

Gouverneur Parents Assn.

Nineteen hundred eighty marks the ten year anniversary of the Gouverneur Parents Association's continuing struggle for humane and rehabilitative treatment for their severely handicapped children.

Although extremely active and frequently stormy, the Association's history is one of considerable accomplishment. Herewith is an account of the history and activities of the Gouverneur Parents Association, from 1970 to the present.

Gouverneur Placement

In 1967, after Robert Kennedy's 1966 visit to the Willowbrook State School, a group of 200 severely and profoundly retarded children and adolescents were transferred from the overcrowded Willowbrook to the Gouverneur State School in Manhattan. Located at 621 Water Street on the Lower East Side, the Gouverneur State School occupied a building owned by the city and formerly utilized as a hospital.

The building was not without its problems, however, being an old structure (late 1800's) in which many hazardous conditions existed. Needless to say, the facility was not appropriate one for this largely non-ambulatory and multiply-handicapped population of children.

Once in the Gouverneur State School, the highly specialized habilitative services so desperately needed by the residents were not provided. A combination of insufficient staffing and physical limitations of the building resulted in a program of services for the residents which consisted primarily of custodial care.

Then in 1970, the State Department of Mental Hygiene was faced with budget cuts and decided to move the children at Gouverneur back to Willowbrook. The parents, relatives and guardians of the Gouverneur children were never officially informed of the proposed move.

Mrs. Willie Mae Goodman, the mother of a severely handicapped, non-ambulatory young girl at Gouverneur, and several other parents became aware that a move back to Willowbrook under questionable conditions was in the offing for their children. As inadequate and inappropriate as Gouverneur was, the parents considered Willowbrook even less desirable. A meeting with the director of Gouverneur was arranged by Mrs. Goodman, but resulted in no resolution of the problem. Mrs. Goodman, along with other concerned parents and relatives, then decided that a more militant approach was called for. They contacted all parents or guardians with children at Gouverneur and mobilized the entire Lower East Side neighborhood around Gouverneur. Madison Street was blocked off and a rally held with the children in their wheelchairs. The Black Panthers, advocacy-oriented young lawyers, and even the Benevolent Society at Willowbrook became involved.

Murray Schnepps, a lawyer and parent of a child at Gouverneur was able to obtain a legal injunction on behalf of the Gouverneur residents which temporarily delayed the State's proposed move. Pressured by the parents and by heavy media coverage of the situation, the State Commission of the Department of Mental Hygiene finally agreed not to close Gouverneur during a meeting held with parents at Willowbrook. A major victory had been achieved by Mrs. Goodman and the other parents.

Formation of Parents Association
From the activist beginnings, the Gouverneur Parents Association



Old Gouverneur Hospital facility on Water Street.

tion was born. Although one victory had been won, the Association now faced the long uphill battle of obtaining rehabilitative care for the Gouverneur population as well as locating a more suitable facility for the residents. While staff shortages remained a problem, the hazardous conditions present in the building were responsible for the facility's loss of accreditation and an accompanying cut-off in SSI funds.

The Parents Association consequently became very active in many areas. They hosted special activities for the residents, such as Christmas and Easter parties and birthday parties. The Association also struggled to see that facility administrators provided the residents with the basic amenities they needed, such as soap, clothing, clean diapers and the like. Their concern, coupled with the dedication shown by many of the direct care staff at Gouverneur, resulted in the maintenance of the lives of 70 to 80 percent of the Gouverneur population.

Willowbrook Consent Decree

During this period in the early 1970's, a class action suit was initiated against Willowbrook State School on Staten Island, charging the institution with inappropriate and inhumane care of its residents. The Willowbrook Consent Decree was subsequently signed in the spring of 1975, mandating the upgrading of the institution as well as eventual placement of class members into community-based settings.

Ironically, the Gouverneur population was not initially considered part of the Willowbrook class, and the Gouverneur Parents Association was forced to take the State to court to settle the issue. The court affirmed that the Gouverneur's residents were indeed class clients are entitled to the same benefits and rights as the other class members.

Move to Flower and Fifth Avenue Hospital

The Willowbrook Consent Decree marked the beginning of a new era for the Gouverneur residents, just as it did for the 5,500 other mentally retarded and developmentally disabled persons who were members of the Willowbrook class.

The Gouverneur Parents Association, which had been applying continuous pressure on the State to move the Gouverneur

population, was now aided by the efforts of the Willowbrook Review Panel. A formal recommendation was made to the New York State Department of Mental Hygiene, asking that a plan be submitted for the evacuation of the Gouverneur Unit on an urgent basis. The State, after having prepared and submitted several proposals (all of which were rejected by both the Review Panel and the Parents Association due to insufficient long range planning), presented both parties with the Flower Fifth proposal. The plan proposed that the State Department of Mental Hygiene (later to be come the Office of Mental Retardation and Developmental Disabilities) contract with the Mental Retardation Institute and New York Medical College to provide a comprehensive rehabilitative program for the residents of the Gouverneur facility.

This program was to provide increased and more specialized staff, better programming and therapy, better medical care, and more appropriate clothing for the residents to meet the total medical, social and environmental needs of the population. However, the move to Flower Fifth was not to be a permanent step, as community placement remained the long-term objective for each client.

During the summer of 1978, the transfer of the 154 Gouverneur clients from Gouverneur to Flower Fifth Avenue Hospital at Fifth Avenue and 106th Street in Manhattan was accomplished. Since that time, twenty-seven members of the Gouverneur class have moved into specialized community settings. United Cerebral Palsy of New York State (PIPP III) and the Working Organization for Retarded Children (WORC) both provided specialized care for these former Gouverneur residents in apartment settings of three persons each. All are based in regular apartment buildings in the community with the opportunity for a normalized life style.

Plans call for the placement of the remaining Willowbrook class population at what is now officially termed Flower Hospital into 3 to 6 bed facilities throughout New York City. In addition to WORC and UCP State, the New York Catholic Guardian Society and Community Resource Center for the Developmentally Disabled have pledged their com-

mitment to serve this severely handicapped population in the community. In the meantime, Flower Fifth Avenue Hospital was purchased last year by the Archdiocese of New York, to be operated as a specialty hospital. Regulatory responsibility now rests with the Office of Mental Retardation and Developmental Disabilities.

The Parents Association's efforts have turned largely to monitoring both the present program at Flower Hospital and the placement of the children and young adults into community-based settings. According to Mrs. Willie Mae Goodman, the major problems encountered at the Hospital are poor administration and leadership. These problems have resulted in inappropriate spending and planning and insufficient programming for the residents.

Current Activities of Association

Under Mrs. Goodman's direction, the Gouverneur Parents Association has initiated several new committees and activities since the Flower Hospital move. The Clothing Committee, for instance, composed of Flower Hospital staff and one parent, assumes responsibility for submitting the clothing needs of the children to the administration. In breaking away from the reality of the past, emphasis is placed on individualized clothing for each child. As a result of the Committee's efforts, a charge account has been established at Macy's so that appropriate, up-to-date clothing can be purchased for the residents.

The Committee has also been influential in changing the hair care of the children. Staff were taught about the different care

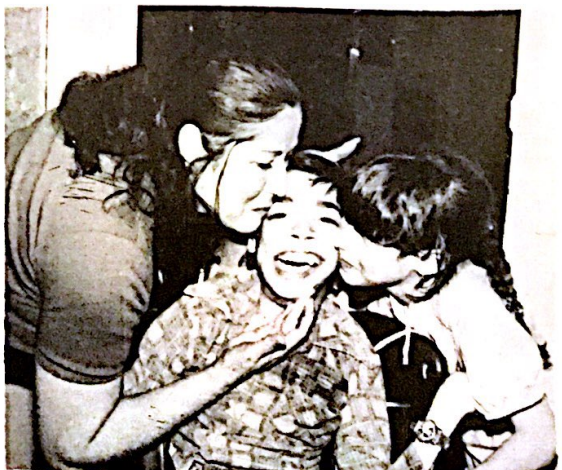
requirement of the black residents' hair as compared to those of the white residents. Shampoos were changed and shampooing schedules rearranged to accommodate the different needs. The Committee was also successful in getting beauticians to come in and cut the residents' hair.

As another activity, the Parents Association has established a Visiting Program whereby the direct care and professional staff of the Flower Hospital program visit the various types of community residence and apartment programs housing developmentally disabled persons. The goal of the program is two-fold: to demonstrate to the staff the importance of their role in preparing the Flower Hospital residents for community living and to show them just what community living will mean for their charges once they leave. As a result of the program, staff who were naturally fearful that their jobs would end as the children were placed now have a better understanding of the total picture, and many are interested in making the transition themselves to working in a community setting.

By way of other activities, the Parents Association has encouraged the administration to make changes that emphasize normalized living and individualization. Children were being awakened much too early in the mornings and were being placed on mats for afternoon naps, rather than returned to their beds as a normal person would be. This problem is being corrected because of the Association's concern. To emphasize each person's individuality, birthday parties are held for each child, and a special Fashion Show



Gouverneur Parents Association President Willie Mae Goodman (right) with daughter Marguerite.



Flower Hospital resident Luis Rivera (center) receives kisses from his mother and younger sister.

Ten Years of Advocacy

was sponsored by the Association last Memorial Day weekend. The Fashion Show was for the entire "Flower Hospital Family", including those who had moved out to the community. New clothing was purchased for each child, made possible by a donation from One to One and fund raising by the Association. The girls were decked out in their new dresses or pant suits, complete with jewelry, perfume and makeup. For most of the girls, this was the first time they had ever worn makeup or jewelry. The boys, likewise, had on new suits or new outfits with smart-looking bow ties and the like. Parents and family members were asked to push their children down the aisle, and Parent Association's Mrs. Vicki Schnepps commented, "you should have seen the dignity of the children for that one day. It was an extremely personal and worthwhile experience for all involved."

The Parents Association is next planning to make a film about their children as an educational tool for the community. It will show the progressive movement of the residents from Gouverneur to Flower Hospital to community settings. The Association is also planning an educational effort aimed at local community leaders and politicians to explain the need for barrier-free sites for the residents. And Mrs. Goodman herself is writing a letter to all the members of the Association to give them feedback based on her own visits to community living settings and to help prepare them for the reality of their own child's move.

All the many people who have come into contact with the Association's president - Mrs. Willie Mae Goodman - know her as an unselfish and untiring crusader for the Gouverneur children. The hours of advocating she has put in for this special population of developmentally disabled persons are truly countless, and to many, Mrs. Goodman is the Parents Association.

At this ten-year anniversary of the rather spontaneous beginning of the Association, Around the Region salutes the Gouverneur Parents Association, and most particularly its leader, Mrs. Goodman. The Association is surely one of the most active and effective parents organizations in the City - one truly run by the parents and relatives for the sole benefit of their children.

The advocacy will not end here for the Association, however. As Mrs. Goodman herself admits, "the fighting never gets easier, and it is always a very emotional thing." The Parents Association will continue its monitoring role

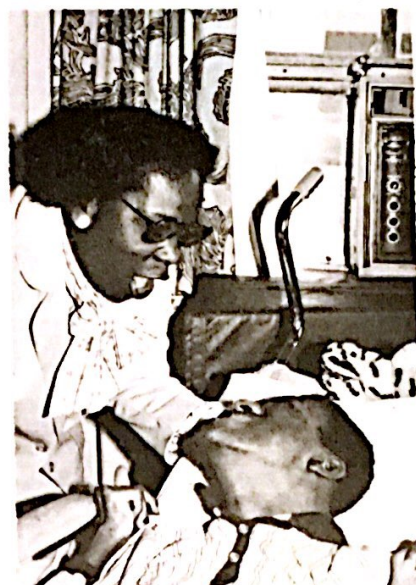


Janice Burgess at Flower Hospital.



Ethea Hyson enjoys looking at the activity around her with new glasses.

in the community, and the entire developmental disabilities community will benefit from their concern.



Parents Association member Mrs. Jameson (left) visits with her grandson Lawrence Sullivan at Flower Hospital facility.

Day After Day

by Jimmy Rivera

Day after day I lay in my room, hoping
someone will visit me soon.
And I smile, for you will only be here
for a while.
I show my feelings by expressions on my
face, for this is the way I communicate.
And when you leave I feel so sad, For
the moments with you have gone so fast.
And so I lay in my room day after day;
For I am retarded the People say



Onlookers applaud as Fashion Show participant steps out.



Former Gouverneur residents are all decked out for the Parents Association Fashion Show held last spring.