

United Cerebral Palsy practices defended

in letters

Parental concern every child's right

I read in your paper of the girl who died while having her teeth taken care of. How grievous the mother was and was suing United Cerebral Palsy. Well, she stated she visited her six or eight times a year for 21 years.

I would like to ask some questions. Why did she dump her at Willowbrook? Who is paying the bills, the state I believe. How can you be a concerned parent seeing your child six or eight times a year? A lot of workers were taking over her job. Too often this is done with children handicapped or retarded. Thank God not all parents are like that.

I know of what I am talking. I had a child made epileptic 23 years ago being injured in the New York schools. Three hundred fifty seizures in 3½ years, because his doctor didn't care and at that time not too many places helped after his death.

I had another son stricken with a fatal brain disease. He lived after brain surgery. I was told if the problem got too much I could place him. I fought to keep him alive and get help. He couldn't talk or even sit up. He was spastic. I sat many nights in a chair next to his bed. I got involved with different groups and hospitals to try to get help. We did patterning at home. It was back-breaking work. I had a large family to raise and I wasn't in the best of health. But I and my family took care of Jimmy. He was given up for dead 28 times. I know of other mothers and families that did the same. Four years later the Lord took him home in his sleep, but he was not in a world all alone with a nurse or aide taking the role of mother.

I could have sued, but I didn't. I didn't pawn my job off on others either, and put the blame on people trying to do a job that by rights was hers. If she had said once or twice a week the facts would have been different.

L. LONG,

Port Richmond

Cerebral Palsy series one-sided

I am writing in reference to your recent series on United Cerebral Palsy. I took great interest in your story as my son has cerebral palsy and I am the vice president of a parents' group on Staten Island made up of the parents of handicapped children.

Your series was informative and constructive in the sense that it pointed out possible conflict of interest and possible impropriety on the part of UCP of New York State. Unfortunately, the series was potentially misleading and totally devoid of any positive comments.

Specifically, you failed to distinguish between UCP of New York State (which is the organization your story was about), and UCP of New York City, and UCP National; all three are essentially autonomous organizations. UCP of New York City is also actively involved on Staten Island and has done a commendable job. My son has benefitted greatly by his involvement with them. However, I find it hard to believe that UCP of New York State could not have improved upon the deplorable conditions that once existed at the Staten Island Developmental Center. Yet your articles make no mention of any improvement or in fact anything positive. To me this seems somewhat one-sided. What I also found disturbing was the positioning of the series of articles in your paper. The first few parts of the series appeared as headlines. Considering the slant of the series, one could consider such positioning as sensationalism.

I hope your future journalistic efforts concerning the handicapped on Staten Island are not limited to the negatives of UCP or any other organization providing services to the disabled. That is not to say that you should not report inhumane conditions, impropriety, or conflict of interest. It is necessary to have the public informed of such damaging conditions. However, it is also the responsibility of the press to inform accurately, which in this case means presenting the good as well as the bad.

GEORGE V. DOERRBECKER,
Annadale

Cerebral Palsy does serve charges well

Now that you have told everyone the awful things about United Cerebral Palsy of New York State at Karl Warner Center, Nina Eaton Center and the PIPP apartments, I think it is time for all to hear some of the good things we do.

Why didn't you tell about all the clients who are multiply handicapped and deformed due to years of lying in bed doing nothing; having their meals literally poured down their throats? They are now sitting in individually adapted wheelchairs, made by UCP staff, learning to feed themselves, learning to chew, learning toileting and dressing skills, taught by UCP staff.

Look at our adapted equipment shops, our classrooms, our programs, our recreation logs, our research and our progress before you judge us. Don't only give a one-sided view.

Yes, we have a boutique that sells very sturdy and yet stylish clothes to our clients. Why don't you do research into the durability and life expectancy of clothes in institutions? I'm sure you would learn a lot. The multiply handicapped retarded population is not "easy" on clothes...

How much more stress is on clothing that is put on a twisted body whose behavior includes clothes pulling? The boutique is directed by a former therapy aide who has worked with this population...

Another thing you should realize in regard to the PIPP apartments is the necessity of control. Only a fool would set up an apartment with three or four clients, provide it with two or three staff members and then hand over food, clothing and transportation money and say, "Run it yourself." U.C.P. is still legally responsible to monitor its clients' nutrition, see to it that they are properly clothed and attending day programming, and that they receive community recreation. It must be assured that its clients receive proper medical and therapeutic care, and if necessary, psychological and sexual counseling. How can you do all that if you don't exercise control.

JOANNE MAHONEY,
Nina Eaton Center,

Willowbrook