EPILEPTICS IN THE COMMUNITY.*

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The Incidence of Epilepsy.

In round figures there are 11,000 epileptics in public mental hospitals, 3,000–4,000 in institutions for mental defectives, just under 4,000, who are neither insane nor mentally defective, in colonies and residential schools, and an unknown number, probably a considerable one, in public assistance hospitals and institutions. How many are living in the community is not known.

Ten years ago the Permanent Committee on Epileptics, a body which has been dormant of late, instituted an inquiry into the number of epileptics known to public authorities in the County of Surrey. The public authorities who were approached included mental hospital officials, poor-law guardians, local education authorities, mental deficiency authorities, maternity and child welfare authorities and the Ministry of Pensions. General hospitals were not approached. 781 cases were found (1), representing ·81 per 1,000 of the population; of these 627, or ·65 per 1,000, were, on account of their epilepsy, chargeable, in one form or another, to a public authority. There were 211 not in institutions, 57 of whom were in receipt of out-door relief. These were classified according to age and mental state as shown in Table I.

Table I.—*Surrey—Non-Institutional Cases.*

	Mental defectives.	Mentally normal.	Total.
Under school age	4	9	13
School age:			
Attending school	6	40	46
Not attending school	16	14	30
Over school age	41	81	122
	67	144	211

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No reference was made to employment in the Surrey inquiry, but the sources of the information made it likely that few epileptics in employment would be recorded.

During the winter and spring of 1936 a wider inquiry into the number of epileptics in the community, their mental condition, their social status and their need for assistance was undertaken by the Central Association for Mental Welfare in certain urban districts of Essex, and in 1937 two further surveys were made, one in Tottenham and Wood Green, and the last in the County Borough of Ipswich. From a statistical point of view the latter is by far the most complete. As the results of the Essex inquiry have already received some publicity (2) a brief summary only is given here; the North London inquiry was more limited in scope and will not be reported; but the survey in Ipswich will be more closely scrutinized.

In each of these surveys we tried to find out, in respect of each patient reported to us, the age, the sex and the mental condition. From the point of view of mental condition the cases were classified under four heads: (1) Mentally normal, (2) unstable or deteriorating, (3) mentally defective, and (4) insane. The unstable or deteriorating we define as those who, while not so retarded in intelligence as to be called mentally defective, are so handicapped by instability of temperament or progressive deterioration associated with their complaint as to render them socially inefficient. Experience shows us that this is a most important if somewhat heterogeneous group. There is obviously a fairly wide margin of choice between it and the group called mentally normal. Especially must this be so in a questionnaire inquiry like this, when the information and judgment of the different people furnishing the reports must vary rather widely. The figures in this group must therefore be taken as an indication only; extensive personal contact with large numbers of epileptics living in the community leads us to think that they should be much larger than they are. In other words there are very many epileptics who are neither insane nor mentally defective, but who have serious mental or temperamental handicaps in addition to their fits.

Essex inquiry.—The areas in the county of Essex which were selected for the first inquiry had a total population of nearly half a million, and included two boroughs, one new housing estate, one rapidly developing country town and an urban area with a new building estate. Cases were received from public assistance committees with their hospitals and institutions, education and health authorities, the Essex Voluntary Association for Mental Welfare, the Royal Eastern Counties Institution, certain neurological and general hospitals, and a few from private persons. As was to be expected, the response to inquiry varied a good deal in different districts and with different authorities, and the available information about individual cases was not always accurate or complete.

Of the 565 cases reported, 125 were in institutions and 440 living in the

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community. The total incidence works out at 1·2 per 1,000 of the population. Table II shows the classification by mental condition and age-group of the non-institutional cases.

TABLE II.—*Essex—Non-Institutional Cases.*

Age.	Mentally normal.	Unstable or deteriorating.	Mentally defective.	No information.	Total.
16 and under	52	2	26	44	124
17–50	135	22	36	91	284
50 and over	14	2	0	16	32
	201	26	62	151	440

Ipswich inquiry.—As stated above, the inquiry in the County Borough of Ipswich was by far the most complete. A provincial town provides a satisfactory unit for investigation. The epileptics in the town do not attend hospitals outside its boundaries and the local authorities have a comparatively thorough knowledge of the population. We were also particularly fortunate in Ipswich. Not only were we able to obtain the sympathetic co-operation of the Education and Public Assistance authorities and again the Royal Eastern Counties Institution, but we also had the help of a particularly efficient local voluntary Association for Mental Welfare, and the ready co-operation of the Committee of Management of the large voluntary hospital serving the district, the East Suffolk and Ipswich Hospital. Further, and still more important, we were enabled through the courtesy and help of the local branch of the British Medical Association to address a questionnaire to all the medical practitioners in the borough. By these means we were able to carry out an inquiry which is certainly more thorough than any other undertaken in this country. The general results of the inquiry are set out in Table III.

It will be seen that a total of 225 cases was received. As Ipswich has a population of 92,000, the incidence works out at 2·44 epileptics per 1,000 of population, an extraordinarily high figure. It is possible that there was a little overlapping between the sources whence the cases were derived, and in those notified by the hospital or private doctors some patients living outside the borough area may have been included. As against this, the replies from medical practitioners were far from complete (29 returns having been received out of 48 doctors circularized), and there must also be a good many slighter cases of epilepsy that were not reported.

The institution and non-institution cases can be considered separately.

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TABLE III.—*Ipswich—General Analysis.*

	Mentally normal.	Unstable or deteriorating.	Mentally defective.	Insane.	No information.	Total
Non-institution:						
50 and over	9	4	1	..	4	18
17–50	67	18	12	..	5	102
16 and under	23	8	6	..	5	42
	99	30	19	..	14	162
Institution:						
50 and over	..	8	2	4	..	14
17–50	5	15	17	6	..	43
16 and under	2	1	3	..	..	6
	7	24	22	10	..	63
Grand total	106	54	41	10	14	225

TABLE IV.—*Ipswich—Institution Cases.*

	Mentally normal.	Unstable or deteriorating.	Mentally defective.	Insane.	Total.
P.A.C. institution	2	9	5	2	18
Mental hospital	..	9	7	8	24
Royal Eastern Counties Institution	..	..	10	..	10
Residential colonies	5	6	..	..	11
	7	24	22	10	63

Institution cases.—Figures for institution cases are needed for the sake of completeness, though they do not directly concern the problem of epileptics in the community. There are, however, two comments which may be made on Table IV, which classifies the institution cases:

(*a*) There are 18 cases in public assistance institutions. It is questionable how far these are suitably placed, whether from their own point of view or from that of other patients in the same wards. They would be more suitably distributed among mental hospitals, mental deficiency institutions and epileptic

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colonies. Two of the cases, indeed, are said to be insane, and 5 mentally defective. The considerable problem of epileptics in public assistance institutions cannot be dealt with, however, while we have no information as to the number and type of cases in these institutions up and down the country.

(*b*) Of 24 cases in mental hospitals, only 8 are said to be insane, while 7 are mentally defective, and 9 belong to the unstable and deteriorating group. It seems wrong that with inadequate accommodation in mental hospitals all over the country, mental defectives should not be put where they properly belong. Further, it should be made possible for many of the epileptics who, after the age of 19, deteriorate so far as to be socially inefficient, to be placed in institutions for mental defectives rather than mental hospitals.

Non-institution cases.—This group, numbering 162, calls for more detailed consideration. In Table III they are classified in age-groups and according to mental condition.

TABLE V.—*Ipswich—Non-Institution cases. Disposal and Age-groups.*

	50 and over.	17–50.	16 and under.	Total.
P.A.C. (Out-relief)	2	10	..	12
Voluntary Association for Mental Welfare	1	14	8	23
East Suffolk and Ipswich Hospital	5	16	22	43
Private cases	10	62	12	84
	18	102	42	162

Table V shows whence the cases were drawn and the age-groups of those derived from each source. Under the heading of public assistance the number on out-relief, 12 in all, is surprisingly small. The Voluntary Association for Mental Welfare has 23 epileptics on its books, only 14 of whom are classified as mentally defective. The care of the other 9 individuals by the Association shows how usefully an organization can sometimes stray outside its set boundaries, and may perhaps be suggestive of future development. We may assume that children of school age, as well as the public assistance and voluntary association cases are under some kind of supervision, but the remainder, namely all those of 16 and over, who were notified to us by the East Suffolk Hospital and by private doctors, probably receive no social supervision at all. The counterpart of these cases, numbering 93 in all, is not to be found in any previous English survey. They demonstrate beyond all question that there are very large numbers of epileptics who are quite unknown to local health, education or public assistance authorities. This is not to say that they are not in need of help; on the contrary, experience in the three surveys shows us

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that very many of them are badly in need of help and advice in one form or another. Of those classified, 80% are mentally normal, 18% are unstable or deteriorating, and 2% mentally defective.

In the questionnaire addressed to private doctors information was also asked for about employment. Of 69 cases over school age no less than 55% are in employment, and another 12% are married or working at home; 23% are said to be incapable of work, 4% are of independent means, and only 6% are capable of work, but cannot get it. But we must remember that Ipswich is a town in which unemployment is comparatively low and opportunities of work above the average, and that the reports were collected in a period of good trade. Moreover we have no evidence of the type of work done by these epileptics. Much of it may have been irregular or badly paid. In all probability, therefore, the picture suggested by the figures is brighter than the facts would justify.

It would be fallacious to apply figures obtained by local, and in many ways incomplete, inquiry to the whole country, but by doing so we are enabled to get a rough indication of the magnitude of the problem. Thus, according to the Surrey figures there are in England and Wales about 25,000 epileptics who, on account of their epilepsy, are chargeable to public authorities. Of these 5,500 are insane, 10,250 are mentally defective, while the remaining 9,250 are not certifiable under either the Lunacy or the Mental Deficiency Acts. According to the Ipswich figures there are, in round numbers, 4,000 insane epileptics in the country, 18,000 mental defectives, 23,000 who are unstable or deteriorating, and 46,000 who are mentally normal. These groups added to 6,000 unclassified would make a total epileptic population of 97,000. About half this number are epileptics over school age, who are living in the community.

It is difficult to find in the literature any satisfactory estimates of the incidence of epilepsy in the general population. Davenport, 1923 (3), collected a large number of statistics giving estimates of the incidence of epilepsy in various countries, and among different groups of people, but the figures are not very convincing. Pollock, 1931 (4), reports that epilepsy was found in, 5·15 per thousand of men drafted for the American army in the great war, but the percentage varied in different States from 1·2 to 12·7 per 1,000. In the discussion on Pollock's paper, Hodskin (4) referred to a survey in Hampden County, Massachusetts, based on inquiries addressed to every medical man in the county. The survey gave an incidence of 4 per 1,000. A more satisfying survey was made by Anderson, 1936 (5), in a nine-county area in the State of Michigan with a population of 73,000. Information was obtained from doctors, school-commissioners, health agencies, nurses, social workers, judges, teachers, clergymen, old residents and members of county child health committees. As a result an incidence of 2·10 per 1,000 was found, the number living in the community being about four times as large as the number in institutions.

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Social Care.

Fits are the cardinal feature of epilepsy, but in reality it is not the fits which cause so much suffering to epileptics as the social handicaps which the fits entail. There is a strong prima facie case for social care of epileptics in the community. For there exists no organization to advise or help them, no authority who has any duty or responsibility towards them. Only if they are children whose fits are so severe that they cannot attend an ordinary elementary school, or if they are certifiably insane or if, being mentally defective, they are brought to the notice of the appropriate local authority do epileptics come under the notice of any public authority. It is impressive to compare this almost total neglect of epileptics with the elaborate organization set up for the ascertainment and help of some other classes of handicapped citizens, e.g. the blind, the cripple and the mentally defective.

The need for social care impressed itself on the social workers who undertook the surveys I have reported above. The most cogent evidence for that need is the warmth of the welcome which they invariably received on their visits. The epileptic and his family were glad of the interest and sympathy which the visits betokened. Frequently they were in need of simple commonsense advice, advice as to the management of fits, and as to the right type of employment and the means of obtaining it. But more than commonsense advice is often needed, and to give it the social worker must be trained and experienced in mental health work. For the problem of the epileptic in the community may be stated as a problem of mental ill-health. And it may be divided into two parts, the ill-health of the patient and the ill-health of his family. The ill-health of the patient is a long story, which can only be briefly summarized here. Associated with or due to his epilepsy there may be mental defect of varying grade, a difficult temperament, uncertain memory, periods of irritability or confusion preceding or following fits, slow or sometimes rapid mental deterioration. These are innate, part and parcel of his complaint. But superimposed on them are all the mental strain and stresses resulting from our failure to provide the epileptic with a proper environment. First among them is want of occupation, and the enforced inaction it brings with it. The anxiety of relatives with regard to fits and the distress of relatives when fits occur are others. Greatest of all is the patient's realization that he is, and is always destined to be, in some way an abnormal member of his family circle and of society at large, if not a useless burden who would be better out of the way. These added mental stresses are always in action. It is a commonplace observation that want of occupation and unhappiness increase the incidence of fits. More fits leave their inevitable mark on the patient's mind, and so the vicious circle goes round and round, with destruction of personality as the end. Important, too, is the mental ill-health of the family. Fits by themselves involve no small strain. They are dramatic, unpredictable, and often very

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distressing to witness. But as will already have become evident, fits are only part of the story. Periods of irritability and depression in the patient, his anxiety about work and his resentment against society, must leave their inevitable mark on those who have to live with him. And above all these, there is often in the parents' mind the haunting fear as to what is going to happen to the patient when they are no longer there. The family with an epileptic in it has hard work to be a happy family. These fears, anxieties and mental stresses in the home are very real things. They impressed themselves forcibly upon the investigators who prepared these reports, and, although I have little experience of visiting epileptics in their homes, I can confirm the story a hundred times over from letters and talks with patients of my own who have gone out into the world.

The next step, undertaken by the Central Association for Mental Welfare, was to try out an experimental piece of social care, and endeavour to form some estimate of its usefulness. It would obviously be very difficult to do much for the old established epileptic with years of unemployment behind him, and we decided to make a start with more promising material, viz., children who have recently left residential special schools for epileptics. Of all classes of epileptics these stand, perhaps, more in need of supervision and help than any. At a difficult and impressionable period of life they have to leave a guarded institutional routine and face up to the stress and competition of the outside world.

About 70 children and young people were received who had left residential special schools within the last year or two, and who were living in London or the Home Counties. Mentally defective cases were excluded, as well as those resident in institutions. Their ages ranged from 14 to 18, with an average of just over 17. These children had all at one time been considered to suffer from epilepsy so severe as to prevent them attending ordinary elementary schools. They must not, however, be taken as typical of the special school group. Many children whose fits had persisted in large numbers will have been retained at the colonies or transferred to other institutions, and other children will have been notified to the Mental Deficiency Acts authorities. I have elsewhere (6) made a general survey of the fate of children leaving a large residential school.

This group of 71 comprises the more hopeful section of the special school leavers. The cases were all visited in their homes, some of them several times, and their parents or friends interviewed. The more important findings are set out in Table VI. It will be noted that while 30% are adjudged unfit for work, only 10% are fit for work and unemployed. The number said to be in satisfactory employment, 54%, is encouraging, but it must be remembered that in many cases the employment is only temporary. 31% of the total are free from fits. The classification under the heading " clinical picture " represents an attempt to answer the question how far, for this particular group of

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TABLE VI.—*Residential School Leavers.*

	71 cases. Average age, 17. %	26 "hopeful" cases. Average age, 20. %
Employment:		
In satisfactory employment	54	73
In unsuitable employment	6	—
Unemployed and fit for work	10	19
,, and unfit for work	30	8
	100	100
Medical:		
Free from fits	31	50
Receiving medical treatment	64	48
Home conditions:		
Unsatisfactory economically	24	17
,, socially	12	14
Clinical picture:		
Employed and reasonably well adjusted	33	54
Needing advice and help to be socially efficient	42	42
Probably never socially efficient	25	4
	100	100

epileptics, social care is required. In the construction of this picture the judgment of the social worker obviously counts for much. One-third of the whole number are in work and reasonably well adjusted to their surroundings; 42% need skilled help, advice and supervision if social efficiency is to be achieved or maintained; and 25% are considered to be permanently socially inefficient. Of the 18 cases assigned to the last group, the cause of the inefficiency is severe paralysis in 1, grave mental deterioration in 4, frequent or severe fits in 7, temperamental difficulties in 1, and a combination of the last two causes in 5 cases. I think it fair to deduce from these figures that while skilled social care would no doubt be useful for all epileptics, including, of course, those who can never be socially efficient, in over 40% of this particular group it is likely to make the difference between social efficiency and inefficiency. How far the figures would apply to epileptics in the community generally one cannot say, but the benefit is likely to be less.

As a matter of interest, a further inquiry was set on foot to find out the

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later history of the most hopeful group of residential school leavers. Accordingly, 26 cases were investigated who had left school four or five years earlier who, at the time of leaving, were clear or almost clear of fits, and who, at that time, were judged to be sufficiently intelligent and well adjusted to make their way in the world. These were, therefore, specially selected cases, and the table shows, as one would expect, a brighter picture. 73% of the cases are in work, and 50% free from attacks. In the clinical picture only 4% are socially inefficient, but the number needing supervision and help for the achievement or maintenance of social efficiency is the same, 42%, as in the other group.

It is considered that this inquiry has shown the need for skilled social care in a particular group of epileptics, and the supervision and assistance that they are now receiving is demonstrating the value of that care. Incidentally the inquiry also supplies evidence of the value of residential schools. Without such schools these children would have been deprived of education and of medical treatment under supervision, and the outlook for them, whether medical or social, would have been far less hopeful.

Suggested Lines of Treatment.

The first step in the medical care of every case of epilepsy should be a short period of residence in a well-equipped neurological centre. Clinical examination of the central nervous system and observation of the march of events in the attacks must be supplemented by investigation of the blood and cerebrospinal fluid, by X-rays of the skull, by encephalography, and ventriculography in many cases, and by electro-encephalographic records taken during and between fits. Endocrine anomalies must be sought for, and a survey of the patient's general physical health undertaken. The findings, checked up and correlated with the patients' personal and family history, would show certain cases where focal cerebral lesions, syphilitic infection, endocrine imbalance or metabolic disorders indicated special lines of treatment. The field for cerebral surgery is small, but, with intensive investigation of every case, is likely to increase. Fits of hysterical origin would be eliminated.

While the general physical and neurological examination in hospital is proceeding the patient's mental condition should be observed. His intelligence should be assessed by standard tests, and observation and note made of his behaviour and response to various situations. The relation of temperamental difficulties to the occurrence of fits is often important. Conversation with the patient will lead to provisional judgment of his relation to others in his home or at his work or school. Before the end of his stay a fairly comprehensive picture of his mental outlook should thus be obtained.

Meanwhile the case should be placed in the hands of a trained psychiatric social worker who would call at the patient's home, find out about the social and economic conditions prevailing there, and, by talking to the parents and

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others, construct a picture of the reactions of the patient in home life, noting the difficulties that arise, and endeavouring to assess the part played in their origin by the patient or by others in the immediate environment. Where the patient goes to school, a talk with his class teacher may be of great importance.

At the conclusion, therefore, of his stay in hospital the physician will have a considerable body of information on which to base his diagnosis and to lay down lines for further care and treatment. The neurological and general physical examination will be supplemented by an assessment of the patient's mental capabilities and abnormalities, and by some knowledge of his environment and social reactions, and of difficulties that may have arisen in his home and school. It is suggested that the patients may now be sorted out into the following five groups:

(1) Those requiring further specialized physical treatment, neurological or otherwise. These cases should continue to attend the neurological centre either as in-patients or out-patients.

(2) Cases without neurological or other findings that call for special treatment, who are of reasonable intelligence and normal temperament, and whose homes are free from gross emotional stress. These are patients whose only difficulty is their fits, and they form, perhaps, a major part of the whole group of epileptics. From the medical point of view they require general advice as to diet, sleep and mode of life, and a regulated course of treatment by anticonvulsant drugs. This could be furnished by the patient's ordinary medical adviser, whether under the Insurance Act or otherwise, or by the out-patient department of the nearest hospital, but in every case the patient should report at stated intervals at the neurological centre where his case was originally investigated. Three-monthly visits would be required at first, but the intervals might be extended later on. Increase of fits or the appearance of new signs or symptoms would, of course, call for immediate report.

(3) Cases where maladjustment is a prominent feature. These include patients who are sensitive, egocentric and find it difficult to get on well with those around them, and those who have periods of mental abnormality serious enough to constitute a social handicap. Also those whose maladjustment arises, as it so often does, from difficulties engendered by unwise or ignorant parents or by grave emotional stresses within the homes. These patients need psycho-therapeutic treatment and might well attend an out-patient mental clinic or other psycho-therapeutic centre.

The services of the psychiatric social worker form an integral and a most important part of the scheme of treatment of the three classes just enumerated. Whether the patient is attending the neurological centre, is under the care of a local practitioner or of a psychotherapeutic clinic, the social worker should keep constantly in touch with him to see that the general rules laid down by his doctor are carried out, to help him to obtain suitable work and to give him the assurance that there is always someone, sympathetic and skilled, to whom

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he can turn in difficulty. More than all, the psychiatric social worker must, by regular reports, provide a most important link between the patient and the medical man who has charge of him. By this means, effective treatment would extend far beyond the confines of a bottle of bromide or luminal.

(4) Cases who are mentally defective or so deteriorated mentally that, on that account, they need care, supervision and control. There already exist arrangements for the social supervision of mental defectives. Cases within this group who are fit to remain in the community should, therefore, be placed under statutory or voluntary supervision. Deterioration coming on after the age of 19 cannot, in law, be called mental defect, but patients who exhibit this deterioration are better classed with the mentally defective, and would be suitable subjects for voluntary supervision.

(5) Cases for institutional treatment. These will include those who are certifiably insane and a good many who are mentally defective, including those of low grade, those who have many fits and those who present conduct difficulties.

Educable children of school age, who have been excluded from day schools on account of their fits, should be sent to residential special schools. The lower limit of educability in these schools is now roughly indicated by an intelligence quotient of 60. Many older patients will also obviously require institutional treatment. These are patients who have fits so often that they have no chance of obtaining work, whose homes are bad, who are difficult to get on with or definitely anti-social. A complete change of environment often has the happiest effect on patients whose presence at home gives rise to serious problems, and sometimes there is a dramatic diminution of fits as well; but it is not fair to expect the voluntary epileptic colonies to receive those who are markedly or chronically delinquent.

There is a good deal to be said for a much wider use of institutions. Many young epileptics, after the period of investigation at a neurological centre, would do well with, say, a year or two at a colony. They would there have the best chance of getting rid of their fits, but, short of such a happy event, they would receive training in a suitable occupation, they would learn a good routine of life and accurate fit recording would help to determine the optimum dosage and timing of drugs.

Summary.

Evidence has been brought forward to show that the usual estimate of two epileptics per thousand of population is certainly too low and that, in fact, there are probably at least fifty thousand epileptics over school age living in the community. A considerable proportion of these suffer social handicaps arising out of their fits, or of some form of mental abnormality. Supervision by properly trained social workers would probably do much to ameliorate or remove these social handicaps. In other words, the disease is one that needs

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and deserves social as well as medical treatment. Neither form of treatment can be effective alone; the two must be linked up. This is, I believe, the cardinal point in the treatment of epilepsy.

With this as a basis I have sketched out the general lines of a scheme of treatment. Such a scheme provides no simple answer to the question whether epilepsy belongs to the neurologist or the psychiatrist; it obviously encroaches on the provinces of both.

It calls for no increase of institutions except in so far as more beds in neurological centres may be required. And it does not ask for legislation. The care which it envisages must be provided first by voluntary agencies, but ultimately should be a charge on public funds.

I wish to thank the Central Association for Mental Welfare for permission to make use of the reports of their investigations. I am particularly grateful to Miss Margaret Cullen who has been personally responsible for almost the whole of the Association's work among epileptics, and who has given valuable assistance in classifying the results.

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