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A study of fifty epileptic children.

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UNIVERSITY OF LOUISVILLE

A STUDY OF FIFTY EPILEPTIC CHILDREN

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In Partial Fulfillment of the
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Of Master of Science in Social Work

By

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TABLE OF CONTENTS

LIST OF TABLES

INTRODUCTION

This study has been fostered by developments in three fields of endeavor, each of which has contributed directly to the writer's approach to the subject and the conclusions which will be made. First is the trend in medical care toward the recognition of the fact that particular illnesses imply particular problems and necessitate specific forms of medical and social treatment; with these ideas in mind and to provide the recommended treatment specialized programs have been developed and purposive organizations founded. Also, during the past ten years medical research has provided a much better understanding of epilepsy, its implications, and methods of treatment, both of the manifestations of the illness and the person having it. At the same time educators were attempting a constructive approach to the school problems of the epileptic child. The results of some of the thinking and planning for the education of such children were presented in various studies[1,2,3,4] which were important in implementing

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[1] Epileptic Children, (The Committee for the Study of the Care & Education of Physically Handicapped Children in the Public Schools of the City of New York, Report of the Subcommittee of Epileptic Children, The Board of Education, The City of New York, 1941).

[2] R. L. Dixon, "State Hospital School for Epileptic Children", The American Journal of Psychiatry, CIII (May, 1947), 811-813.

[3] Olive A. Whildin, "The Epileptic Child & the Public School", The Nervous Child, Vol. 6 (January, 1947), 99-104.

[4] The Epileptic Child in Illinois (Illinois Committee for Handicapped Children, June, 1943).

an awareness of medical-social needs which were not being adequately met.

In 1944, sponsored by the National Association to Control Epilepsy, the contributions of the three fields were united in New York City in the Baird Foundation Clinic. The aim of the clinic is as follows:

> Our aim is to know the physical and mental conditions as well as the emotional and environmental life of the child in order to reduce the child's seizures to a minimum by medication; to teach the child reasonable precautions while assisting him and his family to overcome necessary restrictions; to evaluate the child's intelligence, vocational ability, social and personality endowment; and to assist him in making the most of them through education and training; to prevent or treat conduct and behavior disorders which arise because of the child's difficulty with his family and community; to interpret the epileptic child to his family and community, for example, the school, the "Y", etc., so that he may develop his potentialities and use them.

The purpose of this study is to delineate some of the problems faced by the non-institutionalized epileptic child in Louisville so that the facilities already available in the community can be measured against the needs and the concepts of the program outlined above. Because the writer's interests are both the impact of illness on the patient and his family and how a community organizes to meet its needs, part of the study will detail the local actions which gave it impetus. The writer plans to present first a survey of the current knowledge of epilepsy for without such orientation the findings of the study cannot be appreciated. The findings themselves will be presented in three sections:

the first will be concerned with the children, their medical care, and their social adjustment; the second will describe some of the attitudes of the family toward the child with his illness; and the third will cite some of the problems which the family faced because of the child's illness.

The writer wishes to express her appreciation for the privilege of participating in this project. It has afforded opportunities for observing both the functions of the various agencies whose records have been used and the integration of the functions of these agencies. There has been also, the opportunity to observe at first hand the impact of illness on family life as the writer was able to follow some of the children out of the medical setting into their homes.

CHAPTER I

SOME FACTS ABOUT EPILEPSY

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SOME FACTS ABOUT EPILEPSY

"Epilepsy" is derived from the Greek word for seizure, which in its turn is frequently used as a synonym for a convulsion. This has proven confusing as there are some types of epilepsy which do not manifest themselves in convulsive episodes.[1] "Perhaps the best way to put it is this: a seizure is a temporary loss or impairment of consciousness; it usually occurs without apparent cause; and it is usually accompanied by muscular movements which may range anywhere from a slight twitching of the eyelids to a violent shaking of the entire body."[2] Epilepsy is described physiologically as a tendency to periodic involuntary neuronal explosions[3] or more simply as an electrical brainstorm. These recurring attacks of involuntary behavior may be associated with mental or physical disturbances or both.[4]

The incidence of epilepsy is about once in every two hundred persons (0.5 percent of the population); the incidence

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[1] Ephraim Roseman, M.D., and Charles D. Aring, M.D., "The Present Status of Epilepsy", California Medicine, LXVI: 38-44, 1947. (Reprint)

[2] Herbert Yahraes, "Epilepsy - The Ghost Is Out of the Closet", (Public Affairs Pamphlet #98, 1944), 4.

[3] Roseman & Aring, op. cit., p. I.

[4] Ibid.

is the same as that of tuberculosis and diabetes.[5] In addition, one out of every ten persons (10% of the population) has a predisposition to this disorder. Approximately 500,000 persons in the United States are subject to seizures and for every person having seizures twenty have the physical potentiality for seizures.

According to Dr. William G. Lennox (the foremost authority in this country on the subject of epilepsy) the public monies expended on this disorder are used in the main for those epileptics who are cared for in mental hospitals and in special colonies.[6] His research has ascertained that about 50,000 persons receive this institutional care, three-fourths in mental institutions and one-fourth in colonies. He estimates the cost of this care at $20,000,000 yearly. Therefore, since 90% of those with seizures are in the community and since a large proportion cannot secure employment because of their illness, the total direct annual cost must be at least $100,000,000.

While no two seizures are exactly alike there are four main characteristics which are usually present in varying degrees: impairment or loss of consciousness, involuntary muscle movements, abnormal sensations, and psychic or mental

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[5] William Lennox, M.D., Science and Seizures (2nd Edit. New York: Harper & Brothers, 1946) p. 21.

[6] Ibid.

disturbance. Clinically three types of seizures are recognized, depending on which of the above mentioned elements predominates.

Grand mal epilepsy is that which is most usually thought of by the general public in its concept of this disorder. It is most commonly recognized by its tonic-clonic convulsions but the convulsion may be either tonic, clonic, both, or atonic. A seizure may begin and remain focal; it may begin focally and spread according to a physiological pattern without the loss of consciousness (jacksonian epilepsy), or rapidly or slowly become generalized accompanied by loss of consciousness. In about one half the cases there is an aura or warning that a seizure is to occur that comes just before consciousness is lost. This manifests itself to observers as pallor, dilated pupils, or jerking of muscles. The patient may feel moody, irritable, or may perhaps experience extreme well-being.

The aura comes first, then loss of consciousness and almost simultaneously a spasm or tightening of all muscles. There may be a gurgling, groaning, sucking sound, or actual cry. The patient falls, becomes dusky, and salivates profusely. After a brief space of time the rigidity changes to a jerking movement of the extremities and the color clears. In a minute or so the jerking movement stops gradually and the patient is relaxed, breathing heavily, sweating profusely, and insensitive to pain. Sometimes control of the bladder and bowels is lost. Also the tongue and lips may be bitten. After a convulsion a patient may sleep heavily for hours or may have a period of irrational, bizarre or violent behavior. (This is not to be confused with a psychomotor seizure.)[7] Also, after a severe convulsion, an intense headache, muscle soreness, or vomiting may be experienced. Some sufferers have no after effects at all.

Sometimes single attacks of epilepsy occur at widely separated intervals (months to decades). Bursts of two or more may occur at frequent intervals, or they may occur in groups of rapidly repeated seizures without return to consciousness between seizures (status epilepticus) culminating at times in death if measures are not taken to stop the attack. A seizure may last for a few seconds or the jerking may continue over a long period of time.

Seizures may occur both in waking and sleeping hours. If a patient sleeps alone he may know only by the presence of saliva on his pillow that he has had an attack.

The aforementioned subspecies[8] of grand mal, jacksonian, or focal epilepsy, refers to a seizure in which the patient retains consciousness and can watch the jerking or feel the numbness which creeps upward from the hand or foot but is powerless to stop it. This convulsion may be confined

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[7] Statement by Dr. Ephraim Roseman, personal interview.

[8] Supra, p. 4.

to an arm or leg or one side of the face or it may spread to the other side of the body, in which case consciousness is lost. The importance of this particular form of grand mal is in its indication that the attack arises in a certain portion of the surface of the brain, that opposite to the side in which the seizure is first manifested.

Petit mal epilepsy is frequently overlooked because the seizures which are characterized by brief lapses of consciousness usually last only a few seconds. However, these seizures are the most frequent and distinctive of the various manifestations of the illness. Generally the patient does not fall, and if one does not know the nature of his illness and the form it takes the seizure may go unnoticed. On close observation a rhythmical three per second blinking of the eyes is noted, occasionally accompanied by twitching of the face; sometimes there is also twitching of the upper extremities but movement in the lower extremities is rare. These seizures may occur without warning. The patient usually ceases any activity in which he is participating and may drop what he has in his hands but may continue to walk, swim, or ride a bicycle. The sufferer may stare fixedly into space, or lose his place while reading or speaking. He may blush or become pallid and there may be a glassy appearance to the eyes. Consciousness returns abruptly and fully and there are no unpleasant sequelae. The patient experiences a transient unconsciousness, is sometimes aware that a seizure has occurred and sometimes unaware of the incident.

Petit mal differs from grand mal in several ways other than those characteristic of the seizure manifestation itself: petit mal attacks are more prominent during adolescence; petit mal attacks occur much more frequently than grand mal attacks; petit mal attacks alone result in little if any mental impairment; and petit mal attacks rarely occur for the first time after adolescence.

Psychomotor epilepsy is also referred to by some physicians as epileptic equivalent, psychic equivalent, or epileptic fugue state. This type of seizure is hard to describe and to diagnose because no two patients display the same type of spell and the attacks of the same patient may not follow any particular pattern. In brief, psychomotor seizures are characterized by periods during which automatic activity is carried on, usually accompanied by changes of emotion (especially anger), and for which the patient has a complete amnesia.[9]

In a seizure of this type a patient acts as though he were conscious. The attacks usually last for only a few minutes but may go on for hours or days. The patient is rarely hilarious during an attack; more frequently he is morose and irritable and may become ugly or violent if forcibly restrained. If convulsive movements are present they

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[9] Roseman & Aring, <u>op. cit.</u>, p. 2

are usually of the tonic or rigid variety and the patient does not fall or jerk but may clamp his jaw, drool a little, or become dusky in the face.

In considering a psychic seizure it is important to know that it may be manifested only as a period of sharply altered disposition or as an aggressive anti-social act which the patient cannot account for as it is foreign to his usual temper or action.

Seizures are due to a combination of causes and the combination is different in different individuals and may differ in the same individual from time to time. The fundamental cause in all seizures is an inherent predisposition present when the patient was conceived and remaining with him throughout his life. This predisposition can be determined or visualized by means of records made of the electrical waves of the brain. Research workers believe that a paroxysmal dysrhythmia of brain waves is probably present in about 90% of epileptics during the interseizure period.[10]

Contributing causes to seizures are those physical conditions in which seizures occur more frequently than they do in the general healthy population. These contributing causes are broadly classified as defects of the brain, disorders of body function, and emotional disturbances. Defects to the brain include congenital or birth injuries, injuries

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[10] Ibid.

occurring after birth, malnutrition and defects in circulation prior to birth, effects of anaesthesia at birth, infections settling in the brain or its covering leaving scars, hemorrhage in the brain, and tumors.

Some of the abnormalities in the rest of the body which affect the brain only secondarily are diseases of the kidneys, toxic complications of pregnancy, a great lowering of the blood sugar, and a disturbance of the internal glands, especially those governing sexual maturity and the balance of fluids. A number of drugs may also induce convulsions.

Emotional disturbances as precipitating factors are readily recognized and many patients have seizures following some unpleasant or terrifying experience or may have an increase of seizures during periods of unhappiness or worry. These are common in adolescence.

Seizures start in about 70% of the persons having them before they are twenty. The first two years of life is the peak age for the development of seizures and the other high point is during adolescence.

Prevalent is the impression that mental deterioration is an accompaniment of epileptic attacks. One or more of the following causes may be responsible for mental clouding in a patient: (1) the mental defect may be primary and the seizures only an accompanying and relatively minor feature; (2) an injury to the brain may be the principal cause of both mental impairment and seizures; (3) mental impairment may be a result of seizures; (4) sluggishness of mind may be the result of drug treatment; and (5) mental dullness may be the result of psychological or social mistreatment.[11]

Within the last ten years[12] research workers have learned how to use a machine called an electroencephalograph (electric-brain-writing) both in the diagnosis and treatment of epilepsy. It has been determined that each type of epileptic seizure has a brain wave pattern distinctive from that of the other types. About 80% of epileptics can be diagnosed without the use of the electroencephalograph (EEG).[13] However, in the remaining 20% of the cases the skilled use of the machine plus knowledgeable interpretation of the results is of definite value. With the increase of knowledge regarding the seizure manifestations themselves the EEG assumes more importance in prognostic and therapeutic studies. The EEG is expensive and there are still not many machines or qualified operators available.

Also available to the physician in making a diagnosis is the air encephalograph or pneumoencephalograph. This process involves the replacement by air of the fluid in the cavities of the brain. The air-filled cavities are then seen by X-ray and any abnormalities such as tumors may be noted. This

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[11] Lennox, op. cit., p. 52 ff.

[12] Yahraes, op. cit., p. 15.

[13] Roseman & Aring, op. cit., p. 4.

is one of the most painful of processes and severe headaches follow the operation. The use of this technique is not recommended except in the most obstinate of cases. The skillful use of the EEG can be equally as effective in the determination of the localization of a lesion, scar, or tumor.[14]

The first seizure or the appearance of questionable symptoms should be the impetus toward the securing of medical advice. The sooner treatment needs can be determined and instituted the smaller will be the amount of damage from seizures both to the body and to the personality.

After the diagnosis has been made the treatment method that is of most value in the control of the seizures is drug therapy. The desired effect of this treatment is complete cessation of attacks with a minimum of toxic symptoms. Such results can be expected in 90% of grand mal and psychomotor seizures if therapy is handled expertly.[15]

Dilantin sodium is often described as the "sheet anchor"[16] in the treatment of epilepsy. It is of greatest value in the treatment of both grand mal and psychomotor seizures but has little effect on petit mal attacks. Its use is begun gradually and the subsequent dosage can only be determined by the patient's physician. Adequate control cannot be expected

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[14] Statement by Dr. Ephraim Roseman, personal interview.

[15] Roseman & Aring, op. cit., p. 6.

[16] Ibid, p. 4.

overnight--it may take several months.

The toxic effects concomitant with the use of dilantin delineate vividly the reasons therapy cannot be undertaken except by a physician. The way in which the dosage is controlled is the only way in which the toxic reactions to the drug can be controlled, reduced, or eliminated. These reactions are expressed in the form of ataxia, drowsiness, blurring of vision, morbilliform rash, and more often fever and gastric distress. Hypertrophy of the gums sometimes occurs with the prolonged use of dilantin, this is especially true for children. Proper mouth hygiene including frequent massage of the gums can prevent this to a large degree; in some cases it may be necessary to remove the excess gum tissue surgically. In a very few cases there is an increase in the amount of body hair; this is unattractive but its effect on the personality is not as damaging as that of persistent, uncontrolled seizures. Fortunately, in the case of younger children this hair does eventually disappear.[17] Other effects which occur only rarely are loss of weight, excessive fatigue, drowsiness, or undue excitement.

If after the maximum amount of dilantin is given the seizures have not stopped or diminished in frequency and severity another anticonvulsant drug, usually phenobarbital, is tried. When neither of the drugs is effective alone, the

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[17] Statement by Dr. Ephraim Roseman, personal interview.

combination of the two may be quite effective. The toxic effects of phenobarbital are composed mainly of drowsiness, morning lethargy, or a "hung over" feeling which limit the amount of the drug which can be prescribed. Because phenobarbital is a sedative there is some reluctance to give it to a patient whose mentality is somewhat retarded. It frequently has an unfavorable effect on the ability of children to make good social adjustments, especially in terms of increased irritability, activity, and aggressiveness.

Mesantoin has been found to be effective in the treatment of grand mal and psychomotor epilepsy but ineffectual in petit mal. Investigation has shown this drug to be relatively non-toxic and the appearance of drowsiness would seem to be the only limitation to the dosage. In comparison with dilantin there is a relatively low occurrence of ataxia and skin rash.[18]

Tridione has been the most successful of the drugs in the treatment of petit mal. This drug should not be used for grand mal attacks and should be used discreetly or with another anticonvulsant when a patient has both petit mal and grand mal. Psychomotor seizures are not affected by tridione. A patient taking this drug may have a rash or stomach upset, or may feel fatigued or drowsy.

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[18] Ephraim Roseman, M.D., and Charles D. Aring, M.D., "Epilepsy", Progress in Neurology and Psychiatry, p. 11. (Mss not yet in print).

An anticonvulsant should never be withdrawn completely and suddenly from a patient. Such an action will almost inevitably precipitate a convulsion in a susceptible person. Once the seizures are under control some authorities[19] advise the continuation of medication for a period of three to five years, even though no seizures are experienced. Then the anticonvulsant may be gradually reduced over another one to two years.

The expense of drugs in the treatment of epilepsy is not great. Drugs are cheaper when purchased by their chemical names and in large amounts. For instance, a year's supply of phenobarbital costs approximately $2.75 while a year's supply of luminal (the trade name for phenobarbital) costs $9.10.[20]

Sometimes seizures can be eliminated by a surgical operation when they are thought to be caused by tumors, meningiomas, or gliomas (abscesses) of the brain. However, in such cases further treatment with drugs is necessary.[21] Such operations are so serious and require the skill of such a well-equipped surgeon that they should never be undertaken without competent medical and surgical advice.

In regards to general treatment of epileptics the

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[19] Roseman & Aring, "The Present Status of Epilepsy", _op. cit._, p. 6.

[20] _Ibid._, p. 7.

[21] Roseman & Aring, "Epilepsy", _op. cit._, p. 10.

maintenance of the best possible health is the best policy. This includes regularity of habits that pertain to eating, sleeping, and elimination. All conditions detrimental to general physical health should be eliminated and any conditions with which seizures are known to be associated should be remedied.

This discussion would not be complete without the inclusion of what will be referred to hereafter as "paroxysmal behavior disorders." Persons who have seizures may exhibit disturbances in mood and behavior which are the result of the interaction of the fact of their seizures and difficult circumstances. However, such behavior in persons who have never had a recognized convulsion may be a peculiar form of seizure. This behavior may take the form of destructiveness, disobedience, untruthfulness, assaultiveness, hostility, impulsive running away, unprovoked fits of temper, or periods of "mean disposition" superimposed on a background of good behavior and reasonableness. In the past these actions have been designated as symptoms of "behavior problems" or "temper tantrums" in children and "psychopathic personality", "hysteria", "schizophrenia", or "criminality" in adults. Recently it has been thought that these disorders have a relation to epilepsy. It has been determined that a large proportion of such "problem children" have abnormal EEGs. Some of these children have responded to treatment with sedatives, in others a combination of drug therapy plus psychotherapy engaging both the child and his parents has been of value in modifying the behavior pattern. Attacks of peculiar or antisocial behavior in children or adults cannot be diagnosed as epileptic without the demonstration of an abnormal brain wave (cerebral dysrhythmia). "This whole matter is being actively investigated and results should be of greatest importance in solving social and legal as well as medical problems."[22]

One question often raised is "is epilepsy inherited--should an epileptic marry?" Lennox[23] has concluded from clinical and electroencephalographic studies that epilepsy per se is not inherited but a tendency or predisposition to it most likely is. He cautions that an attempt to breed out an undesirable trait may cause the loss of desirable ones.

The attitudes of the general public toward the epileptic which in turn shape the attitudes he has toward himself are the basis for his consideration as a handicapped person.

> Besides the fear of seizures in public, emotional conflicts arise over occupation, finances, conflicting duties, and love and marriage. An attitude of hopelessness and feelings of social and personal inferiority often constitute a more serious handicap to a person with epilepsy than do the seizures themselves. Seizures isolate a person from stimulating contacts. As social outlets close, activities become contracted, interests narrow, and a state of inertia, combined with despondency and hopelessness, develops and may closely simulate mental deterioration. Maintenance of the patient's emotional equilibrium and of his morale, and the possibility of

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[22] Lennox, op. cit., p. 45.

[23] Roseman & Aring, "Epilepsy", op. cit., p. 14.

> preventing mental deterioration through intellectual, social, and moral stimulation are too often neglected.[24]

This statement points up the value of early diagnosis and institution of treatment, combined with the understanding of his illness by the patient and those in his particular environment or community.

More and more emphasis is being placed on the problem of epilepsy in childhood. Seizures in infancy and childhood are more common than later in life because hereditary traits tend to show themselves early due to injuries at birth and the manner in which the nervous system develops. In a study of children who had isolated convulsions in childhood one fourth became epileptic or feeble minded. It is figured that about 20% of patients whose seizures began at puberty or later had an isolated convulsion as an infant.[25] Also, almost one half of all persons admitted to institutions with convulsions are under twenty.[26]

Several attempts have been made to determine statistically the number of epileptic children in the population. Dr. Lennox has stated that there are 250,000 epileptics under

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[24] Lennox, op. cit., p. 115.

[25] Ibid., p. 97.

[26] The Epileptic Child in Illinois (Illinois Committee for Handicapped Children, June, 1943), p. 17.

twenty years of age in the country.[27] The White House Conference report proposes an estimate of 8.0 to 9.0 per 1,000 for the total population under twenty which, on the basis of the 1940 census, would mean between 380,000 and 430,000 epileptics under twenty in the U. S. Other studies have found approximately 2 epileptics per 1,000 population in the school age group.[28] Using this conservative incidence and the figures of the 1940 census there are approximately 191 epileptic children in Louisville. 147 of these are within school age, i.e., five through nineteen years.

Claiming particular attention of late has been the personality of the child with seizures and the effect of his attacks upon his personality.

> . . . . the personal characteristics and problems of most convulsive children are very similar to one another if one knows what to look for. . . . . Sudden variability in mood with impulsive actions and periodic, apparently unprecipitated irritability are notably conspicuous. Physical hyperactivity and restlessness are almost as prominent. The attention span is apt to be short and power of concentration poor. In school, arithmetic is most likely to be the subject presenting exceptional difficulty. No one of these symptoms is, of course, specific for an underlying convulsive disorder, but their combination is so frequent as to be impressive. . . . . Any boy or girl whose life at home or in a community is punctuated by repeated seizures meets and reacts to the attitudes of others with extremes of behavior which are in no way characteristic

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[27] U. S. Congress, House of Representatives, Aid to Physically Handicapped, Hearings before the Committee on Labor, Subcommittee on Aid to Physically Handicapped, House of Representatives, 79th Congress, 1st Session, pursuant to H. Res. 45, Part II, Epilepsy, May 24 & 25, 1945. (Washington: Government Printing Office, 1945), p. 1315.

[28] The Epileptic Child in Illinois, p. 17.

> of his illness and vary to degrees which are influenced by the child's personality and the way he and his seizures are handled. This type of secondary reactions to a convulsive disorder is by no means characteristic of the symptom or illness which produces it.[29]

In one study 46% of the children included had mild to severe personality disorders. Of the 65 cases with severe personality disorders, six had a specific psychological insult associated with the onset, in six the onset was preceded by a period of mounting difficulties in the home, in five cases the personality disorder was responsible for serious exaggeration of the existing epilepsy, and in forty-eight the personality disorder contributed to the course and outcome.[30]

A summary of a Rorschach study of thirty epileptic children revealed that they had deficient intellectual control over the affective emotional and instinctive spheres, were anxious, aggressive, reacted predominantly as extrovert types, had a tendency toward opposition, poor mental efficiency, and slight bradypsychia.[31]

From the foregoing presentation of the facts of

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[29] Charles Bradley, M.D., Management of the Convulsive Child. (Reprinted from The Rhode Island Medical Journal, Vol. XXIX, No. 11, Nov., 1946), pp. 4-5.

[30] Edward M. Bridge, M.D., "Emotional Disturbances in Epileptic Children", The Nervous Child, Vol. 6 (January, 1947), 11.

[31] Jose Peinado Altable, "Rorschach Psychodiagnosis in a Group of Epileptic Children", The Nervous Child, Vol. 6 (January, 1947), 22.

epilepsy it can be concluded why the epileptic and his problems is the concern of social workers. In 75% of the cases medical treatment can eliminate 75% of the seizures: but medical care and seizure control is only the means to an end. That end is the successful adjustment of the sufferer in his own particular environment--this is the province of the social worker demanding the skills of the caseworker, the community organizer, the social planner, and those persons whose talents lie in presenting the plight of others to the community in a forceful and productive manner.

CHAPTER II

BACKGROUND INFORMATION

A. Why this study was made

B. Method and scope of the study

CHAPTER II

BACKGROUND INFORMATION

A. Why this study was made

Social workers can discharge their full responsibility to their clients only when they undertake to help remove the obstacles which confront them and their clients.[1] To a small group of such responsible workers can be attributed the first spark of concerned interest which has culminated in our present social work community's attention to the problems of the person who has epilepsy.

Early in 1947[2] the medical social workers at the Nichols Veterans' Administration Hospital became concerned about the number of veterans coming into the hospital with epilepsy. Case work with these men revealed that they were troubled by their inability to secure employment because of their seizures. The attitudes of their families and of the general public toward them with their illness was the basis for much psychic trauma. These workers believed that their patients could achieve a successful adjustment to their illness only after their problems had been interpreted to the community and were understood. Therefore, they asked the

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[1] Kenneth L. M. Pray, "Social Work and Social Action", Proceedings of the National Conference of Social Work, 1945.

[2] Statement by Mrs. Grace Caswell, personal interview.

Inter-Agency Committee of the Health and Welfare Council of the Louisville Community Chest if it would be interested in sponsoring a program which might lead to a community project aimed at the integration of the epileptic into the community.

At a meeting of this Inter-Agency Committee on July 1, 1947, it was agreed that the agencies would plan jointly in working out a program. Those present represented fifteen agencies and each agency spokesman presented its particular concern with epileptics. Much of the discussion centered around the personality of the epileptic, his employment problems, the attitude of the public toward the epileptic, and his attitude toward himself. In the area of children it was stated that the need for dental care was particularly striking as many of the children broke their teeth during a seizure. It was further suggested that there was a need for special care for the young child just developing epilepsy. Special classes in school were thought to be particularly necessary as the child felt out of place in school with normal children and was very conscious of his problem.

At this meeting it was decided that a small subcommittee be appointed by the larger committee to study the possibilities and approaches to the problems of the epileptics. It was further agreed that the social agencies be asked for statistics and information about the epileptics under their care.[3]

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[3] Minutes of the meeting of the Inter-Agency Committee, July 1, 1947.

The activation of the subcommittee coincided with the establishment of a Section of Neurology at the School of Medicine of the University of Louisville. This section was to be headed by Dr. Ephraim Roseman, whose army and civilian career had encompassed much research, study, and teaching in the field of epilepsy. He immediately identified himself with the aims of this committee. The appearance of such a well-qualified ally in the medical community gave fresh impetus to the interests and activities of the committee.

On September 4th the second meeting of the Inter-Agency Committee was held. There were twenty-seven persons present, including four members of the medical profession and one member of the faculty of the Kent School of Social Work. The subcommittee, composed of Mrs. Louise Wood of the Health and Welfare Council, Mrs. Grace Caswell of the Nichols Veterans' Administration Hospital, Mr. David Dobson of the Jewish Vocational Service, Mrs. Grace Richardson of the Kentucky State Employment Service, and Mrs. Cora Lucas of the Family Service Organization, was presented.

The results of the survey made of the epileptics known to the various agencies were discussed. Of the 102 cases reported, 27 persons were under fourteen and 17 were between the ages of fourteen and twenty-one, the greatest number in these ranges being reported by the Louisville and Jefferson County Children's Home. The Louisville Public

Schools did not return its questionnaire.[4]

Dr. James Rogers, who had headed the Neurology Clinic at the General Hospital from July, 1942, until July, 1946, stated that the majority of the patients there were in the low income group. In 1943 approximately forty to fifty patients attended the clinic regularly, but he thought the number had probably doubled. He stated that the physicians had some difficulty in deciding whether epileptic children should attend school. The two problems which he saw were those of diagnosis and treatment. He thought that some of the patients should be institutionalized to allow the physician to control their activities.

Dr. Roseman spoke generally about the incidence of epilepsy and about the two national organizations, The American Epilepsy League, Inc., and the National Association to Control Epilepsy, Inc., which are interested in combatting the disorder and its effects. He also mentioned Lennox' _Science and Seizures_ and Putnam's _Convulsive Disorders_ which would give an understanding of the illness. He remarked that "every epileptic should be an educated epileptic." According to his calculations there should be about 3,000 epileptics in Louisville.

Dr. O'Brien of the Louisville and Jefferson County Children's Home stated that there was a need for some special

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[4] Statistical results of the report of the Inter-Agency survey.

place for children with epilepsy. She had found the epileptic to be hyperirritable and unable to fit in with the other children at Ormsby Village as his personality was not suited to institutions.

The remainder of the meeting was devoted to the discussion of the employment considerations of the epileptic. It was decided that the subcommittee would consider whether a study of other phases of the problem should be made.[5]

Just after this meeting of the committee, the University of Louisville convened for its 1947-1948 session. Students returning to the Kent School of Social Work for their second year of training which would result in the awarding of the degree of Master of Science in Social Work looked to the community for suggestions for thesis material. It was their thinking that the thesis should be a contribution to local social planning and study and not just the fulfillment of a scholastic requirement.

In retrospect it now seems that the interest in the problem of the epileptic was generated spontaneously and without knowledge of the interests of the Inter-Agency Committee. However, because the students are included in the social work world of Louisville, it is very probable that they did hear of this project and it grew in their interests as something they might use as thesis material. The students

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[5] Minutes of the meeting of the Inter-Agency Committee, September 4, 1947.

thought they could do the research, the results of which would equip the subcommittee to plan concretely.

This idea was discussed with Miss Mathilda Mathisen, Professor of Medical Social Work, who presented it to the Kent School Administration. At the same time it was ascertained that the committee would accept the work of the students and utilize it. Approval was given for a project of two main sections, each having two subsections. One was to treat the veteran with epilepsy and the other to consider the child with epilepsy. Each subsection was to be a thesis in its own right.

In planning this particular thesis, a subsection on the epileptic child, it was decided that the best way to depict adequately and fully the problem was by determining just what did happen to some children with epilepsy. The writer, therefore, proposed to study the medical care, schooling, behavior, attitudes, and social problems of fifty school age children with epileptic seizures living in the community and to present the results of this study to the committee for its consideration.

B. Method and scope of the study

The fifty children included in this study were selected by the writer in several ways. When the project was first formulated it was planned for the group to be composed mainly of referrals from the public schools; the teachers were to be asked to submit the names of epileptic children in their present classes or of epileptic children whom they had formerly taught. However, when the school did not follow through in obtaining this information it was necessary that another method of case-finding be utilized.

Consequently, the files of the Children's Free Hospital and the Louisville General Hospital were resorted to and a clearance was made for all children born in the years 1927 through 1941 and registered with the hospital in the years 1942 through 1947 as being epileptic. This six year period and this age group were chosen for several reasons: it was believed that there would be a better opportunity of locating children so recently known; this is the age period when the child is preparing himself to make his own way in the world and when he is thrown into contact with large groups of people through schooling, etc.; and this period would best represent the resources we could expect to find available now to the epileptic child. Because diagnostic files are maintained only on the children hospitalized at the Louisville General Hospital this search, combined with that of the Children's Free Hospital records, did not complete the roster of children needed in the study. Therefore, the writer spent ten Tuesday afternoons in the Neurology Clinic of the Louisville General Hospital, in which clinic the epileptics are treated, locating children for inclusion in the study. Other children have been referred to the writer by workers in various social agencies in the community, by Dr. Roseman from his private patients, and by the workers and volunteers at the Wesley Community House.

The composition of the group and the sources of referral will be discussed in greater detail in Chapter III. However, the writer believes that the fact that there was difficulty in locating fifty epileptic children in Louisville and Jefferson County points immediately to the need for a case finding program in order to consider fully and adequately the extent of the problem.

Because of the feeling of some of these children and their families around the epilepsy, each child has been assigned a number by which he is known in the study and his identity is thus protected throughout the project.

After the children were selected a schedule was prepared covering the source of referral, the history of and type of seizure, medical care and control achieved, hospital social service department registration, school achievement and measurement of learning, institutionalization, behavior problems, other relatives with seizures, family's attitude toward child with his illness, present status of child, and family's ideas about community resources which might help them or would have helped them in planning for the child. There was also a place on the schedule for information which would be of value in presenting a brief case history of the child.

All information to be found in the medical histories of these children was recorded on the schedules. The writer also reviewed the Social Service Department records and those of the Department of Psychiatry at the Louisville General Hospital for a better understanding of the facilities available in the public hospital for the treatment of those with epilepsy.

The cases were then cleared in the Social Service Exchange. The records of all cases known to the Family Service Organization, the Children's Agency, and the Mental Hygiene Clinic were reviewed and the information obtained therefrom used in completing the schedules. Miss Elizabeth Brown, who is doing a subsection thesis on the epileptic children known to the Orsmby Village branch of the Louisville and Jefferson County Children's Home, provided information regarding the institutionalization of the children in this series. There is some duplication of cases, and where this is the situation this writer has studied the child when in the community; Miss Brown has studied the same child while under the jurisdiction of the mentioned institution.

The writer has interviewed the parents or the patients in about one fourth of the cases. This was made possible through attendance at the Clinic and by arranged home visits or appointments. While the writer recognizes the value of a personal interview around each case in the study, limitations of time and transportation made this an impossibility. All private patients and their parents were seen, as were the parents of the children referred by those at Wesley House.

For the most part the writer was able to ascertain the whereabouts and status as of March, 1948, of the children studied by the analysis of agency records and by the interview. However, where this was not possible the assistance of the school authorities was requested in locating these children through their records.

All of the children have not been under treatment during the whole interval of the study, but they have epilepsy and with or without medical care have made some adjustment. Again a need is determined just from the method of the study itself. There is the necessity for a follow-up on children who are diagnosed as epileptic in order to ascertain that they are provided with adequate medical care and that other community facilities are made available to them where needed.

Private patients were included in the study to emphasize the fact that the problems presented by the epileptic child do not recognize the limitations or lack of limitations of the family purse. The impact of the fact of his epilepsy on the child and on his family is much the same regardless of how much the family is equipped to pay for medical care.

In the following chapters the findings of this study will be presented by statistical analysis and by narrative incorporating brief case histories of some of the children.

CHAPTER III

THE CHILDREN, THEIR MEDICAL CARE, AND THEIR SOCIAL ADJUSTMENTS

CHAPTER III

THE CHILDREN, THEIR MEDICAL CARE, AND THEIR SOCIAL ADJUSTMENTS

The sources referring children to this study are noteworthy and significant: first, because they depict the wide range of those concerned with the problems of the epileptic child, and secondly, because they reveal vividly the need for a case-finding program. These children were referred to the writer by persons in the various agencies who recalled having carried a particular epileptic child or a family in which there was such a child at some time. No diagnostic files are maintained by social agencies which would indicate in any way specific problems in a family. The diagnostic files at Children's Free Hospital are complete, but Louisville General Hospital diagnostic files are maintained only for hospitalized persons. While private physicians would know their patients by diagnosis no such survey has been made and the physician might be reluctant to disclose the names of his epileptic patients for many reasons. The writer was unable to ascertain whether or not the Louisville Board of Education keeps a register of such children.

Seventeen children were located through the history room files of Louisville General Hospital; nine were picked up by the writer through clinic attendance; six children known to the clinic were referred by the Chief of Neurology Service as depicting various phases of problems encountered by the epileptic child; and one was referred by the social worker in the Department of Psychiatry. Five children were found through the files of Children's Free Hospital (the greatest percentage of children referred by this agency were below the age limit set for this study). Of the referrals from Mental Hygiene Clinic, two were those of children with paroxysmal behavior disorders. One referral was of a child known to Louisville General Hospital Pediatrics Department whom the Mental Hygiene Clinic psychiatrist recalled having seen in that department (the child is not registered at Mental Hygiene Clinic). Three children who are private patients were referred by the Chief of the Neurology Section after discussing the writer's project with their parents. A worker

TABLE 1

SOURCES REFERRING CHILDREN FOR STUDY

Referral Source	Number of Referrals
Louisville General Hospital	
Record Room	17
Clinic	9
Clinic Chief	6
Department of Psychiatry	1
Children's Free Hospital	5
Mental Hygiene Clinic	5
Private Physician	3
Family Service Organization	1
Other	3
Total	50

at Family Service Organization recalled having had a family in which there was an epileptic child. The workers and volunteers at Wesley House referred three other children, two of whom participate in the activities of the settlement; the family of the third was known to one of the volunteers and agreed to participate in the study.

Of the fifty children included in the study, twenty-two are white boys and five negro; there are nineteen white girls and four negro. The differences in the proportions of white and negro is to be accounted for by the fact that Children's Free Hospital takes no negro patients, and no referrals through Wesley House or the Chief of Neurology in his capacity as private physician involved negroes. Of the thirty-three children referred by some department at Louisville General Hospital, where no color discrimination is made, eight were negro. The incidence of epilepsy is not predominant in one sex nor is it greater in white persons than in negroes. The writer believes that the only significance in the proportionate differences in race is the acceptance among negroes of childhood convulsions as normal and the lack of knowledge regarding epilepsy and its treatability.

Two children who are only five years old have been included. One little boy is the brother of an older boy in the study. The other, a little girl, was included because of the mother's deep concern regarding planning for the child's school attendance. It was believed that the opportunity to discuss her concern with the writer would be of real therapeutic benefit to the mother.

TABLE 2

FIFTY EPILEPTIC CHILDREN INCLUDED IN STUDY
BY YEAR OF BIRTH, SEX, AND COLOR

Year of Birth	Male White	Male Negro	Female White	Female Negro
1927		1	1	
1928	2		1	
1929	1		2	
1930	2		3	
1931	1			1
1932	2		2	
1933	1	1		
1934	1	1	2	
1935	1			1
1936	1	1	1	
1937	2	1	1	
1938	1			
1939	3		2	1
1940	1		1	
1941	2		2	1
1942	1		1	
Totals	22	5	19	4

Thirty-eight of the children were treated for their epilepsy at some time in the clinic or on the ward at Louisville General Hospital. Twelve were known to the Department of Psychiatry, either on the ward or in the Personal Consultation Clinic. Nine children were hospitalized at some time at Children's Free Hospital. Sixteen were known to the Mental Hygiene Clinic; however, only a few of these were carried for treatment, in the remaining instances the family did not follow through after the initial interview or the referral was made for a psychometric examination. The writer does not consider it a fact that only ten children were treated by private physicians. More than ten children probably had the services of private physicians at some time, but this could not be verified in the process of this particular study. One child received care through the Kentucky Crippled Children's Commission and one child had a period of hospitalization at Central State Hospital when no other satisfactory plans could be made for him.

TABLE 3

MEDICAL AND PSYCHIATRIC TREATMENT FACILITIES UTILIZED FOR CHILDREN WHILE IN COMMUNITY

Facility	Number Using
Louisville General Hospital	38
LGH - Dept. Psychiatry	12
Children's Free Hospital	9
Mental Hygiene Clinic	16
Private Physician	10
Ky. Crip. Child. Comm.	1
Central State Hospital	1

One child was known to Louisville General Hospital, Louisville General Hospital Department of Psychiatry, Children's Free Hospital, Mental Hygiene Clinic, and Central State Hospital. Another was known to Louisville General Hospital, Louisville General Hospital Department of Psychiatry, Mental Hygiene Clinic, and a private physician. Twenty-five of the children were known to only one treatment agency, eighteen were known to two facilities, and five were known to three. In general, the child with a poor adjustment to his illness was known to more agencies.

Twenty-one of the children were currently known to Louisville General Hospital Neurology Clinic as of December, 1947. However, of these only twelve were attending clinic regularly and could be considered receiving adequate medical treatment. In several instances the child was not being seen at the clinic, but a parent or relative was coming in for his medication. Three of the children appeared in the clinic infrequently, usually for a renewal of medication. Six came sporadically to the clinic; impetus to their attendance seemed to be given by the experiencing of a seizure or a series of seizures after they had stopped taking medicine or had allowed it to run out. No follow-up was done on children who failed to keep clinic appointments. The only way the doctor had of knowing the progress of the patient, the effect of the medication, or particular problems the family might be experiencing in helping the child was in his brief interview with them if they came to the clinic.

One child was being seen by a member of the Department of Psychiatry and his medication was being provided him there. Four were being treated by private physicians. Seven children were in institutions where they would have medical care of some kind available. One child was under the supervision of the Kentucky Crippled Children's Commission and while she was not currently on daily medication the length and number of her seizures had been cut down; she was being treated by the Commission's neurological consultant. Two of the children were receiving no medical care although they had previously had treatment and medication had been advised; the families of both of these children were trying to arrange for their institutional care because of the behavior problems which they presented. Two of the children were dead.

TABLE 4

TYPE MEDICAL SUPERVISION BEING RECEIVED AS OF DECEMBER, 1947

Type Supervision	Number Children
Louisville General Hospital	21
LGH - Dept. Psychiatry	1
Private Physician	4
Custodial	7
Ky. Crip. Child. Comm.	1
None	2
Unknown	12
Dead	2
Total	50

The medical supervision which twelve of the children were receiving was unknown. Three of these children had been known at Children's Free Hospital at the time the diagnosis was made but had been known to no community agency since that time. Two had been seen briefly at Mental Hygiene Clinic but had not continued their contacts with the agency. One who had been seen at Children's Free Hospital had also been known at Louisville General Hospital, but no treatment recommendations were ever carried out. The other children had been known at LGH but had not attended clinic for long periods of time, usually more than a year. One of these children had attended clinic regularly until December, 1945, and excellent control had been maintained over his seizures; he suddenly stopped coming and the writer has learned that he moved with his family to another county.

"Medical advice for convulsive disorders should be sought as soon as suspicious symptoms or a seizure appears . . . . Comprehensive treatment should be instituted early, in the hope of preventing subsequent attacks and breaking up whatever tendency to habit there may be."[1]

TABLE 5

TIME ELAPSING BETWEEN FIRST SEIZURE AND THE SECURING OF MEDICAL CARE

Time Elapsed	Number Children
less than year	20
1-2 years	10
2-3 years	3
3-4 years	3
4-5 years	2
over 5 years	8
unknown	4
Total	50

Of the children in this study twenty received medical

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[1] Lennox, op. cit., p. 112.

care within a year after the first seizure manifestation. Ten had had medical care within two years of the appearance of obvious symptoms. Three went for about three years before their conditions impelled their families to seek assistance. Three were without medical care for approximately four years. Two had to wait for almost five years before enough concern was engendered to send the family to a clinic or doctor with their child. Eight children had seizures in some form for over five years before medical advice was secured: one child manifested psychomotor seizures for approximately thirteen years before her family finally sought psychiatric help for what they considered a behavior problem. The information available on four of the children was not adequate, either as to onset of illness or date of institution of treatment.

Over one half the children included in the study had grand mal attacks; it is the writer's belief that some of these children had in some instances petit mal or psychomotor seizures also, or both. This opinion is based on descriptions given of behavior of the children. Grand mal attacks are most dramatic in their manifestation, cannot very well be overlooked, and would be more of an impetus to securing medical treatment. Eleven children had grand mal attacks along with another recognized type or types of seizures. Petit mal and psychomotor seizures are often labeled as behavior problems, acting queer, or failure to pay attention. Only two children were diagnosed as having only petit mal seizures, while in eight cases petit mal was recognized in combination with another type or types of seizures. "Petit mal are often overlooked but are most frequent and most distinctive of the seizures of epilepsy."[2] Six children were diagnosed as manifesting only psychomotor seizures, but eight displayed this syndrome in combination with grand mal, petit mal, or both. Three children had all three types of seizures. Two displayed paroxysmal behavior disorders.

"Because the frequency of seizures fluctuates, patience must be exercised. A certain treatment may need to be used many months before its value is established."[3]

Twenty children had known regular medical treatment either at Louisville General Hospital or from a private physician. Some of these children were not receiving treatment in December, 1947, but during the time they did receive treatment they attended clinic regularly. Of the twenty there was good control of seizures maintained in nine instances; by good control is meant the cessation of seizures with medication. In eight cases fair control was secured; there were seizures, but they were less in number and of shorter duration than the patient had formerly experienced. In three instances control had not been achieved and the doctor was still trying to ascertain the optimum dosage for

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[2] Ibid., p. 26. [3] Ibid., p. 149.

the patient.

Four patients had frequent treatment during the time they were known to the hospital and of these two had secured good control; one had achieved fair control while one had shown no improvement. Twelve children had sporadic treatment, appearing at the clinic now and then, usually after a seizure or series of seizures. Medication gave good control to five of these children when they managed to "stick with it" for a period of time. Three had achieved fair control and the results of the irregular supervision was unknown in four instances.

TABLE 6

CONTROL OF SEIZURES SECURED BY
REGULARITY OF TREATMENT

Control Secured	Regularity of Treatment			
	Regular	Frequent	Sporadic	Unknown
Good	9	2	5	1
Fair	8	1	3	3
Poor		1		
Still experimenting with dosage	3			
Unknown			4	10
Totals	20	4	12	14

The regularity of treatment was unknown for fourteen children. Of these one had achieved good control, three fair control, and the results of the irregular supervision was unknown for ten children.

Sixteen of the children included in the study have a history of a head injury at some time prior to the onset of their seizures. However, in most instances the history of the injury was not very adequate or comprehensive, especially as to the extent of the injury suffered and the length of loss of consciousness, if any. One child in the group is spastic; other children for the study might have been located through the Kentucky Crippled Children's Commission's Cerebral Palsy program as approximately 40% of spastic children are also epileptic.[4] However, that group of children has a peculiarly complicated problem and is having its needs already met by a specialized medical and social care program. Consequently, it was thought advisable to include just one such child in this study in order to touch on that particular problem.

The majority of children having adequate and regular medical care experience no need for hospitalization for their seizures.[5]

Twenty-five of the children were not hospitalized at any time at Louisville General Hospital and Children's Free Hospital for their epilepsy. The other twenty-five had a total of sixty-two hospitalizations, covering periods from one day to three months; these included periods spent as patients of the Department of Psychiatry of the Louisville General Hospital. Two of the children had six periods of

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[4] Statement by Dr. Ephraim Roseman, personal interview.

[5] *Ibid.*

hospitalizations each, and a third was hospitalized eleven times for seizures. A total of ninety plus hospital weeks of treatment was provided these children.

TABLE 7

HOSPITALIZATIONS FOR EPILEPSY BY NUMBER AND DURATION*

Number of Hospitalizations	Duration								Total Children
	Less than wk.	1 wk.	2 wks.	3 wks.	4 wks.	6 wks.	2 mos.	3 mos.	
1	1	2	3	5					11
2	5	4	3	1				1	7
3	3	1	2						2
4	3	2		1		2			2
5									0
6 and over	13	4	4	2					3
Totals	25	13	12	9	0	2	0	1	25

*Based on the twenty-five children who were hospitalized.

Children were hospitalized for diagnostic purposes, to attempt control of the seizures, and for behavior problems and emotional disturbances concomitant with the seizures. A large proportion of those of less than a week's duration were admissions from the accident room, the family, through fear, misunderstanding, ignorance, or disinterest bringing the child in whenever he had a particularly severe seizure. One child died seven hours after admission to the hospital in <u>status epilepticus</u>.

Some of these hospitalizations could have been avoided if the family had had an understanding of the child's illness and had been encouraged to bring him into the clinic for regular treatment. The long periods of hospitalization could have been eliminated had there been a colony or convalescent home for epileptic children. The boy who was on the ward for three months stayed that long for the simple reason that there was no other place for him to go, his home environment having been one of the disturbing factors in his reaction to his illness.

The epileptic is the problem of the social worker, and the epileptic patient cannot be adequately treated without the services of the social worker.[6]

TABLE 8

HOSPITAL SOCIAL SERVICE DEPARTMENT REGISTRATION BY PROBLEM AND YEAR

Problem	1942	1943	1944	1945	1946	1947	Totals
Schooling	3		1				4
Family relationships		1	1			1	3
Response to letters from another agency		1	1	2			4
Referral made to another agency				1		1	2
Post discharge planning	1	1				1	3
Financial	1	1					2
Social study and case work around illness	1	1	2				4
Other				1			1
Totals	6	5	5	4	0	3	23

During the six years, 1942 through 1947, sixteen of

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[6] *Ibid.*

the children in the study were known to the Social Service Department at Louisville General Hospital and service was rendered around twenty-three specific problems. In four instances the social service worker and the school visiting teacher or nurse worked together to effect the patient's better adjustment to his school attendance and work. In three cases case work service was directed toward the improvement of family relationships when some strain had been engendered by the impact of the child's illness on a parent or sibling. Four contacts were in response to inquiries from other agencies regarding the child's illness. Referrals were made to other agencies in two cases. The Department was requested to help plan for the post-discharge care of three of the children. In two cases assistance was needed in planning financially for the securing of the necessary medication. Four children were referred specifically for social studies and case work service around their attitudes towards themselves with their illness. One patient was referred for assistance in filling out the necessary papers after it had been recommended that she be sterilized.

The writer, on the basis of clinic observation and interviews with patients, believes that the Social Service Department would have been used more often prior to 1947 had the doctors in the clinic been more aware of the social implications of epilepsy. After the Section of Neurology was established at the hospital the Department would have been used in relation to most of the patients seen in the clinic had there been adequate staffing and a worker available in the clinic.

The mental status of seven of the children could not be ascertained and the school history of four of them was unknown. Of those who attended school regularly and were not in a special class, one had superior intelligence, seven rated as average, two were dull normal, one had borderline intelligence, and the mental status of one was unknown. Three of the children were in special classes by reason of their inability to perform the regular classroom work, not because of their convulsive disorders.

Of the five who have never attended school, two are not yet of school age. Two have never attended because of extreme mental retardation and one has not been entered as she is still having numerous seizures despite concerted efforts to obtain some degree of control over them.

Five of the children were withdrawn from school as a direct result of their epilepsy; this was done at the parents' request, on the advice of the doctor, or because the school could no longer manage the behavior problem which the child presented. One child never returned to school after he had his first seizure; one discontinued schooling to go into the hospital for a pneumoencephalograph and never returned. The two feeble-minded children who discontinued schooling were acceptable to the school authorities who made efforts to integrate them into the work of the special classes; however, the mother of one arranged for him to be excused from school attendance and the medical authorities recommended the exclusion of the other on the basis of her very deteriorated mental and physical condition (gonorrhea and pediculosis among other things).

TABLE 9

SCHOOL ATTENDANCE BY MENTAL STATUS
JANUARY, 1948

School Attendance	Mental Status[7]						Total
	Superior & over	Average	Dull Normal	Border line	Feeble minded	Unknown	
Regular attendance	1	7	2	1	1	1	13
Special class			1	1	1		3
Never attended			1		2	2	5
Withdrawn due to epilepsy		1	2		2		5
Withdrawn due to other illness		1			1		2
Withdrawn due to other reasons	1	3	7	2	3		16
Unknown			1		1	4	6
Totals	2	12	14	4	11	7	50

The two children who were withdrawn from school because of illness are probably out of school due to seizures or some complication thereof. However, as the writer was unable to verify this, they are considered as out of school due

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[7] Florence M. Teagarden, Ph.D., Child Psychology for Professional Workers (Rev. Ed.; New York: Prentice-Hall, Inc., 1946), p. 393.

to an unknown illness.

Of the fifteen children withdrawn from school for other reasons, eight were institutionalized, two because of feeble-mindedness after irregular school careers, three for delinquencies although while in the community they attended school regularly, and the other three were institutionalized because of behavior problems. Three of these children were of average or normal intelligence. One girl, rated as superior, withdrew from school because of pregnancy, and six reached the age when they could legally stop school for work, marriage, or because they no longer wished to attend.

The significant fact in the consideration of the school adjustments of these children is that the school has tried to integrate them into class groups best suited to the physical and mental problems presented. No child seems to have been discouraged from normal school attendance because of convulsive seizures. In fact, the school does seem to have "bent over backwards" in some cases to keep the child in his regular class. For instance, one school health teacher assumed the responsibility of working with one of the boys around his daily medication when the home situation precluded any help for him there. In another case, the teacher wrote the doctor in the clinic citing an article in a current magazine and raising a question about the child's extra-curricular participation in the band in consideration of the content of the article.

Only four of the families of the children in the study were not registered in the Social Service Exchange. The remaining forty-six were registered by from one to more than ten agencies with an average registration by five plus agencies. Nine families were known to more than nine agencies. This information is not presented to signify that the presence of an epileptic child in the family gives rise to more problems than the family can handle without outside assistance, but rather as a delineation of the fact that when facilities were available they were used by the particular families with whom this study is concerned. Also, the group as a whole had been unable to function without outside assistance which might be an indication of insecurity and instability and, therefore, it might be expected that these children would have more problems of adjustment.

Elsewhere in this chapter it is mentioned that some of the children were institutionalized during some part of the study period. These periods of institutionalization were occasioned by minor delinquencies as a result of which the child stayed for two or three days in the Children's Center of the Louisville and Jefferson County Children's Home, disposition problems which also necessitated short periods in the Children's Center, and major delinquency charges where the child went from Children's Center to the Ormsby Village or Ridgewood Departments or to the Greendale House of Reform. This topic will not be further developed in this study other than to cite the statistics and their implications.

Thirty-five children were not institutionalized for dependency or delinquency reasons. Fifteen children, five girls and ten boys, spent time in the Children's Center, two on dependency counts, nine on delinquency charges, and four on both dependency and delinquency charges at different times. Twelve of the children were in Children's Center more than once; of these one was there sixteen times and another fourteen. Seven boys were committed to the Ormsby Village Department of the Louisville and Jefferson County Children's Home, three on dependency charges and four for delinquency. One boy spent two and one half years at the Greendale House of Reform for manslaughter. Two negro children were at the Ridgewood Department of the Louisville and Jefferson County Children's Home, one boy for delinquency and the other, a girl, for dependency. One boy was sent to the Tennessee Industrial School by his parents but remained there only a few days.

What is not known about these children is how many commitments were direct results of their illness, seizures of a psychomotor type or a furor conclusion to a grand mal attack; how many were due to the family's inability to care for the child at home because of the problems his illness occasioned; and how many of these children would have found medical care and training suited to a better resolution of their problems in an epileptic colony or farm had such a facility been available.

An effort was made to ascertain the behavior problems displayed by these fifty children, but the writer does not consider that complete information was secured on this particular phase of the study. Of the fifty, there were only two cases in which the child presented no behavior aberrations but the adjustment of thirteen of the children was not known. Some of the complaints made of the children's actions at home and in school were of hyperactivity, disobedience, failure to answer questions, stubbornness, noisiness, inattention to discipline, and attempts to attract attention by various mannerisms. One child's parents complained that he was restless and threw things; another bothered the other children at home and in school. A teacher reported that one of the boys was restless, unable to stand the school routine, and consequently played hooky.

In neighborhood groups some of the children were aggressive, bullied the other children, were destructive, told lies, and were careless of their deportment when with the opposite sex. Community difficulties ranged from manslaughter to taking bus trolleys off their wires and pilfering from five and dime stores.

The misunderstanding which the families and the community as a whole brought to the consideration of the epileptic resulted in his treatment as a "problem child" rather than as a sick one. When the child and parents were known to Mental Hygiene Clinic or Louisville General Hospital Department of Psychiatry an effort was made to recognize the behavior problems that were part of the child's illness, those that were part of the child's reaction to his illness, and those upon which the illness and its effects had been imposed. However, in the greater number of instances the child was considered a behavior problem and treated as such; the reasons for this were lack of knowledge, facilities, and personnel.

TABLE 10

STATUS OF CHILD AS OF MARCH 1, 1948

Status	Number Children
In school	16
At home	12
Employed	1
Institutionalized	9
Housewife	2
Removed from city and country	4
Dead	2
Unknown	4
Total	50

In March, 1948, sixteen of the children were attending school regularly. Twelve children were at home. Five had never attended school, two because they were not yet of school age and three because of their mental or physical conditions. Seven were at home because of physical conditions: two for unknown illnesses, one because of spasticity and epilepsy, two because of mental retardation and failure of the family to encourage school attendance, one because of an illegitimate pregnancy, and one recovering from a fractured fifth cervical vertebra. One boy was gainfully employed, his seizure having been controlled by regular medication and clinic attendance. Two of the girls were married, one having two children and the other three. Two of the children in the study group are dead, one having died as a result of her epilepsy and the other having been killed while absent without leave from Ormsby Village. Four of the children have moved from the Louisville and Jefferson County Area.

Nine children were institutionalized. Two were in Ormsby Village on delinquency charges, and two had been committed to the Kentucky Training Home (formerly the Institute for the Feeble Minded) from the Children's Center. One girl had been placed in the Masonic Home by her parents as they could not cope with her behavior and their own problems of health and relationships, too; one girl had been admitted to Maryhurst because of her inability to adjust at home due to her retardation; one boy had been committed to Central State Hospital with a diagnosis of epilepsy with psychosis; one boy was in LaGrange State Reformatory for stealing a truck; and one boy was in prison in Georgia for having killed a man. The adjustment of four of the children was unknown.

CHAPTER IV

THE ATTITUDES OF THE FAMILY AND THE CHILD

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> . . . . we have been much impressed by the influence of the attitudes of other members of the family upon the patient's welfare. If the family group as a whole takes a realistic and helpful point of view about the illness, the patient is placed in the best possible situation to profit from his medical treatment and find a place in society. On the other hand, if relatives have a sense of shame about the disorder, and make the patient bear the burden of their own anxiety and distress as well as his own, the benefits of otherwise adequate treatment may be nullified. The danger is particularly great with young patients. An overprotective attitude on the part of the parents during formative years is apt to perpetuate an immature adolescent approach to life on the part of the patient.[1]

The writer has attempted to ascertain some of the attitudes which the parents of the fifty children in the study had toward their children and their illnesses.

Predominant was the fact that the great majority of the parents did not understand the child's illness and its implications. This misunderstanding was caused by the parents' inability to comprehend due to their own mental limitations or emotional blockings, by indifference and neglect, or by the failure of anyone to offer them the opportunity to understand. There was one grandmother who administered a dose of turpentine whenever her granddaughter had a seizure and refused to consider any medical care; the parents of this

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[1] Jerry C. Price, M.D., and Tracy J. Putnam, M.D., "The Effect of Intrafamily Discord on the Prognosis of Epilepsy", <u>American Journal of Psychiatry</u>, C (March, 1944), 593.

child were so involved in their own particular problem of relationship to each other that they welcomed the grandmother's willingness to take the child off their hands and had no concern about her physical well-being. Many of the parents wanted to help their children but did not know just how to do this most constructively. Related to the failure to understand the child's illness was the attitude of hopelessness displayed by some parents.

While many regarded their epileptic child as different from other children, they displayed an acceptance of him with that difference. However, in some instances the parents reacted to the "difference" by being over-protective, not allowing the child to play with other children, not allowing him to go on errands, accompanying him every place, and never leaving him alone. In some of the cases this reaction was recognized as a response to tremendous feelings of guilt, sometimes surrounding the supposed inherited factor of the child's illness and in other instances because of the desire to reject and ignore the child. There were some examples of overt rejection, the parents attempting to place the child, not following medical advice, and at times not even recognizing the child's need for medical care.

> Case Number Fifty - This sixteen year old negro girl, having grand mal seizures, has been attending Louisville General Hospital Neurology Clinic sporadically since July, 1945, and relatively good control of her seizures with medication has been secured. She is an only child, conceived out of wedlock, but born legitimately, her parents separating soon after her birth. The patient's

mother is now about thirty-three years old. Patient is a large, unattractive girl, illegitimately pregnant. She said she had been in high school when forced to stop because of her pregnancy. Both the doctor in the clinic and the writer had been impressed by what seemed to be her mental retardation and wondered about her school adjustment. She gave every indication of being a deteriorated epileptic. Follow-up of the Social Service Exchange registrations revealed that this child has constantly been openly rejected by her parents. She has been in Children's Agency foster homes and has also been at Ridgewood three times on dependency charges and in Children's Center four times on the same charges. Although the Louisville General Hospital record indicates that a tentative diagnosis of epilepsy was made in 1934, the Children's Agency record, while recounting some neuropathy, does not mention convulsive seizures. However, the patient had some kind of nightmare in the foster home which might have been a nocturnal seizure. Perhaps, too, the mother did not give this information for fear it would hinder placement of the child. Significant was the fact that in 1944 this girl had an IQ of 124, which raises the question of whether she has really deteriorated since that time or is only meeting with apathy and withdrawal the culmination of a life of rejection.

Case Number Twenty-seven - This eighteen year old white girl began having grand mal seizures when about six years old. No regular medical care was ever secured for her, and when her family moved from the country to Louisville this neglect was continued. However, because she had seizures on the street and was brought into the Accident Room at the Louisville General Hospital she soon became well-known both to the medical and Social Service staffs. The move to the city resulted in the complete disintegration of the family, the parents separated, the patient and a sister remaining with the mother. When the patient was seen in the Accident Room on 11/9/45 the doctor who saw her described her as a "pitiful, miserable human being"; she had gonorrhea and was infected with pediculosis. Also in 1945 she was given a psychological examination and an impression of feeble-mindedness was confirmed with the comment that the testing suggested that social and emotional factors had played a large part in preventing the development of her potential ability to its fullest level. The child's mother worked, leaving her to beg and solicit on the streets; she had never attended school regularly, and after she became so grossly infected the doctors advised against her return to school.

> The Juvenile Court, the Children's Agency, the Social Service Department of the Louisville General Hospital and the Department of Psychiatry, and the Family Service Organization all knew the family, but it was the concensus of opinion that case work service was of little value and that the only solution was the institutional care of the child. The mother's only interest in her was in using her in her court battles against the father. After six hospitalizations at Louisville General Hospital for a total of forty-five days, six committments to the Children's Center on delinquency charges and four on dependency charges, the patient was finally committed to the Kentucky Training Home in September, 1946.

Parents of children having private medical care, while understanding intellectually the child's illness, were ashamed of the fact that the child was an epileptic, kept the facts of his illness from their friends, and were loath to discuss the subject with the writer at first. One mother agreed to participate in the study only after being assured that the writer would be leaving the city in June. In the case of some of the children who are receiving clinic care and where the cultural and economic advantages of the family were limited there seemed to be more real acceptance of the child with his illness, the subject being discussed freely in the family, the neighborhood, and with friends. The following quotation has impressed the writer as being particularly appropriate to this study:

> Success or failure in treatment seems to depend upon the individual child and the individual family and no correlation was found between the probability of success or failure and the economic status of the family. Thousands of children have survived poverty and physical deprivation with a vigor and resourcefulness that is astounding and this vigor, of course, stems from family relationships which, though they existed in poverty, still had

love and emotional security.[2]

Some of the parents resented the fact of the child's illness and displayed this resentment by neglecting to ascertain that he took his medicine, by indifference and failure to co-operate with the clinic or doctor, and by punishing the child when he had a seizure. One family told the epileptic son that he was crazy and constantly threatened him with committment to Central State Hospital.

Although not all of the children were resented, rejected, and unloved by their parents, love and concern for the child's welfare could not alone accomplish his adjustment to his illness if accompanied by apprehension and a misunderstanding of the illness itself.

The parent's attitude toward his epileptic child is determined by his attitudes toward himself as a parent and toward himself as a person. If his own needs are not being met he cannot adequately meet the more specialized needs of a sick child. One mother was worried about her husband's illness and was consequently cross with her epileptic son. Another mother could not bring much understanding to the problems of her epileptic daughter because she was involved in the problems of her only son who was a patient at the United States Public Health Service Narcotic Hospital. One

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[2] Lillian J. Johnson and Joseph H. Reid, "An Evaluation of Ten Years Work With Emotionally Disturbed Children", Monograph IV, The Ryther Child Center (Seattle, Washington, October 15, 1947).

mother tried hard to co-operate in providing the necessary care for her son but had so many fears about herself and her inadequacies that she was unable to function with any degree of success. Stepmothers, especially, seemed to feel that their position in the affections of the father was being threatened by this sick child and their whole attitude was centered in the defense of themselves and consolidation of their position as the central and only one for the receipt of affection and interest.

Not all parents are mature enough to accept that role and again their immaturity manifests itself in their treatment of the sick child. The mother of one of the children sympathized freely with him in the way he felt about his illness and consequently made no effort to help him accept his medication; instead, she "went along with him" when he did not want to take it because she "felt so sorry for him". In another instance the mother felt so sorry for herself because she had such a problem child that the child was constantly fighting her as well as his illness. There were also parents who felt so sorry for the child because of his illness that they wanted to relieve him of all responsibilities relating to it even though he was old enough and mature enough to accept them with their help and support.

Several parents, mainly in broken homes, could verbalize the fact that they did not love the child but could accept the responsibility and need for medical care for him.

On the other hand, parents who professed love for their children exonerated themselves of responsibility for what had happened to the child by stating that they had done all they could for him and by seeking to evade further responsibility by the fact that "after all he is a sick child." In one instance both the father and stepmother developed illnesses of their own which necessitated the child's removal from the home.

> Case Number Thirty-nine - This ten year old white boy began having petit mal seizures which are now well controlled with medication at the age of eight. He is an intelligent boy whose family is financially and socially affluent and who has every cultural advantage. There is an air of sophistication and boredom about him which gives the impression of precocity. While beautifully mannered, he does not seem to relate too well to others, there is no spontaneity and impulsiveness, no real boyishness about him. He is the oldest in a family of several children. His response to his seizures was one of irritation and resentment. He had always been a leader in his school group and was looked up to by the other children; he resented the kind of attention brought to his lapses of consciousness by his friends. His way of handling this was to learn to use them to get admiration and attention and to make the others laugh; this implied feigning seizures. He told his mother at this time that he thought his place in life was as a comedian, to make people laugh. He will not take the responsibility for his medication. He beats on his younger brothers, He isn't cruel to them, but jabs them whenever he gets a chance. He has become very agreeable to anything his parents suggest for him to do, but has no suggestions of his own; it is hard for them to get his real feelings.
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> The mother feels a tremendous amount of guilt about the patient's illness. She recalls a grandfather who daydreamed, and she herself can soar away from reality; she describes herself as "a dreamer". She says she must bear as much of the illness as she can for the patient and, therefore, takes responsibility for his medicine and has never tried to help him take this over. He takes riding and swimming lessons and is permitted to ride his

bicycle ("every time he goes out of the house with it I know he may not come back alive but I'm determined that he miss nothing--I must share this with him"). There was never any expressed concern regarding what he might do to someone else if he "blacked out" while riding his bicycle, and the writer does wonder what will happen when this boy is old enough to drive a car. The mother says that before she realized it all the family plans were revolving around this one child. With the guilt is also a sense of shame, stigma, and suppression of the knowledge of the child's illness. Not even his grandparents have been told about it. The mother has an intense fear that their friends will find out about this, yet she wishes there were someone with whom she could talk about the child's illness. She has read all the suggested books and knows much about epilepsy, but her attitude is that this can't be happening to me and my child.

Case Number Nine - This nine year old white boy began having psychomotor seizures when seven years old and has had regular treatment since eight years old. With medication has come a control of the seizures, and the teachers have reported a great improvement in both the child's school work and behavior. This child and his mother were seen in the clinic where the mother encouraged him to present his physical condition to the doctor. There was the impression of considerable warmth in their attitudes toward each other. The patient had greeted the doctor effusively, almost aggressively, but again conveyed the impression of friendliness and comfortableness with people. He displays no unhealthy attitudes toward his illness, discussed how he was getting along in school and at home freely, and accepts the responsibility for his medication. He is the middle child in a family of five, having two older sisters and two younger brothers. The father, who works regularly, has only one arm, having lost the other in an accident. The two sisters had speech impediments for which they attended special classes. Although the family has been deprived financially at times when the father's union is on strike, they are considered one of the normally stable families in the neighborhood. The relationship of the parents is perhaps better than that found in their neighborhood.

The house is filthy, there is no bathroom, and the kitchen tap is the only source of water. It is believed that the mother just doesn't know how to keep house although she displays average intelligence and a fair degree of education in her contacts with others. She seems to

> recognize and accept her own limitations and knows where and how to get help with family problems which she cannot handle. She attends a Mother's Club and participates in the parent and child activities of a nearby settlement house. The patient was allowed to go to camp when he was only six because he wanted to go and his sisters had gone. He is considered a normal boy of his age group. There are some fights and temper outbursts, but they are no more frequent than in the other boys in his environment. Some of his aggressiveness is thought to be due to the fact that he has two older sisters, one of whom might smother him if he were not self-assertive. The patient attends a school which has a large percentage of children with problems. The teachers are accustomed to these children, like to work with them and their parents, and are ever-alert to their needs. They are rather astute at recognizing danger signals and doing something about them.

It would seem that parents who do not understand or accept themselves and parenthood cannot be expected to function adequately in helping to effect their child's adjustment to himself with his illness.

An effort has also been made to delineate some of the ways in which the children in the study reacted toward their illness. There were some instances in which the child had evidently made an acceptable adjustment, usually with the control of the epileptic attacks. In the cases of the children who received medical treatment at the onset of their seizures which resulted in the prevention of further attacks there were no problems of adjustment indicated other than those which were present before the illness manifested itself. It must be recognized that the child's attitudes and reactions toward his illness have their basis in his pre-illness personality and in the attitudes of those around him.

For this reason, while certain reactions to his illness may be expected in a child, it cannot definitely be said that he has an "epileptic personality."

In the majority of cases where the child did have difficulty in facing his illness because of the attitudes of those around him, he reacted by withdrawal, resentment, feelings of difference from the other children, aggression, and by using his illness to gain attention. Other prominent reaction patterns were running away, feelings of shame, and temper tantrums. The children, as was to be expected, displayed generally the same misunderstanding of their illness as was found in their parents; they seemed to think that they were "different children" rather than "sick children." Consequently, they sought to ignore this idea by withdrawal, feigned indifference, and running away, or met it head on by aggressive acts and by capitalizing on the attention-getting aspects of their "fits."

> The social problems created by the existence of seizures can occasionally be met successfully by ignoring the attacks. This solution is seldom a satisfactory one, however, for it involves the psychologic disadvantages of suppression and also usually the practical disadvantage of inadequate medical care. A day of reckoning usually occurs sooner or later, and the problem is then more difficult to face than it would have been earlier.[3]

Four of the children whose seizures had occurred early in their lives, who had been greatly protected by their families, and who were thought to be mentally retarded seemed to

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[3] Price and Putnam, op. cit., p. 597.

have no idea they were ill. Their reactions were more to the attitudes of those about them than to their seizures. They were demanding children, hyperactive, requiring much attention, and showing an extreme amount of dependency.

> Case Number Forty-three - This six year old white girl began having epileptic seizures when she was three years old and has had regular medical treatment since her fifth year. She represents quite a problem neurologically as she has grand mal, petit mal, and psychomotor attacks. The optimum medication has not yet been determined for her. Her petit mal seizures are of the myoclonic variety and they are often severe enough to cause her to fall. She has many scars from such falls. Her gums are slightly hypertrophied and she has an excessive growth of body hair. A considerable portion of her brain is gone and there is the probability that she will be a dull child. She is the youngest of seven children and because of her illness is the center of the family's attention. Because of the nature of her seizures she has been restricted in her play and is never left alone; if it is necessary that her mother leave the room for a moment she is placed on a couch and surrounded by a barricade of pillows. Both parents say they know they are spoiling her and neglecting the needs of their other children, but they do not know what they can do about it. They have worked along with the doctor in attempting to gain control of this child's seizures. Other than the slighting of the other children, the cost of the patient's medication is a source of worry to them as is the attitude of the oldest daughter who is now beginning to want to entertain her beaus at home but is ashamed because of her sister's illness. The patient herself is hyperactive, demanding in her relationships with others, very dependent in her attitude, and requiring constant attention. She does not seem to have any idea that she is ill and as she has little contact with children her own age, no feeling of difference. Her parents have been concerned about her schooling, but until her seizures are controlled this cannot be attempted even though a visiting teacher will be sent into the home by the County School Board. This mother, incidentally, is showing the strain of coping with this child twenty-four hours a day, plus the other demands of her large family.

A method of exhibiting resentment toward their illness and their rejection of it was found by some of the children in ignoring their medication, failing to take it at all, or taking it only after there had been a great deal of attention obtained from the other members of the family. Other children used their seizures to control family relationships. One little girl manifested a seizure whenever there was a family argument.

As the children grew older some of them exhibited extreme sensitivity about their seizures while others tended to overcompensate, both indicative of non-acceptance of the illness itself. One patient cited his attitudes toward his illness as follows: (1) feels he is not wanted at home; (2) feels he himself is at fault for the teasing he gets because he fights back when teased about seizures; (3) he cares little about his home life except for his father; (4) he doesn't mean to be mean but finds himself doing something he didn't intend to do; (5) resents highly being called crazy and being teased about his convulsions; and (6) resents being asked not to take part in basketball, etc., because an epileptic. This same boy brooded about his illness and wished he were dead. One girl was able to displace all her true feelings about her illness on what she termed a rather unhappy home situation. Another child who had always been a leader and held a high position in the esteem of his school mates was irritated by his seizures and by having his classmates call attention to them; however, he learned that he could use his seizures to make the other children laugh and began to feign them. Two boys made intensive efforts to resolve their feelings about their illness through understanding it. However, they were defeated in their efforts by unhappy home situations; the fathers and stepmothers were unable to give them the supportive interest and understanding which they needed. Two of the children showed concern over the way they behaved in their seizures, "why do I do what I do?", "I can't help it--I want to do better--what can I do to make up for it?"

Other reactions were those of extreme shyness, feelings of rejection, feelings of persecution, insecurity and inferiority, selfishness, and quarreling. Some of the children also seemed to be unable to get along with the other children of their own age.

> Case Number Four - This sixteen year old white boy has grand mal and probably psychomotor seizures which started when he was six years old. His mother died when he was two years old, and he was placed in an orphanage where he remained until he was eleven. His seizures were controlled by medication while he was in the orphanage, but when he returned to his father's home he began to have daily seizures. He was then taken to Louisville General Hospital, but only fair control was ever achieved because of the home situation. His father had remarried and the stepmother overtly rejected the patient; his brothers, who were older, had made their own plans which did not include the patient. He was, therefore, in Children's Center once on a delinquency charge (he ran away from home due to the parent's abuse), twice on dependency charges, and was at Ormsby Village on a dependency charge from July 29, 1947, until February 20, 1948, when he was admitted to the Central State Hospital. The patient had an IQ of 99 and completed the 8A grade in school. At home the family resented him and his illness, told him he was crazy, neglected him emotionally, abused and intimidated him, and discouraged him from

> trying to follow medical recommendations. He fought with the other children, sometimes having as many as fifteen fights a day, picked on people, lost his temper, and was cloudy and confused at times. He reacted to his family's attitude toward him by wishing he were dead, feeling inferior, withdrawal, aggression, running away, failing to take his medicine, capitalizing on his fits to gain attention, brooding and thinking about his dead mother. When the nurse at school indicated an interest in working with him regarding taking his medicine he responded immediately to the attention which she gave him as if starved for affection. He was hospitalized twice at the Louisville General Hospital, remaining three months one time while efforts were made to plan for his care away from home. He was constantly disappointed in his hopes that someone in his family would want him. He summed up his own situation by commenting that "I sit and dream of how it might have been to have had a mother who understood me and how different home might be."

To treat the epileptic child with the aim of achieving his adjustment to his illness implies not only the understanding of his attitude toward his illness, but also of his attitude toward himself and the environment which molded him.

CHAPTER V

THE PROBLEM AS SEEN BY THE FAMILY

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All families have problems, some threaten the solidarity of the family, some are transitory, some are long term, all have causes. The writer has tried to determine what family problems the family itself thinks were caused by the presence in the group of an epileptic child. This presentation is weighted by the fact that about twenty per cent of the children were mentally retarded and would have caused serious family worries even if they had not had epilepsy.

Leading all others was the fact that a satisfactory parent-child relationship seems to be seriously threatened when the child has epilepsy. Some of the ways in which this threat is manifested are delineated in the material in the preceding chapter. The next complaint was that the presence of such a child in the family group causes continuous and intense worry. Part of this worry centers around planning a future for the child. Many parents are dissatisfied with the facilities available and expressed fear regarding what would happen to the child if anything happened to them. The cost of medical care was also an item that had caused considerable family stress, especially where the family was ineligible for Louisville General Hospital care or where the family, although receiving care at Louisville General Hospital, had to purchase the medicine.

Because the family did not know when the child might have a seizure and because they did not know how he might react to some request made of him or some comment made to him, there was, in some instances, great tension while the child was in the home. However, when this same child was away from home the parents were worried about him.

The epileptic child caused a strain also on the relationships of the parents to each other. Perhaps the father wasn't as sympathetic and understanding as he might have been with the mother because she had to be with the child such a great part of the day. Usually, too, only one of the parents accepted the responsibility of the child's care and the understanding of his illness. Sometimes one parent would become impatient and want to discipline the child despite the objections of the other parent. Also, there was the problem of sibling relationships; the epileptic child would take a great share of the parents' time, he might fight with and bully his brothers and sisters, and the well children might make fun of him or call attention to his illness.

In this era of crowded and inadequate housing the presence of an epileptic child in the home, especially one with nocturnal attacks, created a great problem in arranging sleeping facilities. Also, the parents wanted to have the child near them so they could hear him if he had a seizure.

One family complained particularly that they were unable to get proper rest because of the son's seizures; however, they still were not able to accept his need for medical care and make it available to him.

In several instances the fact that the family still had to support the child although he was of working age was recognized as a problem. It was also a financial hardship when the family had to plan to pay for the child's care away from home.

Much parental concern centered around the failure of their friends to understand and accept the child's illness. They went to great lengths to conceal the true facts because they had experienced real limitations in their own social contacts and those of the sick child and his siblings when they revealed them. Consequently, they either withdrew from social life or evaded discussing the child's illness, thus living perpetually on a "powder barrel." Several mothers commented that it had been extremely helpful to talk with the writer about their child and his problems--"if you only knew how I want to talk about this with someone whom I know will understand--just to get some of this off my chest to someone."

One mother said she was constantly involved in explaining to her neighbors that her son was not responsible for some of the things he did, it was part of his illness.

Another mother said she knew she was spoiling her child, but did not know how to keep from so-doing; she was also concerned because she could recognize that she was neglecting her other children who needed her, too. One family felt so badly about the son's illness that they found they were letting all the family plans revolve around him to the exclusion of his brothers and their needs.

Families who had brought themselves to the acceptance of the fact that their epileptic child needed institutional care experienced a real setback when they could find no suitable facility available. There was a recognized strain on the mother who had to contend for twenty-four hours each day with a child whose seizures were not yet under control or with a child who was unreasonable and fought with his siblings. In one family the father's intense worry over an only child almost made him ill himself. In another family both parents did manifest real physical illnesses after a period of intense conflict with and worry over the daughter with psychomotor attacks. One mother had her own livelihood as a living-in domestic threatened by the fact that her epileptic son, who lived with her, made trouble between her and the other employees. In one family where the epileptic son had had considerable difficulty with the law, the appearance of seizures in a younger son precipitated many fears regarding his future.

Cases Number Nineteen and Eighteen - This twelve year old white boy with focal grand mal seizures had treatment immediately at their onset and the treatment effected their cessation. He is alert, intelligent, in his proper grade in school, and until recently when he cut his knee quite badly worked a paper route with another boy earning two dollars weekly. He is friendly, self-assured, and perhaps overly aggressive, but he lives in a community where the aggressive child has a better opportunity to survive as a personality. The father is an alcoholic and he and the mother have separated innumerable times, the children always staying with the mother. There are two older brothers, two older sisters, and an eight months old sister. At the time the patient was seen by the writer the father was in jail, having been sent there for non-support of his family. The attitude of the mother was one of warmth and interest, but there is probably a tendency to over-protection. It is too early to say that this child has made a good or bad adjustment to his illness, and the true feelings of the patient and his mother toward this illness are not known.

However, any adjustment they make will be colored by the fact that the patient's eighteen year old brother, a grand mal epileptic, is in LaGrange State Reformatory for stealing a truck. In 1942 he was sentenced to five years at the Greendale House of Reform for the fatal stabbing of a fourteen year old boy who had made fun of him because he had seizures and called him "fitty". He had sworn to get this boy and his parents had tried to keep him in; however, they had given him the knife as a Christmas present. This brother was known to Children's Center; Mental Hygiene Clinic had worked some with both the mother and child, and he had also been hospitalized at Louisville General Hospital Department of Psychiatry. He was a dull normal boy with an IQ of 87 in 1942. He was known to have episodes of extreme confusion and irritability following the seizures. In 1942 it was stated that he had definitely adequate emotional responses to his trouble with the community and that there was no question of his delinquency being an epileptic equivalent (psychomotor epilepsy). A psychiatric conference note in 1943 commented that he was a sick boy but there was no institution fitted to the case--"the boy should be offered some sort of environment with constructive activity where he can be medically controlled." The mother had little understanding of this boy's illness and his reaction to it. She stopped giving him his medication at one time because she thought it hurt him. She sympathized with him and would not help him take his medicine when he didn't want to. However, she did write to various foundations, hospitals, etc., for information regarding epilepsy and tried to find out if his stealing was connected with his illness.

When the writer talked with the mother of these boys she displayed much emotion and talked about the older son. She said she worried about what was going to happen to this second son who was now having the same kind of illness as the first one had had, would the same thing happen to him? The home situation had not changed except for the fact that she was no longer working because of the young baby in the home. She did not think she would take her husband back this time unless she could be sure he would "do right."

Case Number Forty-two - This twelve year old white girl has grand mal, petit mal, and psychomotor epileptic attacks and is also mentally retarded. At the age of three she was given a pneumoencephalograph when her parents sought medical advice because of her slow development. They were told that there was a growth in the midfront brain and that she would always be slow; her sister who is eighteen months younger was already ahead of her in walking and talking. Her mother worked with her trying to teach her and integrate her into the family group. She was entered in the public school, but the mother was constantly having to go to school to explain that she was not like the other children and could not learn as they could. The teachers had said she was spoiled at home. When she was eight she had her first petit mal seizure and soon began having grand mal attacks. Private doctors told the family nothing could be done about it, so some relatives in another city arranged for her to be seen at a hospital there. She was given a complete work-up and her parents were advised that nothing could be done for her; they advised that she be placed in an institution in fairness to the parents and the other children. The family tried to get the patient into a private school or home, but the only one which would take her charged one hundred fifty dollars monthly and the family could not afford it. It was finally possible for her to be placed in the handicapped class at one of the public schools. She is a lovely looking, friendly, natural, appealing child who gets along well with the other children in school who thought nothing of it when she had a seizure. She worked hard and would do school work when she came home in the afternoon. When she was eleven she began having more seizures and was most irritable at home. Private medical care was secured, and with a cessation of her seizures came an increasing amount of temper tantrums, demanding behavior, and actual violent fighting with the mother.

With the increase in the child's behavior problems the mother began having all kinds of aches and pains and fears concerning her own physical health. She had a thorough physical examination and was told her symptoms were caused by worry, after which they disappeared. The father travels and is at home several days every two weeks, at which time all the family routines have to be changed. He cannot understand what the mother has experienced in having to cope with this child almost constantly. He tries to discipline the patient when she has irritable outbursts, and it is hard for him to accept these episodes as part of her illness. The young brother thinks his sister is very funny and tries to imitate her. His mother tells him that his sister doesn't feel well and he should not do this. The patient and her sister used to be very close friends. Now the sister seems to resent the attentions given her and patterns her own behavior to get attention for herself. The mother has told her her sister is different and her condition is something to be kept within the family. She told several of her good friends and this "backfired" on her, so now she is close-mouthed about her sister. The mother doesn't tell anyone about the child's condition, she just says she isn't well. "People are not very understanding." The mother dreads the coming of summer and would like to place the patient in a foster home, preferably outside the city. She displays a considerable amount of guilt when she talks about this--she thinks the family can be better Christians by learning to integrate the patient. Also, each year the parents go to the Christmas party of the handicapped class because then they can see how fortunate they are and how much better off their child is than some of the others.

This mother has finally decided to place the patient with a woman who is moving to the country to live. She stated she didn't even want to know if the home was approved for boarding children. She had been three years in making up her mind to take this step and felt relief just with the making of the decision. The patient is being removed from school, and the mother has no plans for her at present regarding further schooling.

The epileptic child is a threat to his family group; the extent of the threat depends on how secure the family has been, their inter-family relationships, their understanding of the illness, and the facilities available to them in meeting the child's specialized needs.

When the writer interviewed the parents of some of these children they were asked what facility they thought might help them most in meeting the needs of their epileptic child. Some of the suggestions made were: (1) a visiting teacher for the child's first year of school, then a special class based on his needs and physical condition; (2) the opportunity to talk with other mothers of other epileptic children to know how they handle them; (3) a special school which would keep the child from eight to four and supply medical supervision; and (4) a place such as a colony or farm where a child could get custodial care and also medical care, schooling, and vocational training. The request for group sessions or the opportunity to discuss their problems with persons having similar problems was made by over fifty per cent of the mothers with whom the writer talked.

CHAPTER VI

SUMMARY AND CONCLUSIONS

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The findings of this study of fifty epileptic children in Louisville and Jefferson County are significant in their implications, both as to social planning in the community and the better co-ordination and utilization of facilities already existing.

The writer experienced difficulty in locating children for the study, necessitating a wide range of final referral sources. This indicates that the epileptic child is the concern of many and varied agencies and facilities. It was also necessary to utilize many resources in following the children from the time their illness was diagnosed until the present because no follow-up encompassing all those known to have the illness is done on epileptics by the various medical agencies. In general, the poorer the child's adjustment to his illness the more treatment facilities were utilized in trying to meet his needs. The majority of the children did not receive regular or adequate treatment and long periods of time elapsed between the onset of the seizures and the securing of medical care. More children seemed to have been brought for treatment for grand mal seizures than for any of the two other types of attack. However, the majority of the children did not continue with treatment, and without regular and adequate medical care the cessation of the attacks could not be effected. The children in the group experienced more hospitalizations than might have been necessary had there been follow-ups made from the clinic and after the child was hospitalized for the first time; some of the prolonged hospitalizations might have been eliminated had there been appropriate institutional care available for the epileptic child. The Social Service Department at the Louisville General Hospital was used both as an aid in the treatment of the patient and in planning for his adjustment into the community; with the recognition of the social implications of epilepsy by the medical profession the Department could have been used to a greater extent had it been adequately staffed with a worker available to the clinic.

Only a small percentage of the group had stopped school because of seizures; the school has tried to integrate epileptic children into the regular school program according to their abilities and needs. However, some of the children have never attended school because there was no facility available for their special needs; several of these children are grossly retarded. Significant in the school adjustment is the fact that many of the children left school for reasons other than their epilepsy without receiving the vocational training and guidance which is so necessary for the epileptic child. Over fifty per cent of the children were average or dull normal in mental status. However, a large percentage (twenty-two) were feeble-minded, having IQs under seventy. It is not known how many of these children are deteriorated epileptics and how many are feeble-minded because no opportunity was given them to utilize their capabilities and develop their potentialities. The Social Service Exchange registrations on the families of the children in the group indicated that the majority were unable to function without outside assistance which fact might indicate insecurity and instability and, therefore, imply more problems of adjustment for these children. It was also apparent that social agencies and community facilities were used by these families when they were available. Thirty per cent of the children were institutionalized for dependency or delinquency; there is a need for a further evaluation of these institutionalizations as to the physical, emotional, and environmental factors involved in an effort to ascertain whether or not some more specialized program could have met more adequately the needs presented by these children. The majority of the children presented behavior problems of a similar pattern, i.e. they reacted in fairly identical ways to the attitudes of those around them which were for the most part similar; these same reactions would have been manifested by a normal child had he been the subject of such attitudes. Their treatment was more that of a "problem child" than that of a "sick child." When last known to the writer forty-six per cent of the children in the study were institutionalized, were at home unable to attend school or participate in work activities, or had died as a direct or indirect result of their illness. Thirty-two per cent were attending school, but more intensive study of some of these children revealed they had not made an acceptable adjustment to their illness. The present status and whereabouts of sixteen per cent was unknown other than that eight per cent had left the area of the study. In the remaining six per cent, one boy was successfully employed after medication had resulted in cessation of his seizures, and the two girls were married and the mothers of families. However, one girl had to live with her parents in order to care adequately for her children and the other had been known almost constantly to social agencies because of her marital difficulties.

The attitudes which the parents brought to their child with epilepsy were those of misunderstanding, overprotection, overt rejection, guilt, shame, neglect, resentment, and acceptance. There was a displacement of attitudes toward other family situations onto the child with his illness; also, some of the parents were too involved with their own problems to consider the needs of the child. Some of the parents reflected their own immaturity in the handling of the child, some looked upon him as a threat to their own affectional position in the family, and others tended to evade all responsibility for the child and his care. No correlation was found between probable success and failure of adjustment and the economic status of the family. In general, the attitudes which the parent previously had toward the child and toward parenthood were emphasized and exaggerated by the child's manifestation of epileptic seizures.

The sooner the child had treatment after his seizures occurred the better was his adjustment and the less severe were his reactions to the fact of his illness. However, where definite destructive attitudes were brought to the child with his illness he reacted by withdrawal, resentment, feelings of difference, aggression, attention-getting, running away, temper tantrums, shame, misunderstanding, feigned indifference, ignoring the seizures, sensitivity, over-compensation, extreme shyness, feelings of rejection, persecution, insecurity, and inferiority, and selfishness. It did seem that the child's attitudes were not formed by the fact of his illness, but rather by the attitudes which those in his environment displayed toward him with his illness.

Problems which the family thought were occasioned by the presence within the group of an epileptic child involved family relationships, finances, housing and social limitations. It was thought that the child threatened the existing parent-child, parent-parent, sibling, and parent-sibling relationships because of the misunderstanding of his illness and his special needs. Much worry and tension centered about planning for the child's future and the families were particularly distressed by the lack of facilities and lack of co-ordination of existing facilities to assist them with this planning. Financial problems were those of the cost of medication, medical care, support of the older child, and providing for the care of the child away from home. Parents limited their social contacts rather than tell their friends the nature of the child's illness because of the general public's lack of understanding of the nature of epilepsy. There was a noticeable strain on the mother who tried to integrate the epileptic child into the family group when this was combined with caring for the home and several other children. Some parents developed illnesses when the problems presented by the child seemed to have become too great for them to handle.

The parents of the children in the study were especially interested in having an opportunity to discuss the treatment in the family group of the epileptic child and to obtain more adequate knowledge regarding the nature of his illness. They also felt that a specialized institution was indicated for the care of some of the children. It was also thought that a school situation where the child's medical needs were recognized and met would be of value to them in keeping the child within the family group.

In regard to the two particular needs of epileptic children which were mentioned at the first meeting of the Inter-Agency Committee,[1] dental care due to broken teeth and special schooling for those just developing epilepsy, it can be stated that with early recognition of the nature of the child's illness and the institution of regular medical care both of these problems would be eliminated. The writer found no instance of broken teeth due to seizures in any of the fifty children, although other types of bodily injuries were reported. The best time to treat epilepsy is when the child has had only one or two seizures; however, if the optimum medication is difficult to determine, the parent, school, and source of medical care can plan together for meeting the child's needs until such time as he can enter the regular class. Facilities are available for these children when schooling and medical care are the only problems; what is lacking is the co-ordinator, especially when the parents cannot move independently.

From this study of fifty epileptic children in the Louisville and Jefferson County area who were of school age between 1942 and 1947 and who were known as epileptic during some part of that time, certain conclusions may be drawn.

The epileptic child is to be considered a handicapped child as he is prevented from developing as an adjusted and useful member of society because of his physical condition

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[1] Supra, p. 25.

and the attitudes which those in his environment have toward that condition. He is the concern of the community because his ability to make a successful adjustment to his illness contributes to the general well-being of the community; when he does not receive adequate treatment he may become not only a problem at home but in the school, the neighborhood, and the community, thus affecting the adjustment of others.

The knowledge of the general public regarding the nature of epilepsy, its extent, social implications, and amenability to treatment is limited and for the most part erroneous.

The adequate delineation of the extent of the problem of the epileptic child in this area requires a case-finding program. Such a program might be facilitated by the establishing of epilepsy as a reportable illness for research purposes.

Epileptic children in Louisville and Jefferson County are not receiving adequate medical care, nor are they adjusting to their illness and with their illness to their environment. There is the need for the careful evaluation of the services which this community is offering the epileptic child and his family to determine how his needs can be met more fully and successfully. Some co-ordination of the services which can be offered by the public schools with those of the social and medical care facilities in the community seems to be indicated to provide fuller consideration of needs and to prevent duplication of interests and services.

Adequate treatment of epilepsy considers not only the child's seizure manifestations, but all of his individual problems; his personality, his environment, and the attitudes of those in his environment toward him with his illness. Its aim is his adjustment into his environment in a way which enables him to use to the fullest extent his abilities and capacities. It requires the services of not only the physician, but also the psychologist, psychiatrist, social case worker, and vocational counselor. No facility providing such an integrated service exists in the State of Kentucky.

The writer believes that some epileptic children, exclusive of those who are mentally retarded, may benefit from a period of institutionalization. Such a course of treatment would be warranted if the situation in the home precipitated emotional disturbances which in turn encouraged seizures. The right institutional experience while a foster home was being found for the child or while the home situation was changing might prevent the development of an unhealthy attitude toward his illness on the part of the child. When medication cannot be found to control a child's seizures, a specialized institution might give him the training and the acceptance which it is so important that he have while efforts are being made to obtain relief for his physical condition. The program of such an institution should encompass schooling, vocational training, medical care, and psychotherapy adjusted to each child's individual needs. Such an institution is not available in Kentucky.

The importance of the parent-child relationship is emphasized when the effect of the attitudes of the parent upon the epileptic child in forming his own attitudes toward his illness is considered. Since the child reacts to the attitudes of those about him rather than to the fact of his illness per se treatment must include the interpretation of the child and his illness to those about him. Because such a child is considered a threat to their stability by the family, his treatment must consider him as a member of a family and not just as a person with an illness. Some provision for the recognition of the role of the parents in the treatment of the children and the opportunity for them to share their feelings regarding their child's problems would probably result in their being better equipped both in attitude and practical knowledge to help the child.

Finally, in considering how the epileptic child can best be integrated into his community these concepts of Dr. Lennox should be continually kept in mind:

> Epilepsy is a handicap physically in effect only a minute fraction of the time; its severity and effects are extremely variable. Most of the popular opinions about epilepsy are false. Knowledge of those best informed

regarding causes, consequences, prevention, and treatment, if absorbed by doctors and the general public, would be the greatest possible aid to epileptics. Epilepsy is a handicap susceptible of cure. Even if not cured, epileptics, given a fair chance, can be productive and happy members of society.[2]

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[2] U. S. Congress, House of Representatives, *Aid to the Physically Handicapped*, *op. cit.*, p. 1323.

APPENDIX

SCHEDULE

Number: Age: Sex: Race:
Where treated: LGH: CFH: Private doctor:
Other (specify):
Age onset seizures:
Age institution treatment:
Type seizure: Grand mal: Petit mal: Psychomotor:
Combined types (specify):
Other (specify):
Medication prescribed:
Phenobarbital: Dilantin:
Tridione: Phenobarbital and Dilantin:
Phenobarbital, Dilantin, Tridione:
Phenobarbital, Dilantin, Tridione, Benzedrine:
Other (specify):
Control secured: Good: Fair: Poor:
Still experimenting with dosage:
Regularity of treatment: Regular: Frequent:
Sporadic: None: Unknown:
History of head injury: Age:
EEG confirmation:
Dates of hospitalizations for seizures:

Hospital Social Service Department Registration:
Problem: Schooling: Financial:
Family Relationships: Other (specify):

Present grade in school:
Why stopped school: Advice private doctor: Advice clinic:
Request school: Other (specify):

Grade completed:
Measurement of learning:
Social Service Exchange Registration:

If institutionalized, when:
Where:
Why:

Behavior problems manifested:
Home:
School:
Neighborhood:
Community:

Other siblings:

Other members family having seizures: Mother: Father:
Brother: Sister: Other (specify):
None:

Family attitudes toward illness:
(1) acceptance
(2) resentment
(3) shame
(4) unashamed
(5) he's different
(6) love
(7) over-protection
(8) rejection
(9) helpfulness
(10) misunderstanding, ignorance
(11) other (specify)

Patient's attitude toward illness:
(1) acceptance
(2) resentment
(3) shame
(4) unashamed
(5) withdrawal
(6) dependency
(7) attention-getting
(8) misunderstanding
(9) aggression
(10) run away
(11) feels different
(12) temper tantrums
(13) other (specify)

Family problems caused by illness:
- Financial:
  - Cost medical care:
  - Cost support:
  - Other (specify):
- Family relationships:
  - Mother-father:
  - Parent-child:
  - Sibling:
- Housing arrangements:
- Planning future for child:
- Tension:
- Worry:
- Other (specify):

Present status child:
- School:
- Employed:
- At home:
- Institutionalized:
- Housewife:
- Other (specify):

Community resource which family thinks would be most helpful to them in treating patient:

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