The Queens Rehabilitation Program is designed to provide total rehabilitation for children handicapped with orthopedic, neuromuscular, or cardiac disabilities through enlisting the cooperation, and coordinating the activities, of professional groups, interested agencies, organizations, and individuals in the community.

Queens Rehabilitation Program for Handicapped Children

By LEONARD W. MAYO, S.Sc.D., and ROBERT M. WEBB, M.S.

NO MATTER what the size of a community, its future rests on the well-being of each of its members. Among the members of every community are those who are economically deprived, emotionally or mentally ill, or physically handicapped. These impairments are often such that they interfere, to a greater or lesser degree, with adequate functioning on the part of the individual in the community's enterprises, whether these enterprises are learning, making profitable use of leisure time, or earning a living.

In order to sharpen the focus from a broad and hazy look at the variety of differences in communities and in individuals, let us adjust our lens to pick out one physically handicapped child in a large metropolitan area and try to discover what may be done to help him through a more effective organization of the community.

Seen by a casual observer, Harry appears to be a pretty normal boy. His eyes are alert and clear, and he looks intelligent; his shoulders are broad and sturdy; and his appearance is neat, at least not any dirtier than the usual accumulation which 12-year-olds can assemble without obvious effort. But if you watched him walk, you would not notice the upper portion of his body because his right leg has been amputated at the knee, and he uses crutches.

Understanding for Harry

People who see Harry on the street for the first time usually react with pity. Sometimes they offer to help him across the street or give him a seat on a crowded bus. Some turn their eyes away so as not to embarrass him. Sometimes his contemporaries show a different reac-

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Mr. Mayo is director of the Association for the Aid of Crippled Children, New York City, an agency devoted to the interests of handicapped children and youth. He has had long experience with child welfare programs. At one time a high school teacher, a director of athletics, and the chief parole officer of a training school, he is, in addition to numerous civic and national posts, the honorary president of the International Union for Child Welfare and on the board of the Child Welfare League of America.

Mr. Webb has been director of the Queens Rehabilitation Program, Jamaica, N. Y., since its inception in 1954. His earlier career included posts with the Department of Welfare and the Domestic Relations Court, New York City, the Queensboro Council for Social Welfare, Jamaica, and the Stamford (Conn.) Community Council.

tion: "Hello, Crip. Bet you can't do this." Whatever their reaction, it is frequently not one of acceptance, understanding, or a desire to help. As a matter of fact, most people, adults as well as children, do not know how to help. They may remember Harry when they are asked for money for Easter Seals or the March of Dimes as a kind of payment to the gods for their own healthy bodies, but they are not very likely to get Harry into their clubs at church, their activities at school, or their outings at the beach unless they do so in a way that makes him feel "special" and "different."

What is Harry really like? How does his family feel about him? How does he feel about himself? What does he need to help make him whole? Can he find this help in his community? Taking everything into account, what can his neighbors and the community do in a practical and constructive way to help him make the grade and, at the same time, add to his own self-respect?

In Harry's community, the Borough of Queens in New York City, there is a demonstration program set up to help answer these questions. Sponsored and financed initially by the Association for the Aid of Crippled Children, it is called the Queens Rehabilitation Program. Part of the program is a diagnostic and evaluation center, called a division, in one of the public hospitals in the borough. Harry's physician learned of this, and sent him there to be thoroughly studied so that recommendations could be made for his rehabilitation—emotional, mental, and spiritual, as well as physical.

Harry and his mother came to the diagnostic and evaluation division of the Queens Rehabilitation Program where an appointment had been made. Harry did not have to wait in a cheerless room for a long time. He waited a while because it is a busy place, but the room is attractive, and there are magazines and books to look at. The physician saw Harry and his mother in a private examination room. When Harry had been given a thorough medical examination, a social worker talked to the mother and learned about the home, the other children in the family, and their relations with each other, the father and his job and earning capacity; the mother's feeling about Harry ("Harry's a good boy, but he broods an awful lot") and her attitude toward his disability ("Of course, I love him, but, well, it's hard to know how to treat him like the others. His crutches and all make him different").

That same day, if there was time and Harry was not too tired, or maybe another day by appointment, Harry saw a physical therapist who made an evaluation of his muscular development, his ability to walk, to climb stairs, to handle his crutches, and the strengths and weaknesses of his limbs. An occupational therapist saw him, too, and tested his coordination, his ability to dress and undress, and his capacity for the many activities of daily living. A speech therapist tested his facility with words, and a psychologist gave Harry a battery of tests which showed his intellectual capacity, his learning ability, and his deeper attitudes and feelings about himself and his relation to other people. A medical specialist in orthopedics took a careful look at his leg to determine whether it was possible or advisable to use some appliance other than crutches to help him walk.

Finally, after all these specialists had an opportunity to become acquainted with Harry and his family, and after they had made a thorough evaluation of him and his needs from their own points of view and consulted with each other to check their findings; after all available information from his school, his church, his family, and other agencies which have had to do with him in the past was correlated—the team got together and put all the pieces into one comprehensive and total evaluation of Harry as a whole person. What did they find?

Harry's is a relatively simple story. He set off one Sunday, ostensibly for church, with some change in his pocket for the collection but landed instead in a movie theater. Timing himself so that he would get home when he was expected, he left the theater to cross the street to a bus stop. As he ran from behind a parked car, he stepped into the path of an automobile, leaving no time for the driver to stop. Amputation saved Harry's life but cost him his leg.

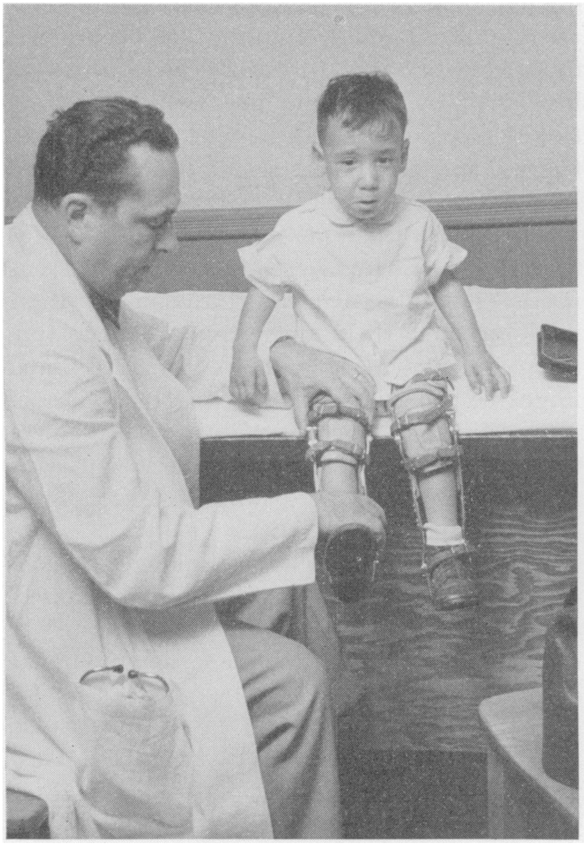
Before the accident Harry had not been happy at school. He attended sporadically, using any available excuse to stay away, truanting with increasing frequency despite punishment. Examinations showed that his hearing was defective, but this was not known until after the accident. His brothers and sisters, although not as well endowed intellectually, did better at school and were favored by their parents for this reason. Harry's father resorted to severe physical punishment to deal with him, and this, combined with the obvious preference shown by his mother for the other children, made the boy feel rejected and bitter. He was ready to use his disability as a means of getting even with his parents and as a means of avoiding school legitimately. Yet, at the same time he thought of his amputation as a punishment for his truancy and particularly for his deceit in not going to church the day he was injured.

The Rehabilitation Program

What to do for Harry? A useful and simple solution would be to fit him with a prosthetic appliance so that he could walk without crutches and look very much like other boys. Simple? Yes, except for the painstaking patience Harry would need to learn to walk again, to go through with the fittings and adjustments, and to get accustomed to the artificial leg. Above all, Harry had to want to walk and be willing to give up the newly found means of getting attention and favored treatment his crutches had given him.

Another easy matter would be to supply him with a hearing aid so that he could follow the teacher's instructions and understand the work in class and thus be able to put his intelligence to use. Easy? Yes, except for the adjustment to the hearing device and the reshaping of a boy's whole lifetime of feelings about school and other people.

And what about Harry—not merely his physical problems, as important as they were—but Harry as a person? A pattern of truancy is not easy to change. A fear of physical punishment for any infraction of rules is not readily overcome. The deep guilt which Harry felt because "God punished him" by destroying his



leg is difficult to clear up. If it takes time to learn to use an artificial leg and a hearing aid, how much more time and skill are needed to set straight the deep emotional disabilities that had ridden him even longer, and that his poor hearing and his traumatic experience served to aggravate?

The diagnostic and evaluation division of the Queens Rehabilitation Program sent its recommendations to Harry's physician, who arranged to get the prosthetic appliance and the hearing aid. At the physician's request, the physical therapist at the division helped to train Harry in the use of his new leg, and the speech therapist taught him to use his new "ears." Their work was carefully checked as they went along by competent medical men—Harry's own physician and specialists. But Harry's physician was at a loss to know where to get the help that the recommendations made it obvious Harry needed. He fully accepted the recommendation for guidance for Harry and his parents, but where could he turn to get the expert advice?

The physician understood that the Queens Rehabilitation Program included services other than those of the diagnostic and evaluation division, for a friend of his was serving on a committee of the program which concerned itself with the development of such services as Harry and many other handicapped children need.

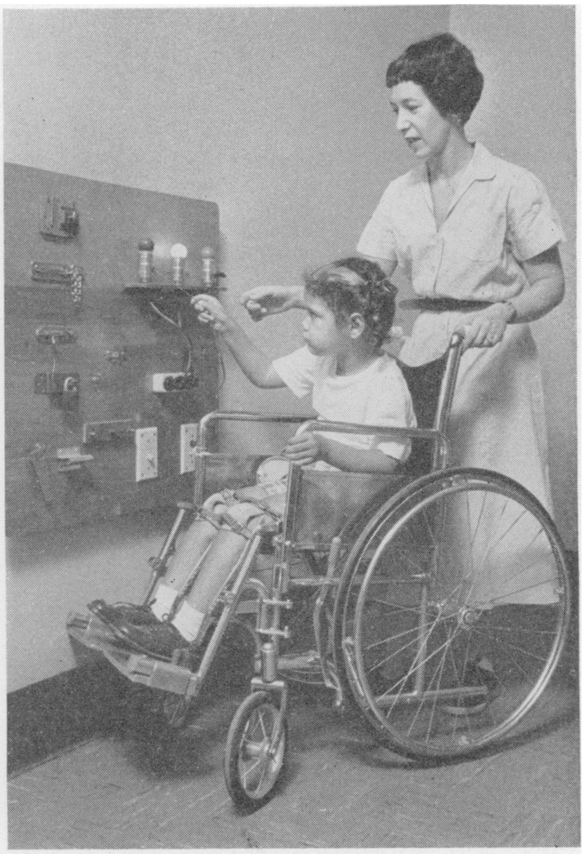
It is the aim of the program to locate the children who need service, to acquaint the agencies, hospitals, and other facilities with their needs, and to stimulate such organizations to provide the care which the children require. Harry's physician is one of hundreds of Queens citizens who take an active part in this endeavor, and he knows that Harry's case is not unique. Although it was an accident that caused the boy to lose his leg, there are children suffering from poliomyelitis, cerebral palsy, muscular dystrophy, and cardiac conditions, and children who are congenitally malformed or who have suffered a birth injury. Many need help, and it is for all, rather than for any one group exclusively, that the Queens Rehabilitation Program exists. The program is planned to demonstrate that, through community organization methods, it is possible to help the handicapped children of a community with the services that exist or can be developed, and that it is not always necessary or desirable to construct a building in which to house a rehabilitation center.

How is this being accomplished? What are the methods and tools of community organization, and how can Harry and others be better served because of them? As those experienced in the process will know, community organization is neither coercion nor manipulation, nor does it consist of imposing a pattern upon a community according to a preconceived plan, whether or not the community wants it. Community organization provides for bringing the principal elements of a community together under skillful leadership to face the most important things that need to be done in any field, deciding how they can be accomplished, and then carrying out a plan of action. In the Queens Rehabilitation Program, these things were done in the following way.

Basics of Community Organization

First there was an idea. In this instance, the idea was that a better job could be done in finding and treating the handicapped children and youth of the Borough of Queens. The idea had to be tested against the experience of responsible persons. It was discussed with public officials, department heads, hospital administrators, and experts in rehabilitation. When it seemed to be correct, according to the advice received from these persons, the next step was to get together a representative group of Queens residents and lay the idea before them for their reactions and their suggestions. They were the people who knew their community and might be expected to be able to give a correct evaluation of their community's willingness and readiness to accept a demonstration such as the one proposed, to work with it, and to cooperate in its aims.

Here was the place where a fundamental concept of community organization was used, namely, that no program may be expected to succeed unless the responsible leadership of the community is behind it. The group called together was representative in the statistical rather than the sociopolitical sense, as Alexander and McCann (*1*) make the distinction. That is to say, there were people from educa-



tion, government, medicine, social work, and civic and fraternal work—not elected by the organizations to which they belonged, and not officially speaking for those organizations. For example, the president of the medical society expressed the general views of organized medicine, but he was not delegated by the society for the purpose of expressing its majority opinion on a specific issue.

The group, designated later as a planning and coordinating committee, discussed the plans and proposals which had been submitted to it by the Association for the Aid of Crippled Children and suggested some amendments.

After several meetings, there was agreement that a demonstration program should be undertaken in Queens, and that it should have five main areas of concern: case finding, care and treatment, recruitment and training of professional personnel, public education, and research. In order to work out the details of methodology, separate subcommittees were set up. Again, careful selection was made to assure the participation of as representative a group of people as possible in order to secure the advice and guidance of the people most closely concerned with the work with handicapped children and to make sure that these people took an active partnership role in the development of the program. It was considered important that its growth should be along lines which they chose as important, and that, as it progressed, it should be their program and not one imposed on them or which they were "talked into" supporting. It is a simple but important principle of community organization that sound progress is achieved only when the community itself understands, supports, and is a part of that progress. It is frequently easier and faster to raise funds for the construction of a building than to work out other and perhaps better ways of serving people, but accomplishments are more likely to be permanent when they are planned and carried out jointly even though it may take three or four times as long to achieve results.

As an example: it is very important to ascertain certain facts about a community before trying to help solve a problem. One way to obtain facts is to have a survey made by experts from outside the community. These experts, having in mind an ideal, can quite quickly examine the community to see how closely it approaches perfection; then, they can, again with a considerable amount of speed and with great accuracy, record the comparison between present fact and ideal goal, and, finally, they can draw conclusions and make recommendations based upon their expert knowledge. In certain circumstances, and to meet the needs of certain communities, this kind of survey is useful and valuable. But sometimes the experts leave the community nothing more than a list of improvements which it should make to bring itself closer to the ideal. What happens then? The reaction, more often thought than stated, is very likely to be: "So these experts have examined us under their microscope and have found out that we ought to do thus and so. Why should they tell us how to run our town? They simply do not understand our situation. If they think such and such should be done, let them do it. We like our town as it is, and no imported expert can tell us otherwise."

But there is another way to conduct a survey, or in any event there are certain things a community can and should do before the experts come in. It takes longer and is more work for all concerned, but it is also more likely to produce lasting results; that is, the community can set up committees of its own citizens. They need not be experts, but they must be interested and intelligent individuals with a broad outlook. They should examine their community and find out the important facts about it. Having found them, they should study and decide whether or not the facts indicate correction. They should spend a lot of time at this job, and they may make some false starts. They should have professional assistance; this need not be an expert in the usual sense but a community organization worker who can provide the technical knowledge and act as the spark plug and generator for their machine. When their survey is complete, these citizens can make their recommendations to their fellow townsmen, and then the reaction of the community may well be: "We have looked at our town, and we find that we need thus and so. We know that we need it, and we want to do something about it. We intend to see that something is done, and we do not intend to relax until it is done."

In Queens many people have been involved in planning ways to provide better service for the handicapped children in the community. Committees in which physicians, ministers, nurses, social workers, businessmen, housewives, and health educators worked and talked together have met over a period of years. Some of them were set up for specific purposes of relatively short term—for example, to plan the establishment of the diagnostic and evaluation division: Where should it be? What kind of a staff should it have? What should be the job of the various members of its staff? What children should it serve? How should they be served? Others were formed along more general lines—for instance, to work for the integration of service to handicapped children within the framework of existing casework and group work agencies: What services existed in Queens? How far were they serving handicapped children? Were they prepared to go further? What major gaps in service existed? How much understanding was there on the part of the staffs and lay leadership of those agencies as to what is meant by total rehabilitation? What was the best way to get more understanding?

As in the example given above of two ways to conduct a factfinding survey, there was a conscious choice made in Queens between two ways of serving handicapped children. It would have been possible to conduct a fund-raising campaign for a building to house treatment facilities, to employ expert campaigners, and to gather the necessary money. A new service, admittedly needed, would then have been superimposed on the existing community resources, without relation to any of them or coordination with their purposes. Instead of taking that more usual direction, those who planned the Queens Rehabilitation Program decided to spend time, effort, and money in pulling together the common interests of many people and organizations. By developing a general concern, providing a means for getting real understanding, and offering a channel for cooperative

effort, it was believed that the results would be more permanent and more securely based.

What has all this done for Harry? His physician knows that the boy needed the services of a skilled caseworker and that his physical adjustment would not progress very far until he and his parents were on better terms. The service which Harry needs is now available to him through a family casework agency, and he and his parents are consulting regularly with a staff member there. It was harder to get Harry's mother to accept the need for that than it was to make her understand the need for an artificial limb, but progress is being made. Similarly, it is harder to work with a group of agencies to the end that they develop services for themselves than it would have been to say, "You need a rehabilitation center. We will build it for you."

Working together for an aim which the community wants and knows it wants and needs, mobilizing all available resources of mind and heart and strength for a mutually understood goal—these are community organization methods. They are applicable, with suitable adjustments, anywhere, for any community, under public as well as private auspices.

Have the results justified this approach?

Tangible and Intangible Results

Thus far the results have been of two kinds. One is tangible and concrete: A casework agency has inaugurated a special program for handicapped children integrated with its regular service to families and children.

A group-work agency has developed an experimental project to work with handicapped girls as a part of its general program. A special course for teachers who have handicapped children in their regular classes has been set up. School guidance counselors have been made acquainted with careers in health work and the variety of skills and interests which their pupils may develop in order to prepare for such careers. Two hundred children have been evaluated at the diagnostic and evaluation division in the Queens Hospital Center; many of them have been given muscle reeducation, have had appliances fitted, have been guided in the activities of daily living, or have had counseling service. Two other hospitals have also set up the beginnings of a treatment service.

The other kind of result is intangible and not capable of scientific measurement. For example, many people are more aware of the fact that handicapped children are children—that youngsters like Harry are not pathetic laboratory specimens of deformity but are children with feelings, reactions, emotions, and sensitivity. By the simple process of working together in committees on common problems, physicians, social workers, and other specialists have come to a greater acceptance of each other's skills; representatives of various groups have come to see that they have mutual concerns; people in different walks of life have arrived at an understanding of what each has to contribute to the other and of what all have to give to the total community. The accomplishments of the program are their accomplishments, not the achievements of outsiders.

REFERENCE

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Surgeon General Burney

Dr. Leroy E. Burney, a career officer in the Public Health Service, became the eighth Surgeon General of the Public Health Service on August 8, 1956. He succeeds Dr. Leonard A. Scheele, who resigned to become president of the Warner-Chilcott Laboratories.

Preceding his appointment, which is subject to United States Senate confirmation, Dr. Burney was State health commissioner of Indiana and secretary of the Indiana State Board of Health, on detail from the Public Health Service from July 1, 1945, to August 1954. For the next 2 years he was Assistant Surgeon General and deputy chief of the Bureau of State Services of the Public Health Service. He had been assistant chief of the Division of State Relations in 1943 and 1944.

Dr. Burney established the first mobile venereal disease clinic service in Brunswick, Ga., in the late thirties. In 1945, on detail to the Navy for 5 months, he was sent overseas by the War Shipping Administration to devise effective control measures for communicable diseases, especially the venereal diseases, in various Mediterranean ports. On returning to the United States, he became director of the former Public Health Service District 4 (now a part of Region 7) at New Orleans.

Dr. Burney joined the Regular Corps of the Public Health Service in 1932 after completing his internship at the United States Marine Hospital in Chicago in 1931 and subsequently receiving an M. S. degree in public health at the Johns Hopkins University School of Public Health, which he attended on a Rockefeller fellowship in 1931 and 1932. He received his doctorate in medicine from Butler University and the bachelor of science degree from Indiana University.

Dr. Burney is a past president of the Association of State and Territorial Health Officers and has been an active member and officer of various State and national medical and public health associations. He was born at Burney, Ind., on December 31, 1906.