these homes,” according to a letter Assistant Commissioner Mollie Greene sent to the Center’s executive director.

Greene referred the matter to the Division of Civil Rights in the state Attorney General’s Office “for further review and we do not have any additional information at this time,” Butkowski said. The Attorney General’s Office declined comment.

In March, the Center’s group homes received three stars — the highest grade possible on five measures, including “compliant with health and safety standards” — in a provider report card compiled by the Department of Human Services. But the overall grade slipped from three to two stars in a September report, largely because it scored low on “follows up timely with protective and corrective actions in response to critical events.”

The report cards once included the number of complaints filed and how many were substantiated. But last year, Human Services scaled back the depth of information because provider agencies found it “punitive” and “families and the general public” criticized it as “too technical,” according to the DHS website.

Interviews with two former employees, who spoke to NJ Advance Media on the condition of anonymity, fearing retribution from the close-knit Orthodox community, said at times management operated on a shoestring budget and skimmed on essentials. Requests to take children to the doctor were at times denied, and behavioral problems were “solved” with medication to make them sleep or calm, they allege. They both expressed grave concern about Leah’s deteriorating health.

A dream come true

The Special Children's Center became Leah's home when she was 11.

Her mother, a Central Jersey resident, thought it was a dream come true for Leah, her second of four children, who would impulsively run into traffic. Leah needed more support and supervision than her family could provide at home, she said.

"For years I walked around thinking she was in an amazing program," she said. "They had someone sleeping outside her bedroom on an air mattress to monitor her. I was so happy. It was a Jewish home, and the staff were sweet beyond sweet. This was not just a paycheck to them."

Leah was born with **Cornelia de Lange syndrome**, a genetic disorder found in one-in-10,000 births, and autism spectrum disorder. Besides developmental delays, small stature and other physical abnormalities, people with Cornelia de Lange often live with medical conditions like gastroesophageal reflux disease, or **GERD**, that can weaken their teeth. But with medication and oral hygiene, tooth decay can be kept in check.

To keep her digestive system and her teeth healthy, Leah needs to take medication to control the acid reflux and brush regularly. She can't do this on her own; someone must hold her hand and guide the toothbrush. And for years, according to medical logs her mother checked, the staff seemed to be taking good care of her, Leah's mother said.

Conditions dramatically changed in 2021, her mother said. On visits, Leah's mother said she found the medicated toothpaste tube sealed. A text message from a worker confirmed what was going on.

"Her (anti-reflux medications) were often not given with the rest of the meds we force fed her. When instructed on giving medications I was told they weren't important and to not worry if she didn't want them," according to the text message to Leah's mother.

“Also, we were supposed to sign off on all the medications, including the toothpaste, which wasn’t opened and didn’t have an accompanying toothbrush, and I would leave them blank for R (code for refuse) for months.”

According to the state’s investigative report shared with Leah’s mother, employees and managers from the Center told the state Leah would aggressively act out and run out of the bathroom when it came time to brush her teeth. She refused to finish meals and became a picky eater.

On weekend visits, the family said they noticed Leah’s increasingly gaunt appearance, her thick hair turning wispy and her anxious demeanor. Her mother said Leah would squeeze her face, but at the time she didn’t know Leah was in constant pain.

On Thanksgiving weekend 2021, Leah’s mother received a text from Bender, the executive director, explaining they were taking Leah to Monmouth Medical Center South’s psychiatric unit because her behavior was out of control, and staff “needed a break very badly,” according to a text message exchange reviewed by NJ Advance Media. Leah’s mother called the hospital and demanded they not admit her. The manager instructed employees to take Leah to another Center group home, which was vacant, Leah’s mother said.

On Dec. 11, 2021, she received a text claiming Leah is “climbing the walls” in pain.

Leah’s mother said she is horrified she did not see how much pain her daughter was experiencing. Anyone who has suffered through a toothache knows how painful that is; the idea Leah lived with throbbing pain throughout her mouth for months devastates her, she said.





This photo of Leah in an emaciated state was taken Jan. 31, 2022, during a family visit to the Special Children's Center in Lakewood. Courtesy of Leah's Family

Doctors at Monmouth Medical Center South noted Leah has been “physically and mentally declining de-conditioning probably related with poor care in her group home,” according to a physician’s report from a visit on Dec. 21, 2021. “She has been showing progressive aggressive behavior which could be the consequence of what is mentioned above.”

Group home employees, meanwhile, were instructed to ignore Leah’s mother’s frequent calls, according to texts employees later shared with her:

“(Leah’s) mom is texting me if she is sleeping. Am I allowed to reply to her?”

“I think you should ignore her, no? When she texted and called me this morning I ignored her.”

“Oh ok. I was told I’m not allowed to communicate with her directly to the parents, but in a way I feel so bad that she’s worried for her child...I feel terrible to ignore her...What should I do?? Help!!!”

After leaving the Center, Leah spent nearly a month recovering at the **K Hovnanian Children Hospital** at Jersey Shore Medical Center in Neptune.

In a Feb. 7, 2022, report, Chief Pediatrician **Dr. Steven Kairys**, who directs the hospital’s Child Protection Program, wrote: “The horrendous nature of dental decay should have been picked up much earlier and dental restoration plans developed. From talks with a worker who is no longer at the group home, (Leah’s) teeth were never brushed and there were no visits to a dentist.”

Leah “arrived emaciated,” Kairys wrote. “There was no organic reason for her weight loss. She clearly has difficult eating patterns and there is no evidence that her precipitous weight loss was ever tracked and followed at the group home and no

evidence that any medical attention or intervention was carried out of the group home administration.”

Leah moved into a group home run by Bancroft in March 2022. But a frightening medical complication nearly claimed her life a few months later.

Leah was sedated to have her teeth removed on June 20, 2022. But later that day, she aspirated blood and choked on gauze left behind, according to medical records. Paramedics took her to Virtua Voorhees Hospital, then to Children’s Hospital of Philadelphia, where she was put on a ventilator in a medically induced coma. Leah’s siblings rushed to her bedside to say goodbye, their mother said.

She spent nearly two months recovering at the hospital, then returned to the group home run by Bancroft in Voorhees.

In September, the family’s attorney filed a lawsuit in state Superior Court alleging gross negligence against the Special Children’s Center.

“(Leah’s) case is unique in an absolutely horrific way. It’s the most extensive case of dental hygiene neglect I have ever seen,” said David Cohen, an attorney in Red Bank who has represented disabled and senior clients for 25 years.

The Center’s attorney Thomas Madden of Parsippany replied to the lawsuit in December, denying any negligence and pointing an accusatory finger at Leah and her mother.

“Plaintiffs were guilty of sole and/or contributory negligence which was the proximate cause of the damages or injuries,” according to the court filing.

Cohen called this a boilerplate response. If this is the defense the Center uses at trial, “disappointment and outrage would be understatement,” Cohen said.

Another family sued the Center last year alleging life-threatening neglect of their daughter.

The young woman with “profound disabilities ... was left unattended, unsupervised and without proper safety measures in place, which allowed (her) to jump out of a window in her group home and sustain serious and permanent injuries” in August 2020, according to the lawsuit. The family’s lawyer declined comment on the pending case.

In October, The Center became the target of a whistleblower lawsuit filed by a group home employee, who claims she was fired for insisting managers take a resident’s claim of sexual abuse by two co-workers to police. The state investigated the assault claim last year but did not substantiate it, the lawsuit said.

No substantiation of abuse or neglect

Despite explicit findings from physicians, photos and internal text messages from group home workers documenting Leah’s suffering, the state declined to substantiate allegations of abuse and medical neglect.

“An unsubstantiated finding does not mean that the provider agency has no further responsibility or obligations,” according to the investigators’ report. “Oftentimes, and as in this case, there were related concerns noted during the investigation... Some of the released concerns included (her) low weight and the fact that none of (her) teeth could be saved.”

The state reopened the investigation in September at her mother’s urging, after NJ Advance Media shared the department’s own inspection records obtained through an Open Public Records Act request. The records detailed numerous violations at the Center’s group homes from 2020 to 2023. Even though the children’s names were redacted, Leah’s mother said she recognized her daughter’s experience in instances in which state inspectors documented missed dental and doctor visits and the reason for trips to the hospital went unexplained.

“Separately each and cumulatively, all of the findings point to how it was possible for (Leah) to get hurt the way she did. The abuse and injuries could have been prevented if DHS did their job and regulated the Special Children’s Center accordingly after

discovering all of these deficiencies,” her mother said.

The state inspectors cited the Center for hiring more than a dozen group home employees without first completing criminal background checks. It found about a dozen group home workers began employment without receiving mandated safety training.

In their second investigation in October, state inspectors determined Leah had been verbally and psychologically abused by being locked in her room and by workers joking about it. Staff also erred by not reporting a cyst, the investigative report said.



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Leah's bedroom door at the Special Children's Center was locked and a rope tied to the bannister to keep her inside, according to this photo obtained by her mother. State Department of Human Services

investigators cited the center for verbal and psychological abuse for locking her in and joking about it in a text message.

But they did not change their findings about the medical neglect or abuse. The claims were still “unsubstantiated,” according to the report.

Cohen, the family’s attorney, said his clients hope the lawsuit will force the state and group home providers to take their responsibility of protecting people who cannot speak for themselves more seriously.

“The well-meaning people tasked with protecting folks in group homes are doing their best but clearly they are not stopping the abuse,” he said.

In its annual report, the Ombudsman said “families often share stories of loved ones...being physically and emotionally abused, including through improper medicine administration, filthy living conditions and restrictive group home practices. Individuals with autism often end up in the back of police cars and in acute care hospital emergency beds for days, if not months, before being discharged on a new mix of psychotropic medicines.”

Paul Aronsohn, the Ombudsman, said he and other disability advocates want investigations that are “more robust, more transparent, and more meaningful for individuals and families.” They also want to give the state more aggressive tools, like fines, to make group homes more accountable — “something that exists for nursing homes, assisted living residences and hospitals, and something that should exist for state-licensed agencies serving children and adults with disabilities.”

Aronsohn said he is optimistic change can happen under the Murphy administration, adding the “commitment to getting it right runs deep and wide.”

While the Department of Human Services does not have the legal authority to fine a group home, it can suspend or revoke a license and appoint a monitor to oversee improvements, spokesman Tom Hester said.

The Murphy administration appointed a monitor for **Bellwether Behavioral Health**, who found dozens of violations involving medication errors, unreported abuse and problems with cleanliness, Hester said. In 2019, the state **revoked Bellwether's license** to operate group homes, where 400 people had lived.

Three group home industry representatives declined comment on the idea of instituting fines, and defended the state's diligence in investigating claims of harm. But they agreed it was time to collect the data on investigations and bring families, workers, advocates and state regulators together to discuss solutions.

"If we were in the same room and could have an open discussion, it would be a more productive way to go about it," said Tom Baffuto, executive director for the Arc of New Jersey, who suggested the Ombudsman take the lead. "If there are real and significant and habitual problems, the state needs to enforce significant consequences. But it pains me when the system is painted with a broad brush."

Valerie Sellers, CEO for the New Jersey Association of Community Providers, noted the state has "some of the strictest provider oversight in the nation," such as requiring investigators follow up within 48 hours of a complaint being filed.

Sellers said there also must be a recognition of how "extremely challenging" this work is.

"Direct-support professionals are often working with individuals with severe behavioral challenges. They have to learn to tolerate verbal abuse and physical abuse in many instances," Sellers said. "We are paying people \$18 an hour to experience all of this and yet there are families that either lack this awareness or simply feel that it's their job."

Cathy Chin, executive director for the Alliance for the Betterment of Citizens with Disabilities, another trade organization, called for an advisory group to discuss "the root causes of abuse, neglect and exploitation" and "accountability strategies."

“We all know that people with intellectual or developmental disabilities are at greater risk and experience higher rates of abuse, neglect and exploitation than the public,” she said, adding that “safety... is the number one priority” for families who “remain forever vigilant” because “they wisely operate under the assumption that abuse, neglect and exploitation will not disappear.”

“She continues to amaze us”

Shortly after Leah was evicted from the Center, her mother filed a complaint with the Ocean County Prosecutor’s Office’s Special Victims Unit. Last week, Ocean County Prosecutor Bradley D. Billhimer said in a statement to NJ Advance Media “after approximately two years of active investigation, we advised there is insufficient credible evidence to bring criminal charges. The investigation, however remains open.”

Leah’s mother said she is stunned.

“None of the evidence, testimonies, medical reports or the fact that she remains injured is enough,” she said. “They are looking for corroboration from the actual staff who neglected and abused her — that’s the lunacy of the whole thing.”

Efforts to help Leah regain her health are ongoing, and frustrating, her mother said.

She is appealing the denial from Leah’s Medicaid insurance provider to pay for permanent dentures, saying Leah will pull out replaceable dentures. Officials at Children’s Hospital of Philadelphia said in a letter it “would pose a grave risk to her health.” Amerigroup, the insurance carrier, has not rendered a decision.

Otherwise, Leah is “absolutely thriving” at the Bancroft group home, her mother said. She is no longer given anti-psychotic meds. She is slowly adding pounds to her doll-like 4-foot, 5-inch frame. Her mother hopes she’s on the right path as Leah will soon go to another group home when she turns 21 and moves into the adult system.

Through her own methods of sign language, Leah appears happy — especially on her weekly trips to Wawa for a soft pretzel, a warm cookie and a Slurpee. “Wawa is one of the few words she can say,” her mother said.

“It is astounding to see how a human soul and body can be brought back from the brink of death with proper care and love. She continues to amaze us with her will to survive and thrive.”

NJ Advance Media Staff Writer Ted Sherman contributed to this report.

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