

Dr. Kotch Prelude to Action

By Mark Fast

What has California done to reform the way in which it treats retarded children?

Well California, roughly, has the same population as New York, yet New York has twice as many institutionalized mentally retarded persons as California. They have about 25,000, we have about 12,000.

The reason why we don't have as many as New York is because about 10 years ago a leading European expert on mental retardation came through California. He visited our institutions for the mentally retarded. His response was "You don't take care of your mentally retarded persons as well as we take care of our cattle in Denmark."

This statement received a great deal of publicity, and through the publicity several reporters actually visited the state institutions and wrote articles on them. Finally, the state legislature appointed a study commission to investigate this problem and found several interesting facts. One is that the state was not providing any services to parents until the family actually broke apart. There was no intermediate service to provide. There was no effort made to help the family to keep their child at home.

The second thing commission found was that the amount of money the state was spending on mental retardation was astronomical. It was around \$200 million. So the commission immediately recognized if it could do something that would be better the service, yet cost less money, it was something that it should do. Its key recommendation was that services should be provided to parents when a child is diagnosed mentally retarded and that those services should be not the same nor be provided by the same state departments that provided residential care including the Department of Mental Health.

Our Regional Center Program grew out of this, and it's administered by our Department of Public Health. The Department of Mental Health now only receives a person in a state institution if the regional center screens that person and says he is appropriate. What used to happen was that a retarded person went to a state institution. If the institution had an opening, they admitted the child. Now the person only goes to a state institution if they are sent there by the regional center.

On What basis do they send them?

The regional center has

two funding bases from the state— one for staff and operating, and one for purchasing service. If the child only needs residential care, for example, the regional center can purchase care in the family home, foster home, or in a board and care home. These are much cheaper than what the state can provide. For example, you can get those for about \$400 a month, whereas, in California, residential care in state institutions costs about \$8,000. That's quite a little difference in cost to the state.

Secondly we've been able to reduce the number of institutionalized retarded persons almost by a third in just the three or four years of the centers' existence. We now have fewer patients in our state institutions than we had in 1969, and we're programming it to go down to about 10,000. Is it safe to say that ideally there should be none or very few, institutionalized retarded?

If we went to Willowbrook, for example, we would find that 2/3 of the children there would not need a state hospital. In other words they don't need a doctor every day to look at them like a sick person. But it is true that about a third of the kids there are really quite severely handicapped and need ongoing medical care.

We found this to be true in California. On a survey the state did of our state residents, two thirds didn't need the state institution. They were there because there is no other facility or community service to help the family keep the child at home.

Is the situation comparable in New York?

Oh, I think so, and our state institutions in California are a great deal better than in New York. But I can say, frankly, that both of them are dehumanizing systems. They do not help the person to grow, but instead they reduce him to a vegetable status, so that he's less trouble to the people who are taking care of him. Is there evidence in the new California programs that bringing retarded children out of institutions helps?

Yes. This is substantiated in three ways. First of all we have evidence that a person coming out of a state institution and going into a small family care group develops better, not only from a personality point of view, but also in his ability to

cooperate and work with other people.

Secondly, the persons moving out of state institutions leave the same staff there to serve fewer patients so the program in itself is improving, simply because they have the same staff with fewer numbers of clients.

Finally, it's saving the state money because we have a lower rate of institutionalized persons. This is important from the taxpayer point of view.

Is there anything in New York State comparable to the program in California?

Not that I'm aware of. My understanding here is that, for example, on Staten Island you don't even have a diagnostic service for the mentally retarded. One manned, say, by a pediatrician, public health nurse, social worker and psychologist. This is the basic core group of professionals which should evaluate re-

arded children.

We found, in our experience, that one quarter of the children coming to us actually weren't even mentally retarded when they had a good evaluation. So that's the first thing that is extremely important.

Why were they brought there?

They were brought there because they were referred by doctors who thought the children were retarded. They were children who had behavior problems, or hearing problems, or visual problems, or cerebral palsy, or a combination of these kinds of handicaps.

Are many children hospitalized because their parents want them to be?

I don't think that's true. I think most children who are hospitalized in our state institutions are there because their parents just couldn't face it any longer. They had struggled with it without any help, essentially feeling very isolated and alone.

Are the parents who now have their children back at home glad about the change?

Most of the parents we are dealing with never had their child go into the state institution. For example, last year our center had 167 requests for state institutional care, but when we actually evaluated them only 35 were bonafide and the remainder are in community programs at the present time.

I think the important thing about the regional center is that the state invests money earlier in the course of care of the retarded child. It thereby prevents disability and long term institutionalization.

What kind of programs are carried on outside the hospital?

Outside of the hospitals, we have a public school program for all children who are mentally retarded. Not just the mildly retarded or the trainable retarded which New York has, but also a program in the public schools for the profoundly retarded. So if a child starts out at a profoundly retarded level, at three years of age he's improved to where he can go into what we call the trainable level. He can move up within the same system, so that education is responsible for the training

of all retarded children from zero I.Q. right up to the very gifted. I think this is the way all states will eventually go.

I think the other interesting thing is the relationship between the regional center and the state institution. A person can only be admitted to a state institution if they're screened through a regional center. The regional center decides that the state institution is the proper role and the proper facility for that person, and we admit a person to a state institution for a specific program in a specific period of time. The case is reviewed and remains active with the regional center, even while the person is in a state institution.

Who staffs regional centers?

The regional center is composed of an interdisciplinary group of professional people- pediatricians, social workers, public health nurses, nutritionists, psychologists, educators and this kind of personnel. We also have a community advisory board that's composed of professionals who advise us. Lastly, we have a mental retardation area planning board that's composed of parents of the mentally retarded, so that we have a parent group that has a policy input in the terms of how the center provides services.

In what way?

Well the mental retardation area plan actually governs budget, and is proposed and written by the parents with the assistance of the professional staff on the area planning board. The regional center is responsible to the area planning board for implementation of policy.

One of the more general problems of medical care on Staten Island is the conflict between consumers and providers. There is a feeling among some community groups, particularly minority community groups, that providers (officials in hospitals, and so forth) dominate all programs on Staten Island and that this is a bad thing. Is there a similar problem in California?

Y there is, and I think this is a universal problem here in the states. The medical profession has been very strongly entrenched and feels it has done a very good job in terms of medical care.

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.