

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 before 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

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