

directing council



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EPILEPSY IN THE AMERICAS

The Directing Council at its XV Meeting requested the Director to study the incidence and distribution of epilepsy in the Americas, and the legal and other types of discrimination to which sufferers from this condition are subject and which impede programs directed towards the solution of the problem of epilepsy.

The Mental Health Section of the Health Promotion Branch, of PASB, organized a meeting of a study group which dealt with the epidemiology of mental disorders in Latin America. The group attempted to establish certain standards aimed at achieving the unification of techniques, classification, operational definitions, and areas of study.

The Study Group, which was composed of 15 participants and 11 observers from 7 countries in the Americas and from the World Health Organization and the Pan American Health Organization, met in Washington, D. C., from 29 March to 3 April 1965. The Study Group examined various items, among them the resolution of the Directing Council, and held specific discussion on the epidemiology of epilepsy, regarding which it adopted a provisional terminology for use in epidemiological research on the disease.

In addition, the Study Group made the following statement:

"Having considered Resolution III of the XV Meeting of the Directing Council of the Pan American Health Organization, XVI Meeting of the Regional Committee for the Americas of the World Health Organization, it is recommended that:

- a. The existing literature on epilepsy research in the Americas be collected;
- b. The existing epilepsy programs and services in the Region be evaluated, and the establishment of services, particularly community care centers for purposes of case detection and follow-up, be promoted;

- c. A study group be convoked as early as possible to design a program aimed at:
 1. conducting an epidemiological survey of the prevalence and incidence of epilepsy in selected areas in the Americas; and
 2. conducting an investigation of the social conditions, and ecologic, nutritional, and toxic factors relating to possible causes of this condition, as well as of the cultural attitudes relating to the adjustment of the epileptic to the community and to work."

On its part, the Latin American Mental Health Information Center (MHICLA), established within the Pan American Sanitary Bureau for the purpose of collecting, analyzing, and distributing information on mental health, has begun to make bibliographical studies, and has made an inventory of epilepsy services and of the legal aspects of the disease. It has collected the papers, articles, and other publications which have appeared on the subject between 1950 and 1963. A directory of psychiatric services in Latin America is now in preparation and will serve as the basis for an inventory of anti-epilepsy services.

As to the legal aspects of epilepsy, an investigation was begun in two different but complementary directions. The first was centered on bibliographical research. In this regard, mention should be made of the major research effort made by the American Bar Association, which devoted five years to the compilation and analysis of the legal aspects of mental disease in the United States of America, including a study of epilepsy, and of "The Legal Rights of Persons with Epilepsy, a Survey of State Laws and Administrative Policies relating to Persons with Epilepsy", a document published by the Epilepsy Foundation in 1965.

In addition to these studies, books and articles on the subject were also reviewed.

The second direction was a direct investigation of legislation currently in force in Latin America regarding legal restrictions for epileptics. In this area, mention should be made of the cooperation given by the International Labour Office through its representatives in the Americas. Data on 19 countries are currently available. Apart from the information on the United States of America prepared by the American Bar Foundation and by the Epilepsy Foundation, the remaining information is less useful because it lacks data on the legal capacities and legal responsibilities of epileptic persons, as well as on the administrative and social consequences of epilepsy. Social restrictions do, in fact, exist and have been publicly denounced by national institutions for the protection of epileptics. But these declarations have not been supported by methodical study, and originated rather from unorganized observations. A study of the public attitude towards epileptics would require the training of teams of specialists in the behavioral sciences and a considerable outlay of funds for research.

Briefly, the work done in compliance with Resolution III of the XV Meeting of the Directing Council has been preliminary and exploratory. It has laid the foundation for epidemiological research on a continental scale. Although data on the legal status of epileptic persons were compiled, they need to be completed at the regional level before programs aimed at the treatment of epilepsy can be established. Such studies will require sufficient numbers of personnel and a sufficient amount of funds. MHICLA would act as the coordinating agency and provide the necessary technical advice.

No concrete study has been made of the financial implications of a regional study of legal and other types of discrimination against epileptics in the Americas. It would therefore seem advisable to make a study of the entire continent, bearing in mind that legal provisions and social measures applying to epileptics are not stated specifically and must therefore be searched for or discovered within the legal order and social conditions of each country. Such a study could serve as the basis for formulating standards and programs for every aspect of epileptic care at both the national and international levels.

One of the countries of the Organization has begun an epidemiological study of mental disorders which specifically includes epilepsy. A similar project in another hemisphere country is now under consideration.

It is hoped that the results of these two projects will facilitate a correct evaluation of the personnel and financial requirements for a continent-wide project of epidemiological and legal research on epilepsy in the Americas.

A progress report on these studies will be submitted by the Director to the Directing Council in due course.