

Willowbrook School A Medical Disaster Area

By John Signoriello

Willowbrook State School for the Mentally Retarded has been the subject of a great deal of controversy of late. Hit hard by budget cut-backs enacted by the State Legislature last year, the sprawling Department of Mental Hygiene school-hospital complex, which presently houses more than 5,000 mentally retarded children and adults, has lost more than 60 members of its staff through lay-offs and attrition. Over-worked ward workers have been unable to care for their charges properly — many of whom are unable to dress themselves or control their bowel movements — and living conditions at the school have degenerated alarmingly. Severe overcrowding is the rule in almost every ward, and the facility's over-taxed medical staff has been unable to control the spread of endemic hepatitis which is presently threatening to reach epidemic proportions.

Conditions at the school, dismal even in the best of times, received a great deal of publicity recently in a series of articles that appeared under banner headlines in the Staten Island Advance. The articles, written by Advance reporter Jane Kurtin, described conditions at Willowbrook in graphic terms and pointed

out that the institution has consistently fallen short of standards set by the State Department of Health. The only reason Willowbrook is allowed to remain open, one Health Department official was quoted as saying, is because of the lack of other suitable facilities for mentally retarded children and adults. "Where there is less need," he explained, "we can be stronger in getting compliance with regulations."

Spurred by the surge of publicity, at least one Island legislator, Assemblyman Edward Amann, demanded an immediate investigation. Greeted, at first, with almost unanimous approval, Amann's action soon lost some of its popular support when it was learned that the investigation would be carried out, not by an independent agency or State Committee, but by the Department of Mental Hygiene itself, and, presumably, at their leisure and within the scope they deem most appropriate.

Meanwhile, conditions at Willowbrook continue to worsen, and alarmed parents groups, such as the Benevolent Society, whose members have children in residence at the school, have been meeting with the facility's Director, Dr. Jack Hammond, in an attempt to have him declare the institution a medical disaster area. Doing so, they claim, would force the Federal Government to dispatch U.S. Public Health Service emergency task force teams to Willowbrook. The PHS teams, they say, could help out the facility's overburdened medical staff, thereby alleviating some of the appalling conditions there which have been repeatedly described, even by the Department of Mental Hygiene itself, as "inhumane" and "intolerable." Hammond, however, has consistently balked at the idea. Asked why at a recent meeting, he reportedly replied, "Because it would be disloyal to my superiors."

Last week, the Staten Island Coalition for a Family Hospital, a group of local doctors, nurses and citizens who advocate complete consumer control over all health services, added its voice to the chorus of protest over Willowbrook by issuing an 8-page "position paper" outlining their appraisal of the situation at the institution, its root

causes and some possible solutions. The paper was drawn up by the group's 8-member Steering Committee, several of whom actually work at Willowbrook, and copies will soon be sent to close to 1,000 people who may be presumed to have some sort of vested interest in the institution, including local, City and State officials, parents with children in residence at the school and a host of prominent figures in the medical profession.

Referring to conditions at Willowbrook as a "horror," the paper begins by outlining a series of steps the Coalition wants taken immediately. They include: (1) immediately halting admissions to Willowbrook State School and all other State Schools currently over their census; (2) immediately declaring the institution both a "social" and "medical" disaster area so as to obtain Federal and State relief; and (3) immediate

passage of legislation to establish a "State-wide study commission," with a budget, to investigate and report on the "use, availability and effectiveness" of existing State facilities for the mentally disabled.

Concerning the proposed commission — the formation of which Coalition spokesmen claim is the most urgent need — the paper states:

"It (the Commission) must be entirely independent from the State Department of Mental Hygiene and be composed of State legislators and parents of the handicapped, as well as out-of-State specialists well-versed in the subject of providing health care and training for the mentally handicapped. The commission should be mandated to report its findings within 18 months and those findings should include recommendations for basic changes in the State School system, as well as other services for the developmentally disabled

presently offered in the State of New York...."

The bulk of the rest of the paper is devoted to describing specific corrective measures, 22 in all, that the Coalition feels should be implemented at Willowbrook to alleviate the appalling conditions there. The section describing those measures is prefaced by a brief statement outlining what the paper terms the "principled basis" those reforms should be founded upon. That section, in essence, is a capsule explanation of the underlying consumer-control philosophy the Coalition advocates.

"The people who pay and are served by the institution must have power over policy and resource allocation," a portion of the statement reads. "Recommendations must win the support of the consumer public to insure their implementation and not rely on influencing any one small group or special interest... Self-reliance on solving problems is vital. The thousands of parents and workers who are served by and employed by Willowbrook can solve the majority of problems through communication and cooperation..."

The group's health philosophy, defined in the paper, then goes on to describe, in detail, the corrective measures the Coalition advocates.

They include:

(1) establishing parent control over the administration of Willowbrook with machinery to recall administrators who reject accountability to the community they serve;

(2) establishing parent committees to coordinate protection and control of their children as part of overall parent control over policy and resources in Willowbrook;

(3) priority hiring of additional social service staff to carry out the proper placing of residents into foster-home settings, sheltered work settings and programs;

(4) opening the facility's laboratory for 24 hours a day, 7 days a week, to correct the present 4 and 5 day a week shift operational inadequacy;

(5) priority correction of the inadequate and unsuitable food situation which leads to general nutritional disorders - such as anemia, poor skin conditions, vulnerability to infections, pro-

longed periods of illness and mental deficiency.

(6) busing all residents in the "trainable" and "educable" categories into community public school programs to "normalize" their living experience;

(7) gearing the educational programs inside Willowbrook toward productivity and work to insure dignified and self-esteem building experiences for the intellectually handicapped, instead of the impossible ultimate goals now sought-after which penalize the vast majority of the residents

Underlying all the corrective measures suggested in the paper is a fundamental belief held by the Coalition - that is, that the State School system, as it presently exists, must be replaced by some other system which does not shut mentally retarded persons away, out of sight and out of mind, in massive, prison-like structures similar to those at Willowbrook. That belief is clearly stated in the paper's opening paragraph, which states:

"The answers to the problems created by Willowbrook State School cannot be postponed. They must combine immediate reforms with long-term plans and services to end, once and for all, the obsolete, inhuman and economically wasteful State School system."

In place of the present system, the Coalition would like New York State to adopt a "Regional Center" program similar to the highly successful one presently in operation in California. Under that program, only the most severely retarded persons are ever institutionalized, and then only after being thoroughly screened, according to strict criteria, by experts at a Regional Center usually located in a hospital somewhere near or in the State's densest population areas.

The rest - those who can exist and be cared for in minimally supervised settings - are kept in the community, either with their parents, in foster-home settings, or in small, comfortable, privately-run board and care homes. Under the system, special health care and services are purchased for retarded persons by the State, out of a special fund, from private doctors, clinics and hospitals - at costs far

lower than those incurred at State institutions. Boarding fees for retarded persons unable to live at home with parents are also paid for by the State, as are any fees for special educational training not provided by the Board of Education. The costs, in both cases, are far lower than those a State Institution would incur were it forced to provide those same services.

Members of the Coalition are not the only ones who feel that California's system is more efficient and humane than New York's. Even some high-ranking members of the N.Y. State Department of Mental Hygiene are willing to admit that massive, sprawling complexes like Willowbrook are remnants of the un-enlight-

ened thinking of some "experts" in the past. In a recent interview, one of them, Assistant State Commissioner Ellen Rettig, said the Department would like nothing better than to phase them out of existence.

A first step in that direction, she said, would be to release 1/3 of the residents presently in New York's State Schools for the Mentally Retarded, since statistical studies undertaken by the Department of Mental Hygiene indicate that they don't belong there anyway.

"We know they would be better off in the community," she said, "but where are we going to send them if we let them out. Unlike California, community-based services for the Mentally Retarded in New York State are woefully inadequate in terms of the number of persons they can

handle. Those that do exist - most of which are funded in whole or in part by the Department of Mental Hygiene - already have long waiting lists. There just isn't any more room in the CRMD classes offered by the Board of Education; or in the few privately-run homes for the mentally retarded; or in the clinics that

offer health services and therapy to developmentally retarded children. Before we can even begin to think about releasing people from schools like Willowbrook,

we must first expand the community-based services we can offer them when they get out. To do that, we need money, and money is the one thing we don't have any of."