

# A Multidisciplinary Approach to Services for the Epileptic

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THE U.S. CONGRESS in 1961 indicated that progress in research into the diagnosis, treatment, and long-term management of neurological problems had reached the point where widespread application of the findings was possible (1). Following recommendations of a task force, the Surgeon General of the Public Health Service in January 1962 officially created the Neurological and Sensory Disease Control Program (NSDCP). This program was terminated in June 1970.

One primary concern of the NSDCP was epilepsy. A multidisciplinary approach to improve services for the epileptic was undertaken through studies, service demonstration grants, training grants, and educational and informational activities. Considerable data accumulated on the serv-

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ices available and the difficulties encountered in delivering services to the epileptic, but this material has not been widely disseminated. The purpose of this paper is to make the accrued material available to those interested in the problems of epilepsy.

### Resumé of Studies

Lack of firm statistics on which to base programs for the epileptic was identified as a serious problem. Continuing studies were funded to answer specific questions about epilepsy.

Developmental projects. A series of developmental projects was undertaken to identify and analyze the needs and resources available to patients with neurosensory disorders, including epilepsy, in California (2), Florida (3), Louisiana (4) Mississippi (5, 6), New York (7), North Carolina (8–14), Ohio (15), Oregon (16), Oklahoma (17), Pennsylvania (18, 19), Rhode Island (20), and Washington State (21). The resulting voluminous reports of these projects identified the States' needs in the control of epilepsy, and created a cooperative awareness of the need for action among interested private and public agencies.

Members of planning committees for these proj-

ects were able to verbalize the information required but in most instances were not able to surmount the problems of collecting firm data. All States affirmed that the true prevalence of epilepsy was especially difficult to assess since epilepsy is so easily hidden. Patients usually have no readily recognizable physical defect. Because of severe difficulties encountered in obtaining employment, motor vehicle licenses, and insurance, epileptics are often motivated to keep their seizures secret. All the States ultimately used national figures to obtain prevalence estimates for their own populations, supplemented by studies of individual case records from selected hospitals and community agencies. Inpatient hospital records revealed few patients with epilepsy because, once clinically diagnosed, these patients were treated on an outpatient basis.

Questionnaires developed for some projects were sent to many institutions, organizations, and practicing physicians in an effort to obtain data on prevalence of the disease and facilities available for treatment. Unfortunately, not enough questionnaires were returned for the information to be meaningful, and many returned questionnaires were incomplete. All respondents recommended further epidemiologic studies concerning the distribution of epileptics in the population.

All 12 States reported that the existing facilities were inadequate to give suitable medical care to all patients afflicted with neurological and sensory disorders. Services and facilities were insufficient and poorly distributed geographically within the States for the purposes of screening, diagnosis, treatment, and rehabilitation. It quickly became apparent in some States that, while these projects were designated as statewide assessment projects, many sections of the State did not have the facilities for assessments. No reliable estimates of the number of people needing services but without access to the few existing in a State could be adequately determined.

The number and distribution of neurologists, neurosurgeons, pediatricians, and paramedical personnel were determined for each project State. The majority of medical personnel were clustered around metropolitan areas, with a paucity of trained personnel available to rural communities. No satisfactory ratio was determined for the number of neurologists required to meet a local area's needs. Most neurologists functioned on a "consultation only" basis, with hospital practices of many neurologists and neurosurgeons restricted to universities

or large, well-equipped institutions in metropolitan areas. All reports stressed the need for continuing professional education of the personal physician in the treatment of convulsive disorders to reduce the time interval between discovery of new knowledge and application of that knowledge to the patient. Available facilities for training medical personnel were assessed. It was concluded that present educational facilities were incapable of meeting the urgent demands of growing populations.

Better mobilization of available resources through organized community health activities was an identified need in several States. Among the chronic neurological and sensory diseases, least had been contemplated or achieved for epilepsy in community-controlled activities.

Each project developed recommendations to officially recognize needed action. The following proposals submitted by the directors of the State assessment projects were thought to have applicability in all States:

- 1. Closer coordination of all agencies offering services to patients with neurological and sensory diseases
- 2. Specific assessment of needs and resources by local communities
- 3. More medical specialists and allied medical personnel, with greater coordination between these workers
- 4. Expansion of neurological care programs in urban areas, with implementation of diagnostic and screening programs in rural areas
- 5. Establishment of permanent advisory committees in the States for continuity of effort and coordinated approach to the neurological and sensory diseases.

Approximately \$586,000 in Federal funds were granted for these State developmental projects.

Overview of epilepsy. Columbia University's division of epidemiology, under a \$57,000 contract, reviewed the problems of epilepsy on a national level and offered recommendations for improvement of the situation. Its review of the literature (22) from 1958 through mid-1964 revealed 206 publications on the community aspects of epilepsy. Simultaneous pursual of the following three objectives was recommended in the report to achieve a major advance in the campaign against epilepsy (22):

- 1. A radical change in the hostile climate of social opinion.
  - 2. Multiplication of services to patients.
  - 3. Intensified conduct of research.

Table 1. Average annual incidence rate for convulsive disorders per 100,000 residents of Rochester, Minn., selected periods, 1935-67

Selected periods	Male	Female	Total	
1935–44	30. 1	26. 1	27. 9	
1945–54	52. <b>7</b>	42. 7	47. 1	
1955-64	46. 8	41. 7	44. 1	
1965–67	42. 6	30. 0	35. <b>7</b>	

Source: Reference 24.

Specific methods of implementation included establishment of a strong national voluntary organization, increased dissemination of new material to practicing physicians, increased consultation services for physicians, coordination among currently existing programs, an increase in research in community programs, additional casefinding to bring more patients under medical management, and efforts to remove the barriers to employment, particularly to the adolescent.

Prevalence and incidence. The need for more accurate prevalence and incidence rates for epilepsy prompted a contract with the Mayo Clinic. The most complete estimates of prevalence and incidence came from this clinic. Methods and sources for intensified case ascertainment not included in the prior study (23) were investigated. The categories identified were diagnosed convulsive disorder, suspected convulsive disorder, and circumscribed or isolated seizure related to an acute but possibly recurrent alteration of metabolic or structural brain integrity or of unascertained etiology. Preliminary data concerning the average annual incidence rate for convulsive disorders per 100,000 residents of Rochester, Minn., are summarized in table 1 for selected periods during 1935-67. The prevalence rate of convulsive disorders (diagnosed epileptics only) per 1,000 residents of Rochester on January 1 of selected years from 1940 through 1965 are given in table 2 (24).

Services and facilities available to the epileptic. In 1965 and again in 1967, with the aid of the Service and Service Training Subcommittee of the Public Health Service Advisory Committee on the Epilepsies, staffed by NSDCP members, the Epilepsy Foundation of America published "A National Directory of Clinic Facilities for the Diagnosis and Treatment of Epilepsy" (25).

It quickly became apparent that while this directory was a step in the right direction, there were numerous omissions. In addition, no complete in-

vestigation of all services, medical and social, had been published for any State. In 1967, in an effort to identify all resources available to persons with epilepsy and to determine the need for development of new resources or the expansion of old ones, a survey was completed in Indiana (26) with partial support granted by NSDCP. This survey identified needs for increased outpatient facilities, increased electroencephalographic facilities staffed by trained electroencephalographic technologists, and increased public education and enlistment of community support. The rationale for these needs was supported by describing the existing situation.

The Public Health Service Advisory Committee on the Epilepsies endorsed a series of opinion surveys of existing services and facilities available to epileptics in six selected areas within the United States. The committee thought that such information would provide important background knowledge to guide future programs in epilepsy. The surveys were conducted in Oregon (27, 28), Montana (29, 30), Virginia (31), Mississippi (32), New Mexico (33, 34), and Metropolitan Philadelphia (35).

Physicians, public health nurses, State and local government health personnel, educators, employment counselors, and representatives of voluntary agencies were questioned. These surveys identified the following major problems:

The provision of multidisciplinary medical services to all portions of a State

Medical services to newly diagnosed or poorly controlled adult epileptics

Continuing education in the convulsive disorders for the practicing physician

Employment of all epileptics

Education of children having seizures under poor medical control.

Communications. A contract was awarded in 1962 to Capitol Consultants, Inc., a firm specializing in

Table 2. Prevalence rate for convulsive disorders, diagnosed epileptics only, per 1,000 residents of Rochester, Minn., January 1 of selected years, 1940-65

January 1	Male	Female	Total
1940 1950 1960	3. 3 5. 3 6. 0	2. 2 3. 6 5. 2	2. 7 4. 3 5. 5
1965	5. 5	5. 3	5. 4

Source: Reference 24.

health and educational communications, to conduct a nationwide survey of problems in communication relevant to the neurological diseases (36). This project was not designed to provide statistical results or conclusions but rather was planned to gather and evaluate by interviews and conferences at the national and local levels the opinions, attitudes, problems, and recommendations of family practitioners and of those responsible for disseminating information to physicians. Approximately 800 medical practitioners, educators, and health field executives in various sized communities throughout 48 States were contacted. Alaska and Hawaii were not included.

The major problems identified were poor use of existing media by those wishing to communicate and a combined lack of motivation and time on the part of the busy practitioner. The educational role of representatives of pharmaceutical companies appeared to be significant—perhaps more than their education or training should warrant. These representatives were highly esteemed by practitioners, particularly in terms of information gained about drugs. Most of the physicians interviewed listed the representative as one of the top three sources of new information. Medical practitioners also viewed the medical school complex and the community hospital as sources of information on new medical trends. The report stressed the need to improve the public's understanding of neurological and sensory disorders (36).

Postgraduate medical education. Evaluation of the symposium as a method of postgraduate medical education followed 3 days of discussions on the care of the epileptic, presented by Jefferson Medical College and Pennsylvania State University in Harrisburg, Pa., May 27–29, 1965 (37). Ninety-eight of 145 symposium participants responded to a questionnaire. The results revealed that basic problems in the design of the symposium were specification of its objectives and delineation of its audience. The physicians' verbalized goals for attending the symposium were to improve their differential diagnosis of seizures and to better prescribe treatment.

The greatest single cause of an ineffective symposium was thought to be lack of communication between speakers and the audience. A number of procedures for improving speaker-audience communication were suggested, including submission of a full text or abstract of each speaker's talk so that other panel members and the audience could review advance mimeographed copies. Panel discussions

following formal presentations were recommended to increase responsiveness of the speakers to the needs of the audience. The evaluators concluded that, despite the limitations of the training method and the heterogeneity of the audience, the symposium can be used successfully for training (37).

Pediatricians and seizures. During 1967 the American Academy of Pediatrics, in cooperation with the NSDCP and the Public Health Service Advisory Committee on the Epilepsies, surveyed members of the Academy to determine the number of seizure patients under care, population served, degree of specialist care by neurologists compared with care rendered by general pediatricians, specific information on therapy, and opinions as to unmet needs. Of 7,287 mailed questionnaires, 3,192 or 43.8 percent were returned. Preliminary results indicated that about 75 percent of the Academy members provided long-term total care to the epileptic and about 25 percent referred patients permanently to neurological specialists.

J. E. Snyder, M.D., assistant vice president, Presbyterian Hospital of the City of New York, in personal communications of March 12, 1968, and February 26, 1970, submitted preliminary reports of the survey stating that the following three major problems were cited by pediatricians.

Lack of public understanding of epilepsy

Lack of professional knowledge in diagnosis and treatment of epilepsy

Lack of an effective organization for dealing with vocational problems of the epileptic

National voluntary agencies. In 1962, the National Health Council, Inc., was awarded a \$13,940 contract to identify, analyze, and summarize programs of national voluntary organizations with specialized interest in epilepsy (38). Four national voluntary agencies, with 38 State and local affiliates and at least 37 other State and local groups without national affiliation, were identified.

The National Epilepsy League, Chicago, the oldest of the four organizations, was incorporated under that name in 1949. The organization was founded and incorporated in Boston as the Laymen's League Against Epilepsy and subsequently renamed the American Epilepsy League. In 1949, following merger with the National Association to Control Epilepsy, the headquarters were moved to Chicago. The League works with other national and international groups to benefit people with epilepsy.

The United Epilepsy Association, New York City,



Project administrator discussing with mother of patient the social and educational problems of her young son

was established in 1944 as the Association to Control Epilepsy, Inc., and subsequently was renamed in 1945 the National Association to Control Epilepsy, Inc., in 1952 the Epilepsy Association of New York, Inc., and in 1954 the United Epilepsy Association, Inc. This association concentrated its activities principally in the New York City area until the 1960's and stressed research development.

The Epilepsy Foundation, Washington, D.C., was established in 1954 as the Federal Association for Epilepsy, and concentrated its activities on the National Children's Rehabilitation Center in Leesburg, Va., a facility for epileptic children with special educational and adjustment problems.

The American Epilepsy Federation, Boston, Mass., established in 1959 with the aid of the American Epilepsy Society—an association of physicians interested in epilepsy—was formed of State and local epilepsy organizations interested in forming a unified national organization (38).

The National Health Council, Inc., concluded in its report that although each organization started with a similar basic purpose, the emphasis and methods by which these purposes were being accomplished differed. As a result, a voluntary national agency to provide leadership in meeting the problems of epilepsy was lacking (38).

On January 7, 1965, the American Epilepsy Federation and the United Epilepsy Association merged into a single agency, the Epilepsy Association of America, Inc. (39, 40). The impetus of the National Health Council report in effecting this consolidation has been recognized. The Epilepsy Association of America and the Epilepsy Foundation united as the Epilepsy Foundation of America on January 1, 1968, after a 6-month period of transition (41). The National Epilepsy League, while working closely and cooperating with the Epilepsy Foundation of America, has retained its independent status. The Epilepsy Foundation of America is now recognized as a strong voice for the epileptic.

## **Service Demonstration Projects**

Of all neurological disabilities, epilepsy is the most amenable to control by public health methods. Early evaluation and rehabilitation can prevent both physically and socially devastating effects to the individual.

Diagnostic problems in epilepsy may be simple or tremendously complicated. Lack of uniform definitions and criteria, the presence of multiple neurological handicaps, changes in diagnostic practices, and the subtlety of early neurological manifestation, all contribute to the serious problem of diagnosing persons with convulsive disorders.

Experience with large-scale provision of services to the epileptic was scanty before the 1960's, and only limited material was available for use of the NSDCP staff and consultants in developing a program for epileptics. We will briefly review the published data that were used to determine program policy.

Early efforts in delivery of medical services. In July 1950 the first public health program for children with seizures was inaugurated in Maryland. A multidisciplinary team approach was used in which each patient was evaluated and, when indicated, treated by a clinician particularly interested in epilepsy, a public health nurse, and a social worker. Case conferences were initiated concerning some children in which all professional people involved in the cases, including the referring physician or agency, participated. Patients ultimately were returned to their private physician when practicable. To serve rural areas of the State, a series of consultation clinics on epilepsy were regularly scheduled for more than half of Maryland's 23 counties (42).

The Maryland program demonstrated the amenability of epilepsy to preventive measures and therapy. A review of patients seen in the Maryland epilepsy program after a minimum 6 months of treatment showed 63 percent of the patients reasonably controlled, 27 percent improved, and only 10 percent with little or no improvement (43).

From July 1, 1950, to December 31, 1953, 79 percent of 689 patients had a definite diagnosis of epilepsy, 12 percent did not have a seizure disorder, and 9 percent did not complete the diagnostic procedures. Removing the suspicion of epilepsy from any child was considered an important function of the program. Some children had simple fainting spells, breathholding spells, behavioral disorders, or hysteria and were in need of a suitable facility for instituting appropriate treatment (45).

The Maryland program stressed the fact that the child, if untreated, is likely to become dependent, unemployable, and a permanent public responsibility. Cost per child for maximum restorative treatment is far less than supporting a dependent, unemployable, crippled adult.

In Virginia, a series of traveling multidisciplinary clinics, staffed by a permanent university-located master seizure clinic, effectively demonstrated that modern therapeutic measures can be extended to children living in all areas of a State and that by making diagnostic and treatment facilities available, the seizures of a large number of these children can be controlled and the personal misery and loss to society that are so commonly associated with epilepsy can be averted (31, 46, 47).

In California, demonstration clinics offering diagnostic and treatment services were opened in Contra Costa County in 1960 and in San Bernardino County in 1961. Each patient received a pediatric diagnostic medical examination, a neurological consultative examination, routine laboratory studies, X-rays, psychological screening, and assessment of family functioning. Diagnostic services were provided to 236 children from 228 families during the 2-year demonstration period. The children, referred mainly by private physicians, were found to have medical, social, and educational difficulties and were in dire need of comprehensive diagnostic and treatment services.

Two-thirds of the children had at least one other major handicap. Approximately half of the children had mixed epilepsy and more than one-third had focal seizures. At referral, one-fifth of the children had one or more seizures daily. With therapy, 58 percent of the children became seizure free, and an additional 24 percent showed a considerable reduction in frequency of seizures. In Contra Costa County, over 90 percent of the families reported that the child was being seen by a family physician, but more than one-third of these children had not been treated for their seizures by the physician.

In San Bernardino County, 70 percent of the children were currently under medical care and, again, more than one-third had never been treated for epilepsy. A diagnosis of no convulsive disorder was made for one of every six children examined in the clinics. Most of these children had a serious medical or social problem for which they needed help and obtained appropriate referral from the epilepsy project.

The major service provided by the California demonstration project was organizing a multidisciplinary team to completely evaluate a child and his family and bring together those persons interested in the child to plan and coordinate his care. In this way the project was able to determine gaps in community services and to identify those services needed for the children. As a result of the 2-year demonstration study, it was recommended that epilepsy be included in the list of eligible handicapping conditions for the California Crippled Children's Services Program. It was also stressed that a social work staff should be made available to provide social diagnostic services to children with suspected or known epilepsy. The availability of psychiatric services was recommended. It was emphasized that vocational planning, counseling, and training services should be made available to the child with epilepsy at the earliest possible age, while he is still attending school (48–51).

In Wisconsin, a Variety Club Epilepsy Center providing multispecialty services to both adults and children was established in 1956. During its first 5 years, the clinic served more than 500 adults and children. The largest number of patients were in the age ranges of 10 to 20 and 30 to 50. Through the direct efforts of the clinic, early changes were made in education of the epileptic child in Wisconsin, in vocational rehabilitation, and in adoption of a model motor vehicle law. Although an exact breakdown of costs for the patients seen at the Variety Club Epilepsy Center has not been published, it was stressed that cost was minimal if the patient could be rehabilitated to a functioning citizen (52).

The essential role of the public health nurse in Hawaii's program to control seizures was further evidence of the importance of the multidisciplinary approach (53).

Experience in Idaho during the late 1950's indicated that clinics were desirable not only for the child with epilepsy but also for children with all forms of neurological disorders, including cerebral dysfunction, cerebral palsy, mental retardation, behavioral disorders, and specific disorders of learning. Epilepsy is frequently associated with other handicaps in children, and duplication of personnel might be avoided by combining the clinics (54).

The Colorado Crippled Children's Services Program for epilepsy was initiated in 1956, and by 1961 it was extended to cover about half of the counties in the State. This program initially hired physicians on a fee-for-service basis. The major problem was in finding physicians with interest and training in the treatment of epilepsy. The physicians eventually located were interested in assisting the whole child and provided many of the services given by a multidisciplinary team. Treatment appeared adequate by this method; the physicians were also able to function on a limited basis in educating the community (55).

In 1951 the Michigan Epilepsy Center and Association initiated a mobile electroencephalography laboratory consisting of an 8-channel electroencephalograph mounted on a suitable truck. The laboratory was driven more than 1,000 miles during a 10-week period each summer. Stops for the mobile unit were determined by invitation of county medical societies. In addition to providing a report on the EEG to the referring physician, the neurologist would add diagnostic considerations and suggestions for continued management of the patient, based on the referring physician's medical statement and on the patient's previous medical and social history. In addition, the physician staffing the mobile unit lectured on epilepsy when requested. One major problem of the mobile unit, which eventually led to its discontinuance, was lack of a total approach to the patient. It was recognized that many medical and allied disciplines could work better in a combined treatment of each patient (56).

Prior identification of social problems. A survey of handicapped children in Georgia in the mid-1950's revealed that of more than 1,200 children approximately one-third had one handicap, another third had two handicapping conditions, and one-third had three or more handicapping conditions. The average for all the handicapped children was 2.2 conditions per child. All the children needed a diagnostic appraisal and a plan of care. Almost three-fourths needed psychological or social services for the child or the parent. Particular attention was given to the great need and universal inadequacy of family counseling (57).

In Montgomery County, Md., nearly 75 percent of the school children referred for special education in that county had a history of one or more seizures. Evaluation of 200 indicated that the seizures of only seven were not controlled by medication. These children were referred to special education not because of their seizures—only one sympton of the problem, with very little significance for educational planning—but because the condition that caused the seizures also caused learning problems. Children with several disabilities frequently have seizures as an associated problem. Their disabilities include visual perceptual or visual motor difficulties, auditory imperception, motor speech problems, poor gross coordination, mental retardation, cerebral palsy, compulsive hyperactive behavior, and withdrawn, anxious behavior.

A larger group of epileptic children in Montgomery County attended regular classes, functioning as

normal children. Their seizures were controlled, and they had no other exceptionalities. Their cases were known to the Maryland State Department of Health and to the school nurse, but to few other people. Frequently, the classroom teacher had no knowledge of the child's epilepsy unless a seizure occurred in school. The parents had been told by their physicians to treat these children as normal. Frequently, neither physician nor parents had discussed the condition with the child. The school accepted him, and no special service was necessary. On the surface, this appeared to be a good arrangement but in reality a significant problem had been ignored. Interviews with a sample of these youngsters in Montgomery County High Schools indicated that they were functioning under a cloud of fear and uncertainty. Since they were so "normal" they thought they dare not raise questions. The sampling implied that the child should be told the truth about his condition and indicated that the facts might be easier to live with than the anxieties (44).

In Michigan the Detroit School System established a special program for epileptic children in 1935. Data were reviewed for the 765 pupils who attended the special school from January 1935 to June 1947. This review indicated that (a) most children with epilepsy may be educated in the schools normally provided in any community, (b) approximately 10 percent of epileptic children may need some special consideration and services in school if they are to receive an education in accordance with their aptitudes, (c) institutional or custodial care will be needed by some children with seizures but usually for those with mental and orthopedic defects rather than epilepsy, (d) adequate medical services for diagnosis and treatment are prerequisites to educational services for epileptic children, (e) all levels of intelligence are represented in a cross-section of epileptic children, (f)epilepsy may be expected to have some negative influence on the educational progress of children but may be minimized by early medical care and appropriate educational services, (g) a special program for the education of epileptic children is considerably more expensive than the education of normal children, and (h) education of the public about epilepsy should be more vigorously promoted (58).

During the school year 1958–59, a special survey concerning handicapped children was made in 106 U.S. cities with a population of 100,000 or more.

These 106 cities represented 29.4 percent of the total U.S. population and 28.4 percent of the 5- to 17-year-olds. Of the 106 cities, 98 responded to the survey. Twenty-two school systems (22.4 percent) reported that they did not admit epileptics to public schools. In schools accepting them, the majority were educated in the usual classes in regular schools.

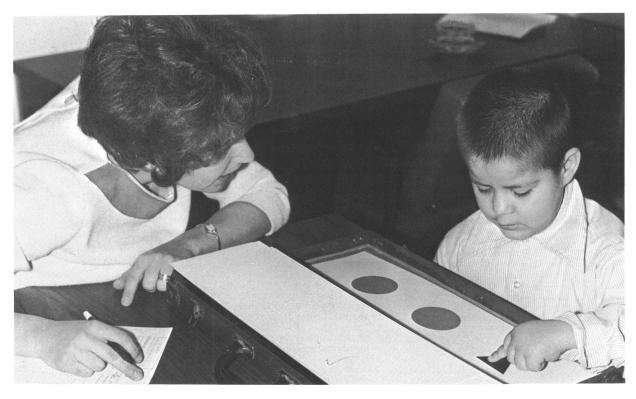
Home instruction was the next most frequent type of educational plan for children with epilepsy. Thirty-three cities reported delayed school admission of epileptic children. Most of the school systems followed criteria prescribed by State or local departments of education for special education placement, and applicants were reviewed by a team composed of a psychologist, a school administrator, and a neurologist or pediatrician.

Twenty-eight percent of the communities provided a team for personal evaluation of children with epilepsy, 27 percent of the communities offered transportation to children with epilepsy to and from school, and 8 percent placed an attendant in service during the transportation. As a result of the survey, a broad community program for children with epilepsy was recommended, with a close working relationship between the school systems and the community diagnostic facility (59).

NSDCP multidisciplinary clinics. On the basis of available information it appeared possible to establish clinics to provide services to epileptics in all parts of a State at a reasonable cost. It also was evident that the family physician was reluctant to treat seizures, and that many epileptic patients were in dire need of social and educational rehabilitation in addition to medical care. The multidisciplinary approach to the patient, as used in Maryland, Virginia, California, and Wisconsin, was seen as a method that offered new hope.

An early demonstration contract was awarded Barrow Neurological Institute, which clearly proved the feasibility and reaffirmed the need for such clinics. Dr. David Daly, then chairman of the division of neurology at the Institute, contributed immeasurably to NSDCP in formulating future plans on the basis of his experience with this clinic.

A fundamental objective in the NSDCP's attack on epilepsy was to foster multidisciplinary case-finding, diagnosis, treatment, and essential follow-up services where these were not currently available. This objective was approached by encouraging the development of specialized regional programs for convulsive disorders in broad-based community, regional, or statewide demonstration projects.



Psychometrician testing mental development of a young patient

Initially, some programs were limited to epilepsy, and it was later planned to develop these clinics into a generalized diagnostic and evaluation program for all neurological diseases.

The following criteria (60) were developed by the NSDCP in stimulating and evaluating sound community service demonstration projects:

- 1. Availability of medical and teaching centers as a resource for skilled medical manpower and technology
- 2. Potential for further development of regional or satellite clinics for referral and followup: usually a community hospital.
- 3. Effective liaison with State and local health departments and voluntary health agencies.
- 4. Recognition of the importance of continuing education for physicians in the diagnosis and management of epilepsy.
- 5. A community-based organization to provide information on epilepsy for lay and professional groups.
- 6. Potential for future expansion of epilepsy service to a broader diagnostic and evaluation neurological service.

Service programs were initiated with Federal funds and the understanding that after no more

than 5 years the project would be dependent on local funds. The rationale for this approach was that once the benefits of such a program were demonstrated, local health resources would continue the services (60). Twenty-five service demonstration programs were funded by NSDCP from 1963 to 1970 (table 3).

Two types of clinics evolved. In one type, the clinic was a regional center of competence where patients could be referred for complete evaluation. At such central clinics, research activities and service functions were closely integrated. The clinic, in addition, served as focal point for professional training and public education. The other type of clinic involved development of a network of satellite clinics throughout the area served and staffed by people from the central clinic. The same agency need not sponsor the central and satellite clinics as demonstrated in North Carolina, where satellite clinics were sponsored by the State health department and central clinics by Duke University and the University of North Carolina. Descriptions of two central clinics (61, 62) and one satellite clinic service (63) have been published.

All the clinics attempted to provide a multidisciplinary approach to each patient, with the services

Table 3. Service demonstration projects funded by Neurological and Sensory Disease Control Program,
1963-70

State	Institution	Project title	Dates funded	Funds awarded (thousands)	Satellite clinics
Arizona	Barrow Neurological Insti- tute, St. Joseph's Hospital of Phoenix.	Epilepsy demonstration project	June 1963 to December 1967.	\$350	No
California	State department of public health.	Demonstration program of services to patients with neurological disorders.	July 1964 to June 1966.	130	No
California	State department of public health.	Northern California epilepsy project (University of Cali- fornia San Francisco Medical Center).	July 1967 to June 1969.	180	No
Colorado	Denver General Hospital	Comprehensive community neurological services for Denver.	October 1967 to June 1970.	170	No
District of Columbia.	Research Foundation of the Children's Hospital of the District of Columbia.	Seizure clinic to serve the Greater Washington Metro- politan Area.	August 1966 to July 1969.	160	No
	University of Illinois College of Medicine.	Exemplary service for neuro- logical disorders in children.	July 1964 to June 1967.	117	No
	Indiana University Foundation.	Demonstration epilepsy project for the State of Indiana.	July 1966 to September 1969.	250	Yes
Kansas	Institute of Logopedics	Evaluation center for neuro- logical communication disorders.	March 1967 to June 1970.	175	No
Maine	Thayer Hospital	Evaluation services for the child with a handicap.	July 1964 to December 1967.	175	No
Michigan	St. Joseph County Health Department.	Physical, neurological, and psychological evaluation and treatment of the child with behavior and learning problems.	October 1963 to March 1965.	23	No
Minnesota	American Rehabilitation Foundation, Inc. (for- merly Kenny Rehabili- tation Institute).	Comprehensive diagnosis and management of school children with subtle neurological and sensory impairments.	July 1962 to June 1967.	280	No
Minnesota	St. Paul-Ramsey Hospital (formerly Ancker Hospital).	Total neurological care in Ramsey County, Minn.	January 1964 to December 1968.	130	No
Mississippi		A State community organization and planning project for speci- fic neurological and sensory disease conditions.		287	Yes

See footnote at end of table.

of a neurologically oriented physician, psychologist, social worker, public health nurse, vocational counselor, education consultant, EEG technologist, and secretaries. In most areas, the coordinated effort of these workers was a novel approach.

In the District of Columbia project, the unique position of neighborhood health aide was created. A man or woman from the local community, either a high school graduate or student working toward that diploma, was selected on the basis of intelligence, maturity, and initiative. The aide assisted with clerical tasks and with children in the playroom during clinical hours, contacted families who failed to keep clinic appointments, and encouraged families to receive continued medical care. A social worker worked with the aide if problems kept the

patient from medical care; if the problems stemmed from procedures or personnel at the clinic the aide relayed this information so that reasonable alterations in the functions of the clinic could be considered. The aide also made home visits to obtain information regarding a patient's health environment, to assure that medication was being stored out of the reach of siblings, and to assist parents in arranging convenient and easily remembered scheduling of medication. Basically, the neighborhood health aide's function was that of liaison between hospital and community.

The following problems in delivery of health care were encountered in almost all the demonstration projects:

1. In few areas of the country were services avail-

Table 3. Service demonstration projects funded by Neurological and Sensory Disease Control Program, 1963-70—Continued

State	Institution	Project title	Dates funded	Funds awarded (thousands)	Satellite clinics
	The Curators of the University of Missouri.	An epilepsy clinic for the Kansas City area.	January 1965 to December 1967.	\$81	No
New Jersey	State department of health_	Expansion of existing consulta- tion service for convulsive disorders to include a com- prehensive neurological pro- gram.	July 1963 to June 1968.	240	Yes
New Mexico	University of New Mexico School of Medicine.	Regional seizure control center	July 1966 to June 1970.	230	No
North Carolina	Dorthea Dix Hospital	Neurological diagnostic clinic for North Carolina depart- ment of mental health.	July 1964 to June 1967.	100	No
North Carolina	Duke University Medical Center.	Establishment of clinic for eval- uation of special epileptic disorders.	April 1966 to March 1969.	43	· No
North Carolina	State board of health	A program for the control of convulsive disorders and re- lated neurological diseases in North Carolina.	July 1964 to June 1969.	149	Yes
North Carolina	University of North Carolina.	Plan for the development of a medical neurological evalua- tion center at the University of North Carolina.	July 1964 to June 1969.	(1)	No
Oregon	Good Samaritan Hospital and Medical Center.	Clinic for children with epilepsy, learning, and behavior problems.	January 1966 to December 1968.	97	No
Pennsylvania	Allied Services for the Handicapped, Inc. (Scranton).	Comprehensive diagnosis, evaluation, and management of children and adults with neurological and sensory impairment.	June 1965 to May 1968.	84	No
Tennessee	University of Tennessee College of Medicine.	Regional neurological diag- nostic clinic.	July 1964 to December 1967.	58	No
Virginia	State department of health.		July 1966 to June 1969.	180	No
Wisconsin	University of Wisconsin		September 1963 to July 1967.	95	No

<sup>&</sup>lt;sup>1</sup> Unknown

able to provide long-term, continuous management of all the epileptic's problems. In some areas the Crippled Children's Services Programs provided multidisciplinary care to the child, but few services were available to the newly diagnosed adult epileptic or the adult epileptic encountering medical or social difficulties.

- 2. The need for multidisciplinary clinics was recognized, and in some States attempts had been made to establish such clinics before funding by NSDCP. In most instances the sources of support were effervescent.
- 3. Once funds became available, recruitment of trained personnel was extremely difficult. There simply were not enough pediatric neurologists, neurologists, psychologists, EEG technologists, neurologically trained social workers, public health nurses, and educators and vocational counselors with special interest in the neurological sciences. In almost

all the projects, salaries allocated for one or more of these consultants were left unspent because such a person could not be recruited.

- 4. In some parts of the nation, the cost of drugs became a prohibitive factor in continuation of therapy. In many areas, drugs were provided for children through the Crippled Children's Services Programs and for adults through Welfare and Vocational Rehabilitation Programs.
- 5. Although statistics between projects were not comparable, all projects noted considerable rehabilitation, by the multidisciplinary approach, of "hard core" epileptics not reached by previous treatment methods.
- 6. Cost per patient could not be determined. In many projects, considerable expense and time was involved in community education, which improved conditions for all epileptics in the area.
  - 7. Considerable evidence of an unspecified rela-

tionship between learning disability and neurological impairment was accumulated, and it was impossible to develop a management program that did not involve a broad educational plan.

8. All the programs were recognized as providing a needed service to their region. Despite this, most clinics were unable to find a stable source of support to maintain a multidisciplinary approach to patients.

In many areas of the nation, States are developing comprehensive medical services for all their residents. The development of these services is expensive, and many States cannot afford to develop regional centers of specialization at the same time. Yet these regional centers of specialization are necessary for patients with severe problems and for continued clinical research and advancement of clinical knowledge.

# **Training Grants**

Postgraduate education. The shortage of neurologists in the United States was documented by the developmental projects, so numerous continuing educational programs to advance and broaden the practicing physicians' knowledge of neurological disorders were funded. In addition, grants were awarded universities to provide highly qualified physicians additional training in specialty areas of neurology.

At the Children's Hospital of the District of Columbia, 19 physicians, eight of whom received NSDCP stipends, received pediatric neurology training from 1962 to 1969. Followup in 1969 indicated that 12 of these physicians occupied positions in teaching hospitals, four were in private practice of neurology or pediatrics, and three were in government or military service.

At Massachusetts General Hospital, five neurologists received 1 year of training in electroencephalography from 1963 to 1967. Followup in June 1969 indicated that one was an electroencephalographer in a university epilepsy center and the others were in private practice.

A conference on recruitment and training of clinical electroencephalographers, sponsored by the Committee on Training and Education of the American Electroencephalographic Society, and supported by NSDCP contract, was held in Los Angeles, Calif., in June 1969. The following recommendations were made (64):

1. An immediate and practical review of current EEG practices, including topics such as training

procedures, estimated competence of neurology residents, and number of professional electroencephalographers produced.

- 2. Increase the number of trainees in electroencephalography by admitting persons with backgrounds in the basic sciences in addition to the medical and clinical sciences.
- 3. More formalized EEG training in neurology residency programs, with this portion of the training commencing no later than the beginning of the third year. Daily continuous exposure to EEG's was stressed.
- 4. Inclusion of a professional electroencephalographer on the staff of major teaching hospitals with approved neurology training programs.
- 5. Exploration of increased communication between independent individual clinics and teaching centers and development of new means of continuing postgraduate education in electroencephalography for physicians.
- 6. Exploration and promotion of new techniques in EEG, particularly transmission by telephone, with the recommendation that such transmission be included whenever possible, particularly in relation to stroke patients, in current activities of the Regional Medical Programs Service.
- 7. Advancement of training and certification programs for EEG technologists by teaching laboratories and teaching centers.

Neurological nursing. Information from advisory groups indicated that there were not enough nurses to give professional care based on new approaches to prevention, treatment, and rehabilitation of persons with neurological disorders.

The education of nurses for specialized practice is vaguely defined in the current nursing educational system of the United States. The imperative demand for well-prepared nurses to help provide enlightened clinical services for patients and to collaborate in the scientific research so essential to effective medical and nursing intervention in the numerous debilitating neurological diseases is unquestioned. In an effort to improve the situation, numerous short-term training and continuing education programs for nurses received enthusiastic response. In addition, two graduate programs in neurological nursing at the masters level and a 12-month post-baccalaureate internship in neurological nursing were developed.

From January 1966 to June 1970, a program leading to a master-of-science degree in neurological-neurosurgical nursing was supported at the Graduate School of Nursing, New York Medical



Director of convulsive disorder unit explaining procedure of electroencephalogram to young patient

College. The program, extending through two academic years and one intervening summer session, emphasized clinical practice and the study of basic science. Trainees were also introduced to methods of research and clinical inquiry. Four trainees were enrolled the first year of the program and three in the second.

The University of California San Francisco School of Nursing also proposed a 2-year educational experience in neurological and neurosurgical nursing. The program consisted of a basic 1-year medical-surgical course leading to a master-ofscience degree, followed by a second year of individually planned programs in neurology and neurosurgery. The project was scheduled to begin in September 1967; however, no trainees were recruited. During the second project year (1968–69), four first-year students were enrolled, but by the end of the summer session two of these students had withdrawn from the program. Two completed their courses at the post masters level and are now instructors in baccalaureate programs in Vermont and Missouri.

At the University of Florida College of Nursing, an internship program in neurological nursing was started in July 1966. During the first year, two nurses completed the program; one remained at the University of Florida and the other obtained employment at the Veterans Administration Hospital, presumably to head a neurological unit.

Selection of nurses for the internship program was based upon completion of the baccalaureate program in nursing, licensure to practice nursing in Florida, academic standing in the upper half of the class, and display of leadership in nursing, as attested by three letters of reference. The program was for 1 year and consisted of supervised work experience under the direct supervision of a special coordinator and team leader. Formal classes were also provided. For the second year no nurses were recruited in the program.

Many nurses interested in applying for the internship did not have a baccalaureate degree; therefore they were not qualified to enter the course. The internship program was then opened to diploma school graduates and associate degree graduates with 1 year of nursing experience. It was thought that this action would not affect the quality of the teaching nor the types of experiences or instructions given the students. Re-evaluation of the program also resulted in shortening the curriculum to 9 months. No academic degree was offered for the year's work, and the stipend was well below the minimum salary for registered nurses. Both of these factors were thought to be major drawbacks in recruiting of candidates. For the third year of the project with the revised program, three trainees were recruited.

The results of these three programs indicated considerable difficulty in recruiting trainees and providing adequate professional recognition for specialized neurological-neurosurgical nurses.

Electroencephalographic technologists. The importance of the electroencephalogram in establishing a diagnosis and following the course of a patient with cerebral disease is well recognized. The role of the EEG technologist is crucial in providing a technically good record for the electroencephalographer to interpret. Traditionally, EEG technologists have been trained by apprenticeship, with scant attention to the fundamental principles of technology. Before 1963, formal training was available only in selected university hospitals. From 1963 to 1970, NSDCP awarded training grants in EEG technology to eight institutions. In July 1969, a total of 146 persons had completed or were in training in these eight programs. The majority of technologists trained in these programs were employed in community hospitals, private clinics, or private physicians' offices in the States where they had received their training (65).

Two conferences, funded by the NSDCP, recognized the need to identify technologists who are well trained and who have proved by examination their competence in providing EEG's (66,67). As a result of the first conference, a two-part written and oral examination for EEG technologists was established (65).

Withdrawal of Public Health Service funds has made continuation of the training programs uncertain. In two institutions, stipends are no longer being awarded to trainees, and one institution will start charging tuition. Local funds have been sufficient to continue only a few programs (65).

Neurological social workers. A series of programs were funded at schools of social work throughout the country to specially emphasize training in the

identification of social problems associated with neurological and sensory disorders. An extensive monograph on this subject has been published (68).

## **Educational and Informational Material**

One major problem of the epileptic is a lack of understanding of his disorder on the part of the general public and, to some extent, by professional people.

NSDCP answered inquiries and distributed pamphlets. Talks and radio interviews were given by members of the professional staff. A phonograph record was distributed with 30- and 60-second radio spot announcements and programs lasting  $1\frac{1}{2}$  and  $4\frac{1}{2}$  minutes (69).

Displays were shown at numerous medical society and specialty meetings, and pamphlets in quantity were made available to physicians to distribute to their patients and other interested persons (61, 70-73).

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From 1962 to 1970 the Neurological and Sensory Disease Control Program (NSDCP), U.S. Department of Health, Education, and Welfare was involved in improving delivery of service to epileptics by a program of studies, service demonstration grants, training grants, and educational and informational activities.

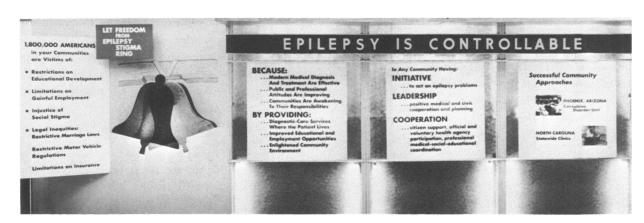
A series of studies revealed that the prevalence and incidence of epilepsy are difficult to assess in most areas of the country. A 1969 study from the Mayo Clinic provided the most accurate available data. Existing facilities in many areas of the country are inadequate to provide medical care to patients afflicted with neurological and sensory disorders. The majority of specialty care for the epileptic is available in urban areas, with a paucity of trained personnel available to rural communities, and travel to urban areas is usually difficult. The problems of the epileptic are best handled by a multidisciplinary team dealing with medical, psychological, and social problems. A strong united lay group and increased public education are vital for improvement of services to the epileptic.

Continuing education is essential for all physicians involved in the care of epileptics to keep them abreast of new developments. Physicians are often reluctant to treat epileptics—most likely because of uncertainty about treatment procedures. The cost of providing services to the epileptic is far outweighed by the gains resulting from rehabilitation.

From 1963 to 1970, a total of 25 multidisciplinary demonstration clinics were funded throughout the country. Two types of clinics were used. One type consisted of a regional center of competence, and the other type was a system of satellite clinics to bring specialized services to people in all parts of the State. These clinics demonstrated that adult epileptics throughout the country often have great difficulty in finding available services. Recruitment of trained personnel is difficult. The cost of drugs may present severe problems, particularly for adults. Rehabilitation of "hard core" epileptics not reached by previous treatment methods is possible through the multidisciplinary approach. The multidisciplinary neurological clinic provides a needed service, but in most areas of the country funds for this type of service are not available.

Increased training programs for subspecialties in the neurological sciences and for training of electroencephalographic technologists and neurologically oriented social workers are desirable. Special postgraduate training of nurses in the neurological sciences does not appear feasible until a need is recognized for this type of nurse and increased stipends are provided during the extra training period.

Continued education of both lay and professional people and continued improvements in methods of accomplishing this education are essential to improving the delivery of services to epileptics. From experiences gained by the NSDCP in working with the epileptic, it is obvious that many of his problems are solvable. The presence of solutions is hopeful, but a concerted effort is still needed to assure delivery of improved services to all epileptics.



Educational display of the Neurological and Sensory Disease Control Program, Health Services and Mental Health Administration