

Some pay for doing

'right thing'

By SANDRA ZUMMO

The state is paying some parents of retarded children substantial sums for doing the "right thing" — something other parents say they have been doing for years without any monetary compensation.

While the state will supply approximately \$3,500 annually to parents taking their children out of the Willowbrook Developmental Center, those who never placed their children in the institution receive no such funding from the state.

When Governor Carey signed the Willowbrook consent decree last year, paving the way for sweeping changes at the Island developmental center, one of its prime mandates called for the placement of Willowbrook residents back into the community. In fact, the state was even willing to spend some money to support its contention that family love and the home environment are equally as important a part of rehabilitation as physical and occupational therapy.

Those parents who apparently suspected the same years ago and kept their retarded children at home, got a financial slap in the face when the Department of Mental Hygiene unveiled its plan to further successful community placement for Willowbrook residents.

As an incentive for parents to reclaim their offspring, it made them eligible for family care funding to the tune of \$291.70 a month — \$273.70 for home-care for their child, plus an \$18 monthly allowance for the child.

Community residents offering their services as foster parents to the 200 Willowbrook clients who are native Islanders, are also eligible for such remuneration.

Natural parents who decided against institutionalization in the first place are excluded from such state funding. Consider the situation of this Annadale couple:

Ann and Bill were surprised when they became the parents of twins in 1967. They weren't prepared for it, but neither were they too panicked by the prospect of now having to provide for six children.

Bill didn't have the greatest job, but his name was "on the list" for a city job, and, when the kids were all in school, Ann could take parttime work. They knew they'd never be rich, but an-

anticipated a fairly comfortable existence for their family.

They were soon to learn that they could not set the stage for the playing of their own life script.

It was when the twins, Allison and Marcy, were three months old that Ann began to notice marked differences in their behavior. Allison was raising her head, kicking her feet, turning over. Marcy just lay quietly in her crib. She brought this to the attention of their pediatrician. He had his suspicions, but, rather than make what he was sure must be a devastating diagnosis, he referred them to a neurological pediatrician.

His suspicions were confirmed. Marcy had cerebral palsy.

Though they knew there was no cure for their infant's condition, Ann and Bill were determined to provide her with every opportunity to make progress — and to keep her at home. If it took all their time, energy and money, they vowed that their severely retarded daughter would not be placed in an institution.

Ann is just one of many parents who feel that they are being "punished" for electing to keep their mentally retarded offspring at home. "They won't give us any help," she says bitterly, "yet, I figure, over the years, we've saved the state a lot of money."

During Marcy's lifetime, they've saved the state \$225,000, since it would have cost \$25,000 to maintain her in an institution for each of her nine years. And, under existing legislation, they will continue to save the state money, while having to struggle making do with their own.

"It's like these people are being paid to take their kids out of Willowbrook," Ann remarks. "I never even considered placing Marcy there for a minute; I knew they couldn't give her the love and attention her family could."

When the Department of Mental Hygiene developed the Metropolitan Placement Unit to coordinate the dispersment of Willowbrook residents into the community, it gave MPU the right to

enter into Individual Purchase of Services Agreements. Through these, it can contract for any type of specialized service not already provided to a client in the community. When the service agreement runs out, money to extend it is available through Chapter 620 of 1974 mental hygiene legislation. This money follows the resident into the community and is available to him throughout his lifetime.

If none of the existing agencies, Staten Island Aid for the Retarded, United Cerebral Palsy, Mental Health Society, can provide a particular service to the non-institutionalized person, his parents have no recourse through purchase of services agreements. They must pay out of their own pockets.

Whether or not, as Ann contends, natural parents are in effect being "bribed" to take their children home, one thing is evident — they are being funded for performing the parental duties that some parents of brain-injured children never relinquished.

"It's like busing," insists Cora Hoffman, to explain the Department of Mental Hygiene's funding policy. Special assistant to department deputy commissioner Thomas Coughlin, Miss Hoffman contends that "it's a temporary remedial measure to meet the measures of the consent decree." Though she admits that "legal people are up in arms," because they feel this remedial measure absolves parents from their legal obligations to their child, she does not feel that what the department is doing is fundamentally wrong.

"The major focus of the consent decree was to place people in the least restrictive environment, their home. We must provide protection from harm as a constitutional right. This was a way to make up for the harm we've done these people in the institutions."

Claiming that the department did not mean to discriminate against parents who kept their children at home, she mentions that there is currently talk of extending money to them, though no legislation to that effect is pending at the present time.

Such a program of aid to parents of non-institutionalized children has been employed in the state of Michigan for the past 3 years. Unlike the monthly stipend which natural and foster parents receive under New York's present program, no direct advancement is made to parents.

David Rosen, director of the Oakland-MacCombs Regional Office of Mental Retardation in Michigan, and a member of the Willowbrook Review Panel, explains how that program works.

"What we do is admit the family to our family-care caseload. Then we provide funds for a trainer to come into the home and work with the client, thus freeing the parents to have more time for their other children, take parttime employment, or just have a few hours reprieve from the overwhelming task of caring for a handicapped child. We keep the family on our caseload and our case managers continue to check on the situations, seeing that programs are appropriate and making changes where necessary."

In addition to providing specially trained homemakers, the Michigan program allows an individual contract to be drawn up for each family, wherein funds are appropriated for specific services: i.e., therapy, prosthetic devices, wheelchairs and even home modifications.

Even though Bill finally got his city job a couple of years ago, the family is just about making ends meet. They can't afford to have a ramp put in so Marcy can get around more easily in her wheelcahir and, despite hospitalization benefits that have minimized medical bills, there is still part of the cost of wheelchairs and braces to be absorbed by the family, not to mention the cost of having to provide diapers for their partially toilet-trained daughter.

Bill makes \$100 too much a year to qualify for Supplemental Security Income and the family is also ineligible for food stamps.

"Okay, nobody said, 'have six children,' but nobody said, 'have a handicapped child, either,'" says Ann of some people's insensitivity to her family's plight.

Though she's appreciative of homemaker service that she has been allowed under a special state program, she doesn't feel that the 12 hours a week it provides are enough. "When they first started last year, they gave us 20 hours of help; now we're down to 12. It's a help, but, if I had extra money, I could hire someone to work with her longer."

Miss Hoffman and others have cited the task of determining eligibility as a major stumbling block to the implementation of a funding program such as Michigan's here, but the state might pattern its criteria on that very same model. Rosen explains that his program admits clients who have been adjudged "institution eligible" and whose parents' financial picture meets the terms of a means test normally administered before institutionalization.

Reflecting on such a program's future in our state, Rosen observes that "It would be a good fiscal move since it would cut the cost of institutionalization. It would also be invaluable in keeping kids out of institutions in the first place, by making it easier for their parents to keep them at home."