

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."

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