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EPILEPSY, SELF AND SOCIETY:
A STUDY OF THREE GROUPS OF ADOLESCENT EPILEPTICS

<u>MICHAEL JAMES OLIVER</u>

SUBMITTED FOR EXAMINATION FOR THE
DEGREE OF DOCTOR OF PHILOSOPHY
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ABSTRACT

The major aim of this substantive study in sociology is to examine some of the societal, social and individual meanings associated with epilepsy and to look at some of the implications of these meanings both for society and for individuals. Like all other disciplines sociology has its own way of dividing up the world and this study draws upon three areas of this division, the sociologies of deviance, medicine and knowledge. The experiences of three groups of adolescents with epilepsy are studied in depth; one group living in the community, one group serving sentences of borstal training and a third group who are associated with a hospital specializing in treating those with psychiatric problems.

Chapter One raises the fundamental question posed in this study, which is 'why do epileptics have trouble?' and suggests that the basis of such trouble is the way society treats the individual epileptic rather than any difficulties inherent in the illness itself. Chapter Two then examines some of the methodological issues relevant to doing interpretive sociology and describes the techniques used and developed during the research. Chapter Three studies some of the social meanings associated with epilepsy from a historical perspective and discusses how these meanings change over time. Chapter Four looks at some of the special (professional) views about epilepsy and attempts to relate these views to historical and personal experiences of the professionals concerned. Chapters Five and Six are squarely within the interactionist tradition and discuss the experiences of the three groups of adolescent epileptics utilizing the concepts of role and self. The final Chapter develops the concept of non-visible social deviance in relationship to social control in past and present society and suggests a number of reasons why epileptics do indeed have trouble.

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EPILEPSY, SELF AND SOCIETY:
A STUDY OF THREE GROUPS OF ADOLESCENT EPILEPTICS

Page

CHAPTER ONE

CHAPTER TWO

CHAPTER THREE

CHAPTER FOUR

Page

CHAPTER FIVE

CHAPTER SIX

CHAPTER SEVEN

CHAPTER ONE

EPILEPSY: A SOCIOLOGICAL ACCOUNT

INTRODUCTION

This is a study of three groups of young male adolescents who have one thing in common - they are, or have been labelled as, epileptic. However the members of each group have arrived at different points in their lives or 'careers'; at the time of the study one group were living in the community with their families, a second group were in a borstal institution and the third group were attending a London hospital because they were diagnosed as having psychiatric problems associated with their epilepsy. The study will examine the responses of these individuals to the particular circumstances in which they find themselves and will compare and contrast both the different experiences that individuals have and their differing abilities to negotiate outcomes stemming from the application of the label epileptic. Some attempt will be made to locate these 'private troubles' in wider context by considering a variety of social meanings associated with epilepsy and by discussing the general topic of 'deviance' in relation to specific forms of social control.

From the terminology used in the opening paragraph it will be obvious that the general approach adopted in this study is a sociological one utilising concepts derived largely from symbolic interactionism and its offshoot, labelling theory. The concepts employed are only intended to be sensitizing rather than definitive following Blumer's (1954.147-8) distinction between the two:

> "A definitive concept refers precisely to what is common to a class of objects, by the aid of a clear

> definition in terms of attributes or fixed bench marks ..... A sensitising concept lacks such specification of attributes or bench marks and consequently it does not enable the user to move directly to the instant and its relevant content. Instead, it gives the user a general sense of reference and guidance in approaching empirical instances,"

These concepts will thus be used to clarify some of the empirical material obtained in the study and will not be scrutinized systematically themselves for what follows is a substantive study of epilepsy and not a critical examination of a particular sociological theory nor an exercise in methodology.

The general question which this study sets out to explain is, why do epileptics have trouble? for it is generally agreed that they do. As has recently been commented (Harrison and West 1976.1)

> "Whatever else epileptologists may disagree about, there seems to be universal accord that people with epilepsy have 'trouble'."

Throughout this monograph the medical and the sociological explanations for this trouble will be discussed, the former stressing the importance of the clinical condition from which the individual is suffering and the latter emphasizing the social reaction that is applied to the individual or group. Before proceeding to discuss these explanations in more detail it may prove useful to consider a number of other explanations that have been put forward in the considerable amount of literature that has accumulated on epilepsy over many years. These other explanations do not necessarily appear in the literature in the guise presented here, rather they represent themes which occur consistently in much of the work already done.

OTHER THEORIES AND EXPLANATIONS

a) The Historical/Cultural Explanation. This argues that historically and culturally epilepsy has been regarded as evidence of possession, sometimes by good or evil spirits, sometimes by God or the Devil. Despite recent advances in medical science purporting to show quite clearly that an epileptic fit is simply the symptom of an underlying physical illness, and while most people now accept this medical explanation, there exists nonetheless a historical or cultural 'lag' in which these earlier explanations are still given credence, either consciously or subconsciously, among society at large. Consequently epilepsy remains feared by both those who are afflicted with it and by the rest of society. (1)

b) The Social-Psychological Approach. This argues that because the epileptic may unpredictably lose control of his movements, it is feared that 'instinctive brutality may at any moment cause him to go berserk and act with irrational savage strength'. This loss of control signifies a reversion to a more primitive stage of human development where the 'will' was unable to exert adequate control over the body. Similar arguments have been put forward to explain many of the irrational fears associated with racial prejudice against blacks. (2)

c) The Psycho-Analytic Explanation. This argues that the epileptic is feared because he looks normal and there are no visible signs to set him apart from the rest of the population. Thus, if the epileptic looks like the normal person and the normal person looks like the epileptic, then epileptic seizures can afflict the normal as well as the epileptic who, after all, is normal in all other respects. Similar arguments have been advanced in the past with regard to prejudice against homosexuals; because the homosexual looks like the heterosexual, homosexual behaviour can be indulged in by the heterosexual too. This indistinguishability of the two groups - normal/epileptic or homosexual/heterosexual - gives rise to a deep-rooted and unconscious fear resulting in the stigmatization and ostracism of the deviant concerned. (3) Bagley (1971) suggests that there is a similarity in prejudice arising against both of these groups.

d) <u>The 'Epilepsy as Death' Explanation</u>. The connection between epilepsy and death is noted by a number of writers in a variety of different spheres. The most sophisticated discussion of this is provided by Watson (1974.83) who argues:

> "Both sleep and epilepsy are related to dying in the sense that they are seen to be symbolic deaths".

A consultant psychiatrist (Taylor in Herrington Ed 1969.107) who has worked extensively with epileptics, notes:

> "If we were without any medical knowledge and observed the phenomenon of epilepsy, we would observe in an epileptic fit a brief excursion through madness into death."

Additionally, Harrison and West (1976) in their survey of public images of epilepsy found that the public sometimes equated fits with violence and death. Many mothers, for example, on seeing their child have a fit, stated that "I thought he was dying". (4)

In putting forward an alternative sociological explanation it is not intended to deny the validity of any of these explanations nor to replace them completely, but to show that they are inadequate in themselves. The problem as Runciman (1969.20) has pointed out, is that:

> "When our subject matter is people, their collective behaviour has to be explained by reference to factors both inside and outside of them .... we need not only to understand the forces acting on them (institutions, parties, economic conditions and so on) but also the psychological predispositions operating more, as it were, from within (oedipal, jealousy, sibling rivalry, or even genetic predisposition)."

Thus the theories discussed above tend to be a single factor or monocausal explanations whereas hopefully a truly sociological explanation will be able to take in a wide variety of factors.

THE MEDICAL AND SOCIOLOGICAL APPROACHES TO EPILEPSY

While there may be a number of competing or complementary theories purporting to explain the reasons why epileptics have trouble, it is undoubtedly true that medicine and the medical profession have achieved predominant rights to pronounce on the exact nature of this trouble. Hence it is hardly surprising that these pronouncements are based on their understanding of the world in terms of what is sometimes called 'the medical model' or 'the clinical perspective'. This model or perspective sees illness, disability and even deviance largely in terms of individual pathology. It is based upon a scientific conception of abnormal or deviant behaviour as symptomatic of an underlying pathology. Therefore once the cause can be identified the underlying pathology can be treated and cured, resulting in the disappearance of the symptoms or behaviour. Thus the model identifies four distinct aspects; cause, symptom, treatment and cure.

However, the model, like all models, is an abstraction from the real world, and an idealized one at that. Therefore while epilepsy is regarded as an individual pathology it is rarely possible to identify the underlying cause through the manifestation of symptoms, treat this cause and thereby provide a cure. At best the symptoms can be held in check through treatment, or the underlying cause can be identified but not cured; failing that the person suffering from epilepsy can be placed in an institution or left to his own devices, though offered repeat prescriptions for anti-convulsant medication as the sole means of treatment. He may, if he is lucky, grow out of his epilepsy but only in rare cases can he be cured completely by the application of pharmacological preparations and the clinical approach.

This of course raises the very important question of whether medicine and the medical profession are appropriate in defining what is (and is not) epilepsy and treating its consequences. In short, while the medical profession is unable to cure the vast majority of epileptics, it is able nonetheless to control to a greater or lesser extent the fits of a substantial number of those suffering from epilepsy and this of course has substantial benefits for the individuals concerned and for society as a whole. However it remains true that for some epileptics, the treatment is worse than the illness; anti-convulsant medication may leave the sufferer worse off than before because of the possible short and long-term side effects that it may produce, operations are a hit and miss affair and may change the condition for better or worse or leave it unaltered, and confinement may produce institutionalized people unable to make their way in the outside world. The consequences of this medical approach to epilepsy have been summarized as follows (Szasz 1966.3):

> "In the initial decades of this century much was learned about epilepsy. As a result physicians gained better control of the epileptic process (which sometimes results in seizures). The desire to control the disease however, seems to go hand in hand with the desire to control the diseased person. Thus, epileptics were both helped and harmed; they were benefitted insofar as their illness was more accurately diagnosed and better treated; they were injured insofar as they, as persons, were stigmatised and socially segregated ..... It has taken decades of work, much of it still unfinished, to undo some of the oppressive social effects of 'medical progress' in epilepsy, and to restore the epileptic to the social status he enjoyed before his disease became so well understood. Paradoxically then, what is good for epilepsy may not be good for the epileptic."

The effectiveness of this approach based on the medical model will be discussed in more depth later in the thesis but one of the major problems associated with it can be usefully discussed here; namely its tendency to see the trouble experienced by epileptics as stemming from individual pathology, that is, as a consequence of the illness itself or the inability of those afflicted individuals to make their way in the world. This is not to say that epileptologists have not recognized that there is a social dimension to epilepsy (Laidlaw and Richens 1976.15):

> "But epilepsy is also a social distinction; those diagnosed as having epilepsy are to a greater or lesser extent penalised both

> economically and socially. For this reason alone, epilepsy remains a medical diagnosis with social consequences....."

However while recognizing that the trouble associated with epilepsy may be socially based, the medical profession have continued to operate within the parameters of their own restricted conceptions of the world, i.e. the medical model or clinical perspective.

The sociological approach adopted here is not completely antithetical to the medical one, but rather is complementary to it and seeks to draw out some of the social dimensions associated with the trouble epileptics experience. In the context of mental handicap Booth (1978.206) points to two aspects which characterize the sociological as opposed to the medical approach:

> "First, that the salience with which the handicap features as an aspect of a person's identity and the degree to which it pervades their performance of social roles does not hinge merely on the gravity of impairment but on the signficance that is attached to it by the handicapped person and those with whom he associates. Second that the way in which the handicap is revealed, its conspicuousness and the appearance it assumes may change on different occasions in different places at different times."

In effect what is being said is that there is no simple causal connection between the extent of the illness or underlying pathology and any adverse social consequences; for example, it is not always or even usually those with the severest physical handicaps who end up in residential care, but rather those who experience a variety of social problems like family break-up or death of caring parents. Rather consequences and outcomes may vary according to the meaning

BOOTH, T.A. "From Normal Baby to Handicapped Child". Sociology. 12.2.78.

attached to individual illnesses by the sufferer and his associates, and also that such consequences may change dependent upon time and place. This theme on the selective and situational nature of much deviance will be amplified further later in the work.

Most of the social aspects of the trouble associated with epilepsy are well known and have been well summarized (Betts et al. 1976.147):

> "To be epileptic means being exposed to the fear of having attacks, being at a disadvantage in terms of work and personal relationships, being open to prejudice which exists in both the lay public and in the medical and nursing professions and sometimes to suffer disturbing symptoms not directly connected with the epilepsy."

It would perhaps be useful to summarize some of these social aspects of trouble before proceeding further.

In interpersonal relationships, the person with epilepsy does not appear to be ill or handicapped for most of the time, and he has to live with the psychic tension of deciding whether or when to reveal the facts of his epilepsy as well as with the fact that he may impose this upon others involuntarily at any given moment. As one sufferer has eloquently put it (Betts et al. 1976.147):

> "To awake in a street, which for the moment I cannot recognise, lying in a filthy gutter, wet and messy because I have soiled myself, my thoughts confused, surrounded by strangers, half-curious, half-disgusted: this is the nightmare with which I have to live."

Not all epileptics suffer such extremes of course but it remains true that epilepsy can and frequently does disrupt many interpersonal relationships. These disruptions may vary from over-protectiveness of parents, ridicule from peers, rejection by sexual partners to awe or disgust from strangers, and may sometimes lead to suicide or suicide attempts.

Those suffering from epilepsy may find that their school careers are interrupted either as a result of medical treatment that they are required to undergo or they may be provided with some form of special education either at home, in a hospital school or most likely in a special school for the physically handicapped or educationally sub-normal. This recourse to segregated education on behalf of the education authorities may occur for a number of reasons; the epileptic may have fits which disrupt the school and affect the abilities of classmates to concentrate, he may have petit mal absences which can mean that he misses certain vital parts of lessons and consequently he may be regarded as retarded, or he may be taking such a heavy dosage of anti-convulsant medication that this affects his mental abilities and leads to him being labelled a slow learner. It is generally agreed, particularly by those who have experienced it and also by the parents of handicapped children, that special, segregated education is inferior to education in an ordinary school. Consequently many epileptics receive inferior formal and informal education and this makes the problem of coping with the stigma of their epilepsy even harder to resolve or negotiate in a potentially hostile social world.

In employment the epileptic is likely to suffer little better fate for many jobs are regarded as being beyond his capabilities. It is commonly assumed that epileptics should not be allowed to work with machinery, high buildings or other possibly hazardous situations, but this is often not the case and many epileptics are able to work perfectly safely in such conditions. However it is not just in manual occupations that the person with epilepsy may experience discrimination but in the professions also; epileptics cannot train to be doctors or nurses and the Department of Education and Science is extremely reluctant to admit those so afflicted to teacher training courses. Other professions may have no formal regulations which specifically exclude epileptics, but in practice many may be weeded out at the interview stage or fail any medical examination that may be required. In its unemployment statistics the Department of Employment does not distinguish between various disability groups but a recent study (Campling 1976) of unemployment amongst those discharged from rehabilitation centres showed that 44% of epileptics were unemployed and that as a group, they did worse than most of the other disability groups in the survey.

However it is not just a matter of discrimination but of the general attitudes of society towards people with epilepsy. There have been a number of studies which show that attitudes towards epilepsy are more prejudicial than those towards other illness, as the following table shows:

<u>Attitudes of Employers towards Potential Applicants</u>

	Personnel Directors (as accountant)	School (as accountant)	Administrators (as teacher)
MOST ACCEPTABLE	Non-disabled	Non-disabled	Non-disabled
	Tuberculosis	Tuberculosis	Tuberculosis
	Wheelchair	Wheelchair	Wheelchair
	Deaf	Deaf	Deaf
	Psychiatric	Psychiatric	Ex-prisoner
LEAST	Ex-prisoner	Epileptic	Psychiatric
ACCEPTABLE	Epileptic	Ex-prisoner	Epileptic

(Rickard, T., Triandis, H. and Patterson, C. "Indices of Employer Prejudice Towards Disabled Applicants". <u>J. of App. Psychol</u>. 47.1963.52-5)

CAMPLING, 1976, "Getting Back to Work". <u>New Society</u>. 1.4.76.

While the methodology associated with such studies as this raises some questions about the findings, it nonetheless supports the general contention that epileptics do indeed experience trouble. Other studies, notably in the United States (Caveness et al. 1949.74), have attempted to chart the course of prejudice towards epilepsy and have found that while there has been a marginal improvement in public attitudes there still exists considerable prejudice. More recently some studies in this country have attempted to illuminate some of the dimensions of this prejudice (Scambler 1976, Harrison and West 1976). These have found three common factors associated with prejudice towards epileptics:

(1) fits, accompanied by frothing and foaming at the mouth

(2) images of violence, particularly among the young

(3) associations with mental illness - diminished responsibility - funny in the head.

It is commonly assumed that this prejudice stems from false or insufficient knowledge on the part of the general public and that it falls to the medical profession to provide the correct facts. However, this study will argue that the medical profession is in part responsible for this knowledge, for as has been suggested (Harrison and West 1976.9):

> "Some responsibility for the construction of prejudiced ideas about the epileptic lies with the medical profession, who, under the guise of science, have generated erroneous concepts like 'the epileptic personality' or more recently 'epileptic equivalents'. It is certainly the case that many negative traits have been attributed to the epileptic on grounds which are, or were at one time, claimed to be 'objective'."

However the relationship between medical knowledge and the attitudes of the general public will be considered in more detail later in the thesis. At present it might be appropriate to say something about the ideas and concepts which inform this study and the sociological theories from which they have been drawn.

SOME SENSITIZING SOCIOLOGICAL CONCEPTS

The most important concept informing this work is that of deviance, which is defined as follows (Becker 1963.9):

> "Social groups create deviance by making the rules whose infraction constitutes deviance, and by applying those rules to particular people and labelling them as outsiders. From this point of view, deviance is not a quality of the act the persons commits, but rather a consequence of the application by others of rules and sanctions to an 'offender'. The deviant is one to whom that label has been successfully applied; deviant behaviour is behaviour that people so label."

This definition emphasizes two things: namely that deviance is not the individual consequence of some underlying physiological, psychological or social pathology but is created by people or groups making rules about it, and secondly, that a deviant is only a deviant when he has been labelled as such.

While most sociologists would agree with the points made in this definition, there have been many criticisms of what it has left out or does not say. Thus labelling theory, as it has come to be called, has attracted many critical reactions; it has been 'labelled' itself as nothing less than a new paradigm in sociology, it has been ignored, largely by traditional criminology, and it has been misrepresented and ridiculed - "Wham - bad society comes along and slaps them with a stigmatized label" (Akers 1967). Most of its damning criticisms however focus on aspects that it neglects and Gouldner (1975.38) for example, criticizes labelling theory for not going far enough in considering aspects of social structure and power:

> "While it sees deviance as generated by a process of social interaction, as emerging out of a matrix of an unanalysed society, it does not see deviance as deriving from specified master institutions of this larger society, or as expressing an active opposition to them."

Thus it is argued that labelling theory does not consider the wider social structure within which the social reaction to deviance takes place. More specifically Taylor, Walton and Young (1973.169) see power as the missing element in the theory:

> "it is unfortunate that ..... the social reaction theorists choose to ignore the way in which deviancy and criminality are shaped by society's larger structure of power and institutions."

In a rejoinder to his critics, Becker (1973.181) has reminded them:

> "Labelling theory then, is neither a theory, with all the achievements and obligations that go with that title, nor focused so exclusively on the act of labelling as some have thought. It is, rather, a way of looking at a general area of human activity: a perspective whose value will appear, if at all, in an increased understanding of things formerly obscure."

However the point of this discussion is not to provide a critical evaluation of labelling theory but to discuss the usefulness of deviance as a sensitizing concept to the presentation of material collected in an empirical study of epilepsy. Hence the crucial question at this point is whether epilepsy can be appropriately considered as deviance.

Before considering that, the more general question of whether an illness or physical disabillty can be considered as deviance is worth discussing. The traditional sociological answer to this general question would be that illness and disability are not deviance for while they may be divergences from the norm of health or physical capability, there is no devaluation associated with these divergences. The ill or handicapped person occupies a legitimate social status, what Parsons (1951) has called the 'sick role'. This view of both illness and handicap is currently being challenged, notably by Freidson (1970.207):

> "A great deal has been written on the problem of defining what illness 'is'. But whatever else it may be, illness is a type of deviation, or deviance, from a set of norms representing health and normality."

and

> "..... by definition a person said to be handicapped is so defined because he deviates from what he himself or others believed to be normal and appropriate."

While there are a number of issues still unresolved in this debate, there is ample evidence that in the specific case of epilepsy it does fall within the rubric of deviance as defined by Becker. Firstly society has rules about health and what (or who) is healthy even though in one sense everyone is epileptic in that epilepsy is merely electrical activity in the brain. However society creates rules about the physical activities of the body which this electrical activity stimulates and those who go beyond these rules are labelled epileptic. Secondly the deviant label is applied both in a formal way by the doctor who supplied the label epileptic or one of its more sophisticated counterparts, or informally in social interaction through terms like 'fitter', 'wobbler' or 'nutter'. Thus for the purposes of this study, epilepsy will be regarded as deviance and this concept will be used to further explicate some of the trouble encountered by epileptics generally and those of this study more particularly.

A number of other sensitizing concepts drawn from a number of areas of sociology will be discussed elsewhere in the text but the question as to why epileptics have trouble cannot be resolved just by discussing labels and their application but the knowledge upon which labelling processes are based also needs to be considered. According to Berger and Luckman (1971.15):

> "In so far as all human knowledge is developed, transmitted and maintained in social situations, the sociology of knowledge must seek to understand the processes by which this is done in such a way that a taken-for-granted 'reality' congeals for the man in the street."

The crucial question for the sociology of knowledge then becomes: on what basis does the man in the street come to fear epilepsy and exhibit prejudice against epileptics? The explanations alluded to earlier posit either cultural or instinctual factors identified by social scientists, but which can be referred to as 'second order constructs' (Schutz 1967) and which are abstractions from the reality of everyday life as it is lived in real world situations. Recently some sociologists (see Douglas 1971) have argued that for any explanation to be truly sociological, it must be based on events occurring in everyday life as it is actually lived. Thus an explanation of why epileptics have trouble should take account of those who interact with, as well as those who suffer from epilepsy.

To the sociologically informed reader it will be obvious that much of what is being said is based on the work of Alfred Schutz and his analysis of what he calls 'the lifeworld'. For him (Schutz 1962.7):

> "All interpretation of this world is based on a stock of previous experience to it, our own or those handed down to us."

Thus the way we experience the world is mediated by the knowledge we have of it, whether this knowledge be acquired directly in social interaction with others or by drawing on the social stock of knowledge that has been handed down to us. Indeed, Schutz recognises that not all knowledge of this world is directly acquired (1964.131):

> "It seems a mere truism to state that only an exceedingly small part of our actual and potential knowledge originates in our experience. The bulk of our knowledge consists in experiences which not we but our fellow men, contemporaries or predecessors, have had, and which they have communicated or handed down to us."

Thereby Schutz distinguishes between knowledge acquired through direct experience and what he calls 'socially derived knowledge'. However, despite an extremely detailed later analysis of knowledge in the lifeworld (Schutz and Luckman 1974), the relationship between direct experience and socially acquired knowledge remains as yet somewhat neglected; and it is this neglected relationship which will be a main focus of attention in considering why epileptics have trouble.

Berger and Luckman (1971) have suggested that social life becomes an ordered and orderly process constructed in the face of havoc and chaos by the everyday activities of individuals occupying the particular social worlds concerned. In this study it will be suggested that in constructing order from chaos, in mediating the 'kaleidoscopic flow of everyday events', individuals make use of the social stock of knowledge which has been acquired in three different and distinct ways:

(i) by direct experience of events in the everyday world,

(ii) by rumour, hearsay, story-telling, and media reporting, and

(iii) by advice and pronouncements from the professional expert.

These three ways of acquiring or drawing upon the stock of knowledge give rise to three kinds of knowledge; the typification which is knowledge derived from direct experience, the stereotype which is knowledge based on hearsay, reports, etc., and the ideal type which is knowledge based on the experience and expertise of particular groups of professionals. *

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* In choosing this particular terminology I recognize that I am treading a path that other, more eminent writers have trodden before, viz. Schutz - typification, Weber - ideal type, and Lippman - stereotype; but I do not propose to enter into a lengthy discourse concerning differences or similarities of usage. It is sufficient to say that my usage will follow that outlined in the text above. However I should point out that I am aware of the difficulties over the use of ideal type and its clumsy derivative ideal-typical knowledge but I choose such terminology in preference to professional knowledge because it is intended to be more generic - I refer to lots of different kinds of professional knowledge, i.e. medical knowledge, psychiatry, criminology and sociology.

In relating these three kinds of knowledge to the trouble that epileptics encounter it will be argued that it is the kind of knowledge derived directly from experiencing epilepsy in everyday life which is most likely to be accurate and hence enable social interaction to proceed without concommitant fear and prejudice. However by considering epilepsy as non-visible social deviance, it will be shown that relatively few typifications get added to the social stock of knowledge for the great majority of epileptics are able to conceal their epilepsy from a potentially hostile social world. Consequently typifications about epilepsy are swamped in the social stock of knowledge by stereotypes and ideal types, which it will be argued later produce a distorted or biased picture of what epilepsy really is. The bases of these different kinds of knowledge will be considered in later chapters as will the exact relationship between them. For the present it is necessary to discuss the conceptualization of epilepsy as deviance in more detail.

EPILEPSY AS NON-VISIBLE SOCIAL DEVIATION

Non-visible deviation may be just as common as visible deviation and social interaction with what Becker (1963) has called secret deviants, may be just as frequent or even more frequent than interaction with the visibly deviant, but the occasions when the deviation becomes apparent are much less frequent.

Hence typifications do not get added to the stock of knowledge. What Goffman (1968) calls the 'evidentness' of the deviation is severely reduced. As a result, established typifications grounded in experience are often not available in the stock of knowledge, either public or personal, and so when a non-visible deviation becomes a public issue interaction takes place, reality is constructed by reference to ideal type and stereotype, rather than typification. As a result, social interaction and reality construction is more unpredictable, uncertain and ambiguous. Sociologists working in the field of crime have clearly shown that invisible crimes such as fraud and illegal profit-making have far greater consequences for the economic and social structure of society than do crimes of a more visible nature. David Gordon (1973.166) has recently calculated:

> "The economic loss attributable to Index Crimes against property - robbery, burglary and so on - are one fifth of the losses attributable to embezzlement, fraud and unreported commercial theft."

By analogy, it is part of my contention that non-visible social deviance poses a correspondingly greater threat than does visible social deviance, to the painstakingly constructed micro-social world of everyday interactions and relationships. Obviously, by their very nature, the extent of non-visible crime and social deviance is difficult to quantify and this will have consequences for the methods used in attempting to substantiate my contention, but that discussion will be reserved for the following chapter.

The first question concerning the social visibility of epilepsy obviously centres on the number of epileptics that there are in the general population and there have been attempts to estimate this. (5) Probably the most important survey was the one undertaken by the College of General Practitioners (1960) which estimated that the prevalence of chronic epileptics in the general population was 4.19 per thousand. This would mean that there are around 300,000 people in this country suffering from epilepsy as compared to 53,000 suffering from Parkinson's disease and 37,000 who have disseminated sclerosis. However, these figures may be a considerable underestimate of the prevalence of epilepsy for there is a number of reasons why cases may go unrecorded:

(i) parents and relatives are only too willing to forget such happenings;

(ii) accurate epidemiological data may be difficult to obtain, for epileptics are dealt with by a variety of medical practitioners - paediatricians, geriatric specialists, neurologists, psychiatrists and general practitioners;

(iii) concealment may be deliberate for a variety of reasons, to be explored later.

But visibility is not just a question of prevalence for epileptic fits may not themselves be visible; they may be controlled by anti-convulsant medication or they may only occur when the epileptic is alone or at night. Grand mal is the most visible form of fit and probably accounts for over half the fits that occur, but grand mal epilepsy can be relatively well controlled. Petit mal fits may occur as momentary lapses in consciousness and observers may not even know that a fit has occurred. The symptoms associated with psychomotor or Jacksonian attacks can be so varied that they may not be recognised as epilepsy by the layman. Some attempts have been made (College of General Practitioners 1960) to estimate how well fits are controlled, as the following table indicates. The two categories used, major and minor, refer to grand mal and all other kinds respectively.

Control of Fits by Type of Fit in Chronic Epilepsy

	Major Epileptics		Other		Total	
	No.	%	No.	%	No.	%
Completely controlled	424	44.2	81	32.4	505	41.7
One fit in the year	123	12.8	23	9.2	146	12.1
More than one fit	353	36.8	134	53.6	487	40.3
Not known	59	6.2	12	4.8	71	5.9

Similar data was found by Pond et al (1960a) in their survey of 14 general practices, and they found little differences between male and female epileptics.

Therefore, while there may well be high prevalence of epileptics in the general population when compared to certain other illnesses, the nature of its social visibility through the fit means that epilepsy becomes a public issue less often than less common but more visible illnesses or social deviations. Apart from seizures there are few, if any, visible signs which distinguish the epileptic from the non-epileptic, though those who Goffman (1968) calls the 'own' or the 'wise' may be able to recognise fellow sufferers through tell-tale scars on the head through falling, or other non-apparent attributes.

Not only are many forms of epilepsy invisible but many individual epileptics make deliberate and determined efforts to keep concealed their particular deviation. The fact that epilepsy does indeed create 'trouble' for its possessor coupled with the control of fits through medication has given many epileptics the motivation and the opportunity to 'pass' as normal. Kleck (1968a.1247), using a series of interviews and questionnaires, found:

> "As expected, all respondents chose not to reveal their stigmatized condition to at least some persons significant to their life space, although as a group they varied in their openness to others.... The interviewees tended to be less secretive regarding their illness than the parents but all persons in the sample chose to hide their disability from some of their interactants. If voluntary disclosure took place it was directed toward persons with intimate relationships (close friends) rather than casual relationships (acquaintances) with the discloser."

Obviously, phenomena as complicated as social relationships are difficult to quantify but Graham Jones (1965.487) conducted a study of the disclosure patterns of epileptics employed in a large steel works with a labour force conprising 10,000 men and 400 women. He found 39 cases of epilepsy of which:

> "Only a third were disclosed voluntarily; and of the 26 cases noticed because of a fit at work, some had lied about their previous history. This was not unexpected, since it was well known locally that many organizations would not employ anyone admitting to a history of epilepsy and would dismiss any employee unfortunate enough to have this condition disclosed."

Of course this only takes into account visible or revealed epilepsy and although 39 epileptics in a work-force of 10,000 seems roughly to accord with the prevalence in the general population according to the College of General Practitioners survey, when the 12-year timespan and changes in the work-force are taken into account, it seems that there was almost certainly a considerable number of epileptics who were able to pass. But as has been stressed earlier, the extent of non-visible deviation is exceedingly difficult to estimate.

Another area where it is both possible and worthwhile to 'pass' is in driving and obtaining a driving licence. Legally a person with epilepsy is not allowed to drive a car but in 1970 the law was amended so that some epileptics are allowed to drive; the main condition is that the person shall have had no daytime attacks for three years. Should the epileptic not meet these requirements, and yet wishes to drive, he has two options open to him - he can drive without obtaining a licence or he can falsify his medical history when applying for a licence. An early survey estimated that 19% of all adult epileptics admitted to driving but a study by Hierons (1956) found that of those adult epileptics old enough to drive, almost two thirds in fact did. None proposed to stop and many had obtained licences by failing to mention their epilepsy on the application form. All of those questioned were subject to fits of one kind or another but the survey did not uncover any accidents involving epileptics. This last conclusion is regarded with some suspicion by Pond et al (1960.b.294) in their study:

> "Nineteen patients admitted to holding a driving licence or at any rate driving cars. The total number of adults over 18 in this series is about 150 so that approximately 15%

> of them drive, which means that there are about 6,500 drivers with epilepsy on the roads.... The fact that there are so many epileptic drivers suggests that no serious conclusions can be drawn from 'Hierons' report on motor accidents involving epileptics."

Both of these studies were conducted a number of years ago when there was an absolute ban on epileptics driving and prior to the boom in private motoring in the late '60s and early '70s and it is, therefore, likely that, at present, there are considerably more than 6,500 epileptics driving motor cars.

Thus it is part of this argument that while the extent of non-visible social deviance is difficult to quantify, it is nonetheless widespread. Specifically, epilepsy is a common and widespread deviation which, because of its few visible symptoms and the motivations of its sufferers to 'pass' makes relatively few public appearances. Consequently, stereotypes concerning the nature of epilepsy and the characteristics of epileptics form the basis of public perceptions, whereas other more visible social deviations allow typifications, based on experience at firsthand, to be added to the stock of public knowledge. When someone has an epileptic fit in public, participants in the interaction can only draw on inaccurate stereotypes which often prove inadequate in actual social situations. The actual experience of being involved in an epileptic fit may well be dissonant with the sort of experience that the stereotype has led to expect and thus a threat to predictable, smooth flowing interaction is posed.

The failure of someone to keep their place or to behave in accordance with what Hilbourne (1973.499) calls "the normal pattern of social exchange and reciprocity", poses a threat to the micro-social order, painstakingly constructed social reality. Goffman (1971.450) graphically spells out the consequences of such a failure with regard to mental illness:

> "The manic gives up everything a person can be, and gives up the everything we make out of jointly guarded dealings.

> His doing so, and doing so for any of a multitude of reasons, reminds us of what our everything is, and then reminds us that this everything is not very much. A somewhat similar lesson is taught by other categories of trouble makers who do not keep their place."

Taylor (Herrigton Ed. 1969.107) makes a similar point with regard to the potential threat that a seizure can provoke:

> "Every fit reinforces the view of witnesses that the epileptic cannot be relied upon to participate fully in society, since he is liable, at any time, to go out of control. Therefore, unless he can be cured, he must be set apart; he must be reformed, or else rejected."

Hilbourne (1973) suggests that social interaction of an untroubled kind takes place by taking for granted biological normality, and disability thus creates havoc for social order thereby 'disabling the normal'. According to the theory being presented here, not all disability is potentially disrupting for visible deviations can be accurately incorporated into the stock of public knowledge through typifications. Thus it is mainly non-visible deviation or disability that can pose serious threats to socially constructed reality.

There have been few studies explicitly concerned with examining the relationship between visible and non-visible disability but Zahn (1973) has recently reported on one such study. She found that people with clearly indicated impairments had less difficulty with inter-personal relationships than those with non-visible or ambiguous characteristics. She explained her findings thus (Zahn 1973.122):

> "This clarity, as indicated by severity of functional limitations, inability to work and established sexual impairment legitimizes the sick or disabled role for incumbents and concurrently facilitates unimpaired inter-personal functioning. When the health condition is in doubt, greater problems in inter-personal relations seem to arise."

Thus visible handicap may be legitimated through the sick role, whereas the non-visibly handicapped person's status is uncertain or at least ambiguous; should he be assigned a sick or a normal role? But legitimate status is not assured by the ascription of the sick role - drug addicts, political terrorists and child murderers are often labelled as sick but their behaviour is not consequently legitimated. The argument concerning ambiguity of status is sometimes expanded to include theories of 'marginality' (viz. Lemert 1951) but this is only troublesome to public order when people are ascribed to the wrong group or treated in an inappropriate manner. The epileptic will provoke trouble not because he has been wrongly assigned to the normal rather than the sick role, but because there will be few typifications regarding his deviation within the stock of knowledge. Thus the construction of order from the havoc an epileptic fit can cause will be accomplished by utilizing ideal and stereo-typical knowledge.

One study (Kleck et al. 1968.b) has attempted to investigate the kind of problems that various social deviations, including epilepsy, might pose for social order. In a laboratory experiment using miniature silhouette figures representing the self and various other categories, a number of students were asked to place these figures on a rectangle and the distance between self and various categories were measured. They were ranked from nearest to farthest as follows;

(i) .... liked professor
(ii) .... friend
(iii) .... blind
(iv) .... negro
(v) .... stranger
(vi) .... amputee
(vii) .... epileptic
(viii) .... mental patient
(ix) .... disliked professor

Part of their conclusions are relevant to the above discussion in that they state (Kleck et al. 1968.b.114):

> "The way in which the stimulus objects are grouped is interesting in that figures representing stigma with no external physical signs (epilepsy and mental patient)

> are placed significantly further from self than are those which are accompanied by or defined by an easily identifiable physical indicator (e.g. amputee)."

Kleck and his colleagues then designed an experiment to ascertain whether the findings revealed in the figure placement test were reflected in everyday interaction. They specifically hypothesized that persons interacting with someone they believed to be epileptic would prefer a greater interaction distance than with someone who was not epileptic. Secondly they anticipated that if subjects were constrained to interact with an epileptic and a non-epileptic at the same inter-personal distance, the latter interaction would be characterized by higher levels of eye contact. The results of testing the first hypothesis showed that (Kleck et al. 1968.b.117):

> "Average chair placement was such that nose to nose distance between C and S was 5ft 4ins in control condition and 6ft 6ins in epileptic condition."

However they found no difference with regard to degree of eye contact and they explain that this may be because, while degree of eye contact may be an indicator of affective or inter-personal intimacy, it is also a means of obtaining information, and this may be particularly important when interacting with someone who is stigmatized or atypical. A similar experiment was carried out in the study mentioned earlier by Harrison and West (1976) when, at the end of a series of street interviews, the interviewer revealed himself (falsely) to be an epileptic. While more than half the respondents confessed to being surprised, in all but a minority of cases they realised that this was a potential 'social gaffe' and consequently indulged in remedial repair work enabling the interaction to proceed untroubled.

So far then, two general propositions have been advanced; firstly that fear and prejudice are directly related to the kinds of knowledge people bring to real world situations; and secondly, because epilepsy remains a non-visible deviation, the actual encounters with epilepsy will be mediated largely by stereotypical and ideal typical knowledge. These and the issue of the effects that epilepsy may have upon the self-conceptions of individuals so afflicted, will be considered at length in later chapters.

CHAPTER TWO

METHODS AND RESEARCH TECHNIQUES

THE NATURAL HISTORY OF A RESEARCH PROJECT

The main reason for my own interest in the topic of epilepsy stemmed from my own experiences over a number of years teaching in the Education Centre of a borstal institution. During this time a number of inmates came into my classroom and had fits during the lessons. A number of others fell asleep during my classes, some no doubt because I was probably a boring teacher, but many upon investigation at the end of the lesson were found to be labelled as Ep 1 or Ep 2 - the prison medical classifications for those suffering from epilepsy. The reason for their slumberings was not, I was somewhat relieved to find, my lecturing but the fact that they were on heavy doses of anti-convulsant medication. Over the years, as I encountered more and more epileptics in my classroom my curiosity grew for I knew no-one in the world I inhabited outside the institution who was an epileptic.

Of course I made tentative enquiries as to why there should be so many epileptics in this institution only to find from experienced prison officer colleagues that epileptics were common in all penal establishments. When I asked why this was, I received a number of explanations ranging from 'Many epileptics have a criminal personality' through 'epilepsy weakens their minds and makes them unable to resist impulses to do wrong' to 'when they have fits they just don't know what they are doing', and so on. I was neither impressed nor convinced by these explanations but had little opportunity to pursue the matter further at that time.

A couple of years later as an undergraduate on a sociology degree course I had the opportunity to write an extended essay on a subject of my choice. I chose to look at what had been learned and written about the relationship between epilepsy and crime - the consequences of which I had witnessed some years ago in my classroom. I was surprised to find that people had been commenting on this (supposed) relationship for more than a hundred years (this literature is discussed in more detail in Chapter 4) and that a number of physiological, psychological and social explanations had been advanced. To an undergraduate still under the spell of encountering labelling theory for the first time, these explanations seemed highly unsatisfactory to say the least.

One 'fact' stayed with me when I had completed my undergraduate studies. Whatever disagreement there was about reasons it was generally agreed that there were approximately twice as many epileptics in prison as their prevalence in the general population would lead to expect (Gunn 1969.1977). To put it crudely, there were approximately 4 epileptics per thousand in the general population whereas in prisons there were 8 per thousand. Even allowing for the fact that much of my undergraduate naivete had rubbed off, I was not convinced that this 'statistical fact' could be explained either in terms of biological, psychological pathology or the social background of the individual. Thus when I was offered the opportunity of doing research for a higher degree, I decided I would like to examine the relationship between epilepsy and crime with specific reference to the epileptic prisoner and his experiences.

Writing this in 1979 it seems unreal that I was worried about gaining access to enough prisons to make the study worthwhile, when in the last few months television cameras have been inside maximum security prisons, prisoners have been interviewed by television and radio and the Home Office is pursuing a much more enlightened policy with regard to access to penal establishments. However, it was undoubtedly true that in 1975 prison gates were shut tightly to outsiders (some of the reasons for this are discussed later in the Chapter). However as a former employee I felt reasonably confident that I could gain access to sufficient prisons to make the study worthwhile. On this basis I set up the research project, embarked upon the preliminary reading and so on.

Next, through old contacts, I was able to negotiate access locally to the borstal institution where I had previously worked, and I was therefore able to begin the first piece of empirical research. However, coinciding with the completion of this part of the study came news from the Home Office that my study would have to be confined to prisons in Kent and that access would have to be negotiated locally with each Governor. I knew this was impractical for two reasons: firstly not all, or even most, governors are sympathetic to the aims of research, and secondly, the prisons in the Kent area would not provide a sufficiently wide data base.

Therefore, nine months into the research, I was faced with the fact that although I had gathered a reasonable amount of empirical material there was little chance that I could complete the project as it had been originally formulated. In discussion with my superviser, it was decided that I would broaden the project out somewhat and as I had a series of taped interviews with adolescent male epileptics in a borstal, I would attempt a similar series with adolescent epileptics in a mental hospital and a further series with another group living in the community.

However this idea produced a number of methodological difficulties of its own in that, perhaps fortunately, I was unable to find a mental hospital that had sufficient numbers of adolescent epileptics within its walls and further, in trying to locate epileptics in the community I ran up against the metaphorical walls of 'confidentiality' from both the medical and social work professions. However I was able to locate a London teaching hospital who had sufficient male adolescent epileptics on their books, though not in-patients, and through the national voluntary organization for epileptics and their families, I was able to locate a similar number of adolescent males living in the community.

Only one problem now remained; the original study had intended to focus around the question 'why are there so many epileptics in prison?' and this was no longer appropriate. As a handicapped person myself I had long been aware that many of the problems experienced by people with all kinds of handicaps were not intrinsic to these handicaps but rather were produced by the way the society in which they lived treated them. Therefore the general question 'why do epileptics have trouble?' seemed an appropriate one against which to analyse the material already gathered and upon which to focus for that about to be collected.

METHODOLOGICAL ORIENTATIONS

It can be said that there are two methodological orientations guiding this work and both need to be discussed briefly. Firstly it is an interpretive study rather than a positivistic one; that is to say that it neither conceives of the social world as an absolute moral order in which all social meanings are the same for all competent members of society nor does it see this social world as existing independent of the individual members who comprise it. Consequently the procedures to be utilized in studying this social world need to take account of this view and hence approaches characteristic of the natural sciences are not likely to be appropriate. Rather by conceiving of the social world as being socially constructed and negotiated by men during their everyday activities, methodological procedures appropriate to this view need to be utilised. These procedures will be discussed in the following sections.

Secondly this study has a situational rather than a causal orientation for sociologists who have adopted interpretive methods have invariably adopted a situational rather than a causal approach. The causal approach has tended to take the phenomenon under study for granted and thereby concentrated on searching for specific causes of behaviour. On the other hand the situational approach shows little concern with etiology but instead focuses on the response of the individual to the particular situation in which he finds himself; if it is etiological at all, it is in its interest in how particular phenomena are constructed, in how people come to believe that x causes y. Obviously such an approach is concerned both with those who define social states and impute meanings as well as those to whom labels are attached. It is also dynamic in that it sees both individual and social definitions as a process emerging from complex and competing interactions.

Probably the best and most famous of the situational approach is Becker's writing (1963) concerning the social meanings surrounding marijuahna use. He suggested that the activities of certain people, who he called 'moral entrepreneurs', gave rise to a certain set of social meanings associated with marijuahna use, and how these meanings, and indeed the pharmacological effects, were modified in the specific social situations in which marijuahna was actually smoked. There have been criticisms of this aspect of Becker's work, the most recent of which (Pearson and Twohig 1975) argues that too little significance is given to pharmacology. However, this misunderstands Becker's basic approach which does not deny the importance of pharmacology in certain situations, but simply denies its importance in the specific situation under study; that is, the smoking of 'pot' by jazz musicians.

A similar situational approach will be adopted in this study; the activities of doctors, psychiatrists, criminologists, social workers, workers with voluntary organizations will be examined and their significance as moral entrepreneurs assessed. Additionally the situational responses to being labelled an epileptic will be studied, specifically the response to being an epileptic in the community, to being an epileptic in borstal and to being an epileptic with psychiatric problems will be examined. And both the activities of the labellers and the responses of those labelled will be scrutinized in terms of the way knowledge is distributed and utilized.

METHODOLOGICAL IMPERATIVES.

Thus having laid down what is to be accomplished in this study and the broad approach necessary for achieving it, it now becomes necessary to outline how it will be done. The first step is to adopt the two methodological imperatives suggested by Phillipson and Roche (Wiles Ed. 1976.56):

> "The first is contained in the slogan 'back to the phenomenon', and the second is contained in the slogan 'show how the phenomenon is built up'. The former can be called a descriptive imperative and the latter a constitutive imperative."

(i) Descriptive Imperative - 'Back to the Phenomenon'

Going back inevitably means adopting the method usually called participant observation. However such a term does not mean the same thing to all sociologists, there are a wide variety of techniques subsumed under such a term. According to Douglas (1972.18) there are two extremes to this method, one is the Martian approach, the other total immersion. The Martian approach implies full observation with no participation and is a technique which even anthropologists have found difficult to achieve. Its opposite, total immersion, implies full participation as well as complete observation and again has rarely been achieved with perhaps the honourable exceptions of Castanada (1970) (3) and Griffin (1962). Usually sociologists have settled for a finite amount of observation and a limited amount of participation and the exact relationship between the two has often been a matter for description and justification in their chapter on methods. The relationship between observation and participation has been recently summarized as follows (McCall and Simmons 1969.1):

> "participant observation involves some amount of genuinely social interaction in the field with the subjects of study, some direct observation of relevant events, some formal and a great deal of informal interviewing, some systematic counting, some collection of documents and artifacts, and open-endedness in the direction the study takes."

In this respect this present study is probably little different from the majority of works in interpretive sociology.

Those working in interpretive sociology have often chosen bizarre, dangerous, romantic or degrading settings in which to carry out their participant observation and have thus gone to great lengths to obtain access to their observational settings, ranging from posing as a look-out to observe homosexual activity in public toilets, through pretending to be mentally ill in order to gain access to a psychiatric hospital, to hanging around on street corners with gangs of juvenile delinquents. It is not my intention to denigrate this work, much of which has been pioneering and has produced changes for the better in social and organizational policies. However it has raised certain problems such as the morality of obtaining access to situations through deceit and the ethics of observing criminal activities in a passive and non-interventionist manner. Additionally adopting this method has placed limits on the situations in which it is practical or possible to observe. Hence there have been many interpretive studies of the powerless but few of the powerful (Thio.1973); the deviant activities of alcoholics, homosexuals, hustlers, the mentally ill and so on have been subjected to repeated scrutiny, but there have been few similar studies of the deviant activities of political terrorists, soldiers, doctors, business men or even professors of sociology. Effectively practical considerations of danger, access, information retrieval and so on have placed limits not simply on how much can be observed, but more importantly on what can, and indeed, what cannot be observed.

In the light of these remarks and recent developments in sociology drawing its inspiration from the work of Alfred Schutz (1967, 1970), calling for a sociology of everyday life, it is suggested that interpretive sociologists could minimise some of the problems mentioned above by refining their concepts, testing their hypotheses in their own everyday worlds. After all, sociologists may be husbands, homosexual, mentally ill, wife beaters and so on and could thus choose their deviants for study from their own social worlds. Additionally their use of concepts like class and power have usually been in situations remote from their own everyday worlds, in factories, classrooms, hospitals, prisons; there have been few interpretive studies of class in the university or the exercise of power in sociology departments. Despite these somewhat facetious remarks, there have been some interpretive studies grounded in the everyday worlds of the sociologist; Becker's (1963) study of jazz musicians, Polsky's (1971) study of pool room hustlers and Plummer's (1975) study of the sexually stigmatized represent the very best of this genre.

Sociologists have generally however been reluctant to follow such an approach and to the cynical it might appear that they are unwilling to subject themselves, friends, relatives, colleagues and lovers to the same rigorous and inquisitorial scrutiny that they are prepared to subject others. A more important and relevant reason is their fear of allowing personal values and feelings to intrude upon their studies - but as Gouldner (1971.45) has pointed out:

> "theory will (therefore) tend to devolve around, and consequently be shaped by, the limited facts and personal realities available to the theorist."

And he cites an eminent example of the intrusion of personal values Gouldner (1971.44):

> "Max Weber's general theory of bureaucracy was influenced both by his historical, scholarly researches and by his first hand acquaintance with German bureaucracy and, in particular, with Governmental rather than private bureaucracy. The German Governmental bureaucracy, both as experienced social structure, and as a cultural ideal, constituted for Weber a personal reality that served as a central paradigm for all bureaucracies; it provided a framework for organizing and assimilating the facts yielded by his scholarly researches."

Thus if one of the founding fathers of the discipline was not immune from the intrusion of personal values into his work, then it is not unreasonable to assume that nor are the more humble practitioners of the craft immune from such intrusions.

Indeed many researchers do recognise this intrusion of personal values into their work and then are at great pains to avoid any biasing or contaminatory effects that this may have. The argument being presented here goes further than that, and suggests that sociologists should choose to work in areas connected with their everyday lives - black sociologists should do interpretive studies of prejudice, female sociologists should study women, handicapped sociologists should study disability, divorced sociologists should study marriage break-ups and so on. Researchers, whether adopting Martian, total immersion or some in-between method of participant observation, have generally assumed that it is relatively easy to plug into situational social meanings. All that is needed is a basic understanding of the 'argot' and then the researcher can happily move from the world of his subjects to the world of the university based researcher and back again, almost as easily as changing clothes. But there are problems connected with this moving from situation to situation for (Douglas 1972.11):

> "the specific situation in which any human communication takes place becomes the contextual determinant of the meaning of that communication for the individuals involved."

Thus not only does the researcher face the problem of understanding the meanings of the situations in which he participates but also that he may change those meanings by his very participation.

All participant observers therefore are faced with these twin problems to one degree or another - understanding the social meanings of the situation within which they are working and the contaminatory or biasing effects that their very presence may cause. While there have been ingenious and sometimes successful attempts to overcome these problems, the suggestion is that sociologists should focus on situations in which they participate as insiders, members in their own right. Thus, by recognising the inevitability of the intrusion of personal values and feelings and by working in situations where the researcher participates legitimately, some of the methodological problems of interpretive sociology can be minimised. Weber (1966) suggests 'verstehen' as the appropriate method of minimising such problems but draws a distinction between the logical/rational and the empathic/appreciative approaches. In the past, most sociologists working with the 'verstehen' method have adopted the former approach but in this study it is the latter, the empathic/appreciative approach that will be followed. (4)

At this point it is probably appropriate to say something about the intrusion of my own personal values into this work and the effect this has had both on my understanding of the situational social meanings under scrutiny and any biasing effects my presence as an observer may have had.

Firstly, with regard to the intrusion of my own values, as a disabled person confined to a wheelchair for the past fifteen years my experiences have led me to believe that many of the problems common to disabled people are less concerned with their disability than with the reactions of other people to this disability. As Lemert (1967.16-17) has eloquently put it:

> "Although physical handicaps partially restrict opportunities for achievement, the more critically operating limits come from an overlay of interpersonal and formal social barriers founded on cultural stereotypes about physical defects. As many physically disadvantaged people say, the problem is less the handicap than it is the people."

Specifically my work on epilepsy has been shaped by a belief that having epilepsy is considerably less of a problem than being epileptic in a hostile social world.

Secondly, with regard to understanding the specific situational meanings; no doubt some methodological purists will want to turn my earlier arguments against me and argue that a valid interpretive sociology of epilepsy could only be accomplished by an epileptic sociologist. My answer is that my own personal circumstances and the similarity of treatment that society hands out to all disabled people will enable me to achieve an empathic and appreciative understanding of the meanings of the situations in which I am working. The same argument can be used with regard to the contaminatory effects of my presence; the empathy between myself and my subjects was a two way one and therefore I was regarded as a legitimate member of the situation in which I was participating. Evidence of this was the number of times I was asked for advice of a personal nature or on the effectiveness of the local groups or meetings I was attending. (5) In short, this study, like all interpretive studies, is a compromise between participation and observation, but it is a compromise designed to minimise the dual problems of understanding specific situational meanings and reducing contaminatory effects: but is is not a compromise which will prevent me from rendering an empathic and appreciative account.

(ii) Constitutive Imperative - 'Show how it is built up'

This imperative poses problems of accessibility of a different kind; it is not simply a matter of gaining access to situations where participant observation can take place, but also of examining how individuals in positions of power actually come to hold the views they do and the effects these views may have on their everyday practices. One of the most powerful of these groups, the medical profession, are extremely sensitive to any detailed scrutiny and the authors of one major study of adolescent epileptics in Canada (Goldin et al. 1971.73) have recently complained:

> "The helping and healing professions have long been concerned with intrinsic value, integrity and rights of the individual personality. Indeed, this concern has stood as the hallmark of the professional and as a basic tenet of his code of ethics. The client's or patient's right to privacy and confidentiality has always been a major

> part of this code. The adherence of this confidentiality norm has been, for the most part, exceedingly strict. The rigidity with which this principle has been applied leads the authors to the question of whether over-strict conformity to a norm or value can result in hurting the very people it was designed to protect. Our experiences as researchers leave us no alternative to an affirmative answer."

Confidentiality is not the only stumbling block the researcher will come across but also fear, anxiety not to know how things really are, the desire for a quiet life, worry over extra work or responsibilities that research will involve are other factors which will influence those with power to decide whether the researcher will be granted access or not.

The question of accessibility is relevant to 'showing how this phenomenon is built up' in that those in positions of power over access are also often those who have power over definitions. Hence the crucial role of those who are in a position to constitute the phenomena of 'the epileptic', 'the epileptic criminal' and the 'mentally ill epileptic' are unhappy about or unwilling to have their own activities studied or scrutinized. The following paragraphs outline some of the reasons for this unwillingness in this particular study, the effects this had on the direction of the research and the 'solution' that was arrived at eventually. A detailed description of the phenomena will be provided in Chapter 4.

Certainly this study has been plagued with problems of accessibility relevant to showing how the phenomenon is built up. What was initially begun as a study of the relationships between epilepsy and crime with particular reference to the epileptic prisoner, has changed considerably as a result of these problems. The Home Office were reluctant to grant access to any of the institutions under their control for the following reasons; (i) they have their own staff researchers and were reluctant to allow outsiders access whose findings they would have no control over; (ii) they were worried about any risks to security, and (iii) they were concerned about whether the research might involve extra work for the staff and hence any additional expenditure through overtime. There were two other factors which overhung these accessibility negotiations as unspoken silences. There was the recent publicised dispute between eminent sociologists Cohen and Taylor over the publication of their book on prisons (1972) and this was coupled with the fact that a number of other outside research projects had produced findings which were openly hostile to the Home Office, the Prison Department and their work. Ultimately limited permission to conduct a study was granted but only on condition that one institution at a time was studied, the catchment area was restricted to Kent, no access to medical records was allowed and all interviewees would have to be volunteers.

In the light of these accessibility problems it was decided not to proceed with the original research proposal but to examine three different groups of male epileptics between the ages 15 - 24; one group in a borstal institution, one group attached to a London hospital with psychiatric problems and another group living in the community and contacted through local voluntary groups. (More will be said about these groups in relevant chapters.) With only one of these groups was access to medical records allowed so the views of the medical profession generally were studied through formal publications, informal conversations and attendance at several conferences. All in all, it's true to say that the nature and shape of this work has been constrained by what is referred to in the literature as 'the research bargain' - that is, the variety of compromises arrived at between researcher, subjects, and those in positions of power to grant access to these subjects.

This detailed discussion of accessibility problems is intended to show how difficult it is to study social life, a point hardly acknowledged by many positivistic sociologists committed to the natural scientific method. One can hardly imagine the natural scientist allowing his research to be constrained by the kinds of accessibility problems discussed here, or him striking a 'research bargain' with his data but these are inevitable problems for the interpretive sociologist.

The solution, as outlined here, is to abandon commitment to the scientific method and instead clearly and accurately describe how all the data was collected and then detail how such data was analysed. Thus, having located this work generally within the field of interpretive sociology and discussed some of the problems involved, it remains to outline the specific techniques used in obtaining the data before detailing how the data was analysed.

SPECIFIC RESEARCH TECHNIQUES.

(i) Reading the literature

As was mentioned above, one of the major problems of this research was that there was little access to formal documents such as medical records, doctors' reports and so on and thus there was little opportunity to examine directly the relationship between professional conceptions and the individuals' response to their situation as patient, client or member. However this kind of information was studied indirectly by reading a large amount of literature of all kinds; medical, historical, psychological, criminological, sociological and so on. Newspapers, journals and publications produced both by voluntary organizations and the drug companies were also studied. (For full list, see bibliography.)

(ii) Observation

A number of local voluntary groups, known as 'Action for Epilepsy' groups were visited over a period of 18 months, a series of more intensive visits were carried out over a period of six weeks and a number of visits were made to the London Hospital over a period of six months. (Full list of visits, hours spent in observation etc. will be included in Appendix A.) During these visits conversations were carried out with doctors, prison officers, social and voluntary workers, epileptics and their relatives. Additionally a number of conferences and formal visits were made. Finally a small number of epileptics having fits were observed.

During these observations, accurate records of dates, who conversations were with and the kinds of incidents occurring, were kept. In the literature on how to do interpretive sociology almost all writers recommend that detailed accounts, logs or diaries are kept, and that they are written up as soon as possible after a period of observation has ended. (Bogdan and Taylor 1975) The idea of accurate and detailed recording of observation harks back to the methods of natural science but such procedures were not followed in this study. Having no commitment to the scientific method, the production of such data has seemed unnecessary, and the inevitable process of editing and selecting has occurred as part of the natural cerebral function of recalling and remembering events which may simply have been noted in field notes. Indeed, a case could be made that such a selection process is more appropriate in that only the important or significant events will be recalled. In this writer's opinion it seems to make little difference whether evidence is selected from detailed notes or memory. What's more, the participant observer following the approach advocated here, is a legitimate part of the world he is studying and therefore there is no problem of recall and writing up in an environment totally removed from that within which the research was undertaken.

(iii) Compilation of a Data Sheet

The data sheet was a piece of paper with a number of sub-headings (see Appendix B) on which relevant sociological information such as family size, kind of residence, number of schools attended etc., were recorded. The information was collected in a number of ways; by informal conversations with interviewees, by conversation and questioning of others who knew the subject, and in the case of the borstal trainees through scrutiny of their criminal records, known as 11.50's. This objective information was thus checked by a technique referred to in the research literature as 'triangulation' - the establishing of a fact from a number of different sources.

(iv) The Questionnaire

The major research technique of this, and perhaps most sociological studies has been the questionnaire, and accordingly most space is used in discussing methodological problems associated with this technique. Whether questionnaires contain formal closed questions for scaling purposes or open ended questions using topic areas, their use gives rise to three kinds of problem; who to ask, what to ask and what kind of credibility to give to the answers. These problems need separate consideration, and will be discussed with reference to the work, cited earlier by Caveness and his colleagues, not because this work is a particularly bad or good example, but because it is concerned with epilepsy and is similar to many other studies. Hence it can be used to highlight some of the general problems associated with questionnaires.

The major ethos behind the problem 'who to ask' has usually centred around attempts to generate a random sample, usually checked by statistical techniques, so that generalizations based on a statistically reliable sample can be made. Caveness and his colleagues over a period of thirty years have interviewed 1600 respondents every five years, using a replicated probability sample down to block level in urban areas and to segments of rural townships in the case of rural areas. All in all 150 sampling points have normally been utilized and great stress has been placed on the reliability of the sample, with the aim being to produce an approximation of the adult civilian population 21 years or older.

My quarrel is not with the use of these procedures but with the kind of information they produce. Each study has shown a small percentage increase in favourable responses, indicating small improvements in public attitudes. The most favourable opinions were held among the better educated, those in white collar jobs, the younger and urban members of the population. Now, despite the great emphasis placed on the reliability of the sample, this kind of information is nothing more than a single 'well-informed citizen' (Schutz 1964) might indicate with equal validity. More importantly, as mentioned earlier, the everyday experiences of epileptics in education, employment and social relationships probably does not bear out such findings. And most importantly, such findings do not say why things are as the study has suggested they are, nor indeed why epileptics should have 'trouble' at all.

With regard to the problem of 'what to ask', the following questions were contained in the Caveness questionnaire:

- Have you ever heard or read about the disease called epilepsy or convulsive seizures (fits)?
- Did you ever know anyone who had epilepsy?
- Have you ever seen anyone who was having a seizure?
- Would you object to having any of your children in school or at play, associate with persons who sometimes had seizures (fits)?
- Do you think epileptics should or should not be employed in jobs like other people?
- Do you think epilepsy is a form of insanity or not?

The point of re-producing these questions is to show that there is confusion between attitudes to individuals suffering from epilepsy and attitudes towards epilepsy generally - a point which is crucial to the theory presented in earlier sections of this Chapter. This confusion is a common failing amongst many attitude surveys, as McDaniel (1976.41) has pointed out:

> "The current evidence provides some basis for a logical separation of general attitudes towards physical impairments and disabilities on the one hand and attitudes towards disabled persons on the other. Disabling conditions are seen as more inherently undesirable than are the persons who may display them. People may be perfectly willing to associate themselves with a person and accept him on a basis of personal merit, but nevertheless find the disease or injury he has suffered an event definitely to be avoided. I do not find it inconceivable, as Wright (1960) apparently does, that attitudes toward physical disability and towards disabled persons can be distinguished just the same as most people deplore poverty as a condition, or alcoholism, or homosexuality but do not necessarily have the same attitude toward their victims. The point is that while the two sources of attitudes may be correlated, they are not inseparable and do not need to be studied as instances of the same process."

Thus most studies of attitudes or prejudice are subject to this confusion; either the distinction is not regarded as important or the relationship between general attitudes and attitudes towards individuals is assumed to be sufficiently direct that it can be regarded as relatively unproblematic. This work argues that such relationships have been little discussed and are barely understood.

The problem of what credibility to give to respondents' answers has been succinctly posed by Deutscher (1968.319):

> "We are confronted with many serious problems in the methodological domain, but perhaps what is the most devastating gap is our unwillingness (and consequent inability) to come to grips with semantics; what do people intend to convey when they answer our questions, or for that matter, when they speak at all? What do

> people understand to be the intent and meaning of
> our questions?"

But it is not just that there is a problem in interpreting meanings whether it be of questions or answers, but also that people may respond to questions in a different manner to the way they actually respond to a given situation. The classic study of this was by LaPiere (1934) when he visited 251 hotels, rooming houses, autocamps and restaurants with a Chinese couple and was only refused admittance to one. Six months later he wrote to all the establishments they had visited, asking whether they would be prepared to receive a Chinese couple as guests, and he only received one affirmative reply, thus indicating there is no necessary correlation between 'what we say and what we do'.

To sum up so far, three kinds of problem with using questionnaires have been raised and it has been argued that most studies have failed to grapple with these problems in an adequate way. This failure stems in part from the twin aspects of the positivistic approach to sociological research; that is that there is a single 'real' world out there which can be measured, and that this world can be measured by utilizing scientific methodological procedures. What follows will be a description and justification of the questionnaire used in this study, how it attempts to come to terms with the kinds of problem just raised and what other problems it has produced.

In this study the question of 'who to ask' has largely been resolved by practical considerations and not by any desire to provide a stratified or random sample. Hence my initial access to a borstal institution provided a sample of male adolescents between the ages of 15 - 21. This then set the tone for locating samples with similar parameters; e.g. male and age, although the age range was slightly extended to 15 - 24, in order to be able to locate a sufficient number of respondents from the hospital and the local action groups. The three groups then are obviously special in that they are not, nor intended, to stand as representatives of all epileptics, or all adolescent male epileptics, or indeed all epileptic criminals or epileptics with psychiatric problems. Rather they are to be analysed as specific groups responding in specific situations. In essence it is hoped to be able to generalise from the particular rather than to particularise from the general. The dominant approach in much positivistic social science has been in the other direction; to provide general theories which will enable predictions to be made about the behaviour of individuals.

By opting for a non-standardized interview using a series of topic areas, the problem of 'what to ask' largely disappears. (See Appendix C for Topics included in interview schedule.) Admittedly there is the problem of what topics to choose and in this case, various areas were identified by reading relevant literature, informal conversations with various people and personal insights drawn from being part of a similar social world. The interviews were allowed to proceed as conversation rather than by any direct question and answer sessions. Occasionally problems did arise over interpretation of questions but these were not concerned with social meanings as such, which were negotiated as conversations proceeded. Rather they were concerned with misunderstanding the point of a question; thus when a respondent was asked how he felt his parents had reacted to his epilepsy, the respondent replied that his parents were the best people to answer that question. It thus became necessary to explain that I was not interested in their reactions per se, but in his perception of their reaction. Once the point was understood, conversation then proceeded naturally.

The major problem confronting interpretive sociologists in analysing responses is what credibility to give to respondents answers. There are two aspects to this problem, one specific and one more general. Specifically by using the kind of interview schedule described above, a large number of unsolicited as opposed to solicited responses are obtained and this gives rise to the problem of what exact weight to give these responses. The most pertinent example of this is described in Chapter 4, where two out of nine respondents told of incidents where their lawyers had attempted to persuade them to use their epilepsy as a defence to a criminal charge. The alternative positivistic method of establishing that such things actually occur would be to ask all respondents in a random sample the same question about the activities of their lawyers and then depending on the percentage of affirmative responses estimate the extent of this kind of activity. The whole tenor of this work would suggest that even one or two unsolicited statements have a greater validity than even a high percentage of solicited responses from a random sample, although neither kind of response gets over the general problem referred to above - the specific reasons why respondents tell us the things they do.

The general problem then is how we interpret responses to our questions, what kind of epistemological status we give to individual replies. The dominant tradition in social science is to have scant respect for what the individual says. According to Taylor (1976.a.37):

> "The behaviourist, the psychoanalyst and the functional sociologist may then all subscribe in varying degrees to the idea that what the individual says has either no significance, only a secondary significance or may be ignored without penalty in deciding why it was he decided to act."

There is a tradition however, beginning with Wright Mills (1940) through Cressey (1962) and to Taylor (1976.a.) which argues that individuals must be taken at their word in answering our questions. Their replies must be analysed as genuine responses to specific situations or contexts, and that their verbalizations may be more than just excuses or justifications for past actions; these verbalizations may actually serve as mainsprings for future actions (motives) and may actually allow individuals to engage in forbidden behaviour.

While this study is not concerned with relating motives to actions, in the sense that the above mentioned writers intended, it nonetheless accepts the notion that the responses generated should be taken seriously; thus analysis of responses will begin with those responses and the situation in which they took place, and no attempts to subsume them in a wider body of theory will be made. What McHugh (1970.165-70) in another context has called giving 'theoreticity' to an individual's actions will be accorded to the responses generated. Theoreticity will be given to the data gathered.

Much of this data is in the form of transcripts produced from tape-recorded interviews and this can pose problems of analysis for the interviews yielded over 300 pages of transcript. During the past few years, the transcript has become a major source of data for sociological research and while much attention has focused on the epistemological status and theoretical validity of such data, relatively little attention has been given to the mechanical procedures necessary to handle it. Dingwall (1977) has recently described how he analysed transcripts generated in his study of health visitors by using a computerized indexing system but in general, writers using transcript data remain silent about such matters and no attempt is made to say how or why particular sections of transcript are selected, or indeed rejected.

In this study a data sheet was compiled (as described earlier) and from this an individual biography was drawn up for each respondent - these biographies are included as the final section of this chapter both to provide the reader with information about the respondents and also to illustrate how the transcripts were analysed. These biographies were then placed at the head of the relevant transcript so that I was always aware of which transcript applied to which group or individual. Each transcript and recorded interview were then over the period of about 18 months read or played through, sometimes separately and sometimes together, approximately twelve times each. Next to the biography was kept a topic sheet for each individual and at every reading or playback, references to relevant issues were noted in terms such as - EMPLOYMENT p.9, NON-VISIBILITY p.3, FITS IN PUBLIC p.12 and so on.

Thus after these playbacks and readings it was possible to abstract the important topics from each transcript and indeed these were only stopped when subsequent readings or playbacks yielded no new topics for inclusion in the topic sheet. Ultimately then, the material on the some 300 pages of transcript was summarized on the topic sheets. There were two advantages in this; firstly as far as analysis was concerned it was relatively easy to see which topics occurred frequently and which hardly at all, and secondly, when writing about various topics, it was relatively easy to locate relevant sections of the transcript for inclusion in the text.

RELIABILITY, VALIDITY AND THE SCIENTIFIC METHOD

All empirical work in sociology is faced with problems of estimating the validity and reliability of the work undertaken. Much sociological work, largely as a result of its commitment to the scientific method, has placed great emphasis on reliability with the subsequent neglect of the problem of validity. This work is more concerned with validity and agrees with the sentiments expressed by Phillips (1971.16):

> "Estimates of reliability and validity are both of great importance to any empirical undertaking, but the latter is by far the more important of the two. For it is possible,.... to have a highly reliable instrument that is totally invalid. But if we have a valid measure, it must, of necessity, be reliable to some degree."

Thus having spent much of this section on method in criticising attempts to achieve reliability at the expense of validity, it is nonetheless appropriate to end with some thoughts on the reliability of my particular samples.

Where questions of reliability have been raised in interpretive sociology, they have normally been assumed to fit into one of two areas; the deviants observed have been assumed to be either the most committed or the most articulate representatives of a deviant group.

The assumptions underlying the first can be traced back to Becker and what he calls the 'sequential model of deviance'. In this, the assumption of a deviant identity is seen as a process with the outcome at each step being uncertain; the crucial concept linking the various steps or stages is that of 'career'. And it is assumed that each step taken represents onward progression in the deviant career. Thus this group of epileptic criminals, this group of epileptics with psychiatric problems could be assumed to stand not as random (reliable) representatives of the total population of epileptic criminals or epileptics with psychiatric problems, but as the most committed of that particular population; what Lemert has called the 'secondary deviants'.

The assumption underlying the second is relevant to the group of epileptics living in the community, and stems from studies of the membership of various types of voluntary organizations. These studies have shown that it is the more articulate, the more intelligent and usually the middle class who join these organizations for they are more interested in their particular problem, more concerned about obtaining their rights and see formal organizations as their best means of achieving these ends. And it is also assumed that the joiners of organizations are the most committed of their group, for as Becker (1963.37-8) himself states:

> "A final step in the career of a deviant is movement into an organized deviant group. When a person makes a move into an organized group - or when he realises and accepts

> the fact that he already has done so - it has a powerful impact on his concept of self."

However these assumptions are precisely that - assumptions. There have been few attempts to estimate the reliability of the deviants under study, and by choosing non-visible social deviance as an area for study, the problem is further compounded. There has been one study (Blumberg and Dronfield 1976) which attempted to estimate how representative were a group of drug addicts at a clinic of drug addicts as a whole, but while it recognised the problem it failed to provide an adequate solution. Plummer (1975. 123) in his study of non-visible social deviance (homosexuality) argues that such issues are relatively unimportant for such studies will be subjected to critical scrutiny and that is how science proceeds. In discussing a famous study of homosexuality, he states:

> "My point.... is simply that such a study has produced a considerable degree of discussion and refinement - a necessary condition for scientific progress. For example, the central challenge to its argument - that its findings were only applicable to a small, highly pre-selected group of psychiatric respondents - has produced a number of studies in which 'non-psychiatric' homosexuals were the respondents."

The position of this study is also that reliability is not a problem in that there is no commitment to the scientific method; however while reliability of the sample is not being claimed it should be noted that the respondents were all contacted via the same procedure and that this contact procedure has been accurately and faithfully described.

This Chapter has been critical of a number of previous studies using methods derived from positivism. An alternative 'interpretive' methodology has been advanced and the various methods and techniques used in this study have been described in detail. The final section consists of biographies of the individual epileptics who were interviewed throughout the course of this study. These are included for two reasons; firstly they were used to facilitate the analysis of the transcript material as described earlier; and secondly, their inclusion will enable the reader to gain some idea of the life histories of those who participated in the study. Specific references to identifiable events or people have been excluded to preserve the anonymity of the respondents.

INDIVIDUAL BIOGRAPHIES

(i) Inmates of Borstal

1 : RAC

A youth of 18 who has been convicted of a number of offences including burglary, theft, robbery, threatening behaviour and finally assault on father and mother. He also appeared before the Court because he was 'beyond the care and control' of his parents.

He was born of mixed European parentage and he has two younger sisters, both of whom are studious and bright; one is at present studying 'O' levels and the other 'A' levels. The family have lived in various parts of London. There is a history of disharmony in the family; the father normally remains aloof from such conflicts but mother and subject are both said to be very excitable.

He first came to the notice of the local social service department in 1967 when he was said to be beyond the control of his parents. However, he continued to live at home and attend ordinary school until 1971 when he was sent to a special boarding school. He was asked to leave after several episodes of destructive behaviour and a suicide attempt. He returned home under supervision and attended a local day school until it was time for him to leave.

His employment record is somewhat erratic; he was placed in a hostel for working boys after more family quarrels and worked as a roundsman for a London newspaper for a reasonable length of time. But once he lost that job he was periodically unemployed and worked at a number of jobs including messenger boy, general labourer and hodcarrier. During this time he also had accommodation problems, alternatively living in a flat, at home, with friends and sometimes being homeless.

2 : RRK

A young man of 19 who has a long list of previous offences, court appearances and convictions for offences including theft, forgery, burglary, deception, criminal damage, assault on the police and taking and driving away with at least 50 taking and driving aways being taken into consideration. Sentences include a supervision order, a placement in the care of the County Council, conditional discharges, fines and finally, two sentences of borstal training. Also he has had periods of psychiatric treatment and oversight.

He is the oldest by 5½ years in a family of three boys and his father is a consultant surgeon and his mother has sometimes worked as a secretary. According to his social enquiry report he is strongly attached to his mother but regards his father as rather strict and authoritarian. He attended local primary and secondary schools until he was placed in an approved school, a place from which he continually absconded. Since leaving school he has had several jobs but has been mainly unemployed, for he has rarely worked for more than a few days at a time.

3 : RIM

A young man of 16 with seven findings of guilt during the period 1967-75, for offences including theft, burglary, taking and driving away and arson.

He lives in a council house with his mother, father and four other children but was removed from home in 1967 on a place of safety order and was placed in a children's home.

Originally he attended the local primary school but in September 1967 he was sent to a special school, but even with extra attention his work always fell short of his potential. In 1971 he was admitted to a community home but absconded and was then placed in a hospital for oversight by a child psychiatrist. In April 1974 he was returned home and placed at the local secondary school. However, by August of that year he was committing offences again but before a suitable place to detain him could be found, he took an overdose of drugs and was admitted to a psychiatric hospital. While there, as an in-patient, he continued committing offences and was eventually arrested and sentenced to borstal training.

4 : RJM

A youth who is only 15 but has had four previous court appearances, all for burglary.

He is the oldest of five children having two younger brothers and two younger sisters, and lives with them and his parents in a three up and three down council house. He was born in Northern Ireland but moved to the north of England in 1964 with his mother and brother. His father was already living and working in England. RJM also spent a year living with grandparents while his parents were in England. According to social enquiry reports he has had an unstable and insecure home life and has returned to Northern Ireland on at least three occasions - for the birth of his two sisters, and also on the death of his grandmother, an event which distressed him greatly. His mother and father have a very disturbed relationship largely due to father's heavy drinking, frequent periods of unemployment and general lack of support. His mother is contemplating divorce because of father's aggression towards her, and this has ended in her husband attacking her with a knife and consequently, he is due to appear in court.

He attended an infant and then junior school and at 11, he was sent to the local high school. He was regarded as being of above average intelligence and potential but he had a poor school record, often telling lies and showing himself to be resentful of authority. He frequently played truant and he was supported by his mother who supplied him with excuses, in the way of written notes of an inadequate nature, stating that 'he had to go to the post office to cash a Giro cheque', 'to look after younger sister', etc. Eventually he was removed and placed in a community home and a rapid improvement in his behaviour was noted. This improvement continued upon return home but marital disharmony continued at home and after about a month, he rapidly reverted to his former self. The community home was approached to take him back but were unable to offer him a place and after committing further offences, he eventually landed up in detention centre. Much the same pattern on release resulted in the present borstal sentence.

5 : RRM

A young man of 18 who has a number of previous convictions for offences including taking cars without the consent of the owner, driving without insurance and theft.

He lives with his parents and is the youngest of four children; his two older brothers also have a number of previous convictions. He has a steady girlfriend who is pregnant, possibly by him but the matter is not resolved. He has a history of disruptive behaviour and assaults on other boys while at school and has also exhibited aggression towards the staff. He has been subject to a number of fines, two probation orders, 24 hours at an attendance centre, a care order and a period at a detention centre. He was regarded as below average intelligence and due to the constant interruptions in his schooling, he made little progress. He has worked periodically as a carpet fitter and this has been interspersed with several casual labouring jobs and a number of periods of unemployment.

6 : RDR

A young man of 20 who is serving a recall sentence and his offences are confined to the period 1973-76. These offences include theft, burglary, taking and driving away, driving without insurance and driving while disqualified.

He is single and the third of five children and has lived with his family in a local authority flat. Prior to being rehoused in 1962, the family had been homeless for the previous eight years.

Slow progress at school resulted in his being sent to a special school from the age of 11. He was frequently in trouble for bad behaviour but his educational performance was regarded as satisfactory. He left in the summer of 1972.

He worked as a packer in a warehouse until the Christmas of that year and around this time he began leaving home to stay at an undesirable address in London. His parents wanted him 'put away' and he was received into care. He was soon in court for stealing from the local authority hostel in which he was placed. He then returned to live with his parents and settled down, even getting his old job back. However a dispute with his father, one of many for his father was very strict, led to his leaving home and once more being placed in hostel accommodation. He was unable to organize his affairs satisfactorily and eventually landed inside.

7 : RRR

A young man of 19 who has a number of convictions for offences almost exclusively involving motoring; these include being carried in a stolen vehicle, taking and driving away twice and driving without insurance three times.

He is the second eldest in a family of four, having an older brother and two younger step-sisters. His mother was first married in 1950 but the marriage broke down soon after RRR was born and she thereafter found it difficult to manage and consequently RRR spent a substantial part of his childhood in children's homes. His mother has subsequently remarried and she, his step-father and two step-sisters live in a house in Middlesex where they have lived for a number of years. At the age of 10 he was referred to a child guidance clinic and as a result of their assessment, he was placed at a special school for maladjusted children. For the next seven years there followed a number of children's homes and approved schools placements, interspersed with a number of court appearances. At the age of 17 he was placed in an adult hostel, but after committing further offences, he was sentenced to borstal training. On release he went to live with his married sister-in-law in East Anglia, got a job in a factory working as a packer and appeared to settle down. However, he was soon committing further offences and landed back in court, only to receive a deferred sentence. On offending again he came before the court once more and was sentenced to a second period of borstal training.

8 : RJT

A young man aged 17 who has twice been convicted of wounding with intent and once for damage to property.

He was born illegitimately and has lived with and been brought up by his maternal grandparents since birth. His mother later married his putative father and RJT has occasional telephone contact with his mother. Also living within the home is his uncle, and he and RJT have been brought up as brothers.

He attended a secondary modern school and although he had reasonable ability, he was frequently absent and often left work undone - he made little effort and sank to the bottom of his class. He was eventually expelled after a number of violent acts, as follows:

> attempting to gouge the eyes of another boy; kicking another boy; striking a girl on the head with a thick reference book; punching a junior boy in the mouth, cutting his lip and loosening two teeth; throwing custard over a senior girl; provocation and aggression to a teacher under instruction; tearing up a folder belonging to another girl.

With regard to work, he has worked spasmodically as a labourer, sometimes living at home and sometimes staying in a caravan a few miles away.

9 : RCD

A youth of 19 who has a number of convictions for the following offences: criminal damage, handling stolen goods, dishonest handling, possessing an offensive weapon and assault.

He was brought up in Scotland and is the second youngest of five children. He had a deprived childhood in a rough environment and there is a long history of illness in the family. In fact all members had tuberculosis in 1962. His father died in 1969 and his mother is unfit following an accident. He came to London in 1973 and has spent some time living with his elder sister and brother-in-law, but when he was arrested he was regarded as having no fixed abode. Sometimes he has squatted and on other occasions lived with friends.

Educationally he is regarded as average despite a chequered career at school. He attended one infant school and then three junior schools due to the family moving on a number of occasions. However from the age of 8 he was sent to approved schools but eventually, after absconding seven times, he spent the rest of his schooling in two remand homes.

Since leaving school he worked originally as a painter and decorator but on coming to London he worked regularly as a roadsweeper for five months but was eventually sacked for taking too much time off. He has had a number of casual jobs since.

According to his record, he had TB in 1962 and had an operation for a squint in both eyes in 1971. He has refused treatment for his epilepsy in borstal (control of fits by drugs) and has not taken any tablets for two years. He has previously attempted suicide by hanging.

(ii) Individuals in the Community

1 : CJB

A pleasant and obliging young man aged 18.

His father has recently retired from the RAF and is consequently at home most of the time. His mother works part-time in the local toy factory. He has two brothers; one older, married and no longer living at home, and one younger who still lives at home. They live in their own home in a quiet suburb of a popular coastal resort.

He attended four or five primary schools as a result of his father's RAF postings and went to a grammar school in Scotland before finally settling at the local comprehensive. He has eight CSE's, four 'O' levels and was taking six more.

He has started to apply for jobs and has been rejected but has worked on a farm during his school holidays. His hobbies are tennis and table-tennis and he enjoys reading science fiction.

2 : CAW

A somewhat quiet and reticent young man aged 20.

His father is a consultant civil engineer and his mother a marriage guidance counsellor. He has one younger brother living at home and a younger sister at boarding school. They live in their own detached house on an exclusive private estate in one of the local towns.

He attended the local primary school with a two-year gap when the family was in Pakistan and he attended a colony school. He then attended a local boarding school as a boarder for two years, spent some time at a public school in Pakistan when the family returned there, and then continued at his boarding school, but this time as a day boy. He obtained eight 'O' levels and went on to study 'A' levels but broke off when he was in his second year in the sixth form.

He worked for a while with the County Council and then spent a year in Germany, before returning and attending a College of Further Education to complete his 'A' level work.

3 : CGM

A pleasant, cheerful young man aged 20.

His father is a computer programmer and his mother teaches infants. He has two younger sisters, both living at home. They live in an old manor house in London; a house which they own and are currently converting.

He attended primary school and two secondary schools as a result of moving house. He left with three CSE's.

Since then he has had three jobs - a spectable lens grinder, a warehouseman and a clerk, but has usually been asked to leave as a result of the effects his fits have had on other staff. He is currently unemployed.

His main interest is in pop music and playing the drums.

4 : CHW

A young man of 18 who appeared to be heavily drugged and found it difficult to speak coherently for any length of time.

His father is a food scientist and his mother a teacher; he has a younger brother and a younger sister. They live in their own home in London.

He attended a state primary school until he was 8 and was then sent to a private school but was asked to leave shortly before he was due to take his 'O' levels, on account of his epilepsy. He was becoming progressively more worried as his exams approached. This precipitated more fits and eventually provoked a nervous breakdown.

He has since worked for a time as a storeman but is currently unemployed and attends a local authority day centre for handicapped people. He is interested in electronics but finds it difficult to remain interested in any hobbies for very long.

5 : CNT

A young man of 21 who appeared slow, ponderous and badly co-ordinated.

His father is a general practitioner and his mother is a housewife; he has both a younger brother and a younger sister. They live in their own home in London.

He attended private boarding schools, both primary and secondary, and then went to public school. He left with two CSE's Grade I, and six other lower grade passes, two Ordinary National Certificate Credits and a Certificate in Office Studies.

He has had a number of jobs and worked variously as a messenger, a clerical officer, a packer and a trainee storekeeper. He was currently unemployed though registered with the Department of Employment as disabled and hence a 'green card holder'.

He has a number of hobbies including chess, theology, politics and current affairs and reading science fiction.

6 : CMG

A young man of 20 who lives in Oxford but is currently studying at a London College and hence staying with the Secretary of one of the local action groups in London.

His father is a former travelling salesman who is now training to be a silversmith and his mother works as a secretary. She is also Secretary to the local action group. The grandparents are also resident in the family home which is a council house located in a village, but the family is buying the property from the Council.

He attended the local village primary school and then secondary school until he was 13. Then he went to the local technical school where he obtained four 'O' levels, gained 'A' level in Art, but failed to obtain 'A' levels in Maths and Physics. From school, he attended the local Polytechnic taking a course in Art and Design and has now moved to a London College to take a more specialised course in Art and Design.

He has never worked nor, as yet, applied for any jobs; he has a number of hobbies including collecting stamps, coins and matchboxes.

7 : CJE

A fresh-faced youngster, aged 18, who seemed rather shy.

His father is a plumber and his mother doesn't work except for occasional casual farm work. He has no brothers or sisters and lives with his parents in a council house - the same house he has lived in all his life.

He attended the local primary and secondary schools and left at the age of 16 with five CSE's but had failed five 'O' levels.

Since then, he has had one job as a tyre-fitter but left after five days by mutual agreement - 'his boss found out he had fits and he was bored anyway'. He was due to attend an induction course at the local further education college with a view to enrolling full-time on a carpentry and joinery course.

His main interest is sport and he also makes walking-sticks as a hobby, some of which he sells.

8 : CDW

A young man aged 20 who confessed, during the course of the interview, to being a homosexual.

His father works for a security firm and his mother is an office worker. He has three younger sisters. He does not live with his parents but with an older 'friend' in a rented flat on the outskirts of London.

He attended Catholic primary and secondary schools and then went on to the local technical college. When he left the education sector, he had obtained five CSE's and four 'O' levels.

He has worked for the Civil Service since leaving college, as a clerical assistant. His main interests are buses and 'ham' radio.

(iii) Patients Associated with a Mental Hospital

1 : MMH

A young man aged 18 whose father is a security guard and mother a housewife. There is a history of marital instability; the husband has left on several occasions but always returned; the mother has her own psychiatric problems. There is one married sister and a brother living at home - both are older. The family lives in a three-storey council flat.

He attended two primary schools as a result of the family moving and then went on to secondary school. However, at the age of 13, he was involved in an incident where he caught his toe in the drain of a swimming bath and it took several minutes to free him and he nearly drowned. After that his fits began and he also became a persistent truant from school. He was eventually placed in a mental hospital and completed his schooling there.

While living in the hospital he started working in their Stores and continued to do so after discharge. However, he is now unemployed. He goes out very little and his only interests are television and pop music.

2 : MMB

A young man aged 20 who lived with his parents and younger brother. Both parents are said to be hard-working, (occupations not stated), but their marital relationship is very bad. The mother is thinking of leaving and they both see him as the cause. They are fed-up with him and do not want him home. He in turn wants a place of his own though he is currently in the hostel.

He attended primary, junior and secondary schools and then two special schools. When he left, at 16, he had some CSE's and attended technical college, passing first year City and Guilds.

He worked on a building site for nine months and then spent a period at a training centre. Currently he attends the day hospital, doing packing jobs. He enjoys pop music, swimming and games like chess.

He has imagined that cars were flashing lights at him, that a lot of girls loved him and that he was being poisoned at work. At one time he thought he was Jesus Christ and that John the Baptist was inside him. He had a complete breakdown before taking his City and Guilds Examination and on confinement, he tried to strangle another patient.

3 : MCT

A young man aged 21 who was born in Africa and has lived most of his life in Malawi where his father is a lecturer in history in a College of Education. His mother was an art teacher but she has recently died. He has two sisters - one married and still living in Africa and one married and living in the Midlands. He has a close relationship with his brother-in-law who is a doctor. At the time of the interview he was resident in the open ward.

He attended primary and secondary schools in Africa where he passed his College of Preceptors exams. He also took 'O' levels in English and Maths through a correspondence course in this country and passed English.

He taught Indian children at a private school and then came to this country with his mother in 1975 to see whether it was possible to have an operation for his epilepsy. It was not. He remained but his mother returned to Africa. He went to the hostel and became engaged to a girl who was resident there. He was eventually asked to leave by other residents as he had broken a cardinal rule of the community - no sexual intercourse on the premises. He then stayed in a YMCA hostel but was in hospital having his drugs changed, at the time he was interviewed.

His interests include collecting semi-precious stones, chess, acting and all kinds of music.

4 : MDU

A young black man, aged 18, who lives with his parents in a council house in London. His father is a factory worker in a car plant and his mother works part-time in the kitchen of an old people's home. There are two sisters, one brother and two cousins living in the family home and three brothers living in Jamaica.

He attended primary school and then a special school for remedial education. Later, he was placed in an ordinary school but was involved in violence and suspended after attacks on peers with a bottle and a hammer.

He worked as a warehouseman, in a stationery factory and has attended a training course. Currently, he is unemployed. His interests are tailoring, records, films and football.

He was admitted to hospital on several occasions complaining of odd sensations in his hands, arms and legs - "My parts getting off my body"; "My legs have changed".

5 : MSC

A young man, aged 19, who has recently been turned out of the family home. His father died in December 1977 from asbestosis and his mother has kidney trouble and suffers from mental illness (worries a lot). He has four older brothers, though only one lives at home and he is educationally subnormal. There is also one sister living at home and she is aged 16 and engaged. She has recently been involved in a court case in which her former boyfriend was accused of sexual intercourse with a minor. The family lives in a council flat.

He attended primary school until the age of ten and then went to a special school until he was 16 as he was unable to read and write. He did a number of part-time and Saturday jobs while at school.

He was then employed as a butcher's assistant for two years but was eventually sacked as he drove a van into the wall of the yard whilst having a fit.

He has said that he hears voices, particularly that of his dead father and the hospital referral sheet contained the cryptic note, "Diagnosis -

Epilepsy. Also you deal in suicide and imaginations".

6 : MRG

A young man, aged 23, who currently lives in the hostel. His father is a building site worker and his mother a part-time waitress. He has two younger sisters and two younger brothers and one of his sisters has recently qualified as a nurse. The family live in their own home and an uncle lives with them.

He attended two primary schools, (one Church of England and one Catholic), and the secondary school. He left at 15½ with one CSE in Art.

He has had numerous jobs including petrol station attendant, van boy, railway porter, council workman, hall porter and trainee cook. He was currently working in the hospital kitchen.

His interests include all sports, particularly football which he likes to both play and watch. He also likes to travel and he goes to the cinema often.

He was admitted to hospital after a violent family episode and an overdose and is said to be "A reactive depressive psychotic".

7 : MRL

A young man, aged 18, of Mauritian parentage but adopted by a British couple; the husband works as a steel fitter. His stepmother left in 1972 and has remained untraced. He has one 'own' sister who was married and is now separated and living elsewhere. He was currently resident in the open ward but intends to return to live with his step-father.

He attended primary and secondary schools but was frequently hospitalised for epilepsy. Hence, he was eventually placed in a hospital school which specialised in the education and care of epileptics.

He was still at school and had not applied for any jobs though he professed an interest in carpentry, metal work and gardening.

He had a lifelong history of grand mal convulsions, poorly controlled by medication, and he underwent a right temporal lobectomy in October 1977. The immediate post-operative period was uneventful and he was discharged home but became bored, resentful and frustrated and tried to stab himself. He was re-admitted to hospital and then discharged back to the hospital school but became restless, tense and violent, attacking staff and furniture. The staff at the hospital school would be "overjoyed if he could be returned to his pre-operative state".

8 : MMS

A young man, aged 23, who moved from the family home in 1975. His father has left and his mother has a male 'lodger'. There is one older brother and the home is owned by the mother.

He attended a primary school but, after a number of difficulties, he was transferred to an educationally sub-normal school. He then attended an ordinary secondary school.

He worked in a factory, cutting straps, for a year and then was employed as a cleaner in a soft-drinks factory. Since then he has been employed as a porter on several occasions but is currently unemployed and living in the hostel. His main interest is cycling. He has a bike of which he is very proud and which he rides frequently.

His illness is diagnosed as idiopathic epilepsy with personality disorder.

CHAPTER THREE

SOCIAL AND HISTORICAL DEFINITIONS OF EPILEPSY

A HISTORICAL ACCOUNT

Although this study will be essentially concerned with current experiences and problems in the lives of epileptic adolescents, such a study would be incomplete without reference to the fascinating history of epilepsy in a sociologically relevant way. The words of C. Wright Mills (1959.159) are very much taken to heart:

> "Social Science deals with the problems of biography, of History, and their intersections within social structures.... The problems of our time.... cannot be stated adequately without consistent practice of the view that history is the shank of social study, and recognition of the need to develop further a psychology of Man that is sociologically grounded and historically relevant."

The everyday problems and experiences of adolescent epileptics cannot be adequately understood without reference to previous evaluations and social meanings associated with epilepsy, for such evaluations and meanings provide a backdrop to present ones and may, therefore, partially shape the social world in which the epileptic of today lives out his life.

(i) Evaluations of Deviation

A number of sociologists have attempted to relate the way phenomena are perceived, evaluated and treated to the central values or dominant mode of thought in the Society concerned. One of the most influential proponents of this view is, undoubtedly, Parsons (1964) who has argued that, in the U.S.A., societal values centre around notions of health and therefore, deviation is more likely to be considered a problem of illness rather than law, ritual purity or political commitment. This is not to say that alternative or competing evaluations will not exist but that, where a particularly deviant phenomenon has newly arisen or is ambiguously regarded, then the central values of the society concerned will be influential in determining not only how a particularly deviant phenomenon is evaluated, but also how the particular deviants are treated and what methods are deemed appropriate to their treatment and control. Thus, Parsons' identification of the American commitment to health values accounts in part for the process which is sometimes referred to as 'the medicalization of social problems', a process in which a number of ambiguous social behaviours have been labelled 'sick' and those so labelled have been subjected to medical treatment of one kind or another.

This type of analysis has been given a historical dimension, notably by Kittrie (1971) who examined a number of deviant phenomena, such as drug addiction, homosexuality, alcoholism, and mental illness and demonstrated how such phenomena were originally regarded as moral, then legal and now, medical problems. As a result of these evaluations, the particular deviants were subjected to appropriate moral, legal and then, medical modes of social control. This, what almost amounts to an evolutionary progression, appears in the lay as well as academic consciousness, as the Dean of an American college showed when he complained that once his rebellious students would have been burned at the stake, later they would have been imprisoned but today they are sent to psychiatrists.

A major criticism of this approach has been levelled at much of Parsons' work, not simply his discussions relevant to medicine. This argues that there is no one central value system and that social evaluations of moral meanings arise out of group and individual conflicts and that a number of competing, heterogeneous meanings may exist in a society at a given time. The emergence of meanings and evaluations through conflict does not necessarily follow an orderly and evolutionary progression, as Kittrie's study implies, but is contingent on a number of factors, the most noticeable of which is power, albeit economic, social or personal. Gusfield (1972.4) aptly describes this process:

> "The public definition of behaviour as deviant is itself changeable. It is open to reversals of political power, twists of public opinion, and the developments of social movements and moral crusades. What is attacked today as criminal may be seen as sick next year and possibly legitimate by the next generation. Movements to redefine behaviours may eventuate a moral passage, a transition of the behaviour from one moral status to another."

This framework is ideal for consideration of the differing evaluations to which epilepsy and epileptics have been subjected; at one time or another, epilepsy has been regarded as a manifestation of divine or demoniacal possession, as character weakness and, therefore, a legal problem needing to be controlled by laws, and as illness, both physical and mental, and therefore requiring medical treatment of one kind or another. But at no time and in no society have such definitions and treatments been mutually exclusive - they have existed side by side - sometimes in conflict and sometimes in harmony.

The different evaluations give rise to different treatments; in ancient society the scientific explanation of epilepsy, as advanced by Hippocrates, posited dietary treatment in order to reduce the levels of phlegm, whereas the magical explanations posited the use of various pharmacological substances which operated in mysterious ways to alleviate spiritual possession. The conflicting evaluations and treatments stem from a variety of social factors, most notably that the physicians and their patients were drawn from the upper strata of society and, consequently, were able to afford expensive dietary restrictions. On the other hand, the poor were forced to rely on a drug or an incantation which provided a quick and cheap, although mysterious, cure. However, it would be a mistake to exaggerate this distinction and to see the relationship between evaluations and treatments for epilepsy and the status of physicians and epileptics in a rigid or mechanistic way, as the study by Tempkin (1971.81) clearly shows:

> "It certainly would be a mistake to exaggerate this distinction between the dietetic and pharmacological treatment. There existed many educated people who put their trust in mysterious drugs. On the other hand, the pharmacologists often tried to rationalise the action of remedies of doubtful origin."

Such conflicting evaluations are evident throughout the history of epilepsy but it is possible to separate out some of these and provide a few historical highlights of religious, legal and medical evaluations of epilepsy. These are intended to be illustrative rather than comprehensive and should not be read as an attempt to summarize the history of epilepsy.

(ii) The Religious Framework

According to Durkheim (1915.24):

> "One idea that generally passes as characteristic of all that is religious, is that of the supernatural."

It is this idea of epilepsy as part of the supernatural world, of which organized religion is only a part, that provides the orienting framework for this discussion. Thus, at one time or another, epilepsy has been regarded as divine possession - 'the sacred disease'; possession by the devil - 'the falling evil'; or possession by spirits, either benign or malevolent. Usually, whether evaluations have been purely magical or religious, they have nonetheless centred around notions of good or evil, and have been perceived as reward for correct behaviour or punishment for evil-doing.

These different conceptions have given rise to different attitudes towards epilepsy which sometimes existed side-by-side. According to Kanner (1930.174):

> "The two attitudes of horror and adoration have run parallel practically everywhere in the course of the past three thousand years."

The following then have been thought responsible for epilepsy at various times by various cultures; the ancient Babylonians thought it was a special demon called Labasus who was responsible, Hindu mythology cites a female deity called Grahi, the ancient Greeks held a number of gods responsible, depending on the nature and type of fit, including Hera, Poseidon and Aenodeus and, in Rome, epilepsy was thought to be a manifestation of evil spirits. Many of today's primitive societies share similar views on the nature of epilepsy. One writer (Aall-Jilek 1965.64) has made a special study of epilepsy among the Wapagoro, and states:

> "Epilepsy is for them something dramatic, frightening and inexplicable. It must therefore be a spirit who has taken possession of the patient. Whether it is a good or a bad one nobody knows. Some epileptics may be regarded with a certain degree of respect on this account.... but mostly the spirit possessing them is supposed to be evil. More recently they have begun to say that it is the devil - Shetani."

The nearest that epilepsy came to a common universal evaluation resulted from the coming of Christ and the rise of Christianity, and can be directly related to the study of Jesus healing an epileptic boy by casting out an evil spirit from his body. This episode was of such significance for future evaluations of epilepsy that it is worth repeating at length:

> "A man brings his son to Jesus, saying, "Master, I have brought Thee my son, which hath a dumb spirit; and whosoever he taketh him, he teareth him: and he foameth, and gnasheth his teeth, and pineth away...."

> "Jesus demands that the boy be brought before Him and when He saw him, straight away the spirit tear him; and he fell to the ground, and wallowed foaming. And He asked his father "How long is it ago since this came unto him?". And he said "Of a child". And oftentimes it hath cast him into the fire, and into the waters, to destroy him.......
>
> Upon the father's assertion that he believed, Jesus rebuked the foul spirit, saying unto him, "Thou dumb and deaf spirit I charge thee come out of him and enter no more into him". And the spirit cried, and rent him sore, and came out of him: and he was as one dead.......
>
> But Jesus took him by the hand and lifted him up and he arose."

Nowhere is epilepsy mentioned specifically but the description of the boy's ailment leaves little room for doubt and the general concensus by medical and theological experts was that Jesus had cured a case of epilepsy by casting out an evil spirit. Now Christianity was not essentially a class-based movement but had penetrated to all levels in society, and thus the biblical account facilitated the general and widespread belief, prevalent for many centuries, that epilepsy was a case of demonic possession. The belief in demons as a cause of epilepsy persisted well into the Middle Ages and beyond. Indeed, according to Tempkin (1971) during the 15th, 16th and 17th centuries the belief in epilepsy as an instance of demonic possession actually increased and was not confined simply to theologians and the lay populace but physicians were also ready to admit the influence of the supernatural. Tempkin (1971.227) cites the influence of enlightenment ideas as the most important factor in the demise of religious or supernatural evaluations:

> "The rejection of all belief in the demoniac nature of epilepsy reflects a changed attitude towards unexplained and obscure phenomena. What general factors caused this changed attitude, which we call

> enlightenment, need not be asked here. Confining ourselves to epilepsy we must, however, realise that it was this changed point of view which made the demons and witches disappear, rather than any progress in the pathology of the disease, or any fundamentally new clinical observations."

However, the relentless progress of enlightenment ideas to the present day has not eradicated supernatural evaluations from either popular or scientific consciousness. Articles sometimes appear in respectable medical journals commenting on the number of fervently religious epileptics that particular workers have treated (Dewhurst & Beard 1970). Additionally, a recent article in a popular women's magazine (Woman's Own 6.11.76.50) points out that a number of psychic researchers have found supposed connections between epilepsy and poltergeist activity. Finally, a contemporary writer Evans (1953.132) evaluates her own epileptic experiences within a religious framework:

> "An epileptic, if he is not born religious, is likely to become so out of his unconscious and profound excursions into infinity. He must find God, or the source which arbitrarily and often absorbs himself. The healer of death the world's greatest physician, the greatest doctor to mental maladies ever recorded, said to the sufferer of a nervous disease, on sight "Son, thy sins be forgiven thee" and in easing the spiritual strain, fulfilled the physical cure. To grant a wish is to cure a pain. Money buys evil but not good, and the world, the temple is become a den of thieves."

(iii) The Legal Framework

Legal restrictions with regard to epilepsy can be traced back as far as Hammurabi, who according to one authority (Holmes 1976.22):

> "....was a lesser chief who united a number of smaller countries in Mesopotamia and formed them into the Babylonian empire with itself as ruler and Marduk as its chief god. This took him over thirty years to

> achieve, but he was then able to give justice to the people and to grant them good governance, to set forth truth and justice within the land and prosper the people."

This was achieved by producing a code, written on clay tablets which contained among other things, the first coded social stigma against epileptics. This was composed of restrictions relating to three areas in the lives of epileptics; firstly epileptics were not allowed to marry, secondly they were not allowed to give evidence in Court, and finally, slaves who developed epilepsy could be returned to the original seller within one month of the sale.

Most other societies were content to rely on social sanctions as the means of controlling the lives of epileptics. In Britain many epileptics found themselves the responsibility of the Poor Law Guardians and were lumped together with the mentally ill, the poor, the idle and the sick, in workhouses or asylums. The coming of the industrial revolution and the process of industrialization had serious implications for the epileptic as Jones & Tillotson (1965. 5-6) spell out:

> "The drift to the town and the growing complexity of industrial machinery at the time meant the development of a class of industrial rejects for whom it was clear that special provision would have to be made.... The problem of severe epileptics in a city such as Bradford, where the wool trade meant fast-moving machinery and crowded workshops, must have been particularly acute."

The usual result for many social deviants unable to adapt to the requirements of the industrial system was the asylum or the workhouse and it was not until the 1880's that a movement to separate epileptics from the mentally ill began. In the following thirty years eight epileptic colonies were built and segregation was added to the existing policy of isolation. In the U.S.A. epileptics were lumped with other social deviants in practice but from 1895 onwards legal restrictions that had applied to the mentally ill were applied equally to epileptics. Barrow & Fabing (1956.23) writing little over twenty years ago stated:

> "Our laws set epileptics apart as a special group in society and contribute greatly to the stigma against epilepsy. Eugenic marriage and sterilisation laws apply equally to idiots, epileptics and the insane.... Now that institutional care is rarely necessary in the case of epilepsy this condition should be dissociated from mental illness and mental defects in order that the stigma against epilepsy may be uprooted. Enforcing epileptics into the same legal mould with the mentally defective and the mentally ill who require institutional care, separating them only by a comma, the law's conditioned society to associate and to equate these mental conditions with epilepsy."

Certainly, it would be true to say that the last twenty years have seen a de-colonization and an attempt to de-isolate epileptics in both Britain and the U.S.A. However, the life of the epileptic outside the institution is, and has been, surrounded by a number of legal constraints. In this respect, Britain has been more humane than some other countries; for example, marriage between epileptics is not prohibited in this country although in Sweden and in a number of States in the U.S.A. it has been, or still is, on the statute-books; Britain has only recently, (1971), changed the law with regard to divorce and epilepsy, however, in that having epilepsy is no longer recognised as a reasonable ground for divorce. Travel presents another restriction; many countries are reluctant to admit epileptics as immigrants and Australia actually has laws banning them. Driving, almost an essential to life in modern Britain, was illegal for epileptics until recently, and even today epileptics are only allowed to drive if they have been seizure-free for at least three years. This change in the law has brought little benefit to many epileptics for they find it impossible to obtain motor insurance at reasonable prices.

There are two underlying reasons why the social life of the epileptic has been surrounded by more legal restrictions and the infringements of personal freedom than the ordinary citizen is forced to endure. Firstly, the epileptic, like a number of other minority groups, has been unable to conform to the requirements of the Protestant ethic; that is, to work hard and regularly, abstaining from excessive enjoyment of the present in order to store up benefits for the future. That is not to say the epileptic has proved incapable of hard work, but simply working regularly in a factory and coping with a very difficult illness have proved very difficult tasks to accomplish. The second factor stems from the notion that having epilepsy makes people lazy, careless and untruthful; - More will be said about 'the epileptic personality' later. From this stems a notion that epileptics are weak characters who have to be closely watched and rigidly controlled in order that they do not revert to type and become idle liars. In general, however, legal sanctions have only been used as an adjunct to religious, moral and medical sanctions and with few exceptions, have they occupied a central place in social evaluations of epilepsy.

(iv) The Medical Framework

Epilepsy is probably the oldest known disorder of the brain and one of the earliest and most famous medical treatises on epilepsy appeared in the book 'On the Sacred Disease' written by Hippocrates in 400 BC. The book was an attack on supernatural explanations of epilepsy and the consequent fraudulent and superstitious treatments often practised by magicians and charlatans. Hippocrates correctly attributed epilepsy to abnormal cerebral function, and argued that this was caused by an excess of phlegm, one of the four humours, which prevented air-carrying vessels from reaching the brain. This emphasis on the physiological basis for seizures is, according to Lennox (1960) like one tower of a suspension bridge whose twin, however, is more than two thousand years beyond and whose building is not to begin until the nineteenth century. Even though medical science made little progress in understanding the physiological basis of epilepsy, a medical conception of epilepsy survived among a number of medical practitioners, even in periods of excess religiosity when a religious mode of thought was almost totally dominant, as Tempkin (1971.133) says in discussing the Middle Ages:

> "It can be said that the Middle Ages added little to the physiological understanding of epilepsy yet at a time when the vague conception of the falling evil prevailed among the people and even when the educated were inclined to mistake a disease for demoniac possession, it was no small merit for the medieval physicians to have kept alive the tradition of epilepsy as a natural disease caused by natural factors."

The age of enlightenment produced a significant change in social and medical evaluations of epilepsy and its connections with demonic possession. However, this change stemmed from a more rational and enlightened way of thinking rather than from medical or scientific advances and consequently, all that happened was that one set of myths was replaced by another. Thus, in keeping with the morality of the time, sexual excess and masturbation were regarded as the commonest causes of fits. Accordingly, epileptics were discouraged, if not prevented, from marrying and if they found themselves in institutions - workhouses, asylums for the insane and later, epileptic colonies, they were rigidly separated from members of the opposite sex. Treatment reached its zenith when, as late as 1880, one Dr. Bacon reported to the British Medical Association that he had castrated two male epileptics, with the result that, in one case, there was a great improvement.

The foundations of the second tower of Lennox's 'suspension bridge' were laid by Hughlings Jackson who in 1873 wrote:

> "Epilepsy is the name for occasional, sudden, excessive, rapid and local discharges of grey matter."

Since then, advances in neurological diagnosis, the electroencephalograph, improved techniques of brain surgery and the development of anti-convulsant drugs have all played their part in the present dominance of the medical framework for the evaluation of epilepsy. It is only fitting to summarize these trends by reference to Tempkin (1971.3-4):

> "In the struggle between the magic and the scientific conception, the latter has gradually emerged victorious in the Western World. But the fight has been long and eventful, and in it epilepsy held one of the key positions. Showing both physical and psychic symptoms, epilepsy more than any other disease was open to interpretation both as a physiological process and as the effect of spiritual influences..... as soon, therefore, as a rational pathology was established, claiming to explain all diseases as merely physical processes, its explanation of epilepsy became the test of the validity and persuasive power of the whole system. And it is thus that the history of epilepsy becomes at the same time, an example of the history of magic beliefs and their refutation by scientists and scientific physicians."

The medical conception has not completely replaced religious ones and whereas in earlier times, medical notions were silent in a dominantly religious society, today the religious notions are often silent in a medically dominated society. However, radically different conceptions may occasionally erupt as with the recent celebrated case in Germany - The News of the World (22.8.76) carried the following headline:

> "Exorcist Bishop and Death of Girl with Six Demons"

and then went on to relate:

> "A storm has broken over the ordeal of a girl who died, weighing less than five stone, after nine months of exorcism rituals.

> The girl, 23 year old Annalise Michele suffered from epilepsy. But the Roman Catholic bishop of Wuerzburg, in West Germany was convinced that she was possessed by evil spirits.
>
> Without seeking medical advice, he sent two priests to rid her of the six demons which he believed were in her body." (1)

However, despite occasional conflicts, there is no doubt that the medical framework is the dominant mode through which epilepsy is perceived and evaluated in society today. The commonly accepted explanation for this is that epilepsy is a physical illness and was wrongly evaluated in previous times and in other societies. Now, at last, advances in medical science are providing a much more satisfactory basis for the treatment and cure of epilepsy. In the following section, it will be argued that medicine cannot do all that is often claimed for it with regard to the treatment of epileptics and the final section will examine other reasons for the dominance of medicine - a process sometimes called the medicalization of social problems.

THE MEDICAL MODEL AND EPILEPSY

A number of writers (Goffman 1961, Scheff 1975) have identified underlying structural similarities in the way the medical profession go about the business of identifying diseases and curing illness. Having identified a number of crucial variables, they have then proceeded to subject stages of the process of medical diagnosis to a number of searching criticisms, for example, Sheff has this to say about the medical model when applied specifically to mental illness (1975.7):

> "The key attributes of the medical model have yet to be established and verified for the major mental illnesses. There has been no scientific verification of the cause, course, site of pathology, uniform and invariant signs

> and symptoms, and treatment of choice for almost all the conventional, functional diagnostic categories."

In this section, the medical model with regard to epilepsy will be subjected to a similar assessment in order to find out a) whether it can locate the cause of epilepsy, b) recognize the symptoms, c) treat the illness and d) cure the underlying disease or pathology.

(i) Cause

Many epileptologists would be able to accurately describe what epilepsy is, (Reid Report 1969.10):

> "Epilepsy is not a disease but a symptom. It is a word used to describe repetitive stereotyped disturbances of consciousness, of feeling, or of movement which are primarily cerebral in origin. These range from trivial experiences such as a twitch of a finger or a flash of light to frequent, uncontrollable, prolonged convulsive states."

However, the cause of such excessive cerebral activity cannot often be diagnosed. As a general rule, those suffering from fits as a result of either a definite disease of the brain or a disease of other parts of the body affecting the brain may be said to have symptomatic epilepsy. Those many people who have no definite underlying pathology but, nonetheless, have fits are usually said to have idiopathic epilepsy. (For detailed classification of the epilepsies - see Appendix D.)

What is more, as Livingstone (1963.15) points out, numerous other discreet medical conditions may give rise to spells or convulsions of various types, similar to symptoms of epilepsy. (Table I, p.85) So, the manifestation of symptoms may be open to a variety of interpretations of which epilepsy may be only one possibility.

TABLE I

DISORDERS WHICH ARE ASSOCIATED WITH CONVULSIONS OR SPELLS OF VARIOUS TYPES

1. Intracranial infections, e.g., meningitis, encephalitis, cerebral abscess.
2. Intracranial hemorrhage, such as caused by direct injury to the brain substance (at birth or other trauma), rupture of cerebral blood vessel (from disease such as arteriosclerosis or defect such as aneurysm).
3. Subdural hematoma.
4. Concussion of the brain e.g., acute trauma to the head.
5. Metabolic disorders, e.g., tetany (hypocalcemia, alkalosis), hypoglycemic states, phenylpyruvic oligophrenia, hypernatremia.
6. Renal disorders, e.g., uremia.
7. Breath-holding spell (in children).
8. Emotional (functional) disorders, e.g., simple fainting spells, hysterical convulsions.
9. Parasitic brain diseases, e.g., toxoplasmosis, malaria, hydatid cyst, cysticercosis.
10. Narcolepsy and Cataplexy.
11. Allergy.
12. Intracranial neoplastic diseases, e.g., brain tumours.
13. Hypertension and cerebral arteriosclerosis.
14. Syncopal attacks, e.g., carotid sinus syndrome, Stokes-Adams disease, Meniere's syndrome.
15. Toxic
    - a) Drugs, e.g., when taken in excess or if sensitivity is present, many of the commonly used drugs such as ACTH, atropine, Benadryl, boric acid, caffeine, cortisone, epinephrine, penicillin, Thorazine and Compazine will cause convulsions.
    - b) Acute lead encephalopathy.
    - c) Kernicterus.
    - d) Immunizations, particularly pertussis (may also be due to fever).
    - e) Roseola infantum (may also be due to fever).
    - f) Shigella gastroenteritis (may also be due to fever).
16. Cerebral degerative diseases, e.g., Schilder's disease.
17. Congenital cerebral defects, e.g., tuberous sclerosis, Sturge-Weber syndrome, hydrocephalus, cerebral aplasia.
18. Fever in young children (usually associated with infections such as tonsillitis or otitis media), e.g., simple febrile convulsions.
19. Alcoholism.
20. Neurosyphilis.
21. Anoxia, e.g., anesthetics.
22. Eclampsia.
23. Tetanus.
24. Epilepsy.

Scheff (1975.8) has suggested that, specifically with regard to mental illness, where symptomatic behaviour is open to a wide variety of interpretation, a generalized category has developed, in this case schizophrenia: what he calls 'a residue of residues'. Thus, with epilepsy, where fits cannot be diagnosed as symptomatic of a particular disease or have an underlying cause, then epilepsy may serve as a residual dumping ground. Additionally, according to Scheff (1975.9):

> "Mental health procedure and the conceptual apparatus of the medical model posit internal states, but the events actually observed are external."

Again, much the same is true with epilepsy: fits are considered to stem from internal defects in the brain but the events actually observed are external to the brain. However, before any firm statement on the matter can be made it is necessary to look at the diagnostic techniques used by physicians in the interpretations of fits as evidence of epilepsy.

(ii) Symptoms

Accurate diagnosis depends on accurate description of the symptoms of a particular disease. With regard to epilepsy the symptoms can be of a wide and varied nature, ranging from major convulsions in which all limbs jerk and twitch and the patient may froth at the mouth, to minor losses of consciousness (absences) where the patient may not even fall; automatic and repeated movements of the limbs may occur, patients may repeatedly perform the same act, like lighting an invisible cigarette, or repeat phrases over and over again. Additionally, fits may follow a three or four-stage process - there may be a warning period sometimes called an aura, the fit itself may have two stages, the tonic and the clonic, and then a recovery stage, sometimes called the postictal, where the patient may be confused, sleepy or behave automatically - but not all fits may occur in all stages, some may occur without warning, sometimes the warning may occur without the fit, and so on.

It is, then, the job of the doctor to provide a diagnosis for a wide variety of behaviours and to hopefully subsume them under a single label. There are two main diagnostic techniques used by the doctor; a clinical case history and the measurement of electrical activity in the brain by an electroencephalograph machine.

With regard to the first, it is often not possible for the doctor to observe the symptoms at first hand and therefore, he needs an accurate description of the attacks from the patient and any other witness to the attacks. Additionally, he will need to know the age of onset of the attacks and whether the patient had any possibly-related illnesses as a child or whether any injury to his head had occured. As labelling theorists have pointed out (Schur 1971.52-56) behaviours or incidents may be retrospectively reinterpreted to give them presentday significance. Lofland (1969.150) puts the matter succinctly:

> "There must be a special history that specially explains current imputed identity."

And the medical profession may become specialists in biographical reconstruction. In the case of the diagnosis of epilepsy many, if not most, people have at least one fit or absence or trance, and who could not search their memory and find an incident where they may have banged their head too hard?

This state of affairs would not be too important if one could assume that a sufficiently skilled diagnostician is accurately able to assess these descriptions and their significance for eventual diagnosis. However, Scheff (Deutscher 1973) has argued that individuals actively construct their own realities and that in a diagnostic situation, (in the widest sense), multiple realities may exist and be the subject for negotiation between interrogator and interrogated. What is more (Deutscher 1973.342):

> "The interrogator's definition of the situation plays an important part in the joint definition of the situation which is finally negotiated. Moreover, his definition is more important than the client's in determining the final outcome of the negotiation, principally because he is well-trained, secure and self-confident in his role in the transactions, whereas the client is untutored, anxious and uncertain about his role. Stated simply, the subject, because of these conditions, is likely to be susceptible to the influence of the investigator."

Thus, in some situations, physicians may feel it incumbent upon them <u>not</u> to diagnose epilepsy, (suggested by Harrison and West 1976); in others, to diagnose in all cases of possible epilepsy (see following section). And if different physicians adopt different definitions of situations this would account for different and conflicting diagnosis of what is medically the same condition; that is, where a patient may be told by one specialist that he has epilepsy and another that he has not. One of my respondents, for example, was diagnosed as epileptic by a paediatrician but the diagnosis was rejected by the Principal of a special centre for epilepsy.

Nor does the use of the second diagnostic technique, the E.E.G. machine, necessarily make diagnosis any more certain. The machine is used to measure electrical activity of the brain, and often those having epilepsy will exhibit spiked brain-waves on the tracings from the machine. Unfortunately, however, some patients with epilepsy may have normal E.E.G. readings whereas some people who do not have fits may show abnormal patterns in their E.E.G. which are not dissimilar to those occuring in epileptic patients.

According to one writer (Scott 1973) between five and ten per cent of the population may exhibit spiked brainwaves. As E.E.G. measurements have become more complex and sophisticated, so has it become more difficult for individual physicians to agree among themselves as to what particular traces actually indicate about underlying causes. Williams (Harris and Mawdsley Ed. 1974.346-7) has summed up the efficacy of E.E.G.'s as follows:

> "And when it came into clinical use nearly forty years ago, those of us who were working with it hoped that it would soon unfold all the mysteries of epilepsy. The dramatic first recording of the spiked wave accompaniment of petit mal.... related a negative psychological absence to an observed and unequivocal physical presence in the recording, which could be studied, experimentally modified, and sometimes abolished. Yet petit mal is still as common as ever, its physiological basis remains just as obscure, and its treatment is still less effective than is that of the clinically more dramatic grand mal. So too with grand mal - we are not much further along the road. The electroencephalogram has greatly stimulated research, with good fortune it may occasionally point to the first physical cause of grand mal in any one patient, but it does not often add significantly to the clinician's knowledge of what is wrong in any particular patient."

One final problem with regard to diagnosis needs to be discussed and that is the problem of distinguishing between genuine epileptic fits of idiopathic nature and fits which may be hysterical in origin. Probably the most famous discussion of such matters is the debate which has gone on for many years about whether Dostoevsky was a genuine epileptic or someone who was subject to hysterical fits (see Frank 1975). Of course, most epileptologists would argue that in the clinical situation it is relatively simple to distinguish between the two kinds of fit, for example (Livingstone 1963.74-5) states:

> "In some instances the appearance of a hysterical convulsion is exceedingly difficult to differentiate from a true epileptic seizure. However, in most instances the differentiation does not present too much of a problem. Hysterical convulsions are not usually associated with biting of the tongue and there is usually no urinal or faecal incontinence. The onset of hysterical convulsions is generally less sudden than that of true epilepsy, and in most cases bodily injury from this spell does not occur. The hysterical patient does not usually pass into a true stupor at the end of a convulsion as the epileptic usually does."

However, it is not always easy to distinguish between the two kinds of fit for doctors are not always able to observe fits and may have to rely on the case history or the E.E.G., the limitations of which have already been discussed. And the relationship between epilepsy and other psychological or environmental factors is unknown.

The correct time for a diagnosis to be made explicit is not something upon which all physicians would agree either; according to Livingstone (1963.12):

> "Many physicians do not diagnose a disorder as epilepsy until a patient has had many seizures of undetermined cause. I assign a diagnosis of epilepsy to all patients who have seizures of undetermined aetiology regardless of whether they have one seizure or many. In the case of the patient who has had one seizure of undetermined aetiology, I make a tentative diagnosis of epilepsy and continue with this diagnosis unless the passage of time proves that the seizure was a manifestation of some other disorder."

However, Espir states (1967.375):

> "Convulsions can be induced by various means, all brains being potentially epileptic, some more susceptible than

> others, and thresholds may vary at different times in the same person. Thus, convulsions may occur in a predisposed person after a period of fatigue, sequential loss of sleep, hunger, overhydration and/or alcoholic excess or with toxic infective illnesses. So the physician can place no limits on the immediate precipitant or more remote predisposing causes. Even extreme grief or other psychological stresses may appear to trigger off convulsions; it is not by chance that in referring to a series of coincidental catastrophes people say, 'I nearly had a fit'. However, a single fit does not constitute the state of epilepsy, and from the social viewpoint the term epilepsy might only be applied where attacks reoccur with sufficient frequency to be a social handicap."

(iii) Treatment

Undoubtedly, the major form of treatment for epilepsy, once it has been diagnosed, is the administration of anti-epileptic drugs. The success of such anti-convulsants is variously estimated at between sixty and eighty per cent, and if they do not prevent all fits in all epileptics, enable four out of five so afflicted to lead reasonably conventional and normal everyday lives. However, such treatment does not follow the medical model in that only the symptoms are treated and anti-convulsants do not rectify the underlying pathology. Moreover, the continued use of such medications may have considerable drawbacks and social costs.

Not only do doctors disagree about the appropriate time to make explicit diagnosis, but also about when to begin administering anti-convulsants. Some argue that treatment should begin as soon after the first convulsion as possible, but others take the opposite view; viz. Mawdsley (Critchley et al 1974.113):

> "An isolated fit should not lead to the immediate institution of long-term drug treatment. After a single fit it is usually wise to observe the patient

> for a period, and only if further convulsions occur should anti-convulsants be introduced."

This conflict is even more important with regard to young children for it is often argued that seizure-activity can damage an immature brain and thus have consequences that are lifelong for the person concerned. Therefore, so the argument goes, medication must be administered as soon as possible in order to minimise the possibility of permanent damage. However, infants may have fits triggered off by fever, injections, or infantile spasms, cholic and breath-holding attacks can also sometimes be mistaken for fits; thus making the use of anti-convulsants unnecessary.

Part of the problem in this debate is that the way medication acts on the brain is virtually unknown. Woodbury et al (1971.647) put it thus:

> "Despite an abundance of knowledge in clinical and experimental epilepsy and on the drugs effective in the treatment of this disease, a full understanding of the metabolism and mechanisms of anti-convulsant agents is still lacking. Although much information has been accumulated on physiological and biochemical affects of anti-convulsants, the ultimate basic affect, defined as the action, has not been elucidated."

Not only are the basic mechanisms not understood, but many of the drugs also produce side-effects of a short and long-term nature which can sometimes be more disabling than the symptoms themselves. Among the short-term side-effects that have been said to have been provoked by anticonvulsant drugs are drowsiness, dullness, belligerence, hyperactivity, euphoria and aggression. However, there is much less literature on the long-term side-effects of such medications. It has been pointed out (Woodbury et al 1974.530):

> "The epileptic patient receives medication over a protracted period of time - frequently for years and often a lifetime. It is not surprising, therefore, that some side-effects may not be discovered until many years after a drug is introduced. Some of these effects, such as interfering with the thyroid hormones to plasma proteins, may be innocuous: others, such as macrocytic anaemia, are of considerable importance. We are still learning of new observations, such as the potential for osteoporosis caused by increased metabolism of Vitamin D by enzyme induction."

What is more, side-effects are not only a result of being on particular drugs but can also occur when they are withdrawn. In fact, withdrawal symptoms can be similar to the epileptic symptoms, i.e. the fit. Thus (Woodbury et al 1974.137):

> "The withdrawal of phenobarbitol from epileptic patients may lead to an exacerbation of seizures that sometimes proceeds to status epilepticus."

Melville (Harrington 1969.91) comes to an appropriate conclusion when discussing the state of knowledge relative to the drug treatment of epilepsy:

> "A hundred years ago when bromides were introduced for the treatment of epilepsy, there were around twenty-five preparations recommended for this disorder. These range from nitric acid through mistletoe to Indian hemp. Looking at the available anti-epileptic drugs of today, I can hear our successors of the year 2068 having similar amused chuckles at the variety of our remedies for the disease. The treatment remains empirical, often it starts as nothing more than a shot in the dark, and we would do well to remind ourselves that we have little knowledge of what anti-convulsant drugs do to our patients."

Another method of treatment for the epileptic is that of institutionalization and in 1966 (Reid Report), it was estimated that there were approximately 2,250 places for epileptics of which ninety-five per cent were occupied. For administrative purposes, these places are included under Part III (2) accommodation which caters for all people requiring residential accommodation because of age, infirmity or other similar circumstances. It is of interest to note that in all Part III accommodation, eighty-nine per cent of all residents are over the age of sixty-five, whereas in epileptic colonies only thirteen per cent of the population were over sixty-five; thus indicating that old age was not specifically relevant to the institutionalization of epileptics. Additionally, an earlier study (Jones & Tillotson 1965) showed that the prime reasons for admitting patients to colonies were social rather than medical, thus indicating that institutionalization might be for the benefit of society, relatives, friends, etc. rather than the epileptic individual himself. Goffman (1961) has pointed out a similar situation with regard to the hospitalization of the mentally ill. Since 1969, the epileptic colonies have been replaced by special clinics and centres and the ideology of care in the community has been given some practical application. However, while substantially less than two thousand people may be now institutionalized in special clinics and centres, a larger unknown number undoubtedly exists in the wards of mental hospitals and also in prisons; and reference to the population of these different types of institutions will be made later in this Study.

(iv) Cure

The fourth component of the medical model, the cure, is possible in only a very small proportion of all epileptics, but some cases of epilepsy can be cured by an operation on the brain. Trephining or the removal of a small piece of the skull, is an operation that has been performed for thousands of years but it is only since the late nineteenth century that neurosurgery has been practical in certain cases of epilepsy. Usually such surgical techniques are possible only in focal epilepsy, i.e. where the underlying pathology can be identified as arising in a discreet area of the brain; and only then if the pathology is not located near a vital area of the brain, such as a part concerned with speech or the movements of limbs. Just as the mechanisms of action of anti-convulsant drugs is little understood, so with the neurosurgical techniques performed - often operations are performed and the effects carefully monitored in order to assess the effectiveness of the particular operation, (see Taylor & Falconer 1972) but there is no adequate explanatory model which takes account of why some operations succeed and others do not. According to Scott (1973.75) summarizing work done in the U.S.A., Canada and Great Britain:

> "....but half the patients are completely cured; in about a third of the remaining patients there is a marked diminution in the frequency of fits, and in the rest there is little change."

But it has to be remembered that these patients represent a very small proportion of all those suffering from epilepsy and for the vast majority a cure is no nearer now than it was 2,500 years ago when Hippocrates was first putting forward his medical theories.

Thus, if the dominance of the medical mode of treatment for epilepsy cannot be accounted for in terms of its ability to diagnose and effectively cure epilepsy, and it has been argued that it cannot, then the reasons for the present dominance of the medical conception of epilepsy must be found elsewhere.

Before proceeding to discuss these other reasons some empirical material will be introduced to illustrate the difficulties that can often arise in attempting to diagnose epilepsy. Further it will be suggested that particular situations (in this case working in a borstal) can influence diagnostic procedures and outcomes.

A CASE STUDY IN THE DIAGNOSIS OF EPILEPSY

In the previous section it was suggested that epilepsy can be a difficult condition to diagnose and the two major diagnostic tools, the detailed case history and the electroencephalograph can be unreliable. Epileptic fits can produce a wide variety of behavioural disturbances from jerking and thrashing of limbs, foaming at the mouth through minor losses of consciousness to automatic behaviour of one kind or another. Doctors often diagnose epilepsy on the retrospective description of those kinds of behaviour from patients themselves or relatives and friends. The EEG machine is not always helpful, the brainwave patterns measured by this machine are often more 'spiked' in epileptics but not everyone with 'spiked' brainwave patterns actually has fits and not everyone who has fits has 'spiked' brainwaves. Further the major treatment for epilepsy is regular injection of anti-convulsant medication and often the over-dosage or withdrawal of this medication can provoke the fits that it is supposed to prevent.

The point of this brief recapitulation is not to mount yet another attack on the medical profession and its shortcomings but to show that the application of the label 'epileptic' is often problematic. Betts (Harris et al 1974.327) in a study of epileptics in a mental hospital found that at least 20% had been wrongly diagnosed as epileptic. He comments:

> "No less than 20% of the patients in the two hospitals who were labelled as epileptic (and who would therefore feature as such in hospital returns and statistics) were not actually suffering from epilepsy in the customarily accepted meaning (some did not have epilepsy at all: others had, or had had, epileptic fits clearly secondary to other causes which occurred and were recognised before the onset of the first fit). It seemed that anyone in these hospitals who had a fit for whatever reason and no matter how long ago was thereafter called epileptic. Such unselective label-

> ling if unnoticed makes nonsense of statistics, and because of the pejorative nature of the word epileptic may have unfortunate consequences for the individual patient."

Gunn (1977) in his study of epileptics made an attempt to check the accuracy of the diagnosis amongst prisoners and found an 18% disagreement with Home Office figures. Their statistics indicated a prevalence of 8.8 per thousand epileptics sentenced to imprisonment: in one month Gunn's estimate was a prevalence of 7.2.

A number of sociologists (Scheff 1966, Friedson 1970) have commented upon the tendency of doctors to over-diagnose, if in doubt, presume illness. In the specific situation of diagnosing epilepsy in a penal institution, there are informal pressures which may reinforce this tendency to over-diagnosis. There are a number of formal rules and regulations in prisons and borstals, relating to the way epileptics should be treated and the things they are or are not allowed to do. It is the responsibility of the medical officer at each institution to classify inmates as epileptic and one medical officer indicated the application of this informal pressure thus, 'The Home Office don't want epileptics falling off ladders - not because they might injure themselves but because someone might ask an awkward question in Parliament about what an epileptic was doing up a ladder in the first place'.

(i) The Social Construction of Epileptic Borstal Boys

In the detailed discussion of individual cases below, it is not my intention to make definitive statements about whether each individual is epileptic or not, but merely to point out that in six of the nine individuals studied, the classification of individuals as epileptic was problematic. In such a situation, with diagnosis a difficult matter, coupled with 'natural' and informal pressures to over-diagnose, it is not hard to see why there are so many epileptics in prisons and borstals.

A brief methodological note should be inserted here in that what follows is based on taped interviews with the trainees themselves, informal conversations with staff and detailed scrutiny of each inmate's prison record, known as 11.50's. At no time did I have access to the medical records of the trainees concerned but nonetheless it is my contention that the information about to be presented throws doubt on the accuracy of the diagnostic and labelling processes in the following cases.

Case 1 - RIM

A young man of 16 with seven previous convictions during the period 1967-75 for a variety of offences including theft, burglary, taking and driving away and arson. On arrival at the borstal he stated that he had epileptic dizzy spells and he was mentioned as being an epileptic when discussed on the Institution case conference. His 11.50 shows that on 23.5.75 at Wormwood Scrubs he was classified as an epileptic and subject to the corresponding restrictions. Support for this diagnosis is mentioned in that he is believed to have suffered brain damage as a result of an accident when he was 5 years old, whereby he fell onto a live railway line and was hurled several feet in the air before being finally rescued. However there is no visible or clinically recognizable damage to his brain.

According to him, his diagnosis as an epileptic occurred in the following way:

I. When did it first become apparent that you were an epileptic?

R. I'm not an epileptic.

I. You're not an epileptic? Well how come it's on your card that you're an epileptic and that you've been sent to see me?

R. Well, while I was in Scrubs - I had an accident with one of the Staff. He were pushing me about, pushing me against the pipe, knocked me out. Instead of - putting charges against him, I just, sort of set it up fainting. So when I came round, they put me down as an E P.

I. Did the doctor think that you were an epileptic or did he know how you - what had happened?

R. No he didn't, er - he most probably thought I was an epileptic.

And in response to questioning about why the story of epilepsy had been concocted:

R. Well, if I'd have brought charges against him and if it'd have been proved not guilty I could have got six months over it.

The accident referred to occurred during a friendly sparring session between the officer and the trainee - a not uncommon occurrence in institutions of this kind. After the trainee had been accidently knocked unconscious, it was decided by him and the officer together to report the incident as an epileptic fit for the officer did not wish to be charged with assaulting and injuring an inmate and, as the transcript indicates, the trainee did not wish to spend any extra time in prison - something which may have happened should he have made out a complaint which turned out to be non-proven. Epilepsy was not selected randomly as the explanation for his unconsciousness but the trainee has had an interest in the subject stemming from a month he spent in a mental hospital recuperating from an overdose of drugs, and an epileptic girl he met there. Since arriving at the borstal, he has worked on a project about epilepsy in his education classes and most of the teaching staff think he is an epileptic. In fact, they suggested that I might interview him before I had compiled a list of trainees diagnosed as epileptic.

Case 2 - RRK

A young man of 19 who has a long list of previous appearances in court behind him, and for a wide variety of offences including theft, forgery, burglary, deception, taking and driving away, criminal damage and assault on the police. He has had a number of different sentences for these offences including care and supervision orders, conditional discharges, fines and finally two sentences of borstal training; additionally he has had periods of psychiatric treatment and oversight.

There is no mention of epilepsy on his first borstal sentence and he was classified and treated as fully fit - 1A. However in the period between his two borstal sentences a letter from his probation officer states "It has recently been suggested that RRK's behaviour may be related to untreated epilepsy. I understand that RRK has experienced two attacks in the last month, the second of which caused severe injuries to his face and necessitated admission to hospital". According to the trainee he had had one fit prior to his first borstal sentence but gone through that sentence as fully fit, but when released he had had a couple of fits, one of which had necessitated hospital treatment. While in hospital a number of EEG's were taken but the results are not included in his 11.50. However, after these were taken when he was on remand at Ashford awaiting his present sentence, the medical officer, who presumably had access to these EEG results wrote "he suffers from epilepsy which has been diagnosed as 'idiopathic' in nature" (i.e. having no discrete, well-defined, pathological lesion underlying it).

Also mentioned in his 11.50 is his claim to be a heavy drug user, injecting anything suitable that he could get hold of, particularly amphetamine sulphate. According to the trainee, at least one of the fits occurred whilst he was misusing drugs:

R. One of the fits I had last year, I was 'speeding' at the time so someone suggested it might be that.

And a fit that occurred whilst in the borstal coincided with some hallucinatory side effects of LSD that he was experiencing at the time.

R. I had a fit in the middle of the hall. But that morning I'd - cos I was on a lot of drugs before I came in. And when they moved me out of the hospital doctor said I shouldn't have gone cos - I was having lots of flashbacks and things - and I do really feel

I. What are flashbacks?

R. LSD. Sort of trip, a very small trip. And that morning, I took, - I'd been - I was really weird when I woke up, so I think I'd had one before that.

It is accepted that a prolonged use of drugs like phenobarbitone may produce fits of a similar nature to epileptic fits when withdrawn but much less is known about the effects of consistent misuse of other drugs. What is certain is that RRK certainly misused a number of drugs, as the following example shows:

R. I had been speeding all week-end and I had to go to court on a Monday .... and I took these 39 pheno-barb 30's, took the whole lot .... Just sort of, - I couldn't really go to court. I took the whole lot and I was just, sort of, nice and happy, just well enough to go to court. I went into court and then I - fixed up some morphine as well - ended up in hospital.

It could be argued that such seizures do in fact constitute epilepsy even if they are caused by drug overdose. However Jasper et al (1969.1) suggests:

> "convulsive seizures induced by intense electrical stimulation of the brain or by convulsant drugs, as well as those which occur during toxic states such as uremia,

> are not considered epilepsy as strictly defined. These may provide useful models of seizure mechanisms, but since they do not occur in self-perpetuating recurrent episodes and are, on the contrary, self-limiting, such convulsive reactions are not considered to be clinical epilepsy."

Case 3 - RJM

A young lad of only 15 who has made four previous court appearances all for burglary. When he was 4 years old he saw his cousin killed in an accident after falling from a disused railway turntable on which they were playing. According to his mother this had a profound effect on him and he was under the doctor and taking phenobarbitone for an extended period, although his 11.50 did not say how long. While at Allocation Centre awaiting transfer to borstal he complained of dizzy spells and the possibility of petit mal and an EEG was raised. There is no confirmation of either in his 11.50 but he is classified as an epileptic and subject to the usual EP restrictions at the borstal. Since arriving he has complained repeatedly about pains in his hips and back and many staff suspect he is a hypochondriac.

Case 4 - RRM

A young man of 18 who has a number of previous convictions for offences including taking cars without the owners consent, driving without insurance and theft. Before being sentenced to borstal, he was subject to a number of fines, two probation orders, 24 hours at an attendance centre and a period of detention. He also has a history of disruptive behaviour at school including assaults on other boys and aggressive behaviour towards staff. He is classified as an epileptic and according to his 11.50 he has black-outs and therefore takes phenobarbitone. According to him, his taking of phenobarbs began long before his black-outs:

R. I had a very short temper, you know, and I had phenobarbitone, you know, for a temper.

I. Yeah.

R. And, well, it's to quieten you down, and its exactly what this had done for me, for these epileptic fits.

I. Yes but you weren't on phenobarbitone then, were you?

R. I was on in school time, yes.

I. Were you?

R. That's because I was having, had, an extremely foul temper.

I. Yeah.

R. That was what? Since I was what - er about nine, nine years old.

I. Yeah.

R. I'd had this, er, phenobarbitone just for temper and from then on until I was what? thirteen, I carried on with it, then I went into ....

When individuals have been taking phenobarbitone for an extended period, withdrawal of medication will often itself produce fits. According to one textbook (Woodbury et al 1974.137):

> "The withdrawal of phenobarbitone from epileptic patients may lead to an exacerbation of seizures that sometimes proceeds to status epilepticus."

Case 5 - RJT

A young man aged 17 who has twice been convicted of wounding with intent and once for damage to property. He was eventually expelled from his secondary school after a number of violent acts including attempting to gouge out the eyes of another boy, kicking another boy, striking a girl over the head with a thick reference book, punching a junior boy in the mouth thereby cutting his lip and loosening two teeth, throwing custard over a senior girl and provocation and aggression towards a teacher whilst under instruction. According to his 11.50 epileptic fits began when he was 14½ though an EEG taken at a local hospital revealed no abnormalities. He takes anti-convulsant medication prescribed by his GP but these are regarded as precautionary for he has few attacks of either petit mal or grand mal and some of his fits are considered hysterical in origin. In July 1975 he was admitted to hospital because he had taken an overdose of his anti-convulsant medication. He remained in hospital one month and while there he was given another EEG which was said to be outside normal limits but it could not be confirmed that he was suffering from grand mal. The hospital doctor wrote "I felt it reasonable to give the benefit of the doubt and recommended him on an anti-convulsant medication. However, I feel the existence of epilepsy has little relevance to RJT's disturbed behaviour".

Case 6 - RRR

A young man of 19 who has a number of convictions almost exclusively for motoring offences of one kind or another, including being carried in a stolen vehicle, taking and driving away and driving without insurance. At the age of 10 he was referred to a child guidance clinic and as a result of their assessment he was placed in a special school for maladjusted children. For the next seven years there followed a number of children's homes and approved school placements, interspersed with a number of court appearances. At the age of 17 he was placed in an adult hostel, but after commiting further offences he was sentenced to borstal training. On discharge he offended further and was sentenced to a second period of borstal training when my interview with him took place. There are few references to his medical condition in his 11.50 but the following points are noted; a head injury is mentioned, but no further details; he was classified as fully fit 1A in Wormwood Scrubs on 7.2.75 but as epileptic at the borstal on 6.3.75; and it is noted that an EEG was taken on 23.3.76.

The following extract from the transcript of our interview illustrates the problematic nature of interpreting various phenomena as evidence of the existence of epilepsy:

I. When were you first diagnosed as an epileptic?

R. Er - when I was about 16, 17 .... but I had a fall when I was about 13.

I. Yeah. Can you remember what happened?

R. Well, at 13 and 16, I was in a kind of approved school. ...And er, I used to kind of lose my temper a lot .... And they said "Time he had a check" and they wondered what it was and I went for an EEG and er they couldn't find nothing wrong and when I got to borstal I accidentally was in a cell, y'know, with an epileptic, another geezer was epileptic, and er he just happened to start spitting up a lot of blood and that, and throwing a wobble. He pressed the bell and they come in. They said, well, he was an EP and that. And I come here and I was on phenobarb 30 and I went to hospital from here for an EEG and they still couldn't find nothing about me having epileptics. But then they found something wrong with me, er - they still, they said, on the EEG report 'Can't find much about this being an epileptic, but he has got bad tempers' y'know 'going over his temples'. See what I mean. Temper and that was obvious. And ever since then I have been on EP restrictions. But I can have them y'know, I have got them.

I. You do have fits?

R. I did have fits but not, y'know, I wouldn't say - I wouldn't have 'em regularly, y'know what I mean? I only had them now and again ......

I. Can you remember when you first er, when were you - were you diagnosed as an epileptic before you were sentenced to borstal?

R. - I can't well, I don't really know, really, 'cos I, y'see, when I was on approved school .... in a training school y'know unclassified, there was a psychologist there and he gave me so many tablets that I think they, y'know see whether I was an epileptic or not .... I used to have tablets to help me sleep, tablets to cool my nerves and .... that was when it probably got diagnosed as an epileptic.

I. What - when you were in approved school? So the first time you came in here you were treated as an epileptic, were you?

R. Yes, when I come in here, I was treated straight away for 'em 'cos, er - when I went to - Wormwood Scrubs, as I said, that's when I had me first one, and that's when they, I was put on EP restrictions, and as soon as I come here I was on EP restrictions. Ever since I've always been on them.

I. I see. But you say you've had some, you'd had fits before then, when you were about 13?

R. I've had fits before then, yes. Y'know, really bad ones. Y'see my mother suffers as well. My mother ain't an epileptic but - she had got a temper. It just runs in the family.

I. What - temper runs in the family?

R. The temper, well, yes, y'know, really frightening temper. Y'know, if you got bad, worried and all that, y'know, it does make you go.

I. Nobody in the family has fits though?

R. I don't think so. Don't know about my Dad 'cos I never saw him.

I. Did anything happen to you? I mean, I find, looking at your record, one mention of a head injury or something. Did you ever have an accident - hit your head or, something?

R. Think that was when I was in a boarding school, when I fell off a monkey-bar on top of my head .... I think it was that one or - it might have been when I was in remand centre. I can't remember, one of the two. I remember when I was living in remand centre, I was mucking around playing when a geezer jumped on top of my head, and I, I remember them picking me up, I'd pissed, you know, I'd pissed myself and, er they put, er, I couldn't remember what happened then and I was er, I didn't wake up 'til about a couple of hours later. And I was in bed, y'know, I was in bed for about five days. When they decided to get me out of bed, I went down to the other school and I started being sick again. Y'know, and all my insides started to come up. That was when I was about 13. The other one was when I was about - just before I was 13. I was mucking about, y'know swinging on the monkey-bar. I just went straight and missed it, y'know, and landed right on top of my head. I don't know what I done.

The detailed discussion of these six cases is intended to illustrate the point that the diagnosis of epilepsy is much more difficult than many of those studying possible relationships between epilepsy and crime have realized up to now. However given the medical and non-medical pressures imposed upon those involved in the classification of epilepsy in penal institutions, it is not surprising that certain phenomena such as loss of consciousness, previous accident or injury to the head or family history of blackouts, which could be interpreted in a number of different ways, are usually interpreted as evidence of epilepsy. It is almost as if there is a vested interest operating to ensure that all possible epileptics are classified accordingly. One assistant governor told me that Home Office policy with regard to epileptics was that 'it was better to be safe than sorry'. And once an inmate had been classified as an epileptic, the label was virtually permanent. During the research I came across an inmate on his second borstal sentence who had been classified as an EP on his first sentence but had succeeded in getting 'de-labelled'. He had succeeded in getting classified by reporting sick three times and complaining that he was having blackouts. His motive for so doing was that he disliked exercise and was a poor performer in the gym - a fact which is confirmed by his 11.50. Unfortunately his medical restrictions did not allow the easy life he had expected and the trade training course he wanted to take was not allowed and thus he soon became bored. However he found that it was not as easy to get de-classified and a process involving meetings with his parents and the assistant governor, and an exchange of letters involving his own general practitioner was embarked upon and it took nearly two months before the epileptic label was finally removed.

It has been suggested that there may be a number of cases where inmates admit to epilepsy in order to have an easy life, but as the following section illustrates, this is unlikely. The arguments presented here suggest that the crucial factors are historical and situational ones impinging on those who make the diagnoses which are crucial and not the possible motivations of individual inmates.

(ii) The Social Organization of Epilepsy in a Borstal

In the past twenty years much work has been done on illness, especially in the areas focusing on the processes by which people become ill and on those factors which influence differential personal responses to clincially similar symptoms, but as Twaddle (1976.236) points out:

> "Almost nothing has been written that takes into account the organizational settings in which symptoms occur and are responded to."

He goes on to argue that what work has been done, including his own study, suggests that there is a higher rate of utilization of medical services on the part of prison inmates than would be expected in a comparable population not in prison.

For present purposes, these findings would seem to indicate that there would be more inmates in borstal claiming to be epileptics than there actually were 'genuine' epileptics. However there are two important factors which strongly militate against this liklihood, with particular regard to epilepsy. Firstly, as Morris (1963) has pointed out in his major study of an English prison, the notion of 'malingering' is a major influence that shapes the nature and quality of health care. That is, many prison medical officers, hospital and discipline staff believe that many inmates report sick for reasons other than ill health; it may be to get out of work, for a chance to get better food, to meet other inmates, to pass messages, to escape from threatened violence and so on.

Consequently, there is a tendency for many inmates who may be genuinely ill either not to be allowed to report sick by the discipline staff or to be given no medical treatment if they manage to get to the hospital wing by going on sick parade or by reporting 'special sick'. This does not invalidate the argument presented in the previous section concerning the pressure on medical officers to interpret possible symptoms of epilepsy as definite epilepsy; it is simply that in the filtering process, if there is little or no evidence of illness, either in presenting symptoms or mention in medical history then requests to go sick are likely to be treated as malingering. However once it becomes clear that something is wrong, either through symptoms, medical history or persistence in complaining by the particular inmate, then the pressure is overwhelmingly in the direction of a firm diagnosis. And, if a conflict arises between medical and discipline staff about whether someone is really ill or not, it is quite definitely the medical interpretation which holds sway. This can arise where prison officers think that a particular inmate may deliberately have fits to avoid any unpleasant jobs; as one officer put it "These fucking wobblers can throw fits whenever they want to": but it more often occurs when doctors interpret certain behaviours as evidence of mental illness, and discipline staff see the same behaviour as evidence of simply the natural way borstal boys behave and as evidence of nastiness and lack of co-operation, not illness.

A second factor mitigating against inmates deliberately pretending to be epileptic in borstal or any other penal establishment for that matter, is that having such a label attached involves an additional dose of classification, stigmatization and social rejection, in both formal and informal ways. There are special regulations with regard to epileptics in penal establishments and this involves being located in a special cell on the ground floor which has a special floor and special furniture in order that if he has a fit he is unlikely to injure himself in a fall. He is excused physical education classes and games, and is not allowed to work on the farm or with machinery, nor is he allowed to work in the concrete shop or with ladders, and he is not allowed to register with any of the trade training courses. He is actively discouraged from worthwhile pursuits, even mundane things like using upstairs rooms and is usually kept drugged, no matter when he last had a fit. These restrictions can make the life of the epileptic even more dull and depressing than that of the ordinary borstal boy. The inmate referred to earlier, when asked what finally led him to confess that he wasn't an epileptic, replied:

> R. Boredom, I got bored .... got bored you know, they put me in the workshops which was really winding me up, like, so I thought, well might as well confess.

It is not only formal rules and regulations which impose limits on his social world but also the treatment be receives from other inmates and staff. He has the pejorative label 'wobbler' attached to him and occupies the lower rungs of the inmate hierarchy and is treated accordingly. The following extract from an interview illustrates some of the problems faced by those labelled epileptics:

> R. What? Restrictions! I'm not restricted from anything. Just P.E. like, from doing heavy weights y'know, they restrict me but - I know I can lift heavy weights and I can run about like a lunatic all over the gym without having a black-out, sort of thing. As I say, I used to do boxing, I used to do cycling and other sports - but they say, well "this is our law, these are rules laid down by the Government, you abide by them".
>
> I. Yeah.
>
> R. So they restrict me there but, I've done er - well even my cell, its not an epileptic cell. Y'know, epileptic's cells are padded floors and padded walls and low beds, and mine's not, y'know.
>
> I. It's not?
>
> R. No. No.
>
> I. You're - so you're not treated differently in any way?
>
> R. No.
>
> I. You're not?
>
> R. No - not really, well the boys, as I say, the boys don't know, y'know. They'd say to me "What do you go over sick in the mornings for?". I'd tell 'em, I say "Nerves" y'know 'cos if I say I'm an EP, they'd say oh I'm a

lunatic, y'know what I mean, "Disabled bastard", sort of thing, y'know.

I. Yeah.

R. They start to, they take the mickey, y'know.

I. Yeah. They do out of other EP's do they?

R. Yes, they call you "wobbler", sort of thing, you wobble, you do, y'know what I mean .... You go off your head. Some of 'em are frightened of EP's, I mean, when an EP does his nut, he flies, I mean, some EP's they just, well, they've got so much strength in them when they have a fit, y'know what I mean, it's unbelievable. And some of 'em are frightened of them, y'know. That's why they keep out of their way, but, no, I'm treated no different in the wing .... Some are, I know that for a fact 'cos I've spoken to some epileptics.

I. Yeah. But you think that's directly connected with them having fits and not anything else, not because they're on restrictions or because they're given a name?

R. No. Because they're EP's.

I. Yes, but you're an EP in here, but you say you're not treated any differently.

R. Yes, but I'm saying the boys don't know I'm an EP. the boys say "What do you go over sick for in the mornings?". I say "for nerves, I've got nerve trouble".

I. Supposing the boys knew you were an EP but you never threw a fit, do you think that would make any difference? Is it the fact that somebody is called an epileptic which results in the boys taking the mickey out of him, or is it because he actually throws fits?

R. Because he actually throws fits. That is right. And, of course, because he's an epileptic, because he's called an epileptic .... because y'see, boys they like a bit of excitement, they like to see people throw a fit.

I. Yeah.

R. You wobble, you go mad. You pick up anything there is,

> well, I don't, y'know what I mean, but - I never pick up a weapon in my life, but you see other boys, I've seen other boys and they'll pick up weapons, the nearest thing to them and hit the kids, they love it. All excitement y'know. They say with an epileptic if he has a black-out, if he has an epileptic fit in front of them, y'know, they love the excitement .... of watching him, of watching his reactions, sort of thing .... and then when he's recovered, they take the mickey out of him after.

This section of transcript illuminates a number of problems common to epileptics in penal establishments. Firstly, formal restrictions to effectively limit the kinds of interesting pursuits in which inmates often wish to indulge. Secondly, many epileptics are not simply subjected to aimless ridicule but are often systematically teased, in argot terminology - 'wound up' in order to add excitement to the dull institutional life. Thirdly, those epileptics who are able to pass because they have few fits, take every opportunity to do so; they have well rehearsed accounts as to why they are asked to report sick or why they are allocated to an EP cell - in one particular case, the account was presented in terms of the fact that the inmate was sent from another borstal and that was the only cell available and it was not considered worth moving out as he was likely to be discharged soon.

But epileptics are not solely subjected to processes of stigmatization and degradation; at one and the same time they are held in awe and treated warily, by inmates and staff alike. Behind this are myths concerning the strength of epileptics and the feats they are capable of performing. For example, I was told by one prison officer that if I wanted to see epileptics in the later stages of their illness, I should visit the special wing at Portland. He then recounted a story about how all EP's sat in the back row during church parade at this particular establishment and on one occasion he saw an epileptic pick up the long bench that he had been sitting on and hurl it the full length of the church before he sank to the ground frothing and foaming at the mouth.

A final factor relevant to the experience of epileptics in penal establishments, is that whenever they have a fit, it will be treated with suspicion and some fellow inmates and staff will regard it as self-induced. Some epileptics themselves believe that they can bring on fits.

> R. I used to put myself into some, somehow, you know, when I used to get told off at school and that, or get very upset at home. You see, er, I used to say to my Grandad "all right" I said "I'm now going out". I'd say "you won't see me for a long while" I said "I've took myself into a fit". He used to say "All right then, do what you like". And I used to go outside and put myself into one - easily.
>
> I. And you really could? You could put yourself into a fit?
>
> R. Yeah, I could put one, I could put myself into an EP fit.
>
> I. And it was the same as fits you didn't deliberately put yourself into?
>
> R. Yeah. There was no difference at all.

And another inmate told about the suspicion with which his fits were treated:

> R. Well, every time I get, you know, sort of disagreement with, er, an officer, with an officer, and, er, they threaten me with the Block, you know going down into the punishment wing. They reckon that, er, I sort of put on a fit just to stop me from going down the Block.

It is not only inmates and staff of prisons who have difficulty in distinguishing between genuine and hysterical fits for as Sutherland et al (1974.40) point out:

> "Even with modern techniques it is sometimes difficult to determine when hysterical fits end and epilepsy begins."

However the average prison officer uses non-medical techniques in order to determine whether a fit is genuine or not; several kicks are administered to the prostrate inmate - if he is malingering, he will soon get up, but if he is unconscious, then he will not respond.

This is not to suggest that all officers treat all epileptics in this manner, but many have their own practical, common sense notions about who is a genuine epileptic and who may be putting on a fit. In a prison, fits can provide diversions enabling other inmates time to indulge in various criminal activities while the attention of staff is diverted, and they also allow inmates to avoid unpleasant tasks and duties. In this context, the 'swift kick' can be seen as a practical method of ensuring that the chaos and disorder that may develop, is only likely so to do in response to genuine fits. And most discipline officers will have made their own common sense judgements about whether each categorized epileptic is really a wobbler or not - independent of the medical diagnosis.

All of these factors make it unlikely that inmates will claim to be epileptics in order to have an easy time; in my sample 8 out of 9 had been in previous institutions of a similar nature and therefore would be only too aware of the differential treatment given to epileptics.

Thus it is clear that the diagnosis of epilepsy is not simply contingent upon clinical skills and expertise, but the specific situation and the formal and informal pressures contained therein, are also relevant factors.

THE MEDICALIZATION OF SOCIAL PROBLEMS

The first two sections have argued that deviations of all kinds can be evaluated in different ways by different societies or social groups and that current medical domination with specific regard to epilepsy cannot be accounted for solely in terms of the ability of doctors to diagnose and treat and cure epilepsy. Therefore, a further possible explanation for the current dominance of the medical conception of epilepsy needs to be examined. This explanation is often couched in general terms, such as the medicalization of society, the medicalization of social problems or, sometimes, medical imperialism, but the process referred to under these different titles is similar in all cases; Jeffries defines this process as follows (Cox & Mead 1975.viii):

> "Medicine is now being called upon to deal with problems which were once considered moral rather than medical issues - for example, alcoholism, drug addiction, crime, marital disharmony, behaviour disorders and fertility control - as well as the unwelcome fruits of technological and social change - for example, the toll of morbidity from road accidents, smoking and obesity."

Epilepsy can be added to that list, although some would argue that whereas some of the problems included in the above list are obviously non-medical, epilepsy quite clearly belongs in the province of medicine. A historically grounded study demonstrates that this view is obvious only to twentieth-century industrialized man.

The medicalization of social problems has often been regarded as an evolutionary process usually connected with the rise of scientific enterprise and rational thought. The actual process has largely been ignored and only the implications and effects studied in depth; however, close examination reveals that the process itself can be divided conceptually into at least two parts, a) achievement of the right to define certain deviations as illness, and b) achievement of the right to treat these behaviours so defined as illness. Obviously, in practice these did not proceed separately but for clarity, they will be treated here as conceptually distinct.

(i) The Right to Define

The common assumption with regard to the right to define certain behavioural deviations as illness is that it is tied to the rise of science; that medicine as the most prominent profession(s) to utilize scientific principles, thereby becomes the leading professional beneficiary. Thus, Freidson states (1970.303):

> "What is distinct about a complex civilisation like ours, compared to a simple society, is the existence of special classes of men who are engaged on a full-time basis in creating knowledge, formulating laws, morals, and procedures, and applying knowledge and moral principles to concrete cases".

These special classes, usually called professions, become part of the official social order and, thereby achieve the right to impose their definitions on the rest of society. This is not to deny that special classes with specialized knowledge did not exist in primitive societies, but that they did not achieve the power to impose their definitions on the rest of society.

One particular study of epilepsy in a primitive culture illustrates the relationship between lay and professional definitions and the implications of such a relationship for the treatment of epileptics. The Wapogoro regard epilepsy as a disease affecting families and when anyone has an epileptic seizure, it is regarded as a catastrophe for the whole family. The Wapogoro have a number of medicine men, called Mganga, some of whom specialize solely in the treatment of epileptics but their treatment can only take place within the context of lay evaluations of epilepsy as a familial disease. Hence (Aall-Jilek 1965.72-3) states:

> "Medicines are made of leaves and roots. These are boiled together with a hen in a sort of porridge. Every member of the family including the patient must eat this medicine .... The Mganga's treatment is something active and interesting, affecting the whole family."

When a Western-trained physician such as Aall-Jilek started to treat some of the epileptics herself, she found it necessary to operate within the context of traditional evaluations and beliefs in order to make her treatment effective. Obviously, she had a different definition of epilepsy, seeing it as an individual neurological malfunction, but she had to administer her drugs by involving the whole family in ensuring that individual epileptics took their tablets. Additionally, in order to help her better understand and treat epilepsy among the Wapogoro, she constructed family-trees and family case-histories, despite the fact that western medical science would argue that there is very little of a hereditary element in epilepsy and, consequently, that epilepsy does not run in families. The Mganga, as the resident professional expert, operated solely within lay beliefs and carried out his treatment accordingly.

However, the relationship between professional and lay definitions is not simply a function of the development/under-development of the economy, nor the industrial/non-industrial state of the particular society, for even in developed industrial societies, some professions loose the right to define some behaviours as deviant. Thus, the clergy as a profession would no longer claim the right to define epilepsy as demonic possession, though one or two individual clergymen might, as the example cited earlier (News of the World 1976) shows.

Scott (Douglas Ed. 1970.271), working within the interactionist paradigm, attempts to make some generalized statements about this relationship between lay and professional constructions of the stigmatized meanings associated with various illnesses and handicaps:

> "Expert conceptions of stigma reflect prevailing cultural values, attitudes and beliefs. In a sense it is inevitable. Experts must use the native tongue in order to communicate their constructed meanings to laymen and the modes of expression that a language affords are grounded in the core values of a culture. Moreover, it is laymen who usually grant legitimacy to experts claims to special knowledge about stigma; any constructive meanings that are dissonant with lay values, beliefs and attitudes will probably be rejected as nonsensical."

Nonetheless, as organized intervention programmes develop for the stigmatized, so the organisational process becomes more and more bureaucratic and these bureaucratising processes both shape and reflect professional constructions and definitions. These constructed definitions then filter through to the clients of the organizations, the stigmatized themselves who, as Scott forcefully shows, then come to accept these definitions, for failure to operate within the conceptions of the professional and his organization means failure to get the services and benefits that they provide. Thus, Scott's explanation is almost Weberian in that he sees the process of bureaucratization as the intervening variable between the level of development of the society and the ability of professionals to impose their constructed meanings on the rest of society.

Of all the professions that have obtained the right to define deviations, the medical profession is undoubtedly the most powerful;

and the question then becomes, how did they attain this powerful position in modern industrial society? Parry and Parry (1976) argue that much sociological theorising about class has concentrated on processes of individual mobility and failed to consider how groups of professional associations can achieve group mobility. They achieve this collective mobility through, what Parry and Parry call, professionalism, which for them (1976.83) is:

> "A strategy for controlling an occupation in which colleagues, who are in a formal sense equal, set up a system of self-government. It involves restriction of entry to an occupation through the control of education, training and the process of qualification. Another aspect is the exercise of formal and informal management of members conduct in respects which are defined as relevant to the collective interests of the occupation. Occupational solidarity and closure are used to regulate the supply of services to the market. This serves also to provide a basis for the domination of institutions, organizations and other occupations associated with them. Finally, there is the reinforcement of this situation by the acquisition of State support in order to obtain, if possible, a legal monopoly backed by legal sanctions."

They then proceed to document how the medical profession, through this strategy of professionalism, have achieved upward collective mobility and thus their pre-eminent position with regard to the right to define deviations as illness.

Whether the medical profession has achieved its power as a concommitant of the bureaucratisation process or as a result of upward social mobility, it is usually assumed that various deviations have been brought under the control of the medical profession by the process of medical imperialism. The argument goes something like this: the medical profession occupies a very important and powerful position in the class structure of society, and through its almost exclusive control over specialized knowledge related to crucial issues like life and death and its ability to control entry into its own ranks. Thus it is not only able to determine who is and is not ill but, to define which areas of behavioural deviation are appropriate for medical intervention. But not all writers would agree that the medicalization process stems from either the achievement of political power or the occupational strategy of imperialism. Zola (1972.487), in many ways one of the severest critics of modern medicine, argues thus:

> "Moreover, this is not occurring through the political power physicians hold or can influence, but it is largely an insidious and often undramatic phenomenon accomplished by medicalizing much of daily living, by making medicine and the labels 'ill' and 'healthy' relevant to an ever-increasing part of human existence .... nor is this extention into Society the result of any professional imperialism for this leads us to think of the issue in terms of misguided human efforts or motives. If we search for the why of this phenomena, we will see instead that it is rooted in our increasingly complex technological and bureaucratic system - a system which has lead us down the path of the reluctant reliance upon experts."

Additionally, the consumers of medical services represent such a vast heterogeneous group of individuals that it is difficult to articulate complaints or challenge dominant definitions of particular behavioural deviations. What is more, many of the consumers are only too willing to give up autonomy over particular areas of life, for as Johnson (1972.43) reminds us:

> "Medical practice intrudes into areas of social taboo relating to personal privacy and bodily functions, as well as areas of culturally defined ritual significance such as birth and death."

The relationship between the medical profession and other organizations, professional, self-help, academic and so on, and the right to define specific deviations cannot be considered as one of dominance/submission, leader and follower. The nature of such relationships is an empirical question in all cases and the following examples are intended to be illustrative rather than comprehensive. Thus, Alcoholics Anonymous were forced to struggle in the 1930's to achieve the right to label the alcoholic as 'sick', rather than 'a drunk' or 'a bum'; a struggle often opposed to by doctors, or at least not actively supported by them. The extension of medicine into the study of crime and criminals was actively encouraged and eagerly welcomed by criminologists in the early twentieth century. (3) Homophile organizations have campaigned actively to have the label 'sick' removed from their members and in America, they achieved partial success in 1971 when the American Medical Association removed homosexuality from their list of identifiable mental illnesses. More particularly, the British Epilepsy Association accept as their baseline the definition of epilepsy as a physical illness and a major platform of their work is to convince everyone else that epilepsy is only a physical illness. The relationship between medical and other definitions of epilepsy will be examined in more depth in later chapters, for the examples cited are intended merely to show that the relationship between medical and other definitions cannot simply be subsumed under notions of bureaucratization or differential power and status.

(ii) The Right to Treat

Undoubtedly, the most important factor in the achievement of the right to treat a wide variety of deviations has been the enormous success that developed scientistic medicine has achieved in combating physically-caused illness. (4) However, many deviations or illnesses, (including most epilepsy), have no immediately-apparent physical cause, and their etiology may well be psychological, economic or social and/or a combination of these and other factors. Thereby, it may not be appropriate to treat such behaviours according to the model that has proved so successful in combating physically-caused illnesses. Unfortunately, when the success rate of medical treatment of mental illness, homosexuality, alcoholism and so on, fails to match the success rate for the treatment of measles, smallpox, tuberculosis, etc., then explanations are usually couched in terms of deficiencies in the knowledge, rather than the inappropriateness, of the treatment method. And hope is held out, therefore, that in the future, deficiencies in knowledge will be remedied and the medical model will triumph.

Even in those deviations which it is unable to cure, the medical profession is able to provide efficient means of control to the benefit of society as a whole. Initially, the mentally ill were contained in asylums, the chronic sick in residential homes, drug addicts in treatment centres and epileptics in colonies. More recently the development of drugs and the drug industry have meant that many deviants can be controlled in the community at large simply by taking tranquillisers, stimulants, synthetic drugs and anti-convulsants; in fact, it would not be untrue to say that in many instances of behavioural deviation, the pill is replacing the institution as the most common means of social control. Additionally, the rise in importance of drug therapy has enabled medicine to expand its area of treatment rights; for example, many children who cause behavioural problems in school and would have been the concern of the headmaster, parents, local policeman or the man from the School Board, are now given the label 'hyperkinetic' and subjected to drug therapy as the most appropriate means of treatment. (Conrad 1976. Box 1977.)

It should be stressed that as the process of medicalization of deviant behaviour proceeds, this is not solely due to the entrepreneurial or imperialistic activities of the medical profession. The substitution of a treatment ethic for a punitive one reflects a shift in social values towards humanitarianism. And in many cases this substitution has benefits for the deviants themselves. Conrad (1976.18) points out:

> "Hyperactive children are now considered to have an illness rather than to be disruptive, disobedient, over-active, problem children. They are not likely to be the bad boy of the classroom; they are children with a medical disorder. Clearly there are some real humanitarian benefits to be gained by such a medical conceptualisation of deviant behaviour. There is less condemnation of the deviants (they have an illness, it is not their fault) and perhaps less social stigma."

So, too, with epileptics; undoubtedly many epileptics are better off as a result of anti-convulsant drug therapy but as has already been pointed out, this is not without costs in terms of side-effects such treatments often produce. What is more, the removal of the fit from the everyday lives of the population at large may well have adverse consequences on the way epileptics are treated in society. (This argument will be expanded in Chapter 7.)

A factor specifically relevant to the acquisition of the right to treat epileptics by the medical profession is what can only be described as historical accident. As asylums and madhouses succumbed to the process of hospitalization (see Foucault 1967), and the mad became the mentally ill, so doctors inherited a number of epileptics who, though not mentally ill, had initially been confined to the madhouse. Another factor historically specific to Britain was that many epileptics unable to come to terms with the requirements of the new industrial order found themselves in one of the many workhouses. Coupled with this, the medical profession was dominated by senior men, largely from the Royal Colleges, and many young physicians and surgeons were forced by blocked career paths, to move out of the voluntary hospital sector and either work for the Poor Law Boards, thereby inheriting a number of epileptics or found their own specialist hospitals. (5)

(iii) Implications of Medicalization

Undoubtedly, then, the medical profession has acquired a crucial place in the process of defining and treating various deviations as illnesses and as a number of writers have pointed out, this is not without drawbacks. Illich (1975.22) is probably the severest critic of modern medicine and argues that much illness is iatrogenic, that is:

> "the sum of malpractice, negligence, professional callousness, political maldistribution, medically decreed disability and all the consequences of medical trial and error."

It has been a theme of this chapter that the medical profession has, indeed, iatrogenically created much illness in modern society, not solely or even largely because of the kinds of incompetencies listed by Illich - but by acquiring the right to define certain deviant behaviours as illness instead of lunacy, immorality, irresponsibility, or just plain evil. Medicine has thus transformed behaviours from one category to another, thereby labelling them as 'illness', and thus can be accused of conceptual iatrogenesis rather than malpractice or inefficiency.

It is often assumed, too, that to define and treat deviations as illnesses is more humane (Zola 1972.489):

> "The assumption is (thus) readily made that medical involvement in social problems leads to the removal from religious and legal scrutiny and thus from moral and punitive consequences. In turn, the problems are placed under medical and scientific scrutiny and thus in objective and therapeutic circumstances."

However, this argument ignores a number of important factors. Firstly, punishment is a subjective experience and while medical treatment may be objectively (from the point of view of the doctor) therapeutic, it may still be subjectively painful. Additionally, although treatment may be in the patient's own good, his opinions concerning his treatment are usually ignored on the grounds that he is a layman who lacks the special knowledge and detachment that would qualify him to have his voice heard. Finally, the application of the label 'illness' does not automatically provide absolution from individual responsibility, accountability and moral judgment.

The final dangers that should be mentioned with regard to medicalization of deviant behaviour are that the ascription of the label 'sick' both individualizes and de-politicises the particular form of deviation. For example, recently medicalization has intruded into a number of new areas, particularly the law and education. Thus, we have seen opened a number of law clinics, set up to grant access to legal advice to a substantial section of the population who are unable to obtain it under the existing system; and a number of remedial reading clinics have also been set up to teach two million illiterates to read. It is not disputed that these clinics have been very successful in helping large numbers of individuals, but by opting for individual solutions and utilizing the medical model, albeit implicitly by their choice of nomenclature, they direct attention away from other issues. The fact that large numbers of people in a formally democratic and egalitarian society are denied access to law and legal process, or that more than a million people can be discharged from a universal education system unable to read or write, are matters of great social and political importance. To send such people to clinics merely locates their problems at the individual rather than at the societal level.

In conclusion, it would be appropriate to finish with quotes from Kittrie and Freidson both of whom have written on the dangers of the medicalizing process if it continues unchecked. Kittrie (1971.362) examined the effects medicalization may have on individuals, as follows:

> "The therapeutic model now offers the only system of social control unlimited in its potential applications, for by its very aims the therapeutic state is required to look beyond the question of passed misconduct and into those factors of morals, welfare and health which might produce a present or a future state of dangerousness."

Freidson (1970.356) writes on the effects medicalization may have on the society concerned:

> "A profession and a society which are so concerned with physical and functional wellbeing as to sacrifice civil liberty and moral integrity must inevitably press for a scientific environment similar to that provided laying hens on progressive chicken farms - hens who produce eggs industriously and have no disease or other cares."

SUMMARY

The argument so far has suggested that if epilepsy is examined from a historical perspective, then as a particular behavioural phenomenon, a deviation from normal, epilepsy has been evaluated from a religious, legal and medical framework. It has not been suggested that these frameworks are mutually exclusive but that at present the medical framework is undoubtedly dominant. Reasons for this medical dominance were examined and it was found that such dominance could not be accounted for in terms of the ability of the medical profession's ability to diagnose, treat and cure epilepsy as illness. Finally additional historical and social reasons for this medical dominance were explored and some of the implications of the medicalization process were suggested. The ways in which the dominant medical definitions have conditioned the social world in which epileptics live out their lives and their responses to such conditioning will be considered in the following chapters, but it remains to point out that the medicalization of epilepsy will not be regarded as necessarily beneficial for the epileptic nor to his society, for as Szasz (1968.27) has warned:

> "If people believe that health values justify conversion, but that moral and political values do not, those who wish to coerce others will tend to enlarge the category of health values at the expense of the category of moral or political values."

CHAPTER FOUR

THE DEVELOPMENT AND CONSTRUCTION OF IDEAL-TYPICAL KNOWLEDGE

The previous chapter has argued that the social meanings associated with epilepsy are influenced by the dominant social framework within which the condition is perceived. Historical examination has shown that this framework was either a religious, legal or medical one although it was not argued that these frameworks supplanted each other through a process of progressive evolution. Specifically, it was argued that the current dominance of the medical framework was brought about by the actions of men acting in concert and not the necessary result of social and scientific progress.

This chapter will argue that within the current dominant medical framework social meanings are not fixed and absolute. Rather, individuals and groups have to constantly make and remake, construct and re-construct social meanings related to the condition of epilepsy; and while the medical framework may provide a backdrop against which these constructions take place, the relationship between framework and construction is not a deterministic one.

THE ACTIVITIES OF MORAL ENTREPRENEURS (DELIBERATE)

(a) The Social Construction of Moral Meanings

It has been suggested by writers at least as far back as Plato that there are certain fundamental categories of existence that imply opposites; that is, by themselves categories such as good and bad, life and death would make no sense. Inevitably however, this categorizing has taken on the nature of a moral enterprise for, as Douglas (1970.5) has pointed out:

> "It is this categorical distinction which lies behind the dichotomizing of the social world into morally disjunct categories - right side of the tracks versus wrong side of the tracks, criminal versus non-criminal, stigmatized versus non-stigmatized, responsible versus disreputable, evil versus good, black versus white and so on."

And for present purposes it would be reasonable to add epileptic versus non-epileptic to the list.

In recent years the absolutist assumptions underlying the nature of these categories have been increasingly called into question. Thus it has now been recognized that there is no clear dividing line between criminal and non-criminal, homosexual and heterosexual and other similar categories but rather that such categorization is invariably the negotiated and problematic outcome of some labelling process or procedure. With regard to epilepsy, it is now sometimes argued (though not all doctors would agree) that we are all potentially epileptic in that we all have brains stimulated by electrical activity, and where exactly excessive electrical activity warrants the label epileptic is inherently problematic. (1) The majority of the population have experienced a black-out, a momentary loss of consciousness at sometime in their lives and everyday language testifies to the common occurrence of fits of all kinds - 'a fit of laughter', 'a fit of temper' or 'I nearly had a fit'.

The crucial variable in the epileptic/non-epileptic dichotomy is often then dependent on the process by which the label comes to be applied. This process is also crucial to the other dichotomies mentioned above but the point of these remarks is not to provide an introduction to a detailed discussion of labelling theory (2) but to show that labelling is the result of negotiated process rather than the correct application of an absolute category. Once it is recognized that the application of labels is negotiated, it then becomes apparent that such processes can be influenced, either by groups or individuals. Becker (1963) has called such influencing the activity of 'moral entrepreneurs', and it is just this kind of activity which will now be considered.

(b) The Activities of Moral Entrepreneurs

There have been a large number of groups, organizations and individuals acting as moral entrepreneurs and consequently there have been a number of studies, particularly of groups involved in this kind of activity. (Sagarin 1969, 1971. Robinson and Henry 1977.) The activities of these entrepreneurial groups have been in two distinct but not mutually exclusive directions; activities aimed at substituting a less for a more derogatory label or at changing the social meanings attached to a particular label. These activities need to be considered separately.

(i) Label Switching. With regard to attempts to switch from a more to a less derogatory label, there have been a number of successful outcomes resulting from entrepreneurial activity. Probably the most successful group engaging in such activity has been Alcoholics Anonymous who have succeeded in replacing the pejorative terms 'drunk', 'wino' or 'bum' with the morally neutral 'alcoholic'. Similarly the Homophile Movement has appropriated the term 'gay' to replace less endearing terms like 'queer', 'fairy' or 'faggot'. However, not all organizations have been so successful, the Little People of America or its British equivalent The Society for People of Restricted Growth have not succeeded in removing the labels 'midget' and 'dwarf' from general usage.

In the case of epilepsy there has been much discussion among interested parties about whether the term epileptic should be abandoned as historically it has become associated with prejudice. There are a number of difficulties associated with this in that firstly, the term epileptic tends to be used by specialists and lay public alike although each usage may represent a different connotation; secondly such slang terms as 'fitter' or 'wobbler' are not widely known or used; and thirdly, alternatives like cerebral dysrhythmiac or person with seizure are unsatisfactory. An American writer, Walter Lennox (1970.20) who has done much pioneering work on epilepsy puts his view of the matter quite forcibly:

> "Though consideration for the sensibilities of an affected person may require that the word 'epilepsy' be used circumspectly, the delusion that a disease can be lightened by altering its name cannot be condoned. A tiger is not rendered harmless by calling it a kitten, but by pulling its teeth and filing its claws. Epilepsy mostly needs not a new name but a new remedy."

In Britain the balance of views favour the opposite approach; the influential Reid Report in this country was deliberately entitled 'People with Epilepsy' and the final task of the team who produced the Report was to go through the complete text and remove all appearances of the term epileptic. On a number of occasions during participant observation I was rebuked for using the term and asked why I did not speak of people with epilepsy. (3)

(ii) Meaning Changing. Many of the participants in the label switching debate have assumed that to succeed in substituting a less derogatory term will necessarily change the social meanings and hence the status of those deviants concerned. However, some groups have attempted to transform such social meanings by resort to direct action; by becoming a social movement and/or a political crusade and thereby resorting to mass marches, protest meetings, civil disobedience, legal redress and so on. The best example of such campaigns are the black civil rights movement and the Homophile movement (Humphreys 1972) and the sentiments behind such campaigns are encapsulated in the slogans 'Black is beautiful' and 'Gay is good'. The success or otherwise of such campaigns is an empirical question beyond the scope of this study, but it is reasonable to state that such campaigns have undoubtedly had an effect on social meanings.

Because epilepsy is generally regarded as illness rather than deviance, it does not mean that a similar campaign would be inappropriate for illness itself does not have an absolute social or moral meaning and hence can be altered by the campaigns of moral entrepreneurs. Freidson provides justification for this view (1966.209):

> "Illness as such may be biological deviance, but the idea of illness is not, and neither is the way human beings respond to it. Thus biological deviance or disease is defined socially and is surrounded by social acts which condition it."

Additionally some observers of the American scene (Naylor 1977) have suggested that the disabled there have banded together as a social movement and adopted some of the tactics listed above, and significantly, have achieved some measure of success in changing the social meanings attached to such a label.

In summary the former kind of activity has undoubtedly been significant on an individual basis and produced a change in moral status for a number of individual deviants; the latter kind of activity has produced significant changes in social meanings for groups as a whole rather than individuals. However both activities are only separable for analytical purposes and any activity of either kind is bound to influence the other. In what follows the entrepreneurial activity of a number of groups and individuals will be considered with regard to epilepsy in Britain.

(c) The British Epilepsy Association

Before considering this organization's role as a moral entrepreneur, brief mention must be made of its historical development. Many organizations, particularly in Britain, have developed not as a means of providing self-help among the 'own' or 'wise' (Goffman 1963) nor as a political crusade, but rather as a consumer group concerned to look after the interests of its members. Johnson (1977.88) describes the genesis of such organizations as follows:

> "Organizations for the better informing and better representation of the 'ordinary' consumer have grown up in many fields of activity. As well as the bodies which advise on the quality of goods and services offered for sale, there is an impressive number of agencies which offer the same service for such groups as alcoholics, the mentally ill, those receiving social security, the single-parent family, the homeless, the old, the physically disabled and the politically oppressed. Not all the groups which provide this sort of advice and support are new, but even those which have been in the field a long time (Age Concern in its former guise as the National Old Peoples' Welfare Council, MIND as its other self the National Association for Mental Health, serve as good examples) have newly taken on the clear role of social advocate and representative."

The British Epilepsy Association has undoubtedly taken on the role of social advocate and representative for epileptics and owes its birth and development to sponsorship by the National Association for Mental Health (Gairdner 1976.2). It was founded in 1950 and has developed into an organization through which the special needs of epileptics can be considered and voiced and has introduced local clubs and centres and pioneered social counselling. Its aims are:

(a) To assist all those who suffer from epilepsy, both as individuals and as families.

(b) To improve the understanding of epilepsy so that those who suffer from this disability shall not also suffer from the ignorance and prejudice of those around them.

(c) To encourage and assist research into the causes and treatment of epilepsy.

(d) To share our knowledge and experience with people in all parts of the world who wish to work for the welfare of the epileptic.

There are similar organizations in other countries.

In the past twenty five years the Association claims to have achieved a great deal; it claims to have improved the understanding of many of those concerned with epilepsy, particularly within the teaching profession, the health service and among social workers. It has campaigned for better employment prospects, insurance and holiday facilities and has generally made life more tolerable for a substantial number of epileptics and their families. However what specifically concerns us here is its activities as a moral entrepreneur and it would certainly be true to say that the Association has campaigned vigorously at both a national and a local level; it organizes a National Epilepsy Week; publishes newsletters, information leaflets and pamphlets, organizes meetings, seminars and so on. But before considering the specific nature of such entrepreneurial activity, it is necessary to look at some of the structural constraints influencing the extent of this activity.

The amount of activity that a relatively small organization can get involved in is strictly limited for as the Reid Report (1969. 17) points out:

> "For propaganda to reach a wider public, and for a programme of continuing education to be maintained, more money would have to be spent on media such as press, national and local radio, and television than a voluntary body could hope to raise by public appeals, for removing a prejudice has not a strong emotional appeal."

And paradoxically removing prejudices and changing the meanings attached to epilepsy is crucial not only to making a better life for epileptics but also for the future achievements of the Association in its role as a moral entrepreneur. Nightingale (1973) locates the Association as one of the ten unpopular charities to which the public are unresponsive to appeals for money, quoting the typical public response as 'I'm glad I'm not one and don't give'. The crucial importance of favourable social meanings is aptly described by Kemp (1963.86):

> "An interesting comparison has been made with the Diabetic Association, which has a much larger membership than the Epilepsy Association, though in fact there are about equal numbers of diabetics and epileptics. Both illnesses are due to a functional upset of an organ and both are equally a simple bodily ailment. Their work lies along very similar lines, yet the Diabetic Association is more flourishing because they have not had to break down prejudice built up over thousands of years."

Another constraint on the amount of activity the organization can engage in centres around the fact that epilepsy is a non-visible social deviation and thus it is possible for individuals to 'pass' (Goffman 1963). The individual with a visible deviation is unlikely to increase his social visibility by joining an organization whereas the same is not true of the non-visible deviant. According to Birenbaum and Sagarin (1976.128):

> "The visible deviant is both more and less vulnerable, in that he probably lives in a world of greater discrimination but lesser fear than the secret deviant."

It is estimated that there are around 300,000 epileptics in this country but the British Epilepsy Association has only 20,000 members many of whom may be family or friends rather than epileptics. Thus it is reasonable to assume that the vast majority of epileptics do not join either because they have not heard of the organization or because they fear any social penalties which may stem from even a marginal increase in visibility. And while epileptics might constitute what Inkeles (1964) has called "a psychic community", they do not constitute a sub-culture, much less a social movement which might provide some compensations for any increased stigmatization that joining might bring.

The various kinds of activity that the British Epilepsy Association has been involved in have been referred to earlier; their entrepreneurial activity can be described as attempting to provide what Gussow and Tracy (1968) have called in the context of leprosy 'an alternative theory of stigma' or 'a de-stigmatizing theory'. This de-stigmatizing theory, with regard to both leprosy and epilepsy, attempts to demythologize by emphasizing the historical, medical and social errors and confusions which surround them. Scientific and medical evidence is produced to show up the incorrect basis for these errors and confusions and that much of stigmatization stems from 'poorly substantiated historical evidence and reasoning'. An essential component of this de-stigmatizing theory is a redefinition of the situation so that it is the general public who are at fault. Cumming and Cumming (1968.45) point to a similar situation with regard to mental illness:

> "one mechanism is the redefinition of the situation so that the 'public' is held to be ignorant and prejudiced about those who must go to mental hospitals. In this mechanism only the initiated know that such people are not crazy at all, but only temporarily ill, or in need of a rest."

So too with epilepsy; it is the public who are prejudiced or ignorant, who think epileptics are lunatics or violent or possessed, that they cannot work with machines, ride a bike, go swimming or get married. The initiated, the members of the organization, know this to be false. The major platform of this de-stigmatizing theory then, the most important idea to get across, is that epilepsy is purely a physical illness. And there are other organizations who will give support to this idea, who have a vested interest in supporting this platform.

(d) The Drug Companies

One type of organization which merits such consideration is the drug company which has an obvious interest in keeping epilepsy defined as a physical illness and hence keeping up the demand for its products. In the USA nearly 20% of sales revenue is spent on the promotion of drugs (Norton 1973) and in Britain the Sainsbury Committee (1967) found the proportion to be nearly 14%. Much of this is spent on persuading doctors to prescribe a particular brand of drug (Coleman 1977) but drug companies do have an interest in social definitions. A recent study by Conrad (1975) shows how a number of drug companies assisted in achieving a change of social definition in the case of disruptive children - a change from bad, naughty or wicked to overactive or hyperkinetic. In the process a huge market for drugs designed to reduce this overactivity was created. The case of epilepsy is slightly different;

the drug companies did not have to assist in achieving a moral passage, for epilepsy was generally recognized as an illness, but there are substantial rewards to be gained from maintaining such definitions. The Office of Health Economics found that in 1967 the National Health Service spent nearly a million pounds on anti-convulsant medication and with current high profit margins, the drug companies are able to support definitions of epilepsy as physical illness by producing glossy pamphlets, sponsoring research and advertising in the relevant journals. All of this material stresses the fact that epilepsy is a physical illness and that it can be treated by their product.

The purpose of this description of the way certain organizations act as moral entrepreneurs is not to make judgments about the rightness or wrongness of such activity but to show that social definitions are not fixed and absolute, but that they can, and indeed are, shaped and re-shaped by the activities of moral entrepreneurs. However such organizations do have vested interests in maintaining these definitions over time, whether it be in pursuit of high profits or keeping an organization in operation.

(e) The Medical Profession

In the discussion so far, little has been said about the medical profession and its role in social definitions. Undoubtedly a number of physicians such as Hughlings Jackson, Gowers and Lennox, have been instigatory in putting forward the notion of epilepsy as a purely physical illness, and their activities have been built on by the profession as a whole and by organizations such as the British Epilepsy Association and the drug companies. However the present situation with a division between general practitioners and consultants is difficult to assess. What evidence there is (Hopkins and Scambler 1977) suggests that GP's refer almost all patients with suspected epilepsy to consultants who then provide the patients and their family with a formal diagnosis. (4) The role of the medical profession currently could be described as that of providing legitimation for an existing social definition rather than acting in any entrepreneurial function.

(f) Individuals

It is possible for individuals to act as moral entrepreneurs either deliberately or accidentally. Some individuals may choose to 'come out' and reveal their non-visible social deviance either in face to face interactions or through media publicity. Hence unknown individuals for example, may choose to reveal their homosexuality to friends or neighbours, and famous or important people may choose to announce their homosexuality to the world. There have been few systematic attempts to consider the effect of the individual upon social meanings although Klapp's work (1962. 1964) is a first step. In most social deviance there tends to be a polarization of meanings - at one end of the spectrum are the famous, those who have succeeded inspite of their deviance and at the other end stand the failures, the dregs and the drop-outs. Hence homosexuality may be perceived in terms of a number of famous writers, artists and so on or as part of the 'dirty mac brigade', old men who hang around public toilets or who corrupt little boys. So too with epilepsy; the public image polarizes between a number of famous historical figures who may have been epileptic - St. Paul, Julius Caesar, Alexander the Great, Dostoevsky - to those individuals who are violent, criminal or lunatic. (5)

Some systematic consideration of this topic has been given by Schutz (1967. Schutz and Luckman 1974) in his discussions of predecessors, contemporaries and successors and their effects on 'the life-world of everyday existence'. However there has been no systematic application of these ideas to existing everyday worlds and with regard to epilepsy, it is only possible to note that in the world of predecessors, contemporaries and successors there is a surfeit of unfavourable as opposed to favourable social types. At a national level there are few famous people who will admit to having epilepsy (6) and in individual face to face interactions, the vast majority of epileptics choose to 'pass'.

The point of this discussion has been to show that groups and individuals, wittingly or unwittingly, can act as moral entrepreneurs and further that social meanings can and do change as a result of these entrepreneurial activities. However social meanings do not only change as the result of the activities of committed entrepreneurs but may also change as a consequence of the pronouncements of individuals or groups who are accorded a special status on the basis of their specialized knowledge or training. It is to changes of this kind that consideration must now be given.

THE ACTIVITIES OF MORAL ENTREPRENEURS (ACCIDENTAL)

(a) The Role and Structure of Ideal-Typical Knowledge

So far the activities of 'moral entrepreneurs' who have a vested interest in putting forward certain definitions have been discussed; albeit that these interests may range from concern with individual professional status, the continued existence of organizations to a genuine concern for members to high profits. However, the social sciences can also act as 'moral entrepreneurs' either deliberately or unintentionally, even when they are supposedly presenting objective findings derived from scientific studies. In what follows, consideration will be given to the roles of criminology and psychiatry with regard to discussions of the relationship between epilepsy and crime and epilepsy and mental illness. This will be presented in terms of methodological imperative 2 - 'show how the phenomena is built up' (Chapter 2) and will be considered in three ways:

(i) the influence of general theories in criminology and psychiatry;

(ii) historical accident and the confinement of epileptics; and

(iii) the present prevalence of epileptics in prisons and mental hospitals.

Eliot Freidson has written perceptively of what he calls "professional knowledge" and what I have chosen to call "ideal-typical knowledge", and states (Freidson 1970. xvii):

> "In developing its own 'professional' approach, the profession changes the definition and shape of problems as experienced and interpreted by the layman. The layman's problem is recreated as it is managed - a new social reality is created by the profession. It is the autonomous position of the profession in society which permits it to re-create the layman's world."

In what follows in this chapter, consideration will be given to this professional knowledge per se, and the following chapters will consider the effects upon the layman, (the epileptic), and his world.

(b) Criminology

Traditional criminology has been dominated by two major concerns; these can be termed causality and control. Thus it has tended to ask why do they do it? And how can we prevent it? However, when consideration is given to substantive problems such as the relationship between epilepsy and crime, these dominant concerns tend to shape the nature, course and results of the research under consideration.

The causal approach to criminology has developed along three major lines: (i) biological; (ii) mental, that is concerned with psychological and/or psychiatric explanations; and (iii) social, that is concerned with such factors as home and class, or environmental pressures concerned with slums and urban deprivation. Historically the biological determinists were first on the scene and can be traced back to Lombroso who had much to say about the relationship between epilepsy and crime (Lombroso 1876):

> "The perversion of the affective sphere, the hate, exaggerated without motive, the absence or insufficiency of all restraint, the multiple hereditary tendencies, are the source of irresistable impulses in the moral imbecile as well as the born criminal and the epileptic."

Thus for him, there were three main kinds of criminal: the insane, the born and the epileptic; and all three kinds were rooted in an epileptoid base.

With the rise of the related disciplines of psychology and psychiatry, a new type of causal approach became popular and even Lombroso modified his views somewhat in the light of new theories about the relationship between behaviour and mental elements of the individual concerned. These views are currently respectable and have adherents as noteworthy as Sir Martin Roth (De Rueck and Porter 1968.48):

> "Recent observations have made it plain that in so far as there is any increased hazard of violent or anti-social conduct among epileptics, it does not arise from the attacks of epileptic impairment of consciousness but rather from the psychiatric complications of epilepsy."

According to Roth, these psychiatric complications consist of things like changes of mood, alterations of personality, diminished frustration tolerance, loss of emotional control, increased impulsiveness the blunting of sensitivity, increased egocentricity and so on.

Whether such criteria constitute genuine diagnostic symptoms or simply subjectively negotiated and perceived states is a moot point, but the psychiatric view of the relationship between crime, epilepsy and mental illness has achieved widespread academic acceptance beyond the boundaries of psychiatry.

Terence Morris conducted an explicitly sociological study of Pentonville Prison and devoted a whole chapter to illness in the prison setting, clearly differentiating between psychiatric and physical illnesses in the process. However, he unquestioningly locates epilepsy in the section on mental illness and disorder (Morris 1963.196):

> "In 1956, 12 clear cases and fifteen doubtful cases of epilepsy passed through the prison. Without a detailed survey, which could not be carried out, it was impossible to assess accurately the proportion of the daily average population who were mentally ill in the sense of displaying the psychiatrically recognised symptoms of mental or nervous disorder; it is certain, however, that the above figures for suicide, attempted suicide, insanity, mental defect and epilepsy do not present the true character and extent of mental illness and mental disorder in Pentonville."

At least Morris got it right when he said that the figures do not present an accurate picture but he nonetheless accepts that epilepsy merits consideration under the rubric of mental rather than physical disorder.

The third major line along which this approach has developed concerns social or environmental causality. There has been no systematic attempt to develop such an approach with regard to epilepsy and crime but Gunn has examined a number of social factors relevant to epileptics in prison (Gunn 1974). Having failed to find any significant differences between epileptics and non-epileptics in terms of the crimes they have committed (Gunn 1971a) or any evidence of crimes committed during altered states of consciousness, he examined a number of social factors - social class, material conditions in the childhood home, sibship size and parental loss - hoping to throw light on his earlier findings (Gunn 1969) that there were considerably more epileptics in prison than estimates of numbers in the general population lead to expect. He postulated three tentative hypotheses: (i) organic brain factors produce, by a variety of processes, disturbed behaviour which results in imprisonment; (ii) environmental factors lead both to an increased prevalence of epilepsy and an increased likelihood of imprisonment; and (iii) the first two hypotheses operate simultaneously. He concludes (Gunn 1974.514):

> "On balance, remembering that we are dealing with retrospective data, the best summary of the findings is probably that they support hypothesis (iii), suggesting that both organic and social factors account for the excess prevalence of epilepsy in prisons and that the social factors play a bigger role than the organic ones."

The dominance of the causal approach in criminology has led some writers not simply to posit connections between epilepsy and crime but also to infer relationships between epilepsy and specific crimes. A general statement along these lines can be found in a 'respectable' American textbook of criminology (Roebuck 1967.39):

> "The relationship of types of criminal behaviour to EEGs and epilepsy remains unclear. It is known that some epileptics are prone to crimes of violence and that still others commit acts varying from petty assaults to rape and murder during states of altered consciousness as well as during states of clear consciousness."

Associations of such kinds are frequently made as the following examples demonstrate:

Epilepsy and murder and violence - "Epilepsy, itself, may exist without intellectual impairment, but there is usually some form of it. Excessive or brutal violence may occur as can murder and indecent exposure, among other manifestations." (Morland 1966.97)

Epilepsy and rape - "Rape has been encountered in epileptics and in other types of acute mania. The rapist may also be a sadist and murder his victim, either for the purpose of lust or to destroy the only witness to his crime." (de River 1956.41-2)

Epilepsy and arson - "The act of arson, in a pathological arson, is not an ordinary act of arson, but an act actuated by an abnormal impulse .... It is caused also by feeblemindedness or done by insane or epileptic persons .... where epilepsy is the cause, treatment should be in the direction of giving relief from epilepsy." (Sethna 1956.62)

Epilepsy and indecent exposure - "A student is taught the connection between epileptic automatism and exhibitionism. This occurs occasionally, as in the case of the professional man who, when overworked, was apt to become automatic and then exposed himself. But it would appear that the cases are not as frequent as they are dramatic." (Norwood East 1936.200)

Epilepsy and stealing - "The epileptic, during automatic states, may steal things which are not themselves desired: that is pathological stealing." (Sethna 1956.64)

And it has even proved possible for some writers to locate epilepsy as a cause of violent behaviour when the perpetrator of such violence is not himself an epileptic. (Burt 1961.436):

> "Storms of violence, apparently motiveless, and many spells of obstinacy and ill-humour, are highly characteristic of epileptics; and in a member of epileptic stock, who himself shows none of the distinctive physical symptoms, repeated attacks of rage may occur as so-called 'epileptic equivalents'."

In recent years there have been general dissatisfaction with the approach that criminology has adopted and this has in part given rise to what has sometimes been referred to as a new paradigm (Kuhn 1962) variously called 'the sociology of deviance', 'new deviancy theory' and sometimes even 'labelling theory'. This has not resulted in the replacement of the criminological paradigm, but rather has facilitated the development of two separate disciplines with only tenuous links between them. (7) However, in this section general dissatisfactions with the criminological paradigm will remain implicit rather than explicit, and criticism will focus on two specific weaknesses in the criminological approach to the study of epilepsy and crime: (i) its failure to demonstrate causality, and (ii) its failure to provide measures suitable for controlling or removing the phenomenon of the epileptic criminal. Thus it will be argued that the criminological approach has failed to achieve either of its acknowledged aims, that is, cause and control.

None of the studies discussed in the earlier section actually show how epilepsy is linked to criminal behaviour; they either accept uncritically notions, often derived from psychiatric medicine, that epilepsy produces abnormal behaviour which results in criminal activities or they simply assume correlations by utilizing a (small) number of case studies. The net result is that myths surrounding the epileptic criminal are accepted and indeed even perpetuated rather than subjected to empirical and scientific scrutiny. Indeed, de River in his book (1956) preserves such myths by a process which can only be called 'negative correlation'. As a result of his study of over a thousand sex offenders, he catalogues every imaginable (and some not) kind of sex offence but his empirical evidence is based on 29 extensive and in-depth case histories. In none of these cases is epilepsy mentioned as being contributary to the offence in any way but in 27 of these cases it is mentioned negatively, usually in terms like "there is a negative family history of insanity, epilepsy and all constitutional diseases", but occasionally more expansively, "there is a negative family history of syphilis, insanity, epilepsy, cleft palate, premature greying hair, all nervous diseases". Obviously the myths which criminology has in part contributed to, have shaped and structured research to the point that they have shown criminologists not only where to look but also what to look for and to comment on absence as well as presence. It would be interesting to see if political sociologists could make such negatively correlational statements about politicians' family histories, or industrial sociologists about managers' family histories.

Not only has the criminological paradigm failed to demonstrate causality but it has also failed to address itself to the second question - "How can we prevent it?". At least in terms of numbers of labelled epileptics in prison, the numbers are increasing rather than decreasing (see following section - Present Prevalence - for actual figures). Hence, more sophisticated explanations of the relationship between epilepsy and crime have not actually prevented the phenomena occurring - scientific understanding has not led to better treatment or 'cure'.

(c) Psychiatry

According to Taylor (Herrington Ed. 1969.106):

> "Descriptive associations between epilepsy and mental disorder are as old as history and abound throughout the literature."

Such views are derived in part from notions of epilepsy and madness both being seated within the brain, for as Herodotus, an ancient Greek historian once wrote (Herrington Ed. 1969.106):

> "The great Persian King Cambyses suffered from birth with a great disease which some people called sacred and thus it would not be surprising that if the body suffered from a great disease, that the mind was not sound either."

However, the mind/brain proximity is not the only factor influencing ideas concerning the association between epilepsy and mental illness, for as Orley (1970) points out in his study of present day primitive beliefs about mental illness, madness and epilepsy; both madness and epilepsy cause people to lose control of their bodies and behave in ways that they normally would not. This is not to suggest that primitive or modern man believes that epilepsy and madness are the same thing for they clearly do not, but that lay beliefs concerning the nature of both epilepsy and madness often become associated with one another.

Since the rise of psychiatry as a medical specialism, two distinct areas of concern can be identified; concern with the abnormal personality - the psychopath, the sociopath and so on; and concern with identifiable clinical entities such as psychosis, schizophrenia, depression and so on. Interestingly, a similar dual concern can be found in examining psychiatric ideas about epilepsy - notions of the epileptic personality and also about associations between epilepsy and other clinical entities. These two areas will need to be considered separately.

"The epileptic personality" was not a concept given birth by the new medical speciality of psychiatry in the nineteenth century, but was as old as 'the sacred disease' itself. However, in its formative years modern psychiatry gave an empirical basis to such notions and according to Livingston (1963.186):

> "Much has been written in the past about the existence of an 'epileptic personality'. Almost every type of behavioural and personality aberration has been assigned to the epileptic as a manifestation of his 'epileptic personality', such as criminal tendencies, sexual perversions, paranoid traits, suicidal tendencies, perseveration and numerous other psychotic disorders."

However, while many studies of the epileptic personality took place in the nineteenth century, almost all of these were poorly designed and/or badly reported (Guerrant et al. 1962.17-9). The most important factors shaping these early studies were ideas dominant in psychiatry at that particular time - ideas stemming from the work of Kraepelin and Lombroso concerning the identification and description of definite clinical entities which had characteristic courses and unalterable outcomes. Hence as these mechanistic conceptions gave way to more dynamic ideas in psychiatry generally, so notions of the epileptic personality began to change and become more complex and sophisticated.

Towards the middle of the twentieth century, one writer (Arluck 1941) was able to identify the three most widely accepted interpretations of the inter-relationship between epilepsy and personality:

(i) The psychogenic approach - the individual is pre-disposed to paroxysmal disorder because of his specific personality makeup.

(ii) The organic approach - the individual is pre-disposed to convulsions, but specific personality traits such as emotionality and excitability precipitate epilepsy.

(iii) Idiopathic epilepsy is to be found in individuals with diverse personality characteristics.

Arluck carried out a study himself of four distinct groups whom he subjected to a battery of psychological tests but he could find no evidence of the typical epileptic personality. He sided with an explanation proposed by Barnes and Fetterman (1938.908), an explanation which sounds like an early version of labelling theory:

> "Throughout the ages, the term epilepsy has conveyed a stigma of degradation, abnormality and incurability. The youngster who has been refused admission to school because of having fits is publicly humiliated. As a young adult he is discharged from his job. There are idleness, unemployment and shame. The epileptic patient obviously sinks into introspection, worry, brooding and resentment. It is this psychic reaction which frequently explains the peculiar mental states of certain epileptic patients."

Twenty years later Barbara Tizard (1962) reviewed the literature and identified three additional interpretations:

(i) There is no characteristic epileptic personality but a higher proportion of neurotic disturbance is found among epileptics.

(ii) There is no characteristic epileptic personality but epileptics tend to have a personality resembling that of patients with organic lesions, and which differs from that of normal persons.

(iii) There is no characteristic personality common to all epileptics but different types of personality are associated with different types of epilepsy.

She concludes (1962.204):

> "The work surveyed above gives no support to the theory that all or most epileptics share a characteristic personality. It is, however, hardly adequate to

> affirm or refute the other theories that have been advanced. There is some evidence that the incidence of personality disturbance may be high among epileptics, or among some groups of epileptics and that different types of personality disturbance are associated with different types of epilepsy."

Thus it is no longer argued that there is any single or simple relationship between epilepsy and personality and any discernible similarities among epileptics are usually accounted for in terms of one, or a combination of, the following factors: a) fears about having a seizure in public; b) social stigmatization and rejection; c) the effects of institutionalization and d) the side-effects from drugs. Nonetheless, more specific theories are sometimes advanced, the most common of which concerns the association between temporal lobe epilepsy and abnormal personality. Temporal lobe epilepsy usually has an identifiable organic lesion on the brain and is sometimes said to produce violent outbursts, aggressiveness and sexual maladjustment.

Taylor (1972.166) has recently argued for a distinction between peculiarities of character and personality disorder among epileptics:

> "Peculiarities of character in epileptics ought to be separated from personality disorders among them. Personality disorder implies that suffering, on the part of the individual or of society, results from the patient's behaviour. Of these disorders aggressive and rude behaviour, anti-social behaviour and inadequacy are the most apparent. It is generally acknowledged that significant degrees of psychiatric disorder are over-represented only in chronic epileptics, especially those whose disorder began early in childhood."

However, such arguments are only more sophisticated versions of the earlier 'epileptic personality' syndrome: as general psychiatric theories have purported to distinguish between peculiarities of character and personality disorder, so such distinctions have appeared in discussions about the relationship between epilepsy and personality. These more sophisticated and limited theories suffer from much the same problems as the earlier much cruder theories: firstly, such behavioural phenomena as aggression, anti-sociability or inadequacy are social states subjectively and situationally defined and not symptoms of some underlying scientifically demonstrable pathology; and secondly, it is impossible to determine the etiology of such social states, for the effects of stigmatization, institutionalization and social rejection also have to be taken into account and the relationship between these social factors and organic pathology is likely currently to be unknown.

The second aspect of the relationship between epilepsy and mental illness concerns the extent to which epileptics as a group suffer from distinct and discrete psychiatric disabilities. While Taylor (1972.177) argues:

> "there is little evidence that epilepsy in general
> leads to the development of any particular type
> of mental disorder."

most experts would probably agree that mental illness of all kinds is probably more common in persons suffering from epilepsy than in the general population. Pond and Bidwell (1960) in their survey of epilepsy in general practice found that at least one-third of their sample had psychological difficulties and estimated that at least ten per cent of all epileptics being cared for in general practice would require a period of in-patient psychiatric care, at least once in their lives. Other studies have produced similar conclusions; for example, Gunn (1973) in a study of prisons, found more epileptic prisoners suffering from psychiatric disabilities than in a control group of non-epileptic prisoners.

The crucial issue yet to be resolved for those working in this field is whether there is any basic 'neurological mechanism' which can account for this increased propensity to mental illness among epileptics or whether it can be explained in terms of social and environmental factors. While epileptologists would not want to argue for any special 'mechanism', studies have pointed to two particular areas; the close association between epileptic and schizophrenic like psychosis (see Slater et al 1963) and the prevalence of psychiatric disorder among epileptics suffering from damage to the temporal lobe (see Herrington, Herrington Ed. 1969). But not all would agree, Stevens (1966) for example, suggests that any observed differences between temporal lobe and non-temporal lobe epileptics are largely illusory. Still others (Taylor 1972) have pointed to social factors such as disturbed family history or age and chronicity of seizures as being important etiological factors.

There are two major criticisms that can be made concerning the various attempts to link epilepsy and distinct clinical entities. Firstly, there is conceptual confusion, or at least a lack of conceptual clarity among those using the terminology, for as Betts et al (Laidlaw and Richens 1976.176) have pointed out:

> "The relationship between psychotic illness and epilepsy is closely argued, controversial and of historical interest. British, other European, and American psychiatrists hold very different views on prevalence, type and aetiology. The main reason for these differences is probably the use of different diagnostic criteria both for the psychoses and for epilepsy."

Thus, schizophrenia may be defined differently by different psychiatrists and psychomotorepilepsy may refer to either epilepsy originating in the temporal lobe or to a specific type of fit.

Secondly, while most of these studies have used control groups and attempted to locate differences in the groups under study, epileptologists have recognized the importance of social factors. Livingston (1963.197) points out:

> "It is quite obvious that any individual epileptic or non-epileptic, who is continuously exposed to obstacles created by social and economic rejection and who is denied privileges which are considered basic human rights, such as marriage, education and employment, is certainly likely to develop emotional difficulties. Even those epileptics who have been free of seizures for many years encounter social and economic obstacles of great magnitude.
>
> It is of prime importance to understand that most of the emotional disturbances observed in many epileptic patients are not manifestations of the disorder itself, but are the results of a hostile society which has discriminated against the epileptic since the dawn of recorded history."

But, neither medical nor social science has developed measurement techniques which are able to accurately distinguish between individual pathology, whether of a biological, psychological or environmental nature, and the effects of a hostile social world.

So far it has been argued that dominant conceptions regarding the relationships between epilepsy and crime and epilepsy and mental illness have been shaped by more general criminological and psychiatric theories and concerns. Additionally, the limitations in these so-called 'scientific conceptions' have been pointed out and it has been suggested that in some sense, these dominant conceptions have actually created the phenomena they purport to explain. To further understand this, it is necessary to adopt what has earlier been referred to as 'the situational approach' and to examine the confinement of epileptics in historical and current contexts.

(d) History and Situation

(i) Borstals

The most important factor affecting the social organization of epilepsy in borstal concerns the relationship between the number of youths diagnosed as epileptic, who are sentenced to borstal training, and the suitability of epileptics for a sentence which is still regarded (in official policy at least) as an exercise in social training and rehabilitation rather than a punitive term of imprisonment. In order to fully explicate this relationship, a brief discourse on the history of borstal training is necessary.

The first borstal was opened at Rochester in 1908 as a result of a recommendation of the Gladstone Committee (1895) which advocated the separation of the young offender from the hardened criminals who inhabited the prisons. However, under the guidance of the most influential figure in the history of borstal training, Alex Patterson, borstals became a series of training establishments designed to educate and train socially deprived and delinquent youths along lines modelled on the methods used by the public schools to train and educate middle and upper class youths. Although obviously using different criteria, the principle of selection was as important for the borstal system as it was for the public schools, and the adoption of a very careful selection policy for borstals meant that a very high success rate, at least in terms of non-reconviction, was achieved by the borstal system, at least until World War Two. For the purpose of this study, it is important to note that such a selection process would have rendered anyone suffering with epilepsy as unsuitable for the sort of rigorous, open-air, hardworking and physically demanding regime that made up the borstal training programme.

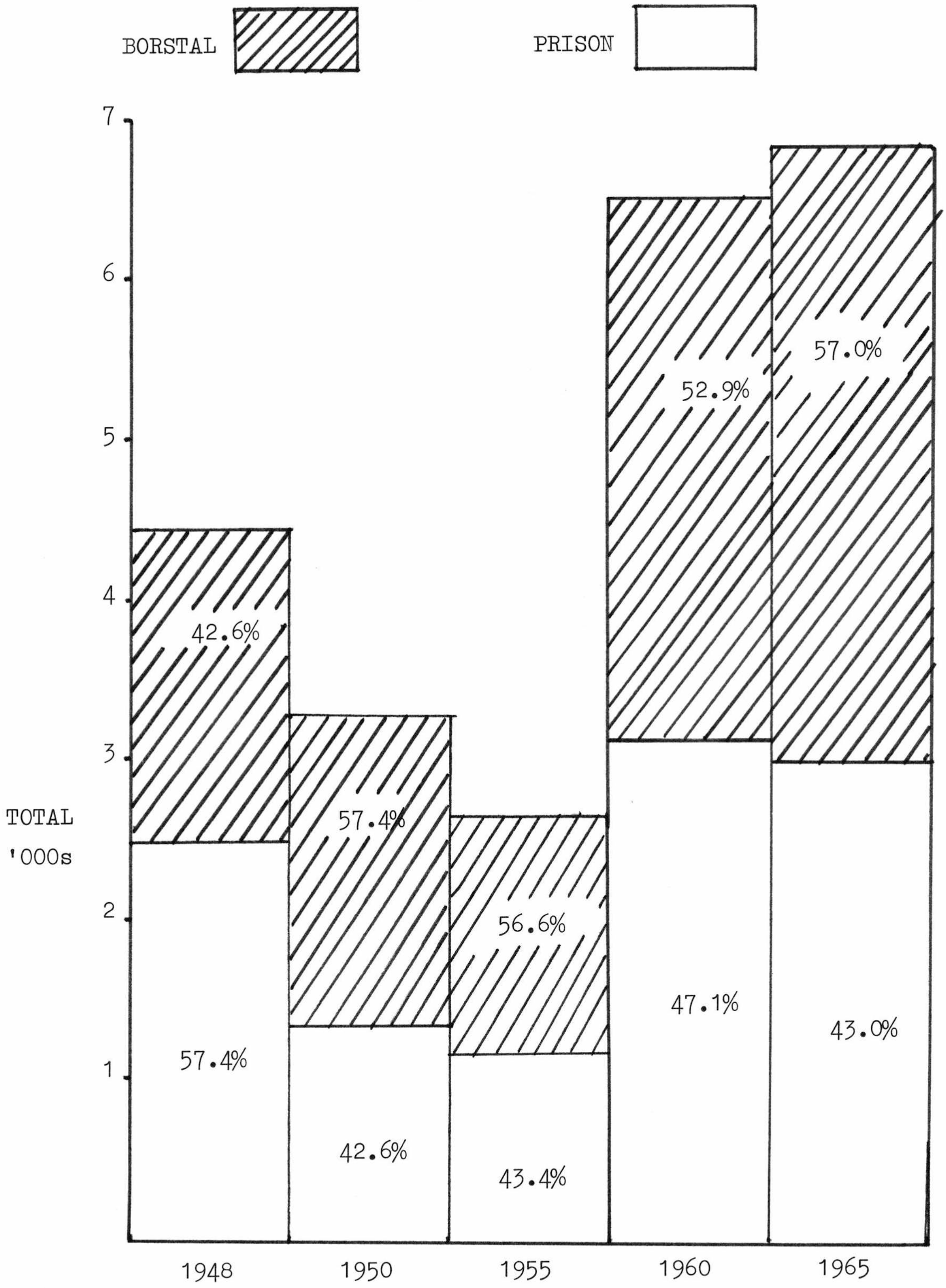
After the War the Criminal Justice Act 1948 made the first inroads into the selection principle taking away the rights of Magistrates' Courts to impose prison sentences on anyone under 17, though Higher Courts could still impose such sentences on anyone over 15. No Court could impose a prison sentence on anyone under 21 unless they were fully satisfied that no other sentence was appropriate. Two new measures were also introduced; the setting up of attendance and detention centres for the young offenders, and the selection principle for borstal training was restated in the Act:

> "having regard to character and previous conduct, and the circumstances of the offence, that is (was) expedient for his reformation and the prevention of crime that he should undergo a period of training in a Borstal Institution."

While in theory, no-one with epilepsy should have been selected as suitable for borstal, the increasing numbers of people convicted of crimes especially in the late 1950's and particularly among the young, meant that all sectors of the penal system were under pressure of sheer numbers. The following table shows that one important result of the 1948 Act was to reverse the balance between the numbers and proportions sentenced to prison and borstal. Additionally, the new attendance and detention centres reduced the actual numbers of young offenders being sentenced to prison and borstal, at least until 1955, but during the following five years there was a more than doubling of the numbers sentenced both to prison and borstal.

Although the principle of selection was still in operation officially, it was during the period 1955-60 that a number of trainees who previously would have been regarded as

NUMBER OF INMATES - 15-21 AGE GROUP



YEAR

DATE	1948	1950	1955	1960	1965
Prison	2488	1374	1132	3099	2957
Borstal	1848	1852	1478	3476	3923
TOTAL	4336	3226	2610	6575	6880

unsuitable for borstal training began arriving at the borstal. This information was supplied by a key informant, a prison officer who has been at the borstal since 1948; and the best-remembered example of a trainee who would have previously not been selected for borstal training was the inmate who had an artificial leg. With regard to epilepsy, trainees so afflicted began to appear at approximately the same time, and my informant can place the date as the late 1950's as it coincided with the popularity of 'rock and roll' music - when trainees began to have fits at the borstal, the twitching and shaking movements were likened to the gyrations of the newly popular 'rock' stars and prison slang for having a fit became 'doing an Elvis'.

The principle of selection which was breaking down informally under pressure of numbers was formally abandoned in 1961 by the passing of The Criminal Justice Act. Walker (1970. 197-8) summarizes the intention of the Act:

> "that no court should be able to send anyone under 21 to prison except in those rare cases in which it decided that only a sentence of three years or longer will fit the case. All shorter sentences should take the form either of committal to borstal or .... of detention centre orders."

In effect what this has finally meant for the borstal training system is that a new principle of selection has been substituted for the old - many offenders aged between 15 and 21 have already spent the maximum two periods (nine months total) in detention and committed an offence not serious enough to warrant a prison sentence of three years or more; consequently, the only place to which they can be sent is a borstal institution. McClean and Wood (1969.252) assess the situation as follows:

> "In fact, the scheme of the 1961 Act is that all medium term training is to take place in borstals."

Thus selection for borstal training is now often a result of previous criminal record and the nature of the current offence rather than suitability to benefit from a period of training.

The disappearance of the selection principle, at least in its original form, and the increasing pressure of numbers in recent years has meant that containment rather than training has become the major organizational goal. Lowson (Mays 1975.156) aptly comments:

> "Of recent years, the pressure on borstal places has led to an ever-shortening length of stay, especially in the closed borstals which are thought to be required for the more criminal type of youth now being committed for training. Little training is possible in such a situation and nowadays there can be little difference between the experience of a lad in a closed borstal and that of a young prisoner in jail."

Thus the abandonment of this principle and the replacement of the original goal of training by the newer one of containment, has effectively meant that those youths with epilepsy who come before the courts are now much more likely to be sent to borstal in the first place and once there, to be merely contained rather than trained to lead 'a good and useful life'.

There is also a number of pressures which structure the process of diagnosis or verification of epilepsy by the medical officer concerned. The prison department has a number of formal rules and regulations relating to the way epileptics should be treated and the things they are, or are not, allowed to do and it is the responsibility of the institution medical officer to classify epileptics officially. There is also informal Home Office pressure on doctors to play safe and when in doubt to diagnose, in order to avoid potentially troublesome incidents that may arise.

Additionally, it has been pointed out previously that the medical profession is inherently conservative in its diagnostic practice, in that it is regarded as much more serious to diagnose as healthy someone who is really ill, than it is to diagnose as ill someone who is really healthy. This situation is especially pertinent with regard to conditions such as epilepsy where diagnosis is problematic. Gunn (1977) in his study, argued that the Prison Medical Service tends to under-diagnose the extent of epilepsy in prisons, but my study of a borstal (Chapter 3) came to the opposite conclusion. Indeed this evidence suggests that the greater prevalence of epileptics in prisons and borstals than in the population as a whole found by Gunn, can be accounted for largely in terms of these pressures to overdiagnose. (8)

(ii) Mental Hospitals

Any links between epilepsy and mental illness have not arisen solely from the development of psychiatric and lay notions about such a relationship but, also, as a result of what was earlier (Chapter 3) referred to as historical accident. The use of the institution as a means of containing social deviants was begun in the seventeenth century and from then on increased in pace and complexity. According to Rosen (1968.158):

> "Folly and madness were no longer to roam aimlessly. Order was necessary, and the mentally and emotionally deranged were to be subjected to discipline in institutions created for this purpose. For the seventeenth and eighteenth centuries, mental illness was to be exiled from the social scene in both thought and practice."

Whereas in earlier times, social deviants of all kinds were accommodated within society, the community and the family, increasing social pressures from industrialization, rising population, severe economic crises, the break-up of stable community and family relationships, and changing ideas about what should be done with and to the non-productive and idle, gave birth to the institution as the key machinery for processing deviants of all kinds.

With regard to epileptics as social deviants, as late as 1850 there were two kinds of institutions in which the majority of epileptics was held - the workhouse and the asylum.

Initially, as workhouses sprung up as a means of punishing the non-productive, little account was taken of reasons for this non-productivity and those who were idle were kept in the same conditions as those who were sick or old or pregnant and hence unable to work. However, after 1834 some attempt was made to segregate the sick from the idle by the establishing of infirmaries within the existing workhouses. The result was that (Longmate 1974.194):

> "The workhouse infirmary, with all its defects, became the poor man's hospital and the sick and infirm wards, at first provided as mainly an afterthought, to provide a service to other inmates, were soon the busiest in the whole establishment."

And the provision of these infirmaries developed rapidly so that by the 1870's (Abel-Smith 1964.49):

> "It was the Poor Law Service which accommodated the bulk of the sick children, the mental cases, the skin conditions, those with epilepsy, tuberculosis and venereal diseases and the unexplored mass of the chronic sick."

While it is not possible to make any accurate estimate of the prevalence of epileptics in these infirmaries, there is some evidence that their number was considerable. Longmate (1974.212) comments:

> "For most of the nineteenth century, however, terms like 'imbecile' and 'lunatic' tended to be used indiscriminately. 'Imbeciles and those afflicted with fits are to be found in every workhouse' warned one workhouse visitor in 1858, estimating the total for the whole country at around 30,000, or about one in six of all 'indoor paupers'. One London workhouse in 1863 classified 32 of its 586 inmates as 'subject to fits' and 17 more as 'idiots'."

As has been pointed out earlier (Chapter 3) many young doctors who were forced out from the private sector of medicine into the workhouse infirmaries hence found epileptics as one category amongst their captive population. Thus one Dr. Rogers who served two London workhouses was able to write of one epileptic (Longmate 1974.214):

> "when a seizure occurred, sprang up and dashed himself to the ground .... He continued by these means to smash his nose, make dreadfully disfiguring wounds on his forehead and face, and from a good-looking became a perfectly repulsive-looking person .... I got him away at last but I had two or three years of him, during which time I had a very extensive surgical experience from his case alone for I was constantly stitching up his wounds."

Thus medical men employed in workhouses were to learn about epilepsy by studying an already institutionalized population; a population which has become institutionalized not because of their particular illness but because of their nuisance value as social deviants, as non-workers in a world which required that even women and children did their share of work.

Not all epileptics processed as social deviants necessarily found themselves in the Poor Law Infirmaries but many were lodged alongside the insane. According to Jones (1955.ix) the history of the processing of the insane can be summarized as follows:

> "In the eighteenth century, madmen were locked up in madhouses; in the nineteenth century, lunatics were sent to asylums; and in the twentieth century, the mentally ill receive treatment in hospitals."

Just how many epileptics were locked up in madhouses is unknown but asylums in the nineteenth century certainly had their fair share. For example, Colney Hatch, newly opened in 1851 had, by 1876, 150 male and 112 female epileptics from total populations of 846 male and 1241 female occupants; thus making proportions of 18 per cent male and 9 per cent female (Hunter and McAlpine 1974.90). This and other asylums either obtained their epileptics directly or had them transferred from the Poor Law Infirmaries which were now developing as specialized places to care for the sick and found the management of the 'epileptic mania' impossible. The majority of epileptics who found themselves in places like Colney Hatch were those suffering from grand mal.

Thus by 1870, epileptics were generally placed in institutions of one of two kinds - the infirmary attached to the workhouse or the County Asylum. However, from this time onwards there developed a "separation movement" in which various categories of illness were isolated both physically and conceptually, and treated in newly emerging special units by newly emerging medical specialists.

One aspect of this movement was the further development of private hospitals, often financed and run by charitable organizations, the most important of which for epileptics was the National Hospital for the Paralysed and Epileptic, founded in 1859. The setting up of this famous hospital in Queen's Square was largely the result of unstinting efforts of Miss Johanna Chandler who found (Holmes 1954.9):

> "there was no provision for the care and treatment of persons suffering with epilepsy except in lunatic asylums, as neither general hospitals nor convalescent homes would receive them as patients."

And according to the same source (Holmes 1954.56) at the National Hospital:

> "Between 1870 and 1880, 30 to 40 per cent of the indoor patients were victims of epilepsy."

Probably the most important aspect of the separation movement with regard to epilepsy was the building of the seven 'epileptic colonies', most of which were built between 1888 and 1905. The Reid Report (1969.95) comments on the development of the colonies thus:

> "The original concept of the epileptic colony was that of an almost self-contained rural community, divorced from the increasing mechanisation of industry, producing most of its own food and making many articles for its own use."

In their heyday, the colonies accommodated over 2,000 epileptics, but one recent study (Jones and Tillotson 1965) shows quite clearly that their function was more that of taking care of social deviants and misfits rather than, as might logically be expected, catering for those suffering from the severest and most chronic forms of epilepsy. The above-mentioned study found that the most important reasons for both admittance into and retention within the colonies were as follows:

- living alone, unable to care for themselves, deteriorating mentally and physically
- admitted from some other type of residential accommodation after a long history of institutional care, with no known relations and no fixed address
- admitted after the death of a supporting relative, and with no others available to assume responsibility for their care
- admitted from families with multiple problems, broken or unsuitable homes

The twentieth century saw the separation movement continuing with, firstly, the reorganization of the Poor Law System after the 1909 Report and then, the eventual creation of the National Health Service. These developments have given rise to a number of special schools, specialist hospitals and other units catering for the needs of epileptics. With regard to the colonies, Jones and Tillotson (1965.15) surveyed their care records and found:

> "at least 61.4 per cent were of low intelligence, 31.7 per cent had severe disabilities while an unknown proportion, probably about 20 per cent had some degree of mental disturbance. These figures suggest a condition which might be called 'epilepsy plus'. Patients evidently come into

> colonies not simply because they are epileptic,
> however severe the epileptic condition may be,
> but because they suffer from multiple handicaps,
> of which epilepsy is one."

The Reid Report, perhaps recognizing that the primary function the colonies were serving was that of processing social deviants, recommended that they should be phased out and that many of the inhabitants could be cared for in the community. The colonies have been largely replaced by Special Centres. Thus the move towards care in the community in the field of mental health generally has been reflected in the treatment of epileptics; the institution is no longer regarded as a suitable means for caring for the vast majority of those with epilepsy. Nonetheless, despite the fact that there are no longer large numbers of epileptics in institutions for the mentally ill, and that doctors would no longer argue that there is any simple connection between epilepsy and mental illness, studies have indicated (Harrison and West 1976) that the general public regard epileptics as mental cases, and the British Epilepsy Association see one of their major tasks as convincing people that epilepsy is physical and not mental illness.

(e) Present Prevalence

EPILEPTICS IN PRISON

(Report on the work of the Prison Dept., HMSO Annual)

Year	Total (Daily Average)	Epileptics (Confirmed)	Prevalence (per 1000)
1966	33,086	577	19
1967	35,009	712	20
1968	32,461	680	20
1969	34,667	675	19
1970	39,028	792	20
1971	39,708	763	19
1972	38,328	834	22
1973	36,774	831	23
1974	36,867	919	25
1975	39,820	1049	26

There are two important points to note with regard to this table; firstly, that the figures include only confirmed epileptics and the annual statistics always additionally includes a category for doubtful epileptics which can range from 25% - 50% of the confirmed and thus substantially increase numbers; and secondly, epilepsy is the only specific illness category for which such figures are recorded, thus indicating that Home Office also take for granted that there is a relationship between epilepsy and crime. (9)

There has been very little work designed to examine the relationship between epilepsy and delinquency, which is surprising, for this relationship should be even more obvious than between epilepsy and crime. More crimes are committed in the 15 - 24 age group than any other, and epilepsy also attacks more people in that age group;

therefore, statistical correlations between epilepsy and delinquency ought to be easier to establish than between epilepsy and crime. As long ago as 1915 Healy found 7 per cent of definite epileptics in 1,000 delinquent cases, but Burt (1962), in his later study, found only two genuine epileptics in the 200 cases he examined. More recently, a World Health Organization study (1957) reported 7 epileptics (2.3%) among 294 boys at a London remand home. During my own research at borstal, on one particular day (15.5.76) there were 9 trainees officially classified as epileptic out of the total institution population of 415, thus yielding 2.2%.

Unfortunately, the precise number of epileptics in mental hospitals in unknown, for the DHSS in its annual collection of statistics does not treat epilepsy as a separate category. Additionally, many of the studies that have focused on epileptics in mental hospitals have not been concerned with prevalence but with particular symptoms or certain kinds of epilepsy; e.g. the schizophrenia-like psychoses of epilepsy (Slater et al 1967) or temporal lobe epilepsy (Taylor 1969). One early study (Lidell 1953) showed that 4.5% of the chronic population of Runwell Hospital had epilepsy and in 1965 the Birmingham Regional Hospital Board carried out a survey of beds in the mental hospitals of their area and found that 718 (5.4%) of their hospital beds were occupied by patients described as epileptic. A more recent study (Betts 1977) of admission to the Queen Elizabeth Hospital, Birmingham, over the last five years, found epilepsy accounted for no less than 10% of all admissions.

The one national survey (Brooke 1963) which treated epilepsy as a separate category produced the following figures:

Patients resident in psychiatric hospitals and units at
31.12.63 with a primary or secondary diagnosis of
epilepsy or epileptic psychosis

	MALE	FEMALE	TOTAL
Primary diagnosis: epilepsy	884	699	1583
Primary diagnosis: epileptic psychosis	1159	1195	2354
Secondary diagnosis; epilepsy or epileptic psychosis	849	917	1766
Total	2892	2811	5703

This indicates a prevalence of 4.3% in the total population of mental hospitals. These figures, and those quoted from the other studies, would appear to indicate that almost ten times as many epileptics may be admitted to mental hospitals as would be expected from their prevalence in the population as a whole - the College of General Practitioners Study (1963) estimated a prevalence of 4.19 per thousand or 0.4% in the general population. A more recent study (Hoenig and Hamilton 1969) of admission to three psychiatric units attached to general hospitals found that between 3% and 4% were admitted with a primary diagnosis of epilepsy, thus providing further evidence of broad agreement about prevalence among the studies discussed.

However, it is not the purpose of this study to discover any 'true' or 'real' relationship between epilepsy and mental illness, but to examine the factors influencing both medical and lay knowledge to the point where both have come to agree that there is an association between the two, and the effects that this may have on those labelled both epileptic and mentally ill.

Certainly most doctors, psychiatrists and epileptologists would agree that people with epilepsy are more likely to experience psychiatric disabilities, but whether they are ten times as likely to suffer such problems is debatable. One recent study (Betts 1974.327) would indicate that these figures may exaggerate any association:

> "No less than 20 per cent of the patients who were labelled as epileptic (and who would therefore feature as such in hospital returns and statistics) were not actually suffering from epilepsy in the customarily accepted meaning (some did not have epilepsy at all; others had, or had had, epileptic fits clearly secondary to other causes which occurred and were recognized before the onset of the first fit). It seemed that anyone in these hospitals who had a fit for whatever reason and no matter how long ago was thereafter called epileptic. Such unselective labelling if unnoticed makes nonsense of statistics, and because of the pejorative nature of the word epileptic may have unfortunate consequences for the individual patient."

His more recent study (Betts 1977) found that 33% of those admitted who had been diagnosed as epileptic were found not to have had epilepsy at all.

With regard to adolescent male epileptics between the ages 15 - 24, there are no official published statistics but DHSS did, on request, provide some figures which enable us to fill out the picture a little. The following table is abstracted from this information:

<u>Admissions of patients with a diagnosis of epilepsy to mental illness hospitals and units in England and Wales</u>

	1970	1974
All ages (a)	577	412
15 - 24 (b)	116	100
% (b) of (a)	20.1	24.3

CONCLUSION

The aim of this chapter was two-fold; firstly, to show how social meanings can be influenced by the wilful activities of both individuals and organizations and secondly, to show how certain specific kinds of knowledge are constituted. In discussing the latter, consideration was directed to the relationship between typifications and ideal-typical knowledge. Holnzer (1968.122) has understood this relationship well:

> "Every specific mode of reality construction, and corresponding store of working knowledge, constitutes a departure of some kind from the "natural reality" of everyday life. The commonsense of a society always provides the broad base out of which specializations arise and to which they are connected, if sometimes only tenuously. This conception of the natural reality which commonsense takes for granted arises out of the sometimes diffuse, sometimes specific, reality experiences of man in his daily routines, out of the communicated and accepted reality constructs of existing special groups .... Yet, no matter how specialized a mode of reality construction may become, no matter how "abstruse" its product may look to the layman, somewhere and sometime it must be referred back to this sphere of commonsense."

Hence, for the criminologist and the psychiatrist, their conceptions about the reality of relationships between epilepsy and crime and epilepsy and mental illness are influenced by their everyday experiences; specifically, the general theories they encounter, the historical context within which they work and the current situation with regard to the confinement of epileptics. But not only that, these professional conceptions come to mirror stereotypical ones concerning epileptics as violent, or epileptics as 'nutters' (Scambler 1976. Harrison and West 1976.). For present purposes, it is enough to point to the connections, the exact nature of such connections will be considered later (chapter 7).

Finally, having attempted to show how ideal-typical knowledge is constituted, it should be noted that such knowledge is usually given higher status, regarded as more accurate than other forms of knowledge. Bogdan (1974.233) has pointed out:

> "Social science holds an ever-increasing position of importance in providing our definitions of reality, since the typologies, definitions, and diagnoses it creates provide sources from which individuals and groups may choose definitions for themselves and others."

It is how individuals choose to define themselves in relation to professional conceptions, ideal-typical knowledge, that will be considered in the following chapter.

CHAPTER FIVE

THE RESPONSE OF THE INDIVIDUAL

In the first chapter it was argued that there is a social basis to the trouble that most epileptics experience. Chapters 3 and 4 have attempted to provide a sense of history and structure to a sociological analysis of epilepsy. This, and the following chapter, will focus on the area of face to face interaction and how it is organized and managed. However the analysis will attempt to build on the earlier sense of history and structure and not simply provide a description of free-floating interactions and negotiations. In order to accomplish such a task it is necessary to make use of the concept of role.

It has recently been argued (Strong and Davis 1977.775) that the failure to explicate links between history, structure and face to face interaction stems largely from the abandonment of the concept of role. They state:

> "The concept of role has almost disappeared from large areas of current sociological inquiry along with all the various sub-categories that it spawned in such profusion .... Although we have much greater understanding of interaction, or at least of the work which it involves, our knowledge of how it relates to social structures is still scanty. Roles served to mediate between the two and they have had no successor. The new sociology of interaction has largely ignored the problems that role was used to solve; the new sociology of structure has largely ignored the new sociology of interaction."

In this chapter then, in order to mediate between structure and interaction, the concept of role will be of crucial importance. There are a number of points that need to be made concerning the use of this concept; generally, it is used as a 'second order construct', that is a term specifically utilized by this research in order to facilitate analysis, and not as a term which is employed or used by the respondents in their everyday lives. Specifically there will be two parameters which guide the usage of the concept - the relationship between an individual and a particular role is dependent upon both the selective attention an individual gives to a role, and the situation within which the interaction takes place. However it would not be correct to suggest that interactionists have not themselves emphasized these points:

The situational nature of role-taking (Lauer and Handel 1977.65)

> "Role-taking of all types is situational. That is, the kind of role-taking in which an individual actually engages is, in part, a function of the social context."

The selective nature of role-taking (Rose 1962.27)

> "The normal role-taking process .... is a tentative process on which roles are identified and given content on a shifting axis as interaction proceeds. Both the identification of the roles and their content undergo cumulative revision, becoming relatively fixed for a period of time only as they provide a stable framework for interaction."

Now while this selective and situational nature of the relationship between individual and role is recognized at a theoretical level, much of the empirical work in this area has depicted role as having a deterministic effect upon individual actors. When this is coupled with the recent return to a more voluntaristic model of man in the social sciences, it is not hard to see why the usage of the concept of role has declined. However, there are two factors which may, in part, account for the discrepancy between what was recognized at a theoretical level and what was produced at a substantive one; firstly, inherent in the very nature of writing up, of translating actions into words, a picture emerges that is more deterministic than the researchers intend (1);

and secondly, those financing and sponsoring research have required findings to be presented in such a way that modification or rehabilitation programmes can be set up.

This study, therefore, recognizes the situational nature of the relationship between role and individual and hopefully in what follows, the writing up of the research, any tendency towards depicting roles in a deterministic fashion can be avoided. To this end, it should be noted that the role-taking process that will be described, is a process that, while taking place in an organizational setting, is nonetheless structured by the 'ideal-typical knowledge' discussed in the previous chapter. Before proceeding to examine the individual responses it is necessary to consider some of the previous studies and the situations within which the responses may take place.

VOLUNTARY ORGANIZATIONS AND INDIVIDUAL RESPONSES

(i) Previous Work - The work of Robert Scott (1970) was referred to in Chapter 3 when his attempt to show how the conceptions professional workers have about blindness can shape the social meanings associated with blindness at a national level was discussed. Another of his works (1969), which is a consideration of the work and effects of blind welfare agencies in the United States, can provide a useful starting point for the analysis of individual responses of those with epilepsy to their own particular social worlds.

Scott considers the responses of the blind in two different situations; situations structured either by stereotypes or by professional conceptions. Firstly he considers the stereotypes of blindness and argues (1969.22):

> "It is impossible for the blind man to ignore these beliefs; they have no choice but to respond to them. These responses vary, but in a highly patterned way."

He then proceeds to identify five different kinds of responses: (1) 'true believers' - those who behave in accordance with the stereotypes. (2) 'those who manage to isolate a part of the self-concept from the assaults made on it by normals' - their personal identities are not those of blind men, but of normal men who cannot see, although they recognize that these are not the definitions that others have of them. (3) 'expedients' - those who adopt the stereotype in certain situations in order to gain benefits of material or other kinds, but who recognize that this response is a facade. (4) 'professionals' - those who deliberately adopt the stereotype but charge a price for it, as in the case of blind beggars. (5) 'independents' - those who seek to preserve their personal identities and resist stereotyping at every turn.

Later in the study Scott (1969.79) considers what has been referred to earlier as ideal-typical knowledge:

> "....the assumptions and theories of workers for the blind concerning blindness and rehabilitation take on new significance, for what they do is to create, shape and model the attitudes and behaviour of the client in his role as a blind person .... it is in organizations for the blind that theories and explicit and implicit assumptions about blindness and rehabilitation become actualised in the clients' attitudes and behaviour."

He then goes on to identify similar individual responses to the situation of blindness in the welfare organization, structured by professional conceptions (ideal-typical knowledge) as he had previously identified for stereotypes. However he makes no attempt to consider the relationship between stereotypes and professional conceptions nor does he discuss whether the response of a particular individual is consistent in situations structured by these different kinds of knowledge; viz. whether an individual may be a true believer in situations structured both by stereotypes and ideal-typical knowledge or whether he can be an 'expedient' in one and a 'professional' in another.

Thus, though Scott's work provides a valuable starting point and a theoretical impetus for this present study, it is inadequate in that it does not give sufficient attention to the selective and situational nature of the role-taking process. Additionally the American system of voluntary organizations is significantly different from the situation in Britain and there are important differences between Blind Welfare Organizations in U.S. and the Local Action Groups of the British Epilepsy Association. The Blind Welfare Agencies usually provide a whole range of social services for their clients from income, employment, education, medical advice, and so on, and often require the client to attend on a full-time basis whereas Local Action Groups only provide assistance supplementary to statutory social service provision, and additionally only require their members to attend weekly or monthly. Therefore, before analysing the responses of adolescent epileptics, a brief description of Local Action Groups will prove useful.

(ii) The Situation - Local 'Action for Epilepsy' Groups - Local groups were set up shortly after the British Epilepsy Association was formed in 1950, and were originally founded as social groups for people with epilepsy who literally had no other means of meeting and were often excluded from ordinary social organizations. However the format of the groups has now changed somewhat, and while they continue to provide social facilities, a number of other functions have been included. Among these are the operation of the groups on a self-help basis, providing information, assistance and mutual support for epileptics and their families;

activities aimed at changing public perceptions of epilepsy at a local level by organizing meetings, writing to the local press, and other similar tactics; and the raising of funds for the central organization. (2)

During the course of this research seven of these local groups were visited on at least one occasion. Some of these visits involved just observing what was going on, some involved my giving short talks about my research, during some the formal interviews were carried out with local officers, family members and those suffering from epilepsy. While the organization and activities of these groups varied somewhat, all the groups were united on two points and it was in these areas that their activities were directed. Firstly, they were all united in putting forward the idea that epilepsy is simply a physical illness; and secondly, that most of the problems experienced by those with epilepsy stemmed from a failure of the general public, teachers, doctors, employers and so on, to realize this simple fact.

The responses discussed in what follows stem from interviews conducted with adolescent epileptics contacted through these local groups, though not all of those interviewed were necessarily themselves members - it may have been their parents who had joined. Nonetheless all were exposed to the view that epilepsy was merely a physical illness and that many of the problems and prejudices surrounding it stemmed from mistaken public perceptions. It is their individual responses to this view of the world that must now be considered.

A number of studies have identified a variety of different responses to social situations or roles considered deviant or disabling - avowal (Turner 1972), disavowal (Davis 1961), denial (Edgerton 1967) and engulfment (Schur 1971) to name a few. From a detailed listening to the tapes of the present study, the basic response of the interviewees to their social situation/role of being epileptics in the community is one of 'acceptance' and acceptance in what can only be described as a passive manner. There was no evidence of any active or dynamic attachment to their role as implied in terms like avowal, disavowal, denial or engulfment. Their acceptance had a taken-for-grantedness about it for as one respondent said:

> R. I just look at it, I look at it this way, I've got something that I can't help. I didn't get it myself, I was born with it and if I've got it, that's it. I can't do nothing about it. So, er, I think if one goes with a negative attitude to it, it's going to make you miserable as well as other people miserable and you're not going to get anywhere in life. I think that if you look at it with a more positive attitude in life, you're going to find that it's not going to bother you so much, and then, if other people, the public, are going to be bothered, you won't be because you know what it's all about and these people don't.

However, there are several dimensions to this acceptance, the majority adopting what can best be described as a positive attitude towards their epilepsy, even to the extent of seeing its initial diagnosis as a relief.

> R. It didn't happen slowly. It was a very drastic thing. Er, I was being taken to Oxford Theatre to watch 'Joan of Arc' during an 'A' level, er, thing and, it was English and we'd all gone there and it was very quiet. It was the trial scene, I don't know whether you know it, anyway, it was very quiet and all of a sudden, I was being carried out on a stretcher. There was this roaring ambulance - and all these people were rushing around. "What the devil's going on? What the hell am I doing here?". I was really panicking. They put me

> into the ambulance and I promptly passed out again. Then I finally woke up in hospital. For some reason I had the impression that I was being dragged in for some sort of emergency operation, that I was dying - or something like that, 'cos it's very dramatic and, er, I said "What's happening? What's going on?". And, er, this nurse said "It's alright Michael, you've just had an epileptic fit". "Phhew! Is that all? Oh, good grief. Thank goodness for that. I thought I was in for an operation". 'Cos up until then, I've never had an operation in my life and I was terrified. (3)

And ultimately, those who positively accept their situation are able to reduce the experience of being epileptic to an insignificant part of their lives. One respondent said:

> R. I tend to, sort of, forget all about it. All the epilepsy means to me is these little capsules I have to take.

and another:

> R. Well, epilepsy's something, it, it's, it's er, er, an abstraction it isn't really, er, it hasn't really got much to do with me, it's I mean, mostly apart from taking, taking my drugs ....

This positive acceptance allows a favourable interpretation to be put on the various everyday problems that may face all adolescents at some time or another, problems such as getting a job or meeting girls.

> I. What about work? Do you think that having epilepsy has affected the kind of job
>
> R. At first, because I can't, as I can't, can't go up scaffolding or drive; by the law I need three years without epilepsy, so that works on drugs, and drugs bar me from machines, electrical machines, employers don't take me in case I have a fit at a machine. I quite understand that, but I'm not interested in engineering so it hasn't had any effect on that, to much extent. I'm more interested in the clerical side or storekeeping.

Er, - I think it has affected me slightly with storekeeping that I can't get jobs where there's machinery, it may be involved in machinery, but otherwise, I think, no.

I. No. You've had several jobs; have you lost any of them because of your epilepsy?

R. No, I haven't. I've gained one, I've gained a job due to my epilepsy. I'm registered as disabled so mmm, it does help, it has helped me sometimes.

Thus while the majority of those interviewed accepted their role in a positive manner, there were two respondents, who while accepting their social situation, viewed it in a negative fashion.

R. It all started and now, sort of, - I've got epilepsy. This is how much, I mean, it's ruined - puts me back. Puts me down the social scale in a way.

I. Yes - you think that's how it's affected you? It's pushed you down?

R. Yes, because - some people must age .... They'd be, er, going out with girls, er, getting in cars, driving back all over the place. As for me - if I start talking to anyone - it's, - the time is very short before someone says, "Oh, but that boy's a nutter, don't you know. He's the one who's got epilepsy. He's a nutter".

And when epilepsy is accepted in this manner, it is blamed for things that have gone wrong in the past or things that may not be achieved in the future.

R. If I hadn't had epilepsy I'd have left at the end of the fifth year. I had eight CSE's at the end of the fifth year and I'd have left then and gone into the RAF like my father, which I'd have been able to do but because I suffer from epilepsy, er, I'm not allowed to join any of the Forces, Police Force or anything else like that. I did find, earlier on, er, 1976, a great interest for, for medical a lot, a very great interest, I was extremely interested in that, but that fell through now, because I can't have that job because I have attacks during the day, the grand mal attacks during the day-time, which only happened recently. Before I had the attacks just as I woke, the grand mal attacks, just as I woke up, you know. They were three or four months apart, but now they're not, they're two or three weeks apart, you see, the grand mal attacks.

I. So what about employment. Have you tried to find a job yet?

R. Yes, I've applied and applied and applied. It's a question of - oh, well, I've no idea what to do in that when I go to the interview they always ask me about health, and that, I'm not going to say I've got nothing wrong, absolutely nothing wrong with me because if I, y'know, if they find out later they'll fire me on, er, false grounds. I might as well tell them then that I've got epilepsy. That's it! They don't want to know me. They'll pick someone else. They may not have, you know, so many qualifications as me but they still don't suffer from epilepsy.

Only one respondent diverged from this acceptance which could either be relegated to an insignificant part of life or utilized as blame for things not working out, and his response could best be described as 'engulfment'. This was probably due to the special circumstance that he lived in a small rural village which was very much a self-contained community in which everyone knew everyone else. Hence his epilepsy was part of his everyday life and also known about by everyone with whom he was likely to be in contact:

R. It's a very small village so they, y'know, it's all, they all sort of know about it. Well, perhaps they don't know about it, but they know, they know I do have fits occasionally.

And again:

> R. The only real way, in one sense, that, well, it's had an effect on me, is the fact that it's, er, you're always aware that, er, somebody is, sort of, follow, hold you back, watch over you, type of thing, y'know.

However this somewhat forced engulfment had positive rather than negative consequences in that the respondent was able to indulge in potentially dangerous pastimes - swimming, climbing trees, riding a bike - knowing that people were aware of his situation and would 'look out for him'.

The general response identified among respondents contacted through local 'Action for Epilepsy' groups was one of acceptance although this had both a positive and a negative dimension. Just how knowledge and ideas about epilepsy held by workers in these groups affected the responses will be considered in a later section, but in the sections immediately following, responses to being epileptic in a borstal and associated with a mental hospital will be considered.

THE INSTITUTION

(i) Previous Work - In recent years sociologists have spent a great deal of time studying individuals in institutional settings, and many of these have focused on prisons and mental hospitals. According to Scull (1977.96-7) most of these studies reached similar conclusions:

> "The consensus was clear. Presented most persuasively by Goffman, it was that the most crucial factor in forming a mental hospital patient was not his 'illness' but his institution; that his reactions and adjustments, pathological as they might seem to an outsider, were the product of the ill effects of his environment rather than of intrapsychic forces: and indeed, that they closely resembled those inmates in other types of 'total institutions', a term that came to encapsulate

> this whole line of argument."

However, studies have shown that different institutions produce different responses; for example Wing and Brown (1970.177) found that differing social environments in three psychiatric hospitals affected the responses of the individual patients:

> "certain aspects of the social environment actually cause clinical improvement or deterioration."

King and Raynes (1968) argue that the effects of institutions vary between different kinds of institution; viz. children's homes and mental subnormality hospitals. They suggest that this may be because of four factors (derived from Goffman's work) concerning the way in which these institutions are managed. The factors are (i) the inflexibility of routine; (ii) the extent of regimentation; (iii) the amount of depersonalization and (iv) the social distance between staff and patient/inmate/client/resident.

The shorthand term for the processes to which individuals are subjected has become 'institutionalization' and hence individuals become 'institutionalized'. Through a variety of strategies variously identified as 'status degradation ceremonies' (Garfinkel 1956) and 'mortification of the self' (Goffman 1961) individuals are stripped of their 'outside' personalities. By forcing them to have short haircuts, impersonal clothing, by the allocation of numbers instead of names, by removing personal possessions and by reducing personal autonomy and choice over a wide variety of personal functions and tasks such as how to dress, when to wash or bath, when to go to the lavatory, to bed, to eat, to smoke and so on, the individual becomes institutionalized. This institutionalization can have an impact upon the individual sometimes identified as role engulfment (Schur 1971.69):

> "One major consequence of the processes through which a deviant identity is imputed is the tendency of the

> deviator to become 'caught up in' a deviant role, to find that it has become highly salient in his overall personal identity (or concept of self), that his behaviour is increasingly organised 'around' the role, and that cultural expectations attached to the role have come to have precedence, or increased salience relative to other expectations, in the organization of his activities and general way of life .... 'Role engulfment' seems a satisfactory term for social-psychological impact on the individual."

While the effects of institutionalization and its pervasive nature have generally been agreed by most writers, the work of Goffman stands in a somewhat paradoxical position. It was his book '<u>Asylums</u>' which provided the impetus for much of the subsequent work on institutionalization, but that was only part of his argument. He was also at pains to point out that individuals will find sufficient social space in the cracks of any institutional order to modify and negotiate the impact of the institutionalization process, and this aspect of his work has not received as much attention and subsequent documentation as the negative effects of institutionalization. Certainly at the borstal studied, the inmates were able to gain concessions from the regulations concerning when to eat, sleep, defecate, and so on by volunteering for jobs which required early or late working or periods of little or no supervision. The removal of personal possessions was often remedied by obtaining, and taking pride in a different set of possessions which could be legally kept - outside clothes were removed but there was great prestige to be had in acquiring a pair of nearly new institution dungarees or a pair of shoes in a style only recently introduced; the effects of the standard prison haircut could be minimized by avoiding a visit to the barber for as long as possible and then retrimming the hair once it had been cut. This latter activity was usually unnoticeable to the outside observer or even made matters worse, but it nontheless had a beneficial effect on the individual above the mere improvement of a cosmetic nature. Other props to personal identity were also cultivated such as beautifully polished and decorated tobacco tins. (4)

(ii) <u>The Situation - Being Epileptic in a Borstal</u> - According to a recent publication (HMSO 1977) there are twenty-two borstals currently in operation and there is a major division of function between the open and closed institutions. Those allocated to the twelve closed institutions are likely to be offenders who have either committed crimes before or have committed a sufficiently serious offence to be deemed to constitute a danger to the public. The institution at which this research took place was a closed one and even within the closed sector (HMSO 143):

> "The Borstal Rules envisage that methods of training will vary as between one borstal and another and require trainees to be allocated as far as practicable in such a manner as to make best use of available facilities."

The important available facilities relevant to allocation at the particular borstal under consideration are educational and medical. In the past ten years a new education centre has been built and the medical block has been substantially redeveloped and existing facilities have been extensively supplemented. The education centre has been specializing in remedial education and the hospital in handling offenders who were psychiatrically disturbed; hence this particular borstal tends to be allocated disturbed offenders of low intelligence, or at least, poor educational attainment.

It has sometimes been argued that the social organization of illness in an institution can be more pervasive than the normal process of institutionalization and consequently can have greater impact upon the individuals concerned. Freidson (1970.326) states:

> "When the sick person is institutionalised, the experience of being ill becomes far more amenable to organisation by staff demands, for the person tends to lose his social and physical mobility, to be isolated from his lay associates, to be cut off from the information he would need in order to assume an active role in the management of his illness, and to be fitted into an administrative routine organised to permit the staff to work in ways they consider effective and convenient. In fact only when he is institutionalised can the sick person be restricted to performing only one role - that of the patient."

While Freidson is talking about the hospital as an institution, it would also follow that the organization of epilepsy as an illness would be more amenable in a penal establishment such as a borstal.

Certainly there are special regulations with regard to the epileptic in penal establishments and this involves being located in a specially designated cell on the ground floor, and being provided with special furniture and a special floor so that if he has a fit he is unlikely to injure himself in a fall. He is excused physical education classes and games, and is not allowed to work on the farm or with machinery, nor is he allowed to work in the concrete shop or with ladders, and he is not allowed to register for any of the trade training courses. However, just as individuals in the borstal were able to modify and negotiate the process of institutionalization and thus render the extent of role engulfment situationally problematic, so too were those with epilepsy able to act in the unorganized cracks of the institutional order left untouched or negotiable by the process of 'medicalization'. (5) Thus despite the existence of formal regulations detailing what those classified as epileptic could and could not do, not all were located in special cells, not all were on medication, and some were able to obtain jobs or partake in leisure activities formally barred to them.

(iii) The Response - The interviews on which this part of the analysis is based were conducted within the borstal institution and took place either in an empty classroom in the Education Centre or in a quiet room in the wing in which the trainee resided. A study of the transcripts of these interviews revealed repeated attempts by individuals to distance themselves from their epilepsy, or rather from the social role of being epileptic in a borstal. They did not deny the fact of their epilepsy, but that their experience was not as painful, punitive and restricted as I had imagined. However they were able to describe these painful and punitive experiences as they happened to others, but never themselves.

The following represent attempts made by individuals at such distancing.

A good example is the attempt by one individual to distance himself from bad fits - thus the respondent is happy to be considered epileptic but is at pains to emphasize that he has few fits:

> R. When I got borstal I accidentally was in a cell, y'know with an epileptic, another geezer was epileptic, and er, he just happened to start spitting up a lot of blood and that, and throwing a wobble. He pressed the bell and they come in. They said well, he was an EP and that. And I come here and I was on phenobarbitone and I went to hospital from here for an EEG and they still couldn't find out nothing about me having epileptics. But then they found something wrong with my, er - they still, they said, on the EEG report "Can't find much about this being epileptic, but he has got tempers, bad tempers,

y'know, going over his temples". See what I mean. Temper and that was obvious and ever since then I have been on EP restrictions. But I can have them y'know, I have got them.

I. You do have fits?

R. I did have fits but not y'know, I wouldn't say - I wouldn't have them regularly, y'know what I mean. I only had them now and again.

Another individual was able to provide graphic descriptions of fits that others had while at the same time stressing that he was not as bad as those he was describing:

R. I've seen a - couple of people in here that have them, epileptic fits, banging their pipe on the head, on the, banging their head should I say. Er, in the Scrubs there was one person, he had about ten in, within half an hour - y'know, he wasn't a nice case y'know, a bad case of this illness.

I. How did you feel about it when you, when you saw people really having fits? Did it disturb you? Did it worry you? Or did you just think it was one of those things, or what?

R. I just thought it was, I did think it was those things. I knew I had epilepsy obviously, and I just thought to myself - well I haven't got it as bad as him.

Another example of such distancing was the respondent who didn't like admitting that the black-outs he had were fits.

R. I have had, the last epileptic fit or black-out, I don't like to call them fits 'cos, y'know, I don't class them myself as fits. The doctor, er, when I go to the doctor he says a fit, I - er - do my nut. I say "It's not a fit. I don't have a fit".

A number of respondents, while admitting that epileptics generally were treated badly in borstal, sought to deny that they were recipients of such treatment:

I. Some epileptics feel that they are not treated very well by others?

R. No - see, I er, I know there's one bloke across at the wing, he's an EP and they all er, y'know, make fun of him, laugh at him and that.

I. But they don't do that with you?

R. No 'cos they don't know.

I. Oh, I see, do you think they would if they knew?

R. Possibly but I won't give them the chance to find out.

Finally, none of the respondents would admit to incontinence which is a fairly common occurrence during fits, though they were prepared to discuss incontinence in others:

I. Do you have any associated problems with it; incontinence or anything like that?

R. Well, I get pains.

I. Do you wet yourself or anything like ....

R. No, no, no, no.

I. Because some people do, don't they?

R. Yeah, we got another lad in here. We believe he has done that before.

There are a number of general points that should be made about this distancing. Firstly the distancing was not always based on reality in that by using the methodological technique of 'triangulation' (Becker 1971), that is by checking with other sources, it was obvious that these respondents did have bad fits, were treated badly in borstal and some were incontinent. Secondly, the responses of distancing were not well worked out, consistent, rehearsed accounts but very much more attempts to negotiate through the interview situation while preserving a relatively favourable self image. Finally, distancing was identified as a response in all but one of the respondents - in this particular respondent he consistently denied that he was epileptic. But this was not denial or disavowal as identified by a number of writers (Edgerton 1967. Davis 1961) in order to protect the individual from harsh societal reaction or to preserve a more favourable self image; it was a denial based on the conviction that the respondent had been wrongly labelled. This denial turned out to have a factual basis and is considered in detail in Chapter 3 (RIM pages 98-9).

This general phenomenon of distancing was also found by Blaxter (1976.198) in her study of a number of different kinds of disability:

> "Epilepsy came into a special category. In fact, none of the sample's epileptics gave any evidence at all that they had experienced any social stigma, but each one expressed surprise and gratitude at this and all told generalised stories about the problems which epileptics usually faced."

Scambler and Hopkins (1975) identified a similar phenomena and proposed a theoretical distinction between 'felt' and 'enacted' stigma to account for the fact that a number of their epileptic respondents felt that epilepsy was a highly stigmatized condition but had not themselves experienced it.

Goffman (1972.102) has provided a theoretical discussion of the conceptof role distance and makes the point referred to earlier (p. 186) concerning the ability of individuals to avoid the pervasive effects of institutionalization:

> "A set of visible qualifications and known certifications, along with a social setting well designed as a showplace, provides the individual with something more than an opportunity to play his role self to the hilt, for this scene is just what be needs to create a clear impression

> of what he chooses not to lay claim to. <u>The more extensive the trappings of a role, the more opportunity to display role distance</u>." (My underlining.)

This was certainly true of the individuals in the borstal. While in other situations their deviation might have remained non-visible, and hence 'passing' would have been a practical possibility, in the current situation their deviation was visible, or at least 'known about' by all and hence distancing became the situated response. And as Goffman has pointed out both theoretically (1972) and substantively (1968), the more extensive and elaborate the social organization of a particular role, the greater the potential for displaying role distance.

In recent years empirical evidence about the ability of individuals to avoid the pervasive effects of institutionalization has gradually been accumulated, particularly with regard to the effects of institutionalization upon long-stay prisoners. Cohen and Taylor (1971) were among the first to point this out empirically in their study of long-term prisoners in Durham and later to provide a theoretical framework for this evidence (Cohen and Taylor 1977). More recently others (Richards 1978. Sapsford 1978) have come to similar conclusions and one writer (Sapsford 1978.143) points out:

> "it would not seem unreasonable to conclude that the extreme condition of apathy and reversion to childish attitudes which is reported from concentration camps and long-stay psychiatric hospitals may be rare in prisons, even among men subject to the uncertainties of the life-sentence."

(iv) <u>Being Epileptic in a Hospital Setting</u> - The hospital concerned is a famous London teaching hospital which specializes both in the treatment of mental illness and epilepsy. The respondents were contacted through the 'epilepsy firm' at this particular hospital and all had psychiatric complications which may or may not have been associated with their epilepsy. There was however a practical difficulty in obtaining the respondents for this section of the research, in that there were not enough respondents in the hospital to make a study similar to the one in the borstal, either possible or practical. Indeed as the previous chapter has shown the figures available suggest that there are only about 100 epileptics between the ages 15 - 24 institutionalized in mental hospitals throughout the country. Hence the chances of a sufficient number being located within one institution are probably nil. Thus, while all the respondents were associated with this particular hospital and all had both epilepsy and psychiatric problems, their links with the hospital are somewhat different.

There were in fact three different kinds of link with the hospital; three of the respondents lived in a hostel in the grounds which was organized on the lines of a therapeutic community and was supervised by an occupational therapist, a social worker and a consultant from the hospital; three were actually resident in the hospital on an open ward and were permitted to go out, to the workshops, to the occupational therapy department, the residents canteen and even to the shops and the cinema; the final two were living at home and occasionally visited the hospital for appointments with consultants, concerning both their epilepsy and their psychiatric problems. The corresponding interviews were carried out in the hostel, on the ward and in the social work department.

The analysis of tapes and transcripts obtained in this section of the research presented greater problems in using empathic techniques. With the two previous groups, it became obvious after a few preliminary readings and listenings that there was a definite patterning to individual responses. However after many hours of working on the tapes obtained from this particular group, the response of the researcher was one of confusion and contradiction. After struggling with this problem it occurred to the researcher that this contradiction and confusion might actually be a patterned response existing within the tapes and not, as had been previously assumed, the inability of the researcher to grasp what was really going on. When the tapes are examined in this light, there are many examples within the transcripts of this confusion and contradiction as the patterned responses to their particular social situation.

All the respondents accepted the fact that they were epileptic and professed to be adjusted to it. Some had faced problems of acceptance initially:

> R. At first I was rather, I felt everything had gone wrong. Why should such, er, why should everything go wrong for me? Everything seemed to be happening at the wrong time. Everything wrong for me and I just couldn't accept it at first. Then .... I'd got it, y'know. Only at the age of 14, I'd accepted it, as being part of my, part of my life.

and had come through to stress the positive aspects of their situation:

> I. Do you think it's affected your life in other ways?
>
> R. The epilepsy?
>
> I. Yes.
>
> R. Er - it's made me more aware of other people and in that sense it's been good. There's this girl I'm fond of and she has - temporal lobe epilepsy, I think it is?
>
> I. Yes.
>
> R. And I do what I can to, in little gestures, to be kind, I do as much as I can but .... people in this ward, in fact, are ignorant. In this ward there's a man, he's had some sort of depression, he can't get out and he

> often comes to me, sits on my bed in the morning and talks to me, y'know, and I sit there reassuring him .... and I do find that other people come to me, a lot younger, and talk to me about their problems although I've got mine as well.

Other respondents were at pains to point out that the initial diagnosis had little effect on them. According to one:

> I. How did you feel when you were actually told it was epilepsy? Did you feel relieved, or sorry, or worried?
>
> R. Well, I felt, well, there's no point in worrying about it. The more you worry about it, the less chance you've got of getting a job. I thought, just, I mean, a person, er, just, y'know, might suffer epilepsy, but so, er, what's that. You got to carry on normally. There's no point in worrying about it.

And another:

> I. Can you remember how you felt when you realized that you had got epilepsy?
>
> R. Er - it didn't worry me because I hadn't known properly. Me mum told me later on like and I said "Well, you've had epilepsy for 2 or 3 years so far; how do you feel?". And I didn't know that I'd had it like, so I didn't worry that much.

However beyond this basic acceptance of being epileptic, there was a general confusion as to how epilepsy might relate to social situation and contradiction as to how epilepsy might have influenced various events in their lives, so that at one point a single individual might say that epilepsy had had no effect on his education and then later in the transcript volunteer examples of how epilepsy had indeed influenced his school career. In order to present a clearer picture of this confusion and contradiction which emerges from the transcripts, what follows will be two extended extracts rather than a large number of shorter and more specific ones. A good example of the confusion a particular respondent felt on assessing the effects of his epilepsy is as follows:

I. What effect do you think it's had on you - having epilepsy?

R. Well - in a sense I'm a shy person.

I. Yes.

R. It goes inward. But I try to be as, er, outward going as I can. I don't like to, er, I suppose we all do, try to hide, like, now and again, like, really, some kind of camouflage but I don't wish to, though now and again I do.

I. Mmm - Do you think that's because of your epilepsy?

R. Yes, I think, that's about it, because of, because of the epilepsy. If it wasn't - stressed so much as being something that I done myself.

I. Yeah.

R. It was just, well - something happened and, er, that's what happens when something goes wrong. That's what we just can't, well you can try and put things right but that isn't to say that you can.

I. No?

R. You can always try; some people just keep on, like, well, well, they just like to keep on having 'em - 'digs' - having 'goes'; and it's all right for people that don't have epilepsy; it's all right for people that say they understand, but they don't understand, really. You know, they've really got to experience it. The person who has epilepsy understands somebody who has epilepsy - twice as well as somebody - who is kind enough to - help towards that person and to make 'em feel more at ease.

I. Yes.

R. You just can't, well - see there's more of other people like. Well, it's a malfunction, it's a malfunction of the brain, a lot of it, a spasm. Well you can't can you? You can't reach the brain unless you've got some pair of hands that, well, that give us 'em.

I. Mmm.

R. 'Cos there's some lads over there, like, well there were, there was, in the hospital. There was one lad over there and - he had an operation and - he swears blind he's blue now. It's done him more harm than good.

I. Yeah?

R. And I'd give all the money in the world not to have an operation.

I. Not to have the operation?

R. Well, y'know, to have the operation; and I just can't, well I've been told that - it won't be able to - it won't be, not a success, but it won't work out because it seems that my epilepsy's not as - easy - easily, er -

I. Can't be cured by surgery?

R. Well it can't be cured by surgery but it can by, er, it can be controlled by pills. But I'm like a flippin' medical cabinet, y'know a shop walking around. Gettin' 'em down, pills galore.

When considering specific issues such as the effects that epilepsy may have had on a particular respondent's education, for example, the confusion can develop into outright contradiction contained within the same passage of transcript.

I. Has it affected you, do you think, educationwise? Have you had a worse education, or a better education?

R. I've had a worse education. In a way, y'know, I feel it has. Yes, it has.

I. What? Because of your epilepsy?

R. Maybe, it is, yes.

I. In what ways?

R. Well, now - when I was at my second school T....C....; things changed. I used to muck about and, er, I didn't really learn anything in that school, y'know.

I. Yeah?

R. It's now I'm feeling, I should have done, y'know, I used to see, I've, I mean, I've seen kids having, y'know, having, er, exams and passing 'em and me doing nothing.

I. Yeah; but, I mean, what connection's that got with your epilepsy? I mean, do you think it's your epilepsy that caused you to muck about, and so on, or ....

R. No. No.

I. Mmm. Did you, did you used to have fits, or anything at school?

R. I had one.

I. Yeah; and what about the other kids? Did they treat you any differently?

R. No.

I. They didn't 'take the mickey' out of you, or anything?

R. Me? - No.

I. You're smiling. Does that mean - is there any significance to that - er, can you remember what happened when you had this fit? What did other people do? Did they panic or ....

R. No they didn't panic; and this was when I was fighting a kid at school. I used to, y'know, I used to have fights at school.

I. Yes - and you had a fit; and then what happened?

R. I went home by running off. I ran home for the night y'know, and they took this boy home. And then my mum came to the school. Then at least they knew.

I. Yes - so you don't think it's affected your education, that you have epilepsy?

R. No way, no way of doing.

I. Has it made it difficult, more difficult for you to learn things?

R. Yes.

I. Is that because of the tablets you take, or not being able to concentrate because you're worried about your epilepsy?

R. Yes, 'cos, y'know, I take tablets and then when I'm, er, at home when I listen to somebody and I really can't concentrate, I'm thinking about things and it - what I should have done at school.

There are a number of possible explanations for this lack of any definitive or clear cut pattern of common response to the situation of being epileptic and associated with a mental hospital. It could be the result of the methodological problems alluded to earlier, in that the interviews took place in three distinct and different situations and with the small numbers involved, it was thus impossible to discern any pattern. In fact, within the material there may well be patterned responses to the three different situations; being epileptic on a hospital ward, being epileptic in a therapeutic community and to being an epileptic outpatient. Another possible explanation could be the traditional psychiatric one - that these individuals are mentally ill and hence the contradictory and confusing responses are clinical signs of personality disintegration and disorganization and a lack of insight into personal circumstances.

The picture of confusion and contradiction emerged from all the tapes with one exception. One individual, who a few months prior to the interview, had undergone a brain operation, was very clear and definite about his epilepsy, how it had affected his life and the effects of the operation. As the following sample of transcript reveals, his responses were very clear and certain:

I. When you say you've got epilepsy, does it worry you? Does it make you feel happy, or sad, or ....

R. No, it doesn't worry me at all.

I. It doesn't worry you at all?

R. No.

I. Do you think it's had any effects on your life and family?

R. Yes, a lot.

I. In what ways?

R. Well, like, y'know, looking after us all the time and you can't get out to places, er, y'know, in case I have a fit. Like wanting to stay with us all the time. Y'know they didn't like leaving me on my own.

I. Oh, I see; and, er, how do you feel about that; do you ....

R. Well I'm OK really, I don't feel nothing.

I. You didn't like your parents always being on hand.

R. No.

I. You wanted to feel ....

R. But now I will, y'know, now I've had an operation - and I don't have any fits at all so my parents don't need to worry about me any more. (6)

While any attempt to choose between the two explanations suggested for the contradiction and confusion found in this section would only be speculation, neither is necessarily hostile to the general argument being advanced in this chapter; namely that individuals respond situationally and selectively to different roles or social situations.

THE INDIVIDUAL NATURE OF SUCH RESPONSES

Thus far, by utilizing the concept of role, broadly similar responses have been identified to being epileptic in a borstal and being epileptic in the community. The response to the situation of being epileptic in a borstal was identified as that of 'distancing', and the response to being epileptic in the community was identified as that of 'acceptance'. The role of being epileptic and attached to a psychiatric hospital gave rise to a variety of confused and contradictory responses which may inthemselves be a patterned response to a particular social situation. Therefore it can be argued that there is no single response to being epileptic but that particular situations can engender specific responses. What needs to be examined further is whether the same individual may respond in a different manner to being epileptic in a variety of different situations in which he may find himself.

Recently Rotenberg (1974) has argued that a neglected variable in labelling theory has been response of the individual labellee to a given label. According to him, the kind and degree of social reaction has been taken to be the major independent variable in accounting for individual responses to particular labels. What has been neglected has been the response of the individual - the question that has not been considered is 'what makes the label stick from the actor's perspective?'. While this paper has directed attention to a neglected but not ignored area, the focus of attention is on how a label may stick or not.

The argument being presented here would see this as too mechanistic a conception; it is not just a matter of how a label sticks but rather whether the individual may selectively respond to a particular label. Taylor (1976. 36) (b), has recently attempted to be more specific about the selective nature of labels and individual coping strategies:

> "Whether a label is selectively embraced, ironically distanced or ideologically adopted depends upon the

> general cultural standing of the term, as well as the specific structural situation in which the individual finds himself."

For him, deviant names or labels, whether formal such as homosexual, sadist, psychopath and epileptic or informal such as junkie, hippie, queer and wobbler:

> "Are continuously drawn upon in daily negotiations and transactions, and have no long lasting identity implications for the persons so named."

However, what needs to be established in this chapter is that individuals do, in fact, selectively respond to the label epileptic. Whether or not this label has any long lasting identity implications for individuals will be considered in the following chapter. To identify these selective responses using the method of participant observation might prove, at worst impossible, in that the observer might alter responses if he tried to observe responses in a wide variety of situations (7), and at best a lengthy and time consuming process. Nonetheless it is possible to identify a number of such responses by talking informally with relatives and friends, by studying case histories, medical records and so on, and, in one particular case, by scrutinizing a report which appeared in the local press. What follows in this section is based on these techniques and concentrates on one particular selective response which was found in a significant number of the respondents. This response will be defined as "Role Rejection".

(i) Role Rejection - Suicide and Suicide Attempts - Sociologists since Durkheim (1952) have been interested in the phenomena of suicide and it has occupied an important place in the sociological consciousness. Durkheim's initial concern was to demonstrate that suicide rates among societies were 'social facts' in that they could be explained in terms of the structure of particular societies and did not have to be seen in terms of an aggregation of individual actions. Since then the focus of sociological interest has shifted somewhat and is now concerned with social and individual meanings associated with suicide (Douglas 1967) and how these meanings affect the interpretation of individual actions as suicide and thereby the construction of suicide rates as social facts (Maxwell Atkinson 1971. 1978). It is not the intention here to add to or extend this tradition but to conceptualize suicide as a particular individual response to a specific social situation. In doing this no distinction is made between suicide and attempted suicide and both actions can be seen as manifestations of the same set of circumstances where only the outcome may be different. The usual interpretation is that suicide and attempted suicide may be totally different activities, both in terms of their social meanings and individual motivations.

What is being argued is that suicide and suicide attempts can be conceptualized as the selective response of individuals to a particular situation. Douglas (1967.275) is critical of this argument:

> "To say that a suicidal action has a general dimension of meaning to the effect that something is wrong with the situation of the actor at the time he commits the suicidal action is almost humourous. This is such a fundamental meaning of just about any suicidal action that it is hard to seriously consider it. But it is precisely this taking of the obvious for granted that has, presumably, lead to the general failure to see the many implications of this fundamental meaning of suicidal actions."

For him, (Douglas 1967.283) suicidal actions can be much more than the selective response to a specific situation:

> "When properly performed, suicidal actions can be used

> in just this way to transform the substantial self."

While this study was not specifically concerned with suicide, no evidence was found, either in terms of societal or individual response, that suicide actions produced this transformation of substantial self.

(ii) Role Rejection in the Community - Among epileptologists there is general agreement that there is a higher potential for suicide attempts among epileptics (Betts et al. 1976.171):

> "There is certainly a higher incidence of suicide and attempted suicide in patients with epilepsy than in the general population."

There have been some studies which give support to these general statements derived from the clinical experience of those working in the field - Taylor and Falconer (1968) lost five patients by suicide from a hundred who had undergone lobectomy and a study by Henriksen et al (1970) in Denmark identified twenty-one deaths by suicide against an expected total of seven. However there have been no scientific studies which verify these clinical impressions.

The most poignant and dramatic example of role rejection occurred when studying a young man suffering from epilepsy who was interviewed during a pilot survey prior to beginning this study and hence was not included in the final group. An analysis of his response would place his situated response as 'negative acceptance' in line with a number of responses identified earlier. However during the course of the interview he made a number of references to suicide attempts:

R. I tried suicide two or three times.

I. Yeah ....

R. Mum said, er, I don't recall it at all but she said one time I was unconscious for six days.

I. Really?

R. I can recall being unconscious for one and a half days with that. That was last year sometime. Er - I just put my fist through a window - in my bedroom. Mum said, y'know, I'd had a blackout and I was found unconscious. Like this - I was then. She didn't say how I was found but I could describe it and she said "Yes that's right".

I. Yeah, but ....

R. And I lost so much blood.

I. Was your epilepsy connected with your suicide?

R. Yes.

I. In what ways?

R. People taking the 'mickey' - and things like that.

I. Yeah. Where was this? At school?

R. Mainly yes. And the er, not being able to get a job, and the frustration through that, and I get so little money anyway. I've £9.70 a week. Ma only asks for £6.00 housekeeping, but er, the people who lived next door originally, they moved to Switzerland and er, a bloke there, he was the same age as me, he now - plays in a, in the Swiss orchestra, French horn. He gets £50.00 for each concert. He could do four concerts a week and get £200.00. I only get £9.70 and I only get £3.70 of that to spend on myself.

I. Yeah?

R. He might, he probably has to pay tax, y'know but he'll still have over £100.00 and that's what frustrates me. And I was practically crying the other Wednesday - 'cos they'd come over, they'd come over here and they visited us. I just happened to ask about him and they told us that, and er, y'know, I was practically crying, I just, y'know, my mum was already starting preparing the dinner, but I didn't eat it - and I went over to a neighbour's who'd said anytime I felt down, I could go over and see him.

I. Yeah?

R. He'd realized, y'know, I was like that and er, he was talking to me and doing his best to comfort me, y'know, he's very good that way.

I. Yeah. So it's frustration caused by your epilepsy or frustration caused by your lack of job or lack of money. Which?

R. Well both really. Well, y'know, epilepsy comes into it, but I suppose, mainly, so little money, and that, 'cos I haven't got any really.

Several months after the interview, the following headline appeared in the local press (Chatham, Rochester and Gillingham News, 18/11/77), "Suicide Victim Found Electrocuted In Bath". He was found by his mother "lying in an empty bath with bare wires on his chest which came from a lead fixed in the light socket. A post mortem revealed that .... had died from an electrical shock". Thus he had succeeded in permanently rejecting the role of epileptic.

Among the eight respondents living in the community and included in this study, one specifically mentioned that he had attempted to commit suicide, though his response in the interview situation had been analysed as 'negative acceptance'.

R. You see. That was the end of school; I was meant to leave it. Er, I asked the doctors if they could say anything positive about me so, that was it, I had to stay on for another year until they could say something positive, after getting a complete file on me, kind of thing, and er, I asked for a medical but he says "No, you don't need one really" and er, well, that was July, that was, and then - er, my little brother said something which upset me, my father said something which upset me, my big brother said something which really upset me and then er,

- I did, er, er, I tried to commit suicide.

I. Yeah?

R. I took a lot of my tablets, and normally it would have easily killed me but, you see, I-I-I just took, just grabbed an overcoat and I went out about one o'clock in the morning, I did. Very depressed. I found I had some tablets, about two full jars in my pocket and, y'know, I just kept thinking over what had just happened and what the hell, what a hell of a life I'm going to get if I can't have a wife, y'know, and what's going to happen when my girl friend leaves, 'cos I knew she was going to leave and that also depressed me and er, what a life am I going to have. So I took all the tablets but fortunately, or unfortunately, they were over three months old and very unstable and so they didn't; they just put me in a coma for four days. Besides the Police picked me up, er I had an attack, a fit, and the Police picked me up and they brought me back here and I went to bed and the next thing I knew I woke up four days later.

I. Yes?

R. Extremely ill.

I. Mmm.

R. I won't try that again. Well, well if I ever do try to commit suicide, it will be well above the dose and I'll make sure they'll be new tablets because, well, I was very sick for, for at least two weeks afterwards.

As has been mentioned previously, I had no access to other records concerning this group of respondents and suicide and suicide attempts were not mentioned in any of the other interviews, nor indeed were any questions posed relevant to this area (8). However allusions were often made by respondents, relatives and friends to 'troubles', 'mental problems' and 'nerves', and I strongly suspect that some of these references were related to suicide attempts.

The point of this discussion is not to make statements about the propensity of epileptics to commit suicide although two out of nine seems abnormally high, but the same individual can respond in different ways at different times to being epileptic - that in the context of the interview the response of acceptance was identified but that in a different situation, rejection was the response. In terms of this argument, the response of rejection was the same in both cases although the outcome was obviously different.

(iii) Role Rejection in a Borstal - In his study Gunn (1977) found that 18 (11.4%) of his group of epileptics interviewed in prison confessed to suicidal ideas whereas only 6 (3.3%) of his group of controls admitted having similar ideas. Further, when their case records were examined 60 (39%) had made suicide attempts against 39 (22%) of the control group. In this study, no attempt was made to elicit responses or generate information concerning suicide or suicide attempts, and none of the respondents brought up this topic themselves. There were two mentions of taking an overdose, but not in pursuit of suicide but as a device to get out of going to court the next day. Thus the information discussed in this section was obtained from the records of the respondents (11.50's).

The staff of prisons and borstals have an interest in being able to identify easily those who are likely to attempt suicide. A charitable view of this interest would see it as a genuine concern to make sure that inmates in their charge do themselves no harm. A more cynical view would see this interest as motivated by a desire to ensure the smooth running of the institution and that no embarrassing questions could be asked, either by press, politicians or other outsiders, about why inmates should want, or indeed, be able to commit suicide. In practice both views exert sway over institutional practices. The major device for monitoring potential suicide risks in the borstal under study was a large 'F' written on the inmates case record (11.50) standing for "felo de se". Of the nine inmates in my sample, six had the case records marked with this large 'F'. The details contained within were very sparse and it is assumed that details were kept in the medical records to which no access was given.

The references were as follows:

> "He was asked to leave (a special boarding school) after several episodes of destructive behaviour and a suicide attempt."
>
> "He has previously attempted suicide by hanging."
>
> "According to his cell-mate, he attempted suicide at .... Allocation Centre, by hanging, and a torn sheet which could have been used was found."
>
> "In July 1975 he was admitted to hospital because he had taken an overdose of his medication but had himself brought this to his grandmother's attention."
>
> "He was committing offences again but before a suitable place to detain him could be found, he took an overdose of drugs and was admitted to a psychiatric hospital."
>
> "He scratched his wrists in a suicide gesture."

Only two respondents actually volunteered information concerning actions which may have been interpreted as suicide attempts. One said:

> R. I was - er, took an overdose once for depression er, that's all.
>
> I. Overdose of what?
>
> R. Tablets. Valium.

I. Yeah. Where did you get valium from?

R. They was my dad's. He used to have nerves at the time. To calm him down. They knocked me out.

I. Why did you take them?

R. Er, every time I went outside my girl-friend's the police was standing out there for me, waiting for me. I couldn't win.

I. And why were they waiting for you?

R. Er - they reckoned I'd done a job, you know. They was going to follow me everywhere I go to see if I done another one so I just stayed indoors and I got fed up - and that's what I took an overdose of valium for.

And another said:

R. That was when I went to Court and got - remanded before I got sent back here this time.

I. Yeah?

R. I had been 'speeding' all weekend and I had to go to Court on a Monday.

I. Yeah?

R. And I took these 39 pheno-barb 30's, took the whole lot.

I. Yeah?

R. Just, sort of, - I - couldn't really go to Court. I just took the whole lot and I was just, sort of, nice and happy, just well enough to go to Court. I went into Court and then I - fixed up some morphine as well - ended up in hospital.

(iv) <u>Rejection in a Psychiatric Setting</u> - There have been no studies concerned specifically with the propensity of epileptics with psychiatric problems to commit suicide and indeed it would be difficult to make any meaningful statistical correlations as suicide attempts are often treated as symptoms of underlying mental illness. Of the eight respondents in this sample according to their medical records, three had attempted suicide on at least one occasion.

As with the other groups, no attempt was made to probe systematically this area and only one of the respondents actually admitted that he had attempted suicide:

R. The hospital, they said there was nothing they could do, there was no way they could cure the epilepsy, and course, I got so upset I tried to slit me wrists. And, um, the nurses 'phoned up the doctor and the doctor 'phoned up the psychiatrist and they sent me to .... (mental hospital).

There were three attempts to commit suicide mentioned on his record and later in the interview he said "this was me third attempt". One other respondent while referring to the incident which led to his hospitalization after such an attempt, made no mention of suicide.

R. I had a blank, I was supposed to be nervous, went kind of blank. Jobs were, weren't going to be too plentiful at the time and Roy 'lost his marbles'.

I. You had a nervous breakdown?

R. That's it, yes. Keep going to put my foot through the telly - just felt like, just felt like - well, I didn't feel like doing anything to, er, er, y'know, I didn't feel like doing anything to the furniture.

I. Yeah?

R. It was just that I felt uptight. Uptight and, er well - I was getting nowhere. It was like being in a paper bag and it was - very hot, very hot air and you couldn't breathe and then all of a sudden, kind of, you had to flex your muscles.

I. Yeah?

R. And come out fighting. It was, it was terrible, well, it was horrible; then you're out for, you're out for six weeks after.

I. Yes?

R. It was a - shaky experience but I think I've weathered the storm.

I. Yeah?

R. I have.

The final respondent gave a different view as to the reason for his admission to the hospital. According to his record he was admitted because he behaved violently towards staff and furniture in the Special Hospital School and tried to stab himself. When asked he responded as follows:

I. So you've been discharged once since the operation but you've come back again?

R. Yes, I had to come back again because I was, y'know, really crying my eyes out over something. I don't know what it was, but my doctors said it was depression.

I. Yes, but you think that now, things are better?

R. Yes, everything's normal now.

I. Do you think there's any connection between epilepsy and, er anti-social behaviour? Er, violence, or misbehaving, breaking things.

R. No. No, I don't.

I. You've never done any of that in a fit?

R. No.

Discussion

Of the twenty-five people studied in the course of this research at least ten had made suicide attempts or had acted in a manner which caused their actions to be interpreted as suicide attempts. It is hard to think of alternative methods of selecting twenty-five male adolescents for study where at least 40% of the sample would have attempted suicide at one time or another. This fact is recognized by those working in the field as the following report produced by an international panel of experts shows (Memorandum 1973):

> "Suicidal reactions are a serious problem in their frequency and their consequences - suicide is the commonest cause of death in epilepsy - of which hardly anything is known apart from its numerical significance."

There are a number of cautionary remarks that should be made concerning this numerical significance of suicide and suicide attempts. Firstly, almost all epileptics have enough tablets to be lethal and thus have the means readily at hand. Equally, as epileptics take far greater amounts of medication the chances of accidential overdoses are much higher and an accidental overdose may well be interpreted as a suicide attempt. Secondly, this numerical significance has become a 'social fact' and may lead to the interpretation of ambivalent or meaningless actions as suicide attempts. Hence putting an arm through a window or finding some knotted sheets may be interpreted as evidence of suicide attempts whereas they may be actions caused by frustration or actions in the course of an escape attempt. Finally, even those actions which are unequivocally suicide attempts may have been precipitated by factors unrelated to epilepsy. Doctors and sociologists have higher suicide rates than many other groups but it is not usually suggested that becoming either may lead to suicide. A scrutiny of the transcripts included in this section reveals that only two actually verbalize their suicide attempts as responses to their epilepsy.

The point of this section however, has not been to investigate the incidence of suicide among epileptics but to show that individuals respond differently in different situations and that includes differing responses from the same individual. Hence, in the interview context responses such as acceptance, distancing and confusion were identified and upon further study it was found that a significant number of individuals had responded in other situations by rejection.

IDEAL-TYPICAL KNOWLEDGE AND ITS EFFECTS.

The way ideal-typical knowledge was developed and organized was described in the previous chapter. What needs to be considered in this section is the effect that this knowledge has on those cast in the role of epileptic, albeit in the community, in a borstal or associated with a mental hospital. One common thread running through this ideal-typical knowledge, whether held by professionals in the voluntary organization, criminologists or psychiatrists, is its 'causal nature'. Hence the problems in living experienced by those in the community are caused not by epilepsy itself, which is simply a physical illness, but by the failure of others to understand this and the prejudice arising therein; those in borstal are there because their criminal behaviour is, in some way, causally connected to their epilepsy; and that the psychiatric problems of those in the mental hospital are related to their physical illness, their epilepsy.

Much of the work within the sociology of deviance and medical sociology asserts the profound effect ideal-typical knowledge and the subsequent application of labels can have upon the identity of the deviant concerned, and in the voluntary sector Scott's (1970) work supports this. At a theoretical level, using psychology as a specific case Berger and Luckman (1967.199) argue that psychological theory often produces the reality it purports to explain:

> "Since a psychology by definition pertains to identity, its internalization is likely to be accompanied by identification, hence is ipso facto likely to be identity forming .... Psychologies produce a reality, which in turn serves as a basis for their verification."

They then cite an example of how different psychologies can produce different internalizations (1967.199):

> "The rural Haitian who internalizes Voudun psychology will become possessed as soon as he discovers certain well-defined signs. Similarly, the New York intellectual who internalizes Freudian psychology will become neurotic as soon as he diagnoses certain well-known symptoms."

A number of studies (e.g. Cressey 1962. Taylor 1976) have shown how individuals will internalize the theories of professionals and verbalize these explanations when called upon to account for their actions. A more mundane example is the plaintive cry seen written on many lavatory walls - "My mother made me a homosexual". Whether the respondents in this study have come to internalize and verbalize the theories of professions (ideal-typical knowledge) now needs to be considered.

(i) The Voluntary Organization - All of the respondents accepted that epilepsy was purely a physical illness and many could give examples of prejudice or misunderstanding on the part of others. One had gone to a bingo session with his mother, had a fit in the hall and awoken to find the hall emptying rapidly and a woman screaming "Oh my God!! He's got rabies". Another had a fit in London and was taken to a West End Police Station and treated as a drug abuser until, after about four hours, he was able to convince the police that he was an epileptic and had had a fit - his medication had been taken as evidence of drug abuse. A third had a fit in the street and awoke to find that his watch, wallet, ring and other possessions had all been stolen despite the fact that the street had been fairly crowded.

It was felt that much of this prejudice stemmed from a lack of education about what epilepsy really was:

> R. I think, I think it's a lack of education really, because people often hear of grand mal and major fits. I think that more education to make people realize that people, various people, in the past had fits - like Julius Caesar, and that fits can even, you can have them once a year or you can have them er, a hundred times a day. It's a matter of degree.

And hence, as another respondent put it, public education campaigns would be a good idea:

> R. I'd be for changing peoples' attitudes to it. For instance, the general public. If the general public could be made aware of what's going on around them in the world of epilepsy, then I think the whole country would be better off.

However, as another said, it should not be an aggressive campaign:

> R. I feel y'know, to bring it, that to bring it to, er, to peoples' attention, make them realize its there, and er, it's a thing to y'know accept. I don't like to rub peoples' noses in it.

One respondent felt that the responsibility for such campaigns might rest with the Government:

> R. It it was, it, it, er, changing peoples' attitudes is really is - is really, er, part of education.
>
> I. Yeah?
>
> R. It might be something that er, - a policy you might suggest to er, - to Government, er not change peoples' attitudes to epilepsy but, er, informing them more about it, er, say in medical terms about, er, facts about the body.

There was no anger, aggression or indignation concerning public prejudice and none of the respondents articulated any specific connection between public attitudes and what happened to them as individuals:

> R. I don't really know much about peoples' attitudes towards it. It's, I-I-I I've never - had any - never felt any indignation. It's always been, I've heard of people prejudiced towards epilepsy but ....
>
> I. Yeah?
>
> R. But nothing else, it's, it, it, there's nothing particularly - there seems nothing particularly important to me, whether people are prejudiced against epilepsy or not.

In fact the tenor of the responses to these organizational views seeing public attitudes as the cause of problems, could best be described as passive in that none of the individuals were actively involved in running the groups nor in taking part in public meetings, fund-raising campaigns and so on. There were only two incidents which could be described as active commitments to the group's views or aims, one where a respondent wore his 'Action for Epilepsy' badge constantly, and another respondent who became actively involved in a door-to-door fund-raising campaign. This latter incident however, was probably due more to the respondent's close personal attachment to the female secretary of the local group whom he accompanied than any active commitment to the group and its aims. Among these respondents there was no ideological embracement of their role as has been identified among certain militant blacks or homosexuals, for example. Any such active commitment came largely from non-epileptics within the group who often seemed to have internalized the organizational viewpoint to a much greater extent than the epileptics themselves who attended the groups.

(ii) The Borstal - There was no evidence from the replies of the respondents that they saw any connection between their epilepsy and their criminal behaviour. In transcript after transcript it became obvious that the possibility of such a connection was something that they had never even thought about and responses were very short and definite. In fact it was the interviewer who had to explicate how such links arise, as the following example shows:

I. Do you think your epilepsy's in any way connected with any of the crimes you might have committed?

R. No. I've only got three previous and they're minor offences, y'know.

I. But there was no - you didn't have any symptoms of fits, or any fits or black-outs before, just after or during, or anything like that?

R. No.

I. Er - you don't think there's any connection at all?

R. No. None whatsoever.

I. Can you remember which began first? Were you committing these minor offences before you were having fits or had the fits started first?

R. No, er, after. After I had the fits. The fits were when I was eleven years old, I had my first black-out, but I never committed my first crime 'til I was, what? Fifteen.

While in other cases the sequence of fits first crime second was reversed, there was still a definite no to any causal connection:

I. Did you commit any crimes first or did you have fits first?

R. Crime that came first, by a long way. Yes, that started when I was about eight.

In none of the cases studied did fits and crime start simultaneously or even remotely within consciously related time.

On occasions respondents went out of their way to point out that if others should try to make their epilepsy an excuse for their behaviour, they should not be believed.

R. A lot of people say it's their illnesses that puts them in places like this - but it's not, it's the individual one that puts theirself in a place like this - at a time like this.

I. So you wouldn't say that - it's got anything to do with ....

R. No. No connection with it whatsoever.

There were, however, two examples where others had attempted to get respondents to use their epilepsy in a causally significant way; once a social worker suggested it be used as a pre-trial bargaining device:

R. They just, sort of, said that er - y'know - investigations had been carried out in the last couple of weeks, after the crimes were committed, er, for epilepsy and they showed that I was an epileptic and that the crimes could be due to my epilepsy. And they wanted to know, they thought more - the social worker thought, she said, she thought more tests should be carried out, treatment and things like that.

On another occasion, with a different respondent, a solicitor had suggested that epilepsy could be used to reduce a sentence:

R. My solicitor, he said to me, when I'd done the crime, he said "Why don't you say you was in a fit?". I said "No". I said "I ain't going to do that". And he wanted me to say I was in a fit when I done the boy. I said "No". I said "I was sober" I said "There's nothing wrong with me". He said "if you said you was in a fit you might get off with it". I said "No". I says "it's not worth saying that - I want to take my punishment".

(iii) The Mental Hospital - The picture of confusion and contradiction that emerged as the response to the role of being epileptic in this particular social situation was carried over into discussions of how epilepsy might be related to the psychiatric problems the individuals were encountering. Some were unclear about whether their epilepsy might be a factor or not:

I. Do you think you'd have to come up here or do you think you'd have to see a psychiatrist if you didn't have epilepsy? Do you think there's any connection?

R. Er - connection with my epilepsy? I dunno. I might when there's, I might have to, I dunno. If I did, it would only be about life outside, like not having a job and things like that. 'Cos that's the only problem I've got outside - no job.

I. Yes. So, you think you probably wouldn't have to see, I mean, er, there are 1½ million unemployed and I don't suppose they're all seeing a psychiatrist.

R. No, shouldn't think so. But, I mean, not only that, I suppose I might have to see a psychiatrist because when I was younger how I was for school. I might have to come up here to see a psychiatrist though it's probably, er, see how I'd be getting on and that.

I. Yeah. I see. So what do you think? Do you think your epilepsy's connected with it or not?

R. Well, connected with what?

I. Your coming up here to see a psychiatrist?

R. Er, maybe, in a way. Y'know - maybe that's one reason.

I. Yeah?

R. That's a reason for coming up here, one reason.

I. But only one?

R. Well, the other reason is like I said. If I not, when I was younger, not going to school, and that. Having that problem.

Even in one case where an individual had worked out that his epilepsy was connected with his psychiatric problem, it was hardly because he had internalized the professional view:

I. Do you think there's any connection between your epilepsy and your psychiatric problem?

R. Er, having been er, having been here and seen a lot of them have had, people like ......, he was telling me a little while ago like, that he imagines people. Like when he was standing at the bus stop one day and suddenly he opened his eyes like, and there was no-one there. I used to imagine that. It was exactly the same thing.

I. Yes?

R. Like people on walls. I used to actually see a picture of them, like, and people at my bedside. I used to see a picture of those. So I reckon that seeing other people, like ...., I don't know whether he's actually been in hospital, but he works there at the moment. Well, they say that once you have actually been in hospital, you can't work and get the full money. Now, he doesn't get the full money so he may have been in hospital like.

I. Yes?

R. But he must have had psychiatric problems which have gone now. I had. I used to have. I lot of people have with epilepsy so it must be to do with it.

Another respondent was able to provide his own explanation totally unconnected with any ideal-typical knowledge he may have encountered:

R. Another thing, me myself, I, er, mostly, er, I am, er, epileptic fits, mostly at full moon.

I. Yeah?

R. Full moon.

I. Why do you think that is?

R. I don't know. I haven't had, er, all full moons but, then when the full moon comes, I have a, I have a fit.

Discussion

It was suggested at the beginning of this section that the dominant sociological conception concerning the influence of ideal-typical knowledge, particularly when used to support professional definitions or labels, was that it had a profound effect upon individuals to whose world such knowledge related. However in none of the groups being studied did this appear to be the case. Admittedly in the voluntary organization professional and respondents' conceptions appeared to be in accord but this seemed to be coincidental rather than determined by any relationship of the individual to the organizational view. With regard to the respondents from the mental hospital there seemed to be little or no awareness of professional conceptions of the psychiatric problems encountered by individuals and hence ideal-typical knowledge was irrelevant to the everyday experience of the epileptics interviewed.

Only in the borstal sample was there any active or dynamic relationship between the individuals and the professional explanation of their criminal behaviour. However this relationship was the polar opposite of what was expected - a denial rather than embracement of any causal explanation. In fact two respondents actively sought to disentangle themselves from the ideal-typical explanation rather than accept and subsequently verbalize it. This is not unlike the response found by Bogdan (1974.215) in his study of Jane Fry, a transexual:

> "Differences between Jane's perspective and the one presented in her medical records revolve around the issue of 'cause'. Jane, presenting her story, does not seem concerned about 'cause'. In speculating in the area of cause, she suggests that biological factors may be at the root of her problem, but in her words "I'm not interested in reasons any more .... all I want to do is

> get it fixed". In rejecting the search for cause, she suggests there is no more reason to explain herself than to explain anyone else. To use the term cause is to make her opinions less valid than those of others. Her refusal to worry about cause is self-affirmation. But Jane is constantly led into discussions of cause in her contacts with professionals. In doing this they start with an assumption that she has come to reject - that she is mentally ill, sick - that she has to be explained."

What's more, this denial was in the face of considerable advantages to be gained from agreeing with the professionals and one writer (Morland 1966.97) has suggested that epilepsy is often falsely used as an excuse for criminal behaviour:

> "It is not uncommon for certain criminals to offer epilepsy as a defence, this usually being revealed on medical examination by reactions or statements on the part of the accused which either show an uninformed knowledge as to what epilepsy is, or by explanations which do not support the classic picture of the condition."

Whether this is the case seems somewhat doubtful but there have certainly been a number of cases (R v Charlson 1 All E.R.859 and Bratty v A.G. for N. Ireland 3. All E.R.523) which suggest that using epilepsy as a 'cause' may reduce a sentence, often manslaughter on the grounds of diminished responsibility from murder. However despite these potential advantages, none of the respondents seemed prepared to relate their epilepsy to their criminal behaviour.

CONCLUSION

Utilizing the concept of role, this chapter has argued that individuals respond to particular social circumstances in a situational and selective manner. Further a broadly similar pattern of responses was identified in particular situations - different individuals responding in like manner to similar situations. However these similar, situated responses were quite different from each other - responses in the community were different from those in the borstal which were in turn different from those in the mental hospital and so on. These responses can be summarized as follows:

	GROUP	RESPONSE
(1)	Community	Acceptance
(2)	Borstal	Distancing
(3)	Hospital	Contradiction and Confusion

Without wishing to anticipate part of the argument to be presented in the following chapter, it will be suggested that these responses can be explained in part by considering epilepsy as a problem that has to be managed by the respondents in their everyday lives. Hence for the group in the community epilepsy did not present a difficult management problem and could thus be accepted; for the group in the borstal there were other more pressing management problems and hence epilepsy was distanced; but for the group in the hospital epilepsy presented constant problems which engendered confused and contradictory responses which further compounded the management problems. However this argument will be expanded in what follows.

The effects of institutions, organizational and professional views upon the responses of individuals were not found to be as important or 'reality determining' as much sociological work has suggested. Hence, in the context of this study, there seemed to be little connection between ideal-typical knowledge and typifications; that is, the everyday experience of those with epilepsy. It will however, be suggested in the final chapter that there is an important link between ideal-typical knowledge and stereotypes concerning the nature of epilepsy and the character of epileptics.

In presenting this argument abundant use has been made of transcript material, often in extended form. This material has largely been allowed to stand for itself and has not been analysed as evidence of something else, albeit false consciousness, underlying deep structure, repression, or other such second order constructs. Responses have been accorded what was earlier termed 'theoricity' and not analysed as meaning something else, not apparent within the transcript.

CHAPTER SIX

SELF, IDENTITY AND THE NEGOTIATION OF STIGMA

So far then, it has been argued that the response individuals make to given labels or roles is both selective and situational. However this raises the question whether individuals are completely malleable and hence their responses constrained by particular events, or whether they can act with some consistency, permanence and stability. It is not just social scientists who have considered this issue but novelists have also discussed the matter (Rhinehart 1972.157):

> "To change a man, the audience by which he judges himself must be changed. A man is defined by his audience; by the people, institutions, authors, magazines, movie heroes, philosophers, by whom he pictures himself being cheered and booed. Major psychological disturbances, identity crises, are caused when an individual begins to change the audience for whom he plays: from parents to peers; from peers to the work of Albert Camus; from the Bible to Hugh Hefner. The change from I-am-he-who-is-a-good-son to I-am-he-who-is-a-good-buddy constitutes a revolution. On the other hand, if the man's buddies approve fidelity one year and infidelity the next, and the man changes from faithful husband to rake, no revolution has occurred. The class rule remains intact: only the policy on a minor matter has been altered."

The picture Rhinehart paints in his novel is of 'self' being completely at the mercy of situations and events, a picture which at least one writer (Brittan 1977.88) has argued can be found in some branches of sociology:

> ".... a purely situational view of the self as infinitely volatile, as being entirely at the mercy of context, is not speculation; it can readily be found in role and labelling theory literature. Accordingly, what is fundamentally an attempt to locate the roots of deviancy

> in societal processes, can also be construed as an argument for the 'self' as situation."

While it is true that in this study an argument for 'self as situation' has been advanced, that is only half the story, so to speak. It may be equally accurate to depict certain role and labelling theory literature in like manner, but this is often because writers have concentrated on social aspects of the self to the neglect but not negation or denial of the importance of individual aspects. Both Becker (1973) and Lemert (1967) have pointed out that labelling theory signifies a re-focusing of attention and not an attempt to replace or falsify previous theories.

The alternative view, deriving largely from psychology, sees the individual as a fixed or stable personality who simply responds to a variety of situations or events. The models deriving from this view account for any variation or variety in responses in terms of differing personality traits, pre- and post- morbid personality and the like. In essence they see the individual as a stabilized, though not necessarily stable, identity who draws upon his inner resources in response to different social situations or environments.

This psychological theorizing when applied to illness or disability sees the response to illness or disability as generated by interaction between the individual personality and the particular illness or disability. The notion of 'the epileptic personality' has already been discussed and it was shown that so-called common personality traits could be accounted for in terms of social and societal responses to the particular illness, and not as inevitable internal states or psychic structures. However being critical of this view does not deny the fact that individuals do respond to the world with some measure of predictability, stability and consistency.

Some sociologists have attempted to take account of both of these views, viz. the self as situation and the self as personal identity, by conceptualizing the self as a process, as a dialogue between situation and identity. This is not the place to discuss this further in the abstract but it is worth pointing out that it has been recognized that constantly recurring situations (i.e. denigration or stigmatization) may have implications for the psychic structure of individuals. In the case of deviance, the concepts of 'master status' and 'secondary deviation' have been developed to explicate further the relationship between individual and situation, and thus these concepts will be used to sensitize the reader to the empirical material which follows.

EPILEPSY AS MASTER STATUS AND SECONDARY DEVIATION

Hughes (1945) formulated the concept of 'master status' to show how being black overrode all other features such as sex, occupation and status with regard to the American negro. Hence being black was the core identity and provided stability and permanence in interactions in widely different situations. Wright (1960.118) has argued for a similar process with regard to physical disability:

> "Physique (as well as certain other personal characteristics) has an enormous power to evoke a wide variety of impressions and feelings about a person. In fact, physical deviation is frequently seen as the central key to a person's behaviour and personality and largely responsible for the important ramifications in the person's life. This spread holds both for the person with the disability and for those evaluating him."

Thus physical disability can become master status and provide what Lofland (1969) has called 'the pivotal identity' thought which all other impressions are governed.

Leaving aside the question whether epilepsy is physical disability or not, for the purposes of this study it has been conceptualized as non-visible deviance. Hence the issue to be resolved is whether non-visible deviance can become a master status in the same way as being black. Certainly it has been suggested that other non-visible deviations can have a crucial effect upon identity, as with homosexuality for example (Gagnon and Simon 1968.360):

> "The homosexual, like most significantly labelled persons, has all of his acts interpreted through the framework of his homosexuality. Thus the creative activity of the playwright or painter who happens to be homosexual is interpreted in terms of his homosexuality rather than in terms of the artistic rules and conventions of the particular art form in which he works."

Thus epilepsy, as non-visible social deviance, can also serve as the framework through which all the acts of the epileptic are interpreted.

The effects that this significant labelling, of treating certain characteristics as master status can have upon individual identity has been detailed by Lemert in his discussion of secondary deviation (1967.40):

> "Secondary deviation refers to a special class of socially defined responses which people make to problems created by the social reaction to their deviance. These problems are essentially moral problems which revolve around stigmatization, punishments, segregation and social control. Their general effect is to differentiate the symbolic and interactional environment to which the person responds, so that early or adult socialization is categorically affected. They become central facts of existence for those experiencing them, altering psychic structure producing specialised organisation of social roles and self regarding attitudes. Actions which have these roles and self attitudes as their referents make up secondary deviance. The secondary deviant

> as opposed to his actions, is a person whose life and identity are organised around the facts of deviance."

The assumption behind the concept of secondary deviation is that social reactions can have a crucial effect upon individuals and their self-perceptions, leading to adjustments or changes in identity, personality or self. Rubington and Weinberg (1975) distinguish between personal and social identity and hence the individual becomes a secondary deviant when his social identity becomes his personal identity as well.

The point here then is to consider whether the term 'epileptic' constitutes a significant label in terms of the identity implications for those being studied. Certainly much of the medical and social treatment of those suffering from epilepsy can be regarded as revolving around issues of stigmatization, punishment, segregation and social control and therefore can be considered in the same terms as Lemert's criminals, prostitutes, alcoholics, drug addicts and the mentally disordered. Thus the essential issue then is whether being an epileptic produces the response of secondary deviation.

The major problem in attempting to resolve this issue empirically is that there is no one significant label to which the individuals can respond. Certainly all were labelled epileptic but one group were also labelled criminal and another psychiatrically disturbed. While the third group may only have had one significant label, one particular individual (8 : CDW) was an admitted homosexual and thereby may have been faced with a similar situation as the other two groups.

Certainly this individual regarded his homosexuality as more likely to provide him with problems than his epilepsy:

R. I don't, sort of, suddenly say "Eh, I'm epileptic" to, sort of be degrading myself. And, er, as I said before, I'm gay, so there's another label on me as well.

I. Yes. That's interesting. Do you find being epileptic any more difficult, or any less difficult to manage than being gay?

R. It's more difficult to be gay.

I. More difficult to be gay. Why is that?

R. Because I find there's a lot more prejudice against gay people than there are epileptics. That's just in my experience.

I. Yes, sure, yes. You can't think of any examples? Er, y'know, say prejudice in that way?

R. Against epileptics, or ....

I. Against you being gay.

R. - Er - Well, when I was at college, er, I started getting involved with this girl. Y'know not a sexual thing, or anything, I was just very friendly, and, er, her boyfriend came and beat me up one night 'cos he didn't like his girlfriend associating with a "queer".

One other individual (4 : MDU) was faced with three potentially significant labels, three possible master statuses; he was black, epileptic and a psychiatric patient as well. However he seemed unable to relate any of these labels to things that might be happening to him and none appeared to be perceived as master status. Being black for example resulted in the following response:

I. Do you think, have you suffered from any prejudice because you're black, do you think?

R. Me?

I. Yes.

R. Suffered any prejudice?

I. Yes.

R. No.

I. I mean, people haven't turned you down for jobs, or - that kind of thing? Not let you join clubs? Or ....

R. No, 'cos they, er, they might not know.

I. Yeah, but people would know you were black; I mean, they'd know ....

R. Oh but really I don't, I don't really go to join clubs because they might not have a club around what I might want to do.

I. Oh I see yes - but you don't, you haven't, suffered any prejudice and that kind of thing?

R. No I haven't.

In terms of Lemert's distinction, neither of these respondents would be secondary deviants as far as their epilepsy is concerned, although for (8 : CDW) his homosexuality was a central fact of his existence; he lived with an older male friend, was interested in the Campaign for Homosexual Equality and had 'come out' at work - he was employed as a clerical officer in the Civil Service. With the other respondent (4 : MDU) there was no evidence that any of the potentially significant labels were crucial to his identity or sense of self and neither his epilepsy, his blackness nor his mental illness produced any easily identifiable roles or self regarding attitudes.

When the individuals are considered within the context of the particular group and situation of the interview, then it is easier to examine their responses utilizing the concepts of master status and secondary deviation. The group living in the community (with the one exception already discussed) had only one potentially significant label that could have had identity implications - the label epileptic. However none of the individuals in this group gave any indication that their lives were organized around the (possible) central fact of their epilepsy. None had any developed policy about whether or how to reveal their epilepsy in social encounters, about who they told, when or where, and this is well brought out in the following transcript:

R. My saying "I'm an epileptic" - I should think that might come out in conversation, perhaps, but it's nothing planned.

I. Yeah, I mean, you don't have a standard kind of policy that you - you slip into the conversation, that kind of thing?

R. Er, no, I don't do that.

I. A regular girl friend for example. When would you tell her? Early in the relationship, or not tell her? Or is it something you don't even think about?

R. It, it, it isn't, I don't think it is really, er, I remember staying with a German family once; er, they knew it because I used to take - I didn't make any bones, I just used to take my pills at supper and breakfast. Nobody worried about it, except "Oh you've forgotten to take your pills", or something, there was nothing in the sense of anything peculiar.

Nor did they give any indication that they had thought about how epilepsy might affect any social relationships they might wish to make:

I. What about social relationships generally? Do you think it's er, epilepsy's affected your capacity to make friends?

R. I - I don't know. I don't think so. It's easy when - meeting new people, I'm not thinking about epilepsy, I'm thinking about the people I'm meeting, if you know what I mean? And if it crops up in conversation I'll mention it.

I. You don't have any set policy about whether you should tell people you're an epileptic, or not?

R. Unless it's important for them to know because I may be involved with them in any sort of way, you know, like my old landlady. Things like that.

Further none seemed to feel that their lives were unduly restricted in terms of the things they were able to do, the places they were able to go and so on:

> I. Are you treated any differently now?
>
> R. No. Er, not at all really. Er - the only times I get, sort of, warned about, er, standing on the edge of platforms - on railway stations, which is obvious why. Or on the edge of roads which are really chaotic and sitting too close to the television, and that's about it. Oh, usually, every other day somebody says "have you remembered to take a capsule".

Only in terms of employment did epilepsy appear significant in the way they organized their social interactions. While one or two respondents had attempted to hide their epilepsy from employers, all now felt that their epilepsy should be revealed when applying for jobs and all said they would and did reveal it:

> I. You don't have any standard kind of policy?
>
> R. Er, no, except perhaps on these, er, employment forms where you might wonder whether you could perhaps call it a - any illness or something like, I mean er, it's er, and whether it might not be politic to hide it.
>
> I. Yeah?
>
> R. Perhaps, perhaps it would be politic, if it came out that you were an epileptic.
>
> I. Yeah. What do you do when you apply for jobs? Do you normally state it on the forms?
>
> R. Er, yes, yes I do.

There was no evidence with the group in the borstal that epilepsy produced any special or lasting responses or self-regarding attitudes. The following is a fairly typical response:

> I. Do you think having epilepsy has affected your social life at all? The things that you do - what leisure things

you get up to?

R. Not really except, y'know, when I - if I'm in the gym and doing weightlifting and running about, just get, get dizzy and then y'know, I can't do it, it stops me from doing it. But otherwise everything's all right.

I. What about things like swimming, football?

R. Well, I've, y'know, when I've done swimming, it's er, and nothing's ever happened but, y'see, if I run, I run about or else I lift heavy weights, y'see, just get dizzy, y'know, feel sick and I've got to put them down, sit down for a while.

I. Can you think of other ways in which epilepsy's affected you?

R. No.

I. Do you normally tell people that you're epileptic?

R. No, I just - er, just forget about it, y'know, I just try not to think about it 'cos - y'know, at the moment, something, something more to worry about if you do.

Nor was there any evidence that other people evaluated epilepsy as master status, a pivotal identity through which all other impressions were governed:

I. Do you think you were treated any differently because you are epileptic?

R. What, in the family?

I. Yes.

R. No, not really. I can't say this really because, as far as I know my brother used to be treated the same, y'know, I was treated the same as him and so was my sisters. Er, to me I was treated no different except - I'd never had quite what I'd want - I'd never have it and never was able to. But, if I needed any help, in any kind of way like, I had, when I had to go to a special school, er, I had to go there and of course, that had to cost money - and that was the only thing that I ever got special, that the other kids didn't in the family.

I. Yeah, and what about friends? Do you feel that they treated you differently in the sense that you weren't, perhaps able to do things, or play the games that they played?

R. No, because there was certain games I was able to, er, chip in but, er, there weren't every game that I was able to chip in. But even my friends then did not treat me no different.

With one exception, none of this group had developed any special techniques or practices about how or who to tell. The one exception (9 : RCD) sometimes worked as a builder's labourer on high buildings and he used to persuade his co-workers to keep an eye on him in case he had a fit; he would obviously not have been given such work had he admitted his epilepsy when asking for a job. Generally however epilepsy was not a problem to worry about, and this held true as far as employment was concerned. While the group felt that epilepsy had to be revealed on job applications, it was of little importance:

R. If I'm going for a job, I'd, y'know, automatically say that I had had one or two fits.

I. Would you?

R. Yes, it would be the only best way, for safety, you know.

I. What about telling people you've been in borstal if you go after a job. Will you do that as well?

R. No.

I. Why not?

R. I'd try to keep that quiet.

I. That's interesting. You'd confess to having epileptic fits but you wouldn't ....

R. Yes, well, borstal is a different thing from, er, illness. I mean, er, when you go out, you know, sort of do a job, get borstal for it, people look at it bad, as if that's bad, you know.

This lack of concern with the management of their epilepsy in formal and informal interactions is certainly thrown into sharper relief when considered against their very real concern with the management of information about their criminal records. Goffman (1968) has discussed this matter at length and argued that as far as non-visible deviation is concerned, the technique of 'passing' can be crucial in information management. Both a criminal record and epilepsy can be seen as non-visible deviations and while the group were unanimous about passing as far as their criminal record was concerned, this was not so with epilepsy. And this passing was designed to avoid any social penalties that might be involved:

I. Does the thought of managing outside, with epilepsy, does that worry you?

R. Oh, no, that doesn't worry me.

I. Not at all?

R. No, I take it as it comes. All you could do.

I. What about your record? When you go for a job, er, do you not, er, tell people about your record?

R. No. Do you want me to get the sack on the spot?

I. I see, yes.

R. You go for a job, you say "right! I mugged a geezer last night and I mugged a geezer four weeks ago, I was on two weeks remand, I've just come out, I'm looking for a job".

I. Yeah.

R. He'll say "look at this, he may mug me as soon as I get my wage packet. No chance".

It was not just a matter of social penalties that might be imposed, but also allowances that might be made because of epilepsy; a kind of everyday version of Parsons' (1951) conception of the sick role:

> R. I don't like admitting to a criminal record.
>
> I. You think that other people would treat you - worse because you're an ex-con than because you're epileptic?
>
> R. Yes, people tend to treat you better, I think, if you've got anything y'know, like epilepsy or anything physically wrong with you.

The group attached to the mental hospital with the one exception mentioned earlier, certainly felt both that others treated them differently because of their epilepsy and also that it had effects on them and their personal identities. Hence epilepsy was perceived as master status:

> I. What effect did it have on you? How did you feel about it?
>
> R. Well, I dunno, but, er, didn't like it at first but, er, there ain't much I can do about it.
>
> I. No. What about your family? How do you think it affected your family?
>
> R. Well I don't know. My mother, I don't think my mother is all that happy about it, but she, she can do nothing about it?
>
> I. Did it affect, er, the way they treated you? Your mother, or other members of the family?
>
> R. Er, treated me, er, well, Mum, er ....
>
> I. Did they treat you better, or worse, or just the same? Did they try and stop you doing things? Or ....
>
> R. Oh, yeah, my mother; she stops me doing things like - if I make an attempt to, er, if, like, for instance, someone in the family says "Let's go and clean them windows. They ain't half dirty" or something. They go and clean the windows, Mother won't let me do it.

> She's scared in case I have one and fall out the window. And, er, what else is it, if I climb up the ladder to a ceiling or something, she don't like that much either.

Further epilepsy may be seen as producing self-regarding attitudes - as secondary deviation:

> R. Well, I find it hard to, er, make friends with er, 'cos of, it is because of the epilepsy because - er - one thing I can't do without, having a good drink without the thought of having a fit. That's always there and it's annoying.
>
> I. Does it make you more ....
>
> R. It makes me, in a sense, anxious, nervous.
>
> I. What about girls? What about girlfriends?
>
> R. Well, I've never had many.
>
> I. Is that because of your epilepsy?
>
> R. Yeah, well in a sense, yes; not so much I feel ashamed of it. The - it's - you get into a relationship and then - you start being ashamed, start feeling embarrassed. You have to tell a person that I have epilepsy.
>
> I. Yes?
>
> R. 'Cos, come what may, I have it anyway. So, er, y'know, there's no need to feel ashamed of it, but there's, there's that certain feeling of embarrassment.
>
> I. Yes?
>
> R. And I feel embarrassed and that's hard to tell her; and if I told her, like, she may just go.

This internalization of negative feelings about epilepsy led some of the respondents to pass in almost all situations:

> I. When do you tell people that you are an epileptic?
>
> R. I, er, I never tell them.

I. You never tell anybody?

R. Only unless they ask.

However other respondents in this group felt just the opposite; that epilepsy was constantly present and that fact had to be introduced as soon as possible. The crucial fact about all these respondents was that having epilepsy was a problem that required constant management; it could not just be allowed to emerge in everyday interactions as was the case with the other groups.

EPILEPSY AS A SIGNIFICANT LABEL.

The aim of this chapter has been to consider whether having epilepsy has had any permanent effects upon the individuals being studied. It has not been suggested that the significance of the label is solely a function of the way it is applied by society nor of the way an individual reacts to its application, but rather the interaction between the two - social application and individual response. This raises the issue of personal stability and consistency in widely differing social situations. As Becker has neatly posed the question (Cosin et al 1977.61):

> "The process of situational adjustment allows us to account for the changes people undergo as they move through various situations in their adult life. But we also know that people exhibit some consistency as they move from situation to situation. Their behaviour is not infinitely mutable, they are not infinitely flexible. How can we account for the consistency we observe?."

Our present task is not to account for the behaviour of the individuals being studied but to assess the effect that epilepsy might have on them; on their personal identity or sense of self. To understand this better at an operational level the concepts of 'master status' and 'secondary deviation' were developed to show how the self, while being a social process, can nonetheless give a sense of stability and permanence to widely differing situations.

An essential component of Mead's discussion of the self is its ability to act as an object towards itself; that is, to take on the meaning of the object given by others. This process is eloquently defined by Matza (1969.109) in his discussion of signification:

> "An object that is to be signified, whether it be man or thing, is rendered more meaningful. To be signified a thief does not assure the continuation of such pursuits; but it does add to the meaning of a theft in the life of the perpetrator, and it does add to the meaning of that person in the eyes of others. To make someone or something stand for yet something else is an act of genuine creation requiring an investment of meaning. The object enjoys - or suffers - enhanced meaning. To be signified a thief is to lose the blissful identity of one who among other things happens to have committed a theft. It is a movement, however gradual, toward being a thief and representing theft. The two movements are intimately related; without a population selected and cast as thieves, we might have to look everywhere to comprehend the prevalence of theft. The casting comes first. Its consequence is to provide a working account of the prevalent level of theft - and thus safeguard most of us from suspicion and interference. In that sense, those selected and then cast as thieves come to represent the enterprise of theft."

Thus to be labelled 'epileptic' is to be signified.

A major difficulty in considering master status and secondary deviation in relation to the present respondents was that a number of individuals were faced with more than one potentially significant label. One individual was black, mentally ill and epileptic, and another was homosexual and epileptic; a number of others were faced with this dual problem - some were labelled epileptic and criminal and some epileptic and mentally ill. It is somewhat ironic that interactionists who stress the pluralistic nature of society should develop operational concepts which fit more easily into an absolutist view of the social order in that they assume that one label or process can be all important for individual identity. (1)

It was only in the group attached to the mental hospital that epilepsy appeared to be a significant label giving rise to master status and secondary deviation. Goffman (1968) has suggested that an important problem with non-visible deviation is that of managing information whereas an important problem for visible deviation is the management of tension. In this group, both seemed problems and tension was created as a result of attempts at the management of information. This is not to suggest a causal explanation, another version of stress or strain theory, for the situation is more complex than that, as Bagley (1971.50) has indicated:

> "Personality disorder in epilepsy is the result of the complex interaction of the personality existing before the onset of epilepsy, the effect of the epilepsy itself, brain damage underlying the epilepsy, the parental reactions, the environmental reactions to the epileptic (child), and perhaps the effects of anti-convulsants."

There was no evidence with the group in the borstal that the label epileptic was significant although it seemed that the label criminal had more meaning for them and indeed probably had implications for their sense of identity. However it could be that this response was in line with the process of 'prisonization' identified by Clemmer (1940) many years ago. According to Hood and Sparks (1971.226) prisonization is:

> "Basically, it seems clear that the new inmate must undergo a socialization process just like that undergone by any new member of any group or culture; if he is not already familiar with them, he must learn at least some of the rules of the inmate community and he may also come to acquire many of the beliefs, attitudes and values of the community."

It was beyond the scope of this study to look in detail at the process of prisonization and thus to comment on the debate concerning whether the process is linear or U-shaped, but it was obvious that many of the attitudes and values of the inmate culture were internalized. This was evident in two areas in particular, when individuals were discussing girls and cars. All of the respondents in this group said (2) that they had had numerous girlfriends and all admitted to driving cars on occasions, some legally and some not. Among the other two groups, while several had steady girlfriends, the majority confessed that they had never been out with a girl, and all said they did not drive, nor did they express any wish so to do.

The group living in the community were labelled epileptic but there was no internalization of this label in the sense that master status or secondary deviation resulted. It cannot be assumed that this was because in their particular circumstances, the non-visibility of the deviation was a determining factor. Other studies of non-visible deviation have found instances of such internalizations; for example, Humphreys (1972.142) sees stigma confrontation as a means of transforming identity:

> "In converting his stigma, the oppressed person does not merely exchange his social marginality for political marginality, although that is one interpretation the socially dominant segments of society would like to place upon the process. Rather he emerges from a stigmatized cocoon as a transformed creature, and characterized by the spreading of political wings. At some point in the process, the politicized 'deviant' gains a new identity, an heroic self-image as crusader in a political cause."

Plummer (1975) identifies a similar phenomenon among homosexuals in his discussion of homosexuality as a way of life. In the area of disability

Scott (1969) identifies a similar internalization and identity transformation with blind people who become 'true believers'.

A general impression of the differing responses in this particular study can best be given by presenting the findings in the form of a table.

GROUP	MASTER STATUS	SECONDARY DEVIATION
Community	None	None
Mental Hospital	Epileptic	Epileptic
Borstal	Criminal	Criminal

What needs to be explained then is why epileptic should be a significant label for one group and not for the others. In order to better understand why this label should have different identity implications for the different groups we need to make use of the concept of negotiation.

THE SOCIAL BASIS OF NEGOTIATION.

Negotiation is a crucial factor in determining the outcome of the application of particular labels for as one writer (Schur 1971.56) puts it:

> "As imputation of deviant character incorporates some exercise of power (for some people label others), it is not surprising that various forms of negotiation and bargaining have been crucial elements in labelling."

What concerns us here is not power in the sense of the ability of others to apply labels, but the power that individuals may have to negotiate the outcome of the application of such labels. There are a number of factors which may be significant in the negotiation process and four will be considered here; (i) the extent of epilepsy as a problem, (ii) family structure and stability, (iii) the kind of education received, and (iv) the employment situation of the individuals. It is not being suggested that this list is exhaustive, only that these factors are important to the outcome of the negotiation process.

The information is presented in the following pages in table form in order to be able to pick out common factors, underlying trends and to facilitate inter-group comparisons. This information is in summary form and greater detail can be found in the biographies at the end of Chapter Two. It is not intended to extract generalized statements from these tables about the extent of unemployment among epileptics, the prevalence of family instability and so on, but merely to show how these factors may affect the ability of individuals to negotiate the effects of their epilepsy.

(i) Extent of Epilepsy (3) - There was no significant difference among the three groups concerning the chronicity of their epilepsy, either in terms of how long they had had it, the number of fits they had or the side effects of medication. Certainly there were inter- and intra-group variations among individuals but no one group had more severe problems of a medical nature associated with their epilepsy than the others.

(ii) The Family - When the family is considered there are obvious differences between the groups. The community group had families which were largely middle class, at least if measured in terms of father's occupation, and characterized by stable structure both in terms of social relationships and geographical mobility. The other two groups came largely from working class families, again in terms of father's occupational status, and were characterized by instability both in terms of social relations and mobility.

THE COMMUNITY SAMPLE

	Extent of Epilepsy	Family	Education	Employment
1:CJB	Major attacks which occur frequently - more than once a month.	Father recently retired from RAF. Mother works p/t. 2 brothers - stable home life.	4 or 5 primary schools. Grammar school. Local comprehensive. CSE's and 'O' levels.	Still at school.
2:CAW	Major and minor attacks. Minor ones happen often - major ones more than 3 months apart.	Father civil engineer, mother marriage guidance counsellor. 2 younger children. Luxury home.	Colony school. Boarding school. College of F.E.	Casual vacation jobs. Still at College.
3:CGM	Major fits about once or twice a year.	Father computer programmer. Mother infant teacher, 2 younger sisters - live in own home.	Primary school. Secondary school. 3 CSE's	Spectacle lens grinder. Clerk. Warhouseman. Currently unemployed.
4:CHW	Major fits about once a fortnight. More frequent when medication becomes unbalanced.	Father food scientist. Mother a teacher. Younger brothers and sisters. Own house.	Primary school. Private school.	Storeman. Currently unemployed.
5:CNT	Minor fits when young - major ones now. Only 2 in last 6 months, but more frequent at night.	Father a doctor. Mother does not work. 1 younger brother and sister. Own house.	Private school. Millfield. CSE's and ONC's.	Messenger, packer, clerk, storekeeper, currently unemployed.
6:CMG	Major fits but occur at intervals of more than 2 months.	Father trainee silversmith. Mother secretary. No other children. Own house.	Primary school. Secondary school. Technical school. Polytechnic. 'O' & 'A' levels.	Not yet worked.
7:CJE	Major fits about once a month but 3 in month before interview.	Father a plumber. Mother casual farm work. No others. Council house - lived all life.	Primary school. Secondary school. CSE's.	Tyre fitter. Currently unemployed. (But about to start college.)
8:CDW	Major fits and minor absences but major attacks usually months apart.	Father a security guard. mother works in an office. 3 younger sisters. No longer at home.	Primary school. Secondary school. Technical college. CSE's and 'O' levels.	Clerk in Civil Service.

THE BORSTAL SAMPLE

	Extent of Epilepsy	Family	Education	Employment
1:RAC	Major attacks but hasn't had one for more than 4 years. Still takes medication.	Polish father & Italian mother - unstable relations. In care of council - beyond control.	Primary school. Special school. Secondary school.	Many labouring jobs but none held for long.
2:RRK	Major fits about every 2 weeks A persistent drug-abuser and also on anti-convulsants.	Father is a consultant surgeon. Mother p/t secretary. 2 younger brothers.	Primary school. Secondary school. Approved school.	Several but rarely worked for long at one thing.
3:RIM	Denies ever having a fit though on medication.	Mother/father & 4 other children. Unstable home life. In care on place of safety order.	Primary school. Secondary school. Community home.	Not worked as yet. Intermittent periods in mental hospital.
4:RJM	Minor fits, described as dizzy spells. Occur every few days. Takes medication.	Born in Ireland. Family followed father to England. Unstable home life. 4 younger children.	Primary school. Secondary school. Community home.	Not old enough to have worked.
5:RRM	2 or 3 major fits a month and he is on anti-convulsants.	Father a factory worker. Mother p/t cleaner. 3 older children. He has been in care.	Primary school, secondary school. School career interrupted by court appearances and DC.	Carpet fitter but interspersed by casual jobs.
6:RDR	No major attack for years but still has occasional minor ones. On medication.	Father works casually. Mother & 2 younger children. Homeless for 8 years, council house.	Primary school. Special school.	Warehouseman and packer. Periods of unemployment.
7:RRR	A few major daytime fits a year but more at night. On medication.	Mother married twice. 1 brother & 2 step-sisters. Spent much time in children's homes.	Primary school. Special school. Approved school.	Packer but mainly unemployed.
8:RJT	Several major & minor attacks every month, takes medication.	Illegitimate - brought up by grandparents. Occasionally sees mother.	Primary school. Secondary school but expelled.	A number of labouring jobs often on farms.
9:RCD	Major attacks but only every 3 or 4 months. Refuses to take anti-convulsants.	Father died 1969. Mother unfit, 4 children. All had TB. Lives in London, mainly squatting.	Infant school. Junior school. Approved school. Remand homes.	Painter and decorator, road-sweeper, No. of casual jobs.

THE MENTAL HOSPITAL SAMPLE

	Extent of Epilepsy	Family	Education	Employment
1:MMH	Major fits but interval between them often more than a year. Still on medication.	Father security guard. Mother housewife. Older brother and sister. Father left home several times.	Primary schools (2). Secondary school. Completed schooling in mental hospital.	Never worked. Currently unemployed.
2:MMB	Temporal lobe epilepsy producing automatic behaviour rather than fits. Occur erratically.	Parents hard-working but bad marital relations. Mother thinking of leaving.	Primary school. Secondary school. Special school. Technical college. CSE's and C & G.	Builder's labourer. Job training scheme Currently doing packing jobs in day hospital.
3:MCT	Major fits which occur several times a month and sometimes produce incontinence.	Father lecturer in Malawi. Mother art teacher but died recently. 2 sisters.	Primary & Secondary in Malawi Passed College of Preceptors exams. GCE English.	Taught Indians in private school in Malawi. Unemployed in this country.
4:MDU	Major fits - poorly controlled by medication. Occur frequently but mainly at night.	Father factory work. Mother p/t kitchen. Large extended family in council flat. Others in Jamaica.	Primary school. Special school. Secondary school (but suspended)	Warehouseman, factory worker, job training scheme but currently enemployed
5:MSC	Major attacks which occur weekly and are poorly controlled by medication.	Father died last year. Mother mentally ill. 5 other children. Council flat.	Primary school. Special school.	Butcher's assistant but currently unemployed.
6:MRG	Major fits but only occurring about once a month. On medication.	Father works on building site. Mother p/t waitress. 4 younger children and uncle at home.	Primary schools (2) Secondary school. CSE in Art.	Petrol pump attendant, van boy, porter, council workman & trainee cook. Now in hospital kitchen
7:MRL	Major fits poorly controlled by medication. None since brain operation.	Adopted and step-father is a steel fixer. Step-mother has left. 1 married sister.	Primary school. Secondary school. Hospital school.	No jobs yet applied for.
8:MMS	Major fits about once a month but brought on by stress and strain.	Father left and mother has lodger. Home owned by mother. 1 older brother.	Primary school. Secondary school. Special school.	Factory worker, cleaner & porter. Currently unemployed

In each group there is one case which does not quite fit in with the overall pattern of their group. In the community the family of respondent 7:CJE could not be said to be middle class but the father works in a craft occupation and the family structure was certainly stable. In the borstal group respondent 2:RRK came from a middle class family but his particular problem was persistent drug abuse rather than epilepsy or petty theft. In the mental hospital sample 3:MCT came from a middle class family but as a social worker told me "his problems started with the death of his mother rather than his epilepsy".

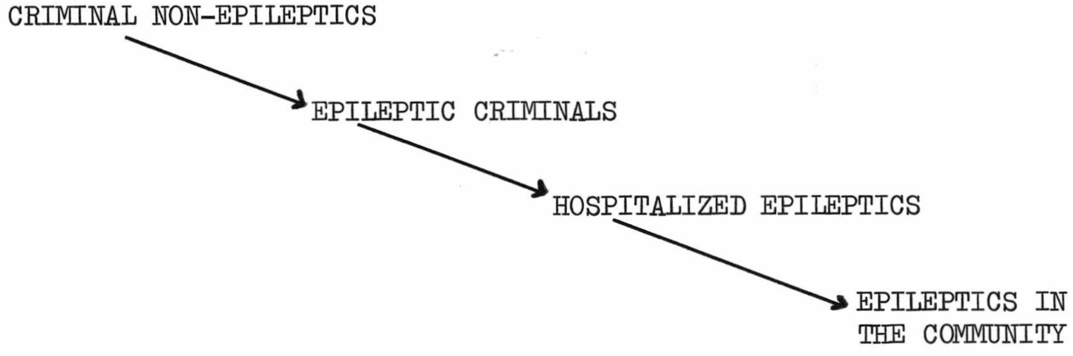
(iii) Education - There are again obvious differences between the groups in terms of both the kind of education received and the qualifications received (4). The group in the community all had what could be called a normal middle class education and the majority ended up with paper qualifications of some kind. The group in the borstal all had had their education interrupted and had also attended special schools either for the educationally sub-normal or the maladjusted, and none had managed to get any paper qualifications. The mental hospital sample fell in between the other two though obviously much closer to the borstal group - all had received special educational provision of one kind or another, but some had managed to obtain paper qualifications.

(iv) Employment - There were no obvious differences between the groups in terms of employment patterns. The majority of all respondents had only had menial jobs on a casual basis and were currently unemployed although one respondent in the community group 8:CDW was regularly employed and 3 others, 1:CJB, 2:CAW and 6:CMG were still in full-time education of one kind or another. (5)

Before proceeding to discuss the effects of this information upon the identities of the individuals being studied, it is worth noting that Gunn (1977) in his study of epileptics in prison carried out a similar comparative exercise. The groups he compared were (i) a sample of non-epileptic criminals, (ii) a sample of epileptic criminals and (iii) a sample of hospitalized epileptics. He found (Gunn 1977.83):

> "In summary there is a social class gradation from the non-epileptic prisoners, to the epileptic prisoners, to the hospital epileptics. .... Parental loss experiences showed a similar trend with the prisoner non-epileptics faring worst, followed by the epileptic prisoners, and once again the hospital epileptics coming out best. In occupational terms however there was a trend for epileptic prisoners to have less job stability than the other groups. Overall it appears that where differences occur it tends to be in terms of the hospital epileptics having better social environments (in childhood) than the prisoner groups."

Bearing in mind the different purposes for which the studies were undertaken and the differing characteristics of the samples, the relative positions of the criminal and hospital epileptics in terms of social environment were roughly in accord. Further, by overlaying the two studies, one on the other, it is possible to produce the following grading from worse to best social environment.



What needs to be considered finally then is the effect that these identified differences might have upon the ability of individuals to negotiate the effects of the label epileptic with regard to their own identities.

NORMAL PROBLEMS, ABNORMAL PROBLEMS AND STIGMA

Everybody has problems of one kind or another but a recent work (Robinson and Henry 1977) has made a distinction between normal and abnormal problems. The crucial fact about normal problems is that they can be solved without disrupting everyday life. Abnormal problems cannot and have a number of characteristics in common; firstly, the problem may be indefinable or not identifiable; secondly, the problem may be identifiable but incurable; and thirdly, the conventional way of handling the problem may cause distress. Certainly epilepsy has these features of abnormal problems - it is often not identified (diagnosed), in the vast majority of cases it is incurable in that only the symptoms can be treated, and conventional ways of handling the problem, surgery, drug therapy or confinement, often cause distress. To have epilepsy then, is to have an abnormal problem, which according to Robinson and Henry (1977.53) means:

> "The unidentifiable, indefinable, uncertain, undiagnosed, incurable or badly handled characteristics of abnormal problems means that the usual practice of resorting to experts to supply a label and to 'tidy away' the problem cannot be followed. Not only that, but the fact that these people have persistent, unsolved difficulties presents a problem to others that they handle by adopting a stigmatizing attitude."

However, the fact that epilepsy is an abnormal problem which society reacts to by stigmatizing the sufferers, does not mean that all epileptics are stigmatized in all situations. As Goffman (1968.163-4) emphatically reminds us:

> "May I repeat that stigma involves not so much a set of concrete individuals who can be separated into two piles, the stigmatized and the normal, as a pervasive two role social process in which every individual

> participates in both roles, at least in some connexions and in some phases of life. The normal and the stigmatized are not persons but rather perspectives."

Thus what is important is the extent to which individuals can negotiate considerations of themselves as a normal rather than a stigmatized person for constant stigmatization can produce a stigmatized identity. All of our respondents had abnormal problems but their responses in terms of identity implications which differed in patterned ways that now needs to be explained. This is where negotiation becomes important; the more individuals are able to negotiate consideration of themselves as normal, the less likely are stigmatizing social processes to have effects upon the self, the more they are forced into stigmatized roles the greater likelihood that this will produce a stigmatized identity. For present purposes, the more individuals were able to negotiate normal roles rather than epileptic ones, the less likelihood was there that epilepsy would become master status or produce secondary deviation.

For two of the groups in the present study epilepsy did not constitute a significant label and we will consider this first.

The Community Group - Certainly this group were able to negotiate consideration for themselves as normals rather than epileptics. The most important factor in this was the family who were able to provide advice, support and ensure access to appropriate medical and social facilities. Edgerton (1967) has shown the importance of 'benefactors' in handling the stigma of mental retardation and for this group, the family were benefactors in managing the potentially stigmatizing effects of epilepsy. Education was important in the negotiation process in two ways; firstly it provided individuals with a sense of worth and achievement and secondly it also made it easier to develop the techniques necessary for stigma management. Finally joining the local Action for Epilepsy group also provided a source of help by meeting others with similar abnormal problems. As one writer puts it (Barish 1971.1167):

> "These activities help overcome passivity and enhance self-esteem as well as encourage a greater sense of personal responsibility."

The Borstal Group - It was not found that epilepsy was a significant label with this group though this was not because they had a particularly sound basis for negotiation. In fact in these terms they probably fared worst of all the groups. However it appeared that being labelled criminal was a more pervasive process and hence more crucial to identity. To put the matter succinctly and somewhat facetiously, it appears that society locks people up quicker for stealing cars than for having fits in the street.

The Mental Hospital Group - With the group in the mental hospital it was found that epilepsy was a significant label, both in terms of master status and secondary deviation. This group had a poor social basis for negotiation in terms of unstable family life and they had experienced interrupted or special education. The one respondent 3:MCT who differed from the general pattern of this group nonetheless ended up in hospital after his mother had died - he had lost his 'benefactor' and could no longer cope with his abnormal problem. Taylor and Harrison (Harre 1976.29) poignantly detail what can happen to epileptics with psychiatric problems:

> "Why was Ronnie's epilepsy so particularly regrettable? Certainly not in virtue of the lethal nature of the condition underlying his epilepsy. Hardly by reason of the severity of the attacks nor their frequency. His fate was not incorporated in the medical significance of his diagnosis, as might that of a leukaemic person. His fate is that of the interaction between his conditions, his potential self and society. The career of persons with non-lethal handicaps is determined by the skill with which they negotiate their

> status (or with which negotiations are made on their behalf). Ronnie had a poor basis for negotiation, was provided with little, achieved none. He became 'an epileptic person'. People cannot be cured of what they are."

So too with this sample from the mental hospital; they had a poor basis for the negotiation of their abnormal problem and as a result, the label epileptic became significant for their sense of self.

In conclusion, let us summarize the argument; all individuals are free to negotiate their status, but the outcome of such negotiations may depend upon the resources that they can utilize. This study has considered four kinds of resources and found two to be significant, family and education. Neither the extent of epilepsy nor employment record appeared to be of particular relevance. Other studies of disability (Taylor 1977) have also found that there is often little connection between the extent of disablement and the problems in living that disabled people may experience. The terms impairment, handicap and disability are often used in different ways to point to these discrepancies. With regard to employment, we know that work can be crucial to identity but it is suggested that it is of considerably less importance with adolescents than with adults who may have undergone extensive training or worked for many years.

CONCLUDING REMARKS.

This chapter has attempted to consider not the selective and situational responses that individuals make to particular labels or social processes, but the effects that such labels or processes might have on individuals, upon their sense of identity or self. In this context interactionists have been sceptical about the value of traditional psychological or sociological theorizing about the individual and, according to Roberts (1977.82-3) they:

> "objected, in particular, to the conception of the individual in terms either derived from purely psychological models of behaviour or as an over-

socialised or conforming member of society."

Neither of these perspectives would prove adequate for this study for there was no evidence of the existence of an epileptic personality or identity, nor did the social role of being an epileptic produce a similar response in all individuals.

What was found was that each group, having arrived at a different point in the social structure, exhibited responses that were similar within the group, but differed radically from other groups. This can be taken to indicate that personal identity is neither a purely individual thing nor a passive response to social roles. Rather the self may be conceptualized as a process involving both individual elements and social aspects. By conceiving of the self as a process it is thus possible to incorporate the situational responses identified in the previous chapter with the identity implications of labels discussed in this one. The findings can be summarized as follows:

Group	Situational Response	Master Status and Secondary Deviation
Community	Acceptance	None
Borstal	Distancing	Criminal
Hospital	Confusion	Epileptic

Hence the situational response of the community group was one of acceptance and this consequently had no identity implications for the individuals concerned - epilepsy was a normal part of their everyday lives. The response of distancing identified in the borstal group was not a defence mechanism developed to enable individuals to come to terms with the situation of being epileptic in a borstal, but a reflection of the fact that it was the label 'criminal' that had implications for their sense of self, and not the label epileptic. Finally the group in the hospital were confused and thus unable to manage their epilepsy in a satisfactory way and consequently the label epileptic became significant for their personal and social identities; in fact their social identities became their personal identities.

CHAPTER SEVEN

CONCLUSIONS: EPILEPSY AS NON-VISIBLE SOCIAL DEVIANCE

Thus far the effects that having epilepsy has had upon individuals has been considered, in terms of the kinds of social experiences that may happen to them, the way ideal-typical knowledge may (or may not) give shape to their experiences and the effects that this may have upon their own self-conceptions. In this final chapter, consideration will be given to the situation from the opposite point of view; that is, the effects that having epileptics in society may have upon public attitudes generally or more specifically, the social stock of knowledge, as Schutz (1964) has called it. While these topics, society's effects upon epileptics and epileptics' effects upon society, are being treated separately, it is not being suggested that they are independent of each other. Far from it, the relationship between identity and society is well described by Berger and Luckman (1971.194):

> "Identity is of course, a key element in subjective reality and, like all subjective reality, stands in a dialectical relationship with society. Identity is formed by social processes. Once crystallized, it is maintained, modified, or even reshaped by social relations. The social processes involved in both the formation and maintenance of identity are determined by social structure. Conversely, the identities produced by the interplay of organism, individual consciousness and social structure react upon the given social structure, maintaining it, modifying it, or even reshaping it. Societies have histories in the course of which specific identities emerge; these histories are, however, made by men with specific identities."

In considering the effects that epileptics may have upon the structure of society, and the social stock of knowledge in particular, the conceptualization of epilepsy as non-visible social deviance is crucial. In Chapter One it has already been shown that the vast majority of epileptics are neither involved in the work of national organizations, nor registered with appropriate agencies, and their visible symptoms (i.e. the fits) are well controlled by medication (1). Further in everyday social interactions (Chapter Five) epilepsy is not consistently revealed or talked about. What will be considered in this Chapter is the visibility of epilepsy as manifested by fits that may occur in public situations and the social visibility of epileptics as a stigmatized minority in society. These issues will be considered separately.

INDIVIDUAL VISIBILITY AND ITS EFFECTS UPON PUBLIC ATTITUDES.

The effect that direct contact with minority groups or individuals who have some minority group trait upon public perceptions or attitudes has been well discussed. The study by LaPiere (1934) showed that public attitudes towards Chinese immigrants indicated prejudice for when he wrote to hotel and rooming-house keepers asking if they would be prepared to accept these Chinese as guests, the vast majority responded in the negative. However when the same keepers were presented with these Chinese face to face, they were invariably welcomed as guests. Similarly, Stouffer et al (1967) found that the attitudes of American soldiers towards their negro colleagues changed substantially for the better after periods of contact. Studies concerned with disability have come to similar conclusions (Anthony 1972.118):

> "it appears that individuals who have contact have slightly more favourable attitudes than those who report no contact."

However some studies have come to the opposite conclusion - that contact with deviants or minority groups may actually increase prejudice. A recent article (Warner and DeFleur 1969) has argued that there are three theories concerning the relationship between public attitudes and the reaction that contact with deviants can provoke. Firstly there is what they call 'the postulate of consistency'; that is, peoples' attitudes, as measured by survey techniques, are a valid guide to the way they would react in real world situations with deviant or minority groups. Secondly, there is 'the postulate of independent variation'; that is, peoples' attitudes provide no real guide to the way they behave in particular situations, 'Prejudicial attitudes need not coincide with discriminatory behaviour'. Thirdly, there is 'the postulate of contingent consistency'; that is there are a number of factors which can modify the relationship between attitudes and actions in particular ways. In the article, they consider two such factors; what they call 'social constraint' and 'social distance'.

The point of this discussion is not to make any judgment about the validity of these particular theories or to add to the growing body of research using attitude survey techniques, for within the interactionist tradition it is taken for granted that meanings are constructed in individual interactions and situations. Therefore the effects that contact with deviants and minorities may have is an empirical question which can only be verified by studying the particular situations and not by a prioritheorizing. To give an example of the point, while contact between blacks and whites in the context of an army platoon may break down prejudicial attitudes, contact between blacks and whites in inner city areas characterized by urban deprivation, high rates of unemployment and so on, may actually exacerbate prejudicial attitudes.

Before discussing the effects that contact with epileptics may have upon the social stock of knowledge, it will prove useful to describe some of the situations in which fits have taken place and the effects that they may have had. In reporting on the kinds of reaction that fits may provoke, the information is supplied largely by the epileptics themselves. Obviously there are a number of difficulties in using these informants who may not be best placed, as the centre of attraction, to provide accurate evaluations of public reactions. Further difficulties may arise in that fits often provoke confusion and clouded consciousness in the sufferers themselves and thus the mental state of the informant may not be ideal for observing public reactions. However the alternatives may also give rise to difficulties; one possibility would be public attitude surveys but as well as being an almost over-worked research technique, such surveys do themselves give rise to methodological difficulties and have been discussed critically earlier (Chapter Two). The second possibility would be some form of participant observation in situations where fits actually occur, but such fits are, by their very nature, unpredictable and it would be difficult to arrange to be in the right place at the right time (2). Thus using the respondents themselves as informants seems the most appropriate device and in fact, it could be argued that this technique is just an extension of the use of 'self-report studies' which are proving both popular and useful in recent criminological research.

Using this revised version of the self-report technique the following public reactions were identified; (a) fear or shock, (b) misunderstanding and confusion, (c) a lack of concern, and (d) a willingness to help. These reactions did not occur on all occasions nor in the presence of all respondents, but all occurred with sufficient regularity to be able to say that they formed part of the general public reaction to fits. One respondent (CGM) indicated the wide range of reactions that may occur:

I. Do you think it bothers other people?

R. Er, I think for those who don't know what's going on, you get the person who'll say, "Oh! Is he all right? What's going on there then?", and then you'll get the twit who'll say "Oh! Come on, let him alone. Give him some air". And all the rest of it, you know, and then you'll get somebody who'll say, er, "Ooh! I don't like the look of him. Is he all right?".

> Y'know the sort of thing. You get all sorts of different people, y'know. It's inevitable really, I suppose, you got to take one with the other. It's just a question of living with it really.

(a) Fear or shock - A large number of studies have identified fear as a common reaction both to epileptics and to epileptic fits. It was a frequent reaction in this study and the following is a fairly typical response (MMS):

> I. How do you think other people felt about ....
>
> R. Well, terrible, nervous and - all shook up,
>
> I. Why?
>
> R. I expect 'cos they'd never seen an epileptic have a fit before and of course, never seeing an epileptic having a fit and then an epileptic has a fit - and they're right there, y'know - and it's scary, proper scary.

An important element in this fear is the violence that is often associated with fits (CJB):

> I. Why were they frightened of you when you had a fit?
>
> R. 'Cos they've never seen nothing so violent, y'know, 'cos I'd start frothing at the mouth as well.

It is not just the general public who are likely to react in this way but also those who might be expected to be used to seeing fits. An inmate from the borstal (RRM) described the following reaction:

> R. Well, they sit there white as a sheet, actually. I seen an officer, he didn't know what to do. I remember coming round. Just after, he just stood there. He'd 'phoned up on our radio, you know his, what he told me, for help, assistance, and er, he just stood there; he was as white as a sheet, didn't know what to do - Well, I say he didn't know what to do, he seemed as if he didn't know what to do, sort of thing, you know.

And the fear provoked by previous fits or fits that might occur can give rise to a 'funny atmosphere' when someone who may have had a fit returns to 'the scene of the crime' (RJT):

R. I sort of, like, used to walk in there and the same people, the old regulars used to be in there. I used to see them wanting us out and I used to get a funny stare, you know, when you walk in. I used to think they're saying under their breath, er, "Here he come again, hope he don't have another one". They called it something, they called me "The Wobbler", they used to call me. I used to go in the house, get a funny atmosphere all round - didn't everyone - all the eyes were on me. So I never used to go, I don't drink a lot, I never drank hardly. I, I go in there, I should have a coke or something. I don't touch alcohol, or smoke or nothing. Don't touch the stuff. That's why, you know, I'd just go in there and have a coke and that. They used to keep staring at me. I stay out of pubs most of the time.

(b) Misunderstanding and confusion - Another very common reaction to an epileptic fit is to want to do something constructive. However when someone collapses in the street there are a number of things which could have caused it and until the cause is known, it is difficult to take appropriate measures. As one respondent (MCT) put it:

I. Do you think they feel embarrassed or worried?

R. They most probably feel worried, yes. 'Cos they don't know what to do. They don't know what's wrong. They don't know whether you're asthmatic, 'cos asthmatics have fits as well.

I. Yes?

R. Just like us, y'know, just like epileptics and, er - they can't tell, that is, until you've told them that it is epilepsy.

The most common public reaction is to send for an ambulance and many epileptics either wake up in hospital or in an ambulance.

One respondent (MMH) remembers one such incident:

R. I remember, I got the feeling once and I was going home on the bus and, er, later on, er, what happened is, er, I felt like I was really going to have one and I told a woman, er, but I don't know if she heard me like, and, er, I tried to tell her and then, er, well, I don't remember nothing from then on and the next I, the next I remember is two ambulance men that ran me getting there or something; and I was at, er, London Bridge and that's further than I wanted to go, y'know.

I. Yes - How did you feel about it?

R. Well, I didn't feel, I didn't like it that much but, well, er, that's it, isn't it. (3).

The most dramatic, though unusual, example of misunderstanding occurred as follows (CMG), when he was in Piccadilly:

R. I was with somebody but he disappeared - And, er, I woke up on the pavement on floor with this policeman, sort of, "What's your name?". Er, "What? Pardon?". It was terrible. I couldn't remember my name properly. I really am terrible, when I wake up at first. I haven't the foggiest idea where I am, what's going on. I usually swear.

I. Presumably he thought you were a drug freak, did he?

R. Yes, I probably swore at him, being carted off to a small room, detained in the doctor's room to find what I had in my pocket.

I. Yes?

R. It was very upsetting.

I. You were upset about it were you?

R. Mmm, it was quite, er, traumatic, being held up between two policemen and being hauled off to a police station. All I could say was "B - b - b - b, what the devil's going on? What are you doing?".

(c) Lack of Concern - A number of respondents had not noticed any particular reaction to fits that may have occurred in public situations (CAW):

I. Do you think other people who have been present have been embarrassed?

R. Er - I haven't really - I haven't noticed it, their being like that.

I. Have you met people afterwards who'd seen you having a fit and felt that they were treating you any differently, at all?

R. Er - no, I haven't er - and I - I've met people, just as my own class, say. I haven't noticed any particular reaction.

But it was not necessarily a matter of not noticing; in one particular situation the respondent (CJE) who lived in the rural village thought that most people were used to his fits and thus tended to take little notice when one occurred in public:

I. Can you remember any time you've had a grand mal in public?

R. Well, I did the other night. I don't know whether you'd call it public or not. There was, y'know, all my mates were round there.

I. Yes. Where was this?

R. I was down the field when I had a grand mal, y'know, and blacked out.

I. Yeah? And what happened? How did people react?

R. I suppose, whenever they see them, they're always doing what they've been, y'know, doing.

I. Yes?

R. I know, a mate of mine, he ran down the 'phone, 'cos my dad's on the 'phone. He ran down and told him and then came back after. Er - well, I don't think they really, er, y'know, worry about it, y'know.

I. Yeah. They're used to it by now, are they?

R. Yes. Well, I think so.

At the opposite end of the spectrum, one respondent (CDW) who lived in London felt that fits in public provoked little or no reaction because they were usually ignored, by everyone except perhaps the odd thief:

R. I had a fit once in Blackheath Village about 10 o'clock at night.

I. Yeah?

R. And, er, well, I was pretty bad because I was just ignored and apart from that I was robbed. Somebody came along and took some money out of my front pocket, and they went through my wallet.

I. What, while you were actually having a fit?

R. Well, probably when I was unconscious afterwards, and they took the ring off my finger.

I. Really?

R. Yes. Just like that. But I find, a lot y'know, if you are ill in the street people are not too interested.

I. Yeah. What do they tend to do?

R. Walk by, or else turn the other way.

Even in highly public and crucial situations, fits do not always provoke the extreme reactions that is often supposed. One respondent (CHW) described what happened during a public ceremony:

R. There was a time up at Windsor - this year - we'd all gone up there to visit some friends and to see the Jubilee Celebrations. We went to see the Queen, there was going to be the Queen up there.

I. Yes?

R. Er, what happened was, I just went away with another - my friend, another friend - and we were watching the Queen. We were watching the Queen and she had just got up onto the stand. I just saw the Queen and fainted.

I. I see.

R. The next thing that I can remember is - being carried - away through the crowd. I can't remember any people saying "Oh heck, oh, why the heck did he have to have a fit here?", or anything like that.

(d) A Willingness to Help - It was not uncommon to find that people were anxious to help, even though, as one respondent (MRG) thought, they might have been shocked into coming forward:

I. How did other people react, do you think?

R. Well, some people, kind of - did offer - help. Some - kind of, er, I suppose, shocked to come forward, to offer help. They didn't know what to do. At least they may not have. You just don't know; some people did help and they didn't know what they were doing.

Another respondent (MRL), who had had many fits in public, found that rarely, if at all, did these fits provoke any strong public reactions or emotions, but that by and large, people wanted to help:

I. Did you have any fits in public?

R. Yeah, a lot.

I. Can you remember any of them, what used to happen?

R. Well, nothing used to happen, really. I just used to, y'know, fall down; someone used to come round me, just used to ask me "are you O.K.?" and all that.

I. What, you used to fall down and scream?

R. Yes, I'd scream if I, if I felt I was going into a fit, like, which I always knew. I used to sit myself down somewhere, y'know. And sometimes, I never do, I just stand up and carry on.

I. Mmm. What did people do? Did people used to be embarrassed or frightened?

R. I don't know.

I. What happened when you came round? Did, er, what did people used to say to you?

R. They'd ask me what was troubling me, like, and I'd tell them that I was an epileptic, y'know.

Help was sometimes forthcoming from people who could be best described in Goffman's (1968) terms as 'wise'. Such an incident had occurred at a party (RRR):

I. Have you ever been in public and felt a fit coming on?

R. Er - I've been to a party, I wouldn't say it's in public, I've been to a party ....

I. Yeah?

R. Y'know, I was drinking, and I mean, it ain't routine when you're an epileptic, but I was drinking and I got so drunk and that, and I felt dizzy - and I looked at this, er - girl who runs the party - I said to her, "look", I said, er, "can you undo the door, I want to run out there", and she says "why? You don't look too good". I said "no, I feel sick". She did know I was an epileptic. Y'know she didn't know at the time she moved, but - one of my mates who I did know, he, er, he went and told her. He slipped up himself and told her, and er, as I went out - I thought she'd shut the door behind me. But no, she'd put her arm round me, y'know. I, er, I did, y'know, I had one coming, a fit, y'know. She was with me all the time. She said I was gone for about five minutes, y'know

> what I mean, but she stood there with me and I, er, I had, er, I felt embarrassed a bit, y'know, y'know what I mean. 'Cos, like, when I generally have one, I generally go somewhere - I generally sit, like when I'm in a room, I generally sit with my head in my hands. Perhaps either that or go to bed. I mean, if it's I do throw one, I won't hurt myself very much. But she stood by me, actually, and I, y'know, I feel embarrassed about it.

Regardless of which of these four general reactions individual members of the public might experience, it was generally agreed that familiarity with fits made it much easier for people to cope with any disruption to public order that might occur. As a basic rule, the more fits one has seen, the more everyday and matter of fact they become. This was described thus by one respondent (CNT):

> I. How do you think other people felt about it?
>
> R. Well, people, often people, where I've had fits, people living in the place where I was in, like, for example, they're used to it.
>
> I. Yes?
>
> R. So they're prepared, and its not too bad, when they happen. They have seen you have them before. They know what you're like, so they accepted it.

Those who are used to seeing fits may not react at all whereas others might react very differently (RAC):

> R. Some of them are sorry, some of them may be a wee bit embarrassed, but other people like, used to me, er, and them, seeing me before having fits, so they don't take much interest in them. But other people that are just newly friends, or something like that, they just feel ashamed and just try to break up the friendship or something like that.

But it is not just a matter of being used to seeing someone have a fit but also of knowing what to do and hence being able to exert some control over the situation. According to one respondent (CJB):

> R. There's one boy who has had, er, has seen me have two attacks and he's, he's dealt with it completely coolly and calmly and - although he said it was a little bit frightening the first time, the second time was nothing. He just realized that it was completely normal for me and that I wasn't going, er, about to jump on him or hit him or anything like that. So, he acted perfectly calmly. He put me on my stomach so that I wouldn't choke or anything like that.

Regardless of whether members of the general public experience reactions of shock, fear, a desire to help or no particular reaction at all, it is clear that previous experience of seeing fits can modify subsequent reactions. To use the terminology developed in this study, direct experience of particular phenomena allows people to build up knowledge based on typifications rather than stereotypes. This suggests that the extent of visibility of particular phenomena is an important factor in shaping public consciousness and adding or amending the social stock of knowledge. Thus the concept of social visibility is not unlike the concept of social distance utilized by Warner and DeFleur (1969) in their study mentioned earlier.

THE SOCIAL VISIBILITY OF DEVIANT GROUPS.

There are two related aspects to the social visibility of deviants and deviant groups; there is firstly the issue of the visibility of particular individuals and secondly there is the issue of the visibility of particular groups or categories of deviants. In what follows the narrow question of the visibility of the particular epileptics studied during the course of this research project will be considered initially, then the issue of the social visibility of deviant groups will be placed in a more general and historical context.

(a) <u>The Social Visibility of the Epileptics Being Studied</u> - Social visibility in the sense used in this section refers to visibility through fits and not visibility through any militant activity, pressure group involvement or 'coming out'. Harrison and West (1976.29) suggest:

> "it is the worst epileptics who are the most visible; those whose seizure control is poor and may be more likely to have associated problems like cerebral palsy or retardation. Others who might present a 'neutral image' are not normally part of people's experience by virtue of the effective concealing of their disorder. The construction of a 'negative' stereotype is not simply therefore a matter of selective perception but of experiencing sufferers who represent only a portion of the total population of people with epilepsy. The public, it seems, have only limited experience of epilepsy and what they see tends to be the 'worst' end of the spectrum."

There is no way, within the context and methods of this study, that it would be possible or desirable to estimate how representative the respondents studied are of epileptics as a whole, nor indeed how representative they may be of adolescent epileptics living in the community, experiencing mental health problems or being processed by the criminal law. However it is possible to compare the three groups in terms of their social visibility relative to each other.

In terms of the number of fits that have occurred in public, bearing in mind that the estimates are based upon subjective, self-report methods, it is possible to see some gradation between the groups. The group having the most fits in public were undoubtedly the group associated with the mental hospital, next came the epileptics living in the community and the group who had least fits in public were the group from the borstal institution. This is in some respects consistent with findings in the previous chapter; namely that the identity implications of being epileptic were most significant for the group from the mental hospital and least significant for the group from the borstal. It is not being suggested that the extent of fits is directly related to effects upon personal identity amongst epileptics generally but rather that frequent fits, allied to factors like family and educational background, may effect the ability to manage epilepsy as a problem in living and hence effect a person's personality or sense of identity.

Social visibility is not just a matter of comparing the groups in terms of fits but also of considering how society treats minority groups, the variety of mechanisms of social control it operates, and ultimately the effects that this social control might have upon public attitudes and the social stock of knowledge.

(b) The Social Visibility of Deviants in Society - Many sociologists, especially those following in the Durkheimian tradition, have noted that deviance of one kind or another is endemic to all social groups and societies although Roshier (1978) has recently challenged this assumption. Durkheim himself (1938.68-9) makes this basic point:

> "Imagine a society of saints, a perfect cloister of exemplary individuals. Crimes, properly so called, will there be unknown; but faults which appear venial to the layman will create there the same scandal that the ordinary offence does in ordinary consciousness. If, then, this society has the power to judge and punish, it will define those acts as criminal and will treat them as such."

Thus, while all groups or societies will define some behaviour as deviant, the kinds of labels applied to different behaviours will vary between these societies. However, all societies, being social constructions based upon the imposition of social and moral order are unable to legitimize all phenomena within their given social and moral boundaries, and therefore certain of these are regarded as deviant. According to Scott (Scott and Douglas 1972.24):

> "Deviance is inevitable because any attempt to impose order on the untidy phenomena of human existence will inevitably result in a certain amount of matter being out of place."

It is not just a matter of the inevitability of deviance to social organization but also that deviance is actually necessary for (and functional to) social order. Durkheim (1938.81) saw the relationship between deviance and moral order, what he called 'the common conscience', as follows:

> "we must not say that an action shocks the common conscience because it is criminal, but rather that it is criminal because it shocks the common conscience. We do not reprove it because it is a crime, but it is a crime because we reprove it."

And, according to him, crime becomes functional because it (1964.102):

> "brings together upright consciences and concentrates them."

Erikson (1966.4) in a historical study of a religious community makes a similar point:

> "Like a war, a flood or some other emergency, deviance makes people more alert to the interests they share in common and draws attention to those values which constitute the 'collective conscience' of the community."

Box (1971) has extended this line of thought and argues that deviance performs at least three 'latent functions' for societies; it may clarify existing social rules, it may also serve to help maintain these rules and finally it may act as a means for modifying these rules and hence minimize potential social conflicts.

However deviance is not only endemic and functional but it can also be disfunctional on one of two levels. At the level of micro-social order deviance can violate the taken-for-granted world of everyday life, the expectations of how given individuals should behave in particular social situations. Thus someone having a violent fit in a public place may violate generalized expectations about the appropriateness of particular behaviour in public situations - it is not expected that a normal, healthy looking person may suddenly become unconscious, thrash and jerk around uncontrollably and possibly urinate or defecate. Berger and Luckman (1971. 116) refer to this violation of taken-for-granted expectations as the 'night side' of reality and spell out some of its disfunctional aspects:

> "the marginal situations constitute a 'night side' that keeps lurking ominously on the periphery of everyday consciousness. Just because the 'night side' has its own reality, often enough of a sinister kind, it is a constant threat to the taken-for-granted, matter-of-fact, 'sane' reality of a life in society. The thought keeps suggesting itself that, perhaps, the bright reality of everyday life is but an illusion, to be swallowed up at any moment by the howling nightmares of the other, the night side of reality."

At the macro-level, deviance can pose a threat to society so fundamental that it can transform the very structure of the existing society. For example, it is conceivable that the level of crime in a society could become so great that it could alter the existing property relations in such a way to change the very nature of that society. Similarly, excessive sexual deviance in a society could substantially effect the social and moral order through its attack on the family so that society would alter fundamentally. However all societies through government and state activity recognize the potential threat that excessive deviance can pose and hence establish means for reducing the potential disruptions arising from such deviance.

(c) Visibility, Non-Visibility and Social Control - All societies or groups attempt to control deviance at both micro- and macro-levels although, obviously, the question of the effectiveness or appropriateness of particular mechanisms of control varies from society to society. Birenbaum and Sagarin (1976.49-50) describe some of these basic mechanisms thus:

> "Social control operates through law, police, courts and prisons; it operates through authority figures on whom we are dependent, such as parents; but it is very pervasive on less authoratitive and formal levels as well. When people get together and talk about their absent friends, when they ridicule rivals, or when they use sarcasm to bring a potentially rebellious member of their group back into line, they are practising social control."

Before moving on to discuss the types of social control that have developed historically, it is necessary briefly to relate this theoretical discussion of deviance to the concept of social visibility. Earlier it was noted that deviance was both functional and disfunctional at the same time to any given society and this paradox is carried over when considering the aims of the various mechanisms of social control. The aim of social control is both to render the deviant non-visible either by execution or exclusion in order to prevent any threat that he might pose to either micro- or macro-social order but also to render him visible in order that he may stand as an example to others as to what kind of behaviour may and may not be tolerated. Foucault (1977.58) notes this ambiguity contained in instances of public torture:

> "in this scene of terror, the role of the people was an ambiguous one. People were summoned as spectators; they were assembled to observe public exhibitions and amendes honorables; pillories, gallows and scaffolds were erected in public squares or by the roadside; sometimes the corpses of the executed persons were displayed for several days near the scenes of their crimes. Not only must people know they must see with their own eyes. Because they must be made to be afraid; but also because they must be the witnesses, the guarantors of the punishment, and because they must to a certain extent take part in it."

In placing the social control of deviance in historical context there are a number of general points that should be borne in mind. Firstly, for present purposes, all behaviour which offends against the social or moral order will be considered together and regarded as falling under the rubric of deviance. There will be no attempt to provide a separate account of historical processes associated with the social control of crime, of mental illness or other forms of discrepant behaviour. This is not just a matter of theoretical fiat or convenience, but it has been suggested that there is an inter-changeability between various kinds of deviant behaviour and the methods used to control them. Thus Penrose (1939) suggested that among European societies before World War Two there was an inverse relationship between the size of prison and mental hospital populations. More recently Gunn (1974.507) has suggested that:

> "there is a considerable overlap of functions between mental hospitals, lodging houses and prisons."

Secondly, in discussing the various methods of controlling deviants, at no time did one method become the only one in use; expulsion, execution, torture or containment within family, institution or community are all methods which have been used at all times. However in certain historical periods, certain of these methods have been dominant both in terms of the number of deviants being controlled and also ideological commitment to that particular method. Finally the aim of what follows is not to provide a detailed historical account of the changing methods of control but to provide a theoretical link between particular social forms and the visibility of deviants as groups in these particular societies.

Over the past thousand years in Britain, it is possible to differentiate into three eras the visible and non-visible aspects of the mechanisms of social control and the following schema provides a general picture of this state of affairs:

Methods of Social Control

ERA	VISIBLE	NON-VISIBLE
Up to 1600	Public spectacles, gallows, stocks, pillory, cage, etc.	Exclusion Family Community
1600 - 1900	Institution	Institution
1900	Mass media reporting	Family, Community.

Up to 1600 the main methods of visible social control were public spectacles of all kinds, and non-visible control was clearly the responsibility of the family, although as Walker (1968.43) points out, families had different resources and ability with which to cope with their deviant members:

> "Families with large houses or estates could keep a lunatic chained up away from sight and hearing, but this was out of the question for the rural labourer or urban artisan. For them the economic and psychological burden of a madman in the household must have been almost or completely intolerable. Many a family simply thrust him out of their home, to become a vagrant and so find his own way to the gaol or the house of correction."

Thus families who were able to cope kept their deviant members contained within the community. Where they were unable to cope, deviants were often simply turned out and left to roam the countryside, for the local village communities often would not tolerate them in their midst. Premature death or confinement in a local gaol, bridewell or asylum was often their fate.

From 1600 onwards there was an ever increasing trend for the institution to become the major method of controlling deviants; not just dangerous criminals or violent lunatics but other less immediately harmful deviants as well - the poor, the crippled, the indolent, the elderly and orphans. The institution was supremely effective in that it provided both a visible and a non-visible means of social control in that it kept deviants out of sight of the public and hence minimized any threat that they might pose to public order. Further the institution acted as a monument and replaced the public spectacle as the visual and visible representation of the fate of those who did not (or could not) conform. Visibility was not just achieved as an architectural structure which could and did impose its threat upon public consciousness but also in a more bizarre way; it was not uncommon for institutions, particularly those containing lunatics, to conduct public tours of their establishments for a small fee, and the public flocked to such outings with a glee reserved for present day outings to the seaside.

The twentieth century has seen a shift back to the containment of deviance within the community. There has been a switch in both practical and financial resources and indeed ideological commitment to care in the community for a variety of deviant groups including the handicapped, the chronic sick, the mentally ill, the criminal, the retarded and the aged, and this shift has been facilitated and buttressed by the rise of new professional groups - community physicians and nurses, health visitors, social workers, probation officers, domiciliary occupational therapists and a multitude of workers from voluntary organizations of one kind or another. The residential institution is still in existence but it tends to be used only as a last resort when the family and community support services cannot combine to ensure the non-visibility of the deviant concerned, and hence contain any potential threats to public order. The visibility of deviance in society is maintained however by the mass media; by television, radio and press reportage of incidents and instances of deviance ranging from crime, mental illness, race and so on.

Before proceeding to discuss the relationship between the visibility and non-visibility of deviance and how it has been handled historically, it is worth noting that even if we conceptualize epilepsy as illness rather than deviance, the same argument is applicable, for as Dingwall (1976.94) points out:

> "illness is normally managed by seclusion. So far as possible it is contained within the family as a private trouble. Where this option is not practicable it is contained within institutions organised to insulate the deviance from public concern and to limit the threat to public order."

THE CHANGING FACE OF SOCIAL CONTROL.

In Chapter Three it was shown that the medical profession had become the dominant one in relation to the right to define and treat a wide variety of deviant or ambiguous behaviours. While it would not be true to say that the medical profession had achieved such domination as an agent of social control, its influence in this sphere is too becoming ever more pervasive. In an influential article Zola (1972.487) attests to this fact:

> "medicine is becoming a major institution of social control, nudging aside, if not incorporating, the more traditional institutions of religion and law. It is becoming the new repository of truth, the place where absolute and often final judgments are made by supposedly morally neutral and objective experts. And these judgments are made, not in the name of virtue or legitimacy, but in the name of health."

In earlier eras the dominant methods of social control were influenced by the way society perceived deviant behaviour. Thus when religion was the major way of perceiving and evaluating deviance, then methods of social control would include ex-communication, exorcism in its variety of forms and religious agents would support other agencies of control such as the family or community. As legalistic conceptions replaced religious ones, the law and legal procedures became the major method of control and it was through such procedures that deviants were committed to institutions. And it was not just institutions for the violent and the criminal but also for the poor or the aged or orphans. With the move away from institutional control, the medical profession and its paramedical off-shoots have become the major supporting groups to the family and community containment of present day deviants.

Specifically with regard to the groups of deviants being considered in this study, it has already been shown that medicine is almost totally in control not just of what epilepsy actually is, but of what happens to individual epileptics. It is almost solely the perogative of doctors to prescribe medication, to decide on surgical intervention and even to authorize institutionalization. A similar situation exists with regard to mental illness and the medical profession again dominates as the result of a process described by one writer (Szasz 1973.167) as the 'manufacture of madness':

> "The conditions or behaviours we now call mental diseases were not discovered as diseases such as diabetes mellitus or myocardial infarction were. Instead, they had formerly been known by other names, such as heresy, buggery, sin, possession and so forth - or had been accepted as customary and natural and therefore were not designated by special names. In the eighteenth and nineteenth centuries, a host of such phenomena - never before conceptualized in medical terms - were renamed or reclassified as illnesses. This process, which led to the creation of the discipline known as psychiatry, is an integral part of the larger process which substituted scientific concepts for religious ones."

And it is almost solely the perogative of psychiatrists to prescribe medication, to decide upon surgical intervention and even to authorize institutionalization for those who <u>they</u> decide are mentally ill.

While medicine has not obtained such a dominant position with regard to the right to control criminals, there has been a move to redefine certain criminal behaviours as sick and a number of structural factors underlying this partial transformation have been well analysed by Aubert and Messinger (1958). Members of various branches of the medical profession also occupy key positions both within the courts and often have autonomy in deciding whether an individual is fit to stand trial or to be sentenced. Szasz (1974.75) puts the matter thus:

> "The current social dialogue between judges (and legislators) on the one hand and psychiatrists (and psychologists) on the other may be paraphrased as follows. The jurists declare:

> 'there are two kinds of criminals, one mentally healthy, the other mentally sick. Only you, psychiatrists (and psychologists) can determine who belongs in which group. You must help us and society by discharging this important professional obligation'. The psychiatrists reply: 'Of course, we shall try to fulfil this important social responsibility to the best of our abilities'."

Once someone has been sentenced, the rapidly growing Prison Medical Service, will often have a major say in what happens to the prisoner, to which prison he will be allocated, what kind of treatment he will receive and so on (4).

Thus we see medicine established firmly as a major agent of social control for a number of deviant groups or categories in society and certainly the prime agent for controlling the particular groups of deviants being considered in this study. There are a number of commonly held explanations for this state of affairs and while these will be considered briefly and separately for analytical purposes, in practice they are often used to support each other or in combination.

(i) Social Control as an ever more enlightened and humane means of treating the deviant. This view sees history as the progressive evolution of reason, humanity and enlightenment in that changing modes of social control reflect the march of ideas about social progress. Thus the move from physical punishment to deprivation of freedom to medical treatment is a reflection of these changing ideas. While this thesis may adequately fit a 'history of ideas' type of explanation, studies of deviants forced to undergo torture, deprivation of freedom or the three major medical forms of treatment - drug therapy, surgery or institutionalization - indicate that these are indeed simply varying modes of punishment rather than a march into humanity.

(ii) Changing Methods of Social Control reflect the rise of science and its application to the field of human behaviour. Hence the switch from the public spectacle to the institution was part of the attempt to provide a suitable environment where the offender could be treated, reformed and rehabilitated for his deviant behaviour rather than merely punished. The rise of medicine as part of scientific progress is a move further along this road to providing more scientific and effective means of controlling deviants. When this argument is subjected to scrutiny, it is found that medical science does not know very much about how the brain operates, the effects of drugs, or why treatment or rehabilitation programmes of all kinds seem to have little effect upon overall rates of deviation.

(iii) Social Control as the changing power of certain groups to persecute others. The leading proponent of this view is Thomas Szasz who historically documents this process with specific regard to parallels between the treatment of witches in the fifteenth and sixteenth centuries and the treatment of the insane in the nineteenth and twentieth centuries. He argues that this process occurred (Szasz 1973.167):

> "....because of the transformation of a religious ideology into a scientific one; medicine replaced theology. The result was the substitution of a medical mass movement for a religious one, the persecution of mental patients replacing the persecution of heretics."

This process was part of a larger one in which:

> "Nature thus displaced God; the state, the Church, and mental illness witchcraft."

However, this thesis is only a partial one confined to certain deviant groups and is explained largely in terms of medical imperialism. The changing modes of persecution are largely the result of the medical profession, and especially psychiatry, taking over control of certain aspects of human behaviour.

(iv) Social Control as the need to impose and maintain order. The argument is given historical specificity by Rothman in his study of the rise of institutions as the major method of social control in the Jacksonian period in the USA. This was an attempt to ensure order and stability in society in the new and changing circumstances of the disappearance of the old order and the rise of the new. Crucial factors in this new order were the growth of industrialization and the spread of urbanization and hence, according to Rothman (1971.xvii):

> "....the asylum was not so much an effort to force the insane from the horrors of rat infested cells as to bring madness under the rigid and unbending control of reason. Insanity could no longer be allowed its ancient autonomy, now it must wear the chains of modern society - not the iron one of the medieval dungeon, but the more unbreakable ones of a new morality .... The institution was a monument to a new ethic, a system to ensure its total triumph. No-one could escape - even into madness."

Urbanization, industrialization and the rise of the institution were not phenomena unique to America at a particular time but other societies such as Britain were undergoing similar experiences. Hence the rise of the institution cannot be seen solely in terms of a solution to the need to impose order in the New Republic.

While these explanations considered this far, have been shown to be inadequate in themselves, they do point the way to a more adequate, structurally based explanation for the changing methods of social control. There are three essential ingredients of a more adequate explanation that can be extracted from what has gone before and it is worth noting these before proceeding further:

(i) All societies need to impose order and changing methods of social control are different methods of accomplishing this.

(ii) A variety of different groups may be used in the imposition of this order.

(iii) The use of notions like 'the trend to more humane methods of treatment' or 'the march of scientific progress' are ideological justifications for the current method of social control.

MEDICINE, SOCIAL CONTROL AND CAPITALISM - A THEORETICAL AND HISTORICAL CONVERGENCE.

The basis for a structural explanation of changing methods of social control were sketched out by Rushe and Kirckheimer (1939.5) in discussing changing methods of punishment:

> "Every system of production tends to discover punishments which correspond to its productive relationships. It is thus necessary to investigate the origin and fate of penal systems, the use or avoidance of specific punishments, and the intensity of penal practices as they are determined by social forces, above all by economic and fiscal forces."

They go on to argue (p.6):

> "It is self-evident that enslavement as a form of punishment is impossible without a slave economy, that prison labour is impossible without manufacture or industry, that money fines for all classes of society are impossible without a money economy."

In a recent work, Scull (1977) applies this kind of structural explanation to the current methods of controlling the deviant within the community. Initially, he shows that the movement to what he calls 'decarceration' is based on two assumptions; firstly that the institution inevitably makes matters worse for the deviant - patients are institutionalized, prisoners are criminalized and the mentally ill are driven mad. Secondly, that community treatment is inevitably superior to treatment within the institution and reference is often made back to mythical days when all kinds of deviants were accommodated within the community.

Both of these assumptions are examined critically and found to be wanting in some respects. With regard to the former, Scull argues that the negative effects of institutionalization has been known for over a hundred years and indeed a decarceration movement did occur in the nineteenth century. Its lack of success moreover was not due to its inadequate evidence or arguments, which were in all respects as good as the critique of the institution developed in the 1950's and 1960's, but as a result of 'structural pre-conditions'. With regard to the latter, Scull argues that there is little or no evidence that community treatment is superior to that of the institution, in fact the opposite may be the case. What has the approach meant in practice? (Scull 1977.1-2):

> "For thousands of the old, already suffering in varying degrees from mental confusion and deterioration, it has meant premature death. For others, it has meant they have been left to rot and decay, physically and otherwise, in broken down welfare hostels or in what are termed with Orwellian euphemism, 'personal care' nursing homes."

Having demolished the usual arguments advanced in favour of community care, what then does Scull put in their place? The answer is a fairly complex Marxist argument which can be polarized around the concepts of labour and capital. In the twentieth century capital's need of labour has changed from a mass of unskilled workers to a more limited need for skilled workers - the emphasis has shifted from quantity to quality. As a result of this, the 'Welfare State' has arisen as (a) a means of ensuring the supply of skill, and (b) in order to 'pacify' the ever-increasing army of the unemployed, the under-employed and the unemployable. Consequently, an infrastructure of state employees has arisen whose job it is to pacify this army and hence we have the 'structural pre-conditions' for a move towards community care. It now becomes cheaper to provide care within the community, especially against the twin pressures of demands to cut public expenditure and the increasing pressure from employees working in institutions for higher wages and a limited working week;or as one writer (Box 1977.23) has put it:

> "The major issue becomes how can the disruptions real and imaginery, be rendered harmless at the cheapest cost per unit. And here keep 'em out, get 'em out and close 'em down becomes relevant."

There can be little doubt that medicine, or rather the medical profession, has had a crucial role in 'rendering deviants harmless' at the cheapest cost possible. While Scull is sceptical about the effectiveness of what he calls 'the technological fix', there can be little doubt that the prescription and administration of drugs does significantly contribute to the maintenance of potentially disruptive deviants within the community in a socially harmless state. Anti-epileptic medication for example, can prevent the majority of fits in approximately 80% of diagnosed epileptics (College of General Practitioners 1960) and it is solely the perogative of doctors to prescribe this medication. Further doctors have other means of control at their disposal, should drug therapy be unsuccessful (Packard 1978.74-5):

> "Around the world thousands of operations are being performed each year on the brains of unruly or deviant persons. A few of the surgeons profess to operate only - or mainly - on persons with clear evidence of organic abnormalities in the brain, such as epilepsy. It should be noted, incidentally, that is is the rare epileptic who is violent towards others during his siezures. If he is unruly at other times it may be

> coincidental. A criminal who has been pistol-whipped a few times may well develop a brain pathology. But in general the evidence of any correlation between provable brain pathology and tendency to violence is skimpy."

But surgical intervention, whether it be on the brain, or perhaps the sexual organs, is usually an effective means of controlling deviant behaviour, whether it be violent or sexual. As Rose and Rose (1976.122) put it:

> "drugs or psychosurgery will indeed 'pacify' individuals, even if they do so by reducing them to cabbages."

Finally, of course, the medical profession can incarcerate those deviants they cannot control by drugs or surgery.

This is not to suggest that the medical profession has expropriated almost complete power in the area of social control, but as the title of Zola's (1972) influential paper suggests, they are the 'agents' of social control. This is spelled out more clearly by Navarro (1976.121):

> "One of the functions of the service bureaucracies - including the medical bureaucracy - is to legitimise and protect the system and its power relations. One aspect of this protection is social control - the chanelling of dissatisfaction - .... But to believe that social control is due to the culture of medicine and the pervasiveness of industrialization is to ignore the basic question of who regulates and most benefits from that control. An analysis of our societies shows that the service bureaucracies - including the medical ones - although willing accomplices in that control, are not the major benefactors. The ultimate benefactor in any social control intervention in any system is the dominant class in that system."

So medicine benefits capitalism and the capitalist ruling class in that the medical profession acts as an effective and relatively cheap agent of social control. But it does more than that (Navarro 1976.208):

> "it contributes to the legitimation of capitalism. And it is because of this legitimation function that the medical profession is serving the interests of the capitalist system and the capitalist class."

This legitimation is performed through what Szasz (1974) has called 'the ideology of mental health and illness' which extends to almost all aspects of society. Scheff (1975) has further suggested that specific labels such as schizophrenia are also ideological labels in that they provide residual categories in which to place otherwise unexplainable deviant behaviour. So too with epilepsy then - it is currently estimated that there are 300,000 epileptics in this country but there are many more who have black-outs, momentary losses of consciousness, fits of temper, hysteria and even fits of laughter (5). Hence the label epilepsy is also ideological in that it provides a label for the residual category of those having fits and it legitimates the social control of those so labelled whether it be by surgery, drug therapy or confinement. It further legitimates these techniques of control in that they often pass for treatment and hence are for the good of the deviant concerned. This legitimation has been called 'the therapeutic impact of social reaction' (Young 1975.65).

To relate this back to the discussion of need for deviation to be rendered visible and non-visible at the same time; in modern Britain we see the medical profession as a major agent in ensuring the non-visibility of deviation in society. Thus in twentieth century capitalist Britain, the medical profession then is an agent of the dominant class whose function is to ensure that deviation remains non-visible and hence poses little or no threat to micro- and macro-social order. It does not however also serve to render the deviant visible as did the institution in a previous historical period. This however is consistent with the development of capitalism which is characterized by an ever increasing division of labour. Hence the task of rendering the deviant visible falls to other agencies or organizations, usually the mass media, which, it is sometimes argued, is also an agent of the ruling class.

Rose and Rose (1976.126) in their critique of what they call 'biologism' summarize the way in which science and its agents, in this case the medical profession, operate as agents of social control in capitalist society:

> "its .... organizing paradigms are permeated with these 'ruling ideas' which express class interest, and that the technologies that they generate are essentially defensive of that class interest, serving to protect it both physically, by manipulating and pacifying would-be protesters, and ideologically, by providing an apparent biological justification for the social order."

VISIBILITY, NON-VISIBILITY AND THE SOCIAL STOCK OF KNOWLEDGE.

We are now in a position to consider the relationship between the various kinds of knowledge identified earlier in this study (Chapter One). For present purposes the crucial intervening variable in the relationship between knowledge and social structure has been taken to be the visibility or non-visibility of the particular deviation under consideration, and in previous sections of this chapter this variable has been discussed in relation to societies generally and twentieth century Britain in particular. At this point it should be noted that it is not the intention of this study to consider the meta question of the relationship of knowledge to particular social forms (6) but to discuss inter-relations between these various kinds of knowledge; what Berger and Luckman (1971) call 'the social distribution of knowledge', and to show how these might be relevant to the question posed at the outset of this study, which was 'why do epileptics have trouble?'.

According to Schutz who has provided the most detailed discussion of the social stock of knowledge to date, there are two basic elements in this knowledge; individual experiences in the world and the pre-existing social stock of knowledge which provide a backdrop against which these experiences are evaluated. Hence he suggests (Schutz and Luckman 1974. 99-100):

> "The lifeworldly stock of knowledge is related in many ways to the situation of the experiencing subject. It is built on sediments of formerly actually present experiences that were bound to situations. Inversely, every actually present experience is inserted into the flow of lived experience and into a biography, according to the set of types and relevance found in the stock of knowledge. And finally, each situation is defined and mastered with the help of the stock of knowledge. The stock of knowledge is thus related to the situation (viz. experience as bound to the situation) as much genetically as it is structurally and functionally."

He goes on to detail the relationship between these basic elements as follows (Schutz and Luckman 1974.135):

> "The basic elements of the stock of knowledge are not the result of the sedimentations of specific experiences. They consist of knowledge concerning the limiting conditions of all such experiences, a knowledge that is more or less automatically given with every experience. The basic elements of the stock of knowledge are still confirmed, modified, or refuted by means of individual experiences, just as my knowledge of the weather conditions in the mountains, of the character of a friend, etc., that has arisen through specific experiences, is later modified and confirmed in such experiences."

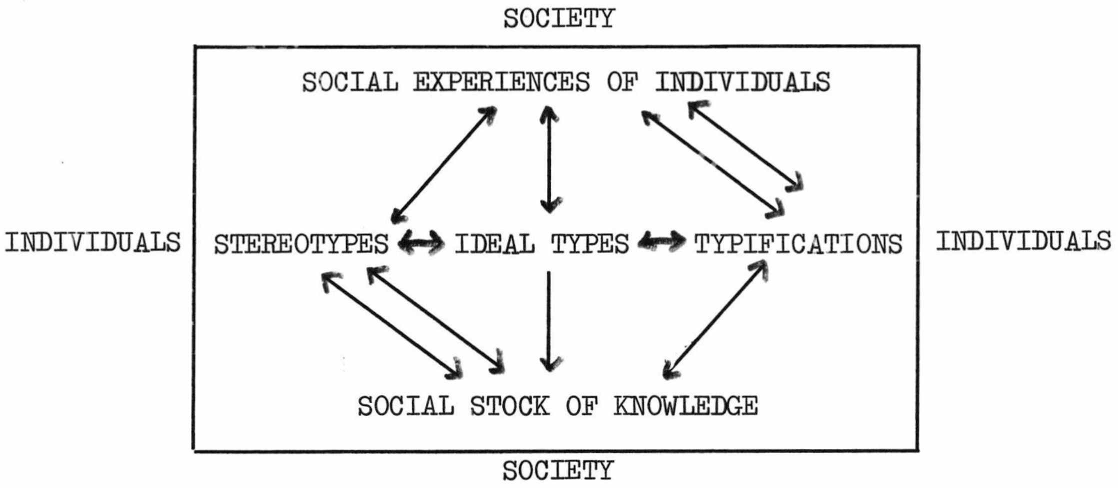
Utilizing these two elements of the social stock of knowledge and drawing upon the three kinds of knowledge identified earlier, (i.e. stereotypes, ideal-types and typifications) it is now possible to put forward a model which will allow explication of the various relationships between the different kinds of knowledge under discussion. The point of this model is not to consider questions regarding the priority of knowledge over experience or experience over knowledge but the inter-relations between the two; though Schutz, in opposition to those from Marx onwards who see social form as the determinant of all knowledge, allocates priority to individual experience. Thus he notes that (Schutz and Luckman 1974.243):

> "Because an individual is born into a historical social world, his biographical situation is, from the beginning, socially delimited and determined by social givens that find specific expressions."

However he goes on to stress (Schutz and Luckman 1974.262):

> "Despite this empirical priority of the social stock of knowledge in relation to any particular subjective one, the subjective acquisition of knowledge is still the origin of all social knowledge."

<u>MODEL - The Inter-relationship and Distribution of Knowledge and Experience</u>.



The arrows linking the various parts of the Model are meant to indicate connections between the various kinds of knowledge and the double arrows indicate links which are of particular importance to the question as to why epileptics have trouble. It is the relationship between knowledge and experience of epilepsy which will be considered first and then the inter-relations of different kinds of knowledge about epilepsy will be discussed.

As both the Model above and Schutz stress, experience is an important factor in building up typifications of epilepsy. However during the course of this study, it has been argued that an important factor relevant to knowledge about epilepsy is that it is usually a non-visible deviation. There are two major reasons for this; firstly fits seldom become a public issue for the activities of the agents of social control ensure that such occurrences are well controlled; and secondly, in most social interactions epileptics themselves choose to pass and seldom reveal their epilepsy. Hence social experience through the building up of typifications plays very little part in adding to the social stock of knowledge about epilepsy. Further in those few cases where epilepsy does become a public issue, it is usually through the actions of the 'worst' epileptics and therefore any typifications that are built up are derived from the most negative aspects of epilepsy.

Thus the social stock of knowledge concerning epilepsy is very much influenced by stereotypes often informed by historical conceptions about the 'real' nature of epilepsy, or by the way the media choose to report particular visible instances of activities involving people suffering from epilepsy. The social control of those with epilepsy, as well as inhibiting the build up of typifications, facilitates the growth of stereotypes. Scull (1977.126) describes how this process occurs in the case of the mentally ill:

> "By removing the insane from the community and sequestering them behind the walls of an institution, the possibility of ordinary people misperceiving and exaggerating the most common factors of mental disturbance was greatly exacerbated. Lacking the corrective provided by close daily contact with such deviants, the public were likely indeed to view crazy people as a threat and a menace. The cases they were most likely to hear about were those of violent mania, since mild cases scarcely merited attention in the mass media. And after all, why else were lunatics locked up in the first place, unless it was because it was not safe to leave them at large."

So too with epileptics; by rendering them non-visible through drug therapy, incarceration or surgical intervention, their characteristics are likely to be misconceived and after all, fits are so violent, disruptive and dangerous to public order that they must be controlled both for the good of society and the epileptic.

One further aspect of the model needs to be considered - the social distribution of such knowledge - that is the inter-relationship between stereotypes, ideal-types and typifications. Scheff has considered this distribution of knowledge specifically with regard to mental illness and argues that at one end of the spectrum exists the opinions of experts (ideal-typical knowledge) and at the other end exists the stereotypes of mental illness; somewhere in the middle stands the general public, being pulled one way by expert opinions and the other by stereotypes (Scheff 1966.70):

> "the conceptions of mental disorder in the public are the resultant of cross pressure: the opinions of experts, as expressed in mental health campaigns and 'serious' mass media programming, pulling people away from stereotypes, but with more frequent and visible mass media productions reinforcing the traditional stereotypes."

This polarization somewhat oversimplifies the complexities of the social distribution of knowledge and in the context of this study is empirically incorrect. In fact there are many similarities in the structure of ideal-typical knowledge and stereotypes - epileptics who commit crimes, who have abnormal personalities or who suffer from clinical illnesses correspond to public conceptions of epileptics as violent, lunatic or criminal.

Thus it is not that ideal-typical knowledge is correct and needs to be asserted over stereotypes through public education campaigns etc., but that stereotypes and ideal-types reinforce each other and contribute to a negative image of epilepsy within the social stock of knowledge. Those who advance ideal-typical knowledge, criminologists, psychiatrists and others, are themselves conditioned by the social expereiences of fellow members of their professions, who, like the general public, tend to encounter the 'worst' epileptics. Not only in their everyday dealing do these professionals encounter these epileptics but the theories generated by these encounters further reinforce and shape any future encounters. Therefore ideal-typical knowledge is unlikely to provide a balancing force to stereotypes but rather these two kinds of knowledge are likely to reinforce each other.

CONCLUSIONS

In the first chapter a number of answers to the question 'why do epileptics have trouble?' were discussed and it was suggested that these were inadequate in that they were essentially mono-causal. It was further suggested that a sociological account of the trouble that epileptics experience would need to consider not only the individual epileptic and the social and historical context in which he lives his life, but also the various meanings that have been negotiated and created for epilepsy and the effects that a variety of means of social control have had upon these meanings.

The major premise that guided this attempt to provide a sociological explanation was the idea that the trouble experienced by epileptics was not merely the consequence of a particular illness but rather that this trouble had a social basis. In order to further explicate this, epilepsy was conceptualized as deviance and in Chapter One some of the social aspects of this trouble were spelled out and some of the implications of this conceptualizing of epilepsy as deviance were discussed. Chapter Three then argued that deviance may be evaluated in a variety of different ways dependent upon the central or core values of the society concerned, and consequently that throughout history epilepsy has been regarded as religious, legal and most recently, medical deviation. It was shown however, that these changing evaluations were not simply the result of the march of progress but rather the consequence of the activities of groups and individuals acting sometimes in concert and sometimes in conflict. This theme was amplified in the following chapter where the activities of a number of moral entrepreneurs were discussed and it was shown how this activity in a number of spheres related to epilepsy was able to affect and influence social meanings and definitions.

Chapters Five and Six then examined the effects that these definitions had upon the individuals to whom the label epileptic was applied. It was demonstrated by reference to three different social situations that individuals respond in different ways to being epileptic and it was shown that the kind of personal resources an individual was able to utilize affected the implications that these labels had for the individual's sense of self. The final chapter then discussed the non-visible nature of epilepsy and showed how this was related to social control and ultimately to the social world inhabited by the epileptic.

Thus it is now possible to summarize the findings of this study and to answer the question posed at the outset. Epileptics have trouble because:

1) historical conceptions about the nature of their condition still exist in the form of stereotypes;

2) the non-visibility of the deviation for the vast majority of epileptics means that stereotypes are not effectively challenged;

3) when epilepsy does become a public issue, it usually involves the 'worst' epileptics and this serves to reinforce stereotypes;

4) ideal-typical knowledge does not provide a counter to stereotypes in that professionals often also deal with these 'worst' epileptics and the stereotypes and ideal-types compliment rather than compete with each other.

Therefore while not denying that epilepsy is an illness which is a particularly unfortunate and uncomfortable one for its sufferers, it is the hostile social world which forms the basis for the trouble which many epileptics experience. To use the terminology of this study, the social stock of knowledge about epilepsy is essentially a negative one and hence when epilepsy becomes a public issue, pre-existing knowledge upon which people draw to evaluate their present experiences provides an essentially hostile backdrop against which such experiences are evaluated. Thus this trouble is not simply related to the illness from which the epileptic suffers but also, and more importantly, as a consequence of this illness being regarded as deviance and treated as such.

Finally there are several general points which merit attention in passing and which might be said to challenge in part some of the 'domain assumptions' of current sociology. Firstly, individuals do respond selectively and situationally to a variety of labels and social processes and while this has been acknowledged, particularly at a theoretical level, research strategies which demonstrate these responses have often not been adequately developed. This study has been one such attempt to demonstrate and substantiate this point empirically. Secondly, those who are incarcerated in institutions of various kinds do not necessarily and inevitably become institutionalized but may develop their own mechanisms of response to counteract such pressures or tendencies. This study has identified and discussed some of these mechanisms. Finally, professional knowledge, or ideal-typical knowledge as it has been called in this study, does not necessarily have the reality determining effects that are sometimes assumed at a theoretical level (Berger and Luckman 1971) or indeed a substantive one (Scott 1969).

At least since Wright Mills (1959) drew attention to the relationship between private troubles and public issues, sociologists have been mindful of their responsibilities both to their subject and to those upon whom they practice their trade. Therefore it might be appropriate to end by drawing out some of the implications of this study for those involved professionally or personally in the management of epilepsy, the final question inevitably becomes, of what practical use is this research in alleviating some of the personal, social and societal problems associated with epilepsy? If nothing else what has gone before has hopefully demonstrated that such problems are complex and complicated ones and hence there are no simple solutions, no magic bullets. The line between epilepsy as illness and epilepsy as deviance is inevitably a difficult one to draw and consequently neither improved medical treatment nor social re-definition present the whole answer to the problem. Nonetheless the advancement of some practical suggestions is possible.

Firstly medical treatment should not proceed on the assumption that the solution to the problem is solely to prevent people from having fits. The major method of fit prevention through the prescription of anti-convulsant medication is itself a double-edged sword for all drugs produce side effects of one kind or another and often have long-term consequences. Further it is not just a matter of physical side effects, such as coarsening of the features, scarring from acne, endocrine dysfunction, osteomalacia and so on, but also more subjective ones such as emotional and intellectual dulling. This has posed a dilemma which has prompted one writer (Yule 1973.18) to ask:

> "Is it better to have a stabilized illiterate or a reader who frequently has fits?"

Secondly, political campaigns like those carried out in recent years by blacks, homosexuals and women, which attempt to achieve a status passage or a social re-definition are unlikely to be successful. Any attempt to organize such a compaign is unlikely to be able to mobilize sufficient support for epileptics are non-visible deviants who can and usually do 'pass' at every appropriate opportunity. However, more 'coming out' should be encouraged, both by ordinary epileptics and also by those famous people who are so afflicted but decline to reveal their illness to the world.

Thirdly, public health campaigns designed to disseminate information about epilepsy should continue and more self-help group activities should be encouraged. Further organizations working in these fields, along with other disability organizations, should actively campaign for anti-discrimination legislation, like the Equal Opportunities and Racial Discrimination Acts, to be placed on the statute books. This would enable epileptics (and other disabled people) to seek redress through the courts when they experienced discriminatory activities, particularly in the field of employment.

While none of these suggestions would solve the problems of epilepsy, the net result would be that the social visibility of epileptics would be substantially increased. To put it in the terms used in this study, increased visibility would allow typifications about epilepsy to be added to the social stock of knowledge rather than stereo- or ideal-typical knowledge. Increased visibility would thereby lead to a reduction in fear and prejudice associated with epilepsy and hopefully reduce the 'trouble' encountered by many epileptics.

In conclusion, as a study in interpretive sociology, hopefully some of the social and personal meanings associated with epilepsy have been grasped, though Evans (1953.167-8) poignantly captures the difficulties in translating such experiences into words:

> "Language is demanded by epilepsy, as by poetry, that simply does not exist; and no amount of agility can create it any more than tight tope walking or dancing can create wings. Language can, however, in the hands of a master, suggest that greater, wordless language within from which mental and spiritual discovery issues. It can suggest truths which are more certain for being inarticulate.... Neither is it to

devalue language to write of its inadequacy while believing in its suggestive powers: for those who contend that it is capable of holding all that exists within and without the mind, usually prove by their style of writing that they know least how to make it go furthest. Words, like money, cannot buy everything: and those who are richest in them, like wealthy people, know their limitations while those who are poorest believe that what they do not possess can do miracles."

FOOTNOTES

CHAPTER ONE

(1) For fuller discussion of these explanations, see Chapter 3 of this study.

(2) For fuller discussion see Bagley (1972.37-8).

(3) For an extension of this kind of explanation to all disability groups, see Safilios-Rothschild (1970.10-11).

(4) The work by Watson (1974) is a consideration of death, its meaning and our ability to recognize it. Specific references to epilepsy can be found within pages 80-83.

(5) For a table summarizing the results of most of the current studies, see Office of Health Economics publication "People with Epilepsy" (1973.9).

CHAPTER TWO

(1) There have been a number of studies of disability groups or illness behaviour which have utilized interpretive methods, e.g. Davis's (1963) study of polio victims, Cunningham's (1977) study of multiple sclerotics and Stimson and Webb's (1973) study of patients' referal patterns to doctors.

(2) For general discussion of the issue of care versus cure, see Illich (1975) and Loudon (1976). For specific implications of cure rather than care for the disabled, see Oliver (1978).

(3) Recently the question of whether Castanada did actually participate in this manner has been raised, or whether, in fact, the whole work, including Don Juan, is fiction (de Mille 1978).

(4) A recently published set of papers by a number of medical sociologists has attempted to overcome some of these problems by reporting on their own experiences of illness and hospitalization (Davis and Horobin Ed. 1977, esp. p 12-13).

(5) On a number of occasions I was asked for advice concerning such problems as medication, the relationship with a doctor or consultant, or the education of a child with epilepsy. Ethically the problem is, should the participant observer actually help with advice on particular courses of action or remain passive? In my case, I chose to offer help or advice whenever I felt competent to do so.

CHAPTER THREE

(1) Subsequently the Bishop and the girl's parents were found guilty of manslaughter on the grounds that they failed to procure the appropriate medical treatment for her illness. Thereby the dominance of medical definitions was re-affirmed.

(2) Part III accommodation refers to residential places which local authorities must provide for groups like the mentally ill, the retarded, the physically handicapped and the elderly, under the National Assistance Act, 1948.

(3) In the introduction to a book by Lombroso (1889), the Committee on Translations of the American Institute of Criminal Law and Criminology welcomes medicine into the study of crime with open arms:

> "Two centuries ago, while modern medical science was still young, medical practitioners proceeded upon two general assumptions: one as to the cause of disease, the other as to its treatment. As to the cause of disease, - disease was sent by the inscrutable will of God. No man could fathom that will, nor its arbitrary operation. As to the treatment of disease, there were believed to be a few remedial agents of universal efficacy. Calomel and blood-letting, for example, were two of the principal ones. A larger or smaller dose of calomel, a greater or less quantity of blood-letting, - this blindly indiscriminate mode of treatment was regarded as orthodox for all common varieties of ailment. And so his calomel pill and his blood-letting lancet were carried everywhere with him by the doctor.
>
> Nowadays, all this is past, in medical science. As to the causes of disease, we know that they are facts of nature,

> - various, but distinguishable by diagnosis and research, and more or less capable of prevention or control or counteraction. As to the treatment, we now know that there are various specific modes of treatment for specific causes or symptoms, and that the treatment must be adapted to the cause. In short, the individualization of disease, in cause and in treatment, is the dominant truth of modern medical science.
>
> The same truth is now known about crime; but the understanding and the application of it are just opening upon us. The old and still dominant thought is, as to cause, that a crime is caused by the inscrutable moral free will of the human being, doing or not doing the crime, just as it pleases; absolutely free in advance, at any moment of time, to choose or not to choose the criminal act, and therefore in itself the sole and ultimate cause of crime. As to treatment, there still are just two traditional measures, used in varying doses for all kinds of crime and all kinds of persons, - jail, or a fine (for death is now employed in rare cases only). But modern science, here as in medicine, recognizes that crime also (like disease) has natural causes. It need not be asserted for one moment that crime is a disease. But it does have natural causes, - that is, circumstances which work to produce it in a given case. And as to treatment, modern science recognizes that penal or remedial treatment cannot possibly be indiscriminate and machine-like, but must be adapted to the causes, and to the man as affected by those causes. Common sense and logic alike require, inevitably, that the moment we predicate a specific cause for an undesirable effect, the remedial treatment must be specifically adapted to that cause.
>
> Thus the great truth of the present and the future, for criminal science, is the individualization of penal treatment, - for that man, and for the cause of that man's crime."

(4) Since the middle of the nineteenth century some diseases like cholera, dysentry and typhoid have virtually disappeared and others like tuberculosis, scarlet fever, diphtheria and whooping cough have faded into insignificance. While many would argue that this is

directly attributable to the rise in modern medicine, others, most notably Illich (1975) feel it is factors like improved diet, better sanitary facilities and enhanced living conditions generally. Specifically with regard to epilepsy, there were no major medical advances between the 1850's when bromides were introduced as a treatment and the 1930's when the electroencephalograph machine was developed. However by the 1930's medicine had achieved dominance both in terms of the right to define epilepsy and to treat epileptics.

(5) For a detailed description of the way the Royal Colleges restricted career opportunities for young physicians, see Parry and Parry 1976. 136-43.

CHAPTER FOUR

(1) For discussion of doctors' inability to diagnose epilepsy, see Chapter Three.

(2) For just such a critical discussion, see Scott and Douglas (1972); Gove (1975); Safilios Rothschild (1970).

(3) Theoretical justification of this position is given by Wright (1960) in her discussion of referring to 'people with a disability' instead of 'disabled people'. According to her, the linguistic implications of the former indicate that the people are more important than the disability; whereas, in the latter, the reverse applies.

(4) For detailed discussion of how this diagnosis is achieved see West (1976).

(5) Hackney (1976) discusses the problem of the famous dead with regard to epilepsy and concludes:

> "To the 60,000 schoolchildren with epilepsy the famous dead are irrelevant. They need recognition in their own right now if the myth, prejudices and injustices of the past are not to be perpetuated."

(6) The only famous (?) individual that this writer has found to come out was an athlete called Alan Blinston who represented Great Britain in the Olympic Games of 1968. It is estimated that

there are 300,000 epileptics in this country, so it is reasonable to assume that there is a number of famous and important individuals among them. More recently a book has appeared (Blofeld 1978) alleging that Tony Greig, the former England cricket captain, suffers from epilepsy. It further suggests that a number of seemingly inexplicable decisions made by Greig when captain, might be related to the drugs he takes to control his fits. While these revelations received some National press and media coverage for a short while, the affair soon died down. Greig himself made no attempt to comment and neither 'came out' nor acted like a 'moral entrepreneur' in the sense that these terms are used in this study.

(7) For a history of the relationship between the two paradigms see Wiles (Wiles Ed. 1976) and Cohen (Rock and McIntosh Ed. 1974).

(8) According to figures used by Gunn (1977.28) the prevalence of epileptics in the general population was 4.5 per thousand and 9.0 per thousand in penal establishments.

(9) The most recently published report (HMSO 1976) includes no figures on the number of epileptics in prison and I have been unable to ascertain why this procedure of counting epileptics has been discontinued.

CHAPTER FIVE

(1) Many of the critics of labelling theory have assumed it to be more deterministic than it was ever intended as Becker points out in 2nd Ed. of 'Outsiders' (1971).

(2) This is based on a talk given by Shelagh McGovern, Action Groups Organizer, for the British Epilepsy Association, 10/10/76.

(3) A similar feeling of relief was identified by Cunningham (1977) in her study of people with multiple sclerosis.

(4) Since this aspect of the study was undertaken, regimes in Home Office institutions have become more relaxed; personal items such as radios and watches are often permitted and inmates are

able to grow their hair much longer. For discussion of relevance of personal possessions in a mental hospital - see Morgan and Cushing (1966).

(5) "Medicalization" in this context refers to the process of treating epileptics in a special way within the institution, including attending twice daily sick parades, being located in a special cell and on restricted labour. Medicalization as it is used generally in this work however refers to the conceptualization of certain behaviours as illness rather than wickedness or criminality or madness.

(6) In discussing this case with the social worker beforehand, she was at pains to point out how badly the operation had affected the patient and how sorry the surgeon was about such an unfortunate case. The patient however took exactly the opposite view and felt the operation was an unbridled success. As lobectomies have been under attack of late, I had approached the interview with some trepidation, expecting to be in the middle, between an angry patient and an unrepentant medical practitioner; ironically I was in between a satisfied patient and a repentant doctor.

(7) A number of sociologists have argued that modern industrial societies are characterized by role differentiation or specialization. That is, the individual is required to play his different roles, father, athlete, sociologist, etc., before different audiences.

(8) The significance of suicide and suicide attempts only became apparent as the work proceeded. Had I been starting the study again, a more systematic attempt would have been made to collect information in this area and relevant questions would have been built into the research design.

CHAPTER SIX

(1) Williams (Thorns Ed. 1976.116-7) has argued as follows:

> "It is, however, the argument (of this chapter) that certain problems concerning the fitting of theoretical intent to research strategies have remained unresolved in symbolic interactionism, largely as the result of

> the inability of symbolic interactionist researchers and methodologists to escape what is, from the standpoint of their own declared theoretical orientations, an inadequate and irrelevant model of theory and explanation for sociology".

He further suggests an unbridgeable gap between ontology and epistemology in symbolic interactionism. My position is less extreme; the problem is essentially a 'translation' one between theory and method. In both the developing of concepts and measurement techniques and the writing up of results, the social world inevitably takes on a more absolute look than interactionists either intend or believe. This occurs largely as a result of the translation of moving, processual social interactions into static immovable words upon the page. However I am not sure that the translation problem is any more resolvable than the unbridgeable gap.

(2) I am not suggesting that these individuals did what they said they did, but merely that the responses were in line with prevailing attitudes towards cars and women within the inmate culture; viz. women are sex objects and cars are used to get you where you want to go whoever they belong to.

(3) No attempt is made to distinguish between the various medical definitions of epilepsy (which are included in an appendix) but merely to point to factors which might make epilepsy an everyday problem for the individuals concerned.

(4) When visiting one of the local groups, I was told of two epileptic children who were in the same class at school. The school had been concerned that both children were a disruptive influence on the other children and wanted to send both children to a special school. One family in which the parents were professional people, read an article in the Guardian about a hospital which specializes in treating epileptic children and demanded that their GP get their son admitted. He was and remained about a month before returning to the school with his epilepsy well controlled by medication. The other couple had never heard of this particular hospital and only visited the doctor for repeat prescriptions. The first boy is happy in his original school - the second has been transferred to a school for educationally sub-normal.

(5) It is hardly surprising that the unemployment rate among all three groups varied little when this is seen against the National economic situation. With National unemployment at a high rate and two groups, the young and the disabled, faced with rates at least twice that of the National average, it is scarcely surprising that all adolescent epileptics find it extremely difficult to get work or to keep it once they have obtained it.

CHAPTER SEVEN

(1) 'Well controlled' in this context means that fits are effectively prevented in the majority of cases although the use of medication may produce a wide variety of unpleasant side effects. Richens (Laidlaw and Richens 1976.220-231) provides a detailed summary of the adverse effects of such medication.

(2) During the course of this study over three years I only managed to be in the right place at the right time once and actually witnessed a fit. However having worked for a number of years as a teacher in a penal establishment, I have witnessed many fits of all kinds. As far as I am aware, apart from these fits mentioned above, I have never otherwise witnessed an epileptic fit.

(3) During the course of this research I was told of many such incidents to the extent that I began to suspect that such incidents were myths, often repeated but rarely happening. Goffman (1963) has discussed the circulation of such myths among disabled people and in this country, the 'does he take sugar' syndrome is probably the best example. However, I was discussing my research on one occasion with a telephone operator who works largely on emergency calls and she confirmed that it is fairly common for an ambulance to be called for someone who has collapsed in the street only to be cancelled a few minutes later when the person has come round and said he was having a fit.

(4) According to the Report of the Work of the Prison Department 1975 (HMSO Cmnd.6523) there are 100 Medical Officers, 72 Visiting Psychotherapists, 92 Nursing Sisters, 37 State Enrolled Nurses and 674 Male Hospital Officers currently employed in penal establishments. These figures do not take into account the number of part-time doctors, sessional psychiatrists and agency nurses also employed on an ad hoc basis. Additionally, as Richards (1977)

shows, in 1946 the first psychologist was appointed and by 1975 there were 84 full-time, 2 part-time psychologists and 30 psychological testers also employed.

(5) Taylor and Cohen (1976) provide a general theoretical framework within which it is possible to conceptualize epileptic fits as 'momentary slips through the fabric' of everyday life.

(6) This question has occupied writers like Marx, Weber, Mainheim, Lukacs and Durkheim and these writings have been well summarized in a recent book (Hamilton 1974).

APPENDIX 'A'

1976

26th - 28th March. International Symposium - "Children with Epilepsy". Organized by the Park Hospital, Oxford and held at St. Catherine's College, Oxford.

1st May - 30th June. Three days a week spent at the Borstal Institution, conducting formal and informal interviews and acting as a participant observer.

28th May. Epilepsy Day - organized by British Epilepsy Association and held at Conference Centre in London.

29th September. Meeting - Sevenoaks Branch, local Action for Epilepsy Group.

4th October. Meeting - Secretary, Sevenoaks local Action for Epilepsy Group.

24th October. Meeting - Sevenoaks Branch, local Action for Epilepsy Group.

5th - 6th November. Meetings with a number of epileptics and their families living locally.

1977

26th January. Visit to Action Campaign for Epilepsy (ACE) a local charity workshop set up to provide craft and social activities for local epileptics.

4th April. Meeting with Secretary, North Kent branch of Action for Epilepsy Group.

26th April. Attended meeting of the Sevenoaks Action for Epilepsy Group.

12th May. Attended meeting of the North Kent branch of Action for Epilepsy Group.

25th May. Further visit to ACE, the charity workshop.

22nd June. Visit to British Epilepsy Association, Head Office.

1977

19th July. Meeting with Secretary, East London Action for Epilepsy Group and attendance at meetings of that group.

20th July. Meetings with Senior Registrar, Senior Social Worker and Warden of Hostel at London Hospital.

26th September. Visit to the Hostel for adolescents with epilepsy, attached to the London Hospital.

3rd October. Meetings with Paediatrician and Social Worker at London Hospital who are involved in a research project studying children with epilepsy.

3rd October. Attended meeting of the West London Action for Epilepsy Group.

6th October. Meeting with Secretary, Bromley Branch of Action for Epilepsy Group.

13th October. Attended meeting of Canterbury, Action for Epilepsy Group, and spoke about my research.

10th December. Attended Symposium on Epilepsy organized as part of British Epilepsy Association's education programme for doctors, at Postgraduate Medical Centre, Kent and Canterbury Hospital.

1978

13th January. Meeting with Assistant Secretary for Education, British Epilepsy Association.

19th January. Meeting with Senior Social Worker, London Hospital.

23rd January. Visit to Hostel for adolescents with epilepsy at the London Hospital.

30th March. Attended open meeting of Bromley Action for Epilepsy Group as guest speaker.

22nd May. Meeting with Senior Social Worker, London Hospital.

As well as these listed meetings, many formal and informal interviews were conducted, numerous telephone calls were made and received and many letters written and received. All in all, approximately 250 hours were spent in this kind of data collection.

APPENDIX 'B'

INFORMATION SHEET

NAME:...

ADDRESS:.......................................TEL:............

HOW CONTACTED:..

FAMILY: - Father

- Mother
- Sister/Brother
- Other

RESIDENCE:

SCHOOLS/EDUCATION:

EMPLOYMENT:

INTERESTS/HOBBIES:

OTHER:

APPENDIX 'C'

INTERVIEW SCHEDULE - EPILEPSY

Preamble - Mike Oliver - from UKC - studying disability, especially epilepsy - would you mind answering some questions - no connection with staff, institution or Home Office - complete confidentiality and anonymity - would you mind me taping interview?

EPILEPSY IN THE COMMUNITY

Topics

NATURAL HISTORY

- when was it noticed that something was wrong? when did fits begin?
- when was it officially diagnosed as epilepsy?
- what effects did this have on (a) you?
  (b) family?
  (c) friends?
  (d) others?

HOW HAS EPILEPSY AFFECTED YOUR LIFE?

- social relationships?
- education?
- employment?
- leisure?
- any other ways you can think of?

MEDICAL AND SOCIAL MANAGEMENT?

- how often do you see your doctor?
- what medication? what effects does it have?
- who do you tell? when?
  why?
  how?
- how do your family/friends feel about revealing your epilepsy?

MENTAL ILLNESS

- what about your other medical problems associated with your epilepsy?
- how come you were referred to this hospital?
- what about the hostel you are now living in?
- is there any connection between your epilepsy and mental illness/ psychiatric problems etc.?

VISIBILITY?

- how often do you have fits?
- have you ever had any fits in public?
- how did you feel about it?
- how do you think others felt about it?
- how does this affect your future actions to people/places etc.?

PHENOMENOLOGICAL EXPERIENCE OF FITS?

- what does it feel like to have a fit? before?
  after?
  during?
- any connections with anti-social behaviour?

END

- which do you feel is more important, cure or changing attitudes of others?
- any other matters which I may have missed?
- any questions you would like to ask me?

APPENDIX 'D'

International Classification of Epileptic Seizures.

Summary Form of Classification:

1. Partial seizures beginning locally:
   - A. With elementary symptomatology (motor, sensory or autonomic symptoms);
   - B. With complex symptomatology (automatism, ideational, psychosensory, psychomotor, etc., symptoms);
   - C. Generalized seizures with local onset. (N.B. All partial seizures can develop into generalized seizures, sometimes so rapidly that the local features may not be observable).

2. Generalized seizures or seizures without local onset:
   - A. Absence of differing form and duration, including "absence status". Absences may occur alone, or in combination with myoclonic jerks, or with increase or loss of postural tone, or with automatisms.
   - B. Generalized convulsive seizures, in the form of tonic, clonic, tonicoclonic and/or myoclonic attacks.

3. Unilateral or predominantly unilateral seizures (tonic and/or clonic) in children.

4. Erratic seizures in new-born.

5. Unclassified seizures. This includes all seizures which cannot be classified because of inadequate or incomplete data.

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