

also the Board of Visitors who stated, "A member of the Board of Visitors who speaks out to the public about conditions at Willowbrook, might as well resign."

But, as evidence of the changing trend in the attitudes of parents with retarded and physically handicapped children, Connie stated, "Whatever the decision of the State Association the majority of the Society is going to move ahead and push for our policies."

One of the policies Connie was referring to is stated in the final report of the conference, "All programs recommended by this conference for care of the handicapped through institutions or community services, should specify governing boards with a majority of parents and consumers at all levels of policy-making and resource allocation."

Mark Marcario, an Island resident who helped organize the March conference, echoed Connie's views about the importance of parent control. "We have to reverse the vested interest approach that has made programs on Staten Island token and not capable of servicing the numbers of people who need them."

Referring to the large amounts of money that have gone to Staten Island Mental Health and Staten Island Aid for the Retarded, two organizations on Staten Island that receive government funds through "community based facilities programs," he claims "There is no outreach to the parents and community with those programs." Speaking from direct knowledge, (his four year old son has Down Syndrome) he related incidents of going to these organizations for help and finding little assistance. Other points of contention are the roles of Drs. Hammond and Sternlicht who, while administering Willowbrook, have held staff positions on Staten Island Aid for the Retarded, a "community program."

Sonia Braniff is another parent and Island resident who helped organize the March conference, she too expressed a need for the "real consumers to have a voice in the delivery of services." One of her motives for becoming active in the conference has also motivated her to attempt to organize all the parents of the 15 groups currently existing on Staten Island to service the handicapped into the United Parents of the

cial. Now, I can contact parents in Westchester, Nassau and all over the City and exchange information and increase our chances of becoming an effective lobbying force."

Mentioning the Cerebral Palsy programs that her daughter is enrolled in as "one of the better groups existing on the Island," she also extolled the deficiency and limited outlook of established programs. "Our group can provide services for about 100 kids and young adults. Other programs can only provide for limited numbers of those who need them. And I know of many parents who have had bad experiences when they have gone to other organizations to try to obtain aid for their children." Federal government estimates place the number of people suffering from some form of retardation or physical handicap at 3 percent of the population - on Staten Island alone this would mean 10,000 people.

While Staten Island is the home for one of the oldest and most professionally respected community mental health services in the country, The Staten Island Mental Health Society, it is often claimed that people with special needs go lacking or their families suffer economic and psychological hardships to obtain services elsewhere.

Sonia Braniff mentioned the plight of the emotionally disturbed children of Staten Island who have begged for classroom space. Mark Marcario wondered about the perennial promise of a "sheltered workshop" for retarded individuals, a promise that remains to be fulfilled. Both mentioned parents they knew who experienced great difficulty in acquiring any aid for their children. But what might stand as the best example of the lack of faith that many of the conference participants have in the State's ability to rectify the disastrous level of care affecting the retarded and handicapped is, of course, about Willowbrook.

A man choked to death at Willowbrook last week. Absent this time were the cameras and newspapers that elicited public support in the past. A doctor declared the man dead and notified his parents he had choked on a morsel of food - a familiar complaint when the headlines were present was that the lack of staff to provide adequate care contributed to the amount of death by chokings at the

as was a letter discovered in the man's file.

The letter written in 1948 to the parents of a retarded child advised them of their son's transfer out of an overcrowded state "school" to "a new wing of Halloran Hospital on Staten Island." In the subsequent twenty four years, the child became a man and Halloran became Willowbrook, and Willowbrook became the site of the man's death last week.

To those who are organizing and working to insure the success of any actions to come forth from the conference that incident as one man stated, "brought everything back home. You could see in this one man's life what a dead-end proposition Willowbrook and large institutions, and the State's present policy were." The Department of Mental Hygiene recently announced that 300 of Willowbrook's patients would be transferred to recently opened facilities -- to "relieve the overcrowding."

To provide a unified basis around which to organize in support of their goals, "to develop a modern and humane system of services for all persons with special needs, and to phase out of existence the New York State School and State Hospital systems in their present form," the conference participants agreed on six principles:

- A continuum of services to the retarded and other persons with special needs from birth through old age.
- Emphasis must be placed on the prevention and intervention in any type of handicap beginning with family counseling and continuing through all levels of health and education services.
- Normal living conditions and integration into community life shall be the right of every retarded or handicapped person and their families. Every retarded person and others with special needs must be enabled to develop to his maximum potential as a productive member of the community.
- A single consolidated agency shall administer all programs, allocate all funds and resources, set standards of care and services and regulate the quality of all services.
- The consumer community of parents of the retarded and others with special needs with the aid and consultation of the professional providers shall determine policy and priorities

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