

# Does UCP overregulate lives of patients in group homes?

By ANEMONA HARTOCOLLIS

On the stark, socially isolated wards of the state institution in Willbrook, Mitchell was known as a hyperactive fire-setter and troublemaker who could barely care for himself.

Today he is thriving in a group home for the mentally retarded operated by United Cerebral Palsy Associations of New York State, a private charitable agency. At age 25, he lives in a pleasant highrise apartment building in Manhattan where he tends a tank of tropical fish, cooks his own meals, and rides a city bus to a vocational training center.

If Mitchell's story is any mea-

sure, the court-ordered program to move the retarded into the community with help from agencies like United Cerebral Palsy is a success.

However, Mitchell's live-in counselor and other United Cerebral Palsy employees say the 89 apartments run by the agency in the five boroughs are mired in unnecessary restrictions. Success is possible, these critics say, only by breaking the rules.

The agency requires most of the mentally retarded clients to eat pre-packaged and delivered food, to ride in company vans and to buy clothing from the company store. Before clients can go to the movies or a restaurant on their own, their counselor must obtain permission from

the central office. Relationships that lead to sexual encounters are forbidden.

Health aides and counselors working in the apartments, who earn \$9,000 to \$10,000 a year, complain of a lack of training and support from the agency. A high turnover among employees has led the agency to replace most live-in counselors with three shifts of hourly workers daily, at increased expense.

UCP tries to dictate the whole lifestyle in the apartments, we might as well be in institutions," said a counselor who has been with the agency for five years.

Walter Rosenthal, a spokesman for United Cerebral Palsy, defended

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the centralized services as economical and needed to insure consistently good care. He said the agency has implemented an internal audit team, "to make our standards more rigid than state and federal standards."

Group homes were developed as an alternative to institutions for the mentally retarded when Gov. Carey signed the Willowbrook Consent Decree. A 1975 judgment in Brooklyn Federal Court, the consent decree forced the state to improve conditions at squalid and overcrowded facilities like the Willowbrook State School, now called the Staten Island Developmental Center.

Willowbrook once housed more than 5,000 patients, and the consent decree called for a less restrictive and more normal environment. In its effort to comply, New York State has turned over much of the care of the retarded to about 270 private agencies, including United Cerebral Palsy.

Called the Post Institutional Placement Program (PIPP), the 3- and 10-bed apartments set up by United Cerebral Palsy are funded by the state and federal governments at a rate of \$143 per day per client.

Mitchell moved from Willowbrook to an agency apartment, which he shares with two other retarded men, in 1976. "I feel my job is to make them as independent as possible," their live-in counselor says, despite a frustrating struggle with the agency's bureaucracy.

Names in this article have been changed or withheld at the request of eight counselors, health aides and case managers interviewed.

Walking down 2nd Ave. to buy groceries and preparing their own meals were rituals Mitchell and his roommates enjoyed. Every Friday one roommate, Peter, took a friend to dinner in Chinatown, spending part of the \$47 weekly wage from his job sweeping floors.

But the three men are losing the responsibility to select meals and the flexibility to eat out.

In May, United Cerebral Palsy stopped giving the counselors \$106 a month for groceries and laundry. The agency has hired Automatic Catering, a company based in Edison, N.J., to deliver pre-packaged food to the apartments.

"We want to be absolutely sure they aren't eating pizza four times a week," Rosenthal said. "The menus are filed by a nutritionist, and if it's Tuesday, it's chopped liver."

During the past five years, their counselor has taught Mitchell and his roommates to ride city buses to their jobs, vocational training, a disco and a restaurant.

Hundreds of other clients living in the apartments are required to travel in a fleet of vans operated by United Cerebral Palsy, at an annual cost of \$650,000. The vans are specially equipped to handle wheelchairs, an advantage over public transportation. But because they are dispatched from a depot in Staten Island, the vans often run late in other boroughs.

Mitchell's counselor won the option for his clients to commute in city buses, but it wasn't easy. He arranged a meeting with United Cerebral Palsy administrators, arguing on the clients' behalf until the administrators drew up a written agreement.

"He likes women and he likes baseball," a health aide said about a moderately retarded man in one of the apartments who has developed a discreet sexual relationship with a neighbor who lives alone.

Sexuality is a controversial area. The agency has adopted a protective attitude, segregating male staff and clients in different apartments from the female.

"If someone can shoot the president or a queen, you can't keep your eye on everybody," Rosenthal admitted. But he said United Cerebral Palsy "has made a policy decision: No sex between consenting adults; retarded or otherwise."

Legally, the mentally retarded are entitled to the same sexual freedom as any normal person unless they have been declared incompetent by a court order, according to Chris Hansen, an attorney for the New York Civil Liberties Union.

Unlike Mitchell's counselor, the majority of employees in the apartments work in shifts. Veteran counselors say the mentally retarded clients become disoriented when staff quit or are absent, as often happens.

Insufficient training contributes to the absenteeism, employees say. The agency requires a course in dispensing medication, which Rosenthal said deals with simple matters like "the difference between a teaspoonful and a tablespoonful." Otherwise, training takes place on the job.

Rita Martin, coordinator of the Community Advisory Board, a group of court-ordered monitors of care for the mentally retarded, complained of the high "burnout rate" in a letter to State Mental Retardation Commissioner James E. Inthone, nearly a year ago.

To compensate for absenteeism, United Cerebral Palsy has assigned overtime work in the apartments to therapy aides from the Karl D. Warner Center, a 450-bed institution operated by the agency in Willowbrook. The overtime plan was outlined in a memo distributed to Warner Center staff last March.

Even Mitchell's live-in counselor is considering leaving the program. The counselor contends his three clients — who read simple phrases, dial the telephone and count money — are ready to manage the apartment themselves, with a visiting supervisor. Although Mitchell and his roommates approve of the idea, it means breaking one more rule of the United Cerebral Palsy program.

Last article in a six-part series.

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