

Our opinion

# State must improve monitoring of UCP, other organizations

What has happened is that thousands of retarded persons have been transferred, in a slow but steady stream, from the custody of the state to the custody of more than 270 private organizations. Those groups not only are responsible for the well-being of thousands of human beings, but also are entrusted with tens of millions of dollars in public funds annually under their contracts with the state.

Yet the state seems unable to effectively monitor the organizations to which it has given responsibility for thousands of lives and millions of dollars. The potential for abuse is real, and the need for remedial action is immediate.

\* \* \*

The Advance, in a two-month investigation of the largest organization now providing care for the retarded, has uncovered alarming evidence of questionable practices involving both patient care and the use of public and patient funds. The organization — the United Cerebral Palsy (UCP) Associations of New York State — has consistently maintained its innocence of any wrongdoing or impropriety.

Here are just a few of the questionable practices identified by the Advance in the course of its investigation:

UCP has, in numerous cases, sought court-sanctioned legal guardianship of patients in its care, acting without the knowledge of a special advisory panel established under the Willowbrook Consent Decree.

A UCP official in at least one instance authorized elective surgery for a patient under the group's care, even though such authorization is prohibited without a court order. When the patient died during surgery, UCP failed to report the incident to the state, as required by law.

## Could the horror of Willowbrook happen again?

Most public officials in New York would answer with a quick and indignant "no."

But the fact is that the state, which in six years has taken great strides toward improving publicly provided services for mentally retarded citizens, appears to be woefully unprepared to monitor the scores of privately controlled organizations that now help to care for the retarded.

\* \* \*

There were nearly 5,000 persons residing at the Willowbrook State School in 1975 when the state, under a federal court order, agreed to make a series of dramatic improvements in the care offered to the mentally retarded and the developmentally disabled

As of today there are only a few hundred persons still in the state's custody at Willowbrook, now known as the Staten Island Developmental Center. Similar progress in deinstitutionalization elsewhere in the state is generally interpreted as a sign that the state, for the most part, has lived up to the terms of the Willowbrook Consent Decree.

But, what has happened to the mentally disabled in New York since 1975? They have not been cured. Nor have they disappeared.

¶ UCP has, on several occasions, made purchases from and awarded contracts to firms with which UCP officials or their families are associated. It also failed, in at least one case, to report the potential conflict of interest to state monitors.

¶ UCP has established a profit-making store from which patients must buy shoes, clothing and other personal items at prices in some cases far above the normal retail price. UCP also has drawn upon patients' personal funds to pay for purchases from its store

The sorry fact is that the state is unable to either support UCP's claims of innocence or to answer the questions raised by the Advance's investigation. The fact is that the state cannot adequately monitor the activities of UCP and the scores of other agencies with custodial care of retarded citizens. The fact is that no government agency today seems to be in a position to provide the sort of intensive monitoring essential if some of the same abuses that became synonymous with Willowbrook are to be prevented from occurring again.

And that should raise not only cries of alarm, but also demands for immediate, remedial action.

To date, the state has conducted only one detailed financial audit of UCP, which cares for nearly 1,000 persons on Staten Island and elsewhere in the state. That audit, completed last winter, found that UCP had kept \$10.5 million in excess Medicaid payments for which it had billed the state and federal governments over three years.

As a result of that single audit, UCP was forced to return nearly \$7 million in public funds to Albany and Washington.

Some say UCP has, on the whole, provided the retarded persons in its care with a better life than they could have hoped for had they remained in the state's custody. Some also have accused the Advance, and others who have questioned some aspects of UCP's performance, of "nitpicking."

But the fact is that questions raised by the Advance should have been raised by the state, and were not. That is hardly surprising since the state Office of Mental Retardation and Developmental Disabilities has a staff of only 20 auditors to monitor the activities of UCP and more than 270 other agencies.

The scandal of Willowbrook arose because people in positions of responsibility did not care about the manner in which the retarded were being treated. When the Advance and others who did care brought the horror of Willowbrook to the public's attention, genuine reforms were won.

But those reforms will not survive on their own merits. They will survive only if buoyed by constant vigilance and concern.

It is clear that the state has not been as vigilant as it should have been in monitoring the affairs of UCP. Responsible officials and legislative committees — including the Assembly Mental Health Committee, chaired by Assemblywoman Elizabeth Connelly of West Brighton — must act to guarantee that abuses do not once again gain a foothold in the mental health system in New York State.

10  
page 2  
JAN