

Here you just don't have services for working people whom everybody would consider middle-class. If you want to say that the Staten Island community falls into the same bracket as the black in Chicago, or the Chicano communities in California, as regards to the handicapped, you'd be very accurate. The professional community hasn't been stimulated to take an interest in the kinds of services that handicapped children need. It requires a lot of cooperation and a lot of openness, or non-doctored people to be part of the treatment and service team. As long as the going motto on the Island is "the private physician in the community" we're not going to get the kinds of contemporary services that have shown themselves to be less expensive, provide better services and turn out a better kind of situation for the families to relate to. You mentioned different categories of retarded children, can you explain that? The mildly retarded generally has an I.Q. from 50 to 75. We know that, with good services, three fourths of them will be self-supporting as adults. The moderately retarded person, with an I. Q. of about 30 to 55, is a person who generally needs guidance most of his life. He can learn self-help, self-skills and work in limited kinds of situations like workshops. The severely retarded person is a person with an I. Q. of less than 30, and generally is a dependent person who needs help and guidance for the rest of his life. Are these I.Q.'s fixed? No. They certainly aren't. It used to be, for example, when I got out of medical school 20 years ago we thought an I.Q. was fixed. When you were born say your I. Q. was 110 and that was it, regardless of what you did. We know now that I.Q. is definitely an enriching process. The learning process and the personality of the person-his ambition, his will to achieve-are just as important as his intellectual ability.

Is retardation generally a physical problem?

Mental Retardation is a limitation of the intellectually handicapped, and there are over 168 different diseases that can cause that. Years ago we used to think it was primarily genetic and, if you remember, 20 years ago we sterilized everybody who came near an institution in California, for example. Now-a-days we realize genetic causes of mental retardation are not too common. Actually, most mental retardation in our experience is environmental. And the lack of prevention in this country to stop mental retardation is one of the greatest desecrations to the health of children existent. We are not doing enough to prevent mental retardation. What sort of environmental problems cause retardation?

Oh, poor prenatal care, for example. What other problems do institutionalized retarded children face?

Historically, an orphaned child in a state institution automatically became the "ward" of the head of the institution in which he was hospitalized. In other words, the head of the institution became the child's legal guardian. You can see the problems in getting such a child out of the hospital to get outpatient assistance under those circumstances. The California law changed that, but in New York and most other states nothing has changed.

How do administrators of state programs react to changes in the direction of more outpatient treatment?

People who run the institutions are very fearful of the new programs. After all, it threatens their jobs. Many of them oppose changes in public and then, when I talk to them as a friend, they admit we're right.

What prevents the regional centers from developing the same kinds of bureaucracies we see in state programs?

Regional centers in California are contracted to the state. By having diverse types running the program,

you avoid bureaucracies. In a state institution for example Willowbrook - the budget is based on the number of patients treated. This, obviously, creates a pressure to keep patients in - to overcrowd and so forth. The situation at Willowbrook is typical of New York - that is how bureaucracies develop.

What first steps can be taken in New York toward developing the kinds of programs you have been talking about?

The first step is to create a diagnostic center and show that it can work. Encourage the state to initiate a study of the problem including a close look at diagnostic centers. I would start by taking the first 100 applicants to Willowbrook and show that 75 don't need to go.

Do you think the grant applied for by the Family Hospital Coalition will help?

I wouldn't count on getting it. That's like asking the hand that feeds itself to bite itself. In California it was the parents who brought the changes. That would make the difference here.

*Editor's Note: Dr. Koch was brought to the Island to outline an alternative to New York State programs for handicapped children (such as Willowbrook State School). He is presently a professor of pediatrics at the University of S. California School of Medicine and Director of the Regional Center for the mentally retarded at Children's Hospital in Los Angeles. He is considered a national and international authority on the subject and, in 1955, launched the first multi-discipline diagnostic and service center at Children's Hospital.*