

Staten Island Advance

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Controversy raises doubts about research at Willowbrook

By SYDNEY FREEDBERG

The disclosure that at least 20 identified hepatitis carriers are attending city public schools has focused attention once again on nearly two decades of human experimentation into that troublesome disease at Willowbrook Developmental Center.

The carriers, three of whom are now being excluded from regular special education classes at PS 69, Merrymount Ave., New Springville, lived at Willowbrook when experiments into the nature and prevention of hepatitis were conducted.

It has not been established whether any of the pupils now identified as hepatitis carriers bear that medical distinction as a result of participation in the hepatitis experiments.

But a parent of a Willowbrook resident, whose admission to the institution in 1958 was "expedited," he says, by his child's participation in the experiments, says he is investigating the effect 16 years of research might have had in producing the present problems faced by the identified carriers.

Anthony Pinto of Bulls Head, a

member of Willowbrook's Consumer Advisory Board and a past president of the Willowbrook Benevolent Society, insists his most important goal is to ensure that mentally retarded hepatitis carriers — who do not have the disease but who can, under some circumstances, transmit it — are not subjected to any greater restrictions than would be placed on non-retarded carriers.

But he says he is interested in learning if the current situation has resulted, in part, from a lack of follow-up to the experiments, which began in 1956 and ended abruptly in 1969 when parents

gave pause to the idea of using mentally retarded children as experimental subjects.

Pinto says project investigators never told him what potential risks existed when his 10-year-old daughter was transferred from a specially constituted, 16-bed isolation unit in Building 2, the site of the research, to Building 23, a non-research facility.

He says no one was ever clear about explaining either the long-term dangers of serum hepatitis to the patient or the types of precautions parents and staff should have taken if a child had become

a hepatitis carrier.

(Such precautions, according to state guidelines adopted in 1975, include making parents and personnel responsible for the care of mentally retarded persons aware of the need for good hygienic practices, especially after caring for open wounds and before eating and handling food.

(Personal toiletry items, the state guidelines say, should not be shared, but no other restrictions should be imposed on carriers when they participate in routine activities such as special education programs.)

What happened to the carriers referring to the hepatitis experiments, "is hard to explain to people who did not experience it themselves. But it was almost as if they didn't want you to ask any questions and that they wanted to keep each parent isolated from the next.

"I was remiss in signing consent in the first place, but I did so because I was told that was the only way to expedite her admission. But I, and I assume other consenting parents, was ill-ad-

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