

At the conference table

By Joseph Killeen

The barrage of media coverage that focused the fickle eye of public attention on Willowbrook State School produced a number of results. Headlines, books, token budget restorations and reams of legislation being some of the more obvious. But, while the headlines fade and the legislature goes into recess what looms to many as the most promising result was a little publicized conference held in March and a series of continuing actions that came out of it.

Billed as a "Policy and Action Conference for the Handicapped," the meeting held on Staten Island was called to investigate the possibility of linking groups and individuals from throughout New York State to gather in a coalition to work for improvement in the delivery of essential services, medical, educational and residential, to all the mentally and physically handicapped of the State. As

one participant commented, "It is an attempt to establish a true consumer movement in the fields of health, education and welfare." Islanders organized and participated in the conference and, as recent interviews indicate, while Willowbrook provided the final indignity, the forces that drove many of them to organize grew out of years of frustration in attempting to deal with established services (or their lack) for the handicapped on the Island.

As Willowbrook provided the impetus for the conference much of the meeting and subsequent action was concerned with actions and policies to relieve conditions at the school. Support for "immediate and direct legislative action" was not recommended. Instead the conference participants discussed with lawyers and an international task force of professionals a series of lawsuits concerned with "the right to treatment and education" of the retarded and handicapped.

Legal actions, which are now pending in New York, joined a series of other suits filed in three other States, Alabama, Massachusetts and Pennsylvania, all of which proved successful.

And as indicated by a comment carried in the final report of the March conference, their ramifications are extensive. "The goal of the Alabama case is not only to guarantee the right to treatment and education, but to explore and document, with court decisions, the failure of institutions as healthy places in which the retarded and mentally ill can grow." If the intended affect of pending suits in New York State is successful, the standards set could possibly force the state to abandon its present mode of delivering care to the retarded and mentally ill. If so, the alternatives and who controls them will become the vital issue.

The State has already admitted the failure of large institutions to treat and care for the handicapped. Statement after statement from officials of the Department of Mental Hygiene have mentioned the development of "community based facilities" which would relieve conditions at the larger institutions. A lack of funds, have been credited with delays in extensions and improvements of these services. But, to those who organized and attended the conference, the "community based facilities" of the State offer little hope for the future.

William Bronston, a clinical physician at Willowbrook and one of the organizers of the conference, in an article in the May 27th edition of the New York Times addressed himself to that question. "In February organization after organization testified to the Joint Legislative Committee on Physical and Mental Handicaps in Albany, building a mosaic protest against fragmented and token services, exclusions, mismanagement and a profound lack of any less drastic alternatives than the institutions offered by the State." To those who attended the conference, the solutions being offered by the state are already "riddled with the attitudes, faults and myopic visions that resulted in the creation of Willowbrook."

To overcome the deficiencies in already established services and to insure a controlling voice by parents in all programs are two of the major goals of the continuing operations of the conference participants.

One of the major difficulties that the organizers of the conference experienced is the traditional hesitancy of parents of retarded and handicapped children to speak out due to the fear of being stigmatized with the onus associated with these types of diseases. As the final report of the conference stated, "There is no royal road to learning, so therefore it is important that parents meet often, be more inquiring and not be bound by what is. Rather, they should seek what might be. We must meet with experts and professionals on equal terms and tell them what we need and what we want. And,

above all, we must put to flight the fear and shame of past years."

Rosalie Amaroso, parent of a child at Willowbrook added another factor to parents fears for speaking out. "Many are afraid and feel frustrated. They fear the State might tell them to take their child out of the institutions and there really isn't anywhere else to go." Rosalie talked of the friction that exists among the Benevolent Society at Willowbrook, composed of many of the parents who serve as the only voice for the parents in the operation of the institution: "The members who have been in Benevolent for a long time don't like the new, active profile that many are pushing for. They don't want to let go of their positions, but, yet, they still don't move ahead."

A recent election of officers for the Society was challenged by "the established element" because a number of "more active members of the society won offices." Basing their challenges on a "technicality" in the by-laws of the organization they have appealed the election results to the State Association for Retarded Children. And as Connie Haney, another parent of a child at Willowbrook, views it "That's just the continuation of the vested interest approach that has affected care for the retarded in the past."

Connie's charges of "vested interest" stem from the fact that Joseph Weingold,

President of the State Association for Retarded Children, is also a member of Willowbrook's Board of visitors, the representatives

Page 1 of 3 page

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

Page 2
of
3 page

through local, regional and state-wide mechanisms. The professional community must be fully accountable to the parent-consumers community.

● The financial burden for services for the retarded and other persons with special needs shall not be solely the responsibility of the individual family, but shall fall upon the state when it exceeds the basic expenditures for a normal child and the state shall be further responsible to guarantee that the services to be provided meet the needs of the person, regardless of the complexity of the need or the profundity of the handicap.

From the appearances the group of parents who met with lawyers, doctors, professionals and other interested community members were acting out of anger, fear, frustration and a host of other reasons. What has come of those meetings is a unified front that is currently waging a number of law suits, studying and solidifying their positions for future actions.

An additional factor to their move for increased services and control by parents was expressed by Doctor Bronston, "The quality of services for the handicapped is a barometer of the quality of service being received by other segments of the community. Education, medical and health services are declining for the majority of the population. Everyone must see the need for this movement."

And a movement is what it appears to be blossoming into. A second local conference is scheduled for June 24th at Mt. Augustine Retreat House on Campus Road, Staten Island with plans to be formulated for a second, "full scale" conference for next Fall. While the local conference will be to establish increased networks of communication between all groups and to discuss problems that would stand in the way of implementing the six points formulated at the March meeting, the Fall conference will be to "develop a thorough analysis of our position and prospects, and establish a long range (two years minimum) plan for implementing those goals through legislation, litigation and public education and any other necessary means."

One can only speculate what the circumstances of the State Association for Retarded Children's founding were. Similar intents such as those being made by the organizer of the conference have been made in the past. But, as notices for the next meeting on June 24th state: "In the next twelve months or so, much can and will happen with or without our support or direction."