

On the day Dr. Mary Ehlenbach toured the Kidz Korner nursing home for children with complex medical needs, she encountered a little boy confined to one of two cribs in a large room. The boy appeared excited to see visitors, and when a caregiver lowered a railing to his crib, he bolted.

"He made a run for it," Ehlenbach, medical director of the Pediatric Complex Care Program at the University of Wisconsin, testified at a recent trial. "He hopped out of that bed and was really jetting for the door." A staff member "intercepted" him.

The child's fate, and that of 139 other Florida children who are living their lives in institutions, no longer rests with nursing home employees - or even state health administrators, who have fought for 12 years to keep them there. It now belongs to U.S. District Judge Donald M. Middlebrooks, who is presiding over a civil rights lawsuit filed by the U.S. Justice Department against state health regulators.

Middlebrooks appears poised to do what civil rights leaders and children's advocates have long failed to accomplish: help free the little boy and others like him.

"It is my tentative belief that the United States has met its burden of proving that the State of Florida is violating the civil rights of children with medical complexity who reside in nursing facilities," Middlebrooks said when testimony concluded May 19 after a two-week trial.

And the judge made clear he wants to act quickly. "The United States filed this lawsuit in 2012, and one of the tragedies of the case is that it's taken over 12 years to even get to trial, which I consider a failing of the judicial system," Middlebrooks said.

"One way or the other," the judge said, "I hope this thing doesn't continue forever...I guess, if you wanted to, you could keep litigating and continue this for years and years, but I sure don't think that solves anything."

In a landmark 1999 decision, the U.S. Supreme Court ruled that it is a violation of the Americans With Disabilities Act and a form of unlawful discrimination to essentially force people with disabilities to live in institutions. Despite that, the Justice Department argued, Florida health administrators had erected barriers for parents seeking to raise their children at home, forcing them to consign their kids to a life of loneliness and isolation in nursing homes.

Florida health administrators have fought the suit for the entire 12 years. Lawyers for the Agency for Health Care Administration, which oversees medical facilities, say the litigation threatens the state's very sovereignty, and that the agency should be allowed to house, treat and finance the care for people with disabilities without interference from federal regulators.

The state has refused to disclose how much it has paid Gray Robinson, a defense firm with about 255 attorneys - and has not responded to a request under the state's public records laws for billing information.

The long-awaited trial began on May 8. Though Middlebrooks heard testimony from several parents, much of the controversy involved a clash of experts.

Dr. Allan Greissman, a critical care pediatrician at Joe DiMaggio Children's Hospital in Hollywood, testified for the state that many of the children living in nursing homes were too frail to live outside long-term care facilities, and many were, in any case, so neurologically devastated that they are incapable of experiencing the joy or comfort of living with family.

"I reject the testimony of the state's expert on this issue...who articulated a series of problematic opinions," Middlebrooks, who presides in West Palm Beach, said from the bench, "such as that some children would derive no benefit at all from family interaction at a home setting."

"In short," Middlebrooks said, Greissman "suggested that nurses in institutions are just better at caregiving. Thus, institutions are a safer environment, and this justifies maintaining children in nursing homes."

Middlebrooks said he found such "testimony not to be credible or persuasive."

Middlebrooks' tentative findings suggest he believes Ehlenbach's testimony as well as that of other experts for the Justice Department was persuasive. Ehlenbach toured the three Florida nursing homes that accept pediatric patients, interviewed the parents of children who live in them, and reviewed medical records.

In her testimony on May 19, Ehlenbach painted a bleak portrait of life for the 140 children who live, sometimes for a lifetime, in long-term care facilities.

"I think I was mainly left with the impression that while they may have been surrounded by people, they were very alone," she said. "They were lonely."

"Most of the children that we saw at all three nursing facilities were either in bed in front of a screen, watching a screen, or were up in wheelchairs - sometimes in the hallways, sometimes in their room with a screen in front of them. Sometimes they were watching, sometimes the screen was just on."

Ehlenbach recounted one particularly disturbing incident from her tour of The Kidz Korner, a 100-bed pediatric unit in a nursing home in Plantation: "So they were beds that had metal side rails on all four sides...but they were bigger than, like, a typical baby crib," she testified.

"And one of the children, when he saw that someone came into -- people had come into the room, really perked up and was moving about the bed and clearly indicating to us that he wanted to get out of the enclosure bed. And so the person who was giving me the tour lowered the side rail, and he - he made a run for it."

A nursing home staff member "intercepted the child and placed him, sadly, back into the enclosure bed. And you could tell he was upset. You could tell that he wanted to interact with us," Ehlenbach said. "So that's something that's really - that's really stayed with me."

"Is there any child in a facility who you believe is not medically appropriate to live in a community?" Lauren Latterell Powell, a Justice Department lawyer, asked Ehlenbach.

"No," she replied.

"Is there any child living in a facility whose condition is such that a nursing facility provides them with the safest place to live?"

"No."

"All children with medical complexity who have access to the appropriate supports and services in the home and community can successfully and safely live with their - with families," Ehlenbach testified later.

During cross examination, an attorney for the state, John A. Boudet, suggested that Florida sometimes used nursing homes as a "bridge" between when children could be discharged from the hospital and then live safely with their parents. He asked whether Ehlenbach had reviewed the records of kids who were sent home.

"Many of them had been institutionalized for years and years," Ehlenbach said, "which, to me, would be a pretty long bridge."

Much of the trial's testimony concerned the biggest roadblock on that bridge: the state's profound lack of private duty nursing. Without adequate in-home care for children with breathing tubes, for example, many parents have no choice but to keep their kids institutionalized.

In his remarks, Middlebrooks said the state's "critical failure to provide families with necessary private duty nursing was the most glaring problem."

"And this was, of course, underscored by horrific stories I heard from a number of desperate parents about their personal experiences attempting to care for their medically fragile children under unthinkable conditions without adequate and reliable nursing help," the judge said.

Middlebrooks suggested the nursing shortage was only an impediment if health administrators do nothing to fix it: "The state has certainly shown that there is a nursing shortage," he said. "What I don't think they have shown is that they can just then say, 'Well, it's a nursing shortage. We can't do anything about it'."

At the trial's conclusion, Middlebrooks encouraged lawyers on both sides to negotiate toward a settlement that ends Florida's institutionalization of children with severe medical needs. But he also wielded a stick in addition to the carrot: He said he likely will order the state to make real reforms if health administrators don't agree to them first.

On Wednesday, lawyers for both sides filed a status report telling the judge they could not reach an agreement on how to remedy the state's discrimination: "At this time, the parties do not reasonably anticipate reaching agreement on language that could be included in a permanent injunction or which would be a settlement."

On May 19, Middlebrooks rejected the idea of his retaining jurisdiction over the case long-term and assigning a court monitor to oversee the state's commitment toward reform. He said such arrangements often just kick the can down the road with little real progress.

"And so if we're going to do something," Middlebrooks said, "let's do something that makes a difference."

The judge said he was "committed to bringing this case to a close - to a conclusion without undue delay. I don't want to contribute further to that 12-year delay."

"I'm not interested in something that goes on for years, because all that does is prolong the problem that the parties have identified in this case," the judge said. "In my opinion, this case has gone on long enough."

Carol Marbin Miller: 305-206-2886, MarbinMiller

Copyright (c) 2023 The Miami Herald