

The Miami Herald

Posted on Sat, Dec. 29, 2012

How Florida limits care for disabled kids

By Carol Marbin Miller
cmarbin@MiamiHerald.com



WALTER MICHOT / MIAMI HERALD STAFF

Christian Perez 13, who is medically complex and disabled, with his father Alex Perez at their home in Westchester this Tuesday, Dec. 26, 2012.

In a drab, cramped conference room in Doral, a 45-year-old single mother is fighting with the state to secure in-home nursing care for her severely disabled daughter — while the 10-year-old fights for her life.

The mother sits across a wooden table from a state hearing officer who will decide whether health regulators were right to insist she get 18 hours each weekday of nursing care for her daughter, and fewer on the weekends, instead of the 24 hours her daughter's pediatrician says are necessary. As her expert witness — a registered nurse — testifies, the woman's daughter begins to cough, then vomit, then struggle for breath

as her breathing tube becomes clogged. The hearing stops as the child's mother and the nurse suction the girl's tube, then clean, change and console her.

Generally lacking in such drama, hearings like the one that occurred Dec. 14 are held hundreds of times each year in Florida as the parents of severely disabled and medically fragile children battle state health administrators for nursing care and services for their children. Without such care, some of the youngsters will end up in nursing homes, something the 10-year-old's mother is trying to avoid.

"I think about it often," the mother says, under questioning from her attorney, Howard Talenfeld. "I'm very concerned."

In September, the U.S. Justice Department said the state had "planned, structured and administered a system of care that has led to the unnecessary segregation and isolation of children, often for many years," in geriatric nursing homes. Children in such homes often spend their days in virtual seclusion, lying in bed or watching television, the civil rights division wrote.

Rationing care

Florida has consigned hundreds of children to such a plight, the Justice Department wrote, by "reducing or eliminating the availability of in-home services that had been prescribed as

medically necessary by a child's physician, without reasonably considering the child's actual needs."

State and federal lawyers are still negotiating over the federal government's insistence that Florida sign an agreement to redesign the state's program, and allow a federal judge to oversee the state's effort.

Justin Senior, the Agency for Health Care Administration's deputy secretary for Medicaid, said Friday the overwhelming majority of pediatric in-home nursing claims end amicably with the child's family doctor and state reviewers in agreement over the care that is needed. "The long and the short of it is we always make sure the child and the family get the services they need — and err on the side of caution," he said.

Senior added: "We need to make sure we are spending our dollars — and they are finite dollars — on the things that provide significant medical benefits to our recipients."

In a deposition last February, the associate medical director of Louisiana-based eQHealth Solutions, which reviews such claims under contract with the state, acknowledged what truly undergirds the state's pediatric private duty nursing program: rationing.

"There are many children who require services in the state of Florida," pediatrician Ian Nathanson said. "There are many requests for services. And there are, in my view, just not enough resources to provide for every single child and every single request."

"It's just a fact of life," Nathanson added.

Hand on the scalpel

Florida separates the wheat from the chaff by declaring what services are "medically necessary" to a child's survival. Health administrators insist the state cannot afford to pay tens of millions of taxpayer dollars for the "convenience" of caregivers who have chosen to raise their frail and disabled children at home.

Florida children's advocates, and the justice department, say AHCA, which oversees the Medicaid insurance program for needy and disabled people, uses "medical necessity" as a scalpel to cut services to families — forcing many of them to turn to nursing homes. The homes are paid from a funding pot that is a federal entitlement.

AHCA administrators characterize their medical-necessity determinations as objective. But records and interviews suggest the agency has exercised significant influence over the volume of services that are cut.

During the budget quarter that ended Sept. 30, 2011, 55.9 percent of in-home nursing claims were rejected, at least in part, records show. The next quarter, the percentage of reviews that were denied dropped to 38 percent.

What had changed? In February or March of this year, AHCA Secretary Liz Dudek said, agency heads "set very clear standards" with the associate medical director of the company that reviews nursing claims for the state. Too many claims were being denied, Dudek said, even though the status of the child had not changed between review periods. Going forward, she added, there should "be no question that we're denying services that should not be denied."

By September — the month the Justice Department accused the state of violating the civil rights of disabled people — denials had been reduced to 19 percent.

Between July 1, 2011, and June 30, 2012, AHCA's private service reviewer, eQHealth, estimated it had saved the state \$44.8 million by cutting private duty nursing and other caregiving hours, according to the company's annual report.

A chunk of the savings, records suggest, arose from the state's decision to declare, as a statewide rule, that parents require no more than eight hours each day for sleeping and grooming. Previously, AHCA allowed nine hours of nursing care so parents could sleep.

"If a family requires sleep, or claims they're required to sleep," Nathanson said in a deposition, a state Medicaid handbook "provides some guides as to how many hours can be approved for sleep." Many families lost at least one hour of care when Nathanson suggested that recent studies show adults do not require more than eight hours sleep. Several of them complained that, as a practical matter, it meant they could only get six or seven hours, because they also had to shower, dress, eat breakfast and maybe put on makeup.

Senior, the state's Medicaid director, insisted Friday that eQHealth had been given no "incentive" to save taxpayer money. "They don't have any monetary incentive at the company to deny hours," Senior said. The doctors who review claims at the company, he added, have taken the same medical oath as the pediatricians whose prescriptions they're evaluating.

Since federal civil rights lawyers accused the state of warehousing disabled children, Dudek, AHCA's chief, has held news conferences and visited editorial boards insisting the state will pay for unlimited in-home nursing care for parents with medically complex children.

"The state believes strongly that individuals, especially Florida's most medically fragile children, deserve to be cared for in the least restrictive setting that can best serve their medical needs," Dudek said in a statement Nov. 30. "Children can receive medically necessary services in their homes in unlimited amounts and duration, up to 24 hours per day, 7 days per week."

Appeal denied

In a news release Dec. 14, Dudek outlined new "safeguards" the agency was putting in place to prevent more frail children from ending up in institutions because the nursing hours of their caregivers had been cut. One provision: "to ensure that no reductions in home health services for children occur unless there is a change in the child's medical/social circumstance, or parental ability to provide care."

One Westchester father, who emailed Dudek directly, suggested the agency head is saying one thing to reporters, but doing something completely different. There is a wide chasm "between your description and the reality on the ground," wrote Alex Perez, whose son was born with a disabling genetic disorder.

Perez and his wife, Jacqueline, are raising 13-year-old Christian at home, but the challenges of his severe developmental disabilities have become increasingly daunting.

Though Christian's medical condition has not improved, eQHealth reduced the boy's caregiving allotment by six hours each day in the company's most recent review — claiming the aides were not medically necessary. This, Perez wrote in his email, despite Dudek's claim that nursing hours will not be cut if the child's health needs remain the same.

"There is a better and more cost effective way that doesn't create a combative atmosphere, one of hopelessness for the parents, one where eQHealth can run amok," Perez wrote in his Dec. 17 email to Dudek, which was also copied to several state lawmakers.

Dudek agreed to send an eQHealth representative to visit the Perezes. But days later, the family's appeal was denied.

Underlying state policy is the belief that virtually anybody — including other children — can be taught the skills of a professional nurse. Florida's Medicaid Handbook, which articulates state policy, allows the state to decrease nursing hours for disabled children "as parents and caregivers are taught skills to care for their child." Under the policy, caregivers can be teenage children and elderly grandparents — who are being asked to oversee ventilators, suction trachs and use feeding tubes.

Elizabeth Fauerbach of Countrywalk is one such parent. Her 18-year-old son, Tyler, was born with a terrible stew of medical conditions and disabilities, including cerebral palsy, developmental disabilities, chronic lung disease, reflux, blindness and a seizure disorder. Tyler is fed with a tube attached to his stomach; since 2006, he has breathed with a ventilator. His breathing tube requires frequent suctioning, which sometimes causes Tyler to gag and become "distressed," Fauerbach wrote in a court declaration.

Fauerbach and her husband have raised Tyler at home his whole life. He goes to church with the family on Sundays, and enjoys listening to the congregation sing. "On Sunday afternoons we read together," she wrote. "We have read all the Harry Potter books, The Chronicles of Narnia, The Girl with the Golden Compass," as well as the books about a dragon named Saphira. The Fauerbachs take Tyler to the movies — he seems to especially enjoy films based on books his mom has read to him — and he sits in his wheelchair at the dinner table every night with his parents and sister.

Tyler, his mother wrote, "is very important to our family and we truly enjoy having him at home with us."

But each year, keeping Tyler at home has become more difficult; Fauerbach describes her twice-yearly battles with the state as "David vs. Goliath" conflicts. In a recent review, eQHealth reduced the number of daily nursing hours prescribed by his pediatrician from eight to zero, Fauerbach wrote. Fauerbach appealed the reduction, and when state Medicaid administrators interviewed her in preparation for a hearing, they asked her why her then-15-year-old daughter could not become Tyler's caregiver, she said.

"She loves Tyler, and wishes she could do more. She's just not trained to do more," Fauerbach told The Miami Herald. "It's not fair to ask her to take on that responsibility. It's a really big responsibility."

In testimony earlier this month, the pediatrician who is the final word on nursing cuts, Nathanson, acknowledged he had not once assessed a parent or other caregiver for eQHealth to determine whether they were capable of the often life-and-death demands placed on them.

In its annual report to the state, eQHealth said that the nursing and caregiving services to parents of severely disabled children were “without a doubt ... our most complicated area of review.

“These reviews not only encompass decisions of medical necessity, but they also factor in the socio-familial conditions in the home, the ability of the parents to care for the disabled child, and whether there are additional children [perhaps also disabled] in the home under the care of the parents,” the report added.

A mother's dread

The state's method for evaluating medical necessity was explored at length in a February deposition, and, later, in Nathanson's testimony this month, in the appeal of the 10-year-old girl with a tracheostomy tube. The Herald is not naming the child or her mother to protect their privacy.

The youngster at the center of the dispute was born with a rare genetic disorder, called Marshall-Smith Syndrome, which is often fatal in early childhood as it involves sometimes severe respiratory impairments. Since her birth, the girl has endured 21 surgeries, many of them involving her head, to correct deformities of her facial bone structure.

The girl's doctor prescribed 24-hour registered nursing care for the child, who could sustain life-threatening neurological damage in moments if her breathing tube became clogged. The state agreed to pay for 18 on weekdays, and fewer on the weekends. This year, the mother was among 1,336 parents appealing cuts to home caregiving — which represented 88 percent of such Medicaid-related hearings overall.

At a hearing on Dec. 14, Nathanson testified the girl did not require additional care, and that any other nursing hours would be for the “convenience” of the girl's mother only. Earlier this year, the mother had been accused by the state of “fraud” for asking for the hours, her lawyer said at the hearing.

Under questioning by Talenfeld, the child's lawyer, Nathanson acknowledged that no one with his company had ever examined the girl, performed any tests, done a safety assessment, read the child's medical records — or even requested a copy of them. In February, Nathanson said he did not know the name of the genetic disorder she suffers from, and knew only that the syndrome involved facial abnormalities. The company also had never explored whether the girl's mother had the skills to take care of a medically fragile child with a breathing tube, the doctor said.

“You've never laid eyes on [the girl], have you?” Talenfeld asked. “That's correct,” Nathanson answered.

Nathanson acknowledged that his company does not encourage doctors to submit detailed medical records — eQHealth's online submission system provides no place to input the

records — and, in the 10-year-old's case, he never asked for them, even though he knew the mother was appealing his cuts.

"I don't have to," he said.

"And that's why you denied this application, isn't it?" Talenfeld asked.

"That's correct."

It wasn't until the girl's mother testified at the hearing — after months of costly legal wrangling — that Nathanson learned she was terrified that her daughter would perish in her care, and that on the rare occasions the girl's breathing tube malfunctioned without a nurse present, the mom was in "panic."

"You're concerned?" Talenfeld asked him.

"Yes," Nathanson conceded. "I'm concerned."

The hearing officer, Rafael Centurion, who works for the Department of Children & Families, has yet to rule.

© 2012 Miami Herald Media Company. All Rights Reserved.
<http://www.miamiherald.com>