

# 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."