

# UCP decides it must act, and a patient pays with her life

By ANEMONA HARTOCOLLIS

On Dec. 7, 1979, a 23-year-old mentally retarded woman, with the stunted body of a child, died on an operating table at Maimonides Medical Center in Brooklyn as she was undergoing minor dental surgery. Her mother might have mourned the death as a shocking, if unavoidable, medical risk, except that her mother never gave permission for the surgery to take place.

More than a year later, the death of Dotinel White has surfaced as a symbol of the dangerous power and risks assumed by private agencies that care for the mentally retarded in New York state.

Dotinel lived in a 450-bed facility in Willowbrook operated by United Cerebral Palsy Associations of New York State, a private, non-profit agency supported almost entirely with government funds.

Critics accuse United Cerebral Palsy of repeatedly and boldly ignoring clear state regulations governing medical treatment of the mentally incompetent. They view Dotinel's case as a tragic consequence of the agency's reluctance to answer to outsiders and its tendency to value official convenience more than patients' rights.

Robert Schornhorn, the agency's executive director, replies that he has been forced to make decisions ordinarily left to patients or their families because the agency has found that "frankly, nobody manifested an interest efficiently."

Agency officials refuse to discuss Dotinel's case specifically, because her mother, Allean White, has filed a malpractice lawsuit against United Cerebral Palsy, Maimonides and the doctors concerned. The officials said it would be inappropriate to comment on pending litigation.

But internal documents obtained by the Advance show that Schornhorn gave the consent for Dotinel's surgery — even though state mental hygiene law forbids agency administrators to authorize elective surgery without a state Supreme Court order.

Dotinel's death escaped the notice of authorities outside the agency because United Cerebral Palsy failed to report the incident to the Governor's Commission on Quality of Care, according to Paul F. Stavits, the commission counsel. Stavits said state regulations require the agency to file a form with the commission on all patient deaths.

Alerted to the death by the Advance, the commission has decided to investigate and a report is expected by September, Stavits said. If wrongdoing is determined, United Cerebral Palsy is liable to sanctions including a fine or withdrawal of its license, the attorney said.

Stavits said the commission is notified of 3,000 to 5,000 deaths in the state system annually, and selects 300 to 400 for in-depth scrutiny. A two-month investigation by the Advance has raised serious questions about the fiscal management,

accountability and direction of United Cerebral Palsy. The agency administers a \$31-million budget, consisting 98 percent of taxpayer revenues funneled through the Medicaid program.

United Cerebral Palsy is in the vanguard of a movement to replace the scandal-ridden state system of care for the mentally retarded with the services of more than 270 private agencies. It is by far the biggest agency housing and treating the retarded in New York City, with 887 residents.

In 1977, the agency took control of seven buildings in the Staten Island Developmental Center in Willowbrook, a state-run institution. The complex operated by United Cerebral Palsy was renamed the Karl D. Warner Center.

It was from the Warner Center that Dotinel was taken to Maimonides Medical Center for tooth extraction, root canal and periodontal work, according to hospital records. An autopsy report filed with the city's chief medical examiner lists the cause of death as "arterial fibrillation (a flutter pattern in the blood vessels sometimes caused by stress) and cardiac arrest during general anesthesia."

Hospital officials said full, rather than local, anesthesia is used to pacify mentally retarded patients who can't reason well enough to cooperate with doctors. An allergic reaction to anesthesia may lead to fatal complications.

Mrs. White said she learned of her daughter's death at 5 p.m. on the same day, only "hours" after it occurred. She remembers that Jerry Berkowitz, the agency's director of social work, called her at Tootie's Unisex Salon, the hairdressing business that she owns and operates in Harlem.

"He told me she 'expired.' That's how he said it, just like nothing happened, like it was nothing important," Mrs. White said. "I asked, 'Why?'"

Dr. Murray Ross, the dentist in charge when Dotinel died, insisted in an interview that the girl's family had abandoned her. He asked rhetorically: "How do you explain that the next day the parents were in the coroner's office? I'll tell you how. The father took one look at the body and he said, 'Oh, good. Now I can sue...'"

"That's degrading," Mrs. White, who is a licensed practical nurse, said when told of Dr. Ross' comment. She said she went alone to the Kings County Hospital morgue and was not aware if her former husband, Charles White (whom she divorced seven years ago), saw the body as well. She is the sole plaintiff in the malpractice suit, which names Dr. Ross as a defendant.

The father could not be located for comment. But the autopsy report, case no. K79-6388, indicates only "that Allean White, the mother, ... had the body."

far from being an absentee parent, Mrs. White said she visited the institution faithfully six or eight times every year since the day 21 years ago when she left her infant in Willowbrook. She said she gave administrators more than one telephone number, including the home number in the Bronx of the eldest of her three daughters beside Dotinel.

Peter Siringano, a member of the Willowbrook Benevolent Society, a parents' group, said that just after Dotinel's death in December 1979, he checked a green copybook kept by the administrator of Building 15, Dotinel's ward in the Karl D. Warner Center. He said he found Mrs. White's signature in the sections logging visits during the mid-summer and early fall of 1979. "A couple of days later, when we went back to look some more, the book had disappeared," he said.

Dr. Ross said United Cerebral Palsy mailed four letters, return receipt requested, to "the parents," seeking their consent for anesthesia. He said the letters were never answered.

Mrs. White, however, denied any contact from the agency prior to her daughter's death. "Nobody asked me for permission, believe me when I tell you," she said. "They don't tell the parents anything until you go over there and find out for yourself."

Sections 27.8 and 27.9 of the state Mental Hygiene regulations prohibit private agencies like United Cerebral Palsy to authorize surgery or general anesthesia without consent. If consent is not available — from a spouse, parent, adult child or guardian — the law requires the agency director to consult a state Supreme Court judge.

If a patient's life or limb is immediately threatened, a doctor is entitled to give consent, and the court can be bypassed.

But Dotinel's surgery was not an emergency measure, and a confidential letter obtained by the Advance indicates that United Cerebral Palsy flouted the law.

The letter, dated May 6, 1980, discloses that Robert Schonhorn, the agency's executive director and top officer, signed the consent for Dotinel's surgery, after she was declared a "noncorrespondent" in the agency's records, meaning her family could not be traced. The letter was written by Dr. Robert Sapin, United Cerebral Palsy medical director, to Glenn M. Rickles, the agency's lawyer.

Despite the extra time and inconvenience of a court hearing, experts vehemently support the consent law.

"Everyone has a right to be free from intrusion" without consent, said David Levine, a lawyer for the Mental Health Information Service. "That's a right founded in the Constitution. Trying to guess what a patient would decide is difficult. That's why there are courts and judges."

Members of the Consumer Advisory Board, an advocacy group for the mentally retarded, suggest that Dotinel White's death rang an alarm for United Cerebral Palsy, by threatening to expose the agency's casual attitude toward parents and the consent process.

Advisory Board members believe Dotinele's death is what spurred the agency to go to Staten Island Surrogate's Court and obtain legal guardianship of at least 47 mentally retarded residents. The 47 were among 71 residents of the Warner Center whom the agency identified as "non-correspondents," or without family.

The Advisory Board went to court to challenge the guardianships, and lawyers for the board and the agency have been negotiating since March.

Advisory Board members were particularly incensed because United Cerebral Palsy obtained the guardianships secretly over the past year, telling the judge in sworn papers that there were no other interested parties.

But the Willowbrook Consent Decree, a 1975 judgment in Brooklyn Federal Court, endows the Consumer Advisory Board with some of the powers of a legal guardian over the mentally retarded residents of the facility.

the Warner Center. The decree requires United Cerebral Palsy to consult the Advisory Board on decisions related to individuals' housing, training and recreation.

Schonhorn, the agency's executive director, said he resorted to Surrogate's Court because he believed the Advisory Board was neglecting its responsibility to the mentally retarded.

"Frankly, nobody had manifested an interest sufficiently," Schonhorn said. "I said, I've gone along like this, and I'm going to try something. Somebody has got to take the bit. Now, had the Consumer Advisory Board taken the bit, I would not have attacked them."

But anticipating a fight over guardianship, Rickles, the United Cerebral Palsy lawyer, sent a memorandum to administrators in the agency last October. The memo appears to contradict Schonhorn's passive characterization of the Advisory Board.

It advises: "We must begin pulling together documentation and recollections of oral conversations delineating CAB's refusal to sign releases for our clients and/or engaging in dilatory tactics..."

"It would also be helpful if you can document any inflammatory statements concerning UCP..."

"Finally, it may be strategically important at this point to flood CAB with numerous requests for releases for our non-correspondent clients."

Chris Hansen, a lawyer for the New York Civil Liberties Union, sent a message to the Surrogate's Court denouncing the guardianship proceeding. He warned guardianship posed a conflict of interest since administrators were hardly likely to challenge their own ability to provide services for the mentally retarded residents.

Mrs. White's malpractice suit, filed July 21, 1980, in Brooklyn State Supreme Court, has not yet come to trial. It asks for monetary damages to be determined by the court.

Explaining her motivation, Mrs. White said: "It's as if Dotinel never lived. Sometimes, when children are retarded, no one thinks about them as 'us.' They're not considered valuable. In this world, you get more valuable the more you know."

"It used to be a shame for people to see you with a child like that," she continued. "Folks are a little nicer now. When people got cancer, society used to shun them. Now the society has turned more outward. It's good that things are coming out in the open, not like it used to be."