The authors describe what was done in one borough of New York City to meet the problem of children with rheumatic fever or rheumatic or congenital heart defects, and the increasing role that health departments are playing in the development of programs and services for these children.

A PUBLIC HEALTH PROGRAM FOR CHILDREN WITH HEART DISEASE OR RHEUMATIC FEVER

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WITHIN the past 20 years new discoveries have made possible the prevention of recurrent rheumatic fever and the operative correction of many congenital heart defects. Health departments are playing an increasing role in the development of programs which use this new knowledge to stimulate the prevention or amelioration of serious cardiac damage in children. Such a program was started in a single health center district of New York City in 1947.

Health department services for children with heart disease or rheumatic fever were not new at that time, but the Lower East Side Rheumatic Fever Project,* (now the Manhattan Cardiac Program) offered a unique approach to the problem.† In a city where official and voluntary agencies have provided care for this group of children for many years, the problem has been and still is the coordination of all of these services so that every child receives the services he needs.

When the program was started its purpose was to study administrative methods whereby the Health Department, through its existing school health services and with the help of cooperating community agencies, could find children with heart disease or rheumatic fever and see that the services they needed were provided for them. It was anticipated that the study, in one health center district, would provide a pattern for a decentralized program for all of New York City.

The project was started in a congested low income area with a high incidence of rheumatic fever and much chronic heart disease. The number of children affected was not known, nor was it known to what degree those in need of medical and other services were receiving them. A survey by cardiologists in 1946[2] suggested that many school children with heart disease were not being identified and that many others who had neither organic heart disease nor valid histories of rheumatic fever were being followed as "cardiacs." At

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NOTE: This paper is a digest of a detailed report made to the Commissioner of Health, New York City.[1]

* The Lower East Side Rheumatic Fever Project was established in the New York University Department of Preventive Medicine, under the joint sponsorship of the New York City Department of Health and Board of Education and the New York Heart Association. Financial support was provided by the U. S. Public Health Service, the New York Heart Association, and the Association for the Aid of Crippled Children.

† San Francisco had begun a somewhat similar program in 1946, but this was not reported until July, 1948.

that time, in addition to routine case finding and follow-up by the school health service, two types of specialized service were provided to assist school physicians. The Health Department's Division of Physically Handicapped Children provided approval or disapproval by a reviewing cardiologist of all applications for changes in type of class placement and borough Cardiac Consultation Service clinics, to which children not already under care could be referred for examination by a cardiologist. These services reached only a small and selected group of children.

When the Lower East Side Rheumatic Fever Project was initiated its objectives were:

1. To find all children with suspected heart disease or rheumatic fever.
2. To attempt to confirm all reported diagnoses.
3. To follow all children with diagnoses in need of clarification as well as those with confirmed heart disease or histories of rheumatic fever in order to be sure that they received the medical and nonmedical services they needed and that the services were integrated.
4. To serve as a clearinghouse for information on individual children suspected of having rheumatic fever or heart disease and on the community services available to them.
5. To collect information on the incidence and prevalence of rheumatic fever and heart disease among school children in one area of New York City and on the services available to them, and to stimulate improvement of existing services and the development of new ones when the need arose.

The personnel provided included a director (a pediatric cardiologist with public health orientation), several part-time consultant pediatric cardiologists, a public health nurse consultant, a public health social work consultant, and a small clerical staff. Five years after the start of the project it was expanded to include all health center districts in the Borough of Manhattan, and became known as the Manhattan Cardiac Program. The objectives have remained the same for the expanded program. Follow-up of cases has been carried out with the help of an active register. The register has also provided data on incidence and prevalence and for special studies of certain administrative aspects of the program.

The study which forms the basis of this report was begun late in 1958 and was designed to evaluate the way in which the program has met the objectives outlined above. The data come from several sources, the most comprehensive of which are a detailed analysis of the records of all cases on the program register between January 1, 1951, and December 31, 1958, and biennial analyses made in 1955, 1957, 1959, and 1961 of cases currently on the register. Since there are no control data available from a comparable area without such a program the evaluation which follows is largely descriptive in character.

Case Finding

Suspected cases of heart disease or rheumatic fever are reported to the program from various sources, with the largest proportion coming from the school health service. Other sources include reports from the Board of Education of children on special instruction at home or in hospitals, and from child health stations, treatment agencies, the Visiting Nurse Service, and welfare agencies. Reporting is thought to be quite complete in the original study area (the Lower East Side) and is constantly improving in the other areas of Manhattan.

Confirmation of Diagnoses

One of the most important functions of the program staff has been the attempted confirmation of all diagnoses. It was learned early that many diagnoses of heart disease and rheumatic fever were erroneous. This is a con-

tinuing problem in areas of New York City where there is no provision for the routine confirmation of diagnoses. Data from a recent study of a sample of 105 eighth grade children from all areas of the city being followed in school as "cardiacs" in 1955, who were examined by cardiologists in the Lower East Side Health Center, show that 31 per cent of the 90 children reported to have rheumatic fever or heart disease were found to have neither. The remaining 15 children were being followed by the school health service even though their treatment agencies had reported them as having only functional heart murmurs.[3] Physicians without special training in the complex diagnosis of rheumatic fever and heart disease in children tend to be overprotective when they are uncertain about a diagnosis and many children are thus falsely labeled "cardiac."

A program cardiologist reviews every cardiac report submitted by a treatment agency and takes one or more of the following steps to confirm each new diagnosis:

1. Evaluation of the competence of the reporting treatment agency—For example, the diagnosis is accepted as confirmed if it is from a pediatric cardiac clinic affiliated with the New York Heart Association and the clinical data are clear and consistent.
2. Confirmation of reported histories of rheumatic fever—This is done either by telephone consultation with the child's physician or by reviewing a transcript of the child's hospital record (if he has been hospitalized). Eighty per cent of the hospital transcripts received give enough information to confirm or deny the diagnosis. Frequently a transcript has revealed that a child admitted to the hospital with a tentative diagnosis of rheumatic fever (which may be all the parent remembers in giving a history) had a discharge diagnosis of tonsillitis or pneumonia.
3. Cardiologic examination in the Department of Health Cardiac Consultation Clinic—Permission for such an examination is obtained from the child's physician who is usually delighted to avail himself of this free diagnostic service.

Sometimes a number of efforts are necessary before a diagnosis can be confirmed or rejected, and not infrequently the child may be followed for several years before a diagnosis can be clarified.

Distribution of Diagnoses

Table 1 shows the changes in diagnosis made for all children on the register between 1951 and 1958. Many children found to have no heart disease on original examination in the Cardiac Consultation Clinic or at the time of the first report to the program and therefore not put on the register are not included in these figures. The only children registered were those with diagnoses in need of clarification and those with confirmed diagnoses of rheumatic fever or heart disease. The per cent of admission diagnoses confirmed varied with the diagnosis. Eighty-three per cent of the children admitted with congenital heart defects were found to have confirmed congenital heart lesions, but among those admitted with rheumatic fever only 74 per cent were found to have had confirmed rheumatic fever.

At the time their records were closed, between 1951 and 1958, or when the study information was abstracted from the records of the children still on the register in 1958, 75 per cent of the children with diagnoses of heart disease or rheumatic fever had histories of rheumatic fever with or without heart disease. Twenty-one per cent of the total in need of follow-up had rheumatic heart disease and 24 per cent congenital heart defects.* In other words, only about one-fourth of the children with diagnoses of heart disease or rheumatic fever were those with congenital heart defects. In 1961, 64 per cent of the children currently on the register had

* Less than 1 per cent of the children had organic heart lesions of noncongenital and nonrheumatic etiology.

Table 1—Per cent of Admission Diagnoses Confirmed and Changed*

Last Diagnosis	All Diagnoses	Diagnosis on Admission to Register: Possible Heart Disease	Rheumatic Fever	Congenital Heart Defect	Heart Disease of Other or Unknown Etiology
Number with each admission diagnosis	4,259	525	2,818	863	53
	Per cent with Each Last Diagnosis Confirmed				
Total	100.0	100.0	100.1	99.9	100.1
No heart disease	14.1	52.4	9.3	6.6	13.2
Possible heart disease	4.4	23.8	0.9	4.1	3.8
Rheumatic fever	50.2	6.4†	74.0	0.3	28.3
Congenital heart defect	18.0	5.9†	0.7	82.7	5.7
Heart disease of other or unknown etiology	0.8	1.0†	0.3	0.2	34.0
	Per cent with Diagnosis Unconfirmed				
	12.5	10.5	14.9	6.0	15.1

* All cases on the register between January 1, 1951, and December 31, 1958.
† Mainly cases with insufficient information on first report to make a more definite diagnosis possible.

had rheumatic fever. Nineteen per cent of the total had rheumatic heart disease and 36 per cent congenital heart defects. The change in distribution undoubtedly reflects a decreased incidence of rheumatic fever and may also indicate an increase in the number of children with congenital heart defects reported to the register because of the new interest in operations to correct these defects. Children with histories of rheumatic fever, however, still constitute the bulk of those in need of public health follow-up.

Figure 1 shows this relationship in terms of the prevalence among children of elementary and junior high school age in the Lower East Side Health Center district of rheumatic fever, rheumatic heart disease and congenital heart defects between 1951 and 1961.* Rates for rheumatic fever with and without heart disease declined from 9.7 per 1,000 children in 1951 to 5.1 per 1,000 in 1957. Rates for rheumatic heart disease declined from 3.6 per 1,000 to 1.4 per 1,000 in the same period. Since 1957 there has been no significant change in either rate. The rates for congenital heart defects have remained between 2 and 2.4 per 1,000 since 1951.

Follow-up

Successive biennial analyses of cases currently on the register show that in Manhattan prophylaxis is being pre-

* At the beginning of the project there was some overdiagnosis in all three categories. Discussion is therefore restricted to the period beginning in 1951.

scribed for an increasing percentage of children with rheumatic fever. In 1957 only 63 per cent of those with confirmed rheumatic fever were reported to be on prophylaxis; in 1961 the proportion had risen to 86 per cent. However, in the detailed analysis of the records it was found that the prescription of prophylaxis is not enough. The risk of recurrent attacks of rheumatic fever was as high among those children in the study group who were on intermittent prophylaxis* as among those on no prophylaxis, but was greatly reduced in the group on regular prophylaxis. Additional data show that there is a markedly increased chance of developing heart disease with each recurrent attack of rheumatic fever. Among the children who had no evidence of rheumatic heart disease when they were admitted to the register less than 5 per cent of those with no recurrent attack were reported to have developed heart disease. More than one-fourth of those with one recurrence and 6 of the 11 children in the defined group who had two or more recurrences were reported to have developed rheumatic heart disease while they were on the register. As a result of these findings the Department of Health, in an attempt to prevent rheumatic heart disease, is establishing a new policy of close follow-up by the school health staff of all children with confirmed rheumatic fever, to see that prophylaxis is prescribed and that the child continues to take it without interruption.

* In analyzing the available data on the use of prophylaxis certain assumptions had to be made. It was assumed that a child under uninterrupted medical care of good quality was taking prophylaxis regularly once it was prescribed. If, however, there was evidence of change of treatment agency or broken appointments, it was assumed that the prophylaxis was intermittent.

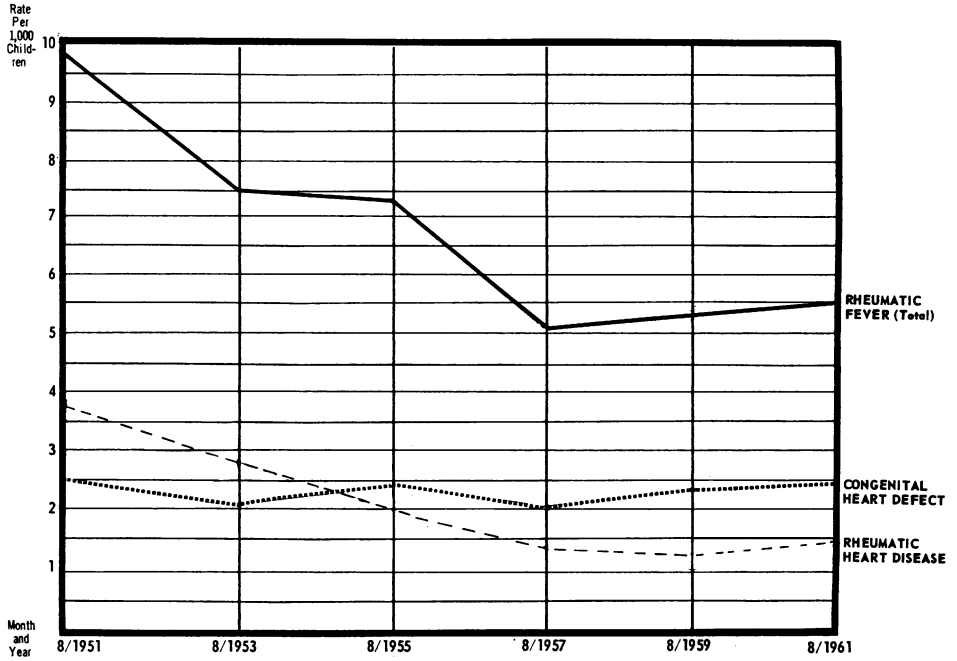

Figure 1—Number of Cases of Confirmed Rheumatic Fever (with and without Heart Disease), of Rheumatic Heart Disease and of Congenital Heart Defect per 1,000 Elementary and Junior High School Children. New York City, Lower East Side Health Center District 1951-1961.

Data on evaluation and operation for congenital heart defects among children in the study group come mainly from the period before open heart surgery was in general use. There were 823 children with congenital heart defects on the register during the study period. Eighty-three per cent of these children had had some evaluation of their lesions. Of the 341 children who had had complete evaluation one-third had been operated on and 6 per cent had had surgery recommended but not performed. For the remaining children, mainly those with noncyanotic defects, an operation was not thought to be indicated at the time of the evaluation.

Many of the children who had had no evaluation or only partial evaluation of their lesions were those for whom the diagnosis of a congenital heart defect was first made after they had reached elementary or junior high school age. It is particularly difficult to get this group under care. The murmur is usually heard on routine examination, the child is symptom-free, and the parents are reluctant to accept the diagnosis or to submit the child to hospitalization for tests which may lead to surgery. A follow-up study of 40 children with unoperated operable lesions, to determine how many had had surgery after the data for the study had been abstracted from their records, disclosed that of the 15 who had been operated on, only one was more than 10 years old at the time of surgery. Of the 25 whose parents refused recommended surgery 17 were more than 12 years old at the time of the recommendation for surgery. These findings point up the importance of early diagnosis in children with congenital heart defects, at a time when parents are most receptive to medical advice.

As a result of follow-up by the program staff, an increasing proportion of children on the register are receiving care from clinics affiliated with the New York Heart Association.* In successive biennial analyses of the records of children on the register at the time of the analysis the proportion of children under the care of affiliated cardiac clinics increased from 48 per cent in 1955 to 76 per cent in 1961 (Table 2). The increase has come largely from the children under care of nonaffiliated clinics and those for whom the source of care was formerly unknown.

Community Aspects of the Program

One unique aspect of the program is that it deals with all children in the area presumed to have heart disease or rheumatic fever, and not just those for whom service is requested. This has given the staff an opportunity to work with all types of physicians, clinics, and other community agencies, and to learn where services need improvement. Telephone consultation with the practicing physician about diagnostic and other problems of his individual patient has been an important function of the program cardiologists, and has led to greater utilization of available community services and improved care for the patients of private physicians. Educational programs and consultation by program staff to Health Department, Board of Education, clinic, and community agency staffs have been a factor in improving and coordinating the services of these agencies. The program office has served as a clearinghouse for information on individual children with heart disease or rheumatic fever, and on services available to them. Where gaps in service have been apparent it has often been possible to stimulate the development of new services.

Conclusions

We believe the net effect of the program has been to identify the great ma-

* The number of affiliated pediatric cardiac clinics did not increase significantly during the period covered by this study.

Table 2—Changes in the Distribution of Medical Supervision of Children on the Register in Successive Analyses of Cases on the Register at the Time of Analysis

Type of Medical Supervision*	Year of Register Count			
	1955	1957	1959	1961
	Total Number			
Total	1,618	1,981	2,187	2,118
	Per cent Under Each Type of Supervision			
Affiliated clinic	48.0	57.2	67.6	75.7
Other clinic	10.2	14.1	9.4	4.5
Private physician	20.1	19.3	16.0	15.7
Other	0.7	1.1	1.9	1.3
None	1.3	0.4	0.7	1.9
Unknown	19.7	7.9	4.4	0.8

* Children in hospitals at the time of these analyses were allocated to the treatment agency referring them to the hospital.

jority of children of school age with actual or suspected rheumatic fever or organic heart disease, to clarify their diagnoses and to promote continued medical follow-up including prophylaxis against streptococcal infections and recurrent rheumatic fever for those with confirmed rheumatic fever, and diagnostic work-up and surgery when indicated, for those with congenital heart defects. Intensive efforts to clarify diagnoses have been in general acceptable to practicing physicians. These efforts have paid large dividends in terms of the "delabeling" of children falsely diagnosed as having rheumatic fever or heart disease and thus of fewer children followed needlessly by the school health service. At the same time follow-up of those correctly diagnosed has improved. The register has been not only an effective tool of follow-up, but has provided the only data available in New York City on the incidence and prevalence of rheumatic fever and heart disease in children.

This program, with continuing consultation to physicians and to treatment and other community agencies, has stimulated the development of more and better services throughout the borough of Manhattan for children with heart disease or rheumatic fever. Extension of much of the program to all of New York City is now being planned.

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