

Hammonton school child's nursing care in dispute

By MICHELLE BRUNETTI POST Staff Writer | Posted: Tuesday, September 3, 2013 10:44 pm

HAMMONTON — At age 4, Victor Martinez is a happy and energetic boy who can't wait to start preschool.

But as a medically fragile child — he is deaf, has a cleft palate and is dependent on a feeding tube and a breathing tube due to a rare condition called Nager syndrome — Victor needs constant nursing care, even as he plays and learns like any other child.

Victor is supposed to start preschool today, and his mom, Nicolasa Martinez, who speaks only Spanish, said through an interpreter she wants him to do so with nurses who have cared for him 12 hours a day for years under the Medicaid program. They use sign language with him and know how to deal with problems that may occur with his breathing tube, she said.

Victor could die or suffer brain damage if that tube disengages or fails and isn't promptly fixed.

But in an era of escalating medical and other costs, the Hammonton School District has hired its own nurse to save about \$15,000 per year, said Supervisor of Special Services John Lavell.

“We hire qualified people,” Lavell said last week, adding that the district handles similar cases at least once a year with other medically fragile students who need constant nursing care. “Any time we look to hire our own.”

He declined to discuss the background or experience of the nurse the district hired, due to the possibility of litigation, he said. But he said he would meet with the family to discuss those specifics. That meeting had been scheduled for this morning, but late Tuesday afternoon Nicolasa Martinez said the school district canceled the meeting and she must reschedule. Lavell did not return a call Tuesday.

Preferred Home Health Care & Nursing Services of Eatontown, Monmouth County, has provided care for Victor since he was 6 months old out of its Galloway Township office. A representative said this is the first district he has dealt with in 10 years to refuse to hire nurses chosen by the family of a medically fragile child.

“We deal with more than 200 school districts in New Jersey,” said Administrator Craig Hoffer, who said Preferred has hired an attorney on behalf of the family.

Hoffer said his agency would charge the district the same rate of \$40 to \$50 per hour for its nurses that it charges the Medicaid program, and the district can apply to Medicaid for a partial reimbursement of those costs.

But from the district's perspective, children that require constant nursing care add considerably to already stretched budgets. At an average of \$45 an hour, for example, the district would pay a Preferred nurse accompanying Victor \$270 a day, or about \$48,600 a year. With more than one such medically fragile child, a savings of \$15,000 per child can add up to a significant amount of money.

Preferred also has a financial stake in continuing to care for Victor during the school day, Hoffer acknowledged.

Federal and state law requires that school districts educate all children.

In May 2012, legislation sponsored by state Sens. Jim Beach, D-Burlington, Camden, and Joseph F. Vitale, D-Middlesex, concerning medically fragile students became law in New Jersey. The law requires school districts to hire nurses who meet the same certification standards required by the Department of Human Services for Medicaid and NJ FamilyCare programs. Medically fragile children are those who require one-on-one nursing care because of medical conditions that can be life-threatening.

The new law also requires that parents of medically fragile students be allowed to choose nurses for their children — if the parents' preference would not increase costs for the school district. While costs may be higher upfront for Victor's current nurses, they may be the same or lower after Medicaid reimbursement, Hoffer said.

Nicolasa Martinez said last week that she was told at a meeting earlier this summer with Lavell and district staff that the school would hire its own nurse, even though she requested continuing with his current nurses.

No one in her family has met the new nurse, she said, and the nurse has never met Victor. She said the district did not return her calls seeking such meetings.

Lavell said he was unable to get through to Martinez with the phone number he had.

Nicolasa Martinez said she wants to stay with Victor once he starts school if a new nurse is caring for him on the bus and in the classroom. That would prevent her from seeking work, she said. She has worked in the agricultural and cleaning fields.

It was also unclear Tuesday afternoon whether the district would allow her to stay in school with Victor, although Lavell said last Thursday she could.

There are three other children in the Martinez family: Francisco, 18, Thalia, 13, and Edwin, 7, and overall Nicolasa said she has been happy with Hammonton schools. Her husband, Victorino, works, but she said she would like to be able to contribute to the family income.

Last year, Victor attended the Atlantic County Special Services School District preschool briefly, and his Preferred nurses were able to accompany him then, said Karen Fullerton-Elsohn, a registered nurse who has cared for Victor since he was a baby and uses American Sign Language with him. But it wasn't a good match and the family pulled him from the program, she said.

Nager syndrome is a rare condition that mainly affects the development of the face, hands and arms and often causes hearing loss because of defects in the inner ear, according to the National Institutes of Health. It does not affect intelligence, although speech development may be delayed due to hearing impairment. Only about 75 cases have been reported in the medical literature, according to the NIH.

Victor has had operations to correct some of his facial anomalies and will have more surgeries in the future, including one to repair the cleft palate, Hoffer said. Eventually, he will have a cochlear implant to improve his hearing (currently a headband holds a device on the outside of his skull), and will be able to breathe and eat on his own once the tubes can be removed in about two years.

"It's temporary. His need for nursing care will end," Hoffer said.

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