

X 818847X

061452

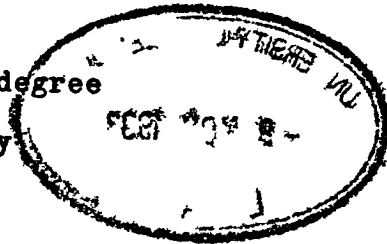
TOWARDS A SOCIAL THEORY  
OF MENTAL HANDICAP

by

Pamela Ann Abbott

Theses  
362.301  
ABB

A thesis submitted for the degree  
of Doctor of Philosophy  
of the Council for  
National Academic Awards



School of Social Sciences,  
Division of Sociology.  
Thames Polytechnic.

April, 1982.

## CONTENTS

	Page
List of Tables	v
Acknowledgements	v
Summary	vi
1 Introduction: society and mental handicap	1
Reference notes	5
2 Sociological work on mental handicap: a review of literature	6
1: Introduction	6
1.1 A note on terminology	7
2: The growth of sociological concern	11
2.1 The biological and the social	12
2.2 Epidemiological studies of mental handicap	14
2.3 The challenge to the biologic-al model	15
2.4 Theoretical developments in sociology	16
3: The deviancy approach	19
3.1 The mentally handicapped as part of the surplus population	19
3.2 Labelling theory	23
4: Sociological studies of social policy	34
4.1 Institutions for the mentally handicapped	35
4.2 Living in the community	37
4.3 Facilities in the community	41
5: The developing social perspective	43
Reference notes	46
3 A sociological assessment of the medical and psychometric models of mental handicap	49
1: Introduction	49
2: Pathology and social labelling	55
2.1 The medical model	57
2.2 The psychometric model	59
2.3 The normative role of intelligence testing	63
2.4 Intelligence tests and labelling	73

3:	Alternative psychological approaches to mental handicap	73
3.1	Behaviourism and behaviour modification	76
3.2	Social competence as the defining variable	78
3.3	Mental handicap as arrested or incomplete development	81
3.4	The work of Luria	84
3.5	Conclusion	89
4:	Conclusion: the need for a sociological approach	89
	Reference notes	91
4	The historical approach: the care and control of the mentally handicapped in pre-industrial society	93
1:	Introduction	93
1.1	The identification of the mentally handicapped	94
1.2	Historical attitudes towards deviants and their implications for the mentally handicapped	96
2:	The ancient world	99
2.1	Israel	99
2.2	Greece and Rome	100
2.3	Later developments	100
3:	Early and high/late middle ages	101
3.1	Feudal England	103
4:	The Reformation and the Enlightenment - sixteenth century to eighteenth century Europe	107
4.1	Changing attitudes to the mentally handicapped	107
4.2	The handling of the mentally handicapped	112
5:	Conclusion	116
	Reference notes	117
5	From deviants to developing people - the mentally handicapped in nineteenth century and twentieth century Britain	118
1:	Introduction	118
2:	The nineteenth century	119
2.1	Attempts to 'cure' the mentally handicapped	122
2.2	The emergence of the 'social problem group'	125
2.3	The handling of the mentally handicapped in nineteenth century England	130
3:	The early twentieth century - the eugenics scare	133
3.1	Science and the mentally handicapped	137

3.2	Social policy and the mentally handicapped in early twentieth century England	143
4:	Social policy and the mentally handicapped in the period after World War II	153
5:	Conclusion	156
	Reference notes	159
6	Current policies and priorities in the handling of the mentally handicapped	161
1:	Introduction	161
2:	Sweden and the normalization principle	163
3:	Britain: 'Better Services' - the reality	168
3.1	Decarceration	173
3.2	Community care in practice	176
4:	Why community care?	182
5:	Conclusion	192
	Reference notes	194
7	Community and individual attitudes towards mentally handicapped people	196
1:	Introduction	196
2:	The problem of community attitudes and the question of community care	200
3:	Empirical studies of community care and public attitudes in Britain and elsewhere	205
4:	Empirical research findings: attitudes, reactions and behaviour	217
4.1	The students	219
4.2	The village: reactions to a hostel being opened	223
4.3	The experiences of families with a mentally handicapped member	230
4.4	General conclusions from the empirical research	247
5:	Conclusion	249
	Reference notes	252
8	Conclusion: towards a social theory of mental handicap	254
1:	Introduction: psychology, sociology and social theory	254
2:	Medical and psychological perspectives on mental handicap	255



2.1	The inadequacies of individualistic explanations	256
2.2	The social functions of medical and psychometric models	260
2.3	The need for sociology	263
3:	The development of a sociological perspective	266
3.1	The labelling and surplus population approaches	266
3.2	The deviancy approach and mental handicap	269
3.3	Requirements in a sociology of mental handicap	279
4:	The importance of history in sociological approaches	283
4.1	Introduction	283
4.2	The development of mental handicap as a social problem	286
4.3	What can be learned from history	293
4.4	A comparative perspective	295
4.5	Conclusion	299
5:	Requirements in a social theory	300
5.1	Introduction	300
5.2	Going beyond a macro-sociological theory	301
5.3	The integration of experience	305
5.4	Future directions	307
	Reference notes	309
	References	312

## LIST OF TABLES

	Page
1: Simplified chart of the classificatory terms in use or recommended for use in England and Wales, 1913-1971	8
2: Equivalent English language terms used in mental handicap	9
3: Private mad-houses established by the end of the eighteenth century	114
4: List of institutions for the mentally subnormal in 1900	131
5: Total numbers of known adult defectives in England and Wales, 1929 and 1936/7	153
6: Mental Deficiency Authority provision, 1 January, 1936	153
7: Cost per inpatient week for selected services in different types of NHS hospital in England, 1969/1970 (in sterling)	154
8: Living conditions for 23,000 mentally handicapped people in Sweden in 1975	166
9: Revenue expenditure (England) on the mentally handicapped	174
10: Cost per inpatient week in different types of hospital (non-teaching), 1976/7	174
11: Cost per inpatient week of different services in different types of hospital as a percentage of costs in acute non-teaching hospitals, 1976/7	175
12: Scientific research, social policy and economic/political factors	302
13: Normalization and community care	304

## ACKNOWLEDGEMENTS

In the course of the preparation of this thesis I have received assistance from a number of people. I would like to express my gratitude to John Downing for the guidance he has given me at every stage, to Diana Adlam who made a number of helpful comments on an earlier draft, and to Roger Sapsford who not only encouraged me when I was tempted to give up but made a number of constructive criticisms and typed some of the final product. I am indebted to the families, students and villagers who so generously gave of their time and made the research especially enjoyable.

## SUMMARY

Traditionally, medicine and psychology have characterised mental handicap as an objectively diagnosable condition of the individual, in no way affected by society. Sociologists have reacted against this dominant paradigm by developing labelling-theory accounts of how individuals and state agencies can create and maintain the category of handicap by stigmatization and differential denial of social resources, and there have been attempts to see the category as a functional one for industrial societies. However, these ahistorical accounts do not add up to an adequate sociology of retardation.

Tracing the history of the condition, as the core of this thesis does, we find that it was not identified as a distinct 'social problem' in the West until the development of industrial capitalism. The key event appears to be the introduction of compulsory education, which presented to a state committed to universal education a group of 'ineducable' children. The reactions to this 'discovery', however, must be construed as part of a whole culture and ideology, and the thesis traces the parallel development of scientific conceptualisations, popular attitudes and treatment provisions in the light of economic relations. (The historical analysis necessarily confounds industrialisation with the growth of capitalism, but limited cross-cultural material suggests the latter as the crucial variable.) The main aim of the thesis is to illustrate the importance of history for sociological theory.

The thesis also considers the necessary role of micro-sociology and psychology in building a social theory of mental handicap which accounts for the experience of individuals as well as the structures of society, and Chapter 7 describes three studies illustrative of what could be done. However, micro-sociology cannot provide a sociological understanding without a historically informed macro-sociology within which to locate it.

## CHAPTER 1

### INTRODUCTION: SOCIETY AND MENTAL HANDICAP

The Mental Health Act 1959<sup>1</sup> defined mental subnormality as a state of "arrested or incomplete development of mind". Two sub-categories were identified:

(a) severe subnormality: "a state of arrested or incomplete development of mind which includes subnormality of intelligence and is of such a nature or degree that the patient is incapable of living an independent life or of guarding himself against serious exploitation, or will be so incapable when of an age to do so".

(b) subnormality: "a state of arrested or incomplete development of mind (not amounting to severe subnormality) which includes subnormality of intelligence and is of a nature or degree which requires or is susceptible to medical treatment or other special care or training of the patient".

This study is concerned with a single major question - how can sociology contribute to our understanding of mental subnormality? (For a critical discussion of the existing sociological literature see section 2 of Chapter 2). The main argument of the thesis is that the dominant social-scientific model of mental handicap is inadequate. In order to understand the role and status of mentally handicapped people in capitalist society, and the role of social policy within the problem of mental handicap, it is necessary to develop an historical and macro-sociological perspective on these questions. At the same time I argue that this must be complemented by a micro-sociological examination of attitudes towards mentally handicapped people, at the individual and community level. It is my intention to demonstrate that the existing sociological literature does not provide a theoretical framework that enables us to understand mental subnormality as a social phenomenon.

Currently available studies are dominated by a medical model which has been taken over by psychologists working within the main-line tradition of clinical psychometry, and this informs most current micro-sociological research in the area - which is either epidemiological, examining the problems encountered by families with a mentally handicapped member, or looks at the 'labelling' consequences of diagnosis but is static and uncritical. (See Chapter 2 Section II; Chapter 8 offers a more critical discussion). Separate from this is the study of changing provision for the care of mentally handicapped people, which has been mainly concerned with the effects of liberal pressure groups on government and the growing awareness of the harm which incarceration in residential institutions can cause.

It is my contention that we can better understand both how the mentally handicapped 'achieved' their current status and why governments have adopted different policies at different times if we adopt a historical perspective which centres on changing socio-economic circumstances. Thus the development of a sociological perspective will initially involve a historical and comparative study of individuals whose mental capacities mark them as 'outsiders' unable adequately to fulfil societal expectations of 'normal' behaviour. Consequently the role/status of mentally handicapped people will be examined in the light of historical changes in attitudes towards and social policy provision for the mentally handicapped. Following Scull, I intend to:-

"... develop an historically informed macro-sociological perspective on the interrelationship between deviance, control, structure, and the nature of the wider social system of which they are both a part and an essential support"

and to

"... demonstrate the superiority of explanations which focus directly on the complex dialectical interplay between transformations in the social control apparatus (and thus in the shapes and forms of deviance) and change in the wider social system." 2

Thus a major objective of the study will be to examine the relationship between different socio-economic conditions, attitudes towards mentally handicapped people and social policy in this area. This will enable us to understand the relationship between societal and individual attitudes towards the mentally handicapped, social policy priorities and the dominant ideology of a society.

A subsidiary purpose and complementary aspect of the thesis is a micro-sociological examination of attitudes towards mentally handicapped people.

Here I contend that the 'problem' of the mentally handicapped, at least in Western industrial societies, is in fact two different problems:-

(a) There is the mainly macro-sociological problem of the treatment, care or placement of the mentally handicapped individual by and in a welfare-state society which has decreed that every 'normal' citizen shall be educated to a certain minimum standard and be expected to maintain himself or herself at a certain level of health and well-being by obtaining paid employment, at a certain minimum standard of competence, and which therefore finds itself with the responsibility for those who fall short of this level in any respect.

(b) Secondly there is the mainly micro-sociological problem of the attitudes of individuals and local communities to mentally handicapped people - to some extent a problem for themselves, particularly in areas where hostels are to be set up, but in many ways even more a problem for their families, who suffer not only from actual prejudice, but also from an expectation of prejudice fostered in them by cultural attitudes to mentally handicapped people, which they themselves frequently share.

An interactionist perspective at the micro-level is more or less adequate for understanding the individual and family problem, though macro-level historical processes

shape our shared attitudes. However, in order to understand social policy towards and public provision made for the mentally handicapped, only a historically based sociological perspective can fully cast light on how the problems arise, though micro-level sociological analysis is still of relevance because the attitudes and experiences of individuals are shaped by and do feed back into their culture. In any case we have not fully understood a phenomenon, as sociologists, unless we can tackle it at both levels.

"What social science is properly about is the human variety, which consists of all the social worlds in which men have lived, are living, and might live ... this requires that our work be continuously and closely related to the level of historical reality - and to the meanings of this reality for individual men and women".<sup>3</sup>

In the next two chapters I look at currently available sociological research and at the medical and psychological models of mental subnormality which inform it, and point out what I see as shortcomings. The following three chapters demonstrate what can be gained from the historical approach to the understanding of mental handicap as a social phenomenon. Chapter 4 covers its sketchy treatment in pre-industrial society. In Chapter 5 I discuss the changes that occurred in the nineteenth century with the growth of compulsory schooling and developments in the twentieth century leading up (in Chapter 6) to an evaluation of what are currently regarded as priorities in the area of mental handicap care and provision. Chapter 7 is a complementary micro-analysis, examining attitudes towards the mentally handicapped at an individual and community level; it contains a report of three small and illustrative ethnographic (qualitative) studies undertaken by the author, as well as a review of the research literature. Finally, Chapter 8 attempts to synthesise the various strands of the earlier discussion into a viable sociology of mental handicap.

It is important for me to point out that social policy issues are not a major focus of this thesis. I do not see it as the role of the sociologist to engage in social engineering. However, I think I succeed in demonstrating that much current discussion and research by sociologists, and indeed psychologists, in the field of mental handicap, start from ill-theorised premises and is therefore doomed to produce unsatisfactory solutions.

#### REFERENCE NOTES, CHAPTER ONE

- 1: Since the 1959 Mental Health Act alternative 'official' definitions of mental handicap have been put forward which suggest that severe mental handicap and mild mental handicap should be regarded as different points along the same continuum and that behavioural as well as intellectual factors should be stressed. The extent to which this has resulted in changes in the way they are handled is discussed in Chapters 5 and 6. The most recent definition is the one contained in the Mental Health (Amendment) Bill 1982, introduced in the House of Lords in November 1981:

To subnormality or severe subnormality there shall be substituted references to mental impairment or severe mental impairment....

'Severe mental impairment' means a state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned....

'Mental impairment' means a state of arrested or incomplete development of mind (not amounting to severe mental impairment) which includes significant impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned.

- 2: Scull, 1977 P11

- 3: Mills, 1959 P146 (Penguin Ed. 1970)



## CHAPTER 2

### SOCIOLOGICAL WORK ON MENTAL HANDICAP: A REVIEW OF LITERATURE

#### 1. Introduction

This chapter reviews briefly a selection of the rather scanty work undertaken by sociologists in the area of mental handicap. The next chapter critically discusses the dominant clinical and psychometric models which have not only provided the framework for most psychological and sociological research in the area, but also the underpinning to social welfare provisions for the mentally handicapped in Britain and other Western industrial societies. Together these two evaluations demonstrate the lack of an adequate sociological framework within which we can understand the role and status of mentally handicapped people - an essential preliminary to empirical research in the field.

One of the initial puzzles in studying mental handicap is the widely varying terminology, historically and presently, between Britain and the United States. It is usual, now to distinguish between two classes - 'severe' subnormality and a 'mild' or 'high-grade' variety.<sup>1</sup> Consequently, as a preliminary to discussing the sociological contribution to date it will be necessary to clarify the terminology used (see section 1.1 below). Thereafter I look at the growth of concern with mental handicap among sociologists stimulated by: (i) the results of epidemiological studies which demonstrated a markedly unequal distribution of mild mental handicap among the social classes, (ii) the growing dissatisfaction with biological and psychological models of deviance, and (iii) the development of dynamic, interpretive perspectives in sociology. Section 3 of the chapter evaluates *theoretical formulations of the problem* of the mentally handicapped and empirical research deriving from these. Finally section 4 reviews sociological

research into social policy towards the mentally handicapped, which demonstrates the inadequacies of current provision for care and re-education but lacks the theoretical framework to offer much in the way of a sociological understanding of the phenomenon itself.

### 1.1 A Note on Terminology

It is necessary to stress at the outset that the terminology used in the field of mental handicap is very confused. There is no agreed international terminology, and words no longer used officially are commonly retained in everyday speech.

The origins of the words commonly used to refer to mentally handicapped people, at least until recently (see Table 2), are in the languages of ancient Greece and Rome. The word 'idiot' is of Greek origin and 'imbecile' of Roman, but it is more recently that they became terms specifically referring to mentally handicapped people. Idiot originally meant a private person, or one without a public office. It suggested a person set apart from society with the connotation of a non- or extra-social individual, a person who lived in a world of his own, more or less outside society. In English law, from the Middle Ages until the end of the nineteenth century, 'idiot' referred to a person of unsound mind, of whatever description: a person incapable of caring for himself or his property or of fulfilling the ordinary duties required of him by the state. (See chapters 4 and 5 for a more detailed historical analysis). Imbecile, in Ancient Rome, was used to describe a person with any form of disability. It was only much later that it came to have a more restricted meaning - referring to severely subnormal people. Words now commonly translated as 'Fool' were used in Ancient Greece and Rome. 'Fool' was used to describe people we would now refer to as mentally handicapped as well as those who were mentally ill. A 'fool' was frequently 'kept' by the wealthy for the amusement and entertainment of the household.

Table 1: Simplified Chart of the Classificatory terms  
in use or recommended for use in England and  
Wales, 1913-1971<sup>1a</sup>

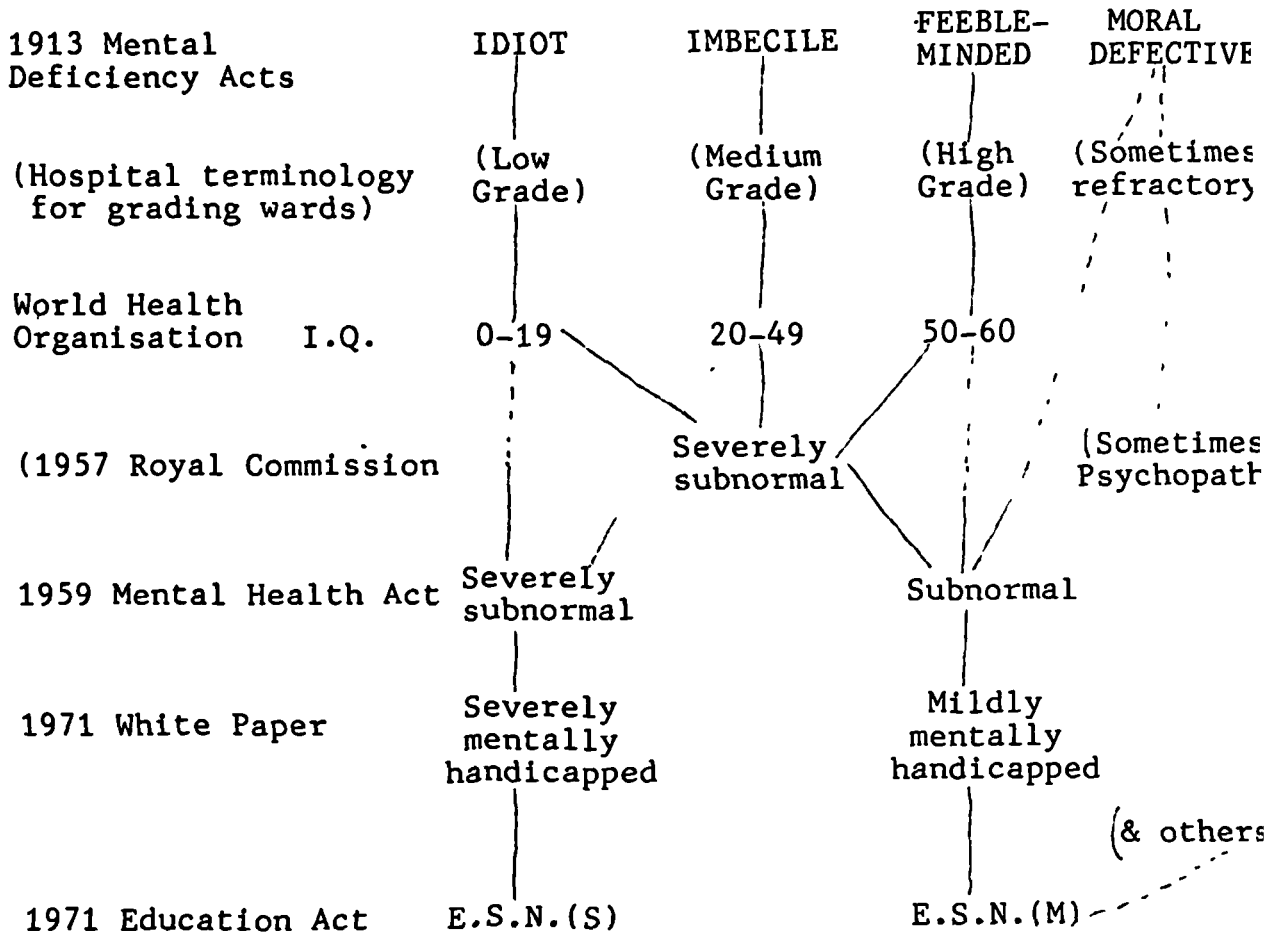


Table 2: Equivalent English Language terms used in  
Mental Handicap<sup>2</sup>

General Terms	Categories	I:Q. Equivalent
Mentally handicapped	High Grade	50-70
	Subnormal	
	Feebleminded	
	Moron	
	Mildly retarded	
Mentally retarded	E.S.N.(M)	
Mentally defective	Medium Grade	25-49
	Moderately retarded	
Mentally subnormal	Imbecile	
	E.S.N.(S)	
	Low Grade	0-24
	Severely retarded	
	Idiot	
	Ineducable	

Two more recently coined terms that have been used for certain mentally handicapped people are 'feeble-minded', and 'moron', a term invented by Goddard in the early part of this century to refer to the mildly subnormal.

In England and Wales prior to the 1959 Mental Health Act the terms 'idiot', 'imbecile' and 'feeble-minded' were used to refer to degrees of handicap - the severely, the moderately and the mildly subnormal respectively. The official terminology since 1959 has been 'mental handicap', as a generic term, with 'subnormal' and 'severely subnormal' being the sub-categories. Since the 1972 Education Act children (under 16 yrs) have been referred to as 'Educationally subnormal (mild)' and 'Educationally subnormal (severe)' - the latter being those previously referred to as 'trainable' with the connotation that they were ineducable. (See Table 1).

In the United States, prior to the acceptance of the terminology recommended by the American Association on Mental Deficiency, the term 'moron' was used as an equivalent for the term 'feeble-minded', and 'feeble-minded' itself was used to refer to all mentally handicapped people. Now the term 'mentally retarded' is in general use, having replaced 'mentally deficient'. (Table 2 summarises the main terms that have been and are used to refer to mentally handicapped people.)

In this thesis I intend, in general, to use the English terminology - 'mental handicap' and 'mental subnormality' and 'mild' and 'severe' to distinguish between what is usually regarded as the two major categories.

The important point to stress, and a significant fact, is that none of this terminology is neutral. Indeed, it is only within the last ten years that it has become normal practice when referring to mentally handicapped people to recognise that they are indeed 'people' - part

of the human race.<sup>2a</sup> Furthermore, all the words in common use convey a notion of diminished status and of stigmatization and imply that the labelled person is less than 'normal', not fully human. They provide stereotypical images - ones that carry with them the notion of certain undesirable characteristics and the lack of other more desirable ones. (See section 3 below). This is reflected in and reinforced by the way in which words like 'moron', 'idiot' and 'fool' are used as terms of abuse and derision. Indeed, there is no available neutral terminology in the field, as is the case with the terminology used to discuss other deviant and minority groups.

## 2. The Growth of Sociological Concern

As I have already stressed, research in the field of mental handicap has been dominated by biological and psychological models. This is because, at least until recently, the 'cause' of the handicap has been seen as inherent in the individual and therefore of little interest to sociologists as such, except for the evaluation of social policy objectives and alternative forms of care within a clinical perspective. (Chapters 3 and 8 develop these points more comprehensively). This evaluative research, which has only developed in the last thirty years, has in general concentrated on studying one stage or another in a mentally handicapped person's life-cycle, pointing to the problems experienced by them, by their parents, and by the community in 'coping' with them and their handicap, and pointing also to the inadequacies and 'failings' of the public welfare services which process and provide care for them.

However, in the same period, a few sociologists have attempted to step outside the clinical model and develop sociological perspectives. This growth in interest has been stimulated by three separate but related developments. Firstly, epidemiological research has discovered that cases of mild mental subnormality are almost exclusively

found within the manual working class. Secondly, biological models of human development have been challenged with the development of theories that stress the importance of environmental factors in the development of intelligence. Thirdly, there have also been theoretical developments in sociology and especially in the area of deviancy theory. Before briefly reviewing these developments I will clarify the important distinctions made between biological and social (genetically inherited and environmental) causes of mental handicap.

## 2.1 The Biological and the Social

The categorization of the mentally handicapped into sub-categories is usually based on psychometric tests, although social competence - that is, the ability to cope adequately in the community as judged by 'experts' - is also a relevant factor. Categorization of this type is mainly for administrative convenience, for determining the placement of the people ascertained as mentally handicapped.

A different method of classifying mentally handicapped people, and one that has especially stimulated sociological interest, is one based on assumed aetiology. It has become an axiomatic (but not totally unquestioned) fact that there are two main types of mentally handicapped people: those whose mental subnormality is the result of specific biological factors (even if these cannot be detected) and those whose mental subnormality results from the inheritance of 'inferior' genes and/or environmental influences - frequently referred to as 'subcultural type'. Indeed, Sar<sup>a</sup>son and Gladwin<sup>3</sup> have suggested that we should use different terminology when referring to these two groups - the former should be called the mentally defective and the latter the mentally retarded.

The argument for distinguishing between the two groups is reinforced by the widely accepted assumption that while all societies recognise and react to the

severely mentally handicapped, it is only with industrialization that the mildly mentally handicapped are seen as different and managed as deviants.

This development appears to be closely related to the introduction of mass schooling - the majority of the mildly handicapped are labelled as educationally sub-normal while at school, but once the period of formal education is completed they apparently merge with the rest of the population. (This offers the possibility for sociological analysis of labelling and this is developed in section 3.2 below).

However, the argument that mild subnormality is socially and historically relative has not gone unchallenged. Edgerton<sup>4</sup>, in a review of the limited anthropological research, argues that 'stupidity' as opposed to more severe mental handicap is recognised in the vast majority of societies - non-industrial as well as industrial. As Ryan<sup>5</sup> has pointed out:

"Although there is scope for much greater cultural relativity than is usually appreciated, especially as regards how the stupid are treated, this does not mean that there will be no stupid people in an ideal society, nor that differences in competence will cease to be socially meaningful. Every society for which there is information has its inept, however variously that is defined. Societies vary, however, in what skills are required and what social support there is for those who, for whatever reason, cannot acquire any such skills. Trying to understand how our society has produced the ones it has, both as regards the number defined as subnormal, and the stigma, and the actual conditions of existence of so many people ..."

It would seem to me that the important consideration is not that 'stupidity' (mild mental handicap) is 'discovered' or at least comes to be regarded as a social problem at the time when a society industrializes, but that what is regarded as 'incompetence' is to some extent culturally relative. 'Subnormality' is a social category, and in fundamentally important ways the social problem of mental handicap is created by



a society as a consequence of the demands and expectations placed on individuals. While it is probably correct to say that a considerable number of those labelled as mentally handicapped in Western industrial societies could function quite adequately in less complex and demanding social systems, this does not mean that in some ways they are not 'really' differentially equipped.

## 2.2 Epidemiological studies of Mental Handicap

Epidemiological studies provide information on the determinants and distribution of mental subnormality in the population. Although, as Morris<sup>6</sup> has pointed out, epidemiological research itself does not require the specialised skills of the sociologist, the starting point for much sociological research in mental handicap has been epidemiological.

Sociologists have become interested in the epidemiological finding that, while organically caused mental handicap is fairly normally distributed throughout all social classes, mild non-organic subnormality is concentrated in the manual working class.<sup>7</sup>

"... in an industrial society, parents of severely subnormal children are evenly distributed among all the social strata in the society, while those of mild subnormal subjects come predominantly from the lower social classes ... mild subnormality ... is virtually confined to people in lower social categories."<sup>8</sup>

This social class bias has been shown to exist by a number of studies in both Britain and the United States.<sup>8a</sup> In addition to this 'discovery', epidemiological studies have revealed a number of other interesting factors for sociologists: for example, that minority and working class children are over-represented in the mildly mentally handicapped category; children who come from disrupted homes and exhibit problem behaviour are more likely to be labelled than those from normal homes or with 'normal' behaviour; the school is the main labelling agency for the mildly subnormal - diagnosed subnormality is highest in

the school years, and lower amongst the pre-school and adult populations.

These findings, as well as reinforcing the arguments for distinguishing between biological and social categories of mental handicap, have provided an impetus and starting point for sociological research. The sociological input has been in attempting to explain the 'causes' of these statistical differences, and to a limited extent in questioning the validity and reliability of the findings. However, the only major empirical sociological research which has attempted to account for and explain the epidemiological findings on the racial and social class distribution of mild mental subnormality in Western industrial society is a small study by Mercer in the United States. (This study is briefly reviewed in section 3.3 below).

### 2.3 The Challenge to the Biological Model

A further factor which encouraged the development of sociological interest was a questioning of the assumption that mental handicap was caused *solely by biological/genetic factors* and was inherent in the individual. In the late nineteenth and early twentieth century degeneracy and eugenic theories had become dominant and it was accepted that mental handicap (when there was no obvious cause) was the result of the inheritance of 'low intelligence' genes. However, by the 1950's environmental, cultural and social factors began to be regarded as increasingly important in 'causing' mental handicap, especially mild subnormality.

An important theoretical statement of this development is to be found in a review article by Sar<sup>a</sup>son and Gladwin<sup>9</sup> published in 1958 - one of the first systematic attempts to establish the social aspects of mental handicap.<sup>9a</sup> The article critically reviews and evaluates the existing, mainly psychological research, as well as suggesting possible directions for future investigation.

They argue that mental handicap is a social and cultural problem in addition to being a biological and psychological one. Attitudes towards mentally handicapped people, they suggest, are culturally determined and are based on criteria of what is and what is not socially acceptable behaviour. This is demonstrated, they argue, by the fact that in Western society mental subnormality is a large social problem, statistically and emotionally, while in most non-European societies it is inconsequential and confined to cases of severe pathological defect.

As a result of their analysis of the literature they conclude: (i) that mental handicap is culturally relative; (ii) that intelligence tests are culturally biased, testing only the ability to deal with the types of problem solving tasks set in schools, and (iii) that a low I.Q. does not reflect the future intellectual or social potential of children. They therefore suggest that future research must be concerned with at least two distinct but related areas: the aetiology of subnormality - both individual and environmental - and the ways in which society defines, processes, reacts to, and attempts to cope with those it labels as mentally handicapped.

The importance of this article lies not in its conclusions or indeed in all its arguments<sup>10</sup>, but in the issues it raises and in the suggested directions for future research. Indeed, the major theoretical and empirical development in the sociology of mental handicap has been concerned with the labelling process.

#### 2.4 Theoretical Developments in Sociology

Research by sociologists in the field of mental handicap has grown since the 1950's, when it began to be realised that they could contribute to an understanding of mental handicap as a social phenomenon and critically evaluate welfare provision. However, few sociologists have seriously challenged the dominant medical models and attempted to develop sociological perspectives, although theoretical developments within the discipline have led

some researchers to believe that there is a possibility of doing so.

In the early 1950's Mendeholm<sup>11</sup> and Perry<sup>12</sup> published separate articles pointing to the need for sociological research to supplement the existing psychological and medical research. This concern has echoed down the years since, especially in the United States, where there is apparently far more research into all aspects of mental handicap than in Britain.

Mendeholm<sup>13</sup> suggested three areas into which sociologists could research: the attitudes of the public towards mentally handicapped people; the problems faced by families with a mentally handicapped person as a member; and the effectiveness of community care programmes for the mentally handicapped. In 1964 Kurtz<sup>14</sup> argued that sociological research could help to bring about a more social perspective on the understanding of mental handicap. Sociologists should concentrate on epidemiological studies, research into attitudes towards mentally handicapped people, and research into the ways in which mentally handicapped people interact with non-handicapped people. Ten years later Rowitz<sup>15</sup> was still stressing the same need:

Sociological research should be concerned with epidemiological studies of service use, patterns in different service dealing systems and the family in the community.

The main role for sociologists has, then, been perceived as one of evaluating social policy provisions and has accepted the proposition that

Mental retardation is a clinical problem susceptible to sociological analysis.<sup>16</sup>

The inadequacies of this approach and the need for sociologists to step outside of the medical perspective has been acknowledged by a few sociologists<sup>17</sup> but as Booth<sup>18</sup> has stressed:

Few sociologists have tried to make sense of mental handicap. For the most part they have been content to study one stage or another in a retarded person's career through life without attempting to step outside the meaning attributed to subnormality by clinical definitions.

The major exceptions are researchers who have examined mental handicap within what I will broadly refer to as a deviancy perspective; in the majority of cases they have been specifically concerned with the mildly subnormal. They have worked within a phenomenological framework and been heavily influenced by 'underdog' perspectives.

Thus the development within sociology, in the United States in the 1950's and in Britain in the 1960's, of dynamic, interpretative models of human behaviour, and more specifically Symbolic Interactionism, stimulated Verstehen studies of mentally handicapped people as 'underdogs'. Studies have subsequently been made of the way in which society 'creates', labels and structures the career of the mentally subnormal. These studies have also been concerned to explain the concentration of the mildly subnormal in racial minority groups and the manual working class and to stress the inadequacies of clinical definitions.

In Chapter 8 I will discuss the contribution that these studies, theoretical and empirical, can make to the development of a sociological perspective on mental handicap. In the rest of this chapter I intend to review the literature which I consider to have contributed to our understanding of mental subnormality as a social phenomenon and which appears to suggest possible approaches or insights for the development of a sociological framework within which to reach an understanding of mental handicap.

### 3. The Deviancy Approach

While the extent to which the mentally handicapped should be regarded as deviant can be questioned (and I discuss this point more fully in Chapter 8), nevertheless the main theoretical developments and bulk of empirical research by sociologists have been heavily influenced by the new deviancy theories, and especially labelling theory. The one recent theoretical contribution to the understanding of the role/status of the mentally subnormal not within this tradition is nevertheless heavily influenced by the ecological research of the Chicago School and functionalist sub-cultural theories and concludes that the mentally handicapped, especially the mildly subnormal, are part of the surplus population-members of the 'culture of poverty'.

#### 3.1 The Mentally Handicapped as part of the surplus population.

Farber<sup>19</sup>, within a broadly functionalist perspective, attempts to develop a sociological framework within which to understand the role/status of mentally handicapped people in industrial society. The three-fold aim of his study is (i) to indicate how the retarded play an important role in maintaining the existing social structure, (ii) to analyse previous social research, and (iii) to suggest avenues for further investigation.

The main thesis of Farber's study, and the one that is of interest for the development of a sociological perspective, is that the mentally handicapped, as part of the surplus population, play an important role in maintaining the existing social structure - that is, they are functional to the maintenance of the system. The marginal population is comprised of the old, the sick, the disabled and the culturally deprived as well as the mentally handicapped - in short, all those groups of people that can be seen as 'surplus' to the smooth economic functioning of industrial society. It arises out of organisational needs; organisations attempt to maximise

efficiency and output, and these groups are seen as being incapable of 'adequately' performing productive tasks. However, this population is regarded as functional to society in three ways: they generate a number of specialised institutions which create jobs; they make possible the effective operation of the basic social institutions; and they aid in the perpetuation of the existing system of social stratification.<sup>20</sup>

The mentally handicapped become part of the surplus population because of their incompetence and as a result of being labelled deviant. But the very presence of a surplus population 'creates' the need to justify the classification of groups of people as 'surplus' - in the case of the mentally handicapped as being intellectually incapable of adequately performing adult social roles, and to develop procedures for identifying and classifying them - in the case of the mentally handicapped, psychometric tests. Farber suggests, however, that the two factors generally assumed to determine the social life chances of mentally handicapped people, the condition itself and/or the consequences of being officially identified, are only contributory factors and that:

"Actually, this situation probably emerges from the 'need' for a labour surplus in a production system based on rational placement of personnel. This surplus is especially apparent at the unskilled, semi-skilled and service occupational levels, which are sensitive to fluctuations in demand in production. For these slots, there are always more candidates in the population than there are slots available. This surplus was present in the early stages of industrialization, and with the growth of automation, is even more prevalent today."<sup>21</sup>

Drawing on the epidemiological studies and arguing that intellectual development is the outcome of a complex interaction of genetic, physiological and socio-cultural factors, he points to the fact that mild subnormality is most frequently associated with other characteristics which can operate to prevent incorporation in the dominant

culture. These include coming from an ethnic minority group, from a low socio-economic background and/or from an unstable family. Indeed, these other social handicaps can affect life chances as much as being labelled mildly subnormal, as other individuals from these backgrounds, who have never been labelled mentally handicapped, also have a tendency to become part of the surplus population. Farber argues that this is because certain groups in society are isolated from the dominant culture and consequently only learn the 'private' culture of their own group - a 'culture of poverty'. Secluded from the major institutions of the 'public culture', even the genetically and physiologically capable fail to develop norms, attitudes and values essential for active participation in the dominant culture. This sub-culture becomes self-perpetuating, because the children of those who have 'failed' to learn the dominant culture are socialized into the alternative culture - the culture of poverty.

Furthermore, Farber argues that it is because of the organizational need, in modern industrial societies, for a surplus population, that inadequate resources have been allocated to the alleviation of the problem. Thus,

... to maximize efficiency the organisation of modern society demands a surplus population in order that its selection procedures may work. The techniques that modern society has developed for dealing with the mentally handicapped have been insufficient, probably because society is motivated to maintaining them as a surplus population.<sup>21a</sup>

Farber suggests that regarding the mentally handicapped as part of a surplus population has the advantage of both incorporating and superseding the two dominant perspectives on mental handicap. During the latter part of the nineteenth century and the early part of the twentieth century the mentally handicapped came to be regarded as deviant in a biological sense, and mental



subnormality was assumed to be closely associated with other forms of deviant behaviour, especially criminality. As a result the mentally handicapped were seen as a 'genetic threat' to the rest of society, and a group from whom society needed to be protected. More recently, Farber suggests, the mentally handicapped have been cast in a sick role and this has led to a concentration of resources into research on possible 'causes' of mental handicap and attempts to 'treat' the subnormal. Both these approaches concentrate attention on the individual and his assumed pathology; Farber points to the importance of social factors in the 'creation' and 'sustaining' of the mentally handicapped as outsiders in industrial societies, and suggests that they are likely to remain 'outsiders' while the need for a surplus population continues to exist.

This analysis does represent an important step forward, but there are a number of theoretical and practical problems with it. One can level the same criticisms against Farber's approach as against the functionalist approach to other social problems: its assumption of a shared set of norms and values, the ignoring of conflict and power, an ahistorical approach and a taking of the social system as a given in which the members of society are required to operate the role/statuses connected with it. Thus his analysis ignores the class nature of capitalist societies, and the possibility that deviance, including mental handicap, is only functional within a particular ideological framework which itself contributes to the maintenance of the socio-economic system.

Furthermore, his acceptance of the 'culture of poverty' thesis means that he 'blames' the marginal population for their outsider position and does not examine the way in which structural inequalities perpetuate poverty, rather than the attitudes and values of the poor.

As a consequence of this he confuses a 'rejected population' with a 'marginal population'. The latter can be seen as a group who can be brought into productive work when they are needed and forced into unemployment when they are no longer required. Migrant workers fulfil this role in some capitalist societies, and possibly women. However, in industrial societies the majority of the mentally handicapped as well as the old and the sick have been rejected - as groups incapable of adequately performing work tasks. The final problem with Farber's analysis is related to this. He appears to argue that all the mentally handicapped are part of the 'surplus' population. In one sense this may well be correct, but the severely handicapped are not only currently 'surplus' to requirements but also have not been able to perform economic tasks in less complex societies. It may well be correct that the way in which our society cares for the mentally handicapped and our attitudes towards them are shaped by their inability adequately to perform productive economic roles, but to lump the mentally handicapped together with other marginal groups does not appear to provide an adequate explanation. This is at least partly accounted for because Farber's account is ahistorical. We need to ask when the mentally handicapped first became labelled as outsiders and managed as deviants, who has the power to label and in whose interest it is to label them as deviant.

### 3.2 Labelling Theory

Much recent deviancy research has been centrally concerned with three foci: deviancy is seen as a subjective reality, as a process and as a consequence of societal and self-reactions. Attention has shifted from looking at the 'causes' of deviant behaviour, and moved to looking at the way in which individuals are labelled as deviant and their subsequent careers. Sociologists have been able, within this perspective, to look at who defines certain behaviour as subnormal and at the subsequent 'career' of the officially labelled person, and to try to

understand what it is like to be 'incompetent' and/or to be a parent of a mentally handicapped person.<sup>21b</sup>

#### Dexter: A theoretical framework

Dexter<sup>22</sup>, over a period of some thirty years, has in a number of articles and a book attempted to develop a sociological perspective on mild mental subnormality, within a deviancy framework. His theoretical paradigm is derived from symbolic interactionism and specifically its development in the sociology of deviancy by Lemmert and Becker.

Although he does not commit himself on the nature/nurture debate<sup>23</sup> he does accept that environmental factors are extremely important for intellectual development. He stresses the need for sociological research into the cultural and environmental determinants of intellectual retardation and development, and he seems to suggest that at least some mild subnormality is the result of inadequate socialization.

However, he is more concerned to examine the way in which individuals come to be labelled as mentally handicapped and the consequences for the individual of being labelled. He points to the fact that the school is the main labeller of mildly handicapped people and concludes that mild mental subnormality is 'created' by industrial societies, mainly because of the demands of the educational system.

I have, I believe, established a 'prima facie' case for believing that mild retardation, garden variety retardation, is a serious problem in our society chiefly because it challenges values of the school and school-connected institutions.<sup>24</sup>

In an industrial society there is an emphasis on rational efficiency and an associated assumption that verbal and written skills are a necessary and sufficient qualification for obtaining work. Those who are unable to achieve

minimum levels of literacy and numeracy are therefore unable to take up adult roles, because of their 'failure' in school, even though they might be able adequately to perform 'adult' social and economic tasks.

Dexter argues, then, that the introduction of mass education and the spread of the protestant ethic 'created' a large proportion of the mildly mentally handicapped. Furthermore, he suggests that the school only labels a proportion of eligibles (that is, those with I.Q's below 70) and that non-labelled eligibles are able to cope adequately in adult roles because they have never been labelled mentally handicapped. Once labelled as mentally handicapped the individual faces two main problems in industrial society. Firstly, in the field of employment he is restricted to low-grade, low-paid manual work, and frequently faces unemployment. Secondly he experiences role conflict. He is seen as incapable of managing his own affairs and frequently referred to as a child, and on the other hand those responsible for his care often treat him as if he were sick or a prisoner. Furthermore, as a consequence of having been labelled and being treated as mentally handicapped the individual develops a negative self-image. Thus

The socially acquired picture of self is  
'the looking glass self' 25

Dexter has pointed to the way in which industrial societies create the 'problem' of mild mental subnormality and the vital role played by the school in this process. However, he does not offer an adequate explanation of why it should be so unacceptable for a group to challenge the values of the school and education in industrial society. But his conclusions concerning the consequences for the individual of being labelled are open to question. On the one hand empirical research, in both the United States and Britain, suggests that the majority of the mildly subnormal merge with the rest of the population on leaving school. On the other, there is

a strong possibility that many of those who require help in coping with the demands of everyday living from welfare agencies would be eligible for labelling as subnormal if they were officially assessed. It is also likely that many of these individuals were not officially labelled and managed as subnormal while they attended school. (The inadequacy of Dexter's theoretical perspective is discussed more fully in Chapter 8).

While Dexter himself has not tested the adequacy of his theoretical analysis empirically, Abliza-Miranda et al<sup>26</sup> have carried out a study in Puerto Rico to test the hypothesis that mild mental handicap is 'created' by industrial societies, that retarded behaviour is the outcome of having been officially labelled and that the 'fate' of the labelled subnormal in any society is a result of the attitudes of that society towards stupidity.

The unique position of Puerto Rico as a developing society (in the process of transition from a non-industrial to an industrial and from a rural to an urban society) enabled the researchers to examine attitudes to the subnormal in a non-industrial society and an industrial society, and to see to what extent industrialization 'created' the problem of mild mental handicap.

In rural Puerto Rico the peasants do not distinguish a 'subnormal' class but rather think of themselves as all being 'stupid' in comparison with the small group of literate people who are seen as intelligent - that is, those who have, as a consequence of their privileged position, had or have access to books and schooling. 'Stupidity' is, then, regarded as a consequence of not having received a formal education, rather than as an inability to be 'successful' in the school system. Thus, while in rural areas fifty percent of the population test out on psychometric tests at a level that would make them 'eligible' to be labelled as mentally handicapped, only the severely handicapped are seen as different.

The poverty ... is more bearable in that it is considered the root rather than the result of stupidity ... It is palpably obvious that the poor's lack of opportunity perpetuates stupidity. That many of the poor might not be able to take advantage of opportunities is masked. Only in a society where opportunities are available can one become aware of differential responses. 27

The researchers were also able to look at 'the fate' of eligibles, in terms of I.Q. score, for the label of mental handicap in the urban areas. They found that measured intelligence was not a good predictor of social and/or occupational 'success'. The results of a sample survey, when generalised to the total population, indicated that while probably 31.6% of the population had an I.Q. score that made them eligible to be labelled mentally handicapped, only 3.2% of the male population were subnormal if a measure of social competence - in this case the ability to cope adequately in a given environment as assessed by the researchers - was used as a criterion. Twice as many of those with 'subnormal' as those with normal I.Q. scores 'failed' to adjust adequately to the demands of urban society. However, a considerable number of those with subnormal I.Q. scores did adjust and others with I.Q. scores in the normal range did not.

What distinguishes the retarded from the normal, then, can be viewed as the ability of the normal to adjust to the urban, complex society as compared with the comparative inability of the retarded to make this adjustment. Similarly, the successful retardate is characterised by this similarity to respond in this respect. 28

They argue that the important factor in bringing about adjustment to the urban environment is not I.Q. level but self-image. Individuals with an autonomous self-image were found to be highly tolerant of frustration; had an ability to take advice and were emotionally stable, whereas those with dependent self-images demonstrated the opposite tendencies. The former adjust to an urban, industrial society while the latter fail to do so.

As a result of their research they conclude that the incompetent behaviour and adjustment 'failure' of the mildly retarded is a consequence of their having been labelled as incompetent and not vice versa. Being labelled subnormal results in the development of negative and dependent self-images, which hinder social adjustment

Although this empirical study appears to give considerable support to Dexter's theoretical framework, that mild mental handicap is 'created' as a society industrialises because of the demands of the school system and the labelling of individuals as 'incompetent' by official agencies, its method is open to question. It is difficult to see how a third of the population could be 'really' mentally handicapped, and it seems likely that I.Q. test results reflected the limited amount of education that most of the sample would have received, and cultural familiarity with the concept of 'doing tests'. However, as I will attempt to show later in this thesis, the introduction of mass schooling is an important factor in the 'discovery' of mild mental subnormality and the consequent development of attitudes towards and treatment of the handicapped.

#### Cultural Relativity and Mild Mental Handicap

Mercer<sup>29</sup> is another who points to the importance of the educational system in 'creating' mild mental handicap because of the way in which it selectively labels children as incompetent. Within a social systems perspective rather than a clinical one, she develops the thesis that the school system in the United States 'creates' the problem of mild subnormality by labelling as retarded those children who 'fail' in the system's terms and have 'low' intelligence test scores. These children, she argues, are not seen as inadequate or subnormal in their own communities.

This conclusion is based on the findings of a small empirical study of children in the school system in Riverdale, California. The survey design utilized was

two-pronged - an agency survey and a field survey, in order that clinical/psychological definitions of mental retardation could be compared with community ones. All agencies with a responsibility for defining and labelling mentally handicapped children were asked to list all the mentally handicapped children they were aware of in the city. This produced a list of children who had been clinically/psychologically labelled as mentally handicapped. Secondly, individuals living in the community were asked to nominate members of their own family or neighbourhood that they considered to be mentally retarded.

The epidemiological findings tended to replicate those of other surveys. The agency lists contained, especially among those labelled as mildly retarded, a far higher proportion of children from racial minority groups and/or low socio-economic backgrounds than would have been expected from their proportions in the total population. However, those nominated by individuals living in the community tended only to be the more obviously/severely retarded and came from all sections of society in approximately the expected proportions.

The main aim of Mercer's theoretical analysis is to explain these findings within a sociological framework. This, she suggests, is necessary because mental subnormality does not exist as an 'objective fact'; people are only retarded when they are so labelled by official agencies and/or members of their community. Furthermore, the line between subnormal and normal is arbitrary, socially determined and culturally relative. Consequently the clinical perspective, which locates subnormality as a condition which objectively exists within the individual and is clinically/psychometrically diagnosable, is inadequate. A social systems perspective, however, enables mental handicap to be seen as an acquired social status, defined by its location in the total social system



vis-a-vis other social statuses, and by the role prescriptions that define the type of 'performance' expected of people labelled as intellectually subnormal.

Mercer argues that society cannot be regarded as a unified whole with everyone sharing a set of norms and values, but is made up of a number of sub-groups or cultures, each with its own set of norms and values. The norms and values of one sub-culture may well differ from and even conflict with those of another, including those of the 'core' middle class culture; it is the latter set which are embodied in the school system. The school, then - one of the main agents of labelling the mildly retarded - has a set of norms and values that conflict with those of children from many ethnic minorities or low socio-economic backgrounds. The school values academic success while the home does not. This explains why children seen as 'normal' in their own communities may be labelled as incompetent in the school system and relegated to a 'special' school.

Mild mental subnormality is thus seen as an achieved social status, whose perception and definition is relative to the expectations placed on individuals by the society/community in which they live. A retarded person is one who has been successfully labelled - and an individual labelled as 'incompetent' in one sub-culture in society may not be labelled as such in another. Psychometric tests and clinical instruments used to diagnose subnormality are not, then, objective measures but codifications of middle class behaviour and reflect the 'core' culture of advanced industrial society.

Mercer has once more highlighted the role of the school system in 'creating' mild mental subnormality. Like Dexter she is arguing within a labelling perspective that mild mental subnormality is 'created' by the requirement in advanced industrial society that all citizens should receive a formal education. They would not be

-

thought of and treated as incompetent if the school did not label them as retarded. (As with Dexter's, this is both a strength and a weakness of her approach). She also assumes, rather than demonstrates, that being labelled as 'incompetent' in one or more social institutions, while not being considered 'stupid' in one's own neighbourhood, influences an individual's self-perception and subsequent development. Furthermore, she does not consider that the terms she used in her survey may not convey the same meaning to individuals in the community as to official agencies. The school may classify all children with a tested I.Q. below 70 as retarded, while the community image of mental retardation may only encompass the more obviously and severely handicapped. They may think of children in their family or neighbourhood as 'bad' at school, 'backward' or slow in learning, but not as mentally retarded.

Finally, while Mercer argues that there are a number of sub-cultures including a 'core' middle class culture in industrial societies, she does not place them in a class society. Thus while arguing that the school embodies and reflects middle class norms and values, and has the official power to label children as retarded, she does not ask where this power is derived from, or where the middle class core value system derives its ideology from - that is, what determines the norms and values of the dominant culture, and more specifically why intellectual ability is so highly valued in these societies. These questions need to be considered if a sociological perspective on mental handicap is to be able adequately to account for the role/status of all mentally handicapped people.

Mercer's and Dexter's work has demonstrated the way in which mild mental handicap is a socially negotiated category (though they tend to ignore or to avoid those cases where individuals whose I.Q.s put them in the mild range obviously 'look' different), but they have problems in conceptualising 'primary deviation'. Both are ambivalent as to whether mental handicap (or at least, mild mental handicap) exists as an objective condition or is

socially created - that is, that it only exists where an individual is labelled, socially processed and develops a negative self-image.<sup>24</sup> Consequently it remains unclear in their accounts whether they maintain that society creates the condition of 'mild mental handicap' or avoid explaining the 'causes' of the initial deviant behaviour altogether, concentrating instead on the ways in which society (the school system) reacts to the deviant behaviour (presumably unmotivated and 'caused' by mild mental handicap) and consequently shapes the individual's self-image and career.

Booth<sup>30</sup> - Mental Subnormality as an Achieved Social Status

The analysis and research referred to above has been mainly concerned with the mildly mentally handicapped, and indeed Mercer argues that the social systems perspective she develops is applicable to the mildly, but not the moderately and severely retarded. However Booth attempts to move outside of the clinical definitions of handicap in a study of severely subnormal children, and to demonstrate that

... becoming a mentally handicapped person is not just a matter of clinical evaluations and diagnosis ... [but] ... that it is a social process that can be understood in terms of the changing meanings given by parents to their child's behaviour and revealed in the way they act and feel towards him.<sup>31</sup>

Mental subnormality is then viewed as an ascribed social status, one created and shaped by human activity. It is conferred on the individual as a consequence of the parents' interaction with their child and their growing awareness that 'something is wrong', that the child is not developing 'properly'.

Two imperatives underlie this approach. The first is that sociologists should focus on the origins and unfolding of the social meanings attributed to a pathology - how do people come to understand what it means to say that an individual is mentally handicapped? Secondly, there is the point that it is deviant behaviour that results in labelling and not the converse; that is, for the

sociologist subnormality is seen as constituted by ways of behaving that the clinician would explain as symptoms or effects of the severe mental handicap.

This approach is developed by studying how the notion of subnormality is created and shaped in the parents as their baby develops and eventually culminates in the child being officially labelled. Booth argues that there are four main stages in the child's career, leading eventually to clinical diagnosis as severely mentally handicapped. The first stage is the arousal of suspicion in the parents - they begin to feel that 'something is wrong', that the child is not developing 'properly'. The second is when suspicion is aroused to the extent that they seek professional advice. At this stage doctors generally prevaricate and try to avoid or at least delay making a clinical diagnosis. During the third stage the parents become convinced that 'something is definitely wrong'. They then seek professional advice, with the intention of obtaining confirmation that the child is severely mentally handicapped. The fourth stage is reached when medical diagnosis confirms that the parents are correct - that the child is indeed severely mentally handicapped.

The parents are now in the possession of a diagnosis which describes their child's 'condition', but what exactly this means for the child and its future development remains unclear. The social meaning and reality of mental handicap is now built up by the parents in the everyday process of caring for and coping with a severely mentally handicapped child.

...the idea of subnormality is brought into being by the imputation of social meanings to physical states

and

... following on the diagnosis, it was left ... to the parents to elaborate the idea of subnormality into an organised social role.

- For these parents their child bears witness to the social reality of subnormality. From this point onwards the child's actions and behaviour are assumed as those of someone who is subnormal and thereby work back on themselves to define what subnormality is.<sup>32</sup>

Within a phenomenological framework Booth shows how the parents of mentally handicapped children develop an understanding of what subnormality is and means. He demonstrates the way in which the parents of mentally handicapped children erect procedures to cope with the growing doubts and uncertainties and subsequently re-organise their lives once the child has been clinically diagnosed and labelled.

However, by concentration on the micro-level, the parent-child interaction, he fails to take account of the possible influence of social attitudes and definitions. The parents do not live in a vacuum, they already have some ideas about what mental handicap means prior to the birth and subsequent labelling of their child; they will have been influenced by societal attitudes to ability and intelligence, the role of the child within the family, and built up certain expectations of what it will be like to have a child. Once the child is labelled they will be influenced by the attitudes of doctors, nurses, family, friends and other members of the community; their expectations will be shaped by what 'experts' and lay people tell them to expect. Micro-sociological analysis of this type needs to be informed by and located within a macro-sociological account that permits an understanding of why the mentally handicapped are cast as outsiders and managed as deviant in our society.

#### 4. Sociological Studies of Social Policy

One further group of studies which have been carried out by sociologists have concerned themselves not with the place of the mentally handicapped within society, but with administrative and social policy towards them. After growing concern with the problems caused by the institutionalisation of problem groups almost wherever it has been used - among the mentally ill, the physically

handicapped, prisoners, war-time detainees and even orphaned and destitute children - attempts have been made to find a way of housing deviant groups, including the mentally handicapped, in the community and offering them something approaching a 'normal' life.

Some of the main results of such studies are outlined in this section. It will be argued, however, that they can produce little of permanent value unless they take account of the broader question of where the mentally handicapped stand within our society and what role they are forced to play in it, which in turn demands that a historically informed macro-sociological account be developed.<sup>32a</sup>

#### 4.1 Institutions for the Mentally Handicapped

The major concern of researchers into what Goffman<sup>33</sup> has called Total Institutions has been the effect of living in large, often isolated buildings, where the individual has little control over his everyday existence, has on the inmates. A syndrome - 'institutionalisation' - seems to occur in long-stay inmates which is perceived to be caused by the institution; characterized mainly by apathy, reduced motivation and perhaps psychological withdrawal, it is seen as rendering the inmates unfit to cope with life outside. Early accounts from hospitals (for example, Martin<sup>34</sup>, Titmus<sup>35</sup>, Barton<sup>36</sup>) suggest that the causal factor is the régime, with patients being rewarded by staff for good, quiet, resigned and co-operative behaviour to the point where such attitudes become habitual. Later work on mental illness and mental handicap hospitals suggested that the physical environment and 'quality of life' may have a part to play; Tizard<sup>37</sup>, Morris<sup>38</sup>, Wing and Brown<sup>39</sup> and King et al<sup>40</sup> all found that environments which are drab, unstimulating and poor in the range of choice they offer tend to produce drab, under-stimulated, dependent patients. Staff-inmate relationships have also been shown to be relevant (King et al<sup>40</sup>).

Morris's<sup>41</sup> sociological study provides a graphic picture of the way our society provides for mentally handicapped people incarcerated in hospitals. Morris found that mental handicap hospitals are isolated geographically and socially and from the mainstream of medical and educational advances and that the inmates had few contacts with relatives and friends. They lived in large wards, had little privacy, retained few personal possessions, and many, having no day-time occupation, spend all their time on the ward. Subnormality hospitals, then, tended to reinforce the dependency of their inmates and to encourage helplessness.

Furthermore, subnormality hospitals experience difficulty in providing the basic facilities necessary for the adequate care of their mentally handicapped inmates. Hospitals tended to be short of trained nurses and of skilled professional workers. This meant that the main function of these hospitals became custodial rather than providing care and training.

Following the results of earlier studies which showed that the standard and type of care usually provided in mental subnormality hospitals was inadequate, King et al<sup>42</sup> set out to investigate the variables which determine adequacy of residential care wherever it might be provided. They compared hospital wards, local authority homes and private institutions for mentally handicapped children and concluded that the adequacy of residential care is not related to the degree or type of handicap or to the size of the institution, but to the management orientation and practices.

In hospitals, the management practices are institutionally orientated, whereas in local authority hostels they are inmate-orientated. In the former, wards are staffed by nurses working within a medical model, whereas in the hostels child-care social workers are employed who are influenced by child-centred philosophies. In hospitals

organizational needs are paramount, but in hostels the needs of the children are put first. The considerable improvements since 1945 in the provision made for 'normal' children deprived of a family life have hardly touched the lives of 'subnormal' children.

These two studies demonstrate vividly the inadequacies of the institutional care that our society provides for mentally handicapped people. Although the implications are not developed, it is possible to suggest that this way of warehousing deviants tells us as much about our society as it does about the mentally handicapped residents.

#### 4.2 Living in the community

Policies of decarceration, community-care and normalization mean that provision should be made for mentally handicapped children and adults to live lives as near those enjoyed by the 'normal' population as is compatible with their degree of handicap. This includes the possibility of totally independent living for the mildly handicapped and the provision of care and support services for those unable to cope alone, whether they remain with their families or not.

Sociological research into community living for the mentally handicapped has concentrated on two aspects: the ability of mildly handicapped people to lead independent lives, and the adequacy of the community care facilities provided, especially those aimed at enabling families to care for mentally handicapped members at home. An important factor underlying both these types of study is the attitudes/behaviour of members of the community at the official and individual level to those labelled as mentally sub-normal. (The importance of this in relation to social policy will be discussed more fully in Chapter 6, and empirically examined at the community level in Chapter 7).

It has been argued that mental handicap is the most stigmatizing of all labels because it implies a less than human mind.<sup>43</sup> Goffman defines stigma as:



...the situation of the individual who is 44  
disqualified from full social acceptance.

But policies of normalization, to be successfully implemented, necessitate that mentally handicapped people are fully accepted in the community in which they live. Edgerton<sup>45</sup> set out to study the everyday lives of a group of mildly retarded people recently released from an asylum, to discern the factors that enabled them to cope adequately in the community. He found that the mentally handicapped appeared to be a highly stigmatized group - and that it was a basic stigma, in that the retarded were seen as incompetent in the management of their own affairs.

One of the most important aspects of their lives was their continuing attempts to 'pass' and to 'deny' in order to maintain self-esteem and to avoid the stigma of being regarded as mentally handicapped. These efforts to 'pass' and 'deny' have to continue despite a 'defective' brain and a general lack of social competence. Indeed, Edgerton found, paradoxically, that despite strenuous efforts to pass, the majority of the subnormals studied relied on 'benefactors' to enable them to manage their day-to-day existence, although they regarded this reliance as 'normal' behaviour.

This study was carried out in the early 1960's, when the ex-patients had lived in the community for an average of six years. Ten years later Edgerton<sup>46</sup> undertook a follow-up study to see if over the intervening period they had adapted more adequately to the demands of living independent lives in the community. He found that the mentally handicapped people had become less obsessed with efforts to pass and avoid stigma, and the majority regarded themselves as 'normal'. Also 'benefactors' played a less central role in the daily lives of these people.

An interesting conclusion of the research, and one that may reflect an important modification of attitudes in Western societies and which is of crucial significance if mentally handicapped people's lives are to be normalized, is that the ability to get and hold down a job is not crucial in demonstrating adequate adjustment:

Community adjustment or normalization may be independent of vocational success - the majority of them felt happier now than then, and their happiness was not a function of their employment. What is more, many of these people now appear to define themselves as 'normal' despite their lack of vocational success.

and furthermore

...if unemployment continues, we shall recognise that maintaining our present commitment to a work-ethic may be counterproductive.<sup>47</sup>

Edgerton has shown how apparently felt stigma and community attitudes to what is 'normal' behaviour impede the integration of ex-hospital patients into the community. The self-perception of the individual and his conception of how other people feel about him influence his adaptation to community living. His study was, however, limited to a small sample of mentally handicapped people who had been institutionalized for a number of years prior to their release.

Not all those who are labelled as mentally handicapped are incarcerated, and of those labelled subnormal during the school years the majority appear to merge imperceptibly into the 'normal' population once the period of compulsory schooling has ceased. The ability of the mildly mentally handicapped to cope adequately in the community may be related, therefore, to whether or not they have been institutionalized rather than to the fact that they have been officially labelled as incompetent.

Farber (see above) has argued that the mildly mentally handicapped are a part of the surplus population and are indistinguishable from other members of the lowest socio-economic group in industrial society.

Henshal<sup>48</sup> carried out a small study in Texas, of Chicanos and Anglos with measured I.Qs between 40 and 70 who had been labelled as educationally subnormal and attended a training centre. The vast majority of subnormals came from low socio-economic backgrounds. Some of them were socially and economically dependent on parents or benefactors, but the majority of them coped adequately without such support. The main findings were that the majority of the group were functioning at a much higher level than would have been predicted from their tested I.Q. score and were coping adequately in the community; those from low socio-economic backgrounds were indistinguishable from other members of the communities in which they lived.

Another important aspect of 'normalizing' the lives of the mentally handicapped is 'permitting' them to enjoy relationships with the opposite sex and to marry. Matteson<sup>49</sup> carried out a study in this country which sheds light on this aspect, as well as providing evidence on the community adjustment of ex-inmates of subnormality hospitals, that suggests that the 'problems' experienced by them are similar to those encountered by the ex-patients studied by Edgerton. She looked at a small number of ex-hospital residents who had married each other after their discharge. She found that the majority, but not all, of the couples made adequate community adjustment - that is, that they were indistinguishable from others occupying a similar socio-economic status.

The three studies referred to above demonstrate that mildly mentally handicapped people can, in general,

cope adequately with the demands of leading independent lives in the community - given no more social work support than many other groups. What they do not adequately explain is why, given this, such a stigma attaches to the label 'mentally handicapped', and why members of this group are frequently cast as outsiders and managed as deviants.

#### 4.3 Facilities in the community

The policy of 'normalization' and the advocating of care in the community also extends to the more severely handicapped - those who, presumably, will always need some help and guidance. If the low status of mental handicap influences the provision made for those who are only mildly subnormal, how much more does it influence that made for the more obviously and severely handicapped? Bayley<sup>50</sup> carried out a survey of community care for the mentally handicapped in Sheffield in the early 1970's, and his conclusions have been supported by the findings of more recent studies (including one by Wilkin<sup>51</sup>). The main conclusion of Bayley's study is that in practice community care means care by the family - the main burden of coping with and caring for a mentally handicapped person falls on his family. (Wilkin goes further than this and argues that the main burden falls on the mother - I take up this aspect of care and develop it more fully in Chapter 6). Consequently when we talk about community care we are in reality talking about care in the community rather than care by the community. Bayley argues that this creates a need to distinguish between 'community care' - a form of care where the community is involved in an active way in the care of the mentally handicapped - and 'care in the community' - where parents struggle to cope with a mentally handicapped 'child' in isolation from friends, neighbours and other members of the community. Bayley suggests that if community care is to work in the way envisaged by those who advocate 'decarceration

and normalization', the community must become more actively involved in caring for the mentally handicapped. This involves voluntary workers helping families and visiting those in hostels, as well as the provision of more and better support services and the closing down of large isolated hospitals.

A major problem with Bayley's argument is that it tends to veer towards an 'arcadian' view of the family. He argues that in the past, close-knit working class communities and the associated extended families provided mutual self-help and support. In these communities, community care was a reality, and if this type of community could be re-created then it could become a reality in the future. Apart from recent research questioning his assumptions about the existence of these communities in the past (at least to any great extent), it seems unlikely, given the structure and ideology of our society, that they will develop in the future.<sup>51a</sup>

Jaehnig<sup>52</sup> in a study of a small number of families with a mentally handicapped child, goes beyond critical descriptive studies of welfare provision to question the psychologists' assumption that it is the pathology of the child that creates problems for the family;<sup>52a</sup>

---

he suggests, rather, that it is the ideology of a society that structures attitudes towards the mentally handicapped and their families. He also argues against the assumption that in the past highly supportive extended families lightened the burden of caring for handicapped members. Furthermore, he contends, social workers, working within the prevalent and pervasive view that the isolated modern nuclear family cannot cope with a handicap, have created handicapped families out of families which just happen to have a mentally handicapped member. Thus, he concludes:

— The object of this study was to examine the —

effect of modern industrial society upon a family with a handicapped child. Its main conclusion was ... that the nuclear family is resilient, adaptable and highly dedicated to caring for its disabled child, and most often carries out this task satisfactorily in spite of formal and informal efforts to intervene - actions which, it might be added, are usually presumed to be benevolent and efficient, but can have pernicious consequences for the family.<sup>53</sup>

As far as the family is concerned they do not accept the 'official' view that having a handicapped child is a tragedy, but see the child as a member of the family, an individual with a unique personality. It is not the child's handicap which causes him to be a burden on his family, but problems caused by his behaviour and the additional financial costs. The felt needs of the parents are for extra financial and social support; indeed one of the main reasons why parents seek residential care for their children is the financial burden rather than the difficulties of coping with the child.

#### 5. The Developing Social Perspective

Sociological studies of social policy such as those discussed in the last section have cast a great deal of light on what it is like to be mentally handicapped in our society. Some of the conclusions are of value as warnings: the institutional (mostly hospital) care which is associated with the view of the mentally handicapped as sick people is consistently inappropriate to their needs and may be positively deleterious. Others are encouraging: some of the mentally handicapped can merge back into their parent sub-culture and apparently become accepted as 'normal', once they escape from stigmatizing institutions such as schools. Attempts are now being made to see to what extent all can be returned to the community, given adequate support services. Yet other studies are frankly critical of the provision which is made - or rather not made - for the support of the mentally handicapped living in the community. However, none of these studies can really give us any understanding of what it means to be mentally handicapped in our society, because they are only snap-shots - ahistorical cross sections of society and social provision at a particular

moment in time. Without an appreciation of the underlying historical forces which contribute to that 'moment' they can understand neither how and why things came to this pass nor the direction of likely (or possible) development.

This charge of ahistoricity and lack of macro-sociological perspective can also be levelled at most of the more theoretical sociological literature, as we saw in an earlier section of this chapter. What the sociological literature has succeeded in doing is to move away from the implicit assumptions of the clinical and psychometric models of mental handicap - that is, that the 'problems' posed by mentally handicapped people can adequately be explained by reference to the assumed pathology of the individual. They have pointed to the vital 'fact' that in order to understand mental handicap as a social as well as an individual problem we need to examine the norms and values, and indeed the ideology, of the society in which the individual lives, and within which he is labelled as an outside and managed as a deviant. Dexter has pointed to the need to examine the 'problem' historically, Mercer has highlighted that being labelled as mentally handicapped is relative to institutional/cultural expectations of behaviour, while Farber has suggested that industrial societies have a functional 'need' for a surplus population, and that the mentally handicapped are a part of this population. Morris and Bayley have shown how inadequate is the provision that our society makes for mentally handicapped people - that they are the "forgotten ones". One of the most interesting and promising lines of research is that developed by Jaehnig, who examined the role of ideology and the images held by professionals in creating 'handicapped' families and relates this to the lack of financial and social support provided to families caring for a handicapped member.

What sociologists have not yet succeeded in doing adequately is to develop a historical and macro-sociological perspective in which to locate micro-sociological insights. \_\_\_\_\_

The rest of this thesis is aimed at beginning to overcome this deficit - examining the role and status of the mentally handicapped and relating this to the ideology of society. Indeed it is my contention that it is the ideology of society, and not the pathology of the individual, that determines social perspectives on 'outsiders' and determines the way in which they are managed. It is this that I intend to develop and demonstrate in what follows. .



REFERENCE NOTES, CHAPTER TWO

- 1: It is a common assumption, for the most part accepted uncritically by sociologists, that the mentally handicapped form a category of people who are essentially different from others. Furthermore there is a tendency in the literature, including the sociological literature, to homogenise or at the most to dichotomise the category of mental handicap. However, there is no reason in terms of form of handicap, aetiology or identification and management practices to assume that there 'really exists' such a unity or dichotomy. The division into sub-groups is arbitrary, based on I.Q. and possibly on social competence (itself a value judgement).
- 1a: Adapted from Boswell and Jaehnig, 1975. p 80
- 2: Adapted from Kirman, 1968. p 687
- 2a: E.G. Fletcher (1972) argued that  
..any individual of the species 'homo sapiens' who falls below the I.Q. 40 mark on a standard Stanford Binet test ...is questionably a person; below the 20 mark he is not a person. p 1
- 3: Sarason and Gladwin, 1958                      4: Edgerton, 1970
- 5: Ryan, 1976 p. 152-154                      6: Morris, 1973
- 7: E.G. Stein and Susser, 1960 (although some sociologists may have assumed too readily that mild mental handicap is socially created that social facts can explain its existence in industrial societies - see section 3.2 of this chapter, and Chapter 8).
- 8: Kushlick, 1967, p 37
- 8a: See, e.g., Stein and Susser (1960), Birch et al. (1970), Mercer (1973), Rowitz (1974).
- 9: Sarason and Gladwin, 1958.
- 9a: Grossman (1972) argues that in this article Sarason and Gladwin were the first to state formally a social-psychological perspective on mental handicap.
- 10: See Dexter (1960) for a critical sociological evaluation of the article. †
- 11: Mendeholm, 1954                      12: Perry, 1954
- 13: Mendeholm, 1954                      14: Kurtz, 1964
- 15: Rowitz, 1974 p 411                      16: Perry, 1965 p 19
- 17: E.G. Mercer (1973), Booth (1978), Tomlinson (1981)
- 18: Booth, 1978 p 203                      19: Farber, 1968
- 20: For a summary of the functionalist perspective on social stratification in these terms see Davis and Moore, 1945.
- 21: Farber, 1968 p 19                      21a: Farber, 1968 p 263

- 21b: See Tomlinson (1981) for an account of the process by which children are labelled as mildly educationally subnormal in the English educational system.
- 22: Dexter, 1956, 1956a, 1958, 1958a, 1960, 1960a, 1963, 1964, 1966, 1973.
- 23: Dexter, 1956
- 24: Dexter, 1964
- 25: Dexter, 1960
- 26: Ablizú-Mirrada et al, 1966
- 27: Ablizú-Mirrada et al, 1966 p14
- 28: Ablizú-Mirrada et al, 1966 p55
- 29: Mercer, 1973. See also Tomlinson (1981) on the process of labelling children as mildly educationally subnormal in the English educational system. This study also points to the class and ethnic biases in selecting and labelling children as E.S.N. (M.) highlighted in Mercer's study.
- 29a: This difficulty with conceptualising 'primary deviation' is one common to labelling theory in general and will be taken up and discussed more fully in Chapter 8.
- 30: Booth, 1978
- 31: Booth, 1978 p204
- 32: Booth, 1978 p219
- 32a: However, see Tomlinson (1981) for an attempt to develop such a theoretical perspective in the case of the mildly educationally subnormal.
- 33: Goffman, 1961
- 34: Martin, 1955
- 35: Titmuss, 1958
- 36: Barton, 1959
- 37: Tizard, 1964
- 38: Morris, 1969
- 39: Wing and Brown, 1970
- 40: King et al, 1971
- 41: Morris, 1969
- 42: King et al, 1971
- 43: Ryan, 1976
- 44: Goffman, 1968 p12
- 45: Edgerton, 1967
- 46: Edgerton and Bercevic 1976
- 47: Edgerton and Bercevic 1976 p 493-494
- 48: Henschal, 1972
- 49: Matteson, 1970
- 50: Bayley, 1973
- 51: Wilkin, 1979
- 51a: However, see Abrams et al (1981) for an evaluation of Good Neighbourhood schemes - schemes designed to develop informal community help:
- The projects...represent a distinct social ideal: an effort to develop patterns of social care that put special emphasis on informality, reciprocity and locality
- but found that they needed to be carefully planned, required formal organisation and had to be integrated with other schemes if they were to 'succeed' in delivering primary help.

52: Jaehnig, 1974

52a: See, e.g., Gath (1978) for a recent restatement of the argument that the mentally handicapped child results in a pathological family. However, Grossman (1972) found responses of families varied and not all became pathological. Hewett (1970) and Darling (1979) support Jaehnig's conclusion.

53: Jaehnig, 1974. P310

## CHAPTER 3

### A SOCIOLOGICAL ASSESSMENT OF THE MEDICAL AND PSYCHOMETRIC MODELS OF MENTAL HANDICAP

#### 1. Introduction

In Chapter 2 I have argued that one major weakness with much of the sociological literature on mental handicap is its implicit, if not explicit, acceptance of the dominant medical model of mental subnormality. In this chapter I intend to critically assess the medical and psychometric models - the latter having incorporated many of the assumptions of the former - arguing that they are inadequate mainly because they focus attention on the individual and his assumed pathology and ignore the wider social context within which the mentally handicapped person lives.

One of the major problems facing any social scientist studying mental handicap is that of definition. Mental subnormality is not a 'thing' that can be touched or defined in terms of shape and substance, but an invented concept suffused with social values, traditions, unintended as well as intended prejudices, and degradation. The concept itself, in our society, appears to serve two major purposes: to separate a group of people, and to justify social action in respect of those set apart. This separation is not necessarily physical, but it does imply that mentally handicapped people are seen as being sufficiently different to need special 'care' and 'treatment' (see Chapters 4, 5 and 6 for an analysis of 'care' and 'treatment' contemporaneously and historically).

The use of the concept 'Mental Handicap' (or equivalent alternative terminology) is not therefore neutral, nor is the identification of individuals as belonging to the category. The labelling process is a preliminary to 'care' and 'treatment' while the initiation of the diagnostic process is the outcome of somebody suggesting that an individual is not developing 'properly'.

It is the result of the development of an idea - the feeling that something is not quite right, that other lives are being affected, that we must find out the source of the trouble and that it is essential to come up with solutions - to alter the individual's status - that will allow us to experience our lives in the way we wish to.

Consequently, while diagnosis is a pathology-orientated process, initiated by someone who feels that something is 'wrong' with another person, and a process in which objectivity and precision are sought, in actual fact it is a process permeated with personal values and judgements. Diagnosis is concerned with the individual and his pathology and tends to be conducted and justified as if only the individual required assessment and help, as if the whole problem is inherent in him. However, diagnosis is always, and inevitably, the outcome of a perceived problem in an individual's development which arises out of a social situation. Thus the labelling process denies the transactional element.

Sociologists need therefore not just to move outside the clinical model but also to examine critically both the defining process itself and the instruments used officially to label an individual as incompetent. We need to ask to what extent this process and the diagnostic tools used reflect the norms and values of a society, and to demonstrate that they are used within a social structure for a purpose - they are not an end in themselves.

The diagnosis of mental handicap in our society would seem to be at once easy and difficult. Some people are so obviously handicapped that it is immediately or almost immediately possible to recognise them - although even then there is room for mis-labelling - people with severe spasticity have in the past been wrongly diagnosed as severely mentally handicapped as the Joey Deacon story<sup>1</sup> so graphically illustrates, and some

extreme depressives might well be taken to be subnormal. On the other hand, at the other extreme mentally handicapped people merge imperceptably with 'normal' people. Indeed, the number of people in the population 'eligible' (at least in psychometric terms) to be labelled subnormal probably far exceeds the numbers actually labelled and managed as retarded people. Underlying all attempts to define and diagnose mental handicap is the problem of defining socially acceptable behaviour, adequate development and adaptability to the demands of the society in which a person lives. These are always based on normative judgements and those with the power to label may not share the same view as to what is evidence of subnormal functioning as other sub-groups in society, or indeed the individuals who are labelled. This has been demonstrated in some of the descriptions of the lives of the mildly retarded in the community discussed in Chapter 2.

The main official labellers of the subnormal are doctors and psychometricians. While clinical diagnosis usually suffices with the more severely handicapped, many of the mildly subnormal are 'discovered' as a result of school failure and subsequently 'failing' on an intelligence test. In the United States psychometric testing is apparently routine for all children<sup>2</sup>, but in Britain (especially since the large reduction in the number of local Education Authorities setting 11+ tests) only children referred by the school to the local authority will be tested.<sup>3</sup> Additionally in Britain, since the 1959 Mental Health Act (see Chapter 1), for a person to be described legally as mentally handicapped it has been necessary to demonstrate subnormality of intelligence (an I.Q. of 70 or less) as well as general social incompetence.

Although psychometric tests are not the only instrument used in diagnosing mental subnormality they have retained an extremely important role, not only in the diagnostic process, but also in classification, which in turn

influences decisions as to future 'care', 'treatment' and placement.<sup>4</sup> It is necessary to ask why they have retained a central position, despite criticism of them, both from within and outside of psychology. In this chapter I will suggest that the way in which these tests are constructed, the content of them, and the assumptions underlying the use of intelligence tests reflects the ideology of our society - that the instrument used in diagnosis, and the very process itself, tells us as much about our society as it does about the individual deviant. Furthermore, we usually label for a purpose, yet the dominant method of diagnosis in the field of subnormality according to Mittler<sup>5</sup> ignores the fact that an inability to learn may be related to our inability to teach. In as much as the labelling process leads to essentialist labels it would seem to solve a problem for society rather than for the individual.

Intellectual assessment is not an end in itself, but it is an important career stage for the person tested. Together with the school 'failure' it can confirm his status as subnormal or can prove that he is 'normal'. Despite the fact that for the individual a great deal hinges on the outcome of the test, many testers continue to use tests as if they were unaware of the limitations of the instrument they are using. An I.Q. is not a magic number, but I.Qs have become correlated, in the public as well as the official mind, with a significance out of all proportion to their scientific status or their relevance to the problems of mentally handicapped people. Indeed, intelligence tests have acquired a mystique, and the official and unofficial societal expectations of their value may often exceed those of many of the testers. Mittler<sup>6</sup> has suggested that many psychologists continue to administer tests because of institutional expectations and pressure.<sup>6a</sup> Furthermore, intelligence tests have been used primarily to segregate and classify. Consequently the continued and dominant use of psychometric

tests in the field of subnormality may reflect the fact that society provides little more for the mentally handicapped than institutional 'care', rather than a 'belief' that test results can be used as a basis from which to help the mentally handicapped person.

This is not meant to suggest that psychology as a discipline is of little or no value in the field of mental handicap. There are psychological theories of cognitive development that would seem to offer the possibility of more adequate diagnosis and classification and provide a basis from which to develop programmes to ameliorate the condition, but psychometrics continues to dominate the field. While in the last twenty years the majority of research in the field of mental handicap has been medical and psychological, these studies

' ...whether psychometric, ethological or experimental, are basically concerned with describing the subnormal rather than with the problem of ameliorating or preventing handicap?

In the same period there has actually been a decline in research into training, rehabilitating and educating mentally handicapped children and adults.<sup>8</sup> Whether this is a reflection of academic interest, the decisions of research grant bodies or a realization that political and economic rather than any other reasons determine whether research findings are implemented or ignored and consequently the futility of research that comes up with 'costly' solutions, is difficult to determine.

What can be said is that the type of research carried out does seem to reflect the attitudes and values of the society within which it is carried out, and that governments do not necessarily implement recommendations arising out of research findings even when they would seem likely to provide a possible solution to a problem. Furthermore, the current 'economic crisis', with us since the mid-1970's, has made it exceedingly unlikely that the government would agree to implement any new schemes that involved increased public expenditure.



The very act of diagnosing and labelling can, then, be said to be a reflection of the social practice in a society for dealing with the 'deviant'. While, of course, informal labelling goes on all the time, it is officially sanctioned labelling that is of crucial significance for the individual's future growth and development. Although informal labelling can influence an individual's self-image and may be the first stage in a process resulting in formal assessment and labelling, the labels attached to an individual or group of individuals by 'experts' - in the case of the mentally handicapped doctors and psychologists - are regarded as authoritative and scientific. In the case of the mentally handicapped the label is also stigmatizing, resulting in diminished status, and so has profound consequences not only for the individual and his future, but also for family, relatives and friends.

In this chapter I intend firstly to argue that the medical model's reification of mental handicap as an identifiable and incurable disease or medical condition akin to being born, for example, with no legs, obscures the nature of the culturally relative judgement involved. Then I will examine the role of psychometric tests as 'hardening the edges' of the definition of the disease, and at the same time giving apparent validity to its 'objective' status. Intelligence, originally a common language concept, becomes to an extent what the tests mean; psychologists have felt bound to come up with concepts like 'creativity' and 'achievement motivation' to catch what are also essentially all aspects of ability but which its newer and more specialised meaning fails to include. Intelligence tests tend to rule the field because it is claimed that intelligence is 'now' measurable while concepts like 'social competence' or 'personal development' are woollier. It will be suggested that the intelligence test has a special place even among other psychometric instruments in that it is, and was indeed developed to be, a normative rather than a descriptive

instrument. Finally in this section it will be pointed out that the assumptions underlying psychometric tests about the nature of people and of ability, when applied to the medical model concept of mental handicap, change it into something subtly different, a distinctive 'psychometric model'. In the last section I consider alternative models of mental handicap available within psychology - the approach through social competence and two variants of a 'cognitive development' approach which could treat mental handicap as more like (perhaps temporarily) arrested development than like a permanent and untreatable incapacity. These are still 'medical model' ideas and I would argue that they are insufficient for an understanding of mental handicap because they take little account of historically conditioned social factors, but they do have fundamentally different implications for social policy. In particular they shift the emphasis from diagnosis to amelioration and remedial education. Such shifts, as I hope to demonstrate in Chapters 4, 5 and 6, can have a profound influence on official, community and individual perceptions of and attitudes towards those individuals we label as mentally handicapped.

## 2. Pathology and Social labelling

Unlike physical calibre, which is readily discernable and measurable by clinical examination, mental handicap involves the measurement of 'intellectual calibre' and/or social competence, which is less easily judged. O'Connor and Tizard<sup>1</sup> have suggested that six factors of the perceived condition are considered relevant when deciding if a person is mentally deficient: anatomical and physiological development, intellectual capacity (presumably I.Q.), intellectual attainment (presumably school achievement), social competence (presumably the ability to 'cope' in the community at an acceptable level), occupational adequacy (presumably the ability to obtain and keep a job), and temperament. Obviously the importance

of each of these aspects will depend on the age of the individual and the degree of obvious handicap. Additional relevant factors, they argue, are the history of the family, its circumstances including current socio-economic status, and the occupational competence of the rest of the family. The interpretation of the relative importance of these factors has not resulted in an agreed definition of mental handicap, although, as Jordan<sup>10</sup> points out, most psychologists and doctors would accept as a working definition the very basic notion that mental handicap implies a sub-average intellectual functioning, present from or soon after birth, and associated with difficulty in learning and/or social adjustment. In most cases it is assumed rather than 'known' that the condition has existed from or soon after birth, and indeed environmental rather than inherited factors are seen as increasingly relevant in the aetiology of mental handicap. Furthermore, the expected level of functioning is determined by reference to the behavioural standards and norms for a given society, and more specifically for an individual's chronological age-group. Coupled with this is the general acceptance of a 'sponge' view of intelligence - that is, that each individual is born with an 'aptitude' to learn - a genetic 'ceiling' to his learning potential.

It follows from this that mental handicap is generally seen as a permanent condition that at the most can be ameliorated but never cured. This basic and fundamental assumption about the nature of mental handicap results in the individual being cast in the role of 'incurably sick', rather than say in that of 'developing person'. In turn this results in a continued search for the essentially 'biological' causes of the behaviour, and even when environmental factors are acknowledged to be relevant there is still a search for the changes in the biological organism that result from the environmental factors. The consequence is a continued focus on the individual and an emphasis on individual pathology.

The diagnosed deficiency is projected into the individual, and little attention is paid to social and societal factors.

In Chapter 2 I have suggested that one way of classifying the mentally handicapped, on the basis of assumed aetiology, is into the organic/pathological (normally the more severely handicapped) and the sub-cultural/familial (normally the mildly handicapped). The former group are usually diagnosed by clinical examination conducted by doctors, the latter by psychometric tests. However, formal diagnosis of all mental handicap is considerably complicated by the wide variation in assumed aetiology, and the wide range of abilities that exist among those eventually labelled as subnormal. In the rest of this section I intend to discuss the underlying assumptions of the models used by doctors and psychometricians when they are concerned with the diagnosis of mental handicap - the medical model and the psychometric model. These two models are considered separately, but they interpenetrate each other, and the former has particularly influenced the latter. However, in terms of diagnosis they do differ: in the former the individual under consideration is diagnosed as subnormal by medical examination and then intelligence tests may be used for clarification purposes, whereas in the latter the I.Q. test score is the major relevant factor in diagnosis - the psychometric test provides the 'scientific' proof of stupidity.

## 2.1 The Medical Model

Medical involvement with the field of mental sub-normality is comparatively recent. As far as can be discerned from the scanty historical evidence (see Chapters 4 and 5), medical men showed little interest in the condition until the early nineteenth century. In the initial phase of interest doctors thought that mental handicap could be 'cured'; when this hope was

shattered they tended to take the opposite view and see it as an 'incurable sickness', the sufferer needing life-long custodial care (although at the time, and indeed since, the provision of residential places has never been sufficient for all or even the more severely handicapped). Parallelling this was the growing dominance of the medical profession in the whole field of mental disorder<sup>11</sup>, where they managed to obtain, and have subsequently retained, administrative control of mental handicap hospitals, and the overall control of diagnosis and treatment.

The medical model still retains at root the idea of mental handicap as an 'incurable sickness', and its way of thinking results in seeing people primarily in terms of what is wrong or abnormal about them, rather than in terms of the community in which they live, the way in which other people behave towards them or the needs arising from this. As Sarson and Doris<sup>12</sup> argue:

The fact that brain injury and certain types of behaviour exist is in itself no basis for concluding that one is the cause of the other

and furthermore

To the extent that we imply or infer such a correlation we obscure the complexity of knowledge which would alter our perspectives of the potentialities of these children.

The inadequacies of the clinical model relate primarily to the fact that it has developed in medicine as a conceptual tool for understanding, controlling and testing physical illness. It is concerned basically with diseases which interfere with the physical functioning of the organism, and consequently the model focusses on individual pathology. The disease is defined by biological signs and symptoms, with a strong emphasis on defining the nature of the abnormal. The medical category of 'mental subnormality' and the diagnosis are seen as descriptive of pathological defects in the individual which are the 'cause' of the retarded intellectual growth.

The only relevant social questions within this paradigm are epidemiological - the incidence and the prevalence of the 'disease'. The model, rather, encourages research on the elaboration and refinement of instruments for the detection of defects, and their biological causes and/or associated consequences. Relatively little attention is paid to the social and personal consequences of labelling and categorization. These are not seen as acts that have any particular social meaning except in terms of administrative decisions about present and future 'care' and 'treatment'. This is because diagnosing mental handicap is seen as exactly the same process as diagnosing any other medical condition. The outcome of the scientific diagnosis is a recommendation for a care and treatment regime. Prognosis is also an integral part of this process - with the mentally handicapped individual it usually involves predicting future intellectual development - what mental age he will eventually reach.

In the case of the mentally handicapped the philosophy of the clinical approach, apparently beneficial to the individual, is used to confirm him in a stigmatizing, diminished status rather than to offer the possibility of changing this status from, say, a 'sick person' to a 'healthy person'. The individual is cast in the role of 'incurably sick' rather than, say, 'developing person'. Furthermore, the 'illness' serves to explain the total behavioural pattern of the individual, and possible environmental/social determinants of behaviour are disregarded, ignored or dismissed as irrelevant.

## 2.2 The Psychometric Model

The medical model reifies mental handicap as a culture-free condition which is objectively identifiable, and psychometric tests in general, and specifically intelligence tests, validate this position by providing a supposedly objective and scientific measure.

However, they have two effects: they harden and clarify the boundaries of the 'disorder' and they contain different assumptions about the nature of the person and the curability of handicap - these differences are enough to make them form a distinctively different model from the straight medical one

The psychometric model is the one dominant in the diagnosis of mild mental handicap - the diagnosis usually takes place after some years of formal schooling. It is the responsibility of the school medical officer to determine if a child is educationally subnormal, and his diagnosis is based mainly, but not solely on the results of a single intelligence test.

The psychometric model is then concerned with measurement and classification. The intelligence test is a screening device used to determine if an individual is capable of benefiting from 'normal' schooling. It does not have to make assumptions about the causes of 'low intelligence' or indeed to make recommendations about what should be done. In this model the mentally handicapped are those with an I.Q. below 70. The consequences of being labelled within this model are not, as they are in the medical model which confers the status of 'incurable sick', implicit in the model. When the assumption is made, as it was in the early part of this century, that the 'feebleminded' are qualitatively different and that the condition is genetically transmitted, official diagnosis can result in being treated as a dangerous deviant and result in life-long incarceration. On the other hand, if a low I.Q. score is seen as partly the result of environmental factors, official classification could have the positive consequence of resulting in the placement of the mentally handicapped individual in a 'special' educational environment designed to develop his abilities to the full.

However, the National Society for Mentally Handicapped Children suggests that even now the procedure is designed

mainly for administrative convenience and is a negative procedure not aimed at deciding what is best for the child.<sup>13</sup> Psychologists have been employed to assess rather than provide possible programmes of remediation for the educationally and mentally subnormal.

...assessment is of limited value in the field of subnormality. In Britain it has been clearly regarded as the main contribution of psychologists. As ... employed it appears more often as an epiphenomenon keeping them busy, stimulating often unprofitable research and leading to the perpetual quest for the philosopher's stone (better and better tests) which will secure more and more accurate prediction.<sup>14</sup>

The model of child development at least implicit in this approach is antitheoretical with respect to the process of development - that is, with regard to what constitutes change in ability and competence, and how it happens. The stages of development are defined statistically; change is seen as a series of quantitative accretions, not related in any special way to the preceding or succeeding ones. Furthermore, the content of each stage is determined mainly by the desired statistical properties of the resulting test rather than any consideration of what is developmentally meaningful.

Intelligence tests are based on the concept of the normal distribution. In this model, then, abnormality is defined according to the extent to which an individual deviates from the population average. In establishing the statistical norm and the boundaries of the 'normal' the psychometrician uses the distribution of the characteristic in the population. The model defines two types of abnormality, one at each end of the distribution - for example when weight is under consideration, at one end are the abnormally heavy and at the other the abnormally light; when intelligence is under consideration, at one end are the intellectually gifted and at the other the incompetent. The statistical model is itself neutral; what is good or bad, desirable



or undesirable is culturally defined. So, while in our society it is generally considered bad/undesirable to be overweight, in some Eastern countries it is regarded as good/desirable. In Western societies it is good/desirable to have a high I.Q. and bad/undesirable to have a low one. This social evaluation is partly related to occupational demands, but also to the requirements of mass education and social control in capitalist societies. (This point will be further developed in Chapters 5 and 8). It also helps to maintain and justify a system of social stratification, in that it is at least partly justified by arguing that those in high-status occupations 'deserve' their socially and economically superior position because they have not only worked hard but are also intellectually gifted. (Although whether or not intellectual ability alone determines occupational success is extremely debatable<sup>15</sup>).

The problem is what we mean by 'intelligence' - does it have a 'factual' 'objective' existence or not? It is easy to say that intelligence is 'what the test tests', or 'what is necessary to do well in school in academic terms', but this does not go very far. Furthermore, there is research evidence to support the view that the demands the society puts on individuals play an important role in determining the level and type of abilities developed.<sup>16</sup>

Culture determines the degree and kind of intellectual ability required for adequate - including measurably adequate - performance in our society.<sup>17</sup>

Psychometricians, however, proceed to measure 'intelligence' as if it does have a 'factual' existence. Although, to be fair, they are aware of the problem of cultural relativity and have attempted, with little apparent success, to develop culture 'fair' or 'free' tests. Furthermore, they tend not to take cognisance

of the 'fact' that cultural relativity also plays an important part in defining what is intelligent behaviour. Thus many test items implicitly assume a middle-class value system.

### 2.3 The Normative Role of Intelligence Testing

The major problem with both the medical and the psychometric models is that while they claim to be descriptive and non-evaluative, they are in practice normative. They are normative because as a result of being diagnosed as mentally handicapped, an individual is either included in the sick class (medical) or excluded from the 'normal' school (psychometric) and in either case is thrust out of 'normal' living into a stigmatized 'surplus' population. Furthermore, clinical diagnosis and intelligence tests interact with the schooling system and the child health system to provide something akin to universal screening for mental subnormality.

The intelligence test plays a central, if different, role in both the medical and psychometric models of mental handicap, and the assumptions underlying the tests and the reasons why they were developed still influence official and community perceptions of and attitudes towards the mentally handicapped. Despite considerable criticisms of the underlying assumptions of intelligence tests they continue to be used as a tool for the assessment of and placement of the mentally handicapped. In order to explain why this is the case I will discuss why intelligence tests retain a central role in the field of mental handicap, but as a preliminary to this I will briefly point out the major criticisms of intelligence tests as measures of innate ability/underlying potential.

Standardized tests of intelligence are designed to measure intelligence and to place an individual in relation to the total population. A basic assumption

underlying the test is that intelligence is normally distributed and that a standardized test is one on which the scores of the total population will produce a normal distribution of scores. The model determines in advance that a given proportion of the population will have 'high', 'average' and 'low' intelligence. This would not be a fundamental problem, however, if the tests were indeed used purely for description - if intelligence were not a normative concept. (In any case, the assumption that intelligence is normally distributed is not correct - although it would be if the biologically subnormal were excluded).

On standardized tests an I.Q. of one hundred is the statistical norm, and the standard deviation is fifteen points. An individual with an I.Q. below about eighty would be considered at least below average in our society and with an I.Q. below fifty severely subnormal. The 1944 Education Act laid down that those with an I.Q. between fifty and seventy were educationally subnormal, and those with an I.Q. below eighty dull. The 1959 Mental Health Act stated that subnormality of intelligence had to be present for an individual to be 'diagnosed' as mentally handicapped. The upper I.Q. limit for classification as severely subnormal is usually taken as fifty and for classification as subnormal usually seventy. However, in practice, the lines of demarcation are blurred; the severely subnormal merge with the subnormal and the subnormal with the normal - arbitrary cut-off points are, in themselves, of little value.

Intelligence tests are used not only to assess an individual's present level of functioning, but also to predict his future developmental potential. The ability to be able to do this is based on the assumption that intelligence tests are both highly reliable and entirely valid. One of the major assumptions of the test is that it measures some 'thing' called intelligence, and that this 'thing' is a fixed, unalterable quantity -

usually assumed to be genetic in origin, but it could be fixed irreversibly by early environmental factors. The test is also assumed to measure 'pure' intelligence - the quantity the individual possesses independent of cultural and teaching influences. It is then assumed that the test not only measures present attainment, but that the results can be used as a basis on which to predict future developmental potential. Psychometricians consequently place great emphasis on its reliability as a standardized measuring instrument.

Note however the paradox emphasised by Kelly (1955) when he defined 'reliability' as the degree of an instrument's insensitivity to change: concern for reliability of measurement may weaken research into transitory or mutable phenomena. Some argue that this has happened in academic psychology, where a view of personality as fixed rather than changing follows all too readily from the search for a reliable measuring instrument.<sup>6</sup>

(If we substitute 'psychometrics' for 'academic psychology' and 'intelligence' for 'personality' this point applies equally to intelligence tests).

An even more fundamental weakness of intelligence tests, and indeed one recognised by many psychologists is the threat to internal validity posed by confounded variables: the test is contaminated by the influence of a number of variables related to the social activity of testing. As a result it is not possible to tell when considering scores on intelligence tests what differences are due to differential intelligence and what to these other factors - even on the assumption that the test can actually test generalised ability as opposed to attainment. These confounding variables include factors such as differential teaching, differential emphasis placed on school work, differential fear and experiences of tests, differential motivation to do well on tests, especially as between individuals from different cultures, ethnic groups and social classes, different

local vocabularies - between regions, ethnic groups and social classes, and the influence of the social situation of the test - the interaction between the tester and testee - on the test results.

This is an important factor given that in our society children from ethnic minority groups and working-class homes are more likely to be labelled as educationally subnormal than children from white middle-class homes.<sup>19</sup> This is at least partly a result of test bias, although it probably also reflects the type of children considered to be a 'problem' by school teachers. However, all the time that intelligence tests test attainment, and the social factors that influence the test are the same as those that influence school success/failure, then tests are only going to confirm the suspicions of teachers.

The underlying assumptions of intelligence tests need to be examined in order fully to understand the ways in which the results of such tests are used, ideologically in our society. (This role of intelligence tests is developed more fully in Chapter 8). This opens wide a fundamental debate about the nature and origin of what we call 'intelligence' and 'intelligent behaviour' - the nature/nurture debate. Despite frequent assertions that this debate is now dead, that we are all now interactionists at least to some extent, the undisputable fact remains: that the historical and theoretical assumptions underlying intelligence tests include the view that intelligence is a unitary, hereditary and basically stable 'thing' - something we possess like the colour of our skin. Despite a changing emphasis within psychology, a move away from a reliance on intelligence tests, they still play a dominant role in medical and educational psychology and the results of such tests are used as if they did measure a fixed capacity - the classification and placement of the child is made to a large extent on the basis of a test score. As Mittler has pointed out:

Some psychologists working in health and education services were unwilling to discard tests which they saw as providing a form of standard interview of which they had extensive experience, and about which there was a great deal of published information. Even those who were in principle willing drastically to curtail the routine use of tests doubted whether they would be able to resist the demands of their employers and professional colleagues, who conceptualise their role primarily as that of testers, with perhaps some involvement in research and teaching.<sup>20</sup>

While the continued existence as a profession and the employment of psychometricians depends, at least to some extent, on the continued use of tests, the search is not for 'new' methods of assessment, but for more refined tests, tests that 'do the job better'. Thus the underlying acceptance of fixed capacity persists, despite the accumulating evidence that suggests that expectations have a considerable influence on outcome - at all levels of ability and attainment.

The nature/nurture debate becomes relevant at this point because, as Ryan points out,

What is ... important is the way in which this debate within psychology reflects a wider social debate on the inclusion or exclusion of mentally handicapped people from so many social institutions. Unfortunately this reflection is not always a conscious process as far as the psychologists themselves are concerned.<sup>21</sup>

Not only does it influence placement, but also whether the 'condition' is seen as remediable or not, and if so how. As Rose has argued, with our present state of knowledge we cannot modify the genotype (what is inherited), but we can improve/modify the environment - that is, provided we accept an environmental component, we can enable every individual to develop his potential by improving the housing, the schooling and the general environment of the more deprived members of our society - the sector from which most of the mildly handicapped come.<sup>22</sup>

However, while Rose is not alone in stressing environmental influences, and Ryan has pointed out that

Evidence can be produced to support either position or neither, depending on the conditions of the experiment, the exact kind of behaviour investigated and the methods and intent of the researcher<sup>23</sup>

nonetheless there is still a general and persistent 'myth' that intelligence and achievement are distinct, and that it is possible to measure innate intelligence and predict future behaviour and achievement on the basis of this.

The assumption that intelligence is totally or mainly genetically determined and the reliance on intelligence tests in assessment results in an emphasis on the individual and his 'failure'. The 'poor' result on the test is accounted for by his 'low' intelligence, but it is the test results which 'prove' he has a low intelligence. Apart from the fact that this view, at the level of use, dismisses any notion of cultural bias in the test, and the problems involved in the 'fact' that testing is a social activity, it also provides no information which can be used to design programmes of education and habituation. In sum, intelligence test scores can only state that the individual cannot 'pass' the test, not why, or what can be done to improve the situation.<sup>24</sup>

In order fully to understand what the assumptions underlying intelligence tests are and the purpose which their use serves in our society it is necessary to go beyond analysing the implicit assumptions and examine the historical development of tests. It is only then that the social, political and ideological underpinnings of the testing paradigm become clear.<sup>25</sup> Furthermore, we need also to examine why intelligence tests were developed in the first place - the perceived need that they were developed to meet. (This is discussed more fully in Chapters 5 and 8). Adequate accounts of the development

of intelligence tests and the implicit and explicit ideologies underlying them have already been developed elsewhere<sup>26</sup> so it will only be necessary, at this point, to look at this briefly in order to demonstrate the importance of these factors in the field of mental subnormality.

Intelligence tests were first 'successfully' constructed in the early twentieth century by Binet in France, who was concerned with selecting those children who were incapable of benefiting from 'normal' schooling and needed 'special help'. However, Galton, a geneticist and the 'father' of Eugenics, had already 'unsuccessfully' attempted to develop tests of general intelligence designed to help select the 'fittest' in a programme of positive eugenics. (The factors leading to the perceived need for programmes of 'positive' eugenics and the influence of the eugenics movement on attitudes toward and the 'treatment' of the mentally handicapped and especially the 'feebleminded' is developed more fully in Chapter 5).

Thus, as Boring<sup>27</sup> points out, intelligence tests were originally developed by non-psychologists, and in opposition to the experimental psychology dominant at the time. Indeed, from the start experimental psychologists questioned the scientific status of intelligence tests. Although the tests, introduced into the United States in 1916, were used widely during the first World War, by the 1920's faith among psychologists in the tests had begun to diminish.<sup>28</sup> Following the publication of the Yerkes Report, which argued that the average American only reached the level of a fourteen year old and that this fact put democracy in jeopardy, and of data which suggested that recent immigrants from Eastern and Southern Europe had average mental ages lower than those of previous immigrants from England and Western Europe, debate ensued.



During 1922 and 1923 an enormous controversy flared over this, but it died down as quickly as it flared up. Despite these developments the variety of tests continued to expand and the day of the pre-eminence of I.Q. tests was at hand. The partial schism between experimental psychology and psychometrics was healed after the second World War, according to Boring,<sup>29</sup> because testing provided employment for psychologists and because, whatever their theoretical inadequacies, tests appeared to work. As a result, experimental psychology no longer 'looks down' on testing. The cynically minded might suggest that this change of heart is not because they now regard intelligence tests as scientific but because testing provides not only jobs for psychologists but also a professional role in medical, educational and criminal institutions.

Intelligence tests were not originally developed as part of a scientific attempt to understand the nature of human intelligence. Galton<sup>30</sup> explicitly set out to 'prove' that intelligence was a biologically fixed inherited capacity, found in different proportions throughout society. The upper classes were innately superior in intelligence, the lower classes innately inferior. The former, therefore, 'deserved' their wealth, influence and high social status as they had 'won' in the fight of the 'survival of the fittest'. Intelligence tests can be seen as part of an extension of social Darwinism, of the struggle for the replacement of 'religious' by 'scientific' explanations. To have suggested in late nineteenth century England that intelligence was not due to genetic inheritance (scientific factors) would not have been to suggest that environmental/ social factors were relevant but to have accepted that ability and indeed social stratification was determined by divine intervention.

Intelligence tests were being developed shortly after the introduction of mass schooling (see Chapter 5) and society was concerned about those who 'failed' to benefit from schooling and who frequently came from 'social problem' families. While Binet wanted to develop intelligence tests to 'discover' and help children who were unable to benefit from schooling in the 'normal' classroom, Terman, who translated the Binet test into English in 1916 (The Stanford-Binet Test), explicitly wanted to use the test to identify the permanently defective individual who posed a threat to civilization.

It is safe to predict that ... intelligence tests will bring tens of thousands of these high-grade defectives under the surveillance and protection of society. This will ultimately result in curtailing the production of feeble-mindedness and in the elimination of an enormous amount of crime, pauperism and industrial inefficiency ... the high-grade cases of the type now so frequently overlooked, are precisely the ones whose guardianship it is most important for the state to assume.<sup>31</sup>

Thus intelligence tests were quickly seen as a 'scientific' tool to identify this group who proved a threat to society and from whom society needed to be protected.

Not only were intelligence tests used to 'discover' and segregate the mildly subnormal - a group thought to pose a threat to civilization - but they also assumed that school 'success' and 'failure' showed who was and was not intelligent. The test items, assumed to measure an innate, fixed capacity, were selected so that they confirmed teachers' judgements of which children were 'bright' and which ones 'dull'. However, the ability to do well at school is related to many factors other than the assumed 'innate' intelligence, ranging from physical factors such as ability to see and hear to individual attitudes to school and teachers' expectations of pupils' progress.<sup>32</sup>

The weakness of intelligence tests as diagnostic and predictive tools results from the underlying assumptions about the nature of intelligence.

Psychometricians

... claim, on the one hand, that it makes no assertion about essential intelligence, and that what it refers to is simply measured intelligence. On the other hand, however, it protests that this measured intelligence has no reference to practical, social and political context<sup>13</sup>

and

When a psychometrician protests that what he says about measurable differences has no political significance but simply refers to the facts which may be classified as true or false, the intelligence test to which he refers is, as a matter of empirical fact, used in practical contexts to assign children to different forms of education, to choose between one individual and another in job placement, and generally to set one man above another. What he does when he rates individuals or groups of individuals on a scale of measured intelligence is to say and predict that one group of individuals rather than another should have privileges ... scientific observations have political implications and the scientist should be aware that that which he reveals may contribute to or ease human suffering.

Psychometricians see intelligence as a 'thing', an attribute possessed in a given quantity by an individual, not as a function of a social matrix - behaviour which is sanctioned and approved by certain powerful groups in society. Intelligence tests were originally developed and continue to justify the status quo. They are used to select and classify individuals and

The function of such selection is not to diagnose the truth, but to prove the inevitability of the status quo.

## 2.4 Intelligence tests and labelling

Intelligence tests are used, especially in the case of the mildly handicapped, to confirm their status by labelling them officially as subnormal. This is an initial process in the individual's career - the outcome of the test, conferring deviant status, determines the way that the individual is 'dealt' with in the future and may influence his self-image. Labelling need not have negative consequences for the individual; it can have positive results - enabling the individual to be allowed to develop his potential. In our society, however, to be labelled subnormal is to be denied opportunity, to be cast aside, to be provided with insufficient help and services and to be labelled as someone who will never develop 'adult' competence. (See Chapter 6 for a discussion of current provision for the mentally handicapped).

The continued use of psychometric tests, then, can clearly be seen as related to what society 'chooses' to do with those it labels mentally handicapped. While the main outcome of selection and processing is classification, and not the development of programmes designed to facilitate individual growth and development, then they remain inadequate. This relates not only to our knowledge or lack of knowledge about how to help the incompetent, but also to how much economic investment and time society is prepared to put into helping a group who are seen as being able to contribute little to society in return.<sup>34</sup>

## 3. Alternative psychological approaches to Mental Handicap

So far I have attempted to highlight a number of practical and theoretical problems that arise from the dominance of the clinical and psychometric models of mental handicap and the use of intelligence tests as diagnostic/placement tools. I have suggested that one reason that intelligence tests continue to be used is

because they serve an ideological and political purpose in our society, in that they provide a 'scientific' justification for the status quo. They rationalise the existing distribution of social, economic and political power - the social class system. In a sense the mentally handicapped are victims of this process.

This does not mean that if we stopped using intelligence tests, or indeed medical and psychometric assessment, then the mentally handicapped would magically disappear. Those who are incapable or have problems with coping with the day-to-day demands of our society would continue to exist, and many would still be seen as contemptuously different. They would still need special help and support, the exact amount depending on the degree of their handicap. However, a radical re-orientation of basic assumptions and methods of assessment could result in more 'adequate' help being given to the mentally handicapped and the development of more positive attitudes towards them.

What does seem to emerge is that the medical and psychometric models merely confirm the status of the mentally handicapped and implicitly contain the notion that little can be done to 'improve' the situation. Furthermore, the use of intelligence tests to assess and classify the mentally handicapped does not help in the development of programmes designed to enable the mentally handicapped to develop their full potential. In the case of the mildly subnormal the social and cultural bias of intelligence tests means that many children are labelled, not because of social incompetence, but because of their general inability/unwillingness to conform to the middle-class norms, values and expectations of the school system. The dominant models of mental handicap mean that people are seen primarily in terms of what is wrong or abnormal about them rather than in terms of the community in which they live, the ways in which people behave towards them, and the needs arising from them.

C  
JBR/MP

The dominant models support the status quo in that the subnormality of the individual, rather than the inadequacies of the environment are 'blamed' for his failure and inadequacy.

Focussing on the differences between people, in preference to the similarities, is a form of exclusion - exclusion from the possibilities of a shared reality. In this way our common ways of thinking about mentally handicapped people reflect society's exclusion of them from any shared life.<sup>35</sup>

I have suggested that the continuing dominance of these models and especially of the intelligence test in the field of mental handicap results from an apparent lack of an alternative model. The role of the psychologist continues to be that of testing, partly because that is what is expected in the system and partly because no alternative method of assessment has yet been adequately developed.

The need for alternative approaches to assessment springs on the one hand from the failure of the intelligence test to provide information which can be positively harnessed to the design of a programme of education or habilitation, but also arises from the need for assessment techniques which allow for an ideographic approach to the wide individual differences found within the mentally handicapped population.<sup>36</sup>

The interesting point to raise here is that there are alternative theories of cognitive development which may be of practical use in the field of mental handicap, but few psychologists have carried out research into their implications for subnormal people<sup>37</sup> (although on the practical side Piagetian theory has influenced educational practices in Great Britain for about the last twenty years and behaviour modification is being used increasingly, especially in the training of the more severely handicapped). My purpose is not to provide a comprehensive review of all possible alternative theories of development, but to show that such theories do exist and in a preliminary way to raise the question of why their implications for the mentally handicapped have not been more fully explored. I would suggest that this relates to dominant attitudes

and values, which place the mentally handicapped low on any priority list that involves public spending.

### 3.1 Behaviourism and behaviour modification

A radically different psychological theory from that on which psychometrics is founded, and which has greatly influenced programmes of remediation and the education of mentally handicapped people, is behaviourism. Behaviourism is an empiricist school of psychology interested in the observation of tangible behaviour and in changing such behaviour by modifying the environment rather than the individual. The approach emerged at the end of the nineteenth century in reaction against the assumptions made by many psychologists of a world of the mind to explain man and his doings and a physical world to explain animals and mechanical objects.

Watson was one of the first behaviourists (in fact he coined the term)<sup>38</sup>. Impressed by the success of the natural sciences he determined to make psychology a science of human behaviour and rejected introspection, pointing out the difficulty of self-observation and its unreliability. He argued that psychology should restrict itself to studying things which can be observed and to formulating laws concerning these things and only these things. Although after him behaviourism tended to move away from the extreme emphasis on visible behaviour and the avoidance of mediating concepts, he represents its early spirit, intentions and hopes. He was an extreme environmentalist and stressed the fundamental equality of man and the possibility (and desirability) of social engineering. Watson laid down the main tenets of the theory in his book Behaviourism, published in 1924, although an article which he wrote in 1913 set out an earlier formulation. Consequently he was writing at just the time when hereditarian thought was influencing social policy and the development of intelligence testing. Indeed, he expressly rejects and argues against eugenic arguments:

Does the behaviourist mean to say that great talent is not inherited? That criminal tendencies are not inherited? Surely we can prove that these things can be inherited?...The behaviourist recognises no such things as mental traits, dispositions or tendencies. Hence, for him, there is no use in raising the question of the inheritance of traits...<sup>39</sup>

and

Objectors will probably say that the behaviourist is flying in the face of the known facts of eugenics and experimental evolution - that the geneticists have proved that many of the behaviour characteristics of the parents are handed down to the offspring...Our

reply is that the geneticists are working under the banner of the old 'faculty' psychology...We no longer believe in faculties, nor in any stereotyped patterns of behaviour which go under the names of 'talent' and inherited 'capacities'.

Furthermore, he argued that it was possible, by changing the environment, to determine the cognitive development of the child.

I should like to go one step further now and say 'Give me a dozen healthy infants, well-found, and my own specified world to bring them up in, and I'll guarantee to take any one at random and train him to become any type of specialist I might select - doctor, lawyer, artist, merchant-chief and, yes, even beggarman and thief, regardless of his talents, penchants, tendencies, abilities, vocations and race of his ancestors.

Thus Watson redefined psychology as the study of behaviour and placed an emphasis on controlling as well as predicting it; moreover, he argued that every psychological event could be described in terms of stimuli and responses. Watson was a populariser of psychology, and from the 1930s to the 1950s American psychology was dominated by behaviourism, which indeed continues to be an influential theory.<sup>40</sup>

It is the notion of controlling or altering behaviour by modifying the environment that has had practical application as Behaviour Modification. The practice of behaviour modification is influenced by behaviourism in that the behaviour therapist is not concerned with the underlying causes of behaviour, but with overt behaviour which they assume to be controlled by social forces and consequently open to manipulation by operant conditioning. In evaluating behaviour the focus is on the immediate, observable and measurable behaviours that characterise the individual's present functioning or malfunctioning. The aim is to control unacceptable behaviour - which is assumed to be the result of a failure to learn.



Thus the essential features of the behaviour modification model are first that behaviour is learned, secondly that it can be analysed and changed, and thirdly that it is best learned through positive reinforcement. It is influenced by behaviourism in that it accepts a deterministic account of human development - Skinner's 'mechanical maturation' - and that it has adopted the scientific method and the language of behaviourism - that is, the primacy of the observable remains, despite some modification. However, it must be pointed out that a number of writers<sup>41</sup> have argued that the basic principles of behaviourism are largely irrelevant to the practices of behaviour modification, which are developed and refined on the pragmatic basis of what seems to work best in the situation.

In the field of mental handicap the behavioural model provides a basis for remediation because it accepts that behaviour can be changed and provides the tools - conditioning techniques - for doing so. Therefore, unlike the psychometric approach, which emphasises that the mentally handicapped child cannot perform and reinforces an underestimation of potential, behaviour modification sees the child as having the potential to be changed - to have his behaviour modified so that it becomes acceptable - as well as the ability to be taught new skills.

Subnormal behaviour is seen as a failure of learning. Aetiology and history are critical only to the extent that they may affect the formation of stimulus-response relationships. A full analysis of the current behaviour and the factors maintaining it may reveal procedures which will overcome apparent limiting biological factors...<sup>42</sup>

Behaviour modification techniques have been used successfully with the mentally handicapped in America and Britain, though questions have been raised as to whether operant techniques or other factors are responsible for the observed changes.<sup>43</sup>

### 3.2 Social competence as the defining variable

Brooks and Baumeister<sup>44</sup> have suggested that as mental subnormality is a social phenomenon, then in order to determine who is mentally handicapped we need to work from the basic premise that the important point is the

view of deviance held by families, friends, educators and the members of society in general. The mentally handicapped are those whose behaviour does not conform to the conventional rules of 'normal' behaviour. In order, then, to diagnose mental handicap it is necessary to develop tests of social competence and adaptation which make 'explicit' what skills are necessary to cope in the 'real' world.

Apart from the 'fact' that there is a tremendous financial and intellectual investment in I.Q. tests and that it is difficult to see how they could easily be supplanted, tests of social adjustment would still be culturally biased, relative, and involve social judgement. They would suffer from many if not all the defects from which I have suggested I.Q. tests suffer. We would merely be replacing one test by another.

A more recent development has been the suggestion that we abandon tests altogether and observe behaviour instead; that ethological and ecological studies of the assumed mentally subnormal in their 'natural' surroundings be developed. Sackett<sup>45</sup> has pointed to the advantages of these methods

...these data (I.Q. scores) do not answer questions about what mentally retarded people actually do with their motor, perceptual, learning, communication and social skills ... quantitative observational methods can be used to address both basic research questions concerning mental retardation and to help solve practical problems of retarded people. These practical problems involve economic, political ecological, social and ethical decisions concerning the life styles of retarded people living in a complex society'

The main contribution of such studies in the field of subnormality is to demonstrate just what subnormal people are capable of doing. The small amount of research already carried out within these perspectives suggests that even profoundly subnormal people can be trained to earn a living, while living independently in non-institutional residences.

These methods still use a quantitative, scientific approach, however, and Edgerton and Langress<sup>46</sup> have pointed to the disadvantages of these methods and the advantages of ethnographic studies. There would appear to be four main problems. Firstly, they do not consider reactive behaviour: how other people react to the mentally handicapped and how this in turn influences the behaviour of the subnormal. Secondly, the method is expensive and difficult to use in public settings. Thirdly, it distances the meaning of behaviour because it chops continuous human behaviour up into discrete units or categories to facilitate counting, and these discrete units are then combined into higher order concepts, a process which results in further distortion. Fourthly, the observer is outside of the phenomenon he is studying; he is recording sequences of behaviour strictly in terms of the observer's understanding of them and therefore cannot penetrate the world of meanings which guide human behaviour.

Edgerton and Langress<sup>47</sup> suggest that ethnography is a more appropriate method for understanding the everyday lives of the subnormal and determining what they are capable of. Edgerton's<sup>48</sup> own research has already demonstrated that 'success' in the community is not easily determined: factors such as I.Q., length of time institutionalized and even the ability to get and hold down a job are not especially good indicators.

If we can 'discover' the important variables in successful community adjustment, then it could be possible to develop remedial programmes to help prepare the mentally handicapped to live independent or semi-independent lives.

While observational studies, whether from the 'outside' or the 'inside', would seem to have distinct advantages over tests, both in terms of assessment and/or developing programmes of remedial treatment, few have been carried out. This is probably related to the time and cost involved as well as the lack of research

interest in subnormality on the part of psychologists and sociologists.

### 3.3 Mental Handicap as arrested or incomplete development

Morrison and MacIntyre<sup>49</sup> have suggested that an alternative to the psychometric approach to intelligence is Piaget's emphasis on the way in which intelligence develops. This approach leads us to search for the conditions and experiences necessary or valuable for the development of intelligence. Piaget's model is a developmental theory of intelligence which postulates a definite sequence of developmental stages, a sequence which is invariant for all individuals. Intelligence, in the Piagetian model, is an attribute of an active organism in some environment. Thus, in common with most theories of intelligence, the theory assumes that the organism develops in a kind of quantitative way - that is, the individual is born with a certain way of handling experiences and in development there is an increase in the amount of data to be handled. Piaget, in addition, proposes a development of the ways in which data are handled. These data-processing methods constitute intelligence.

The two complementary core processes are assimilation (organization of experience in terms of existing schemata) and accommodation (the reorganisation of schemata through disequilibratory experience). When there is a balance between assimilation and accommodation the organism is said to be in a state of equilibrium. The basic structural unit of intelligence, the schema, is a response pattern which is said to have both behavioural and physiological aspects. Schemata are named by the sequences of behaviour to which they refer. Some schemata are innate. The innate schemata are processed and produce new schemata, a process responsible for all intellectual growth.

Thus in Piaget's work there is an emphasis on the activity of the organism and on interactions between the organism and the environment in which the individual

is constructing his own schemata.

But the psychological facts allow us to refute this hypothesis of complete social determinism. Society does not act on growing individuals simply by external pressure, and the individual is not, in relation to the social any more than to the physical environment, a simple 'tabula rasa' on which social constraints reprint readymade knowledge.<sup>50</sup>

Piaget's work is based on the view that

...cognitive development is a coherent process of successive equilibriums of cognitive structures, each structure and its concomitant equilibrium deriving logically and inevitably from the preceding one.<sup>51</sup>

This development proceeds through a number of discrete stages - an invariant sequence with each stage typified by particular ways of behaving. However, these stages are not tied to chronological ages.

Piaget's interest was in developing a system which would account for 'typical' development, rather than with the factors that would result in variations in this pattern. However, an organism/environment interaction model which takes account of the variability of environments could lead to the view that intelligence develops in a non-linear manner, which would challenge the view of static intelligence and demonstrate the poverty of chronological age-based tests. Thus

the main difference between Piagetian theory and the theory behind traditional I.Q. testing is that the latter holds that development is a progressive, continuous process, whereas Piaget's argues that development involves frequent repetitions and even reversals, with an older child at times doing less well than a younger child on the same task.<sup>52</sup>

It is important to raise the question as to how the Piagetian school view the subject of continua in developmental disorders as well as in the normal child, and how this relates to remediation/education programmes. (This is especially important given the influence that Piagetian psychology has had on educational practice in Britain in the last twenty years). The main work in this area has been by Inhelder<sup>53</sup>, a close collaborator of Piaget's. Working with mentally handicapped

children and young people it was possible to demonstrate that children with different grades of defect were qualitatively distinct from one another in terms of their mental operations in ways analogous to stages that Piaget had described in the development of the normal child. Mental handicap did not only involve different degrees of intellectual backwardness, as defined by some linear scale; there are different kinds of mental retardation that differ both from each other and from the normal.

Rees evaluates the contribution of Piaget's developmental psychology for mental retardation and argues that

The final test of the value of a Piagetian interpretation of mental retardation must depend on an evaluation of its effectiveness in increasing our understanding of retardation as well as providing new and better tools for dealing with its attendant problems ... thus far there has been only a slight beginning in investigating this.<sup>54</sup>

He suggests that the value of Piagetian tests for evaluating the mentally handicapped has yet to be established and that if they are to be of value they must help in the development of remedial programmes. With regard to special education, the available evidence suggests that accelerating development is not possible, but Piaget's theory adds emphasis to the view that children learn by experimentation and provides a basis for developing remedial programmes for educating the mentally handicapped. Furthermore, Inhelder's work with retarded children suggests that mentally handicapped children differ from each other and from normal children in terms of their mental operation, and this has important implications for prognosis and consequently for education. It highlights the fact that there are different kinds of mental backwardness, with correspondingly different educational requirements.

### 3.4 The work of Luria

Luria<sup>55</sup> has stressed that human learning takes place primarily by means of language in social intercourse, in a man-made setting which itself incorporates the achievement of human development. He argues that the human child learns through joint practices and speech with human beings and it is by means of the language he acquires, the tools he learns to handle and so forth that the achievements of the human species are embodied and passed on.

The emphasis is on the formation of complex functional systems, found in the course of development, which underly qualitative changes in mental process. Luria rejects the view that mental characteristics are simple manifestations of internal properties which develop in the course of maturation independently of living, and argues that intellectual development, in the process of learning, marks a change to qualitatively new levels of thought.

There are four basic features of this approach to development. The emphasis is on human learning. There is a stress on the role of speech in the process of mental development. It is a developmental approach, and there is an emphasis on longitudinal methods of research.

Luria works from Pavlov's basic assumption that it is language which distinguishes man from the animal. He suggests that there is a direct link between the development of language and the ability to reason. This relationship develops out of and alongside social-mental development. Mental and linguistic development reciprocally determine each other, though they are never synonymous. But it is the development of language that enables man to represent the world to himself, to develop the ability to transcend the here and now, and to go beyond immediate experience. Therefore, there is a close relationship between linguistic development and complex

---

human behaviour. The development of complex mental processes is dependent on the development of language.

The development of mental processes is a result of complex interactions between the individual and his environment, and is not an innate property of mental life that develops with maturation. At each stage of development, concrete forms of activity are presented to the child which pose new problems and new demands; these in turn necessitate the development of new forms of reflex action. A child's mental activity must be seen as the outcome of his life in certain determined social circumstances; human-mental activity takes place in conditions of actual communication with the environment, in the course of which the child acquires from adults the experiences of many generations: language, which incorporates the start (for example, the naming of objects). The child's speech develops in practical activities - in play - in the here-and-now. Later it can be used to predict, and this enables abstraction. Speech, which reflects objective reality, directly influences the formation of complex human activity; it enables the development of abstract thought to take place, which introduces a new process of activity - abstraction - which raises mental processes to a new level.

Luria was able to develop his theory of cognitive development by research in rural parts of the U.S.S.R. in the 1930's when collective farming and mass literacy programmes were being introduced. He was able to compare the cognitive development of peasants who remained illiterate with those who took literacy courses and worked on collective farms. By doing this he was able to demonstrate that the ability to think complexly and abstractly developed with socio-economic development. The structure of all thought, then, depends upon the structure of the dominant type of activity in different cultures. Practical thinking will predominate in societies that are characterised by practical manipulation, whereas the more abstract forms of theoretical activity



in technological societies will involve more abstract thinking. There is, then, a parallel between individual and social development and this enables the interpretation of behavioural differences in developmental terms.

It seems surprising that the science of psychology has avoided the idea that many mental processes are social and historical in origin, or that important manifestations of human consciousness have been directly shaped by the basic practices of human activity and the actual forms of culture.<sup>56</sup>

Luria argues that psychology, in its attempt to be an exact science, has looked for laws of mental activity within the organism and has ignored the social origins of higher mental processes. Psychologists have argued that the patterns determining mental processes are the same for all human subjects, whether from different cultures or from different historical periods, and the same for elementary mental processes as complex forms of mental activity. But Luria suggests that it is necessary to understand

...that higher cognitive activities remain sociohistorical in nature and that the structure of mental activity - not just the specific content but also the general forms basic to all cognitive processes - change in the course of historical development.<sup>57</sup>

Consciousness does not represent an intrinsic property of mental life, invariably present in any mental state and independent of historical development. It is the highest form of reflection of reality - not given in advance, unchanging and passive, but shaped by activity and used by human beings to orientate themselves to their environment, not only in adapting to conditions but in restructuring them.

...mental processes depend on active life forms in an appropriate environment.<sup>58</sup>

In the same way as human action changes the environment, so human mental life is a product of the continually new activities which manifest themselves in social practice. New motives for action appear under extremely complex

patterns of social practice, as new problems are created, new modes of behaviour, new methods of taking in information and new systems of reflecting reality develop.

Thus the social forms of human life determine human mental development. From birth, children live in a world of things which social labour has created and which are the products of history. They learn to communicate and to develop relationships. They assimilate language, which is itself a product of socio-historical development, and use it to analyze, generalize and encode experiences. Language moderates human perception and enables complex mental operations to develop - the analysis and synthesis of incoming information, the perceptual ordering of the world, the encoding of impressions into systems, and the abstract representation of objects and events.

Luria's and Vygotsky's<sup>59</sup> study of twins with speech defects enabled them to demonstrate the changes in the twins' cognitive development which occurred as they acquired complex speech patterns. At the age of 5 years the twins could only use primitive speech, interlocked with concrete actions. They had an insufficiently differentiated structure of consciousness; they were unable to detach word from action, to master orientation or planning activities, to formulate the aims of activity with the aid of speech and so to subordinate their future activity to mental formulation. They were not able to organise complex play of a kind usually indulged in by 5-year olds, and were unable to take part in or organise production of meaningful activity. Their intellectual abilities were very limited and well below those 'normally' developed by 5-year olds. In other words, they could be said to be mentally subnormal.

The twins were separated, and as a direct result the rapid acquisition and use of language developed. The 'primitive' speech they originally used receded into the background and 'normal' language structure developed.

Not only was there a substantial improvement in speech, in terms of clarity, grammar and structure, but speech was also fulfilling a new function. In place of speech interlocked with direct activity and expressive speech, they developed first narrative and then planning speech. More significantly, the whole structure of the mental life of the twins was simultaneously and sharply changed. The acquisition of an objective language system enabled them to formulate the aims of their activities and to begin to construct meaningful play. The possibility of productive, constructive activity on the basis of formulated aims was opened up.

Therefore the results of our experiments show that with the creation of an objective necessity for speech communication, the children were satisfactorily prepared for the acquisition of a language system: not only did they develop new forms of communication with the aid of development verbal speech, but also there were called forth significant changes in the structure of their conscious activity, built upon the basis of verbal speech.<sup>60</sup>

Luria<sup>48</sup> rejects the use of I.Q. tests and argues that a test score tells us nothing about the child or how to solve his or her problems. Furthermore, he suggests, to assume that children who have the same I.Q. in common are equal is a mistake. He argues that attention needs to be given not only to diagnosis, but also to the prognosis of the developmental potential of subnormal children. Thus the causes of subnormal intellectual functioning may be biological and/or environmental factors, and diagnosis must be clearly linked with future treatment. That is, the 'cause' of poor school performance/social adaptation should determine the future programme of remedial help and treatment. A child who is making slow progress at school because of loss of schooling due to illness will need different treatment to that of a child with the same I.Q. and school performance but who has brain damage, or again from a child who comes from an adverse environment.

But how does Luria's (and Vygotsky's) theory of cognitive development help us in the diagnosis of mental

subnormality and the provision of remedial programmes? Luria argues that only those with brain damage or genetic abnormality are 'true mental subnormals'; those whose subnormality is the outcome of an impoverished environment are merely handicapped.<sup>61</sup> It is in understanding and helping this latter group that the theory would seem to have relevance. It enables us to understand how cognitive development is related to the demands of the environment, and the importance of language acquisition for intellectual development. However, it is important to remember that dialectical materialist psychology is about much more than language and incorporates a stage theory of development. Furthermore, the defectology derived from it in Russia does not have an emphasis on language development as its main focus<sup>62</sup>.

### 3.6 Conclusion

It is then evident that theories of cognitive development other than the psychometric one have been developed within psychology, but that relatively few attempts have been made to investigate the implications of these theories for assessing and helping mentally handicapped people. Furthermore, as Ryan has suggested, even when psychologists have attempted to devise programmes aimed at developing teaching/remedial education

The focus ... is still very much on changing the behaviour of each mentally handicapped individual, the behaviour of others ... or the effects of the total environment, are seldom investigated. And because most psychological approaches do not have a sufficiently comprehensive view of what it is like to live one's life as a mentally handicapped person ... the measure of success hoped for does not always materialize.<sup>63</sup>

### 4. Conclusion: The need for a sociological approach

In this chapter I have attempted to evaluate, from a sociological perspective, the inadequacies of the dominant medical and psychometric models of mental handicap. This is not to suggest that the severely subnormal, and even many of the moderately subnormal, do not have an organic basis for their handicap, nor that if we abandoned these models incompetence would magically disappear.

However, both these models assume rather than explain the existence of a 'real' condition of handicap - even if there were such a condition and it had an organic basis, that would still not explain why it is a social problem in our society. Furthermore, the assumptions of these models - that mental handicap is incurable - influence the care and provision made for, and perceptions of and attitudes towards, mentally handicapped people.

One of the main diagnostic tools used in the field of mental handicap is the intelligence test. While many academic psychologists acknowledge that these tests are an inadequate instrument for the diagnosis and classification of mental handicap, and are virtually useless for aiding the development of remedial programmes, they continue to play a dominant role. This cannot be explained by the 'fact' that there is a lack of possible alternatives. Psychologists have developed alternative theories of cognitive development, which would seem to contain the possibility of providing more adequate tools for diagnosing mental subnormality and providing guidelines for remedial educational and training programmes. It is therefore necessary to ask why psychometric tests continue to play such a dominant role in the official diagnosis and classification of the mentally handicapped. I have already suggested that this is related to the ideological and political structure of our society, and later in this study I shall also argue that it is inextricably linked to the way in which, and the reasons why, the mentally subnormal are seen as outsiders and managed as deviant in capitalist societies.

Thus while psychologists have been concerned with the selection and classification of individuals for management within a given system, it is the role of the sociologist to explain why classification takes place on a given basis, and the consequences of this for the individual, his family and society in general. While psychologists will argue that the mentally handicapped are those who are diagnosed to be incompetent on the basis of a 'scientific' measure, sociologists are interested in the processes by which someone becomes labelled and the

'purpose' of labelling. One of the contributions sociology can make in the field of mental handicap, then, is to evaluate the dominant models, to lay bare their underlying assumptions, demonstrating the way in which their use helps to maintain the status quo and influence social perceptions of and community attitudes towards the mentally handicapped.

#### REFERENCE NOTES, CHAPTER THREE

- 1: Deacon, 1974
- 2: See Block and Dworkin, 1972
- 3: This is not strictly true - some schools do test all children routinely - but as far as I am aware this is not the policy of any Local Educational Authority.
- 4: See Tomlinson (1981) for an analysis of the process by which children are labelled E.S.N.(M) in England.
- 5: Mittler, 1980
- 6: Mittler, 1973. See also Locke, 1978, and Tomlinson, 1981.
- 6a: Chazan, <sup>(1979)</sup> in a recent survey, found that the main role of educational psychologists was assessment and that they spent a relatively *small proportion of their time in direct and indirect 'treatment' activities.*
- 7: Clarke and Clarke, 1973a. P5
- 8: Clarke and Clarke, 1973a.
- 9: O'Connor and Tizard, 1956
- 10: Jordan, 1974.
- 11: See Scull (1975, 1977, 1979), Parry and Parry (1976).
- 12: Sarason and Doris, 1969 P24
- 13: N.S.M.H.C., 1974
- 14: Clarke and Clarke, 1975 P24-30
- 15: e.g. Bowles and Gintis, 1976
- 16: E.G. Rosenthal and Jacobson, 1968; Luria, 1976.
- 17: Luria, 1976.
- 18: Sapsford and Evans, 1979 P13
- 19: See, e.g., Stein and Susser, 1960; Coard, 1971; Mercer, 1973; Tomlinson, 1981.
- 20: Mittler, 1973 PV
- 21: Ryan, 1976
- 22: Rose et al., 1976
- 23: Ryan, and Thomas 1980 P124
- 24: See Mittler, 1980, for a more detailed discussion of this point.
- 25: For a more extended critical discussion see, e.g., Kamin, 1974; Lawler, 1978; Evans and Waites, 1981.

- 26: See, e.g., Block and Dworkin, 1972; Kamin, 1974; Lawler, 1978.
- 27: Boring, 1950
- 28: E.G. Block and Dworkin, 1972
- 29: Boring, 1950
- 30: Galton, 1869
- 31: Terman, 1919 p<sub>s</sub> 6-7
- 32: See, e.g., Rosenthal and Jacobson, 1968
- 33: This and the remaining quoted passages in the paragraph are from Rex, 1973.
- 34: See Shearer, 1981, for a discussion of how state financial benefits are weighted in favour of those who are economically active.
- 35: Ryan and Thomas, 1980 p<sub>27</sub>
- 36: Mittler 1973 p<sub>12</sub>
- 37: Indeed, some of these 'theories' do not conceptualise development in these terms at all, but are more concerned with trainability.
- 38: Watson, 1913
- 39: This and the following quoted passages are from Watson, 1924  
p<sub>s</sub> 93, 104 and 113
- 40: For example, Skinner, 1972.
- 41: E.G. London, 1972; Schweiso and Hastings, 1980
- 42: Kiernan, 1974 p<sub>731</sub>
- 43: See, e.g., Kiernan, 1974; Barason and Doris, 1979. For a recent critical review see also Strivons, 1981.
- 44: Brookes and Baumeister, 1977
- 45: Sackett, 1976 p<sub>s</sub> 3-4
- 46: Edgerton and Langress, 1976
- 47: Edgerton and Langress, 1976
- 48: Edgerton, 1967
- 49: Morrison and MacIntyre, 1971
- 50: Inhelder, 1958
- 51: Flavell, 1963 p<sub>s</sub> 36-37
- 52: Bower, 1979 p<sub>s</sub> 119-120
- 53: Inhelder, 1943
- 54: Reis, 1987
- 55: Luria and Vygotsky, 1961; Luria, 1976. See also Sutton, 1980; Douglas and Sutton, 1978.
- 56: Luria, 1976 p<sub>3</sub>
- 57: Luria, 1977 p<sub>114</sub>
- 58: Luria, 1976 p<sub>9</sub>
- 59: Luria, 1961
- 60: Luria and Vygotsky, 1961, <sup>p<sub>107</sub></sup> For a replication of the experiment see Douglas and Sutton, 1978.
- 61: Luria, 1961. This view also underlies official Soviet policy towards mental handicap; see, e.g., Katy, 1962; Sutton, 1980.
- 62: See chapter 8 and Sutton, 1980.
- 63: Ryan and Thompson, 1980 p<sub>s</sub> 127-128

## CHAPTER 4

### THE HISTORICAL APPROACH: THE CARE AND CONTROL OF THE MENTALLY HANDICAPPED IN PRE-INDUSTRIAL SOCIETY

#### 1. Introduction

In Chapter 2 I suggested that one of the deficiencies in much of the existing sociological literature in the field of mental handicap was that it had paid insufficient attention to history. Furthermore, I contended that in order to develop a sociological perspective it was first necessary to undertake a historically informed macro-sociological analysis of changing perceptions of the mentally handicapped. This derives from the view that it is not possible to understand the current situation of the mentally handicapped in our society without examining how they came to be so situated.

Therefore, in this chapter, I will examine historical perceptions and handling of the mentally handicapped up to the end of the eighteenth century. In the next chapter I will complete this historical analysis by examining changes in the nineteenth and twentieth centuries. The main purpose of this will be to argue that definitions of, attitudes towards and handling of the mentally handicapped have always been and still are a function of the nature of a society and its history. The currently dominant models of mental handicap, examined in Chapter 3, tend to assume that the concept 'mental handicap' has not been influenced by time, place and society. I will attempt to demonstrate that the identification, description and explanatory accounts of the people we now call mentally handicapped have varied as a function of time, place and social situation, and that to label someone as mentally handicapped implies a decision about a course of action. Thus all of these always and inevitably reflect a society's views at a particular time about what is right/wrong, appropriate/inappropriate behaviour.



it is of course not possible to 'prove' this without extensive cross-cultural comparison as well as historical analysis, but it will be possible to provide considerable confirmatory evidence.

### 1.1 The Identification of the Mentally Handicapped

One of the main problems in developing a historical perspective on mental handicap is that there is little evidence on attitudes towards the mentally handicapped and the handling of them before the nineteenth century. Apparently no clear distinction was made between the mentally handicapped and other groups of people who were seen as different or presenting a social problem. More specifically, it was not until the end of the eighteenth century that systematic attempts began to be made by medical men and others to distinguish between the mentally handicapped and mentally ill and to 'treat' them separately.

Legal distinctions were made between those who were permanently (and presumably congenitally) arrested in intellectual development and those who were temporarily incapable of assuming responsibility for their actions in the ancient world. A legal distinction of this type was also made in England in the thirteenth century. This distinction was made primarily for administrative purposes and it is doubtful if the categorization of individuals would correspond with modern distinctions.

In the seventeenth century Thomas Willis<sup>1</sup> maintained that it was vital for doctors to distinguish between the mentally ill and the mentally handicapped and suggested two separate clinical categories - the 'foolish' and the 'stupid'; the term 'idiot' however continued to be a generic term for the mentally ill and the mentally handicapped until well into the nineteenth century. Pinel<sup>2</sup>, the French physician who released the 'mad' from their chains at the Bicêtre Hospital in Paris at the end of the eighteenth century, made no clear distinction,

in his writing, between the mentally handicapped and the mentally ill. Hobson has pointed out that

insanity in McNaughton's day [1843] was commonly used, even by doctors, in such a way as to include 'imbecility' <sup>3</sup>

The English Lunacy Act of 1890 applied to the mentally handicapped as well as the mentally ill, despite the fact that by this time attempts to make a distinction between the two conditions were at least fifty years old. Indeed it is still common for the 'general public' to confuse or fail to distinguish mental handicap and mental illness, and Emerson<sup>4</sup> has suggested

...the distinction between the mentally ill and retarded is often difficult to make and impossible to prove even with the professional assistance available to us.

Thus, although there is clear evidence that the existence of people we now call mentally subnormal was recognised in pre-nineteenth century Europe, there is little indication that they were handled as a distinctly separate group. While the more severely handicapped would have been identified as obviously different, many would have died young, victims of the high infant and general mortality rates. The mildly subnormal would have managed in general to have appeared 'normal' but may well have been among those who were unemployed, especially in times of rapid socio-economic change such as the period of Enclosures in Elizabethan England and the beginning of the Industrial Revolution in the eighteenth century. They would have joined the unemployed beggars and vagrants on the margins of pre-industrial society, receiving charity in pre-reformation Europe and being incarcerated in the workhouse after the Poor Law Act of 1601. There is little evidence to support the view that the unemployed/unemployable were cared for by their families.<sup>5</sup> Indeed, in pre-industrial Britain the majority of the population merely subsisted, and a non-productive member

of the family would have imposed an intolerable burden.

It would seem justifiable to claim that while the definite identification of the mentally handicapped as a distinct separate category is a recent development, they have throughout recorded history been part of a socially marginal or deviant group. An examination of historical attitudes towards, and social provision made for these groups, with special reference to the mentally subnormal, should enable us to understand the relationships between socio-economic structures, socially constructed attitudes towards the subnormal, and the type of provision made for those labelled and managed as deviants. As Rosen<sup>6</sup> has suggested:

History derives from challenges experienced by various groups of people, and the ways in which they respond to them. The result is a variety of actions and reactions under different circumstances and in widely divergent ideological climates. Yet these actions and reactions have in one way or another brought us to the present - institutions, patterns of behaviour, systems of ideas - all have developed from something there before. Attitudes towards mental disorders, theories of mental illness, arrangements for the care of the individuals afflicted - all illustrate this tension which is too often overlooked.

A person's social perception is influenced by the core-values and orientations to life of the society or sub-society in which he participates. This has profound implications for the identification and management of deviants. It is not the pathology of the individual that determines how he is managed, but the attitudes and values of those who perceive him.

## 1.2 Historical Attitudes towards Deviants and their Implications for the Mentally Handicapped.

The mentally handicapped are in many ways deviants; they are apparently unable to behave in a 'normal' way in society. Indeed it is this inability that marks them

as outsiders needing special handling. Consequently if we are to understand trends within the field of mental handicap we need first to understand social attitudes towards deviants in general in any socio-historical situation. As Scull<sup>7</sup> has pointed out, it is not until the late eighteenth century that careful differentiation of different sorts of deviance was made, with the consequent consignment of each type to 'experts'. Thus in the pre-modern period little attempt was made to distinguish one type of deviant from another and they were all lumped together in a single ill-defined amorphous entity and responded to in essentially the same way. The reasons for this are, at least in the case of the mentally handicapped, probably two-fold: firstly, the difficulty of identifying causes of deviance, the problem of distinguishing between mental handicap and mental illness discussed below, as well as the probability that 'incompetence' was the 'cause' of vagrancy, begging and petty criminality; secondly, that the available means of 'control' were strictly limited - the major institution for 'warehousing' from the sixteenth to the nineteenth century was the workhouse, and the control of deviants was essentially a communal and family affair.

A historical analysis of man's attempts to deal with deviants can be categorized into: destroying the deviant; segregating him from society either to protect him or to protect society; attempting to make the deviant undeviant, ignoring the deviant in the hope that he will 'go away'. These categories are not necessarily mutually exclusive, and more than one method may be used in any given society. However, one method of dealing with deviants tends to be dominant, and changes in the handling of one group of deviants is usually duly followed by changes in the methods used to control other groups<sup>8</sup> of deviants.

There also appears to be a strong relationship between the way in which deviants are socially perceived and the way in which they are handled. Wolfenberger<sup>9</sup> has suggested that historically the mentally handicapped have, in different times and in different societies, been cast in several main roles. These roles are: incurably sick person; subhuman; social menace; object of pity; burden of charity; holy innocent; and developing person. The role that the individual is cast in, to a large extent, determines the way he is handled. For example, in early twentieth century Britain the mentally handicapped individual was seen as a social menace and was incarcerated so that society could be protected from him.

While it is clear that there is a relationship between social perceptions of deviants and the way they are controlled, what is less obvious is why the mentally handicapped are cast in different roles in different societies. What I intend to do in this chapter and the next (and to develop in a more theoretical way in Chapter 8) is to suggest that the available evidence strongly indicates that the way a society 'sees' its deviants is inextricably linked to the norms and values of a society, themselves a reflection of the dominant ideology. Szasz<sup>10</sup> has highlighted this in his discussion of changing attitudes to the mentally disordered in the seventeenth century, when the dominant Christian ideology with its associated belief in divine will was being challenged by science and its associated belief in reason.

Hence in the incorporated societies of the Age of Reason, science (technology) is the dominant institution, the scientist-intellectual is the interpretation of the laws of nature, schools, hospitals and technological certificates are the leading social symbols, scientific jargon is the official language, and sickness and health, treatment and cure, death and life are the images and rhetoric that fill the popular imagination. To be truly human now means to

worship science (technology, progress), to be virtuous means to be healthy (happy) and to be evil means to be mentally sick (unhappy).

## 2. The Ancient World

There is evidence that mental disorders were recognised in the Ancient World, although there is no documentation of any effort to assist those identified as mentally deranged. Palestine, Greece, and Rome all in various ways cast mentally handicapped people in the role of outsiders and responded to them as deviants. The subnormal were seen variously as objects of derision, aversion, or to be persecuted. The appellation 'idiot' implied horror and disgust and most of those who were labelled forfeited all human rights and privileges.

### 2.1 Israel

The Old Testament of the Bible<sup>11</sup> gives clear evidence that mental disorders occurred and were recognised as such in the ancient world. The available evidence, while providing no clues as to prevalence or exact diagnosis, does indicate how those identified and seen as mentally disordered were regarded and treated by the community.

A strong belief among the Jews was that those who disobeyed the *'will of God'* would be severely punished and that one form this punishment could take would be for the sinner himself or a member of his family to become mentally disordered. The birth of a mentally handicapped child was regarded as a 'punishment' for the sins of the parents.

Despite this, the attitudes of the ancient Israelites to strange, bizarre and inexplicable behaviour was to accept it even though it was seen as different. Mental disorder was regarded as a private, not a public, matter, unless or until public safety was involved. Mentally handicapped people with wealthy relations would have been cared for in the home, while those from poor families would have been turned out to fend for themselves, to be followed, teased and tormented by children, who regarded them as objects of ridicule.

## λ.2 Greece and Rome

The most extreme form of cruelty to the subnormal can be seen in the society of the Spartans (900 - 200 BC) who abandoned and killed anyone who was handicapped. Soon after birth a child was examined by the Town Elders who declared whether it was to be reared. Defective or weakly infants were cast in the river or left on the mountainside to perish. The whole philosophy of the society was 'survival of the fittest'. Infanticide can be seen as the most extreme form of dealing with the deviant or undesirable members of a society.

This practice was commonly advocated and acted upon in other Greek city states. In Athens, children who were blind, deaf or mentally dull were thrown into the river by their parents so that they could be relieved from the burden of their support, while the Greek poet Theogris of Megara wrote<sup>12</sup>

...yet a good man minds not to wed the evil  
daughter of an evil son ... Marvel not that  
the stock of our folk is tarnished for the good  
is mingling with the base.

and Plato<sup>13</sup> advocated biological selection to facilitate race improvement.

In Ancient Rome, too, eugenics was a common practice. In the old Roman law the mentally defective were designated 'mente-capti' (those defective in intellect), and the legal code involved guardianship and prohibited marriage.

## 2.3 Later developments

In the ancient world mental disorders were generally regarded as punishment from the Gods. The mentally handicapped were generally regarded as extra-social beings and commonly ostracized, derided, persecuted, neglected and considered incapable of human feelings and consequently undeserving of help. As sub-human they were not considered as part of the community and therefore were unable to participate in politics and to administer land.

Legally property was protected, but apart from this society generally ignored mental handicap. The ignominy of mental handicap also extended to the medical profession, as Weygenalt<sup>14</sup> has pointed out:

While writers in antiquity gave vivid and correct descriptions of specific psychic conditions ... idiocy has rarely been mentioned until recently.

and Cranefield<sup>15</sup> has noted that there is no clear description of cretinism in ancient medical writings despite the fact that it is evident that endemic goitre and cretinism existed in the Ancient World.

### 3. Early and High/late Middle Ages

The decline of the Ancient World and the fall of Rome was accompanied by the spread of Christianity, which became the dominant religious ideology of the Western world. The spread of Christianity and its underlying doctrine of compassion for the unfortunate led, for a while at least, to an improvement in the plight of the mentally subnormal. Along with other 'unfortunates' they were provided with clothing, food, shelter, and the Institutes of Justinian provided guardians for the mentally subnormal as well as the deaf and dumb.

However, tremendous variability characterized the treatment of the subnormal (as well as other social outcasts) during the medieval period. This ranged from treatment as innocents, to being tolerated as fools, to persecution as witches. Increasingly, however, behaviour that deviated from the norm was perceived as caused by Satan. The treatment of the mentally handicapped was closely related to the way in which they were perceived: when seen as a social menace they were persecuted as witches, while accorded special treatment when seen as sacred beings - 'les enfants du bon Dieu'.

In the medical literature there is little mention of any condition that we would recognise as alluding to the mentally handicapped, although in non-medical manuscripts



there is considerable evidence of the existence of endemic goitre and cretinism (a form of mental deficiency due to lack of iodine). From this literature we can glean some idea of the perception of, attitudes towards and treatment of the mentally subnormal. The oldest picture<sup>16</sup> of a cretin is 'Beuner Meisterloch' which dates from 1215. The picture depicts a figure with three large goitres and a stupid facial expression, holding a fool's staff in one hand.

In the thirteenth century the Encyclopaedias of Jacques de Victory and Thomas of Cantispre reproduced traditional descriptions of monsters and also included 'human monsters', that is cretins, who were included because of their deformities as well as their idiotic expressions. Konrad Von Magenburg<sup>17</sup> in an illustration published in 1349 includes a cretin among his fantastic monsters. Thus:

...a real phenomenon which the medieval observer regarded as a monstrosity was therefore included by him in the same category as fantastic and fabulous Indian monsters.<sup>18</sup>

While the extent to which the Christian ethic of charity and good works permeated the total social structure is difficult to determine, it is evident that some of the mentally handicapped would have been 'cared for' in monasteries and that others were employed by the wealthy as 'fools' and 'jesters'. It is likely, however, that the poor, superstitious peasants and serfs regarded bizarre behaviour as evidence of evil spirits and persecuted those who evidenced such behaviour as witches. Even when this did not happen, the burden of caring for those who were totally economically dependent would have resulted in their being turned out of the house and left to wander as beggars. Many of those we now label mildly or even moderately handicapped would, however, not have been labelled as different to the extent that they were treated as deviants. The majority of this group would have been able to work the land along with the

rest of the members of their community and carry out the other daily tasks requested of them.

### 3.1 Feudal England

The available evidence on the care and treatment of the mentally subnormal in Feudal England is very sparse - probably because the numbers actually identified as subnormal were very small and scattered widely in isolated communities. There is some indication that a few mentally defective people were cared for in the few hospitals, in the same wards as the sick and infirm, and that those who exhibited violent tendencies and bizarre behaviour were seen as a danger to themselves and society and were chained down for years and - it must seem to us - cruelly treated.

Medieval and early modern ideas and attitudes towards the mentally disordered have traditionally been seen as contaminated by demonological ideas about causation. Zilloog<sup>19</sup> has depicted popular attitudes and treatment of the insane as a mixture of superstition, cruelty, and abuse - a view which, according to Neugebauer<sup>20</sup>, is representative of most writers on the subject. However, Neaman<sup>21</sup> has challenged this view and presented new evidence which indicates that in many contexts of everyday life persons with mental disorders were viewed as physically ill and received kind and thoughtful attention.

However, the majority of the mentally defective, unable economically to support themselves or find relatives to support them, would have been left to wander the countryside and to seek Christian charity.

In the medieval period, the dependent ... relied heavily on haphazard and often ineffectual tradition of Christian charity and alms giving ... But neither the church or private individuals made any serious effort to match aid to need ... The family was held liable to provide for its own, and with the aid of temporary assistance or a more permanent subsidy from the community, it generally

did so. Only a few exceptionally burdensome cases, and those without family or friends to call on for support, might find themselves gathered up under one roof.<sup>22</sup>

With the gradual breakdown of Feudalism, from the fourteenth century the numbers of beggars and vagrants increased; many of these may well have been those we now label mildly subnormal, those who were least able to 'cope' with the changing socio-economic structure of society.

The care of those, including the mentally subnormal, who were unable to support themselves was generally undertaken by the church. Monasteries gave shelter and hospitality, and almsgiving was regarded as a Christian duty. Theign Oswald and King Alfred gave alms to the poor, while it was the custom of the Anglo-Saxon Kings to keep 'open house' several times a year. But by the fourteenth century, with what was seen as an alarming growth in the number of 'paupers' (the economically dependent population), local and central government became concerned with what was seen as a growing social problem. In 1349 the 'Ordinance of Labourers' stated that no-one was to give relief to able-bodied beggars (an unknown proportion of whom may have been 'incompetent') and in 1388 regulations were made restricting the movement of serfs, and the impotent poor were forbidden to wander and had to be given relief in the parish in which they resided in 1388. This brought about a marked change in the philosophy underlying charity. The impotent poor (the old, the sick and the obviously handicapped) were entitled to assistance out of public funds or from charities. The able-bodied, (a group that would have included the 'incompetent' as well as the idle) were not.

It was during the Feudal period that a legal distinction was made in English law between the mentally ill and the mentally handicapped. In Saxon and Norman<sup>23</sup> times it was the family's responsibility to keep a mentally disordered member under control and, until the drawing up of the

Statute of Prerogatives, to administer his property. The 'control' was, however, more concerned with the proper administration of property than with the supervision of deviant behaviour. Statute 17, Edward II, C9 & C10 1255, was concerned with the protection of property and not primarily with the care and handling of the mentally disordered.

The King shall have the custody of the lands of natural fools, taking the profits of them without waste or destruction and shall find them their necessaries, of whose fee over the land he shall holden and after death of each idiot he shall render the same to the right heirs so that such idiots shall not aliene, or their heirs be disinherited and a portion shall be distributed for his soul by the advice of the Ordinary.

This is section 11 which refers to 'natural fools', whereas section 12 sets out the arrangement for persons labelled 'non compos mentis'. 'Natural fools' were those defined as suffering from congenital intellectual subnormality, and persons 'non compos mentis' those who had developed their conditions postnally. Natural folly was assumed to be permanent, whereas persons 'non compos mentis' could experience temporary or permanent recovery.

Individuals suspected of mental impairment were examined by a jury of twelve or more members. The examination was set in motion by a writ issued by Chancery directed to the Sheriff, escheater, or to a commission, authorising an investigation of the mental status of the individual in question, to determine the exact extent, nature and value of his property. The specific medico-legal category in question was stated in the writ - several versions of a writ 'de idiota inquirendo' were developed. One version of the idiocy writ directed officials to inquire

...whether the said I be foolish and an idiot  
...or not: and if he be than whether from his  
nativity, or from any other time.<sup>24</sup>

Interestingly, the jury evaluated mental status on questions designed to test social competence. For example, when Emma de Beston, from Cambridgeshire, was tested for idiocy in 1383, she was asked

in what town she was ... how many days there were in the week ... how many husbands she had ... how many shillings there were in forty pence ... whether she would rather have twenty silver groats than forty pence.<sup>25</sup>

Even when an individual was officially 'found' to be a natural fool the government was unable to provide directly for care and supervision. In most cases, therefore, the Crown transferred its custodial rights to private persons for a sum of money known as a 'fine', and control over the idiot's land to a guardian in exchange for an annual rent.<sup>26</sup> The guardian was expected to care for the idiot, to protect him from exploitation and to maintain his estates.

The law then recognised the existence of the mentally defective and provided for the protection of the 'fool' and his property, being primarily concerned with the latter (which resulted in a source of revenue for the Crown). However, the processes for determining whether a person was a 'natural fool' or 'non compos mentis' frequently confused the two groups, and it seems even less likely that a distinction was made between the mentally handicapped and the mentally ill in everyday life. Furthermore only those individuals who owned land would have come within the provisions of the Statute of Prerogatives, probably a very small minority of the mentally disordered.

During the medieval period, we can conclude, the everyday social perceptions of the severely and obviously subnormal were horror tinged with awe. In general, they were probably regarded as supernatural, as punishment for the sins of the parents or as having a special relationship with God, although some may have been thought to have a physical illness. There is little

real evidence as to how the mentally handicapped were regarded or treated, except for those few who were 'legally' tested under the Statute of Prerogatives and placed under guardianship, and even then we do not know how they were handled. The art of the period does, however, depict the 'fool' as a monster, comparable with mythical creations, and some 'fools' were kept at the courts of the wealthy to provide entertainment. However, the majority were probably managed by their families or turned out to become wandering vagrants and beggars and the recipients of Christian charity.

#### 4. The Reformation and the Enlightenment - Sixteenth to Eighteenth Century Europe

The period from the sixteenth century to the eighteenth century marked one of transition from a system of handling social deviants inherited from the Middle Ages - from one where it was seen as essentially a communal and family affair - to one based on institutions, administered by central government. The origins of the major departure from medieval practices in handling the poor, dangerous and disreputable sectors of the community started in the sixteenth century as a consequence of the efforts of the Crown to augment state power and reduce the power of the church. At the same time there were increased demands for the maintenance of law and order. These two factors resulted in an increase in central control and direction in the handling of deviants.

##### 4.1 Changing Attitudes towards the Mentally Handicapped

In the Middle Ages the Christian church had advocated charity towards those unable to care for themselves. The changing attitudes to the mentally subnormal in the sixteenth century are clearly seen in the views expressed by two of the leading figures in the Reformation, Calvin and Luther, who both denounced the subnormal as possessed by Satan. In one of his 'table talks' Luther describes a twelve-year-old subnormal boy he had once seen.

He ... had the use of his eyes and all his senses, so that one might think that he was a normal child. But he did nothing but gorge himself as much as four peasants or threshers. He ate, defecated and drooled, and if anyone tackled him, he screamed <sup>27</sup>

Luther felt that the 'devil' should be taken to the river and drowned, but those with him were opposed to this. The boy died a year later and Luther commented that he was convinced that such changelings were of flesh with no soul, but a devil where the soul should have been.

The idea that the mentally subnormal were the incarnation of the devil or Satan is also found in art. Foucault<sup>28</sup> has suggested that the tree that forms the mast of the 'Ship of Fools' in Bacles' picture 'Stulliferae Noviculae' and is above Besch's 'Ship of Fools' represents the tree from the Garden of Eden - the forbidden tree, the tree of promised immortality and of sin. He suggests that

... this wisdom of fools ... presages both the reign of Satan and the end of the world.<sup>29</sup>

The mentally handicapped were thus seen as inhuman, as the incarnation of the devil or Satan and needing to be destroyed. Witch hunts continued until well into the eighteenth century. Among those tried for and convicted of witchcraft would have been mentally handicapped people.

However, Neugebauer<sup>30</sup>, as a result of studying the legal control of the mentally disordered, has suggested

In the histories of ... psychiatry, macabre scenes of witchhunts and witch burnings have commanded great fascination. The existence and activities of an institution like the Court of Wards have been neglected ... But the picture of treatment ideals which emerges from this collection of legal documents is radically different from that which arises from those other judicial records, witch trials. Government involvement with Court of Wards cases was designated to protect the disturbed person and his property.

Furthermore

In the medieval period royal protection was linked with profit. In the sixteenth and seventeenth centuries this financial dimension gradually disappeared while the welfare aspect was significantly expanded.<sup>31</sup>

He points out that while in the medieval period the royal jurisdiction over the mentally disordered had been handled on an ad hoc and relatively informal basis, in 1540 an Act of Parliament brought them within the jurisdiction of the Courts of Wards and Liveries (abolished during the Civil War in the 1640's) and Guardians were required to care for the idiot and his family as well as manage his possessions. While in theory all mentally disordered subjects came within the province of the Court and any person, with or without property could be brought to official notice, in practice, since official referral depended mainly on private citizens, who hoped to subsequently obtain grants of control, only persons with wealth sufficient to bear the cost of court procedure were reported. Neugebauer, however, argues that an examination of cases handled by royal jurisdiction in the seventeenth century (the first reliable statistics) shows a fairly wide social class distribution. Forty percent were from the landed gentry, twenty percent women who were heiresses or widows and the rest tradesmen, yeomen and agricultural workers. He concludes that the Court of Wards and Liveries

... offered protection and to some degree a monitored guardianship system for persons across the English social spectrum. This points up a small, but nevertheless real, social welfare dimension of royal jurisdiction.<sup>32</sup>

The mentally subnormal did, however, continue to be regarded as figures of fun and to provide entertainment for the wealthy. Horsefield<sup>33</sup> argues that the majority of entertainers kept at the Spanish Court in the early seventeenth century were mentally subnormal.

Foucault<sup>34</sup> has pointed out that the Bethlehem Asylum in London and the Bicetre Hospital in Paris were opened



to visitors so that they could be entertained at the expense of the foolish and mad inmates. As late as 1815 a report to the House of Commons revealed that in one year £400 in admission charges had been collected, meaning that there had been 96,000 visits in that year.

By the seventeenth century informed knowledge of the mentally handicapped was growing. Thomas Willis<sup>35</sup> provides one of the earliest systematic discussions of mental subnormality. He distinguished clearly between mental handicap and mental illness, between congenital and acquired mental defect. The mentally ill are 'foolish' while the mentally subnormal are 'stupid'. The mentally subnormal have a number of characteristics that can be used to identify them - they are defective in apprehension, memory and judgement, behave in a dull fashion and display stupidity in their expression. The mentally subnormal can also be divided into a number of categories according to their degree of stupidity. Willis concludes his analysis by arguing that mental deficiency is usually inherited, although sometimes apparently 'normal' parents have defective children. The list of 'genetic causes' given by Willis heralds those found in late nineteenth and early twentieth century accounts of subnormality, and includes alcoholism, epilepsy and licentiousness among other degeneracies. Willis concludes that mental deficiency can be measured in terms of social adaptability and though it is incurable some of the deficient can be helped to improve.

John Locke<sup>36</sup> also distinguished between mental subnormality and mental illness; however, like Willis's, his classification seems to have more applicability to the middle and upper classes than the majority of the population in seventeenth century England who were engaged in subsistence agriculture. Obviously, the most profoundly handicapped would have been easily recognised in the rural population, but many of the less severely handicapped, while they may have been seen as less competent, would not

have been labelled as idiots or fools.

Some years after the publication of Locke's work Daniel Defoe<sup>37</sup> advocated the provision of separate asylums for the mentally defective. He was also concerned at the prevalent social attitudes towards and provision made for the mentally subnormal.

... I wonder how it came to pass that in the settlement of that hospital they make no provision for persons born without the use of their reason, such as we call fools, or more properly 'Naturals'. We use such in England with the least contempt, which I think is a strange error, since tho' they are useless to the commonwealth, they are only so by God's direct providence, and previous fault. I think 'twill very well become this Wise Age to take care of such.<sup>38</sup>

While Defoe was apparently advocating better treatment for the mentally subnormal and did advocate the licensing and inspection of private Mad-Houses, it is necessary to bear in mind the appalling conditions that existed in institutions for the mentally disordered. We can understand these conditions from a description of the Bicêtre as it was in the eighteenth century:

The buildings were untenable, the cells were narrow, cold and dripping, unlit and unventilated, and furnished with a litter of straw, which was rarely changed and often infested with vermin. Men crouched there covered with filth, in hideous lairs in which one would have hesitated to confine a beast. The insane, imprisoned here, were at the mercy of brutal keepers, who were often malefactors from the prisons. The patients were loaded with chains and tied with ropes like unruly convicts.<sup>39</sup>

Despite gradually changing attitudes towards the mentally handicapped, the general, everyday social perception of subnormals changed little. They continued to be cared for by their families, or turned out to wander as beggars. Their existence was explained by reference to supernatural forces, and as Jones<sup>40</sup> has pointed out:

Superstition, moral condemnation, ignorance and apathy, these were the mental attitudes which dominated the treatment of the mentally disordered in the eighteenth century.

#### 4.2 The handling of the Mentally Handicapped

To understand the social provision made for the incompetent and subnormal it is necessary to understand the social and economic changes that marked the end of the Feudal period and the emergence of capitalism. The mentally subnormal must be seen as part of a larger group which were seen as creating a social problem. During the sixteenth century the numbers of unemployed labourers increased as the enclosure movement continued, at the same time as the one major source of charity, the monasteries, had been dissolved, and the reformation had resulted in changed attitudes to the giving of alms.

By the sixteenth century the large increase in the number of vagrants and beggars was seen as presenting a threat to law and order. The maintenance of law and order was essential to the construction of effective central government and consequently official policies to deal with poverty and the socially marginal groups were determined by the need to maintain law and order, which necessitated the suppression of *vagrancy and begging*. As *Foucault* has pointed out

In the classical period indigence, laziness, vice and madness mingled in equal guilt with unreason. Madmen were caught in the great confinement of poverty and unemployment ... 41

Thus the Poor Law Act 1601 focussed attention on the poor and unemployed but made no separate provision for the mentally ill or handicapped. As a consequence harmless idiots and lunatics continued to be left at liberty as long as they were not considered to be dangerous and caused no social disturbance. If necessary, their relatives or others prepared to care for them were provided with a permanent pension for their support. Those who were seen as a danger to themselves or the community would

probably have been chained in the few existing hospitals or in the Poor Law Institutes that started to be established from the 1630's. They may also have been chained in the 'houses of correction' whose construction an Act of 1575 had recommended.

By the end of the seventeenth century a change in social attitudes to marginal groups, including the mentally handicapped, was taking place marking the beginning of the period of the 'Great Confinement', when idiots, lunatics, criminals, vagrants and the unemployed were seen as a 'threat' to society and were locked away.

It is necessary to question what is meant, however, by 'threat' to society. I have argued that the increase in unemployment was a direct consequence of the process of industrialisation and that a large number of idle people were seen as posing a direct threat to the established order and were consequently incarcerated. This does not fully explain why they were 'confined' rather than excluded in some other way from society, nor why those who were apparently harmless but without employment were also incarcerated. Foucault suggests that this was because it was idleness as such that was condemned, coming to be seen as 'the greatest sin' during the reformation. Society could not allow people to remain idle because this would incur God's wrath. The obligation to work was an ethical exercise and a moral guarantee. Consequently the workhouse was not a mere refuge for the old, sick and infirm, nor just a forced labour camp, but also an institution responsible for correcting a certain moral 'abeyance'.

The first organised effort to provide for the mentally disordered in a total institution was in Paris at the Bicetre hospital established in the seventeenth century. In England this change was reflected in the increased use of Houses of Correction and the Workhouse to incarcerate deviants and the development of Private Mad Houses. The development of the last of these was stimulated by an Act in 1714 that distinguished between the lunatics, and rogues, vagabonds, sturdy beggars and vagrants. Two Justices of the Peace could order the confinement of the mentally disordered and one method that parishes adopted to 'deal' with them was to board them out in

---

Table 3 Private Mad Houses established by the end  
of the Eighteenth Century

Institution	Date opened
Small Receptable - Norwich	1713
Ward for Incurable Lunatics - Guy's Hospital	1728
St. Luke's Hospital, London	1751
St. Luke's Hospital, Newcastle upon Tyne	1764
Lunatic Hospital, Manchester	1766
Lunatic Hospital, York	)
Lunatic Hospital, Leicester	) by end of
Lunatic Hospital, Exeter	) 18th century

---

private houses which gradually acquired the description of 'mad' houses.

During the eighteenth century Houses of Correction and Poor Law Institutions acquired a new purpose in addition to that of providing for the unemployed in periods of crisis, that of regulating the economy. Thus a dual system of treatment of the mentally handicapped developed. Those with wealthy relatives, and some pauper lunatics, were sent to the private enterprise mad houses, where they spent years chained up in terrible conditions. Mad House owners were concerned with making profits, not with the care of their charges. Those whose relatives could not afford to pay the charges of the Mad House, along with the unemployed, the old and the sick, continued to be incarcerated in Poor Law Institutions, where the main emphasis was on putting them to work, making them economically productive, although this practice gradually fell into disuse as it was suggested that it took work away from 'honest' men in the community.

In everyday practice the mentally subnormal continued to be seen as an integral part of the marginal population - those unable to be economically productive and to take

their place as full members of capitalist society. In legal terms, the distinction between mental subnormality and mental illness continued to be seen as important, because of the need to protect property rights. The case of Henry Roberts Esquire in 1743<sup>41</sup> illustrates how a jury was used to judge if a person was incapable of managing his own affairs, whether because of idiocy or lunacy.

He was put in a private room with a jury and they (he said) came round me and asked their questions together, without giving me time to answer. They asked me what a lamb and what a calf was called at one, two and three years old. They gave me a sum of money to tell, which I miscounted, and then I heard them say 'he is not capable of managing his affairs, we will return him incapable' ...

(From an anonymous pamphlet of 1747 published in London and quoted in Hunter & MacAlpine).

This case also provides examples of the assessment procedure used - the type of questions used to assess an individual's intelligence. An 'idiot' or 'natural fool' was diagnosed on the basis of inabilities such as not being able to count to 20, measure a yard of cloth, name the days of the week, answer questions concerned with his daily life, or learn to read.

In the eighteenth century the law continued to recognise, essentially, two categories - the idiot and the lunatic - despite the abolition of the Court of Wards during the Civil War in the 1640's. These were not medical categories, but legal categories determined in relation to civil capacity and legal responsibility as judged by a jury.<sup>44</sup> Juries seldom found a man an idiot, but preferred to find him 'non compos mentis' for a time. In any case a man was only an idiot if he was totally devoid of intelligence. The main legal concern was the protection of property, and in the case quoted above of Roberts, the jury were instructed by the Judge to test if he was capable of managing the considerable properties left him by his father. Thus only those who owned or potentially controlled property would have been 'tested' to determine

if they were incurably subnormal. The vast majority of those incapable of supporting themselves financially would have been cared for by their families or incarcerated in Mad Houses or the Workhouse.

5. Conclusion

Kathleen Jones<sup>43</sup> has succinctly summed up the prevalent conception of mental disorder at the end of the eighteenth century in England:

There was no clear distinction of what mental disorder was and certainly no recognition of the mentally ill or handicapped as a category requiring a distinct form of treatment. The problem was a submerged one ... If their mental condition reduced them to penury they came within the purview of the Poor Law. If it led them to break the criminal code, they were judged by the penal law. If they wandered abroad from their legal place of settlement without means of support they were involved in the rigours of the vagrancy laws.

Mental disorder was explained in terms of supernatural forces, but the mentally handicapped were not seen as 'children of God', but as incarnations of the Devil or other evil spirits. The management of those of the mentally subnormal who were indeed managed along with other marginal groups who were seen as a 'threat' to the developing socio-economic order was to incarcerate them, to protect society from the deviant. However, the majority remained at liberty in the community, to be cared for by their families or to fend for themselves. The radical transformations in the social perception of the mentally handicapped and their handling occurred, as we will see in the next chapter, in the nineteenth and twentieth centuries when they first became clearly differentiated as a separate category of outsiders and managed as deviants in a distinct manner.

REFERENCE NOTES, CHAPTER FOUR

- 1: Willis, 1672  
2: Pinel, 1802  
3: Hobson, 1955 p116  
4: Emerson, 1969 Note 4, p94  
5: E.G. Poster, 1978  
6: Rosen, 1968 p5  
7: Scull, 1977  
8: E.G. Scull, 1975, 1977, 1979  
9: Wolfensberger, 1970  
10: Szasz, 1970  
11: See, e.g., Rosen, 1968  
12: Quoted in Rosen, 1968 p134  
13: Plato, 1966  
14: Weygenault, 1915  
15: Cranefield, 1962  
16: in Merke, 1960 p995  
17: in Merke, 1960  
18: in Merke, 1960 p997  
19: Zilboorg, 1941  
20: Neugebauer, 1978  
21: Neaman, 1975  
22: Scull, 1977 p17  
23: Walker, 1968  
24: Public Record Office, 1898-1955  
25: Public Record Office, 1916-1968 p, 127-128  
26: Public Record Office (Henry VII 298)  
27: Luther, 1652  
28: Foucault, 1971 p259  
29: Foucault, 1971  
30: Neugebauer, 1978 p167  
31: Neugebauer, 1978 p167  
32: Neugebauer, 1978 p164  
33: Horsefield, 1940  
34: Foucault, 1971  
35: Willis, 1672  
36: Locke, 1690  
37: Defoe, 1697  
38: Defoe, 1697 p165  
39: Nowray, 1945 p343  
40: Jones, 1972 p10  
41: Foucault, 1971 p259  
42: Quoted in Hunter and MacAlpine, 1963 p42  
43: Jones, 1972 p3



## CHAPTER 5

### FROM DEVIANTS TO DEVELOPING PEOPLE - THE MENTALLY HANDICAPPED IN NINETEENTH AND TWENTIETH CENTURY BRITAIN

#### 1. Introduction

Perceptions of the mentally handicapped have changed considerably since the beginning of the nineteenth century. The development of apparently more humane attitudes to the mentally disordered, the growth of medical concern and an attitude that mental handicap was curable resulted in a superficial improvement in their situation at the century's beginning. However, this quickly changed when, firstly, it became clear that mental subnormality was not 'curable' and secondly, that the numbers of mentally subnormal people were far greater than had been realised - a 'fact' discovered with the introduction of compulsory schooling. This coupled with the increasing dominance of science and the growing influence of Social Darwinism meant that by the end of the nineteenth century the mentally subnormal were seen not only as social menaces but as a threat to civilization. Scientific knowledge had replaced religious superstition, but the result was the same - the incarceration of the deviant. The powerful eugenics movement continued to have a strong influence on attitudes towards the mentally subnormal, especially those seen as part of the 'social problem group', until well into the twentieth century. This position is well expressed in a report published in 1903<sup>1</sup>

The chronic insane, the epileptic, the paralytic, the imbecile, and idiots of various grades, the moral imbecile, the sexual pervert, the kleptomaniac, many if not most of the chronic inebriates, many hospitalised paupers, especially the ignorant and irresponsible mothers of illegitimate children so common in poor houses, many of the shiftless poor, ever on the verge of pauperism and often stepping over into it, some of the blind, some of the deaf-mutes, some consumptives. All these classes in varying degrees, with others not mentioned, are related as being effects of the one cause - which itself is the summing up of many causes - degeneracy.

The development of intelligence tests (which I have briefly outlined in Chapter 3), partly in response to the eugenics movement, enabled the 'scientific' diagnosis of the mentally subnormal, and the findings of 'family studies' gave scientific weight to the thesis that degeneracy was indeed inherited. Gradually, however, professional opinion became modified; environmental factors were shown to be relevant in generating 'degeneracy', and events in Europe made the more extreme forms of eugenics unacceptable. Since the second World War social science research, social factors and economic changes have resulted in the modification of extreme attitudes towards the subnormal. They are no longer seen as a danger to society, and while few believe in 'magic' cures, mental subnormality is seen as an improvable condition. Segregation is no longer seen as an appropriate way of dealing with the majority of the subnormal, and 'normalization' and 'community care' have become widely advocated (and to some extent implemented). However, community attitudes are still basically apathetic if not hostile to the mentally subnormal, and the ideas of the eugenics movement widely disseminated in the early twentieth century still appear to be influential. Furthermore, while professional attitudes may have changed, the mentally subnormal are still seen as outsiders, along with other groups of deviants, by the general public.

## 2. The Nineteenth Century

At the end of the eighteenth century the mentally handicapped were an integral part of the marginal population who were all handled in the same way. By the middle of the nineteenth century the mentally handicapped were, theoretically at least, seen as a separate problem and handled as a distinct category. We need to consider what changes took place in Britain (and indeed in the whole of the Western world) that caused this shift in practice to come about.



The main influences in the early nineteenth century on attitudes towards and care of the mentally handicapped would appear to be on the one hand the development of psychiatric medicine and its attempts to dominate the care of the mentally subnormal , and on the other the growing fear felt by the Victorians of the 'submerged ten percent', and a concern to instil the Protestant Work Ethic and maintain law and order.

However, the growth of psychiatric medicine and the fight of doctors to control the treatment of the mentally disordered can itself be seen to be influenced by the dominant ideology.

Moral management is seen as the achievement of an impartial and unselfish concern for the plight of the insane ... moral management can also be seen as one among a number of attempts to combat the forces of disorder so threatening to the Victorians. In abandoning the methods of the eighteenth century, nineteenth century physicians were not abandoning their role as guardians of the moral order and agents of social control <sup>2</sup>

Theoretical developments in psychiatry in the nineteenth century can be shown to be influenced by and can only be understood by reference to the wider social context, so that while the reformed asylum was more humanitarian than the institutions it replaced, nevertheless it was

...a structure that formed a kind of microcosm in which was symbolized the massive structures of bourgeois society and its values. Family-child relations centred on the theme of paternal authority. Transgression-punishment relations centred on the theme of immediate justice. Madness-disorder relations centred on the theme of social and moral order.<sup>3</sup>

While the attitudes towards and treatment of the mentally disordered were undergoing an apparent dramatic change, so too were attitudes towards the poor and poverty. Changes in the means of production and of the economic structure of society created the need for an efficient and

mobile labour force. This necessitated making a sharp distinction between on the one hand the able-bodied poor, who needed to be instilled with work habits, to be 'forced' into productive labour, and who needed to be free to move to where labour was needed, and on the other the non-able-bodied poor, who needed to be maintained by society. It was consequently realised that poor relief and confinement in Poor Law Institutions was a bad mistake economically, not only because the unemployed were unproductive and a drain on community resources, but also because the cost of production could be reduced by increasing the workforce. The unemployed, the vagabonds and paupers must be forced to become part of the economically productive workforce. This was legally enacted in England in 1834, when the Poor Law Act introduced the concept of 'less eligibility' - the conditions in the Workhouse were to be made less desirable than the worst conditions outside. The 'poor' would then, in theory, be encouraged to take employment outside rather than seek relief. This change affected the mentally handicapped because many of them continued to come within the provisions of the Poor Law and to be confined to the Workhouse. Furthermore, it reflected a deeply ingrained attitude about the marginal population and the need to maintain law and order and instil a 'work discipline'. Men, women and children were seen as productive labour, their worth was measured by their ability to be economically productive, and those who refused to or could not work were cast aside.

During the course of the nineteenth century the realisation that there existed an unknown, but large group of people who were, because of mental subnormality, apparently incapable of managing their own affairs slowly dawned. However, apart from some attempt to 'care' for the more severely mentally handicapped, little was done to handle the mentally deficient as a separate category until the late nineteenth century. With the introduction of compulsory schooling in the last decades of the century

(which acted, as we saw in Chapter 3, as a mechanism for screening and labelling the mentally 'defective' especially the feebleminded) not only did the identification of this 'dangerous' group become easier, but the group was also seen to be much larger than had previously been realised. Simultaneously the newborn interest in eugenic improvement of society among English and American scientists began to indicate a possible 'final solution' to them as a problem (and a catalyst for the development of intelligence tests) - for the good of humanity, their characteristics should be bred out of the race.

The nineteenth century can, then, be seen as a period when, firstly the mentally handicapped became widely recognised as outsiders and then, secondly, began to be managed as a separate deviant group.

## 2.1 Attempts to 'cure' the Mentally Handicapped

Itard,<sup>4</sup> a French doctor and student of Pinel, is credited with being the first person to make a systematic effort to educate an idiot. Itard was influenced by 'sensationalism' (the idea of the eighteenth century French philosopher Condillac that the basics of all mental life could be reduced to sensory elements), by the humanitarianism of Pinel, and by the romanticism of Rousseau (especially Emile).

In 1799 a boy of about twelve years was found in Avignon. Victor, as the boy became known, was naked, ate all his food raw, drank like a dog, walked on all fours, fought with his teeth and was unable to speak - in sum, he appeared to be a complete idiot. Itard set out to educate Victor. He continued to work with Victor and published two accounts of this work, but eventually, because he was unable to 'cure' Victor, he gave up his work with him. Despite Itard's disappointment, Victor did make considerable progress. He learnt to live in human society and to show affection, and he showed signs of some intellectual growth.

Despite his 'failure' with Victor, Itard maintained that it was preferable to view him as a wild man rather than as a congenital idiot (that is, a creature born ill-favoured, rejected by society and abandoned by medicine). The fact that Victor had made so much progress strengthened the view that man is a product of his environment and not his heredity and influenced developments in the field of mental handicap in the first part of the nineteenth century. (Indeed, the theory of sensationalism, or at least the practice that derives from it, would seem to have affinities with behaviour modification - see Chapter 3).

The importance of Itard's work with Victor is that it was seen as 'proving' sensationalism, a psychology developed by Condillac, and as demonstrating that idiocy was remediable, even if not curable. When Victor was first discovered, Pinner, who believed that many madmen could be cured, advised Itard not to work with Victor as he was an incurable idiot. This view was taken by a number of Itard's other contemporaries, including Bousquet and Esquirol; the latter, interestingly, although he did not develop a theory of degeneration - see below - did point out the importance of developmental facts in mental subnormality and noted that there tended to be a familial tendency towards idiocy (and that 'sometimes also in the same families there is one idiot and other children who are insane'<sup>6</sup>). However, Itard maintained that the hereditary form of idiocy was very rare, that environmental causes were the most frequent, and that most cases could be cured by education. As far as Victor was concerned Itard agreed that he was an 'idiot' but asserted that his condition might as well be explained by cultural loss as by defect of birth. He maintained that he, Victor, was more like an infant of 10-12 months than a simple youth and consequently that he could be treated and cured.

Profoundly influenced by Condillac, Itard maintained that man is not 'born' but 'constructed' - that is, that the environment is the important factor in understanding human development. Thus

Cast on this globe, without physical power, and without innate ideas...man is only what he is made to be by his external circumstances...he enjoys...a capacity of developing his understanding by the power of imitation and the influence of society.'

Condillac's sensationalist psychology was a theory of the way man develops his capacities and knowledge, which argued that man is the product of the reactions of his sense-organs to the stimuli provided by the physical environment. He had demonstrated his theory by using the analogy of the statue man, which had enabled him to explore the functions of senses and the growth of mental life by imaginatively re-creating the hypothetical experiences of the statue as its senses were unlocked one by one<sup>8</sup>.

Motivated by the experiences of pleasure and pain and guided by the mechanism of the association of ideas, the statue man acquired practical knowledge, formed abstract ideas and even moral and aesthetic judgements. In other words he exhibited the full mental capacity of man.

However, Condillac saw himself as essentially an educator and put his own ideas into practice. This practice, the method of education which derives from the theory, has been of equal importance in the field of mental handicap. Thus Itard accepted that man is made, and that he is made as a result of the stimulation of his senses. Consequently, in looking at Victor he developed a program of educating him by awakening his senses. Itard, then, not only influenced attitudes to 'idiots' but, more importantly, developed a method of educating them and demonstrated that even if it did not 'cure' idiots, it at least improved them. Despite his own 'failure' with Victor the view that 'idiocy' was generally the result of environmental factors and that idiots could be educated using a method derived from Condillac's theory of sensationalism was extremely influential.

One of the people significantly influenced by Itard's work was Edouard Seguin, the first acknowledged teacher and leader in the field of mental subnormality. Seguin worked with the mentally subnormal first in Paris and later in the United states. In 1846 he published a text book<sup>9</sup> on mental subnormality which became very influential in Europe and the United states and resulted in the wide-spread adoption of his methods for educating and caring for the mentally handicapped. He was convinced that idiocy was 'curable' and was extremely influential in what has become known as the 'age of optimism'. This was the period, in the early nineteenth century, when

professionals concerned with the mentally handicapped believed that the subnormal could be educated to a standard where they could play a full social and economic role in society. A few special schools for educating the mentally subnormal began to be established in Europe and the United States, those running them being convinced that they could cure the subnormal. These schools were few in number and privately run. (See section 2.3 below).

## 2.2 The Emergence of the 'Social Problem Group'

The optimism of the early nineteenth century soon gave way to doubts and fears as it became 'realised' that the mentally subnormal could not be 'cured' but were a life-long burden on society. Also, with the gradual introduction of formal state education (especially following the Foster Education Act of 1870), the greater visibility of the problem presented by the 'subnormal' with the growth of urbanization, and the changes in the skills necessary at work, it became evident that the number of mentally subnormal people was far greater than had previously been thought. Attitudes towards the subnormal, and especially the feebleminded, began to change; they began to be regarded as a threat to racial survival and as a life-long burden on society - as presenting, in other words, a real and distinct social problem. The idea began to circulate that there was a need to protect society from these 'dangerous' groups not only as part of the general fear that the dangerous classes would contaminate the respectable working classes, but also because of the fear that by being allowed to breed the numbers of social degenerates would grow, posing a threat to civilization.

The first steps in this process was the realization that the 'problem' existed, that there were apparently large numbers of people dependent on society for their care and maintenance because of mental deficiency, and the development of the claim that mental deficiency was hereditary, passed on from generation to generation, and associated with other forms of degeneracy.

One of the first experts to claim that mental deficiency was a hereditary trait was Howe (1848) who



claimed that it was a condition inflicted on those whose parents violated 'the natural laws of man' (paupers, alcoholics, petty criminals - the social degenerates). He was influenced by the School of 'faculty psychology' which in contrast to associationism (which saw the child's mind as a 'blank slate' at birth) attempted to classify innate capacities. Howe not only argued that degeneracy, including mental deficiency, passed on from one generation to the next, but also that it presented a 'real' social problem.<sup>10</sup>

Idiots form one rank of that fearful host which is ever pressing upon society with its suffering, its miseries, and its crimes, and which society is every trying to hold off at arms' length - to keep in quarantine, to shut up in jails and almshouses, or at least to treat as a pariah caste.

Soon after, in 1866, a report from the British Lunacy Commissioners revealed that "

The number of 'idiots', 'imbeciles' and 'febleminded' is very great in the United Kingdom; those in asylums, schools and workhouses form but a fraction of the whole and they abound in all classes of society from the wealthiest to the poorest. It would appear that the errors of our civilized people are rarely noticed in races leading a natural life ... Hidden all too often amongst civilized people and exposed to perish by the savage, these barely gifted members of the human species demand our attention ...

The growth in the fear of social degenerates and of the conviction that there was a need to protect society from them continued during the rest of the nineteenth century. Gradually the emphasis shifted from training/educating the mentally-handicapped so that they could become productive members of society, to protecting society from them by 'warehousing' them. These attitudes were reinforced and given 'scientific' status by the growing acceptance of Social Darwinism, which influenced the development of degeneracy theory and of the eugenics movement.

Degeneracy theory was developed by a Frenchman, Morel, who was arguing that hereditary taint was polymorphous in the late 1850's. (Lombroso, the Italian 'Father of

Criminology', who is usually associated with degeneracy theory, did not publish his theories until the late 1870's.) Sarson and Doris describe Morel's theory as arguing that <sup>12</sup>

degenerations were deviations from the normal human type, which were transmissible by heredity and which deteriorated toward extinction. Deviations from the normal human type included those afflicted with certain physical and psychiatric diseases, for example the epileptic, the scrofulous, the psychotic, the mentally deficient, the moral deviate and the alcoholic. The degeneration was subject to the 'law of progressivity'. The first generation of a degenerate line might be merely nervous, the second would tend to be neurotic, and the third psychotic, while the fourth consisted of idiots who would tend not to reproduce and so lead to the extinction of the line.

Degeneracy theory essentially held:

i) that hereditary taint is polymorphous - that is, the degenerative tendency expresses itself in different ways and with different forms of deviance; and

ii) that acquired traits are transmitted to, and thus that parental experiences have an effect on, the offspring.

(The second of these hypotheses was widely accepted in the nineteenth century, and its adherents included Darwin and Spencer. The first of them profoundly influenced the 'proofs' of heredity put forward in the early twentieth century - see below). However, while Morel and Howe<sup>13</sup> accepted degeneration, they did not subscribe to the 'pessimistic' or 'alarmist' attitudes to the problem of mental handicap which began to develop in the late nineteenth century. The acceptance of a hereditarian view which allowed for the transmission of environmental effects would not in itself lead to pessimism - one could alter the environment and consequently forestall or reverse degeneration. (In fact, the pessimistic implication does not appear even to have occurred to Howe or Morel.)

It was the Darwinian Theory of Evolution, combined with the theory of degeneration, that contributed to a radically different perception of the mentally handicapped. The theory of evolution and the idea of the survival of the fittest in the struggle for existence put degeneration in a broader context: the physically and mentally unfit are no longer seen as the unfortunate victims of the environment and/or hereditary taint but as demonstrably members of an inferior race which ought to be allowed to die

out as quickly as possible. (Note, however, that no special theory of degeneration is needed for this purpose; many Social Darwinians systematically applied the theory of the survival of the fittest without reference to degeneration, simply maintaining that deviant members of society had proved themselves unfit).

However, Social Darwinianism, which so profoundly influenced the Eugenics movement, was not simply the product of evolutionary theory. Its roots can be traced back to classical economic theory, especially Smith's advocacy of free competition in the market-place and the Malthusian theory of population. Spencer, ten years before the Origin of Species was published, expressed views about how society should deal with the incapable that find an echo in Social Darwinianism<sup>14</sup>.

Blind to the fact that under the natural order of things society is constantly excreting its unhealthy, imbecile, slow, vacillating, faithless members, these unthinking, though well-meaning, men advocate an interference which not only stops the purifying process, but even increases the vitiation - absolutely encourages the multiplication of the reckless and incompetent by offering them an unfailing provision and discourages the multiplication of the competent and provident by heightening the prospective difficulty of maintaining a family. And thus, in their eagerness to prevent the really salutary sufferings that surround us, these sigh-wise and groan-foolish people bequeath to posterity a continually increasing curse.

It was Social Darwinianism mediated through the Eugenics movement that had a direct effect upon attitudes to the mentally handicapped. The movement systematised and organised the newer attitudes to them and provided a vehicle for conveying these attitudes into a social action programme ; it therefore had a profound influence on social policy towards them in the early twentieth century (see section 3 below). Galton, the founder of the movement, coined the word 'Eugenics' - the science of the study improvement of the human race - in 1865 and published in 1869 his<sup>15</sup> purporting to establish that ability was inherited by demonstrating the high social and economic standing of the forefathers of eminent Victorians. (It is interesting to note that Samuel Smiles (1859) carried out a very similar study which included industrialists among the eminent and came to entirely contrary conclusions -

that many currently eminent men came from undistinguished ancestries). The Eugenics Movement, however, quickly attracted a number of eminent members who began to publish books and articles aimed at doctors and teachers, spelling out the danger that mental defectives posed to society. Among the most influential of these was Down's Mental Afflictions of Childhood and Youth (1887), F. Beach's Treatment and Education of Mentally Feeble Children (1895), Mentally Deficient Children (1895) by Shuttleworth and Potts, E.S. Talbot's Degeneracy (1898) and W. Ireland's Mental Afflictions of Children (1898). These studies were a prelude to increasing official concern about the 'problem' which was expressed in a Report on Education in 1898<sup>16</sup> and reflected in the powers given to Local Education Authorities in 1899<sup>17</sup> to establish schools for the 'feeble-minded'.

One of the 'problems' highlighted by the movement at this time, and which influenced the assumptions underlying and the developmental course of intelligence tests (see Chapter 3 and section 3 below) was the problem of diagnosis and classification. The National Association for Promoting the Welfare of the Feeble-minded, which included Warner, Langdon Down and Shuttleworth on its committee, turned its attention to the problem of diagnosis in 1896, and in the same year the British Association had sponsored a report on the mental and physical conditions of childhood. The principle was finally established that intelligence was inherited and that tests were needed to measure what this fixed capacity was. In the early twentieth century, when botanists brought to light and verified the long-forgotten Mendelian principle of heredity, it was applied by some eugenicists to the transmission of human characteristics including intelligence. (In fact it resulted in a split between the biometricians - who included Galton and Pearson<sup>18</sup> and emphasised the blending of parental traits in the offspring - and the Mendelians, who emphasised the particulate nature of heredity. However, it was not the mode of inheritance that was crucial; rather it was the 'fact' that mental sub-normality was inherited at all which influenced the programmes of the Eugenics movement.)

The work of Galton and his followers in the Eugenics Movement was to result in profound changes in the handling of the mentally handicapped in the early twentieth century and in attitudes towards them, especially (as I have already indicated) in the move towards warehousing and the search for 'accurate' tests of innate mental ability. Moves towards these began at the end of the nineteenth century as the state began to become 'concerned' with the problem and to make provision for the separate handling of the mentally handicapped. In the nineteenth century the only separate provision that had been made until the last two decades, was the 'private asylums', the majority who did not live in the community being warehoused in the lunatic asylums and the general workhouse.

### 2.3 The Handling of the Mentally Handicapped in Nineteenth Century England

The first special provisions made for the mentally handicapped were private schools/hospitals known as 'idiot' asylums; they were founded originally at a time when at least some concerned individuals still believed that idiocy was curable.

In general we may say that the object of the asylums is primarily educational, and that, originally at least, they were the outcome of a belief that in many cases special education would prepare for the duties and employment of life the children or young persons who gained admission to them. 18

Britain was slow to provide, compared with some European countries and the United States, and the first 'schools' were not founded until the 1840's. These institutions were privately owned and catered either for children whose parents could afford to pay for them or pauper children paid for by the Poor Law Commissioners. The first large-scale public provision made was the Darreth Training School, built by the Metropolitan Asylum Board,

and opened in 1878. (See Table 4). However, as I have already pointed out, the majority of mentally handicapped people were not accommodated in institutions specifically designed or intended for them by the end of the nineteenth century. In 1881, of the 29,452 idiots in public institutions only three percent were in institutions specifically designated for the subnormal; the remainder were incarcerated in general workhouses, lunatic asylums, private mad houses and prisons.<sup>19</sup>

Table 4 List of Institutions for the Mentally Subnormal in 1900

Institution	Date of founding
Eastern Counties Asylum, Essex Hall, Colchester	1859
Western Counties Asylum, Starcross, Exeter	1864
Midland Counties Idiot Asylum, Birmingham	1866
Gorlswood Asylum, Redhill, Surrey	1847
Royal Albert Asylum, Lancaster	1864
Magdalen Hospital, Bath	(1846)*
Middlesex County Asylum, Annexe for Imbeciles	1868
Darenth Schools, Dartford, Kent	1878
Winwick Hall for Boys, Lancashire	
Ancaster House, Richmond, Surrey	
Winchester House, Kingston Hill	
Normansfield, Hampton Wick, Middlesex	

\* Established as a small school in 1846 and later became Magdalen Hospital

---

It was also widely believed that there were many more mentally subnormal people, whose existence was not known of by the authorities.<sup>20</sup>

The introduction of mass schooling, especially after 1880 when education was made compulsory for all, resulted in the 'discovery' of a large number of children who were

apparently incapable of benefiting from instruction in the normal classroom. In 1889 the Royal Commission on the Blind, Deaf and Dumb recommended that feebleminded children should be educated separately. After this a few Local Education Authorities did establish such schools, but the cost was very high as they were not supported by government grants. In 1890 a special committee of the Charity Organisation Society recommended special educational facilities for feebleminded children. In 1895 a committee under the auspices of the British Medical Association, the Charity Organisation Society, the British Association for the Advancement of Science and the International Congress of Hygiene and Demography issued a pamphlet on the 'Scientific Study of the Mental and Physical Conditions of Childhood with particular reference to Defective Children'. This influenced the establishment of a Departmental Committee on Defective and Epileptic Children (1896) which reported in 1898 that there existed a group of children who, while not imbecile or idiotic, were too feebleminded to be taught in the ordinary school. In the following year (1899) the Elementary Education (Defective and Epileptic Children) Act empowered, but did not compel, Local Education Authorities to make provision for feebleminded children to be educated in special schools.

The nineteenth century was a period of wide social reform and philanthropic movements which also witnessed the formation of pressure groups who spoke for the poor and underprivileged. The Charity Organisation Society, founded in 1868, a powerful and prestigious body that co-ordinated charitable efforts of all kinds, included among its numbers Sir C. Trevelyan, a champion of the mentally handicapped. At his instigation the Council of C.O.S. recommended to the government in 1877<sup>1</sup> that they make special provision for the feebleminded (a term introduced by Trevelyan to refer to the educable mentally subnormal), as they were not adequately provided for in the workhouses

or asylums. They advocated state intervention because they felt that this group could be helped so that they would become less of a burden on the community.

The work and ideology of the C.O.S., however, was not purely humanitarian. The organisation was formed as a response to the fears expressed by the middle classes in London in the 1860's. It was concerned with instilling the Protestant Work Ethic and encouraging self-help and thrift.<sup>16</sup> This is of course reflected in its argument that the mildly handicapped should be trained so that they would be less of a burden on society. The attitude to the more severely handicapped was clearly expressed by Miss Denby and Miss Pissent, the founders of the National Association for Promoting the Welfare of the Feebleminded in 1896, an organisation formed to secure the full implementation of the C.O.S. recommendations with respect to the mentally handicapped. Miss Denby was also involved in the foundation of the Lancashire & Cheshire Society for the Permanent Care of the Feebleminded (1898). These two women, supporters of the Eugenics movement, firmly believed in the life-long segregation of the mentally handicapped as the only means of erradicating the problem of the subnormal and were firmly opposed to their reproducing under any circumstances.

### 3. The Early Twentieth century - The Eugenics Scare

The social attitudes that began to gain momentum in the late nineteenth century continued into the twentieth and became more widely distributed. The views of the Eugenics movement began to dominate all attitudes towards the mentally subnormal, and continued to do so until the 1930's. A firm conviction developed that mental handicap was incurable and that the subnormals were social menaces who posed a constant threat to civilization. The only possible solutions were life-long segregation or perhaps the sterilization of the unfit. The most feared group were the feebleminded (the mildly subnormal), who had been 'discovered' with the introduction of mass schooling and



were seen as part of the marginal population - the degenerates. (The theoretical implications are developed in Chapter 8).

Public alarm was aroused as the result of three main factors: the systematic studies of the Eugenics Movement, especially the work of Galton; the development by Binet of 'successful' intelligence tests, and the publication of family studies which purported to provide scientific proof that intelligence was hereditary and that degeneracy was passed on from one generation to the next genetically. These were reinforced by the realization that the mentally handicapped could not, in general, be trained to play a full social and economic role and the 'discovery' of an increasing number of 'feebleminded' children by educators in the school system.

The growing concern about the mentally handicapped must, however, be seen in the context of a change in attitudes to the social residuum in the early twentieth century and general fears concerning deterioration of the race. The Boer War had revealed that there was widespread physical disability among the working class, and this led to a re-examination of the old assumptions about the inevitable superiority of the British social system and of the British race. The concern over physical deterioration gave impetus to the political movement for national efficiency and resulted in the advocacy of social reform. It was argued that human resources were being wasted and that the declining birthrate among the upper, middle and respectable working classes, while the residuum was still breeding at a high rate, meant that there would be a deterioration of the race. Influenced by Social Darwinism, scientific reform was advocated in place of evangelical humanism and deterrent poor relief.

However, many of those who advocated social reform and welfare benefits for the poor also accepted the argument that the race was deteriorating because of the differential fertility of the reputable classes and the residuum. This belief continued despite the fact that the 1903 Interdepartmental Committee on Physical Deterioration found no proof that the race was deteriorating, although they did find that there was widespread poverty,

malnutrition and disease. Although much of this concern was bound up with physical deterioration, the general acceptance of Social Darwinism and degeneracy theory meant that the residuum (the physical degenerates) were seen as a general reservoir of associated hereditary degeneracies (feeble-mindedness being the final stage).

The strong influence of Social Darwinism and the fear of the residuum meant that biological science was looked to, to solve the problem, and the arguments of the Eugenics movement became very powerful. There was a general consensus among political parties that the residuum posed a threat and that degeneracy was hereditary. Consequently liberal and Fabian politicians as well as conservative ones advocated eugenic solutions - although there was not a complete consensus over this, and considerable disagreement as to whether positive eugenics or negative ones should be employed. Beveridge, who played a vital role in formulating liberal party policy in the Edwardian period, justified segregation policies thus:

The ideal should not be an industrial system arranged with a view to finding room in it for everyone who deserves to enter, but an industrial system in which everyone who did find a place at all should obtain average earnings at least up to the standard of healthy subsistence ... The line between independence and dependence, between the efficient and the unemployable, has to be made clearer and clearer ... the men who through general defects are unable to fill such a whole place in industry are to be recognised as unemployable. They must become the acknowledged dependents of the state, removed from free industry and maintained adequately in public institutions, but with a complete and permanent loss of all citizen rights, including not *only* the franchise but civil freedom and fatherhood. <sup>12</sup>

Pearson<sup>23</sup> and Sidney Webb<sup>24</sup> argued that as the proliferation of untalented and malformed children continued, while the intelligent and well-fed failed to reproduce themselves, no amount of reform aimed at clearing up the slums would improve the general condition of the race. What was necessary was state action in favour of the respectable working class and the talented classes - that is, a programme of positive eugenics - possibly coupled with negative eugenic measures, as the only solution to the problem.

The general consensus over the arguments and policies of the Eugenics movement (at least in academic and political circles) is shown by the fact that Russell<sup>24a</sup> not only shared their views concerning the possible deterioration of the race but also felt that negative eugenics were desirable for the mentally defective:

It must be admitted.. that there are certain dangers. Before long the population may actually diminish...and government opposition to birth-control propaganda gives a biological advantage to stupidity, since it is chiefly stupid people whom governments succeed in keeping in ignorance.

and

We may perhaps assume...governments will acquire the right to sterilize those who are not considered desirable as parents. This power will be used at first to diminish imbecility, a most desirable objective.

The general consensus over the need to prevent the deterioration of the race was based on an acceptance of the 'scientific facts'<sup>25</sup>

That the physically and mentally fitter stocks produce physically and mentally fitter offspring

and that

Ability not entirely, but largely, runs in stocks, and these stocks by a long process of social evolution form in bulk the upper classes

coupled with an acceptance that eugenic solutions were appropriate. These views were widely disseminated in, for example, the literary works and plays of Wells.<sup>26</sup>

However, the underlying concerns of the various political groups need to be examined. *Conservatives and liberals were concerned to maintain the Imperial supremacy of Britain and with the provision of a stable, diligent and quiescent workforce with the minimum level of public expenditure. The Fabians, on the other hand, wanted to establish a 'collectivist' social order where everyone worked for the good of all and where everyone received a minimum level of education, welfare and income. It was the latter's acceptance that the residuum were biologically inferior that led them to accept eugenics. Indeed, in the late nineteenth century both Sidney Webb<sup>27</sup> and Ball<sup>28</sup> had argued that society should be reorganised to solve the problem of degenerates:*

...the modern problem is not so much to get the weak out of the way, as to help them to be useful. There is no reason in the process of natural selection, as

such, why every member of society..should not be preserved and help to live as effectively as possible.<sup>29</sup>

In the early twentieth century they apparently became convinced by the arguments for hereditary degeneracy. However, Sidney Webb became persuaded after the First World War that the existence of the casual poor had not been the effect of some 'deviant mutation'. The casual poor were shown to have been a social and not a biological creation, and their lifestyle was not the outcome of some hereditary 'taint' but a consequence of poor housing, inadequate wages and irregular work. The acceptance of environmental theories was further strengthened by his visit to Russia in 1935. Of course, the acceptance of environmental rather than biological causes results in radically different attitudes and policies towards the 'residuum'. Nonetheless it remains true that in the early part of the twentieth century there was still general agreement that the residuum were a biologically inferior class that posed a threat to the race and that political action was necessary to avert the danger that they presented. The degree of penetration of this view can be seen by the fact that it was held by influential members of professions outside politics and the academic world.<sup>29a</sup> (It is important to remember that as far as mental handicap is concerned the group that were identified and were the recommended subjects for eugenics programmes were the 'feeble-minded' - those who represented the final stages of degeneracy. Also, apart from policies of segregation, neither positive nor negative eugenic solutions were ever legally enacted in Britain, though sterilization of the unfit was legislated for in many states in America and in a number of European countries).

### 5.1 Science and the Mentally Handicapped

The development of intelligence tests in the early part of the twentieth century provided a 'scientific' method of diagnosing mental subnormality. Intelligence tests, as I have already argued in Chapter 3, were based on the view that intelligence was inherited and fixed or at least

relatively fixed for life. Mental subnormality, especially feeble-mindedness, was seen to be the result of hereditary factors, the inheritance of 'poor' intelligence genes.

...there are laws of inheritance of general mental ability that can be sharply expressed; low mental ability is due to the absence of some factor and if this factor, that determines mental development, is lacking in both parents it will be lacking in all their offspring.<sup>30</sup>

The Eugenics Movement, and specifically the Eugenics Education Society (founded in 1907) stressed the need to develop diagnostic techniques to ensure the accurate identification of the mentally defective. They argued that there was no doubt that subnormality was inherited and that society needed to be protected from degeneracy. Auden, a eugenicist, a prominent member of the British Association and Medical Superintendent for Birmingham, emphasised in his 1911 and 1912 Reports the need for accurate intelligence tests.

In the case of the feeble-minded there is a general diminution of the general intellectual faculties ... the object of the mental test employed should be to measure not so much the intellectual acquisition already made as the inborn all-round efficiency which we have described under the term 'general intelligence'.<sup>31</sup>

In 1911 Newman had advocated the use of intelligence tests to diagnose defectives in his annual report of the Board of Education. An article by Burt in the Eugenics Review in 1913 made it clear that his own growing interest in intelligence testing was dominated largely by the problem of the mentally handicapped - quoting the work of Galton and the recommendation of the 1908 report, he stressed that "there is no such thing as manufactured feeble-mindedness" and

The fact of mental inheritance can no longer be contested; its importance scarcely over-estimated ... there assuredly can be no problem upon which experimentalists, statisticians and psychologists could so fruitfully concentrate their wisdom as the problem of heredity and its influence upon the mind.<sup>32</sup>

In the same year, at a meeting of the British Association, a joint session of the Physiology and Educational Science session discussed the dispute on the laws of inheritance and the need to develop intelligence tests and the 1913 Mental Deficiency Act gave further impetus to the development of mental tests by forcing more precise diagnosis. The Board of Education gave clear indications that they regarded tests as scientific when they replied to a letter criticising the role of Medical Officers of Health in diagnosing mental deficiency.

...the question of determining whether a child is or is not incapable by reason of mental defect of benefiting by the instruction in an ordinary elementary school is ultimately one which must be decided by a qualified medical man on the application of certain scientific tests.<sup>23</sup>

The development and refinement of intelligence tests was, then, spurred on by a perceived need to identify the mentally deficient. Tests in turn 'confirmed' that subnormality was the 'cause' of other social problems including criminality.

The theses of Lambroso have been wholly discredited by the results of intelligence tests. Such tests have demonstrated beyond any possibility of doubt that the most important trait of at least twenty-five percent of our criminals is mental weakness. The physical abnormalities which have been found so commonly among prisoners are not the stigmata of criminality but the physical accompaniment of feeble-mindedness.<sup>24</sup>

Further 'scientific' proof of the laws of inheritance of intelligence and degeneracy was provided by the family studies, which were undertaken, mainly in the United States, in the last part of the nineteenth century and well into the twentieth century. These studies purported to demonstrate that not only was feeble-mindedness inherited (that is, ran in blood lines as do haemophilia, eye colour and blood group), but also that it was closely associated with criminal behaviour, alcoholism, immorality, pauperism, and vagrancy. Degenerates, it was also discovered, tended

to have large families and this added to the fears of the dilution of national intelligence.

In Britain, Auden, Medical Superintendent for Birmingham, noticed in 1908 when studying the families of mentally defective children that

it is clear that family records such as these point a moral which cannot be permanently disregarded ...society must protect itself from the unrestricted propagation of tainted stock.<sup>35</sup>

But probably the most influential study of inherited degeneracy in blood lines was H.H. Goddard's study of the Kallikak family.<sup>36</sup> Goddard studied the family backgrounds of the children admitted to the Vineland Institution in the United States where he was Medical Superintendent.<sup>37</sup> He prepared charts which he claimed 'proved' that feeble-mindedness was inherited and closely associated with all types of moral degeneracy, although he recognised, as did the other 'hereditarians', that some forms of mental subnormality were not inherited. However, these latter types of subnormality ususally resulted in severe subnormality, were not associated with other forms of social degeneracy and were equally likely to be found among the children of middle- and working-class parents whereas feeble-mindedness (mild subnormality) was found among the lower working class and closely associated with other social degeneracies.

The study of the Kallikaks was published in 1912 and was very influential in England as well as the United States. The study traced the descendents of Martin Kallikak, both from a pre-marital liaison with a girl who Goddard claims was feeble-minded, and from his legal marriage. The genealogical chart demonstrated that

... the line of descent of the Kallikak family from their first colonial ancestors. It was Martin who divided it into a bad branch on the one hand and a good branch on the other. Each of these branches is traced through the line of the eldest son down to a person of the present generation. On the bad side it ends with Deborah Kallikak, an inmate of the Training School at Vineland, on the good side with the son of a prominent and wealthy citizen of the same family, now a resident of another state.<sup>38</sup>

Goddard maintained that Martin Jr. the son of the pre-marital liaison, had 480 descendents, of whom 143 were mentally deficient and only 48 definitely normal, the rest being either unknown or doubtful, although 36 were illegitimate, 33 sexually promiscuous, 24 alcoholics, 3 epileptics, 3 criminal, 8 kept 'houses of illfame' and 83 died in infancy. In contrast, the descendents of Martin's lawful marriage, who totalled 496, all became good, reputable citizens, including doctors, lawyers, judges, and other community leaders.

This study was widely regarded as 'conclusive' proof that feeble-mindedness was hereditary. Its conclusions were supported by other studies including Estabrook's<sup>39</sup> study of the Wans (1912) and Devenport's<sup>40</sup> Hill Folk. The fears of the Eugenics Movement were fuelled by these findings and added to the 'belief' that the feeble-minded posed a threat to civilization.

For many generations we have recognised and pitied the idiot. Of late we have recognised a higher type of defective, the moron, and have discovered that he is a burden, that he is a menace to society and civilization, that he is responsible, in a large measure, for many, if not all, of our social problems. 40

One of the main consequences of these studies was the development of the view, especially in the United States, that the mentally defective should be sterilized as well as segregated. Lapage,<sup>41</sup> writing in England in 1920, argued that sterilization was not necessary if life-long care in institutions was provided from an early age. It was felt that not only would the numbers of the feeble-minded increase, imposing an ever increasing burden on society, but also that the level of general intelligence in the population would decline if mental defectives were allowed to breed.

Degeneration is thus a cancerous blight, constantly spreading, tainting and spoiling sound stocks, destroying race values and increasing social burdens. In fact degeneracy not only



handicaps society but threatens its very existence. Congenitally incapable of adjusting themselves to an advanced social order, the degenerate inevitably becomes its enemy - particularly those high-grade defectives who are natural fermenters of social unrest. <sup>43</sup>

The 'scientific' research and findings of the American studies were replicated, and widely disseminated and echoed in Britain.<sup>44</sup> Tredgold in 1903 stated:

Therefore in 90 percentage of patients suffering from marked defect, the condition is the result of a marked state of the ancestors, which so impairs the vital powers of the embryo that full and perfect development cannot take place ... Amentia is thus not only hereditary, it is also the final expression of progressive neuropathic degeneration. <sup>44a</sup>

However, while Goddard was convinced that the transmission of a mental defective condition followed the Mendelian mode, Tredgold and Lapage were unable to satisfactorily demonstrate that it was inherited in the strict sense of the word - that is, that the condition is carried in the germ plasma of the parents. Instead they regarded mental handicap as more often the expression in the offspring of various forms of mental disabilities in the ancestors, as Tredgold argued

In my experience it is commoner for the ancestors of defectives to suffer from such conditions as insanity, epilepsy, dementia and allied psychopathological states, than it is for them to be actually mentally deficient.<sup>45</sup>

While Lapage<sup>46</sup> maintained that ninety percent of mental deficiency was caused by Neuropathic Inheritance - that is, inherited and inbred, not caused by bad influence of environment or disease, in the first two decades of the twentieth century it became accepted as scientific 'fact' that mental subnormality was hereditary and closely allied with other types of social degeneracy, and in particular that the feebleminded posed a threat to civilization.

The only 'solution' was the life-long segregation of the deviants.

We have seen that lifelong care is essential, and that the most forcible argument in its favour is that every feebleminded person who is not under restraint is a menace to the community: not only is such an individual very likely to become a so-called criminal, drunkard or prostitute, but also he or she may propagate and spread a taint that is wholly bad by having children, legitimate or illegitimate.<sup>47</sup>

These views were widely expressed in medical and psychological writing on mental deficiency, and in the writings of the Eugenics Movement. It is difficult to determine how deeply the views and attitudes penetrated into everyday consciousness, but many of the stereotypes and fears still held concerning the mentally handicapped can be seen to be underpinned by these views. (In Chapter 7 I discuss attitudes to the mentally handicapped).

### 3.2 Social Policy and the Mentally Handicapped in early twentieth century England

The changing conception of the mentally subnormal in the early twentieth century was quickly reflected in social policy. The growing concern about the problems presented by, and the danger of, the mentally subnormal resulted in the government setting up a Royal Commission in 1904.

The Commission was set up specifically

to consider the existing methods of dealing with idiots and epileptics and with imbeciles, feeble-minded, or defective persons not certified within the lunacy laws, and in view of the hardship or danger resulting to such persons and the community from insufficient provision for their care, training and control, to report as to the amendment in the law and other measures which should be adopted in the matter, due regard being had to the expense included in any such proposals and to the best means of securing economy therein.<sup>48</sup>

The Commission, under the Chairmanship of H.J. Gladstone, started receiving evidence in 1904 and published its report in July 1908, having received submissions from 248 witnesses, including inspectors and medical officers of special schools, reformatories, prisons, lunatic and idiot asylums, as well as representatives of all groups who were considered able to give information on the subject. The Commission also obtained details of how other countries dealt with the mentally defective as well as writing to institutions for the mentally subnormal in the United States, Europe, Ireland and Scotland.

The Report expressed considerable concern about the existing provision made for the mentally subnormal especially in view of the size of the problem (it was estimated that at least one in 217, i.e. 0.46 percent of the population, was mentally defective and that at least one in 127, i.e. 0.79 percent of school children, were either idiots, imbeciles or feebleminded) and of the fact that they needed to be adequately controlled in order to protect society.

Of the gravity of the present state of things, there is no doubt ... there are numbers of mentally defective persons whose training is neglected, over whom no sufficient control is exercised and whose wayward and irresponsible lives are productive of crime and misery, of much injury and mischief to themselves and to others, and of much continuous expenditure wasteful to the community and the individual family. 49

Considerable concern was expressed about all the mentally defective, but one group, the feebleminded, were selected out as needing special attention. Many of the feebleminded were not properly trained, according to the report, and as a consequence became criminals, paupers or members of other social problem groups. This meant that they placed an intolerable social and economic burden on the community. Considerable evidence was presented to the inquiry, which led them to come to this conclusion.

The Medical Officer for Pentonville insisted that forty percent of juvenile offenders were feeble-minded, and the Medical Officer for London County Council maintained that there was a high correlation between mental handicap and criminal behaviour, while Dr. Ashley, Medical Officer of the Manchester special schools, maintained that mental defectives who were not properly cared for

...tend to an increase of the criminal and immoral classes, as well as of course the pauper classes. §0

The evidence submitted to the Commission suggested that a large number of feeble-minded men and women drifted into the workhouse before they reached the age of 30 years. In the case of women there was also a tendency for mentally subnormal ones to have illegitimate children. Dr. Millard of Manchester found that of nineteen feeble-minded women in the laying-in ward of the workhouse infirmary, all but two had illegitimate babies. Dr. Tredgold found in a group of sixty-one feeble-minded mothers that nineteen were legally married and that forty-two had illegitimate children. The Physician Superintendent of the Royal Edinburgh Asylum argued that

Feeble-minded young women are subject to overwhelming temptations and pressure towards sexual immorality. Many of them have had illegitimate children and this often at very early ages ... I look on this source of immorality as an extremely grave one in our social life. When illegitimate children are born by such young women the chances are enormously in favour of their turning out to be either imbecile or degenerate or criminal. §1

The perceived 'danger' of the mentally defective also led other expert witnesses, such as Sir W. Chance and Dr. M. Cooke, to advocate their life-long segregation. Miss Denby of the Association for the Permanent Care of the Feeble-minded also pointed to the 'dangers' of leaving mentally subnormal children in the community. The Royal Commission concluded:

... we have pointed out how strong is the argument for the detention of the mentally defective in suitable institutions ... segregation and control should follow immediately on their leaving a special class ... The evidence ... emphasises the necessity of segregation or detention on the widest grounds of public policy. It is very representative and comes from the authorities of prisons, medical officers of special schools, superintendents of county asylums, members of county councils, Poor Law inspectors, medical experts on questions of insanity and disorders of the mind, and from men of general authority and large legal experience, and others ... And ... the mass of evidence is absolutely consistent with our own experience and with the result of our perceived investigations<sup>fa</sup>

The recommendations of the report reflected very clearly three current concepts concerning the nature and extent of mental deficiency. They felt that society needed to be protected from the mentally deficient, and that considerable efforts needed to be made to identify all mental defectives. While in general the mental defectives should be segregated in hospitals, asylums or colonies, it was felt that in a few cases family care or a guardianship order would suffice.

The report received a very mixed reception. In particular, the Eugenics movement, especially the Eugenics Education Society which had been founded in 1907, did not feel that the recommendations went far enough if society was to be protected from the subnormal. As a result the government decided not to introduce legislation immediately but to await further developments.

Two powerful pressure groups - the Eugenics Education Society and the National Association for the Permanent Care of the Feeble-minded - launched a campaign to keep the public informed of the importance of the eugenic problem and to persuade the government to introduce legislation enforcing the permanent care and segregation of the mentally defective. A.F. Tredgold lobbied M.P.'s to propagate the idea that mental deficiency was hereditary and was leading

to the degeneracy of the race. Galton and Montague Crackenthorpe (first President of the E.E.S.) used the columns of The Times to argue the hereditarian case, while Auden, co-founder of the Birmingham branch of the E.E.S. and school Medical Officer for Birmingham, emphasised the problem of racial decay in one of his earliest reports

The recommendations of the Royal Commission ... still await consideration and the problem of mental deficiency remains one of the most pressing and urgent social questions ... Nothing is more striking than the frequency with which more than one member of the family exhibit mental deficit ... In other words, heredity plays a great part in the continuance of mental deficiency.<sup>43</sup>

In 1910 Miss Pissant<sup>44</sup> advocated the permanent care of the feeble-minded in a speech made to a church congress. She justified this policy by referring to the American Family Studies and by giving examples of families in England who despite considerable social work support were too defective to care adequately for their families.

The work of these two pressure groups aroused public opinion,<sup>45</sup> and considerable concern was expressed about the 'danger' that defectives posed to ordinary citizens and to the community. By 1912 the Home Office had received more than 800 resolutions from public bodies, advocating the permanent care and segregation of the mentally defective, including the feeble-minded. The submission of resolutions by public bodies does not of course 'prove' that public opinion was aroused; it does, however, show that there was some general concern. Councils and Education Authorities are elected bodies and they reflect to some extent the concerns of the local electorate, or at least what they feel concerns the local electorate. It is of course likely that only a few vocal and influential citizens expressed 'real' concern, and that this coupled with newspaper campaigns and the work of the two pressure groups, both supported by leading and influential figures, created a 'moral panic', the 'man in the street' being

considerably influenced by the media and official views and fear being widely disseminated.

As a result of this pressure two bills were introduced in 1912, one by M.G. Stewart M.P. and one by the Home Secretary. Both passed the Second Reading and were referred to Standing Committee. After several postponements the latter bill was re-introduced in March 1913 and received the Royal Assent on August 15, 1913. The delays occurred because the Bill was widely attacked both in and outside Parliament. Four newspapers, The Citizen, the Daily News, the Daily Herald, and the Manchester Guardian all criticised the Bill. The fears of the Bill's opponents were expressed in Parliament by among others, the Conservative M.P. Robert Cecil who justified his concern thus:

I confess I feel very nervous about applying any remedy on the grounds of eugenics in the present condition of our knowledge of that science.<sup>56</sup>

It was felt that the Bill went too far in its recommendations and despite a campaign in The Times<sup>57</sup> newspaper by the Bill's supporters the government withdrew it.

The withdrawal of the Bill immediately led to a campaign for its re-introduction, in the media and from pressure groups and powerful citizens. Articles appeared in the Lancet in support of the Bill.

We live in days when even the most sentimental humanitarians can hardly be blind to the fact that for nations, as for individuals, the struggle for existence is still a stern reality and that in the struggle, efficiency is the price of survival ... It is a lesson which is applicable to other matters beside the propagation and conduct of war and nowhere is it more pertinent than in what to do with the furthering of racial fitness.<sup>58</sup>

A new Bill was introduced in 1913, which left out the most controversial clauses in the previous Bill - the clause forbidding marriage and the one permitting compulsory sterilization. Parliamentary opposition virtually disappeared,

the official opposition, agreeing not to *oppose* the Bill. The only effective opposition came from a few back-benchers. One of these, Wedgewood, pointed to the class nature of the Bill and argued that it was aimed at social control and at improving the wealth-producing power of the working class, by incarcerating those who were not able to work at the required level. The measures in the Act were not aimed at all the mentally subnormal but the 'feebleminded', who came from deprived working class backgrounds. But these few voices raised in opposition were hardly heard in the hurry to get the Bill through Parliament and on the Statute Book as quickly as possible.

The 1913 Mental Health Act incorporated the main recommendations of the Royal Commission and also reflected the concern that had been expressed about the inadequacies of some of the conclusions of the Report. Four classes of people were defined as coming within the terms of the Act: idiots, imbeciles, the feebleminded and moral defectives. The first three were clearly referring to people with varying degrees of mental handicap, but it was unclear if moral defectives had to be mentally subnormal. The Act set up a Central Board of Control, and required County and County Borough Councils to ascertain the numbers of mental defectives in their area and to provide and maintain sufficient institutions to 'care' for them. Local Education Authorities were required to report all children over seven years who were ineducable, and were responsible for informing the Local Authority of those leaving special schools who required supervision. Legal requirements were laid down governing the reception and detention of mentally defective persons. Feebleminded females giving birth to illegitimate children, habitual drunkards, vagrants, criminals, feebleminded minors (i.e. those under 21 years) and imbeciles and idiots of any age could be compulsorily detained. Mental deficiency had to be diagnosed by two doctors; once diagnosed an



individual could be detained indefinitely, although provision was made for periodic review of the condition of those detained under the Act. Local Authorities were empowered to put mentally handicapped individuals under guardianship orders in the community, although the provision was not widely used.

The 1913 Act, then, formally laid down the principle of making special provision for the mentally subnormal - it identified them as a social problem group, and gave wide powers of permanent detention of those officially diagnosed as mentally defective. It also marked them out as outsiders, as a group incapable of self-support, a burden on the community, to be hidden away permanently for the protection of society. They were stigmatized as not fully human in a society where to be a 'good citizen' was to be economically and socially productive and where a man's worth was measured by his ability to secure and hold down a job. This view can still be seen to underlie current attitudes to the mentally handicapped, when even in a time of high unemployment it is socially unacceptable to be unemployed. The unemployed are stigmatized and have a diminished status, the mentally handicapped seem more so because they are seen as a burden on society and, in some unspecified way, a threat or danger. (See Chapter 7, where I discuss attitudes and behaviour towards the mentally handicapped at the interpersonal and community level).

Although the mentally handicapped had now become officially outcasts of society, they continued in many ways to be ignored. Many Local Authorities were slow to implement the provisions of the Act. By 1927 Local Authorities still only provided 5,301 beds for the mentally handicapped although the number of ascertained 'defectives' was over 60,000. This seems to have been due to the cost of providing permanent segregation, and suggests that public concern about the 'danger' of the mentally

handicapped may not have been as great as that of government, a few influential public figures and the Eugenics Movement.

It is difficult to convince members of the council that the expense of maintaining the feebleminded who cannot maintain themselves must eventually be borne by the community and that it is a choice between maintenance under improper conditions in Poor Law Institutions, in provision by out-door relief or unemployment benefit, or maintenance in institutions where they are under continuous training and care.<sup>4</sup>

The Board also suggested that mental defectives were a source of danger to neighbours and the community generally, and for this reason it was essential to detain them for life in asylums.

As it became evident that the 1913 Act was not being fully implemented, the government decided to set up a committee in 1926<sup>6</sup> to investigate the current situation with respect to children. The terms of reference of the committee were later extended to include adults. The Wood Committee reported in 1929. It made its recommendations within a conception of mental deficiency that regarded it as a social and a genetic problem. Mental defectives were seen as the last stage of the inheritancy of degeneracy - the degenerate group making up at least ten percent of the population. Particular concern was expressed about mental defectives of the primary amebic type, and it was argued that if all the families of mental defectives of this type were collected together

It would include ... a much larger proportion of insane persons, epileptics, paupers, criminals (especially recidivists), unemployables, habitual slum dwellers, prostitutes, inebriates and other social inefficients than would a group of families not containing mental defectives.<sup>7</sup>

An epidemiological survey carried out for the Committee estimated that 1 percent of the population was mentally deficient, and of these 25 percent were idiots or imbeciles and 75 percent feebleminded. The group seen as the real 'threat' was also the most numerous. The Committee recommended

life-long segregation as the only effective means of dealing with the problem. However, recognising the cost of this, they argued that mental deficiency asylums were to be places of detention, not hospitals. The Wood Committee did not, however, go to the extreme of recommending sterilization as a solution, as had happened in the United States. In 1933, however, the Brook Committee<sup>62</sup> did recommend voluntary sterilization for the mentally defective, not because they felt that it would solve the 'problem' of mental deficiency, but that it might check the growth of a spreading group of people that were not wanted by their parents or anybody else.

The Brook Committee did recommend improved care for mental defectives as well as the provision of training and productive work for those detained in asylums. The economic situation of the depression meant that there was little headway made in the provision of institutions, although by 1937, 81 local Authorities in England and Wales out of 123 were making provision for the accommodation of the mentally defective.<sup>62</sup> There was instead a turn to community care as the 'solution', mentally subnormal people being cared for in the community rather than incarcerated in institutions (see Table 5 and Table 6). This trend can be seen as a response to an economic crisis rather than a change in attitudes towards the mentally handicapped as in 1933 it was still 'officially' held that

High grade mental defect occurs proportionally more frequently in the lowest social stratum than in the rest of the population. In this stratum there appears to be an unduly high incidence of mental defect, insanity, intellectual dullness and epilepsy, as well as tuberculosis and other physical defects. Cause and effect of the conditions found in the social problem groups are debatable but it is possible that selective mating may to a large extent account for this concentration of physical defects and mental defects and disorders. There is evidence that in the poorest districts neighbour marries neighbour and like marries like.<sup>64</sup>

Table 5: Total Numbers of known Adult Defectives in  
England and Wales 1929 and 1936/7<sup>65</sup>

	1937	1928	Per 100,000 pop.	
			1928	1936
Known to local Authority	120,731	61,522	157	297
Ascertained subject to be dealt with	88,699	38,979	99	218
In Institution or under Guardianship	46,170	21,333	54	113
Under statutory supervision	36,307	18,159	46	89

Table 6: Mental Deficiency Authorities Provision Jan. 1 1936<sup>66</sup>

Under Statutory Supervision	36,307
Unver Voluntary Supervision	25,048
Under Guardianship	3,729
On Licence	3,023

#### 4. Social Policy and the Mentally Handicapped in the period after World War II

In the period immediately following the Second World War, Britain became what is usually referred to as a Welfare State. As a result of the Welfare legislation of the late 1940's the care of the mentally handicapped was split between two bodies - the mental handicap hospital came under the control of the Health Authorities, while community services and education were the province of Local Authorities. The mentally handicapped have, however, remained a 'Cinderella' group in terms of resources provided

for them both in hospitals (see Table 7) and in the community. (See Chapter 6 for a more detailed discussion of the philosophy underlying social policy for the mentally handicapped in the last three decades.)

Table 7: Cost per Inpatient Week for Selected Services in Different Types of N.H.S. Hospitals in England 1969/1970 (in sterling)<sup>67</sup>

	Acute non-teaching - over 100 beds	Long-stay chronic sick	Mental illness	Mental handi-cap
Net total cost	55.70	22.50	17.63	14.96
Medical staff	3.10	0.46	0.81	0.39
Nursing staff	13.67	9.55	6.26	5.28
Domestic staff	2.77	1.67	0.60	0.44
Catering	6.07	2.81	2.64	2.23
Laundry	1.20	0.74	0.40	0.46
Power, light & heat	1.88	1.21	0.88	0.78
General cleaning	0.55	0.32	0.15	0.13

The care of the mentally handicapped has, at least superficially, become more humanitarian, and attitudes less negative. Evidence has gradually accumulated which suggests that the mentally handicapped do not pose a threat to civilization, and that it is not necessary to segregate subnormals for life in order to protect society. Even if this were not so, events in Europe in the 1930's and the first half of the 1940's have given distasteful flavours, in the minds of many, to policies or lines of thought which might even appear to be aimed at 'improving the race' by eugenic means. The emphasis has been on

reducing the cost to the community of caring for the handicapped by looking after them <sup>68</sup> in the community, instead of in large institutions (see Chapter 6).

The history of social policy towards the mentally handicapped in the last thirty years has been one of increasing advocacy of community care, but while the policy has been widely advocated, in practice little change has occurred. The Royal Commission (1954-57) <sup>69</sup> received evidence from a large number of professional and other bodies and individuals concerned with the care of the mentally subnormal. These included considerable information on the fact that large numbers of people were detained in mental subnormality institutions even though they had intellectual abilities above the level accepted as the maximum for mental subnormality to be present by many authorities. The National Council for Civil Liberties in particular pointed to many abuses in the existing methods of dealing with the mentally subnormal and argued that the incarceration of people in a subnormality hospital frequently occurred because they were seen as socially undesirable and not because they were subnormal.

The 1959 Mental Health Act, which incorporated many of the recommendations of the Royal Commission, advocated community care for the mentally handicapped who did not require specialised treatment only available in a hospital. The government advocated the expansion of community facilities for the subnormal, but Local Authorities have been very slow to develop community facilities for the mentally subnormal. In practice, community care has meant that the families, and especially the mothers, of the mentally handicapped have had to devote their lives to the care of the handicapped. Indeed the Younghusband Report argued <sup>70</sup>

Perhaps most important of all are efforts to make it possible for the family to care for its physically or mentally handicapped member.

While Local Authorities have been slow to develop community-based facilities for the mentally subnormal, even following 'Better Services for the Mentally Handicapped (1971), a White Paper designed to improve services for the mentally subnormal, hospitals have continued to be criticised. Conditions in subnormality hospitals have been shown to be undesirable for the care of the majority of the subnormal. The facilities are poor, the hospitals have difficulty in recruiting nursing staff and professionals, and are usually isolated from the communities from which their patients come.<sup>71</sup>

The reasons for the changes, or rather the lack of change, in the provision made for the mentally subnormal in the last 30 years are complex. Social, economic and political factors are all extremely relevant. The mentally subnormal are a stigmatized group, who have little economic or political power and consequently are low on the priority list for public spending. Furthermore, as Townsends<sup>72</sup> has pointed out, those in charge of the large subnormality hospitals, who wield considerable power, have a vested interest in the retention of these institutions.

## 5 Conclusion

The social conception of the mentally handicapped has changed markedly in the last two centuries, the period of the rapid growth and development of industrial capitalism. These changes are closely related to the way in which the problem of social control is conceptualised and are a response to the 'needs' of the new socio-economic order. In common with other groups of social deviants/outsideers, the mentally handicapped became seen as different and managed as deviants.<sup>73</sup> They are seen as a 'threat' to the new social order - a group who could not or would not conform to the work ethic, in a rapidly expanding industrial society which was becoming increasingly dependent on a skilled, efficient and co-operative labour force.

The optimism of the early part of the nineteenth century quickly gave way to 'fear', a fear of degeneracy as it was realised that not only was mental handicap incurable, but the numbers were much greater than had been supposed. The introduction of mass schooling resulted in the 'discovery' of the feebleminded, a large, hitherto undetected group. This, together with the development of the 'science' of Eugenics and of psychometric tests, resulted in the 'scare' of the early twentieth century and the period of incarceration of the mentally handicapped.

Since the middle of the twentieth century it has gradually become accepted that the mentally handicapped do not pose a threat to society. The emphasis in handling the mentally handicapped has changed from the advocacy of segregation from the community to arguing that they should be cared for in the community, although in practice little change in the provision of services has taken place. (The economic, social, political and attitudinal factors underlying this change in emphasis are discussed more fully in Chapter 6).

It must be born in mind that in trying to relate changes in the conception of the mentally handicapped to the social provision made for their care, one is describing ideal types - what dominates during a given period. However, change is gradual and therefore there co-exists within any given stage social conceptions and forms of care from the preceding one and the succeeding one. This is further complicated by the way in which professional, public, and official/government attitudes and conceptions change in different ways and how the changes in one area influence changes in others. Furthermore, governments are influenced by political, social and economic factors that



determine the ways in which resources are allocated between the various competing demands. Even in the affluent period following the Second World War the <sup>handling of the</sup> mentally handicapped in capitalist society can be seen to involve a tension between 'protecting' society and the cost of maintaining those who are officially labelled as subnormal. The most recent developments in the official philosophy towards the care of the mentally handicapped can be seen as easing this tension - the more towards community care. This is explored more fully in the next chapter.

REFERENCE NOTES, CHAPTER FIVE

- 1: Report of the Committee on Colonies for the Segregation of Defectives (U.S.A.), 1903
- 2: Skultons, 1975
- 3: Foucault, 1971, p274
- 4: See Itard, 1801
- 5: Condillac 1755
- 6: Esquirol 1845
- 7: Itard, 1801, p91
- 8: Knight, 1968 p82
- 9: Seguin, 1846
- 10: Howe, 1848 p1
- 11: The Lunacy Commission. 1866
- 12: Sarason and Doris, 1969 p210-211
- 13: Howe, 1848
- 14: Spencer 1851 p323-324
- 15: Galton, 1869
- 16: Report of the Departmental Committee on Defective and Epileptic Children, 1898
- 17: The Elementary Education (Defective and Epileptic Children) Act 1899
- 18: Quoted in Lapage, 1920 p3
- 19: Quoted in Davenport, 1911
- 20: Report of the Charity Organisation Society, 1877
- 21: Report of the Charity Organisation Society, 1877
- 22: Beveridge, 1906 p327
- 23: Pearson, 1905
- 24: S. Webb, 1906
- 24a: Russell, 1924 p47 2 p548-49
- 25: Pearson, 1905 (Letters Page)
- 26: See, e.g., Wells, 1904, 1905, 1908, 1930
- 27: S. Webb, 1896
- 28: Bell 1896
- 29: Bell 1896 p19
- 29a: For example Blunt, 1907
- 30: Davenport, 1911
- 31: Auden, 1912 p64
- 32: Burt, 1913 p183
- 33: Public Record Office Ed 50/116
- 34: Terman, 1919 p7
- 35: Auden, 1904 p76
- 36: Goddard, 1912
- 37: Goddard, 1910
- 38: Goddard, 1912
- 39: Eastabrook, 1910
- 40: Davenport, 1911 p66
- 41: Goddard, 1915
- 42: Lapage, 1920
- 43: Stoddard, 1922 p227
- 44: E.G. Tredgold, 1908; Lapage, 1920; Cruikshank, 1924.
- 44a: Tredgold, 1908
- 45: Tredgold, 1908 p16

- 46: Lapage, 1920
- 47: Lapage, 1920 P147
- 48: Royal Commission, 1904 (Terms of Reference)
- 49: Report of the Royal Commission, 1908 Vol 8 P3
- 50: Report of the Royal Commission, 1908
- 51: Report of the Royal Commission, 1908 Paragraph 104
- 52: Report of the Royal Commission, 1908
- 53: Auden, 1909 P75
- 54: Pilsent, 1910 (Quoted in Jones 1972 P197)
- 55: Jones, 1972 P144
- 56: R. Cecil: Hansard 19-7: 1912: 721-738
- 57: Times, 28.11.1912, 29.11.1912.
- 58: Lancet, 14.12.1912.
- 59: Board of Control, 1927
- 60: Wood Committee, 1929
- 61: Wood Committee, 1929 Part III
- 62: Brook Committee, 1933
- 63: P.E.P., 1937
- 64: Departmental Committee on Sterilization 1933  
- (Quoted in P.E.P. 1937, P315)
- 65: P.E.P., 1937 P27
- 66: P.E.P., 1937 P278
- 67: Navarro, 1978 P90
- 68: See, e.g., Jaehnig (1979) for a more detailed account of changes in social policy towards the mentally handicapped in the last thirty years.
- 69: Royal Commission on the Law Relating to Mental Illness and Mental Handicap.
- 70: Younghusband, 1970 P161
- 71: See, e.g., Morris, 1969
- 72: Townsend, 1974
- 73: See, e.g., George (1973), Scull (1978)

## CHAPTER 6

### CURRENT POLICIES AND PRIORITIES IN THE HANDLING OF THE MENTALLY HANDICAPPED

#### 1. Introduction

We are all concerned to improve services for mentally handicapped people and in particular to develop those services which enable a mentally handicapped person to live as normal a life as possible whether in hospital or in the community.

(P. Jenkin, Secretary of State for Social Services, 1980)<sup>1</sup>

This statement, recently made by a Cabinet Minister, sets forth clearly a continuing aim to improve services for the mentally handicapped. More than this, it explicitly enshrines the 'normalization' principle - a principle first enunciated with respect to the mentally handicapped in the Scandinavian countries in the 1960's and now widely advocated as a policy objective in other developed countries, including Britain and the United States.

As I suggested in Chapter 5, the 1960's and 1970's witnessed an apparently revolutionary change in declared public policy (although not necessarily in practice, as I shall argue below) in the handling of the mentally handicapped, the consolidation of the changes being the publication in 1971 of the White Paper Better Services for the Mentally Handicapped. The major policy objective became community care and 'normalizing' the lives of mentally handicapped people. This included the aim of discharging as many mentally handicapped people as possible from hospital and providing suitable accommodation and facilities for them in the local community. Furthermore, the mentally handicapped were no longer to be regarded as second class citizens but rather increasingly to be integrated into the existing general provision of social,

educational and health services provided for the community in which they lived. The stated aim is, therefore, for as many mentally handicapped people as possible not only to live in the community but also to become integrated into it - to become full members of society. These aims have been reiterated by the government in the last year,<sup>12</sup> and it has been explicitly stated that the intention is to provide a comprehensive community-based service for the mentally handicapped. They would not only be entitled to the same range and quality of services as are available to other citizens, but also to services designed to meet their special needs, to enable them and their families to live as 'normal' a life as is compatible with their kind and degree of handicap. 'Normalization', at least in the way it has been interpreted officially in Britain, means positive discrimination - giving extra help to the handicapped so their lives can be, as far as is possible, the same as those of every other citizen.

As I have already indicated, these policy objectives have been considerably influenced by the Scandinavian model of handling mentally handicapped people, originally developed as a response to the mounting criticisms of the effect of 'warehousing' and the associated medical model of mental handicap which I have discussed in Chapters 2 and 3. (A number of research studies already discussed indicated that living in the community did not have these adverse consequences.) Denmark was the first country that introduced legislation specifically designed to 'normalize' the everyday existence of the mentally handicapped, but Sweden's handling of the mentally handicapped is more frequently cited as a model to be emulated.

In this chapter I intend to examine the Swedish philosophy and policies for the mentally handicapped and the extent to which they have been adopted and implemented in Britain. It will be necessary to examine, critically, both the policy of 'normalization' and that of 'community care', to determine to what extent they have been and can be

implemented, to determine to what extent 'normalization' and 'community care' are the same objective, and to ask why these policies became adopted by the Scandinavian countries, North America, Britain and other European countries in the last two or three decades.

## 2. Sweden and the Normalization Principle

Sweden is generally regarded as a capitalist society that provides a comparatively high level of welfare provision for its citizens and caters for the needs of all the members of the society. Thus Scase has argued that Sweden is

... often viewed as a synthesis of the most desirable features of both capitalist and state socialist countries. <sup>2</sup>

Specifically with regard to the mentally handicapped, Lippman<sup>3</sup> suggests that it is precisely because Sweden has this general attitude to social welfare that it has been able to provide a high level of care and facilities and to develop and implement a policy of 'normalization'.

The precise historical antecedents of the policy in Sweden are difficult to determine. However, psychological research appears to have influenced both the leaders of a parent pressure group<sup>4</sup> and those officially concerned with policies for the mentally handicapped - namely, research on the adverse effects of institutionalization and research which suggested that mentally handicapped people could develop more fully in a more 'normal' environment.<sup>5</sup> (K. Jones<sup>6</sup> has specifically cited Tizard's 'Brooklands experiment' as being about the idea of 'normalization', although to what extent this research influenced the Swedes is difficult to determine). However, Grunewald, the Director of the Department for the Care of the Mentally Retarded of the National Board of Health and Welfare, stated in 1969:

In Scandinavia we have been seeking new goals and methods of caring for the mentally handicapped and these have gradually attracted international interest. These goals are part of the

so-called 'normalization principle' ... the normalization principle has come as a natural reaction against over-specialization and institutionalization. 7

The principle of 'normalizing' the lives of mentally handicapped people is not only a policy objective; it is also enshrined in Swedish law. (In fact the mentally handicapped are the only disabled group to have legal rights to services specifically designed for them - 'normalization' for all other groups has meant that no 'special' provision is made for them legally - although Swedish law does ensure that public buildings and other public facilities are designed so that all citizens have equal physical access to them). The Swedish law on Mental Retardation became effective on the 1st July 1968 and has been described as a 'Bill of Rights'. It provides for a wide range of services and stresses that they should be made available to every retarded citizen and tailored to suit individual needs.

'Normalization' as developed in Sweden involves a cluster of ideas, methods and practices designed to enable the mentally handicapped person to have an existence as near the 'normal' as is compatible with his or her degree and level of retardation. Underlying the principle is a perceived 'need' to provide facilities and help for the mentally handicapped to enable them to lead a life as near as is possible to that led by every other citizen. Consequently, one of the main aims is that the vast majority should live in the community rather than be 'warehoused' in large hospitals.

Grunewald<sup>8</sup> has undertaken a detailed study of the existing provision in Sweden and suggested how services for mentally handicapped should be developed in the future in order to bring about 'normalization'. He has emphasised that 'normalization' involves more than just providing accommodation in the community if the mentally handicapped are to lead a relatively normal existence. It means enabling them: to live in their own personal accommodation;

to live in a bisexual world; to experience a normal daily rhythm of life; to eat in small groups; to work (or be educated) in a place physically separate from the place where they live; to be paid for the work they do at a 'fair' rate; to decide for themselves how they will spend their free time; and, in the case of young people, to be able to move away from the parental home to separate accommodation if they wish, as other young adults do. Accommodation for the mentally handicapped should not normally house more than ten residents and should be located in a community that is large enough to assimilate them. Residents in institution-type accommodation should, as far as is possible, have their own bedroom, have holidays away from 'home' and be encouraged to establish and maintain contacts with their families, relatives and other residents in the local community.

In practice, residential accommodation for the mentally subnormal in Sweden is of three main types, all of which are still being modified to meet the demands and requirements of the 'normalization principle', and especially to make possible the integration of the mentally handicapped into local communities. The emphasis has thus been on providing accommodation in the community. The three types are hospitals (which it is hoped will eventually be phased out), residential homes (for those requiring considerable care and attention), and group homes (for those capable of a high level of independence). According to Grunewald, and based on medical and social care needs of mentally handicapped people, it is anticipated that eventually thirty percent will live in residential homes, fifty percent in group homes or completely independently and twenty percent with parents or relatives.



Table 8: Living Conditions for 23,000 Mentally Handi-  
capped People in Sweden in 1975 <sup>8a</sup>

<u>Place of Residence</u>	<u>Proportion</u>
Residential homes	38%
With parents/relatives	33%
Independently	12%
In hospitals	4%
In group homes	7%
In foster homes	2%
Other	3%

---

Although the policy of 'normalization' would seem to have been implemented in Sweden, at least to the extent that the majority of the mentally handicapped are not incarcerated in hospitals, nevertheless the degree to which their lives have actually been 'normalized' is more difficult to assess. Apparently politicians have accepted the policy, at least in part, because it is a less expensive way of handling the mentally handicapped (although whether it would be less expensive if a full range of supportive services were provided is debatable), but the moves to house the mentally handicapped in local communities have met with public opposition arising from the general negative emotional and intellectual attitudes towards the mentally handicapped among the general public.<sup>8 b</sup>

(See Chapter 7 for a more extended discussion of community and individual attitudes to the mentally handicapped). This means that it is unlikely that the mentally handicapped have become integrated into the community, and at another level we can ask to what extent hostels or residential homes provide a 'normal' environment.

However, although we can debate the extent to which 'normalization' has become a realised policy objective in Sweden, the principle has gained wide acceptance with pressure groups and decision-makers in both Britain

and the United States. It is advocated on the grounds that it is a more humanitarian and effective way of handling the mentally handicapped, enables them to develop at all levels of retardation to a degree previously thought impossible, and in Wolfenburger's terms lets them be treated as developing people rather than as incurably sick or as social menaces. (The historical origins of these conceptions of mentally handicapped people were developed in Chapters 4 and 5).

A graphic account of what 'normalization' can mean in practice in the United States has been provided by Robert Meyer. In his book Like Normal People he describes how his brother Roger Meyer (a mildly retarded man) was enabled to move from a residential home to independent living, holding down a job in a restaurant and eventually marrying a girl he had met in the residential home. This was achieved through a careful programme of counselling as well as gradually exposing Roger to the requirements of 'normal' day-to-day living. Edgerton,<sup>9</sup> Henskal<sup>10</sup> and Mattesen<sup>11</sup> (see Chapter 2) have also given accounts of mentally handicapped people leading 'normal' lives, although the extent to which they 'coped' with the requirements of independent living is, in some cases, debatable.

All these examples, however, are of mildly subnormal people, who can apparently be helped to a high degree of independent living. What, though, does 'normalization' mean for the more severely handicapped, who will never be able to live independently? In Eastern Nebraska the Community Office of Retardation has attempted to implement a policy of 'normalization' that has been reported on favourable.<sup>12</sup> Basically the aim is to provide accommodation and facilities in the community for all mentally handicapped people, except for those requiring specialised medical care. Services included educational facilities, integration in 'normal' schools where possible, for all children, adult work centres for all the mentally handicapped incapable of

open employment (for which those capable of it were prepared) and crisis intervention facilities to assist families caring for a mentally handicapped member.

In the rest of this chapter I will examine the extent to which 'normalization' has become a policy objective and been implemented in Britain, and attempt to explain why advanced capitalist societies, or at least their governments, have so readily accepted the principles of 'normalization' and 'community care' as policy objectives in the last two decades. Finally I will suggest that 'normalization' and 'community care' are not clear-cut concepts but mean different things to different people. In particular, public policies are based on an interpretation that does not necessarily agree with that of the major advocates of 'normalization'.

### 3. Britain: 'Better Services'- The Reality

Our services for the mentally handicapped have passed through the same historical stages as those in other developed countries which separated men, women and children off into large and forbidding institutions in remote places to protect the mentally handicapped from the community and the community from the mentally handicapped; providing intra-mural care from birth to death in the belief that mental handicap was a completely static condition requiring life-long institutional support. Hence their professional and social isolation from other services in the community: hence the long history of neglect and lack of public interest, and hence their low priority rating in terms of allocation of resources, even at a time when the public increasingly campaigned for better services for other non-productive and underprivileged groups ... and in spite of the fact that many of the staff in the service have been calling attention to the grave deficiencies that existed for a very long time.<sup>13</sup>

(Baroness Serota, 1971)

This statement by a member of the government was made in the same year as the White Paper Better Services for the Mentally Handicapped. This document laid down plans for the implementation of a fully comprehensive

community service for the mentally handicapped and advocated that

Each handicapped person should live with his own family as long as this does not impose an undue strain on them or him, and he and his family should receive full advice and support. 14

However, by 1971 the case for care in the community for the mentally handicapped was at least forty years old. Indeed, as I suggested in Chapter 5, despite an official policy of incarcerating mentally handicapped people in the early part of this century, probably a majority remained in the community. The 1929 Wood Committee recommended greater use of all forms of community care, and by the 1930's experts<sup>15</sup> were suggesting that given favourable circumstances the mentally handicapped could be cared for at home. In the post World War II period the Royal Commission on the law relating to Mental Illness and Mental Deficiency (1954) recommended a shift in emphasis from hospital to community care, and the 1959 Mental Health Act advocated the development of community facilities and the care of the mentally handicapped in the family home. Local Authorities were to provide advice, support, training facilities and other services required by the families of mentally handicapped people. This was followed in 1963 by a government report The Development of Community Care, which recommended the development of a family-orientated service and an expansion of community care, but also suggested that more mentally handicapped people might need residential care. However, in 1968 The Seeborn Report argued that the belief that community care did exist for the mentally handicapped was still a sad illusion.

Kathleen Jones,<sup>16</sup> soon after the publication of the White Paper, argued that the reason for this lack of progress in providing community services for the mentally handicapped was that

There are two long-standing problems in the services for the mentally handicapped - 'stigma' and 'inertia'. These are linked and underlie all the other problems. They do not get any less, though they perhaps take less overt forms than in the past.<sup>17</sup>

She suggests that there are a number of other problems in bringing about change: problems arising from earlier and now outdated policies for the mentally handicapped, problems arising from current societal attitudes to the mentally handicapped, problems arising from the nature of the mentally handicapped as a group, and problems created by recent changes in National Health Service policies.

In 1979 the Jay Committee, while noting that community care was not a reality, argued that there was a need to go beyond decarceration and to 'normalize' the lives of the mentally handicapped. (It is interesting to note that Bosanquet, in a Note of Dissent, pointed to the fact that this was unlikely to come about because Local Authorities are reluctant to expand services for the subnormal, especially the severely subnormal). Indeed, financial considerations interact with 'willingness' to spend money on the mentally handicapped. A policy of community care means that local authorities have to finance residential provision, facilities and services, while hospitals are financed by central government. As the central government has been reluctant to provide additional funds to local authorities, they have been unwilling to provide those services which are not mandatory.<sup>17a</sup>

What I intend to examine is the extent to which there has actually been a shift from hospital to community care of mentally handicapped people in the 1970's. Also I examine the extent to which a comprehensive community service has been developed and what efforts have been made to 'normalize' the lives of mentally handicapped people.

The 1971 White Paper proposed that Mental Subnormality Hospitals should in the future provide 'treatment', not 'care', and that only mentally handicapped people needing specialised medical facilities and nursing should be hospitalized.

All other mentally handicapped people not living with their families should live in residential facilities such as group homes, hostels, flatlets and foster homes provided by the local authorities. The stated aim was to decrease by 25,100 beds the provision made for adults in hospitals while community provision should be increased by 31,950 places. In the case of children, hospital beds were to decrease by 1,000 and community provision was to be increased by 4,000 places. There was also to be a thirty percent expansion in educational facilities for children of school age and of 4,000 places in Adult Training Centres. Jones has argued that

The intention is that the mentally handicapped will no longer be treated as a segregated, second-class service, but will take an increasing part in the general provision of social, educational and health services for the whole population. Lines of demarcation which have hampered development in the past can be removed, developments which are in accord with current social and administrative thinking are to take place and the provision of more money should be an indication of good intentions. All we need now is goodwill, co-operation and clear priorities.<sup>18</sup>

Five years after the White Paper, the Department of Health and Social Security in a consultative document, Priorities for Health and Personal Social Services in England (1976) claimed that a good start had been made in implementing the 1971 proposals. It stated that between 1969 and 1974 the number of places in residential homes had increased by 3,500 - from 6,000 to 9,500 - and the number of places in Adult Training Centres had increased from 23,000 to 32,000. In the same period the number of hospital beds had decreased by 500 and the amount of over-crowding in hospitals had been reduced. The document advocated the continued expansion of community care so that the 1971 targets could be achieved by 1991.

Despite the official optimism concerning the development and growth of community services in the mid-1970's and a reiteration of a continuing commitment to achieving

the 1971 targets within a twenty-year period, Jaehnig in 1979 suggested that

Community care is nearly as much a myth as it was in 1961 when Richard Titmus questioned the country's commitment and preparation to carry it out. In spite of the seemingly irresistible case for fundamental reform made in recent years, the policies that have emerged are narrow in their conception of the problem, timid in their prescription and ambiguous in their execution.<sup>19</sup>

In the same year the Jay Report found that even what they referred to as 'the modest targets' set in 1971 had not been reached and that the government had quietly dropped the target date of 1991 for full implementation. Even more recently Shearer<sup>20</sup> has suggested that the government's lukewarm response to the report of the Jay Committee means that the commitment to a shift to community care of mentally handicapped people is in danger of being reversed. Nevertheless in 1980, in a D.H.S.S. review of development in mental handicap services since the 1971 White Paper, Patrick Jenkin stated<sup>21a</sup>

The basic principles..are clear...in brief, that of recognising the rightful place of mentally handicapped people in our community and of making the services available accordingly.

The review does, however, go on to point out that restraints on local authority spending make the assumptions of the 1971 White Paper unrealistic, and a D.H.S.S. review of community services published in 1981 explicitly recognises that the White Paper targets will not be met by 1991.<sup>21b</sup> Indeed, a study of community care undertaken by the D.H.S.S. had as one of its major aims 'to clarify policies for the development of community care for the Health and Personal Services in terms of the resources now expected to be available'.<sup>21c</sup> Furthermore, three recent papers by the D.H.S.S. recognise that a considerable improvement in community services is necessary, as well as a continued movement from hospital to community-based care. It is necessary to examine with care what changes have actually taken place in the handling of the mentally handicapped - both moves to decarceration and to providing community services, and to determine to what extent the day-to-day lives of the mentally handicapped have been 'normalized'.

### 3.1 Decarceration

Community care and normalization imply that mentally handicapped people should live in and become integrated into a local community (although Gunzburg<sup>21</sup> has suggested that even the hospital can provide a normalizing environment) yet in the last ten years six new Mental Subnormality hospitals have been opened. Furthermore, plans have been drawn up for more. It is true that these hospitals are smaller than the old ones, but they are still hospitals and work within a medical model of mental handicap. By the mid-1970's one fifth of the 50,000 adults in hospitals were in ones accommodating more than one thousand five hundred patients, one fifth in hospitals accommodating between one thousand and one thousand five hundred patients, and a quarter in hospitals of between five hundred and one thousand inmates.<sup>22</sup> It has also been pointed out that a majority of these patients do not need the specialised medical facilities or nursing care of the hospital.<sup>23</sup>

In addition to large numbers of mentally handicapped people remaining in hospitals, admission of new patients has continued. On average, in each year since 1971, one thousand three hundred mentally handicapped people have been admitted for the first time to a hospital. In 1980 the number of adults still in mental hospitals was 45,000 and the rate of release was about two hundred a year - a rate of reduction of less than two percent per year. There are also over seven thousand children and young people in long-stay subnormality hospitals.<sup>24</sup>

Furthermore, while spending on the community care of mentally handicapped people increased between 1976/7 and 1979/80 and is expected to increase further in the fiscal year 1981/2, so has spending on hospitals (see Table 9).

This low-level expenditure is not only a reflection of the different needs of the physically ill, the mentally ill and the mentally handicapped, but also indicates differing priorities as well as the lack of medical



---

Table 9: Revenue Expenditure (England) on the  
Mentally Handicapped<sup>25</sup>

	Actual Expenditure 1976/7	Proposed Expenditure 1981/82
N.H.S. In-patients	£ 189 m	£ 209 m
Local Authority Residential care	£ 22 m	£ 32 m
Local Authority Day care	£ 30 m	£ 41 m

Despite the continuing level of expenditure on hospital services, mental handicap has remained the 'Cinderella' of the National Health Service in terms of expenditure (see Tables 10 and 11).

---

prestige in mental health specialities, including subnormality, and the lack of economic power and productive potential of mentally handicapped people (or at least that this is assumed to be the case).

---

Table 10<sup>25</sup>: Cost per In-patient Week in different types  
of hospitals (non teaching) 1976/7

Acute	£ 104.78
Mental illness	£ 36.00
Mental handicap	£ 33.68

---

Indeed, not only is spending on the mentally handicapped low in comparison with other groups receiving National Health Service treatment, but there is also a major problem in attracting and retaining staff in subnormality. The Royal Commission on the National Health Service which reported in 1979 argued that the staffing situation was a major problem and was likely to get worse. They found that the recruitment of doctors to the field was poor

in both quantity and quality, that many of the trained nurses were approaching retirement age, that a high percentage of staff were untrained, and that there was a high staff turnover (a situation described by Morris<sup>26</sup> in her study published ten years earlier). They concluded that

The fact that several enquiries have had to be set up in England and Wales and have reported adversely on the conditions they have found in hospitals for the mentally handicapped shows that, whether or not it is carrying too extensive a responsibility, the National Health Service is, in certain places at least, failing badly to fulfil its obligations.<sup>28</sup>

Table 11:<sup>27</sup> Cost per In-patient Week of different services in different types of hospitals as percentages of costs in acute non-teaching hospitals 1976/7

Type of service	Long Stay	Chronic	Mental Illness	Mental Handicap
Medical	27	13	26	13
Nursing	65	66	45	49
Domestic	58	60	27	27
Catering	55	48	45	43
Cleaning	68	55	35	32
Total net cost	44	39	32	30

The official policy of moving the mentally handicapped out of large hospitals and settling them into housing in the community has not proceeded at the rate aimed at by the government in the 1971 White Paper, despite repeated statements that they are still committed to these aims.<sup>27a</sup> However, decarceration is only one aspect of a policy aimed at providing comprehensive community care and normalized life-styles for mentally handicapped people. The other major aspect is the provision of services

and facilities for those not in hospitals. In 1978 the Department of Health and Social Security estimated that there were 110,000 severely and over 350,000 mildly sub-normal people in England and Wales. Of these over eighty percent of severely subnormal children, forty percent of severely subnormal adults and the majority of the mildly subnormal, adults and children, lived at home with relatives or in some form of residence in the community. Consequently any policy aimed at improving the everyday lives of the mentally handicapped must be concerned with those already living outside of hospitals. Yet as a number of studies have clearly demonstrated, community care still tends to mean care by 'Mum' or living in a hostel and still in practice isolated from the community.

### 3.2 Community Care in Practice

Community care in Britain has, in effect, meant leaving mentally handicapped people to live with their families, on the assumption that this provides a more 'normal' environment. (It is of course also cheaper for a child or adult to be looked after by the family than in a hospital or other residential home.) However, where care in the home is impossible then hostels or other residential accommodation within the community is advocated. As well as by place of residence, it is also assumed that the mentally handicapped will become integrated into the community in other ways and enjoy the social and medical facilities provided for all citizens in addition to receiving extra help where necessary. It is, consequently, assumed that this type of care will overcome many of the problems associated with residential care in hospital, including isolation and institutionalization.

However, as Bayley's<sup>29</sup> study in Sheffield has shown, mentally handicapped people can be isolated from the community even when they live with their families. Townsend has suggested that hostels can easily become mini-hospitals, replicating all the 'bad' aspects of the hospitals they are supposed to overcome. Shearer<sup>30</sup>, in criticising the Swedish 'group homes', has pointed out that they end up becoming nothing more than a very smart

version of subnormality hospitals - the life-style inside the residence may be most 'normal' but the residences are still isolated from the community in which their inmates are supposed to live. (For a graphic example of this see Söder<sup>31</sup> - discussed in Chapter 7).

Establishing a hostel in the community is not all that has to be done to ensure that the residents receive the facilities and services they require and have a 'normalized' life-style. People can be just as isolated and institutionalized living in a relatively small hostel as behind a high wall in a large subnormality hospital. (However, it is not 'normal' for people to have their 'friends' come in to see them out of some sort of volunteer commitment. People 'volunteering' to come in and befriend the mentally handicapped residents may help them to become more a part of the community, but it is not 'normal'). If the lives of the mentally handicapped living in hostels and with their families is to be 'normalized' in the way advocated by those committed to the principle, then they have to become accepted members of the community. (This may well involve changing the attitudes and behaviour of many members of the public). Also they have to use the same services and facilities, as far as possible, as other local residents.

For community care to become a reality and for the day-to-day lives of the mentally handicapped to become normalized a fundamental change in current social policy is necessary. Mentally handicapped people will have to become seen as people who need a variety of services and cease to be regarded as a 'category' who require different and inferior services to the rest of the population. More fundamentally, it will be necessary to abandon the medical model and adopt an alternative model, which sees the mentally handicapped not as incurably sick, but as people who can be helped to lead a more 'normal' life-style. This does not, however, mean ceasing to provide specialised facilities and care where required. Indeed, it may be necessary to provide more specialised help in order to enable a mentally handicapped person to lead as independent a life as is possible.

(However, it does mean ceasing to over-protect as parents and care-providers have often done in the past - it means encouraging independence).

What appears to have occurred in Britain is a failure on the part of policy-makers to think what patterns of care are appropriate for mentally handicapped people, and to recognise that different facilities and forms of care may be necessary for different groups of mentally handicapped people. The needs of the mildly subnormal are different to those of the severely subnormal, and indeed there are wide differences in needs between these two groups. The multiply handicapped will also need to be handled in different ways. (A number of studies have shown that I.Q. is not a good indicator of ability to cope adequately in the community - see Chapter 2). Thus, in principle at least, the government has rejected the large subnormality hospital as the major form of care, but the alternatives do not seem to have been adequately investigated.

There has, however, been an increase in educational provision for mentally handicapped children in the 1970's, together with increased provision of Adult Training Centre places; of temporary and permanent hostel accommodation;<sup>316</sup> of financial help (the attendance allowance) for relatives (usually parents) caring for a mentally handicapped member of the family; but basically the services in the community to support mentally handicapped people and their families have remained the same. This is especially true of services for the severely handicapped, whose families often need the most help if they are to cope. Norris<sup>32</sup> after studying day care facilities for severely mentally handicapped teenagers and adults in five separate geographical locations, argued that we deceive ourselves if we believe that the day-care facilities now provided represent a marked improvement in conditions, surroundings or training techniques. He concludes:

Whilst these units included in this investigation were housed in brand new premises without exception these premises were dull in concept and limited in provision. The activities

conducted were too often unstructured, the staffing arrangements were too similar to too many hospitals, the ready availability of expert advice was often less than that to be encountered in these hospitals whose effectiveness we have been questioning ...<sup>33</sup>

Studies in the 1950's and 1960's suggested that one of the major factors resulting in parents placing their mentally handicapped children in hospital was the lack of back-up services in the community and financial assistance<sup>34</sup>. Studies in the 1970's by Bayley<sup>35</sup>, Jaehnig<sup>36</sup> and Wilkin<sup>37</sup> (see Chapter 2) have suggested that families still face these same problems. Bayley's study in particular has graphically illustrated how, in reality, community care has meant imposing a social and financial burden on the families of mentally handicapped people. Families have been left to 'cope' as best they can with little professional support or financial assistance. He points out that parents are often not only prepared, but indeed wish, to care for their mentally handicapped child, because they love the child and regard him or her as an integral member of the family (MacCormack<sup>38</sup> and Jaehnig also found this to be the case). However, parents often continue to care for the 'child' when he has become an adult and they have difficulty in handling him adequately, because of a lack of what they see as a viable alternative. There is no alternative to the subnormality hospital for many who want to find permanent residential accommodation for their mentally handicapped 'child'. This means, for the majority of the mentally handicapped, that they are unable to enjoy life experiences shared by other citizens of the same chronological age - to lead a more 'normalized' life. Indeed, what moves have been made to implement 'normalization' in Britain have been aimed at creating 'normal' families rather than 'normalizing' the day-to-day existence of mentally handicapped people.

The degree to which it is possible to normalize the lives of mentally handicapped people is debatable (the concept itself is unclear). However, leaving this aside, it is evident that Community Care (a necessary

precursor to any form of 'normalization') has not yet become a reality in Britain. The available facilities and services would appear to be inadequate, and will become even more so if more people are 'sent home' from hospitals and less are admitted than previously. Thus, as Doyal has suggested,

Priorities of this kind may appear superficially progressive ... In practice ... the ultimate effectiveness of these proposals is likely to be extremely limited. Local authorities are under as much financial pressure as the National Health Service, so that any health planning which is based on increased support from local authorities is likely to be a rhetorical rationalization of central government cuts rather than a feasible local alternative. Moreover, the concept of 'the community' has been widely used to foster the illusion that outside institutions there is a network of caring relationships consisting of individuals with both the will and also the material resources to help those in need. In fact, as services are cut back in both the National Health Service and the local authority sector, it is usually individuals (usually women) without the necessary resources who are forced to care for those with whom the system can no longer cope. Disillusion about 'the community' and 'community care' have become increasingly important in marking the realities of the situation.<sup>39</sup>

The reality of the situation would seem to be that the mentally handicapped are a low-priority group, in terms of social and economic resources, whether they are living in the community or in hospitals. The Royal Commission on the National Health Service (1979)<sup>40</sup> concluded that while it was possible that community care was cheaper than hospitalization, more research on relative costs and effectiveness was necessary. However, it is fairly obvious that if the families of mentally handicapped people living at home were paid a sum equal to the cost of caring for the person in hospital, or even paid the current rate of wages for 'homemakers', the cost to the public sector would be very large. Indeed, when it is realised that eighty percent of severely mentally handicapped children and forty percent of severely mentally handicapped adults are cared for at home, it becomes evident how much our society relies on the unpaid, non-professional care provided by families and especially the mother. **Thus a**

recent (1981) D.H.S.S. study of community care concluded that

the 'cost effectiveness' of these packages [of community care] depends on not putting a financial value on the contribution of informal carers who may in fact shoulder considerable financial, social and emotional burdens.<sup>40a</sup>

When reference is made to community care of the mentally handicapped, often a sleight of hand is being employed; what is actually meant is care, in financial as well as practical terms, by an individual family for a handicapped member for whom in the past the whole community, though a hospital, might have taken the responsibility.

It is possible to go beyond this and suggest that a policy of community care, as implemented in Britain, imposes a special burden on women. (A recent survey<sup>41</sup> found that over forty percent of men and women thought that women should be prepared to care for a disabled/handicapped family member). The actual implementation of the policy means that the mother is expected to take on the main burden of caring for a mentally handicapped 'child'. The policy has not in practice meant a shift in resources from hospitals to the local communities (indeed this is cited as one of the major reasons why local authorities have not provided more services where they are discretionary and not mandatory), but a shift in the type of labour employed in caring for the mentally handicapped - paid, trained, professional labour (or at the very least, paid) being replaced by unpaid, untrained, seemingly cheap labour. This burden is much greater than that experienced by the mother caring for young children: the mentally handicapped 'child' goes on requiring fairly intensive and regular care long past the time when 'normal' children have become relatively independent; the mother becomes 'tied' by a life-long child. She is no longer able to enjoy the normal life-experiences of other women - relative independence when the children have grown up, possibly returning to paid employment - and this affects not only her but also the rest of the family, including siblings of the handicapped. (See Meyer's<sup>42</sup> account of his family's experiences, to see the profound influence that a mildly subnormal child had on the whole family and its way of life).



An extremely important factor, over and above the relative social isolation of being tied to the home by the demands of the handicapped 'child', is the inability to return to productive employment as the child grows older. Sociological research has pointed to the social and economic plight of women forced to remain outside the employment market while they care for young children<sup>43</sup> - women work not only for the money, and the relative financial independence that it brings, but also for the social contacts that 'going out to work' brings and the increased social status which being engaged in paid employment brings in a society which devalues the domestic role of women.

In conclusion, successive governments since the 1950's have advocated community care for the mentally handicapped without providing adequate facilities for this to become a meaningful means of handling them. Coupled with community apathy and even hostility to mentally handicapped people, this has in reality meant that care either becomes the responsibility of the family or the mentally handicapped are isolated in hostels instead of in hospitals. (Indeed, a substantial number of mentally handicapped people still live in hospital). An apparently progressive and humanitarian policy turns out in practice to make little difference to the lives of the mentally handicapped, although it may impose additional burdens on their families and especially mothers.

#### 4. Why Community Care?

The factors usually referred to as influencing the development of policies of community care and 'normalization' are the findings of social scientific research and field experimentation in the 1950's and 1960's - although, as I have stressed several times, a large number (probably a majority) of the mentally handicapped were never institutionalized even at the height of the 'eugenics' scare. This research was taken to 'prove' that hospital 'warehousing' was dehumanizing, inappropriate and totally

inadequate for the needs of the vast majority of mentally subnormal people, and the researchers advocated decarceration as a policy objective. (It is of course the case that psychological research came to similar conclusions concerning 'normal' children deprived of their family, the mentally ill, the elderly and delinquents in the same period).

I shall argue, first that the accumulating evidence of social influences upon intelligence has weakened if not destroyed the eugenic case for social segregation, secondly that the evidence ... throws great doubt on the hospital as the right environment for the care of the subnormal and finally that the social, occupational and emotional needs of the great majority of the subnormal might be better met within various forms of sheltered, family or community care than in existing hospitals and hostels. <sup>44</sup>

Psychological research suggested that the family, and especially the mother, provided the kind of love and attention necessary for 'normal' development in children, <sup>45</sup> and gradually the notion grew that this was also the case for handicapped children. Research in developmental psychology (especially the work of Piaget) began to suggest that children could be enabled to develop at a faster rate and to a higher level in a stimulating and more demanding environment. These ideas, coupled with research specifically on mentally handicapped children which argued that large hospitals retarded development while small group homes or living in a 'normal' family did not, <sup>46</sup> led to the adoption of a model of mentally handicapped people which saw them as 'developing' rather than 'social menaces' and/or 'incurably sick'. (The ways in which scientific knowledge has interacted with models of the mentally handicapped and with social policy objectives will be discussed more fully in the final chapter).

These advances in social-scientific theorizing and the resultant research findings influenced professionals in the field of mental handicap. Parents of mentally handicapped children were actively encouraged to keep them at home, and it was also suggested that as many mentally handicapped people as possible should be cared for in the community rather than warehoused in subnormality hospitals. Initially this policy resulted in the discharge from hospital of a substantial number of residents who appeared no longer to be 'subnormal'. (The 1959 Mental Health Act changed the definitions so that many of those incarcerated as feebleminded or morally imbecile under the 1913 legislation no longer came within the 'official' definition of mentally handicapped). By the 1960's and 1970's this process was widened to include the suggestion that only those in need of the specialised medical and nursing care provided in hospital should remain there - the majority of mentally handicapped people should live in homes and hostels in the community. (This development was stimulated by research which demonstrated that severely mentally handicapped people not only could be cared for in hostels but also developed more social competence and independence there than when cared for in a hospital).

The government apparently accepted the case for 'community' care and normalization. They passed legislation and issued policy documents apparently designed to bring it about. The idea fitted in neatly with the ideology of Welfarism and equality of opportunity that developed in post World War II Britain - all citizens should be cared for from the 'cradle to the grave' and given equal opportunity to develop their full talents and abilities. Coincidentally it appeared not only to be a more humanitarian policy but was apparently cheaper. (Indeed, in the 1930's many mentally handicapped people had remained in the community for this very reason).

Decarceration has become the watchword in Western societies not only for the mentally handicapped but also for other groups of deviants, including the mentally ill, the elderly and 'petty' criminals. The main justifications are, as in the case of the mentally handicapped, not only that it is more humanitarian but that it is also more 'effective' in bringing about desired goals. However, while there has been research into total institutions which has highlighted the inadequacies of that form of 'treatment', with the possible exception of 'petty' criminals little research has been conducted into the 'effectiveness' of the alternatives. It is assumed that it is the institution that has the detrimental consequences, and that non-institutional care does not. (Note that in the case of the mentally handicapped at least it has been argued that hostels in the community - one of the mainstays of the 'new' policies - replicate many of the assumed detrimental aspects of the hospital).

The question is, then, why community care has been so readily accepted by policy-makers as an alternative way of handling the mentally handicapped and other deviant groups. MacIntyre<sup>47</sup> has argued that in the case of the elderly, community care has been advocated and adopted because of organizational needs and not because it is a more humanitarian form of care than old people's homes. Elderly people are encouraged to stay in their own homes by being told that 'it is better for them', but they are not then provided with the community services they need if they are to enjoy a relatively comfortable existence. (Apart from social and medical reports suggesting that there is a 'real' need for services such as meals-on-wheels and home helps, recent local government economies have meant large price increases for services such as these. Few local authorities now provide home helps free, and those on supplementary benefit are no longer able to claim the money to pay for the service). In this way community

care reduces the financial burden of caring for a growing elderly population. A comparable situation exists with respect to the mentally handicapped; the burden of care - social and financial - is shifted from the community to the family in cases where the family provide for a mentally handicapped member. (MacCormack<sup>48</sup> and Oswin<sup>49</sup> have graphically illustrated the real 'burden' experienced by many families). Policies of decarceration have also resulted in many incompetent individuals being left to fend for themselves - frequently ending up living in inner-city areas on welfare benefits. Many of the ten thousand mentally handicapped people living in England and Wales in 1974 accommodated in foster homes and lodgings would have been leading this type of marginal existence.<sup>50</sup> Many of the more severely subnormal have remained in hospital, and those who have been moved into the community tend to live in hostels that are as isolated from the community as are the larger institutions. This does not necessarily mean that mentally handicapped people should be forced to remain in hospital (and the majority of those who are able to make their wishes known do not want to), but it does suggest that services and support facilities have not been developed to provide them with an adequate standard of living and quality of life when they are discharged. Morais and Morais found, for example, that

Working within a hospital complex where I have been constantly aware that patients regard discharge and 'freedom' as their ultimate 'shangri-la', it has become a salutary experience also to work as a voluntary club-leader catering very largely for former patients once they have achieved their ambition. Many of them fall out of work and often sleep rough. They become bewildered, lonely and disillusioned and sometimes they talk nostalgically of 'the good old days in hospital'.<sup>51</sup>

'Community care' and 'normalization', when employed by decision-makers, appear to be little more than slogans - a way of seemingly introducing more humanitarian policies, but in practice a way of reducing spending on a group who have always been low on the list of priorities. Whether or not the aims of 'community care' and 'normalization' can be achieved does not seem to have been carefully researched, but what is evident is that in Britain de-institutionalization and non-institutionalization have not been accompanied by the development of adequate services and facilities in the community to enable the mentally handicapped either to become integrated or to have a more 'normalized' day-to-day existence. (This is not to suggest that facilities for the mentally handicapped have not been improved in the last twenty years; of course they have, both in hospitals and in the community but there is a long way to go before a comprehensive community-based service becomes fully established).

It seems evident that welfarism, humanitarianism and advances in social-scientific research are not adequate to account for the move towards policies of decarceration in Western societies in the last twenty years. Scull has suggested

...that this far-reaching change in social control styles and practices can be explained both more completely and more parsimoniously by reference to deep-seated changes in the nature and functioning of modern capitalist societies

and furthermore that the

... State's receptivity in the modern era to a policy of decarceration can be traced back to fundamental transformations in the social organisation of advanced capitalism. The pervasiveness, intensity and mutually reinforcing character of the pressure to adopt a policy of decarceration ... are intimately connected to the rise of welfare capitalism. 52

The pressure on governments to reduce spending in the last ten years has resulted in their looking for 'easy' economies. Cutting back on the building of new subnormality hospitals reduces capital spending and cut-backs in the number of beds provided in existing hospitals (and indeed closing some) reduces current spending. The provision of general welfare services in the community means that a minimum provision can be made in the community without increasing spending. Indeed, a government minister has recently suggested that the disabled must share the burden of reduced spending in the current 'crisis',<sup>s2a</sup> and another has argued that by careful scrutinising of the current way of handling mentally handicapped people<sup>s2b</sup> their lot can be improved without increasing expenditure. As Scull, again, has suggested

... it is scarcely surprising to learn that decarceration in practice has displayed remarkably little resemblance to liberal rhetoric on the subject. Indeed, the primary value of that rhetoric (though far from its authors' intent) seems to have been its usefulness as ideological camouflage, allowing economy to masquerade as benevolence and neglect as tolerance. Clearly a certain proportion of the released inmates are able to blend unobtrusively back into the communities from whence they came ... But for many other ex-inmates and potential inmates the alternative to the institution has been to be herded into newly emerging 'deviant ghettos', sewers of human misery ... within which society's refuse may be repressively tolerated. 53

Scull is referring primarily to the mentally ill, but with the addition of the pressure that policies of decarcerating the subnormal places on the family, his description applies equally to the mentally handicapped.

Governments have, furthermore, adopted policies of decarceration in the face of opposition from their citizens (see Chapter 7), who do not want hostels and other day and residential facilities provided for the mentally handicapped within their neighbourhood. Recent research in the

United States has shown, for example, that people's apparent positive attitudes to mentally handicapped people move in a negative direction when they are faced with the prospect of a hostel in their neighbourhood.<sup>53a</sup> Parents may welcome additional facilities and financial help to assist them in caring for a mentally handicapped child, but Ferrara<sup>54</sup> found that while these parents approved of 'normalization' in principle they rarely considered it appropriate for their own children.<sup>54a</sup>

It is also interesting to note that the detrimental aspects of hospital environments, so often cited as the official reason for policies of decarceration, were put forward by philanthropists and other critics of institutions in the last century.<sup>55</sup> These did not, however, result in the government advocating decarceration. Economic considerations and the lack of welfare facilities is one obvious reason why not, but it was also obviously related to the dominant view of the mentally handicapped as social menaces from whom society needed to be protected. Policies of community care are also based on a myth of pastoralism - of the possibility of creating a 'new golden age' analogous to an assumed 'golden age' that existed before industrialization when the community, and especially the extended family, provided care for their sick, old and handicapped members. This myth has been exploded by Laslett's<sup>56</sup> and Anderson's<sup>57</sup> research into the family in pre-industrial England and Jaehnig's<sup>58</sup> research into the care provided by families for a mentally handicapped member. As Bayley's<sup>56a</sup> research has also so clearly shown, care in the community does not mean that mentally handicapped children and adults become integrated into the community. Many are just as isolated living 'in the community' as they would be if they lived in hospital.

The crucial question is, then, as I have already indicated, why social-scientific research findings on the 'horrors' of institutionalization had such an impact



on decision-makers in the 1950's and 1960's and why it resulted in the adoption of policies of community care. There is no necessary logical relationship between the research findings and the adoption of particular policies. Governments could just as easily have decided to improve the hospitals and to provide a more 'normal' life-style within the institution. While advances in knowledge of child development and specifically the development of mentally handicapped children (referred to above) and of an ideology of welfarism (also referred to above) were also relevant factors, they would appear not to constitute sufficient causes. It is evident that economic factors were very important - that governments were especially receptive to these 'new' ideas because they would be less expensive.

For instance a review of community care published by the D.H.S.S. in 1981 argued that

Underlying the policy of encouraging the movement away from hospital or residential care for 'boundary' groups towards alternative community based packages of care has been the belief that these will prove to be 'cheaper' and/or at least as effective.<sup>59</sup>

However, the same survey suggested that it is necessary to consider all the public expenditure costs involved when deciding on the pattern of service for the mentally handicapped and warns that

community based packages of care may not always be less expensive...alternatives to hospital or residential provision

especially as there is a failure to recognise the fact that community care is often only cheaper because parents are caring for the mentally handicapped persons. Thus

families, friends and neighbours make an essential.. contribution to providing more cost effective community based alternatives to long-term hospital or residential care.

It would seem that community care may well be cheaper - when it in fact means care by the family. Indeed, in a consultative document published in 1981 by the D.H.S.S.,<sup>60</sup> which argues (despite the research referred to above) that community care would in general cost less and constitute better value, it is stated that

..services for mentally handicapped people will enable them to live with their families, or failing that in a supportive local community setting

It is necessary to point out that three recent government publications have shown that while there has been a move away from hospital towards community based care, few of the support services that the 1971 White Paper envisaged would be provided to lessen the burden on relatives have materialised. It has been suggested that there needs to be a re-evaluation of policy in this area in terms of cost and effectiveness.<sup>61</sup>

More generally, there would seem to be a case for authorities to review the priority they attach to different aspects of community based services. It appears that increases in provision since 1975 have not been geared directly to providing a genuine alternative to those on the margins of institutional care. It may be that other objectives of community services are considered more important: for example, improving the quality of life for people where there is no need for institutional care or dealing with episodic illness in the community. However, given current and foreseeable resource constraints, the ability of the statutory authorities to pursue all these objectives simultaneously must be in doubt. In these circumstances it is particularly important for local authorities to be clear about their priorities.

Policies of decarceration need thus to be understood not merely as the response of a 'humanitarian society', but also as a consequence of changing ideologies in capitalist societies that develop with the growth of the welfare state, and more specifically as a response to the recurrent economic crises in capitalist societies, when governments are concerned to reduce public expenditure. (It is of course true that the idea of community care developed in the 'affluent 60's' but was most vociferously advocated by the government in the 1970's - a period of economic crises). Magically the use of multivalent concepts like 'community care' and 'normalization' means that two goals - cost reduction and humanitarianism - come together: costs can be reduced at the same time as care is apparently improved. But, in Britain, de-institutionalization/non-institutionalization has not been accompanied by a compensatory development of services and facilities in the community. Thus Tyne concludes the report of a survey carried out in 1978 and designed to investigate what improvements had occurred in community provisions since 1971 by suggesting that there had in fact been little change:

None of these findings would have been in any way exceptional if they had been published in 1968. Yet in the last ten years we have heard repeatedly about the progress which is being made in the development of services for the mentally handicapped people ... My own feeling is that we have made progress, but often only in superficial ways ... The fundamental problems in the organization and funding of our services, however, still remains, and fundamental ideologies about institutions still have not been seriously rethought.<sup>62</sup>

## 5. Conclusion

Whether or not 'community care' and 'normalization' are realizable policy objectives in the short or even long term is difficult to determine - not only because of current economic circumstances but because of attitudes towards the mentally handicapped and more fundamentally because the precise meanings of these terms are not always clear. However, what is obvious is that little progress has been made in the provision of a comprehensive community service in England and Wales. Also, the mentally handicapped and their families are still stigmatized (see Chapter 7) and little progress has been made in integrating them into the community. Slogans like 'community care' and 'normalization' have, then, become rationalizations for decreasing spending in real terms.

The social policy aspects of mental handicap discussed in this chapter are a further demonstration of the need for a social theory of mental handicap rather than a specifically sociological one. Social policy, importantly, involves people as individuals - it profoundly affects the lives of mentally handicapped people and their families, and is influenced by prevailing individual and community attitudes towards the mentally handicapped. This more micro-level analysis which I have largely neglected up until now, will be explored in greater detail in the next chapter. In Chapter 8 I shall go on to examine the extent to which it is possible to develop a social theory

of mental handicap. Finally, as I have also suggested, the interaction between psychological and sociological theories and social policy in this area is a fascinating one, and mental subnormality is a good example of the way in which these interpenetrate each other and are both informed and influenced by economic structures and circumstances. This wider implication of the subject matter of this thesis for the sociology of knowledge will be explored in the final chapter.

REFERENCE NOTES, CHAPTER SIX

- 1: Quoted in Mittler, 1980 Piii  
 2: Scarse, 1976 P614  
 4: See, e.g., Meyers, 1979  
 6: Jones, 1974  
 8: Grunwald, 1969 P9  
 8b: Grunwald, 1969  
 10: Henschel, 1972  
 12: See, e.g., Campaign for Mental Handicap, 1978.  
 13: Quoted in National Society for Mentally Handicapped Children, 1971. P66  
 14: D.H.S.S., 1971 Para 40, P9  
 16: Jones, 1974  
 17a: See D.H.S.S., 1981a, 1981b  
 19: Jaehnig, 1979 P2  
 20: Shearer, 1980. See also Shearer (1980a) for an account of the lack of progress in improving public care provisions for mentally handicapped children since 1945 and especially the lack of progress in improving care provisions in the 1970s  
 21: Gunsburg, 1972  
 21b: D.H.S.S., 1981c  
 22: D.H.S.S., 1979  
 24: Shearer, 1980  
 25: Jay Report, <sup>DHSS P129</sup> 1979. However, D.H.S.S. have stated that expenditure on social services, in real terms, will not increase in the foreseeable future, and this will be reflected in spending on community services for the mentally handicapped.  
 26: Morris, 1969.  
 27: Jay Report, <sup>DHSS</sup> 1979  
 27a: See D.H.S.S. 1980, 1981a, b, c  
 29: Bayley, 1973  
 31: Söder, 1972.  
 31a: Despite the increase in Adult Training Centre places, the rate of increase has fallen short of that envisaged as necessary to meet demand in the White Paper (D.H.S.S., 1981a)  
 31b: Although the number of adult hostel places has grown year by year since 1975, the rate of increase has declined and is considerably less than the 1971 White Paper envisaged was necessary. The number of hostel places for children has
- 1a: D.H.S.S., 1980  
 3: Lippman, 1972  
 5: See, e.g., Grunwald, 1968  
 7: Grunwald, 1969 P1  
 8a: adapted from Grunwald, 1977 P5  
 9: Edgerton, 1967  
 11: Matteson, 1970  
 15: Shrubshal and Williams, 1932  
 17: Jones, 1974 P205  
 18: Jones, 1974 P3  
 21a: D.H.S.S., 1980 Foreword  
 21c: D.H.S.S., 1981a P1  
 23: See, e.g., Mittler, 1980

not increased despite the large decline in hospital places (D.H.S.S., 1981a).

- 32: Norris, 1975  
33: Norris, 1975 P5
- 34: See, e.g., Tizard and Grad, 1961; Moncrieff, 1966.
- 35: Bayley, 1972  
36: Jaehnig, 1974
- 37: Wilkin, 1979  
38: MacCormack, 1978
- 39: Doyal, 1979 P210  
40: D.H.S.S., 1979
- 40a: D.H.S.S., 1981a P3  
41: New Society, 1981
- 42: Meyers, 1974  
43: E.G. Young, 1974; Oakley, 1974, 1976
- 44: Townsend, 1969 Pxi11
- 45: E.G. Bowlby, 1954  
46: E.G. Tizard, 1964
- 47: MacIntyre, 1977  
48: MacCormack, 1978
- 49: Oswin, 1978. See also Bayley, 1973; Jaehnig, 1974; Wilkin, 1978.
- 50: Manning, 1977  
51: Marais and Marais, 1976 P82
- 52: Scull, 1977 P: 12 & 152  
52a: New Society, 1981
- 52b: Mittler, 1980  
53: Scull, 1977 P152
- 53a: Parsons et al, 1979  
54: Ferrara, 1979
- 54a: MacCormack (1974) suggests that the majority of parents who seek permanent care for their mentally handicapped 'child' want a caring, secure environment similar to the one provided at home and do not want their 'children' to be allowed to lead independent lives when they can no longer care for them.
- 55: See Scull, 1977  
56: Laslett, 1972
- 57: Anderson, 1971  
58: Jaehnig, 1974
- 58a: Bayley, 1973. See also Oswin, 1978
- 59: D.H.S.S., 1981a P: 12, 3 and 1  
60: D.H.S.S., 1981b P1
- 61: D.H.S.S., 1981a P6  
62: Tyne, 1978 P7

## CHAPTER 7

### COMMUNITY AND INDIVIDUAL ATTITUDES TOWARDS MENTALLY HANDICAPPED PEOPLE

Mentally handicapped people are stigmatised: the services they receive are poor and segregate them from the rest of us. These two main threads in their lives are closely woven together and each strengthens the other ... Its [Better Services for the Mentally Handicapped] account of the historical background to segregation of mentally handicapped people makes no attempt to look at the misinformed public fear and prejudices, fed by the 'eugenics movement', which added another layer of stigma to an already increasingly stigmatised group ... Poor services to mentally handicapped people have not just developed by chance. They reflect deep-seated social attitudes and values and serious defects in the principles underlying them.<sup>1</sup>

#### 1. Introduction

Up until now I have argued that there is a dialectical relationship between social perceptions of the mentally handicapped, attitudes towards them and the way a society 'chooses' to handle them. In this chapter I intend to explore in more detail attitudes and behaviour towards the mentally handicapped in modern Western societies (most of the research referred to is American or British) at the individual and community level.

It is difficult to determine to what extent public attitudes towards mentally handicapped people influence the policies implemented by governments, or indeed the extent to which changes in policy can bring about a change in attitudes. Lippman<sup>2</sup>, for example, has argued that attitudes towards the mentally handicapped determine the way in which they are handled, but I suggested in the last chapter that economic factors would also seem to play an important role. In Chapters 3 and especially 4 I argued that public attitudes to the mentally subnormal, formed by the 'scientific discoveries' of the eugenics movement in the early twentieth century, were one factor

leading up to the 1913 legislation.<sup>3</sup> It is difficult in retrospect to determine how widespread these negative attitudes, fears and prejudices were. We can of course attempt to determine to what extent the fears and prejudices still influence individual attitudes towards mentally handicapped people and probably, even more importantly, how individuals and communities react to and behave towards the subnormal.<sup>3a</sup>

In the last chapter I argued that current government policy aims at handling the mentally handicapped in the community rather than in isolated hospitals, but that despite statements that the aim is to create a comprehensive community service for mentally handicapped people little headway has been made in actually establishing such a service. Those who claim to speak on behalf of the mentally handicapped and their families have not only criticised local and central government for lack of progress in implementing community care but also argued that mentally handicapped people should be integrated into the community in which they live and that their day-to-day lives should be 'normalized'. Attitudes may influence policy-makers - or at least what they perceive as the attitudes of the 'ordinary citizen'- but at the level of interaction (integration) it is reactions and behaviour that may be of crucial importance. It is of course eminently possible that beliefs, attitudes, reactions, and behaviour do correlate highly, as is often assumed in attitude research, but this need not necessarily be the case. (See below for a more detailed discussion). Simon, for example, has argued that

There is a growing emphasis on community care ...  
But many people have reservations about the success of such a movement not least because they doubt the community's willingness to accept the mentally sick and handicapped as near neighbours.<sup>4</sup>

Thus if we are to move towards a social theory of mental handicap we need to explore attitudes and behaviour not only at the macro-level of policy, but also at the community



and individual level. Only then can we fully understand the ways in which these two levels interact and how they combine to form social perceptions of the mentally handicapped and their role and status in our society. The analysis which follows in this chapter, then, complements that in previous chapters, but also, importantly, it asks to what extent social policy is influenced by attitudes and behaviour at the community and individual level and examines how far current attitudes are informed by outdated 'scientific' perceptions of the mentally handicapped that result in their being seen as either 'social menaces' or 'hopelessly incurably sick'.

As originally conceived, I had intended this chapter to review critically the research on attitudes to the mentally handicapped - research which suggests that where not openly hostile they are negative or at best apathetic and informed by a large number of misconceptions about the nature of mental handicap. This analysis would have raised (as this chapter still does) a number of problems with this research, including salience (how much people actually think about it), centrality (how important a part the concept actually plays in their mental world), and to what extent knowledge of people's attitudes can enable prediction of reactions and behaviour. (Salience and centrality are attributes that are often confused and even more often ignored altogether in research on attitudes). It would also have pointed out the need, if we are to understand community attitudes, to take into account at least three factors: the attitudes of other people in the community towards mentally handicapped people; the personal attitude and feelings of the parents towards their mentally handicapped children which inform their awareness and understanding of other people's attitudes; and the parents' ability to cope with their own feelings and to deal with situations where they 'feel' embarrassed or it becomes apparent that other people have negative attitudes towards the subnormal member of the family.

As I read the literature on attitudes towards the mentally handicapped I became increasingly aware that little of it was concerned with how people actually reacted to and behaved towards the mentally handicapped and how much of it was designed to determine people's attitudes in the abstract. At this time the opportunity arose for me to carry out some empirical research which may provide an illustrative study of how sociologists can examine reactions to the mentally handicapped, by studying the way people behave in the community when they are confronted by mentally handicapped people. The Chairperson of a local branch of the National Society for Mentally Handicapped Children suggested that some of the members of her group might like to talk to me. Eventually I interviewed 11 families with a mentally handicapped member in order to explore how they understood other people's attitudes, reactions and behaviour towards them and the mentally handicapped member of their family. Shortly afterwards an adult student of mine suggested that I might like to meet a group in her village who were 'friends' of a local hostel for mentally handicapped women and discuss with them the reactions of the villagers (generally hostile) to the fact of these women living in the local community. I met the group and recorded some of the conversations I had with them. Finally, almost just to see what happened, I decided to try getting some groups of my 'O' and 'A' level G.C.E. students to discuss mental handicap. I had some notion that I might be able to discern if young, fairly intelligent people had more knowledge of mental handicap than most research suggests is typical of the general population and if they had more positive attitudes. (An analysis of my results is discussed more fully below). These opportunities for empirical research enabled me tentatively to explore the ways in which sociology might be able to contribute to an understanding of mental handicap as a socially constructed phenomenon, and the results are offered as illustrative of the sort of research which could be carried out in a more systematic manner in the future.

Thus in previous chapters I have explored medical and psychological models of mental handicap, past attitudes towards and methods of handling the mentally handicapped, and the way our society currently deals with the 'problems' they present. In Chapter 6 I suggested that the 'second-class' status of the mentally handicapped is at least partly perpetuated by economic factors and that governments in deciding on priorities for the allocation of resources are influenced by what they think are public attitudes. In this chapter I propose to explore these attitudes in order to assess to what extent they, and the reactions of communities and individuals, do perpetuate the 'second-class' status of mentally handicapped people. For as Becker has suggested,

Sociologists ... are not content to make surveys of existing conditions ... They concern themselves with how problems come about and are perpetuated ...<sup>5</sup>

## 2. The problem of Community Attitudes and the Question of Community Care

The care provided for the mentally handicapped can be analysed at two levels: the provision made for their care and treatment by local and national government and voluntary bodies, and the way that people in the community are prepared to help and accept them on a day-to-day living basis. (The way in which the attitudes of others may influence the self-image and behaviour of the mentally subnormal is discussed in Chapter 8). These two levels may well interact; that is, official policies will to some extent reflect and influence 'public opinion', although current government policies are probably *more* influenced by Budgetary Policy, concern over 'Public Spending' and 'public demands' for a reduction in direct taxation than by pressure for 'normalization' by the electorate (see Chapter 6). Indeed, in the United States it is the official move to adopt policies of 'normalization' that has stimulated attitudinal research, although there

has not, as yet, been comparable research in Great Britain.

Many studies of the mentally handicapped have assumed rather than demonstrated the existence of negative attitudes towards the mentally handicapped. In a theoretical paper Ryan<sup>6</sup> suggests

Most of the readers of this paper ... will probably feel a mixture of indifference, disgust and guilt about it.

while D'Alton argues

society in general ... views retardation with alarm, a situation emphasised and overstated by the nature of the treatment and social roles ascribed to those who have been defined as retarded.<sup>7</sup>

The negative stereotype of mental handicap, according to Farber<sup>8</sup>, includes clumsiness, irresponsibility, sloppiness, nervousness, timidity, reticence and abnormality - all characteristics viewed as undesirable - and Townsend argues that Morris's study of mental subnormality hospitals demonstrates that

... strong views are held even among psychiatric and nursing staff. In particular there are fears and prejudices, about violence, promiscuity ...<sup>9</sup>

The influence of these assumed negative attitudes is also of considerable importance, whether or not research proves that they do exist. Kathleen Jones<sup>10</sup> suggests that these 'assumed' fears and prejudices have strongly influenced government spending on services and facilities for the mentally handicapped.

Behind these economic factors lies an attitudinal factor: the mentally handicapped rate a low priority in the eyes of the general public.

and

There are two long-standing problems in the services for the mentally handicapped: stigma and inertia. These are linked and they underlie all other problems.

It is important to consider not only how public attitudes influence public spending (see Chapter 6) but also how stigma impinges on the lives of the mentally handicapped and their families. Bayley's<sup>12</sup> study in Sheffield demonstrates how the interaction of the two causes isolation and strain for many families caring for a mentally handicapped member. Edgerton found that the mentally subnormals released from a hospital in his study did all they could to conceal their 'past'. In referring to the mentally subnormal stereotype he suggests that it is

a stigma which galvanizes the most basic feelings of these retarded persons into a single-minded effort to 'pass' and to 'deny'. To find oneself regarded as a mental retardate is to be burdened by a shattering stigma ... for a former patient to be labelled as a mental retardate is the ultimate horror.<sup>13</sup>

Conferences organised, with the mentally subnormal participating, by the Campaign for Mental Handicap to discuss the welfare of the subnormal have added to our knowledge of how the mentally handicapped experience stigma. The writer of one pamphlet summarizing such a conference concludes

Delegates to 'Our life' taught us that they have sharp and often powerful perceptions of their lives and the way society and providers of services see them. They taught us that among people labelled as mentally handicapped there is a deep and often entirely realistic desire to share experiences the rest of us take for granted in our daily lives. They taught us just how much of their disability can be imposed by our own preconceptions of their capabilities and the limits we deliberately set on their experiences.<sup>14</sup>

Not only are the mentally handicapped stigmatised but by association so are their families. (Indeed, the stigma may be a primary one, as my own research suggests - see section 4.4 below). It is frequently suggested that

a family with a handicapped member is a handicapped family. This idea persists (Radio Times)<sup>15</sup> despite Jaehnig's<sup>16</sup> argument that this is an image imposed by professionals rather than what the families themselves feel. Gunzberg<sup>17</sup> argues that it is generally considered that having a mentally subnormal member reflects badly on the family. This may influence not only the way that 'outsiders' behave towards the family, but the way in which the nuclear family is treated by other kin.

Goffman<sup>18</sup> refers to the sharing of another's spoilt identity as bearing a 'courtesy stigma' - the family members have a spoilt identity because of their close affiliation to someone who bears the primary stigma. Birnbaum<sup>19</sup> found three possible adaptations to this situation: a total acceptance of being stigmatized; a compromise; or an attempt to convey the impression of being unspoilt. He suggests that the mothers of the mentally subnormal provided a very good example of a group of people who have a courtesy stigma and who seek to maintain a normal appearance by carrying on with a 'normal' life-pattern. In order to do this they maintain a 'normal' family life, avoid stigmatising situations and retain social relationships. The main problem confronted by the mothers is when the mentally retarded child reaches adulthood, and it becomes increasingly difficult to retain an appearance of normality.

However, the father of a mentally handicapped teenage boy argues

... of all the people in the world we parents were selected to become different for ever - to carry the stigma.<sup>20</sup>

A correspondent to a Social Work paper feels that

... there seems to be shrinking space and tolerance for the members of our community regarded as subnormal.<sup>21</sup>

Bayley<sup>22</sup> argues that there is an interaction between parents' own attitudes towards the mentally handicapped member and

the way they experience other people's attitudes.

He suggests that

It is difficult to know whether other people's responses were really so curious or insensitive as the parent reported. It is hard to say to what extent the parents who were embarrassed projected on to other people their own feelings towards the subnormal.<sup>23</sup>

Furthermore, the mentally handicapped member, and other people's negative responses to his presence, may be used as an excuse to withdraw from social activities rather than being the cause of withdrawal.

The parents' interpretation of society's attitudes to them and to their subnormal children was related closely to their attitude to social activities in general.<sup>23a</sup>

To support this Bayley quotes as an example the situation of two families, each with a mentally handicapped member, who lived 300 yards apart. One family knew half the neighbourhood while the other knew only one neighbour.

Bayley is, however, aware of the importance of other people's attitudes in determining the degree of integration of the family and the handicapped member in the community. The main argument of his report is that if community care is to become a reality, the handicapped and their families must become an integral part of the community, they must be accepted by the community, as well as the local authority providing services.

Many factors combined to decide the extent to which the families' activities were curtailed by the subnormal being what, and who, he was - the parents' attitude, friends' and relatives' attitudes, the public attitudes and the actual characteristics of the subnormal himself.<sup>24</sup>

Thus considerable importance must be attached to people's attitudes when determining what services to provide for the mentally handicapped. (Alternatively, however, it could be argued that if mentally handicapped people lived openly in the community then attitudes and reactions might

become more positive as people realised that many of their fears and prejudices were groundless). Indeed, the very success of 'normalization' policies depends on favourable attitudes towards the mentally handicapped and acceptance and tolerance within the community.

What is needed is to give a better service - more money, hostels in the community and more tolerant attitudes.<sup>25</sup>

This is equally recognised by politicians and officials. Barbara Castle argued in 1975 that

I am convinced that it is not administrative but rather philosophical and attitudinal changes which are now so vitally needed.<sup>26</sup>

Five years on we may agree with the second part of her statement, but question the former (see Chapter 6).

### 3. Empirical Studies of Community Care and Public Attitudes in Britain and elsewhere

While administrative and political decisions have determined that more and more of the mentally handicapped are cared for in the community rather than 'hidden away' in hospital, this has not apparently been preceded or accompanied by a development of more tolerant attitudes to the mentally handicapped. Whatever the political, economic and ideological factors that have underlain changes in official policy (see Chapter 6), it would certainly seem to be more humanitarian for the mentally handicapped to live as normal a life as is consistent with their degree of incompetence. The main barrier to the mentally handicapped becoming full members of the community would appear to be the attitudes and prejudices of other members of the community as well as the provision of support services by local authorities for mentally handicapped people and their families.

In Great Britain the lack of empirical research evidence on attitudes means that we assume negative attitudes.



This assumption is probably reinforced where there is public protest at, for example, the suggestion that a hostel for the mentally handicapped be built in a residential area and by reflecting on our own views. Most of the available evidence on attitudes comes from surveys conducted in the United States. Much of this has used attitudinal scales and been concerned with abstract attitudes rather than how these are translated into behaviour (see below).

Söder<sup>27</sup> in a study in Sweden, however, was able to study the way that attitudes influenced behaviour - although his work also demonstrates some of the problems involved in studying the workings of community care. Söder studied a Swedish community's attitudes to the mentally handicapped in a residential housing area before and two years after provision was made for twenty-one mentally subnormal adults. Two other areas were studied as controls. He found that in the integrated area, although there was physical integration, there was little functional integration, because there was little contact between the mentally handicapped and local residents because they did not share public facilities such as buses and shops. No evidence was found to indicate that physical and/or functional integration resulted in any change in attitudes.

There was little effect of integrating retarded workers in an area occupied by 'normal' workers and their families. On the one hand no negative reaction and no open discrimination took place. On the other hand no intimate contacts or positive change of attitude could be found.<sup>28</sup>

The example of the town of Geel in Flanders, Belgium<sup>29a</sup> shows that the mentally subnormal can live in the community and be accepted. Since the twelfth century the inhabitants have taken the mentally impaired into their own homes and treated them as if they were members of the family - as fully integrated members of the community.

However, the extent to which these residents were totally accepted by all of the community is more debatable.

The evidence cited above is inconclusive and contradictory as are the results of American studies. While the research does indicate that most people have negative attitudes, some researchers have suggested that there has been a shift of attitude in a positive direction in recent years. Farber<sup>29</sup> has argued that community attitudes to the subnormal are ambivalent. On the one hand there is fear and rejection, but on the other hand an apparent willingness to accept subnormals within the community and to assume some responsibility for their care and rehabilitation. We might argue that this relates to whose community/neighbourhood the subnormals are living in, and whether we are referring to individuals living with families or to those living in hostels and group homes. The former may be more easily accepted than the latter, and it may be easier to accept that the subnormal should live in the community when it is not one's own neighbourhood that they are living in (see below).

The lack of consensus of research findings may equally be a reflection of the weakness of the methodology used in much of the research. Most attitude surveys, carried out in the United States by social psychologists, have used attitude scales. Taylor has pointed out,

Research into social perceptions of the mentally retarded requires that one deals with two dilemmas. The first is the tendency to affix the definite article 'the' to the mentally handicapped, which creates the assumption of homogeneity and thereby generates the error of overexclusion. The other dilemma is the assumption of simple positive regard toward mental retardation as both necessary and sufficient, which causes one to founder upon the 'reductionist' fallacy.<sup>30</sup>

Gottlieb and Siperstein<sup>31</sup>, for example, point out that variation in mental handicap descriptions evoke different attitude responses, and Hollinger and Jones<sup>32</sup> found that

the label 'educationally retarded' was considerably more acceptable than that of 'mentally retarded'. Research has also indicated that the mildly subnormal are viewed more favourably than the severely subnormal, and children more favourably than adults. Puccetti<sup>33</sup> has argued that the evaluation of the mentally handicapped will reflect what is considered necessary for one to be a moral 'person' and suggests that 'a person' must be seen to possess certain physical characteristics and a state of consciousness. Richardson<sup>34</sup> et al found that children's preferences for pictures of other children are related to the ability to ascribe a moral worth, and Vosey concludes

When moral character is not imputed, the entity concerned is not regarded as a person. Since the ascription of intellectual character is a necessary condition of that moral character and to the extent that ascription of intellectual character is influenced by physical characteristic, then the described person may not be regarded as a person.<sup>35</sup>

A related problem in ascertaining attitudes towards the mentally handicapped is age. Kershaw has correctly pointed out that the subnormal are

... tolerated or not in the light of highly irrelevant considerations. If they do not obviously look like 'defectives' and have learnt elementary social behaviour they are quite readily accepted up to the point at which intellectual contact is attempted and fails.<sup>36</sup>

While management of the subnormal is often achieved by those who interact with them referring to them and thinking of them as children (for example MacAndrew and Edgerton<sup>37</sup>), their physical size contradicts this view and makes it difficult to sustain. However, babies and young children benefit from the 'aren't children wonderful' syndrome.<sup>38</sup> All the time that they can be treated and looked upon as babies or young children, dependent in the

same way as others of their age, they do not assume a deviant identity. It is when they are older children or 'adults', obviously different in appearance and degree of dependence, that other people react negatively towards them and stigmatise them.

Attitude surveys also give rise to problems of accuracy of response. Gottlieb and Carmen<sup>39</sup> suggest that people may not express hostile or negative attitudes because they feel that they may not be acceptable; that is, people complete the questionnaire on the basis of what they think or believe to be acceptable answers. However, even if people's 'real' attitudes could be measured, the further assumption has to be made that it is possible to predict people's reactions and behaviour on the basis of knowing their attitudes.

A major problem with attitudinal research in the field of mental retardation is the failure to distinguish between beliefs, attitudes, and behaviour. Fishbein<sup>40</sup> argues that this problem arises in attitude research not only because the concept 'attitude' is used by social psychologists to include beliefs, cognition (attitudes/predisposition to act) and conation (overt behaviour), but also because these three aspects are not necessarily highly correlated. Ableson<sup>41</sup>, criticising the 'naive view' of the relationship between attitudes and behaviour suggests that attitudes make ready certain behaviour so that the appropriate situation will elicit the relevant action. Attitude scales only measure the cognitive dimension and tell us nothing about the affective or connotational dimension. Thus we are very good at doing what we find reasons for rather than vice versa and considerable evidence leads us to doubt that knowledge of attitudes will enable us to predict overt behaviour.

People readily justify what they have done by accommodating their attitude statements accordingly.

The reverse connection has proved even more refractory.<sup>42</sup>

It may well be of academic interest to 'know' what people's attitudes towards the mentally handicapped are, but it is doubtful that this will give us any real indication as to how they will behave towards the mentally subnormal and their families when confronted with them in their day-to-day lives.

### 3.1 Attitudes towards the Mentally Handicapped in Britain

Although the view is often expressed that the mentally handicapped are a stigmatised group in modern Britain, there are few empirical studies of people's attitudes to the mentally subnormal. In order to try to ascertain attitudes it is necessary to look at research not specifically concerned with attitudes to try to develop some tentative ideas. Equally important as the attitudes/behaviour of the lay members of the community are those of people in positions of authority and power - doctors, nurses, social workers and politicians - those whose professional role gives them power to influence and determine the day-to-day lives of the mentally handicapped and their relatives. In practice the two groups are not totally separate, and the attitudes/behaviour of the two groups, lay and professional, will mutually influence each other. But as Mittler argues,

In the final analysis ... it is public attitudes however explicitly or implicitly conveyed that determine policy toward the subnormal ... since definitions of deviance depend largely on the extent to which the public is prepared to accept or exclude such minorities.<sup>43</sup>

He goes on to suggest that current public attitudes in Britain are influenced by the heritage of Victorian attitudes which led to the exclusion of the mentally subnormal from the community (see Chapter 5). While the public appear more enlightened when they condemn 'bad' hospital conditions and press for better treatment, their behaviour is less

enlightened when they 'find' reasons why a hostel for the subnormal should not be built in their neighbourhood.

Lippman<sup>44</sup> compared attitudes towards the subnormal in several European countries. An American, he argues that attitudes towards and provision for the mentally handicapped is better in Britain than in the United States (although even better in Sweden). He maintains that this is because of the general acceptance of a philosophy that society should care for those who cannot look after themselves in Britain. He concludes his survey of European countries by suggesting that

There is a different pattern of attitudes on mental retardation in several countries in Europe, and that difference does relate to the higher quality of services available for the mentally retarded.

and

... there is a thread which runs through the social orders of Catholic Ireland, Judaic Israel, Welfare-state Scandinavia, socialised-medicine England ...

1. Respect for the dignity and potential of each individual
2. Genuine conviction (on the part of the professionals at least) that the retarded can be helped ...
3. Acceptance of social responsibility.  
In England and Scandinavian countries, the taxpayers expect that the government will deliver on this obligation.<sup>45</sup>

Lippman's optimistic view of attitudes in Britain is supported by the findings of a postal survey of a random sample of 3,000 people living in the South-East of England.<sup>46</sup> The survey was first carried out in 1973 and repeated, with the same sample, in 1976. Respondents were asked to indicate which groups of welfare claimants should and should not be helped. While in all cases the number of unsympathetic responses increased between 1973 and 1976, the mentally handicapped were fifth in order of receiving the least number of unfavourable responses in both years, the groups receiving less being the elderly

the physically handicapped, epileptics and the homeless. They received considerably fewer unfavourable responses than, for example, alcoholics, delinquents, the unemployed and gypsies.

A survey published in New Society<sup>47</sup> in 1981 suggests that people are prepared to help the handicapped and disabled socially and financially and feel that they should not suffer as a result of the economic situation. It was evident that some of the sample could distinguish between those with a disability (physical) and a handicap (mental impairment), but that most were confused. Detailed questions were not asked on attitudes towards the handicapped/disabled, but the answers to two questions give some indication of these. While forty-six percent of respondents thought it would be a good idea if a son, daughter or close friend said they were going to marry a physically disabled person (as against nineteen percent who thought it would be a bad idea), sixty-four percent thought it would be a bad idea if the proposed future partner was mentally handicapped (as against eight percent who thought it would be a good idea). With regard to children, seventy-one percent of respondents thought the integration of physically disabled children into the normal school was a good idea (and twenty-two percent a bad idea); thirty-five percent thought that mentally handicapped children should be integrated (and fifty-five percent thought they should not).

The lack of public knowledge, and the persistence of negative or at best apathetic attitudes towards the mentally handicapped may be due to the fact that the majority remain isolated, even when they are not in hospitals. Mentally handicapped children go to 'special' schools and adults to training centres or other sheltered workshops. They are transported to and from schools/training centres by special buses, and as a consequence even those living with their families or in hostels have few contacts with members of the community in which they live.

As a result of this the majority of citizens have no first-hand knowledge of the mentally handicapped. They have stereotyped images, often influenced by outdated 'scientific' knowledge and occasionally stirred up by sensationalised newspaper articles. (Attitudes towards sex and the mentally handicapped, discussed below, are a good example of this tendency.) These images more often refer to the severely subnormal rather than to the mildly subnormal. Shearer, for example, has suggested that

... it is still widely believed that mentally handicapped people are uncontrolled and perverted in their sexual appetites. In the past this belief has been one of the main incentives for shutting them away in segregated institutions.<sup>48</sup>

and Greengross that

The fearful myth that the mentally sick and subnormal ... are promiscuous and have voracious sexual appetites which they are incapable of satisfying responsibly or within a socially acceptable pattern of behaviour, is one that still holds water for many, and although statistics keep pouring out to explode the myth, old prejudices and fears die hard.<sup>49</sup>

This would seem to be a good example of how arguments developed by the eugenics movement and others to justify the permanent segregation of mentally handicapped people have filtered through and still influence people's *perceptions of the mentally handicapped*. The 'outdated' views referred to in the above quotations were clearly expressed in books and articles on the mentally subnormal in the first two decades of this century. For example, in 1903 Barr maintained

In both idiocy and imbecility, the sexual desires are exaggerated in the various grades in proportion to the predominant power of the mere animal over the psychic forces.<sup>50</sup>



However, the view that at least some mentally subnormal men and women have abnormal appetites is still openly stated by 'experts'. Tredgold and Soddy argued as recently as 1970 that in the case of subnormal men

Open masturbation in the presence of others, indecent exposure, indecent assault especially on immature girls, occasional rape and sexual murder are possible.<sup>51</sup>

In the case of

subnormal girls ... in some ways the problems ... are even more intractable ... Some subnormal girls have comparatively strong direct sexual drives ... The gratification aspects of their sexuality will be uppermost. Some girls will discover how to use their bodies to give them power over men and drift into prostitution ... The self-gratification aspects of their need can also drive girls into sexual promiscuity ...<sup>52</sup>

There is indeed some evidence that mentally handicapped men commit more than their fair share of sexual offences, and that although they are not very often violent their victims are often young children. However, the total numbers of mentally handicapped men charged and convicted of such offences appears to be very small.<sup>53</sup>

Kushlick and Cox<sup>54</sup>, in a survey carried out in 1967, found that the stereotype of the mentally subnormal as sexually dangerous was still widely held. However, they also found in their survey of mentally handicapped people living in the community that only fourteen percent of the severely subnormal and five percent of the mildly subnormal displayed sexual behavioural disorders.

The mentally handicapped themselves appear to deny their subnormality and try to pass as normal. Mentally subnormal participants in conferences organised by the Campaign for Mental Handicap refused to acknowledge that they were subnormal and rejected explicitly the 'negative' perceptions of others that went with labelling them as subnormal.<sup>54</sup> Edgerton<sup>55</sup>, in the United States, also found that the subnormals in his study tried to 'deny' and 'pass'.

The negative stereotype of the mentally handicapped influences professionals as well as laymen. McCormack<sup>56</sup> in a study of the experiences of families with a mentally subnormal member, found that many parents felt that doctors (especially General Practitioners) social workers, and other professionals that they came into contact with had little knowledge of the mentally subnormal or the problems involved in caring for them. For example, Rees quotes a social worker as saying

I am not experienced in dealing with the mentally handicapped and assessment of places for them. I feel out of my depth in that situation ... I have a bit of a block about the mentally handicapped anyway.<sup>57</sup>

Jaehnig<sup>58</sup> has argued that it is professionals that make handicapped families out of families with a subnormal member. Mack reports that a gynaecologist told the parents of a mongol baby:

We hear from time to time of mongols who learn to read and write, but in my forty years of experience I have never met one.<sup>59</sup>

Even more depressing was the prognosis given to the parents of a newly-born mongol.

He will grow immensely fat, be incontinent, never talk, never read and not walk very well.<sup>59</sup>

Professional and public attitudes to the mentally handicapped are apparently negative and while they may have become modified in recent years there is little evidence that people are prepared to participate in the community care of the mentally handicapped. Financial help for relatives caring for a mentally handicapped member has increased in recent years but is still insufficient (see Chapter 6) to meet needs. Needs, however, go far beyond monetary help. Ballard,<sup>59a</sup> a social worker and the parent of a teenage Downs Syndrome boy, has argued that while parents coping with a mentally

handicapped child at home need financial help, their 'real' needs are far more wide-reaching - they need help, especially in practical coping. McCormack, herself the mother of a subnormal boy, concluded after a survey of a number of families caring for a mentally handicapped child, that

the situation of the mentally handicapped and their families has improved terrifically over the last decade ... but the needs are there and urgent.<sup>60</sup>

The mentally handicapped remain a deprived group in terms of public spending and are awarded low priority in terms of provision. A report of the National Society for Mentally Handicapped Children in 1974 argued that unless this situation was altered social disaster would result - the government needed to get its priorities right.

We can catch up with the delayed motorways or the council offices, we can never replace the wasted years of people's lives.<sup>61</sup>

Jaehnig<sup>62</sup> has pointed out that many parents, especially working-class ones, are not aware of the financial assistance and aids and adaptations they are entitled to. Parents often have to fight for the assistance that is theirs as of right. However, parents also frequently need social and practical help<sup>63</sup> with homework, 'babysitting', and holiday relief. These are often not provided by local authorities, and the research that has been carried out argues that it is not provided on a voluntary basis by relatives and neighbours either. We can see, then, how the negative/apathetic attitudes of ordinary citizens and professionals interact with the inadequate provision of services (and indeed influence those who decide what services should or should not be provided). However, even more the families share the stigma of the handicapped member and become isolated from the society in which they live. Indeed, many of the advocates of community care and

normalization (referred to in Chapter 6) are often talking about the provision of services that will 'normalize' the family rather than the mentally handicapped member.

#### 4. Empirical Research Findings: Attitudes, Reactions and Behaviour

My major criticism of attitude surveys is that they do not necessarily give any clear indication as to how people react when confronted with mentally handicapped people. Indeed, in the last chapter I suggested that some recent research findings indicated that there was a definite shift to more negative attitudes if people were actually faced with the possibility that a hostel for the mentally handicapped was to be built in their neighbourhood. (This can clearly be seen as a reaction to an event - the possibility of having mentally handicapped neighbours). Thus Carver and Rodda have suggested that

... although we may declare our lack of prejudices towards handicapped people, how we behave when we have to meet them ... may be quite different.<sup>64</sup>

It appears, then, that we need research not only into people's attitudes towards the mentally handicapped but also into how people react to and behave towards mentally handicapped people. This involves analysing patterns of interaction, action, reaction, behaviour and how others including the mentally handicapped interpret these.

In the sections below I discuss the illustrative research referred to in the introduction to this chapter. As I said there, this is intended to indicate the type of research that would fill in the gaps in our knowledge concerning reactions and behaviour and the ways in which mentally handicapped people and their families interpret and understand these reactions and behaviours towards them, and how they in turn influence the ways in which they react and behave towards other people.

Most of the attitude research has used a positivistic methodology - attitude scales - designed to obtain 'hard' quantitative data. To the extent that the scales do measure people's 'real' attitudes the results indicate the extent of negative/neutral/positive attitudes. However, they do not tell us how salient or central the attitudes are nor necessarily indicate how people will behave. One way of obtaining data on how people react and behave towards the mentally handicapped would be to count, by observation, how people actually did react/behave when they came into contact with a mentally handicapped person. Alternatively it would be possible to ask people to recall incidents when they have met a mentally handicapped person and to say how they reacted/behaved and to ask people concerned with the care of a mentally handicapped person to recall, in response to a pre-coded questionnaire, how people have reacted/behaved towards them and the mentally handicapped person in their care. However, there are a number of problems with these methods: apart from the fact that they are time-consuming and the difficulty of obtaining a large enough random sample of respondents, there is the problem of faulty memory, of not wanting to put oneself in a 'poor light' with the interviewer, and in the case of those caring for the mentally handicapped, the problem of how they interpreted other people's behaviour/reaction. I decided instead, because of the problems of obtaining quantitative data and because the research is in the nature of a pilot/exploratory study to use ethnographic/qualitative research methods. This type of research makes possible the identification of the relevant problems (negative reactions/behaviour) and populations. For example, one part of my research is carried out in a village; some of the problems found to exist in such a community might not arise in a 'transient' inner-city area. There is already some evidence that there is less resistance to hostels for 'deviant' groups in working-class areas than in middle-class areas - though this does not mean that negative reactions/behaviour

towards the residents of the hostels does not occur in working-class areas. Qualitative methods are better suited to the nature of a problem such as this one, because they lessen the risk that the researcher's pre-conceived categories will be imposed on the research area to the detriment of the categories through which the participants themselves conceive their situation. (However, it would be necessary at some stage to return to more quantitative approaches, particularly in the service of social policy; one would need reliable estimates of the relative frequency of identified problems in the relevant populations).

Thus in order to begin to explore the problems of reactions/behaviour I:

- i) asked three groups of students in a Further Education College to participate in discussions, chaired by me, on mental handicap;
- ii) interviewed, informally, a small group of residents in a village where a hostel for mentally handicapped women had recently been opened; and
- iii) interviewed, again informally, at least one adult member of eleven families with a mentally handicapped dependent.

#### 4.1 The Students

As a lecturer in a further education college I had the possibility of a 'captive' group of respondents. Originally I considered using an attitude scale and pre-coded questionnaire on a random sample of the full-time students in the department in which I worked (an Academic Studies Department catering mainly for 16- to 19-year-old students following full-time courses leading to G.C.E. 'O' and 'A' level examinations). This would have provided quantitative data on their attitudes towards and their knowledge of and amount of contact with mentally handicapped people. It would have enabled me to compare the responses of a young, relatively intelligent group of English people

with the results of previous research. (It seemed to me that if attitudes were becoming more positive and people beginning to have more 'correct' knowledge of the mentally handicapped, then this kind of group would reveal this.)

However, I decided that my position in the college would compound all the problems of reliability and validity associated with such research, and that I needed to develop a research tool which would enable me to get at the students' 'real' feelings. I therefore decided that if I asked students to discuss the mentally handicapped in groups which I could chair, they might in the heat of discussion reveal more of their 'real' thoughts and ideas than they would filling in pre-coded forms. The discussion-group is after all a fairly natural setting for the student.

The findings reported and discussed below are based on an analysis of typed recordings of three separate group discussions. All the students who took part in the groups were studying either 'O' or 'A' level sociology and were taught by me. I did not obtain detailed information on social class, but all the students involved were beyond the compulsory school-leaving age and were studying to obtain academic qualifications.

The first group consisted of 14 cadet nurses, 2 boys and 12 girls, aged between 16 and 18 years. All were employed full-time by a local Regional Hospital Group and were allowed day-release for two days a week to study for G.C.E. 'O' levels. Some of the students had experience of working on the wards in a subnormality hospital. The second group comprised 20 full-time students studying for G.C.E. 'O' and 'A' levels. All the students in this group were aged between 16 years and 20 years. The third group was made up of 14 full-time students, aged between 16 years and 22 years, studying for G.C.E. 'A' levels, and two part-time students in their mid-forties studying for G.C.E. 'A' level sociology.

I am not suggesting that these students are in any way a representative sample of the population, of their age group or of the college's students. However, some knowledge of their attitudes towards and reactions to the mentally handicapped enables us to form some idea as to whether the educated young do have more knowledge and tolerance and to see what negative attitudes towards and misconceptions concerning the mentally handicapped still appear to be prevalent.

The major problem I encountered in chairing the discussions was to get one started in the first place. The majority of the students did not have any first-hand knowledge of mental handicap and had obviously not thought about it. In a sense I was asking them to consider a 'problem' that was not only not central to their lives but was in fact something they had never really thought about. (If this were true of the total population it would demonstrate again how little use surveys of abstract attitudes are and the importance of studying concrete reactions and behaviour). If I had not had a position of authority over them it would have been extremely difficult, if not impossible, to get them to discuss the issue. (They were not aware, at this time, however, that I was carrying out sociological research in the area of mental handicap, and the idea of discussing the subject was presented as 'getting them to talk about a social problem' prior to my telling them about the way in which sociologists approached it.)

Apart from the cadet nurses who had worked in the subnormality hospital, only one student claimed to have had any contact with a mentally handicapped person. Their knowledge of mental handicap was also extremely poor. Few of the students had any clear idea of what mental handicap was. One group - the second- spent at least twenty minutes trying to decide what it was and eventually asked me to give a definition/description. One of the major difficulties they had was in differentiating between mental handicap



and mental illness. In one group this only became obvious when a number of them started to discuss the behaviour of the patients in a local psychiatric hospital under the misapprehension that they were mentally handicapped.

Once the students realised which group of people they were supposed to be talking about they revealed the negative attitudes and reactions described in previous research. Their image of the mentally handicapped was, however, based on the more severe cases, who often exhibit unexpected and bizarre behaviour, and many referred to the physical, especially facial, features associated with Downs Syndrome (Mongolism). All the students, including the cadet nurses who had worked with mentally handicapped people, admitted some feelings of fear and hostility; a number advocated euthanasia, especially when 'defect' was obvious at birth. They justified this by pointing to the social and economic burden that mentally handicapped people placed on their families in particular and society in general. (When I intervened and asked whether this applied equally to physically handicapped people they were more ambivalent, arguing that their 'brains' were not damaged and that they could support themselves economically.) The majority clearly felt that they, their parents and the neighbours would react adversely to a hostel being opened for mentally handicapped children or adults (especially the latter) in the vicinity of their homes. They justified this reaction by referring to the danger that such people posed to children and elderly people, and although they did not seem clear as to what this danger was there was some suggestion of sexual attacks and other socially unacceptable behaviour. The main concern seemed, in fact, to be that it would lower the 'tone' of the neighbourhood and make it generally a less desirable place in which to live.

It seems, then, that at least among this group of young people more positive attitudes to the mentally handicapped have not developed, and that they have little

knowledge of its nature. A more detailed and systematic study of young people may reveal data that contradict these, of course.

There is one interesting side-light to this study. Some weeks after these discussions had taken place I discovered that another student whom I did not teach, but who was a close friend of several members of group 3, had a younger sister who was moderately mentally handicapped (Downs Syndrome). The one student who said that she had informal contacts with a mentally handicapped teenager was in fact referring to this student's sister, whom she had met when visiting her friend. I spoke briefly to the student, who claimed to be fond of her sister and to take her out on trips occasionally. However, she appeared not to talk about her sister with her friends or fellow-students and had only introduced her to her 'best' friend. She seemed to feel that she shared her sister's stigma and that her status would be diminished if she revealed her sister's 'condition' to people she wanted to 'like' her.

#### 4.2 The Village: Reactions to a Hostel being Opened

If the policy objectives discussed in Chapter 6 are to become fully implemented so that mentally handicapped people become 'accepted' in local communities and integrated into the existing services, then hostels and their residents must be accepted rather than just tolerated. The available research has suggested that community reactions to hostels are usually hostile, and even when there is not adverse community reaction few people in the area are prepared to befriend the residents. There is, however, research that indicates that residents of hostels and group homes can become integrated into local communities. A report of a successful group home in Birmingham stated that it had been

now a group home for two years, neighbours are friendly and helpful.<sup>65</sup>

but the report also stressed that

If group homes for the mentally handicapped are to play an important role in the future, good neighbours with an understanding of the needs of the mentally handicapped are vital.<sup>65</sup>

In this case an important factor in the residents being 'accepted' may have been that they had been carefully selected and prepared and that none of them were visibly abnormal or disabled.

Another 'successful' example is that of Delph Manor,<sup>66</sup> where the residents have become integrated into the local community. In this case the positive approach of the Warden, who has actively encouraged local people to come into the hostel and the hostel residents to go out into the community, seems to be an important factor. Other relevant considerations could be related to the locality in which the hostel is to be sited, the extent to which local people are informed about the hostel before it is opened, the number of residents to be housed there, as well as the factors referred to above - degree of handicap and the approach of the Warden and others connected with the residents.

However, I was not just interested in how people said they felt about having a hostel in their immediate neighbourhood, or even if some local people were prepared to befriend the mentally handicapped residents of an already established hostel. I was more interested in explaining reactions to and behaviour towards mentally handicapped people - in the audience in a real scene, not just the actors. The opportunity arose for me to do some research in a village where a hostel for moderately mentally handicapped women had recently opened. In a sense this gave me an extreme example; the village had not been prepared for the hostel's opening in advance, it had mainly middle-class residents and was a relatively small, closed area. Furthermore, the initial adverse reaction to the opening of the hostel was fuelled by the Warden of a local youth campsite who pointed to the 'dangers'

of housing women 'like that' near children. (The women that I spoke to clearly felt that he meant sexual danger - although it was unclear if he ever said this explicitly). I was interested in local reactions to the hostel, whether these had changed in the three years since the hostel had opened, and the behaviour of the villagers to the 'girls' (as they seemed generally to be referred to).

I could again have carried out some type of random survey of the local residents, but this again presented all the problems of getting at people's 'real' feelings and at 'true' descriptions of how they had reacted and behaved. Alternatively I could have lived in the village and carried out participant observation, but I would not have been able to obtain sufficient data in the time I had available and would have had to spend the time exploring what to look for rather than getting any 'real' data. My entry to the village (being told about the hostel and the reactions to it) had been via a mature student who offered to introduce me to a group of 'friends of the hostel'. I was subsequently introduced to the group and they agreed to discuss with me what had happened in the village when the hostel had opened and subsequently. I spent several hours with them talking about the hostel, its residents and the village, directing the discussion in order to get them to talk about their own reactions to the hostel and those of other villagers and the ways in which villagers had subsequently behaved towards the 'girls' living in the hostel. While this method had the advantage of getting the group talking and remembering incidents as well as talking about the 'problems' in general, they were aware of what specifically I was interested in and the particular incidents they recalled may well have been the exceptions, examples of extreme behaviour rather than of typical behaviour. However, most of the group were themselves sympathetic to the hostel being in the village, and while in some ways they may have wanted to put the opponents 'in a bad light', what they said about their

own reactions should counteract this trend by giving the opposite point of view.

As I have already said, the village was inhabited mainly by middle-class people. All the housing in the village was privately owned. The village itself is on the edge of London and about five miles from a main shopping centre. Many of the inhabitants commute daily to London. The group I spoke to was comprised of women, and although I did not ask them for information that would enable me to determine their social class definitely, their life-style was middle-class.

The hostel was converted from a house that had previously been a Seamen's Home. The residents all came from a subnormality hospital and were all moderately handicapped; some had physical disabilities, some speech impediments, one member had frequent epileptic fits, and some had other socially unacceptable behaviour such as dribbling and open masturbation. Thus the 'girls' looked and behaved deviantly but were representative of the type of mentally handicapped people for whom care in hostels in the community is advocated.

As I have already stated, the members of the group I spoke with were basically sympathetic to the hostel and its residents at the time I carried out my research. They felt that while the opponents of the hostel had been more vocal and persistent in expressing their views, most of the villagers were apathetic. They had not actually supported or opposed it.

The reaction has generally been from those villagers who don't want a home rather than from people in general that might come into contact with them.

The news that a hostel for the mentally handicapped was to be opened in the village was greeted initially with mixed feelings by the villagers. They were very upset that the first indication they had that a hostel was to be

opened was a report in the local newspaper. The initial reaction was to call a village meeting, at which a considerable amount of concern about and opposition to the proposal was expressed. A qualified nurse said that at this meeting many displayed a complete lack of knowledge of the mentally handicapped, obviously confusing them with the mentally ill and referring to them as 'raving nutters'. Many parents expressed concern for the sexual safety of their children, this fear being added to by the Warden of the local campsite for young people, who put forward the existence of the camp and the danger to campers as an argument against the establishment of the hostel. As one person put it

... the majority of the people were horrified to think that we were going to have - to quote their own words - 'lunatics' in our village that might murder their children.

Not all of the villagers shared the 'fear' of the mentally handicapped, and some expressed sympathy for their plight, but nevertheless they felt that the hostel should not be built in 'their village'. In general few had any 'real' knowledge or contact with the mentally handicapped. As one elderly schoolteacher said,

Well, I had never had any contact with mentally handicapped people until they came to our village.

Three years after the hostel had been established there was little evidence that villagers had modified their attitudes or their opposition to the hostel. One woman in the village, the qualified nurse, had organized a group of 'Friends of the Hostel', and a number of women from the village visited and helped at the hostel, but they had generally not been those who were opposed to it originally. Contact with the residents had to some extent modified the attitudes and beliefs of those who belonged to this group. As one respondent put it,

Now my reactions were mixed. I was a little bit frightened as I sat amongst them. I felt slightly nauseated the first time I went because some of them weren't very good to look at. All of them liked physical contact and wanted to come up and touch you and this added to my fear and my reactions, but it went on for several weeks - going along on Tuesday afternoon - and then suddenly, I am speaking personally now, one person who hadn't ever spoken since she was brought to the home (but was quite capable of doing what she was told to do after a period of meditation) suddenly looked up when I came into the room and shouted out in a very hoarse voice 'my friend, my friend' and got hold of my arm and from that moment I felt all the feelings I had about not wanting to be there and distasteful feelings fall away and I became totally involved.

However, a hard core of the village remained opposed to the hostel being sited near the village. As a number of people told me regarding their own acceptance of the 'girls',

But it hasn't covered the whole district. We still have a group of people who won't accept them.

Additionally some of the villagers felt that the mentally handicapped residents had too comfortable an existence, as I was told:

Their life at the home is, well, to quote some villagers, to be envied.

Although none of the residents from the home had committed a 'serious' offence their behaviour in the village had been interpreted by some villagers as justification for their original opposition and confirmed for them that they had been right to oppose the hostel. Local people had objected to their behaviour in church and in the village generally and had succeeded in having them prevented from attending church services, and their access to the village was restricted. I was informed by one villager, who was not 'really' opposed to the hostel

But I think that if they weren't strictly supervised we might get the conditions that the nucleus fear.

This view was based on an incident that had been witnessed at the home and which was described as evidence of the inherently violent nature of the girls.

One one occasion, when the sister was absent on holiday, we had a lot of cast-off clothing brought to the home, and it is customary for sister to allocate these to various girls, and one particular girl saw a dress that she'd like and she took it unbeknown to us. And another girl knew that she had taken it and started a violent argument with her and before we knew where we were not only were the girls fighting and scratching each other's faces, but the nurses were getting the worst of it ... So you see some of their fears are not unfounded ...

(All the fears of the village?)

Yes I think so, because one can't predict their reactions unless they are under medication. For my own part I've no fears but I think that anyone that's around then that they weren't fond of might suffer.

The general impression of the villagers who helped at the home was that the negative reaction to the residents had come from those villagers who didn't want a home rather than from members of the public in general that they might come into contact with. A member of the volunteers always accompanied the residents on shopping trips to a nearby shopping centre.

You see, we take them into big places like Woolworths and supermarkets and I think they sort of get lost in the crowd, people don't seem to notice them ... No real reaction to their features or the fact that they are mentally handicapped - not in public. Not the public in general.

Despite the fears and apprehensions of the villagers there seemed to have been few incidents to confirm their continued fears. The majority of the disabled women are not allowed into the village on their own, and there had been no serious incidents involving any of them in the village. However, the behaviour of those who had been allowed out on their own was perceived as 'rather a nuisance'.



We had a village shop - you see we have one that's light-fingered, that is why she's there, and every time she goes into the shop, she asks for something which has to be got from under the counter or from the next room, and takes things, so she had to be stopped. Another one is an inveterate smoker and will pester people for cigarettes and cups of tea. She's had to be stopped.

All these incidents combined with the original negative attitudes and reactions result in a continued general hostility to the hostel and its residents. It was difficult for me to gauge what proportion of the villagers were actively hostile, but they were obviously vocal and influential. Few villagers had campaigned on behalf of the hostel and its residents, and there was little evidence that any of the villagers had developed more positive attitudes to the mentally handicapped as a result of meeting the hostel's residents. Even some of the women I spoke to, who were actively helping at the hostel, had some doubts as to whether or not it should have been opened and showed some of the fears of the 'girls' that they claimed were voiced by those opposed to the hostel. In general, then, we can conclude that, in this village at least, there was considerable opposition to a hostel for mentally handicapped women being opened in the first place, and that this opposition had not diminished three years later. It also seems that villagers selectively remembered what were probably fairly isolated incidents of unacceptable behaviour exhibited by a small minority of residents, to confirm their 'worst fears'.

#### 4.3 The Experiences of Families with a Mentally Handicapped Member

While a number of the studies of the mentally handicapped have described the problems confronting the families which contain a subnormal child, in both caring for and in deciding to seek residential care,<sup>67</sup> few have been concerned with the way other people's behaviour and attitudes affect the family. I was interested to discover

how the parents felt about other people's attitudes and behaviour towards them and whether they experienced it as stigmatizing. While accepting Bayley's<sup>69</sup> point that the relations' sensitivity to the way other people behave will be conditioned by their own attitudes, I would nevertheless argue that the experience of parents will give us insight not only into people's attitudes but also their reactions to behaviour towards the mentally handicapped. I have already suggested that there is considerable evidence that the mildly subnormal feel stigmatized and are 'hurt' by other people's behaviour towards them. It is not practical to question the more severely subnormal or even to know if they are aware of the meanings of the reactions or behaviour of other people towards them. Those nearest to the subnormal are their families who share their stigma and diminished status.

#### The Sample

I was given the names and addresses of fifteen families prepared to co-operate in my research by the Chairwoman of a branch of the National Association for <sup>Mentally</sup>Handicapped Children. All were resident in a London Borough and members of the association. Eleven of these families were located and interviewed.

In seven cases the mother was interviewed, in three the mother and father were seen together, and in one case a grown-up sister.

#### The Subnormals

- 6 adults - All attending a local authority training centre and living in the parental home
- 1 adult - Resident in a mental subnormality hospital
- 1 child - Pre-school age
- 4 children School age, attending E.S.N. (S) schools

## The Families

All the families regarded their mentally subnormal members as handicapped and as requiring fairly constant care and attention. Although four of the adults had been ascertained as mildly subnormal, none were thought of as capable of independent living, of high levels of self-care or of 'open' employment. This contrasts sharply with the experiences of the research department of the local authority who attempted to carry out a sample survey of the mentally handicapped and their families using the case records of the Social Services Department as a sampling frame<sup>70</sup>. They found a number of cases where this 'mentally handicapped' label was denied by the family and several where the 'subnormal' had married and the spouses had no idea that their partners had ever been ascertained as handicapped.

These families may be typical of those who have come to accept the fact that they have a mentally handicapped member, but not necessarily of all those with a subnormal member. They have also 'publically' acknowledged this acceptance by joining the association, from which they also receive a certain amount of mutual help and support.

The degree or type of handicap of the subnormal in the sample families meant that all of them were fairly obviously subnormal, either because of behaviour or appearance. Therefore these families are likely to experience the negative attitudes, reactions and behaviour of other members of the community in which they live, and additionally have experience of the knowledge, behaviour and attitudes of those professionals who routinely come into contact with the families of the mentally handicapped.

These families are atypical in that they were self-selected; that is, they had agreed to take part in research at the request of a third party. They were all members of a local branch of an association for the mentally handicapped and the majority were actively involved in the activities

and running of the branch. The association provided mutual support, information on rights and entitlement to services and acted as a pressure group at the local level. Much of the social life of ten of the families centred around the association and its activities. This means that they might to some extent have been cushioned from community attitudes and insulated by their group membership. Indeed their membership and participation in organizational activities may have been deliberately to enable them to maintain the appearance of a normal family while avoiding situations that would be likely to be embarrassing or involve stigma.<sup>71</sup>

Furthermore, these parents had chosen to become members of and participate in the activities of a voluntary organization. There is, for example, some evidence that the middle-class are more likely to join voluntary organizations, and although not all of these families would be classified as middle-class on the basis of father's occupation, all except one family lived in owner-occupied houses. One family lived in a council house, and the mother was a qualified art teacher, but the *Chairwoman of the Association* described the family as 'poor'. Thus while most epidemiological studies have found that severe subnormality is distributed randomly among all social classes, and mild subnormality concentrated among the working-class, the sample were heavily biased to the lower middle class.

The sample also did not contain any families where the mentally handicapped member was non-organically mildly handicapped. The secretary of the association told me that the parents of mildly subnormal children that they contacted usually maintained that their child was not mentally handicapped and that they did not want to have any contact with the society. The problems faced by these families and their experiences of other people's attitudes and behaviour may well be different from those of parents with more severely handicapped children.

Nevertheless, the evidence from other research into the families of the mentally handicapped does not seem to indicate that social class is an important variable. The slight indications that it could be are self-contradictory; while some researchers (e.g. Mercer<sup>72</sup>) have argued that working-class families are more accepting of and more likely to care for a mentally subnormal member, others have argued the reverse (e.g. Jaehnig<sup>73</sup>), and have suggested that it is lack of knowledge of rights to financial help and services which hinders the attempts of working-class parents to care for their subnormal child at home.

The experiences of these eleven families are not the same. Some feel intensely that they are stigmatized as a consequence of having a handicapped member and that other people openly display negative reactions towards them and the mentally subnormal. These negative reactions were displayed by relatives, friends, the 'general public' and professionals. Conversely, others felt that everyone had been and was very helpful and kind. Despite this, my own subjective impressions - gained from looks, inflections in the voice and other cues - indicated that they had all had disturbing experiences and all felt that other people regarded them as 'different', pitied them and to some extent avoided them. Also, they all seemed to structure their lives as families so as to avoid possibly embarrassing situations - for example, by not asking friends to babysit, by not inviting friends or relatives who they felt would object to or be embarrassed by the presence of the subnormal member. Probably what came over most clearly was a feeling that people's attitudes were ambivalent: that at an abstract level they experienced sympathy, but when confronted with the possibilities of direct contact with the mentally handicapped tried to avoid it. (They reacted in a way that was not consistent with their previously expressed attitudes).

In a very important way, perhaps, the major influence on these families' lives were their own attitudes, usually

reinforced by the actual or perceived attitudes and reactions of others, including the acceptance of the idea that the mentally handicapped child was their responsibility, that it was their duty to care for the child and 'shoulder the burden'. This meant in all but one case that the mother did not work and that the family structured their lives around the needs of the mentally handicapped member. The lack of help from relatives, friends and neighbours resulted in the isolation of the families and especially of the mothers.

### The Sample Families

- Family 1    Father, Mother, 3 sisters.  
              M.H. member Trevor (second child) aged 15 years  
              S.S.N. (brain damage)
- Family 2    Father, Mother  
              M.H. member Diana (only child) 9 years old,  
              brain damaged, dumb, unable to walk, doubly  
              incontinent, looks normal.
- Family 3    Father, Mother  
              M.H. members (a) John, young adult, I.Q. 56,  
              looks subnormal, slight problems with speech.  
              (b) Susan, young adult, I.Q. 60, looks normal,  
              capable of high level of self-care.
- Family 4    Father (deceased), Mother, 1 son and 1 daughter  
              M.H. member Mary (eldest) 21 years old, Mongol,  
              I.Q. 60+
- Family 5    Father, Mother (deceased), sister  
              M.H. member Donald (younger sibling) Mongol,  
              I.Q. 50, 32 years old.
- Family 6    Father (deceased), Mother, 3 married sisters,  
              1 brother.  
              M.H. member Paul (youngest) 3½ years old,  
              Mongol, not talking or walking.
- Family 7    Father, Mother  
              M.H. member Mark (15 years old). I.Q. 50,  
              no official diagnosis but exhibits violent and  
              bizarre behaviour.

- Family 8      Father, Mother, 2 brothers (1 older, 1 younger)  
M.H. member Gregory, 15 years old, brain  
damaged, severely subnormal, dumb, doubly  
incontinent, mobile.
- Family 9      Father, Mother ,1 sister (older, married and  
partially sighted)  
M.H. member Sandra (adult), severely subnormal,  
blind, no formal diagnosis. Walks and talks.
- Family 10     Father, Mother, older brother (married)  
M.H. member Elizabeth, subnormal, I.Q. 57,  
30 years old. No diagnosis
- Family 11     Father (deceased), Mother, 2 sons, 1 daughter  
(all younger)  
M.H. member Judith (31 years old), Mongol,  
permanent resident in local subnormality hospital.

#### Method

The interviews were conducted in the homes of the families. They were focussed interviews. Generally I asked the parents about their experiences and the replies were tape recorded. I rejected the idea of using a formal interview schedule and decided instead to ask the parents to discuss with me their experiences of having a mentally handicapped member and particularly to talk about how other people had reacted and behaved towards the family in general and the mentally handicapped member in particular. During the interviews I only interrupted in the flow of conversation to direct the respondents back to the general area in which I was interested when they wandered away from the point. I did, however, ask questions at the outset about the occupation of the head of the household and for details of other members of the family, apart from the mentally handicapped one. (Family 3 refused at the outset to discuss the attitudes and behaviour of other people.)

The main reason for choosing this research method was that I wanted the parents to talk freely and give me details of the ways in which they had experienced the reactions

and behaviour of others. I explained at the outset that I was interested in negative and positive reactions and those of relations, friends, neighbours, people they met and professionals they came into contact with. This meant that I focussed their attention on a certain aspect of their experiences of having a mentally handicapped member of the family. The disadvantage was that I might be asking them to focus on aspects of their lives that they had not previously thought about or considered central in their day-to-day lives. Also they were likely to remember the few outstanding (probably negative) reactions rather than the routine, day-to-day ones. However, the alternative, non-focussed interviews, would have been too time-consuming and may have provided little data on my own area of interest. The type of research method I used provides valuable qualitative data which not only sheds light on people's reactions and behaviour, but can also be used to generate hypotheses that can be tested by more quantitative, controlled methods.

### Findings

A number of important factors need to be looked for in interpreting and understanding the feelings and experiences of the parents. Of two factors that other research has shown to be of special relevance, one is age - young children benefiting from the 'aren't children wonderful' attitude. In the sample only Paul (Family 6) was of an age to benefit from this. The other main factor is degree of handicap - the mildly subnormal being less stigmatized than the severely handicapped. Elizabeth (Family 10) and Susan (Family 3) were both mildly subnormal and not obviously handicapped, while Mary (Family 4) was only mildly subnormal but was obviously handicapped (Down's Syndrome). As Mary's mother explained,

She is so borderline in lots of ways which I think makes it more difficult. It's more difficult for her and it's more difficult for us ... Mary knows that she is the oldest one in the family, so therefore she resents being looked after by her sister who is 3 years younger.



Furthermore, being obviously Down's Syndrome in appearance and the fact that she realises that she is a Mongol make life more difficult for her. Her mother recalled finding a card that Mary had written as part of a game of playing nurse:

- . It's fun to read them actually, but I was very upset one day when I found a card saying 'I am a mongol, but I'm not handicapped, I'm normal, you know.'

Mary is not accepted by the wider kingroup as a member.

I found things are difficult ... we have invitations to weddings, family affairs - Mary is not invited. She is treated in this way because she is a mongol, not because her behaviour is abnormal. She is being treated as an outcast on the basis of prejudice.

Another factor is the experiences of the families of the different categories of members of the community that they come into contact with - relatives, friends, neighbours, strangers and professionals. While some families (1, 2 and 6) saw all the attitudes and reactions of other people as negative, others found only some people or groups displayed negative attitudes and reactions. Mary's mother, for example, was very critical of the negative attitudes and unsympathetic behaviour of relatives, was extremely critical of professionals, but had not experienced any adverse reactions from neighbours.

My neighbours are very good on the whole.  
My neighbours next up that way have always  
been ever so good.

However, none of the families had never met stigma or negative attitudes or faced problems because of the unsympathetic behaviour of other people at some time. Many of the families felt that ignorance was one of the major factors, coupled with a lack of sympathy and understanding. Mary's mother referred to her experiences at an Open Evening at the Adult Training Centre.

I was detailed to talk to different groups and I was quite amazed that even in these days there is so much ignorance concerning mentally handicapped people. They just could not understand when you took them to the workrooms that even the most seriously severely handicapped child can be trained to do something. I just couldn't understand it.

We had one group and I think they really thought that all mentally handicapped children were absolutely mad. Yes I think of course that this is a very common failing. People will mix up the mentally ill and the mentally handicapped. This doesn't only apply to people - it applies to people in the social services, people in hospitals - unless they actually have contact with the mentally retarded as opposed to the mentally ill.

Elizabeth's mother (family 10), who was also Chairperson of the local branch of the Association, felt that there was just a general lack of interest in the mentally handicapped, that they were forgotten by society. Social workers, health visitors and doctors had little knowledge of the mentally handicapped, and family doctors could rarely give the parents the kind of practical help that they all too frequently needed. She concluded the interview by pointing to what she felt most clearly demonstrated the lack of concern for the mentally handicapped.

The local Social Services don't keep a register for the mentally handicapped. They inherited a register which was so utterly out of date, the information was unbelievable. I mean people were dead, or married and the spouses did not know that the spouse was mentally handicapped. The house had been demolished. It was a fiasco, absolutely. I think that it is vitally important that there should be a register for all the mentally handicapped of every age within the Borough boundary. I am hoping that it will be set up very soon, but they are hedging it very much indeed with how difficult it will be to keep it up to date. How can you talk about needs? How can you work out the needs of future residential accommodation if you haven't got a register for people who are going to use that future accommodation?

(The problem referred to was encountered by the local council when they attempted to carry out research into future residential care facilities that needed to be provided.

The researcher generated a stratified random sample of all the mentally handicapped people with an intelligence quotient of less than 60 (according to the register) or who had attended the Junior Training Centre, or were currently (as far as could be ascertained) attending the Adult Training Centre and were, at the time of the survey, over 16 years old. Elizabeth's mother is pointing out how out of date the register was, and not suggesting that the spouses of those who were married should have been/should be told that their partner had been 'diagnosed' as mentally subnormal when they were younger.)

The experiences of the families varied greatly, and of course it is difficult to tell if this is a result of their own feelings and attitudes influencing their interpretation of events and situations or of real differences. Nevertheless, all had bad experiences where they had felt embarrassed or stigmatised by the behaviour of other people. A typical experience was that recounted by Judith's mother (family 11)

I know once we were at the seaside and we were sitting on the beach and the children were together and this happened. This person's children came down on to the beach early and they were playing with Michael and Judith and they were playing happily together and then the mother came from nowhere and my goodness me did she let out a thing. She said "I would never have let them come down on the beach if they were going to play with someone like that".

Furthermore, parents anticipated adverse reactions. Paul's mother commented (family 5)

I've found wherever I've taken him he's been accepted. Perhaps now as he's getting a bit older it's going to become more difficult.

Diana's mother (family 2) also felt that things would get more difficult as she (Diana) became older. Judith (family 11) had eventually been permanently hospitalised because of her mother's anticipation of future problems.

This is one reason why something would have to be done. She went into the ---- hospital when she was 21. Caroline was 3 and Michael 19, coming up to 20. I have seen so many families where the brothers have girlfriends and this causes unpleasantness, and I thought 'Oh dear, we can't have that ...' I said we have got to do something before Michael starts going serious with girlfriends, before Caroline goes to school and brings friends home. We don't want to make any unpleasantness.

Donald's sister (family 6) felt that people's behaviour was a result of thoughtlessness and ignorance rather than deliberately unkind or prejudiced.

But certainly I think in the general run of people, people just seeing mentally handicapped people for the first time are frightened.

However, she was also aware of the fact that Donald understood when people were making fun of him and that this upset him. He had, for example, been very upset when children had laughed at him when he travelled on the bus.

In contrast to many of the parents, Diana's mother had received considerable sympathy and help from a friend:

Well, most people were sympathetic. Well a friend I had at the time, well still have - was very sympathetic. In fact she looked after Diana a lot for me.

But this mother, more than any other I visited, already felt lonely and isolated, and needed more help and support than she was receiving from neighbours, friends, family and the Social Services.

However, Trevor's family was the only family that expressed a feeling of bitterness at the way the whole family had suffered. They felt that they had been cut off from their wider family and from friends and the community.

Let's put it this way, there were relations we have not seen since we found out about Trevor;

and

We have only been invited to tea with Trevor once to my brother-in-law. He thinks we should put Trevor away. (Father)

The mother and father felt that in general people in Britain had 'bad' attitudes to the mentally handicapped. The mother referred to the remarks of a local shop assistant

A couple of weeks ago the woman in the newsagent said to my husband, 'fancy bringing a child like that in here!'

and went on to quote an incident in a local shopping centre which she suggested was a 'typical experience'.

We went out shopping in B\_\_\_\_\_ and this young man stared at us. I turned round and he was still staring.

Furthermore

We always go abroad for our holidays, people in Sweden have very good attitudes to the mentally handicapped, they are far more advanced than we are.

In almost complete contrast to this family's experiences were those of Gregory's family. Gregory is of much the same age as Trevor, and like Trevor has siblings and is severely handicapped. The parents felt that Gregory had not restricted their social life and they had no real problems obtaining babysitters when they wanted to go out. As far as relatives were concerned they had experienced no adverse reaction at all, and referring to neighbours the father commented

They go out of their way to make sure their children speak to him, tell them to speak to him. They say good morning to him, wave to him and he waves back, and they are especially kind and we have never had any trouble with any of the neighbours.

The third family with a teenage boy (family 7) had experienced mixed reactions - typical of most of the parents. In general they felt that people were apathetic rather than negative in their attitudes.

I feel it is part of our duty in society to make people more aware that the mentally handicapped exist, and talk about it rationally and logically and not push it under the carpet. I cannot say that the reactions I have found have been much one way or the other - there has been some discussion of it, especially with the friend I work with, but again, I suppose, largely a case of sorry for you, not saying this outright of course, followed by indifference. The subject doesn't come up again, certainly they never advance it ...

They had received considerable help and sympathy from the wife's relatives, but had been completely cut off by the husband's. The husband obviously felt deeply hurt by the reaction of his relations and refused to discuss them.

Mark's mother and father felt that adverse reactions stemmed mainly from ignorance, and came most frequently from children.

Mark loves fishing and the men, adults, were marvellous, but the children used to take the mickey and they made fun.

But they also suggested that people often betrayed their 'real' feelings by looks on their faces and what they left unsaid rather than by their behaviour, especially a fear of 'deviant' sexual behaviour.

(Mother) When I talk to people and I say Mark is mentally handicapped and as soon as they know he is coming up to 16, you see, you know what I mean? I don't want to put it into words but you see it before they even say it ... Dear God, they all think of the average child. It is an unspoken look; I suppose maybe I would be guilty in the same way, but there is that fear of danger to 'my daughter'.

However, the father felt that this might only be their interpretation of people's looks.

I agree that there may be an attitude or a look, but if so it is a subjective opinion on our part. Whether we see it or not we think that we see it because certainly I don't think it is ever said ... It might be that they have a look on their faces, but you see we may become hypersensitive on this and also very biased.

What Mark's parents felt most strongly, however, was the lack of more general help and sympathy from the community. Their lives were severely restricted by an inability to find suitable babysitters, and Mark's mother had difficulty getting shopping as Mark refused to go to the shops. Their feelings about lack of provision and priority for the mentally handicapped came out most strongly when they discussed educational provision. Mark was due to leave the E.S.N.(S) school he was attending and his parents had recently been informed that there was no alternative day-care provision available for him. His mother expressed her views strongly.

you see because I am here all day to listen to, say, Woman's Hour or some programme arguing for nursery schools for children up to 5 years so that mothers can go out to work, and I get so angry I think What the heck! You have a perfectly healthy child with everything going for them; alright, wait until they are 5 to go out to work. How do they think a mother copes with a handicapped child? The thing is they are pushing and shoving and there is all this propaganda for nursery schools for the healthy child, the child who can cope, who can play and do what they want, but nobody pushes for nursery schools for our children, and that makes me angry.

Parents often found the reactions of relatives more perplexing than those of friends and neighbours. Bell<sup>74</sup> has suggested that even when nuclear families live at distance from their relatives there is some degree of social help, and while recent research has revealed that the idea that in pre-industrial Britain strong supportive extended families were the norm may well be false, it could be expected that families would turn to the extended family for help and sympathy. The experiences of the families varied greatly. When Donald (family 5) was young his grandmother helped his mother to care for him, while both of Mary's (family 4) grandmothers had found it difficult to accept and understand her and had refused to help in caring for her. Diana's mother (family 2) had suggested that the reactions of relations were

... mostly sympathetic, but none of them really understood. I did once try to explain to my sister and sister-in-law, I only wanted someone to listen to me. Instead they turned round and said well why don't you send her away ... they couldn't bear to think of me in that situation so get rid of it.

Other parents had experienced very hostile reactions from relations (families 1, 3, 7 and 12) while Sandra's (family 8) mother suggested

Well, I have one cousin who won't come and visit us .. he feels guilty when he's got two normal children and I've not. I think you get this quite a lot

and furthermore

Relatives can't understand why you can't visit and it is very difficult to take a handicapped child into a home if you know that the person is very houseproud ... I have literally given up on some.

The help and assistance of professionals and their attitudes and behaviour were also perceived in different ways by different parents - although the general impression was that they were not especially helpful or knowledgeable about the problems faced by the families.

Diana's mother (family 2) was in general extremely grateful and appreciative of the help that she had received from health visitors and social workers. She felt that they had been very good to her, although the main help seemed to have been in giving sympathy and social support rather than in financial or practical help. But during conversation Diana's mother revealed that the social workers basically did not understand her needs and the problems she faced.

I had a social worker - very kind, came when he could ... I wanted her to go into the hostel - six weeks' summer holiday used to be murder for me. I asked if she could go into the hostel mid-week, my husband wasn't able to drive her there and I asked if he could find someone to take her there



and he said "just this once" and I never asked again. Just this once, he said as if I was asking for the moon. You know, so I never asked again ...

Mary's mother (family 4) was extremely critical of the professionals that she had come into contact with

- . I've shed more tears because of social workers and people who have come to the home than I have over lay people who don't know. I've found social workers don't really understand the situation.

She felt that social workers just do not understand the problems faced by a young mother trying to cope with a handicapped child and tied to the home. Her main criticism, however, was the tendency of professionals to

Put down all the difficulties of a mentally handicapped child to the fact that it is mentally handicapped

Sandra's mother (family 9) also found that

Social workers seem to know very little about the mentally handicapped.

and

I found doctors very ill-informed about mental handicap.

She also experienced a common reaction from professionals when Sandra was young. They refused to accept her statement that there was 'something wrong'.

Elizabeth's mother had come up against the assumption of the Social Services that the parents should provide a home. The question had arisen because the local authority was considering the possibility of providing a group home for the mentally handicapped, but was apparently having problems finding a sufficient number of handicapped people capable of managing in such an environment (Elizabeth is mildly subnormal and in her thirties).

They haven't got enough applicants that they consider capable of living in them. Well, I consider Elizabeth is quite capable of being in the group home and at a meeting this came up. Miss ----- said something about parents not putting in applications and I said I had put in an application a long time ago, but that I had never had an answer, and that I would like Elizabeth to be considered to live in a group home. But one of the members of the council said the group home is to provide homes for those who have no home of their own. It isn't to provide homes for those who are quite adequately taken care of at home.

She also felt that social workers failed to tell parents of their welfare rights, and that while they were someone to talk to, they could rarely provide the type of help that parents really needed. She quoted the case of one mother she knew of who had a doubly incontinent daughter and who had to do all her washing by hand. The 'real' need of this mother was for a washing machine or at the very least a spin drier, which the Social Services could not provide. She concluded

Well, when you think, the most valuable financial benefits that are available are from a charity, well that says it all doesn't it really. It is the Rowntree Trust which is the most valuable contributor and it is a charity, where they have all got to make an application and make a good case.

Perhaps the general feelings of all the parents with respect to the attitudes and behaviour of other people, and the general treatment they and the subnormal member of their family received, is best summed up by one mother who said

You get hardened to people's reactions.

#### 4.4 General Conclusions from the Empirical Research

The general picture that emerges is that most people have little or no knowledge of the mentally handicapped and what knowledge they do have is second-hand. People in general seem rather frightened of the mentally handicapped.

As one student said:

They look so strange, they are so different.

Furthermore, as Carver and Rodda have pointed out

... there are many commonly held, but not always openly expressed, attitudes towards disability. Not all prejudiced behaviour stems from consciously held hostility. Ignorance which leads to blind stigmatizing, fear and paternalistic benevolence - may all play some part in unfavourable attitude formation.<sup>76</sup>

What emerges strongly is that there is no one set of attitudes concerning or reaction to the mentally handicapped, and that there is a strong social ambivalence to the subnormal. Many people are concerned about and feel sorry for the mentally handicapped, but are often ignorant about subnormality and frightened by the appearance of the subnormal and their behaviour. Social stereotypes of mentally handicapped people are usually based on the more severely handicapped with their 'strange appearance' and 'unpleasant behaviour patterns'. Furthermore, while one subnormal person living with his or her own family may be tolerated or even accepted, many people react differently when a number are housed in a hostel or community home. This adverse reaction is often a result of the widespread belief that the mentally retarded are sexually frustrated and promiscuous and pose a 'threat' to women and children (a view developed and propagated by the 'eugenics' movement - see Chapter 5).

The experiences of the parents interviewed were apparently fairly mixed, some experiencing open hostility from all they met and others receiving considerable help and sympathy from friends, relatives, and professionals. However, I often felt that parents were reluctant to admit that they had had stigmatizing experiences. Many of the parents also appeared deliberately to structure their lives in order to avoid possible embarrassing or stigmatizing occasions. They restricted their social life, so that they only went to events, visited homes and other places

where they knew in advance that they would be welcome. Family 3, for example, did not do anything or go anywhere where the 'children' could not go with them and be accepted. Consequently, like most of the other families, their social life centred mainly on social and other activities arranged by the local branch of the Association.

All the parents felt that there was a lack of general concern in the community for the mentally handicapped and that this was reflected in the low level of services and facilities provided for them and their 'children'. As Bayley<sup>77</sup> has so adequately shown, parents care for their 'children' in the community, rather than the community providing care for the mentally handicapped. This is not so much because of hostility towards the mentally handicapped, as ambivalent attitudes, apathy, a lack of knowledge and a lack of concern. This is reflected in the low priority of mental handicap provisions in government spending (see Chapter 6).

## 5. Conclusion

In this chapter I have attempted to develop some understanding of the attitudes towards, reactions to and behaviour towards mentally handicapped people (children and adults) at the community and individual level. I argued that studies of attitudes were insufficient and discussed my research, which provided illustrative studies of the type which would enable us to develop a clearer knowledge of how people react and behaviour. It does not, however, tell us why they have these reactions, although I have suggested that this may be partly the result of a filtering process (the filtering down through the years of the arguments put forward by the supporters of eugenics at the turn of the century), lack of any real contact, lack of knowledge and a 'natural' response to 'deviant' appearance and behaviour. Indeed, as Shotter has pointed out, it is extremely difficult to understand why people act in the way they do, and to distinguish between intentions and causes.

In explaining our actions to others we have, ideally, to give our reasons, tell of our aims or intentions, say what we expect to result and why. In practice, however, our intentions are often as obscure to ourselves as to others ... Unlike actions, events just happen ... to explain them we must seek their causal principles ... So we must be clear when investigating ... phenomena whether it is reasons (or something having the logical structure of reason) or causal principles that we seek; the two belong ... to two distinct spheres of thought and investigation.<sup>78</sup>

My own research suggests that the mentally handicapped and their families are stigmatized and that at the individual and community level they tend to be outcast. Thus the lack of 'concern' for mentally handicapped people demonstrated by the inadequate level of facilities and services provided for them is compounded by people's negative reactions. As Hunt claims:

Community attitudes towards the mentally subnormal ... are easily observed. They too readily reveal themselves in the lack of facilities provided and in a widespread reluctance to deal with the severely subnormal in as considerate a way as with the physically handicapped ... Although even the latter can show just how little the general public understand and accept their disabilities.<sup>79</sup>

However, while some individuals and groups react in a hostile way to the mentally handicapped this cannot be generalized to all, although it is interesting to note how the women that I interviewed in the village shared many of the fears of those who had actively opposed the hostel. Also the differing experiences of the families suggest that not only are there many individuals who are sympathetic towards the mentally handicapped and prepared to accept them as members of the community, but the parents' own attitudes and reactions are an important factor - a background against which they interpret the way that people they come into contact with react and behave. It is also possible that one mentally handicapped person, living with and 'controlled' by his family is seen as less of a 'danger' and 'threat' than a hostel. One also wonders to what extent opposition to hostels is based on 'fears' of the

behaviour of the residents or financial considerations, such as the value of property in the area declining as it becomes a 'less desirable' area in which to live. (The village I studied was considered a 'desirable area' and property values were high compared with the surrounding areas).

Thus while it is possible to get some idea of attitudes, reactions and behaviour towards the mentally handicapped, it is more difficult to determine what underlies these attitudinal and behavioural patterns - how negative images of the mentally handicapped are built up and sustained. Although one suspects that, until their own lives are actually affected, most people just don't think about or concern themselves with the mentally handicapped. When they are forced to think about the 'problem' their reactions are negative and tend to reflect and reinforce the decisions made by central and local government on the low level of spending on services and facilities for the mentally handicapped. Apathy rather than hostility probably most accurately describes most people's attitudes and reactions towards the mentally handicapped, at least up to the point when their own lives are affected. These reactions being based on inaccurate suppositions about or lack of knowledge of the mentally handicapped.

The 'problem' posed by these reactions to those who want to 'normalize' the lives of the mentally handicapped are intractable. It is easy to say 'educate the public', 'change attitudes' so that people are prepared to have a hostel or group home next door, to accept them as equal citizens and to share facilities and services with them. However, while the existing literature concludes (a conclusion that my own research supports) quite clearly that the majority of citizens are not fully prepared to accept the mentally handicapped as integral members of the local community, there is no definite proof of how people's images of the mentally handicapped are built up, where their fears and prejudices come from. Individual and group

reaction to deviants and deviant behaviour are complex; only when we begin to look at them within the history and the social structure of the society within which they have developed and are sustained can we begin to gain an understanding. Attitudes, reactions and behaviour can be described at the micro-level but they can only be understood within a macro-sociological perspective - a perspective I intend to develop in the next chapter.

#### REFERENCE NOTES, CHAPTER SEVEN

- 1: Campaign for Mental Handicap, 1972a p1
- 2: Lippman, 1972
- 3: Mental Deficiency Act 1913
- 3a: In a television report on Nationwide, 21 December 1981, reviewing the International Year of the Disabled, it was stated that the mentally handicapped had benefitted least from the year. This suggests that mental handicap arouses less sympathy than other disabilities or handicaps - or at least is seen as somehow less deserving of charity or help.
- 4: Simon, 1972 p2011
- 5: Becker, 1966 p1
- 6: Ryan, 1976 p153
- 7: D'Alton, 1970 p38
- 8: Farber, 1968
- 9: Townsend, 1969 pxxi
- 10: Jones, 1975 p203,205
- 11: Jones, 1975
- 12: Bayley, 1973
- 13: Edgerton, 1967 p205
- 14: Campaign for Mental Handicap, 1973.<sup>p1</sup> See also Heshusius, 1981.
- 15: January, 1980
- 16: Jaehnig, 1974
- 17: Gunsburg, 1973
- 18: Goffman, 1968.
- 19: Birenbaum, 1970
- 20: R. Ballard in Community Care, Tuesday 23 February, 1977.
- 21: Quoted in a letter to Community Care, August 14, 1974.
- 22: Bayley, 1973
- 23: Bayley, 1973 p240
- 23a: Bayley, 1973 p262
- 24: Bayley, 1973. p240
- 25: Reported in Community Care, 26 February, 1975.
- 26: The London conference of the National Society for Mentally Handicapped Children, March 1975.

- 27: Söder, 1972
- 28: Söder, 1972 P250
- 28a: Referred to in Foucault, 1971
- 29: Farber, 1964
- 30: Taylor, 1975 P101
- 31: Gottlieb and Sipperstein, 1976
- 32: Hollinger and Jones, 1970
- 33: Puccetti, 1968
- 34: Richardson et al., 1961
- 35: Vasey, 1975 P32
- 36: Kershaw, 1973 P16
- 37: MacAndrew and Edgerton, 1966
- 38: Davis and Strong, 1976
- 39: Gottlieb and Carmen, 1975
- 40: Fishbein, 1967
- 41: Abelson, 1972
- 42: Abelson, 1972 P25
- 43: Mittler, 1970 P3
- 44: Lippman, 1972
- 45: Lippman, 1972. Ps 62 and 67
- 46: Norris, 1978
- 47: New Society, 1 January, 1981
- 48: Shearer, 1972 P3
- 49: Greengrass, 1976 P14
- 50: Barr, 1903
- 51: Tredgold and Soddy, 1970 P40
- 52: Tredgold and Soddy, 1970 P41
- 53: Walker and McCabe, 1973
- 54: Referred to in Townsend, 1969
- 54a: Campaign for Mental Handicap, 1973. See also Heshusius, 1981.
- 55: Edgerton, 1967
- 56: MacCormack, 1978
- 57: Rees, 1978 P41
- 58: Jaehnig, 1974
- 59: Mack, in New Society, 15 July 1976
- 59a: Ballard, 1977 (See Note 20)
- 60: MacCormack, 1978 P144
- 61: National Society for Mentally Handicapped Children, 1974. P61
- 62: Jaehnig, 1974
- 63: See Bayley, 1973.
- 64: Carver and Rodda, 1978 P33
- 65: Community Care, 26 June 1974
- 66: David, 1975
- 67: E.G. Tizard and Grad, 1961; Bayley, 1973; Jaehnig, 1974.
- 68: E.G. Birenbaum, 1970
- 69: Bayley, 1973
- 70: Shanks, 1976
- 71: Birenbaum, 1970
- 72: Mercer, 1973
- 73: Jaehnig, 1974
- 74: Bell, 1968
- 75: Laslett, 1972
- 76: Carver and Rodda, 1978 P103
- 77: Bayley, 1973
- 78: Hunt, 1961
- 78: Shotter, 1974 P58



## CHAPTER 8

### CONCLUSION: TOWARDS A SOCIAL THEORY OF MENTAL HANDICAP

#### 1. Introduction: Psychology, sociology and social theory

In this chapter I intend to suggest what a sociological perspective on mental handicap can contribute to our understanding of the phenomenon and how it relates to the existing medical and psychological models. In doing this I will highlight the inadequacies of the existing medical, psychological and sociological perspectives, and argue that it is necessary to develop a historically informed comparative macro-sociological account. Such an account would enable not only an understanding of the role and status of mentally handicapped people and of why they are a stigmatized group, but also why the medical and psychological models, inadequate as they are, have dominated the field and so profoundly influenced official, professional, community and individual attitudes, reactions and behaviour towards mentally handicapped people. However, I also intend to argue that a macro-sociological account is by itself inadequate and that in order to develop a social theory of mental handicap we require not only a micro-sociological input, but also insights from the other social science disciplines including psychology.

In this chapter, then, I intend to integrate the earlier chapters and to develop a theoretical perspective which overcomes the weaknesses of the existing one. In chapter 2 I critically discussed the existing sociological contribution, pointing out both its strengths and its inadequacies, while in chapter 3 I examined the dominant psychological and biological/medical models and their inadequacies. Chapters 4, 5 and 6 demonstrated the contribution which history can add to an understanding of how current institutions came about. In this chapter I want to talk about what is required of a sociology and social theory of mental handicap - indeed for social policy

issues as a whole. I will also point to the importance of micro-sociological perspectives as one side of a social theory - which, however, need to be grounded in a historical and macro-sociological account.

The chapter deals with the inadequacies of individualistic explanations in general and the dominant psychological/biological/medical models in particular. This will be followed by an examination of the contrasting perspectives in existing sociology and the directions in which sociological perspectives may be developed further. Finally I will discuss the requirements of a social theory. In the process the discussion extends beyond the confines of mental handicap into what is required of a social explanation and into the sociology of knowledge - that is, the interaction of economics, societal institutions, social policy and 'science' - of which mental handicap is just a case-study.

## 2. Medical and Psychological Perspectives on Mental Handicap

Medical and psychological involvement in mental handicap exists at two inter-related levels - the aetiology of the condition and the diagnosis of the condition. Mental handicap is seen as due to biological/genetic/environmental factors, and it is argued that some cases <sup>it</sup> can be diagnosed by clinical methods, at or soon after birth (for example <sup>by</sup> blood tests in the case of phenylketonuria), in early childhood (for example <sup>by</sup> medical examination in the case of brain damage), or during schooling by psychometric tests (usually in cases of mild retardation where there is no apparent underlying biological condition).

In this section I intend to discuss both levels and suggest why, as they stand, they provide an inadequate foundation for a fully social theory of mental handicap, in that they concentrate on the individual and his 'condition' and tend to ignore the social aspects, including the vital factor that diagnosis and labelling are themselves social processes.

## 2.1 The Inadequacies of Individualistic Explanations.

The major assumption underlying both the medical and the psychological model is that the 'cause' of mental handicap is inherent in the individual - that it is an attribute of the individual and exists whether or not it has been diagnosed and the individual labelled. Consequently mental handicap is seen as a result of biological/genetic factors inherent in the individual or as a result of early environmental deprivation. (Most specialists in the field now agree that a theory of multiple genetic causation cannot explain all I.Q. differences between individuals). The individual is viewed as a machine determined either by biology/genetics (programmed hardware) or early environment (programmed software) or both. In this model little weight is given to immediate environment (input) and none at all to any notion of the individual interacting consciously with his environment. (Even those psychologists who have been critical of the dominant medical and psychological models have in the main only argued for more emphasis on 'input'; this tends to upgrade mentally handicapped people from machines (incapable of experiencing suffering) to animals (capable of experiencing suffering), but it does not raise them to the status of human beings capable of acting on and reacting to their social and physical world).

Individualistic explanations focus on the individual and ignore the wider social context; they do not ask how, why and by whom individuals are selected out and labelled as intellectually (and by implication socially) incompetent. Nor do they ask what mental handicap means to those involved in the diagnostic and labelling process, including the individual himself, his family, his neighbours, the members of the community in which he lives and the professionals who diagnose his condition and decide on how he shall subsequently be handled. Individuals are labelled in a social system and this factor must be recognised; accounts of mental handicap that ignore the

social, political, economic and historical context are inadequate as they stand (as indeed are those that simply blame labelling agencies - biological and sociological reductionism are both inadequate).

We must accept that mental handicap does exist, if by this we mean a condition which leads individuals to have difficulties in coping with day-to-day living in a given society because of limited intellectual functioning. (We may question, however, what 'cut-off' points are critical and to what extent society 'creates' many of the problems encountered by those with limited intellectual abilities). However, seeking possible 'causes' and predicting the consequences of this limited ability is more complex than the existing individualistic emphasis suggests. Many people in the 'normal' population have a biological/genetic abnormality which would be 'blamed' as the cause if they were to be diagnosed as intellectually incompetent. (The fact that they have not been so diagnosed suggests that they are competent to stay out of the hands of the diagnosticians). Conversely, assumptions are made that individuals are mentally subnormal because there are obvious signs of C.N.S. damage. This can result in individuals being classified and handled as if they were mentally handicapped, when in terms of potential intellectual functioning they fall within the normal range. Furthermore, when individuals have the same biological/genetic condition which invariably 'causes' mental subnormality (for example Downs' Syndrome) they can vary widely in potential for intellectual and social development - a fact that is often totally ignored within the individualistic framework.

The continued search for causes, even when these are seen as outside the individual in origin, still focuses attention on the individual. It is now argued by some workers in the field that the notion that mild subnormality is 'caused' by a combination of the inheritance of 'poor' genes and an inadequate environment (however that might be measured) is a mistaken one. Ryan<sup>2</sup> has maintained that

C.N.S. damage is likely to be the 'cause' of most cases of mild mental subnormality. (Indeed, in the U.S.S.R. for an individual to be classified as mentally subnormal C.N.S. damage must be diagnosed - although it is difficult to establish this conclusively). In support of this view research has indicated that mothers of mildly subnormal children (almost entirely working class) have a significantly higher level of obstetric complications than would be expected by chance. These children also have low birth-weights (an indication of a poor environment during gestation).<sup>3</sup> These two factors indicate that the 'cause' of the subnormality is probably minimal C.N.S. damage rather than a 'poor' environment and inadequate early socialization in infancy and childhood. It has also been pointed out that environmental factors such as inadequate diet in infancy, poor standard of child-care and lead pollution can cause minimal brain damage.<sup>4</sup> It is then argued that mild subnormality in many cases, if not the vast majority, is due to minimal brain damage, and that this explanation accounts, as well as do the eugenicist or environmentalist ones, for the observed class distribution of handicap. Furthermore, the 'blame' is no longer put on the parents but on medical/environmental causes which could have been avoided by society.

To the extent then that discovering the 'causes' of subnormality can help to solve the problem, if it is the case that mild subnormality is the result of minimal brain damage, a step forward has been made. It is possible to prevent, to a large extent, birth injuries, to ensure that expectant mothers and babies are adequately nourished and that lead is taken out of petrol; the extent to which this happens does depend, nevertheless, on economic, social and political factors. (However, we still need to note that the distinction between what is and what is not subnormal functioning is arbitrarily and socially constructed and that if there is a functional need for an under-class or surplus population then the arbitrary cut-off point can always be raised. As Haldane suggested

as long ago as 1938, any increase in the numbers of people being classified as mentally handicapped is more likely to result from greater difficulties in finding appropriate employment for all those seeking it than from a decline in general intelligence; to this extent mental handicap is more of a social than a biological problem).<sup>5</sup>

Our attention has therefore been directed not only to possible environmental causes, but also to the fact that social, political and economic factors may be important. The evidence from epidemiological studies demonstrates that it is extremely rarely that a child from a higher social class has an I.Q. below 80 unless he has one of the recognised pathological syndromes. Consequently almost all mildly subnormal children come from the sector of the population who tend, for whatever reasons, to receive inadequate medical care and to live in poor inner-city areas with their lack of open spaces, inadequate housing and generally inadequate facilities. Ill-health, including mild subnormality, at least in capitalist societies, broadly follows the distribution of income, and income is the major determinant of the distribution of housing and medical care facilities. Furthermore, an individual's quality of life is profoundly influenced by access to goods and services, both publicly and privately provided.<sup>6</sup> To the extent that mild subnormality is due to societally created inequalities and inequalities of access to financial rewards and publicly provided goods and services, then action can be taken to reduce the numbers of mildly subnormal people.

However, while our attention has been directed to socially created inequalities and the need to examine social, political and economic factors, the focus of attention is still on the individual and the 'causes' of his statistical abnormalities. The focus is still on the causes of low intelligence rather than directing attention to the genesis, structuring and functions of the mental

handicap role. It leaves open the possibility that if low intelligence could be prevented then other people would have to fill the role and occupy the status currently occupied by mentally handicapped people.

## 2.2 The Social Functions of Medical and Psychometric models

The two models of mental handicap, with their individualistic assumptions, are not just theoretical; they were developed for and continue to be used for a social purpose - to diagnose individuals who are mentally handicapped. Indeed, educational psychologists spend most of their time (and are under pressure from employers to spend even more time) on assessment and related administrative work,<sup>7</sup> and clinical psychologists in subnormality hospitals spend a considerable part of their time assessing patients.

As I argued in chapter 3 these two models - the medical model defining disease in terms of biological symptoms and the psychometric defining abnormality in terms of statistical variations - claim to be impartial arbiters of what is and what is not 'abnormal'. The claim is that diagnosis is based on scientific measurement - clinical diagnosis and psychometric, especially intelligence, tests. These two models have traditionally been used to diagnose mental subnormality, the medical model in cases of severe subnormality and the psychometric in cases of mild subnormality (although as I have previously indicated, the latter model is frequently used to confirm clinical diagnosis and to assist in the process of determining methods of handling).

However, diagnosis is a first step. Once an individual is ascertained as mentally handicapped then decisions have to be made about future career - both in terms of future placement, others' perceptions of him and indeed his own perception of self. Thus diagnostic decisions made by doctors and psychologists have a considerable influence on the individual's future, because he is assigned to a category and has conferred upon him a role

which in our society carries with it a stigma and a diminished status. (Indeed, as I have pointed out in chapter 7, it is not only the individual but his family as well that becomes stigmatized). Doctors and psychometricians, as scientists, are absolved from responsibility for the consequences that follow on diagnosis, because of the claim that the tools used in the process are scientific and that they are objective arbiters of what is 'normal' and 'subnormal'. Apart from the fact that research has demonstrated that the diagnostic tools (especially intelligence tests) frequently employed are culturally and class biased, resulting in the mislabelling of individuals, it is one role of the sociologist to point out the social and moral consequences of labelling of individuals.

Firstly, it is important to remember that people do not belong to a category until they are placed in one, and that the diagnostician determines his own definitions and sets his own limits for his categories. The model is constructed by the definer, and this model determines not only what he perceives but also the types of questions he will ask of the empirical world. The scientist does not produce a model independently of the purpose for which it is to be used, and he constructs it within a constraining set of circumstances, including social, political and moral ones.

Secondly, by focussing attention on the individual and his assumed pathology there is a strong tendency for the fact that mental handicap is in an important sense socially created to become obscured. We tend to forget that our adjectives come from comparisons - that is they express relative not absolute states - and therefore that 'abnormality' includes many elements of social judgement. This is especially important when the diagnosis and classification is based primarily or exclusively on the results of intelligence tests, where arbitrary cut-off points are used to determine if an individual is or is not



mentally subnormal. However, it also applies when other factors are considered. Children are frequently referred to psychologists for assessment because they are 'not up to standard for their age', because they are misbehaving in school or because they are seen as abnormal in other ways. (Coard has described how West Indian children are mislabelled in the English education system as E.S.N.)<sup>8</sup>. Even in the case of biological abnormality, social judgement plays a part in classification. Down's Syndrome children are almost invariably classified as ineducable and committed to E.S.N.(S) schools despite the available evidence pointing to the fact that some could benefit from being educated in an E.S.N.(M) school.

Thirdly, psychologists and doctors tend to ignore their role in the process. While they think of themselves as professionals, as neutral arbiters of the facts, they are employed and paid for a purpose - to screen out the mentally retarded - although it could be argued that Educational Psychologists should act, as Binet originally intended intelligence tests to be used, so as to prevent children who do not have a low I.Q. being labelled as subnormal and sent to special schools. (We do in fact know that this is not the case and that children do get sent to these schools with I.Qs above 70, although 70 is the generally accepted cut-off point in theory).

Finally the sociologist, by emancipating himself from a medical model of biological events and a psychometric model of statistical distribution, can evaluate these models as just two among a number of ways of describing mental handicap, in the light of the social ideologies underlying them. By adopting this stance it is possible to secure the ground on which to assess the social implications of mental handicap diagnostic processes - and indeed practices and services. I pointed out in chapter 3, however, that psychologists are also not totally unaware of the criticisms I have made of the medical and psychometric models - especially the criticisms

of the racial and cultural biases of intelligence tests and the apparent inability of professionals working in the field to develop programmes of remedial help. Nonetheless, psychologists still retain an individualistic stance even when they place more emphasis on the immediate environment and developing potential. The interesting question for the sociologist is why the available alternative approaches have not been taken up and used more widely when it has been demonstrated that they enable the mentally handicapped to develop to levels beyond what was previously thought possible (although it is correct to say that Piaget's work has influenced educational practice, and behaviour modification has become more widely used in training/teaching the mentally handicapped and in the training of nursing staff, teachers and parents in the use of the advocated techniques). As I have also argued (see below), the approach to the mentally handicapped used in the U.S.S.R. and based on the work of Russian psychologists such as Luria and Vygotsky has resulted in radically different methods (in theory at least) of assessing and handling mildly subnormal children. I would suggest that the major reason is that the medical and psychometric models as they are currently used serve a particular purpose - they screen out a population who are seen as of little value in our society - and as I have argued in chapter 6, any changes that would involve additional expenditure are unlikely to find favour with decision-makers.

### 2.3 The Need for Sociology

I have already indicated that my criticisms of the current psychological perspectives on mental handicap are that they are inadequate as they stand. The dominant psychometric model has been severely criticised from within the ranks of psychologists as well as from outside. I am not suggesting that psychology cannot contribute to an understanding of mental handicap as a social phenomenon and consequently to a social theory. Indeed, I would argue that psychologists have already made valuable contributions - they have demonstrated that social perspectives of the mentally handicapped and the way that they are handled profoundly influence cognitive, linguistic and social development as well as self-image and individual

understandings of the world in which they live.<sup>9</sup>  
My contention is that in order to develop a social theory of mental handicap it is also necessary to develop a sociological perspective, and furthermore to incorporate insights from other social science disciplines.

This raises the issue of the relationship between psychology and sociology, because I am not suggesting that sociology can provide an adequate explanation when psychology cannot. Indeed, if I were to do so I would fall into the trap of arguing for sociological reductionism. But if psychology and sociology are not necessarily antagonistic, are they necessarily complementary? Do they examine and explain at different levels of social reality - the individual and the social? Traditionally psychology has tended not to take account of the realities of the social situation (although humanistic psychology has begun to stress the need to take into account the way that individuals understand their social situation and in terms of methodology (ethnographic) and focus of intent it is coming very close to micro-sociology). Thus one of the common responses to this question is to suggest a division of labour between the two disciplines, each concentrating on different aspects of the problem. Clarke and Clarke<sup>10</sup> have suggested, specifically with reference to the field of mental handicap, that psychology should be concerned with normative questions (diagnosis, classification and treatment) while sociology should examine technical questions (research into alternative forms of care). Even if we accept this as a viable proposal it raises a number of problems because psychologists would be working within the assumed consensus that sociologists were in the process of questioning and this is likely to create conflict because the sociological research is likely to uncover and challenge the popular assumptions and hidden arguments upon which current psychological practices are based. Furthermore, while the majority of psychologists continue to argue for a positivistic methodology and the importance of controlled experimentation, they are likely

to question the status of sociological research findings which are not based on such methodological assumptions.

The opposite view is that the differences between psychology and sociology are not merely ones of level of analysis and methodology, but that the division reflects the dominant values of society - it is an ideological division. The opposition between psychology and sociology is seen as the result of a society that stresses individualism and perpetuates the divergence between the individual and society. This divergence represents the social reality of our society and it also results in the social sciences fragmenting into specialist areas within which any attempt to understand and know the totality is abandoned. This has led some Marxist critics<sup>11</sup> of the social sciences to argue that they are part of bourgeois ideology, a form of mystification that helps to obscure rather than understand or explain social reality, because they cannot, as separate disciplines, grasp the totality, but merely reflect bourgeois categories of knowledge.

This criticism has some validity because it is aimed at the attempts of academics to maintain disciplinary boundaries intact in an effort to protect the purity of their disciplines. Nevertheless, different disciplines do ask different questions, the answers to which can all contribute to the understanding of social phenomena and the development of social theory. However, as I have already indicated, I do not propose to approach the ambitious path of developing a total explanation of mental handicap, but merely to demonstrate the contribution that sociology can make to our understanding of mental handicap as a social phenomenon, without committing the falacy of sociological reductionism - for we, as C.W. Mills<sup>12</sup> has stressed

Do know that many personal troubles cannot be solved merely as troubles but must be understood in terms of public issues - and in terms of the problem of history making. Know that the human meaning of public issues must be revealed by relating them to

personal troubles and to the problems of the individual life. Know that the problems of social science, when adequately formulated, must include both troubles and issues, both biography and history, and the range of their intricate relations.

### 3. The Development of a Sociological Perspective

In this section and the next one I intend firstly to review the existing contribution made by sociology to our understanding of mental handicap, then to suggest what is required in a sociology of mental handicap, and then to integrate the historical analysis developed in Chapters 4, 5 and 6 into a more general sociological account of mental handicap. In Chapter 2 I reviewed the existing sociological literature on mental handicap and suggested why it was inadequate, arguing that it is necessary to develop a historically informed macro-sociological account within which micro-sociological analysis has an important role to play.

#### 3.1 The labelling and surplus population approaches

As I indicated in Chapter 2, sociologists have developed two approaches to mental handicap outside of the clinical framework. They have tended, however, to take over and use uncritically the categorisations of mentally handicapped people developed by clinicians and used for administrative purposes - particularly the 'belief' that the mentally handicapped can usefully be divided into two or three relatively homogeneous and independent categories defined by intelligence/social functioning (although even here they may question the 'cause' of the 'low intelligence' implied in the clinical/psychometric approaches). At the micro-level, sociologists have begun to develop a labelling perspective on mental handicap<sup>13</sup>, although much of this research has focused on the mildly handicapped. At the macro-level, Farber<sup>14</sup> has developed a functionalist perspective that locates the mentally handicapped as part of the 'surplus' or 'marginal' population in advanced industrial societies.

The micro-sociological work has tended to concentrate on the role of the school as a screening and labelling agency,<sup>15</sup> and the role of stigma in the lives of mentally handicapped people,<sup>16</sup> although Booth<sup>17</sup> has examined the ways

in which parents, through interacting with their child, build up an understanding of what mental handicap means. This research, heavily influenced by symbolic interactionism, has directed attention to the process of labelling individuals as incompetent and given insight into what it means for the individual (and indeed for his family) when he is labelled as different - as incompetent. It has also stressed the relative nature of what is seen as mental handicap (incompetence) both historically and culturally. In particular Mercer<sup>18</sup> has highlighted the problem of mislabelling - children being categorised as retarded because they do not conform to the culturally normative expectations of the school system.

The inadequacies of this perspective were also discussed, and the ahistorical approach with its lack of attention to power and social structure was seen as inadequate to form the basis for a sociological perspective on mental subnormality. Thus the approach directed our attention away from an endless search for the 'causes' of mental handicap (physiological, biological, genetic or environmental) and stressed the importance of understanding the process by which individuals became labelled as retarded and handled as outsiders (deviants). However, in this perspective the mentally handicapped (or at least the mildly handicapped) are regarded as part of the 'underdog' population - a group who are created by society - so we "get the impression that people go about minding their own business and then bad society comes along and slaps them with a stigmatizing label."<sup>19</sup> This position, then, commits the fallacy of sociological reductionism - mild subnormality is thought to be adequately explained sociologically. In rejecting the psychological model it switches the 'blame' from genetic/biological/environmental causes to the social labellers (teachers, psychologists, doctors) and the normative expectations of the school. Finally it does not adequately explore the historical and cultural context within which the action takes place, nor the official position of the labellers, including their role and status and the origin of their power.

An alternative sociological approach to the labelling perspective is to see the mentally handicapped as part of the 'surplus' population - a group marginal to the

production needs of industrial societies. Farber<sup>20</sup> suggests that such an approach overcomes the normative and evaluative implications of regarding retarded people as deviants and enables an understanding of the role and status of mentally handicapped people in such societies. He argues that the 'surplus' population (which comprises the old, the sick and the poor as well as the mentally handicapped) is functional to the maintenance of industrial societies, and is self-perpetuating - forming a culture of poverty passed on from one generation to the next. (There is some confusion as to the status of the biological/genetic mentally handicapped who may well be part of a surplus population but who are not integral members of a 'culture of poverty').

Farber's approach is in some ways similar to the view dominant in the early twentieth century, that the mildly mentally handicapped were social degenerates - part of a group who lived at the margins of society, were parasitic on it and were seen as posing a 'threat' to its stability. (This resulted in the advocacy of Eugenic solutions and life-long segregation - ideas that are by no means dead<sup>1</sup> - see Chapter 5). What differentiates Farber's approach from this one is not his description of the marginal population but his argument that it is an inevitable and functional feature of industrial society - functional because a surplus labour force encourages competition and rational efficiency, and the care of marginal groups provides occupational roles. This approach attempts to locate and explain the role and status of mentally handicapped people. Their marginal status and peripheral role account for why they are stigmatized and tend to come low on any priority list for public spending. Farber's analysis parallels the Marxist argument that capitalist societies need an underclass or reserve labour force who are 'prepared' to take on the dirty unpleasant jobs that nobody else wants and can easily be made 'redundant' when their labour is not required. However, his analysis is different in that he 'blames' the perpetuation of this

stratum on the 'culture of poverty' (socialization) whereas Marxists argue that it is perpetuated by the power of the ruling class and the dominant ideology in capitalist societies.

The two theoretical positions outlined above have not stimulated sociological research in the field of mental handicap. This is despite the fact that the symbolic interactionist approach has resulted in the growth of sociological interest in other marginal/deviant groups where previously a medical/psychological model dominated (for example, alcoholism, mental illness and sexual deviations). It is difficult to determine why this is the case - although it is true that the mentally handicapped provide research subjects that are difficult to work with, although not necessarily more so than the mentally ill. It could be that sociologists are influenced by the dominant image of the retarded as a 'lost cause' or because they cannot be glorified like the mentally ill, reformed like the alcoholic, or 'cured' like the sick; neither can they be easily seen as unfortunate victims like some other groups of disabled people. Furthermore, mental handicap appears not to be a central concern in the lives of most people (see Chapter 7) and they are not usually thought of now as a moral, economic or physical threat to themselves or society.

### 3.2 The deviancy approach and mental handicap

The dominance of a medical model of mental handicap would tend to suggest that medical sociology (or the sociology of health and illness, as it has more recently become known, as sociologists in the area have attempted to move outside of a clinical framework) should be able to contribute to a sociology of mental handicap. Yet, as I have indicated above and in Chapter 2, the main contribution to date has been made by sociologists working within a deviancy perspective. Interestingly, recent trends in the sociology of health and illness have been heavily



influenced by labelling theory developed in the sociology of deviancy, and at the same time as sociologists have attempted to demedicalise conceptions of deviancy there has been a tendency to conceptualise the sick and disabled as deviants.<sup>22</sup>

However, while sociologists working within a deviancy perspective researching in the area of mental handicap have concentrated on the school and psychologists as labelling agents, sociologists of health and illness have concerned themselves with medical personnel, especially doctors. The important factor that has been highlighted is the power of the doctor in diagnosing, making prognosis, and controlling treatment, especially in the case of severely and moderately handicapped people. The power and prestige of medical men is clearly demonstrated, as is their dominance over other health and welfare workers in a field where the scope for medical intervention is very limited.<sup>23</sup>

In the field of mental handicap sociological (and other) research has frequently taken for granted the power position of the doctor (and other professionals), his dominant role in the labelling process, and that his definition of the 'patient's' condition and prognosis shapes that of the parents.<sup>24</sup> Booth<sup>25</sup> has questioned this view and argues that the parents develop their own understanding of what mental handicap means in the process of interacting with their child. However, he does not develop this and suggest what implications it might have for the development of conflict between doctor and parents, although other sociologists have argued that the professional ideology of doctors together with their claim to be the sole arbiters of illness (mental handicap) can result in conflict.<sup>26</sup> Studies have suggested that in the case of the severely mentally handicapped, conflict between doctors and parents can arise as a result of faulty communication concerning the child's condition, development and prognosis. This conflict is unrelieved by the way in which parents are excluded from case conferences and discussions concerning their child (with whom they have closest contact and of

whom they take day-to-day care) because they are seen as not having the 'appropriate expertise'.<sup>27</sup> At the micro-level this research has pointed to the power of medical men in defining and controlling the situation. (At the macro-social level sociologists have demonstrated how doctors obtained this dominant position during the nineteenth century; see Chapter 3 and section 4 below).<sup>28</sup> Much of the research carried out from within a deviancy perspective parallels this research, in that it is informed by an interactionist theoretical framework and examines the labelling processes, but in this case the role and power of teachers and psychologists, as representatives of the school system, in labelling the mildly handicapped.

This deviancy perspective has probably, to date, contributed most to the understanding of subnormality as a social (and not just medical/biological) phenomenon, ~~but~~ the notion that retarded people can or should be regarded as deviants by sociologists has not gone unchallenged. Edgerton, for example, has specifically rejected this notion and argued that mildly retarded people are not deviants because they do not consciously reject the normative values of society and indeed they strive to achieve normality - to be accepted by 'normals' as normal. In fact "their behaviour ... presents the very antithesis of social deviance".<sup>29</sup> The controversy, then, centres around two factors: the extent to which calling a group deviants implies that we accept a negative image of them and whether or not behaviour has to be motivated to be regarded as deviant. Sociologists who have examined the role and status of the mentally handicapped from a deviancy perspective argue that while individual motivation may be a relevant factor, so is how behaviour is perceived and interpreted by the audience - mental handicap can then be seen (or at least the observable behaviour of mentally handicapped people) as a form of deviancy in the same way as mental illness, alcoholism and disability are - unmotivated deviancy. (Although we might ask to what

extent at least some mentally handicapped people are able consciously to act in certain deviant ways in order to obtain help and support from others - Edgerton's<sup>30</sup> own research material suggests that this is a possibility). Like other forms of behaviour that are seen as deviant, mentally handicapped people's behaviour often violates normative expectations and is often thought to require the attention of agents of social control (official or unofficial). Labelled individuals have a diminished, stigmatizing, status and sociologists (and others) cannot ignore the fact that mental handicap constitutes one of the most extreme possible forms of deviation from standards of behaviour acceptable to the community (see Chapter 7).

As I have indicated above, interactionist sociologists have made a major contribution to the small literature on the sociology of mental handicap. This perspective like the other 'New Deviancy Perspective' recognises that deviancy does not arise unannounced, but has to be identified, interpreted and subsequently fashioned, and that reactions to deviant behaviour depend on the tolerance level of the audience and the nature of beliefs about deviancy in a community. It raises the questions of 'deviant to whom' and 'deviant from what' and when something is said to present a social problem 'problematic to whom'. When behaviour is said to be embarrassing, threatening or dangerous it asks 'says who?' and 'why?'. The emphasis is shifted from the individual and his assumed pathology, and directed towards the society in which he lives and especially the agents of social control. Interactionists see the social order as a negotiated, emergent, interpretative process in which individuals constantly confront each other and construct their own worlds. Three exhortations arise from this: to look at the processes involved in daily life; to look at the meanings and symbols that evolve in any situation; and always to view individuals as being in interaction with others who play an important part in

shaping any encounter. As utilized in studying deviant behaviour it suggests: looking at deviancy as a category which is relative to individual interpretations and inquiring into the manner in which deviants and agents of social control actually perceive themselves and the world around them; moving away from the picture of the deviant as possessing a static 'condition' and focussing instead on the process of becoming deviant in terms of labelling; studying the day-to-day existence of deviants; and studying the role of reaction in shaping deviancy, both informal and formal, public and private. It is not the individual characteristics of deviants which are seen as crucial, but the ways in which individuals/groups come to be labelled as outsiders and handled as deviants. The value of this approach in studying mental handicap is that attention is not focussed on causes of behaviour and individual pathology, but on the ways in which individuals are selected, labelled and subsequently handled, and the ways in which this shapes an individual's self-perception and his future career. In the field of mental handicap the main empirical study is Mercer's<sup>31</sup> (see above and Chapter 2) analysis of the labelling of children in the American school system as mildly retarded. However, while she examines in detail the process by which children are selected and labelled, and indicates the institutional consequences of this process, she assumes rather than demonstrates that being labelled retarded influences a child's perception of self and results in a negative self image. (Dexter<sup>32</sup> does the same - but there is research which does demonstrate that being labelled and handled as subnormal creates a negative self image<sup>33</sup>)

This perspective provided an important departure in deviancy theory, but it has been widely criticised. In its defence, it has been pointed out that labelling can only be understood when it is placed in a theoretical framework which gives insights into the social processes involved - that is, when it is placed within the larger context of social organization and social control.

Lemert's distinction between primary and secondary deviation suggests that individuals can avoid being labelled, reject the label (Edgerton)<sup>35</sup> or be labelled for only part of the day (Mercer)<sup>36</sup>. Factors such as social class, ethnic group, family organization and behaviour can influence whether or not someone is labelled (Stein and Susser,<sup>37</sup> Mercer<sup>38</sup>), and different social agencies are concerned with labelling different groups of subnormals (Mercer)<sup>38</sup>. Finally, labels are only a first stage; understanding what the label means is an emergent process that develops in the process of social interaction (Booth). The fruitfulness of this perspective is then that it is dynamic; it examines the process of labelling and the labellers as well as the labelled.

There are, however, a number of inadequacies and weaknesses in the approach, despite its obvious advantages over previous approaches. It has been criticised for not being able to deal with the 'causes' of deviance, although Plummer<sup>39</sup> has argued that this is criticising a theory for what it never intended to do. However, some labelling theorists imply that society is the 'cause' of the deviant condition/behaviour. Mercer and Dexter, for example, appear to be saying that the school 'causes' mild mental handicap. While it does direct attention away from the determining constraints of biological, psychological and social forces, this suggestion introduces the new determinant of social reaction. Mild mental handicap is said to exist only in the dialogue of forms; it does not enjoy an absolute or autonomous existence. It is important to realise that social expectations do to some extent determine what is or is not an adequate level of functioning, but it is equally vital to be alert to the possibility that this level of functioning may be 'caused' by factors other than the symbolic internalization of others' evaluations and social labelling (see section 2 above). Furthermore, by accepting the clinical/psychological system of classification into mildly and severely handicapped these theorists tend to reinforce the belief that scientific theories and systems of fact can account for and explain distinctions between people. Also, by conducting research and formulating theory on the notions of the differences between preconceived categories and by trying to explain these differences

rather than pointing to the range within populations and overlapping categories they have done much to reify the categories. (This is equally true of most other sociological research in the field of mental handicap.)

Furthermore, the labelling approach remains subjective and voluntaristic. It lacks an awareness of history, and ultimately it lacks a critical position towards society, despite its apparent radicalism, because it

fails to see that men - superiors as well as subordinates - may be powerfully constrained by institutions, by history, and indeed by biology.<sup>40</sup>

Interactionists emphasise the deviant and the 'problem' he presents to himself and others, but not the society within which he emerges and operates. Furthermore, there is no consideration of why the label is stigmatizing, how stigmatizing labels developed historically, or their role in social control and their relationship to the distribution of power within a society. One of the interactionists' most valuable contributions is that they direct attention towards agents of social control and to the process of deviancy amplification, but labelling theory and deviancy amplification are not synonymous.<sup>41</sup> Labelling is tied to symbolic interactionism with its insistence on the symbolic component and the ways in which societal reactions result in an increase in deviance, and to a symbolic re-ordering of self and the world. By not questioning the historical development of societal conceptions of mental handicap, or the values inherent in categorizing people as mentally handicapped, the interactionists have merely criticised school officials, doctors and other professional labellers. Thus they criticise the middle level of power without questioning societal values. Consequently they do not question why individuals are labelled as mentally handicapped, the functions of labelling some children as 'school failures' and the reasons for labelling some individuals as 'outsiders' or 'misfits'. In order to do this it is necessary to examine the ways in which deviant values are inextricably linked with social structure - that is, it is necessary to develop

a two-fold understanding of the social system to encompass both the way it officially comprehends itself, and its nature as it objectively exists. Questions need to be asked about how and why we see the world in a particular way and what shapes our view of reality in a class society, with its unequal distribution of resources and power. Interactionists share with other deviancy theorists

... a common flaw - they attempt to understand deviance apart from historically specific forms of political and economic organization.<sup>42</sup>

A more fruitful approach may be that developed by structural Marxists as an attempt to overcome the deficiencies (outlined above) in the interactionist approach. This approach stresses the need to understand deviance production as a process which involves the development of and changes in deviant categories and images, and to examine where these images and categories came from, and what they reflect about the structure of priorities in given societies. In terms of understanding how mental handicap became deviance, and the mildly subnormal deviant it is necessary to examine the structural, economic and political dimensions of the society in which these definitions and images emerged and developed, to understand how certain correlates of industrial/capitalist development weakened traditional methods of coping with the mentally handicapped and how the emergence of scientific and meritocratic ideologies sanctioned intellectual stratification and differential handling, and how the contraction of unskilled jobs increased concern over the danger that the feeble-minded were assumed to represent. (See Chapters 4 and 5, and section 4 below)<sup>42a</sup>

One structuralist approach that has been developed explicitly to understand the role and status of the mentally handicapped in industrial society is the functionalist one (see Chapter 2 and above). Farber<sup>43</sup> explicitly rejects the view that the mentally handicapped are deviant and argues that they are better regarded as incompetent and part of the surplus population. (However, it is possible to argue that the marginal surplus population is deviant in that they do not participate in the major institutions

of society and consequently deviate from the norm). This argument can be seen to parallel the Marxist argument that capitalist societies need a surplus or reserve labour force, to help keep the level of wages down and to provide a group of workers who can be brought into production and forced out as need fluctuates. Farber argues that this surplus is an inevitable and functional feature of industrial society, and that its members are part of a sub-cultural group whose continued existence results from the internal pathology of the group, but Marxists regard the problem as arising from the social divisions necessary to maintain an economic system based on private profit and located in the relationship between the working class and the political and economic structure. Integral to both these arguments is the notion that the 'reserve' or 'surplus' population could fill occupational slots, if sufficient jobs were available. To what extent all mentally handicapped people could fill occupational slots, even in routine manual work, is debatable - some multiply handicapped severely subnormal people obviously could not. However, as Haldane<sup>44</sup> suggested as long ago as 1938, in a society offering employment for all, slots would be found for many now considered incapable of employment because of mental handicap. Research in this country has demonstrated that even moderately handicapped people can adequately perform routine manual jobs in open employment.<sup>45</sup>

An interesting line of development in the area of mis-labelling and the labelling of children from minority groups and the lower working class as educationally subnormal as a result of apparent school failure has been made by Coard,<sup>46</sup> with special reference to West Indian children in the English educational system. He argues, using as a basis the statistics of the Inner London Education Authority, that a large number of children from West Indian homes are wrongly placed in E.S.N. (M) schools. This is a result of the prejudices of (white) school teachers and bias in assessment, especially resulting from the use of I.Q. tests. (See Chapter 3). He argues that this heightens the negative self-image that black children



already have as a result of living in a white society. The mis-labelling of immigrant black children is inextricably linked to the role that immigrants play in British society, (sociologists have arrived at a similar conclusion concerning the role of immigrant/migrant labour in Western Europe), providing a reserve labour force. Coard suggests that immigrants came to England after World War II for two reasons, because of the lack of employment opportunities in their own countries due to colonial exploitation by the British ruling class in the past and because British society needed the services of West Indians and other immigrant workers as a 'surplus labour force' to do the 'dirty' jobs that native workers were no longer willing to do. Immigrants, Coard suggests, perform three main tasks: they increase the supply of unskilled labour in relation to demand, which helps to keep wages down and profits up; they perform many of the menial and unwanted jobs when otherwise there would be a labour shortage; as an underclass they divide the working class and dampen militancy because native workers feel that their jobs are endangered, but on the other hand enable native workers to move one rung up the social status ladder from the lowest position - the immigrants provide a group for them to look down on. From this analysis of the role and status of immigrants Coard argues that if immigrant children/the children of immigrants received equal educational opportunities then there would no longer be a pool of cheap, mobile labour, and this would pose a threat to the existing social order. *We can, therefore, understand why "so many of our black children are being dumped in E.S.N. schools, secondary modern schools, the lowest streams of the comprehensive schools ..."* It is possible to expand Coard's analysis to other deprived and minority groups in our society and the ways in which the educational system operates to reproduce the existing relations of production and maintain the status quo.<sup>47</sup> This analysis, then, adds to our understanding of why so many apparently biologically normal children from the lower working class and ethnic minority homes are labelled as E.S.N. (M). (It is interesting to compare the ways

in which children are selected and labelled as E.S.N. in Britain and the United States with the U.S.S.R. - see section 5 below). It also ties in with criticisms of the cultural biases of I.Q. tests (see chapter 2) and the way in which the feebleminded came to be seen as a dangerous group, a threat to civilization in the late nineteenth and early twentieth centuries (see Chapter 5) - the perception of the mentally handicapped developed at that time still influences 'popular' attitudes, reactions and behaviour to the mentally handicapped in our society (see Chapter 7). Card's analysis points to one fruitful line of research that could be developed.

### 3.3 Requirements in a sociology of mental handicap

The main theoretical position of sociologists who have attempted to study mental handicap, outside of the clinical model, has been interactionist and the general tendency has been to conceptualise mental handicap as a form of deviancy. However, as I have indicated, the dominant medical model of mental handicap and the power that medical men have over the lives of mentally handicapped people have suggested to some sociologists that a medical-sociological framework is more appropriate; Dexter,<sup>48</sup> for example, has argued that what is needed is a clinical sociology of mental handicap. Conversely Farber,<sup>49</sup> within a structural-functionalist perspective, has attempted to analyse the role and status of the mentally handicapped by locating them as part of the surplus population. Sociologists working within all these perspectives/frameworks have been concerned to understand mental handicap as a social phenomenon, The final area of sociological concern is the study of social policy provision for the mentally handicapped - especially evaluating the adequacies of existing provision.

All the research has contributed to our understanding. Social policy research has demonstrated the inadequacies of the existing provision in our society, although it has tended not to question the overall framework of provision but to examine what type of care is most appropriate within the existing services (see Chapter 6). The interactionist and marginal population approaches have demonstrated that

sociology can make a valuable contribution to an understanding of mental handicap. (See above for a critical evaluation of these theories). The existing literature has provided a greater insight into mental subnormality as a social phenomenon and raised a number of interesting and perceptive questions - including whether the mentally handicapped can be viewed as deviants.

However, an evaluation of the sociological contribution to date suggests that it is inadequate because of the theoretical perspectives that inform the researchers. Sociologists like other social scientists are concerned with understanding and explaining social processes, with answering how and why questions. The 'facts' that are collected to enable answers to these questions to be given do not 'speak for themselves'. The 'facts' have to be structured so that they make a point, tell a coherent story - the theories that are constructed by social scientists are intended to do this. Although the facts do provide constraints on theories, there is an under-determination of theory by facts - an analysis of the facts cannot, therefore, conclusively prove, or for that matter disprove, a theory. I have argued that both the psychological and sociological theories developed to date are inadequate - they either do not take adequate account of all the relevant factors or their theoretical interpretation is inadequate. My main criticism is not that they have got the facts wrong, but that their interpretation/theoretical construction is inadequate - I am criticising theories from within a particular theoretical perspective.

Indeed within sociology (and this is equally true of all the social sciences) there are a number of competing paradigms or perspectives, the main divisions being those between conflict and consensus, and micro- and macro-sociological theories. While some sociologists have suggested that these are not so much antagonistic perspectives as opposite sides of the same coin, I would suggest that they do represent real differences,

However, a theory that can explain conflict as well as consensus and micro- as well as macro-social processes would seem to be necessary. This is not to argue for a synthesis of the competing theoretical views - such an attempt would be arrogant and probably fruitless. Any attempt at fitting all the elements from the different schools into a theoretically neat framework would result in its proponent becoming increasingly distanced from the very social reality he or she attempts to understand. What I want to stress is the need for a structural analysis that takes cognizance of the role of consciousness and agency in social and historical development and consequently of our capacity as social actors to understand and criticise our social environment. While accepting the importance of agency it is necessary to realise that we are born into a society which already exists and which has a more or less agreed distribution of roles and functions and in which the basic institutional arrangements are fixed.

While I do not intend to discuss these philosophical/theoretical problems in detail, it is essential to point out that sociology is in a state of 'constant revolution', and that while abstract theoretical work in sociology is divided into competing paradigms, each arguing for a particular way of understanding society, most sociologists get on with empirical studies of social phenomena. Nevertheless, whether stated or left unstated all sociologists work within a paradigm that not only structures the questions they ask, but the conclusions they arrive at. The sociologist is not a neutral and value-free observer, and research findings are not undisputed 'facts' but interpreted accounts of reality. Thus as Hindness has argued (with reference to official statistics, but by inference to all factual evidence), the use

... of social statistics for scientific purposes is always and necessarily a theoretical exercise and further that different theoretical problematics must produce different and sometimes contradictory evaluations of any given set of statistics. The evaluation of social statistics is never reducible to a purely technical evaluation. <sup>50</sup>

Sociologists working from within different theoretical paradigms approach their research in different ways, use different research methodologies and evaluate/interpret

the results within the theoretical constraints of that paradigm. Research/analysis is not necessarily rejected or accepted because it has been carried out within a particular paradigm, but it is evaluated by sociologists working from within different theoretical perspectives; that is, research/analysis is criticised on the basis of its theoretical underpinnings as well as its technical merit and conclusions.

Having pointed to the inadequacies of the existing research on the basis of its theoretical underpinnings it is necessary to state what an adequate theory would be like. What is necessary is a level of analysis which is able to address itself to all aspects of experiences which control our existence as human beings, an approach which rejects the view that the problem of mental handicap is the personal property of a number of pathological individuals and their patterns of behaviour, and which instead argues that their patterns of behaviour must be seen in relation to society and its structures, and to the character of that society's reactions to that behaviour. It is essential to take as a starting point that all human activity is essentially social behaviour, and that all human behaviour takes place within a social context, with a certain social structure and organization. Thus theory must be adequate at the synchronic and the dynamic levels and must be a critical theory;

... one which attempts to account for the sufferings and felt needs of the actors in a social group by seeing them as the results of certain structural conflicts and hence giving a historical account in quasi-causal terms of the latent contradiction between the sorts of needs, wants and purposes which the social order gives rise to and the sort of (inadequate) satisfaction it provides. §1

We need, therefore, to develop a structural account to enable a description of micro- and macro-processes, including theoretical and ideological underpinnings. Phenomena must be seen as wholes or parts of wholes; the parts can only be understood within the whole, and the various parts only have meaning when they can be seen together as a whole. We need a historically and cross-culturally informed macro-sociological account to enable us to understand why and how the mentally handicapped are handled in our society. We need to explore

when and why mentally handicapped people become labelled as outsiders and managed as deviants. It is necessary to develop a critical theory which attempts to understand mental handicap within a specific form of political, economic and social organization - an analysis which attempts to establish the relationship between mental handicap, social structure and social change. This will enable us to understand better the process by which mental handicap is subjectively conceived (see Chapter 7) and mentally handicapped people are objectively handled (see Chapter 6).

In Chapters 4, 5 and 6 I attempted to look at changes in perceptions and handling of mentally handicapped people from the earliest times to the present, but concentrating on the change from pre-industrial through industrial to advanced industrial society. In the next section I intend to build on this and develop the type of analysis referred to above and show how this provides a context and theoretical paradigm which begins to enable us to understand how and why current policies for handling mentally handicapped people developed as well as their role and status in modern Western societies.

#### 4. The Importance of History in Sociological Approaches

##### 4.1 Introduction

Ford has perceptively asked "Why does everything go on as normal?"<sup>52</sup> This is an important question and leads us to ask why so much sociological analysis assumes that the current situation can be studied as it is without considering how and why that situation developed. We consequently forget the important fact that our perceptions of normality are conditioned by the society in which we live, and by that society's history:

We must remember that the investigator, whether a biologist, an economist or a sociologist, is himself a part of history and that if he ever forgets that he is a part of history he will deceive his audience and himself.<sup>53</sup>

We also tend to ignore the fact that there are times when 'normal' patterns are thrown into disarray and chaos, and at these times society undergoes qualitative changes.

That is, there are both crucial moments and whole periods in history when institutions and 'normality' are fundamentally altered. We need, therefore, to understand conflict and change as well as normality and consensus - the objective structure as it has historically developed as well as the way it is currently experienced, and the ways in which the existing situation can be changed to meet perceived needs. While it is true that there is interest in studying patterns of handling and social perceptions of mentally handicapped people as they currently exist, a historical (as indeed would a cross-cultural) analysis enables us to put this kind of survey in a wider context. By focussing on a particular socio-historical context we are struck by the fact that definitions of mental handicap apparently change according to economic and ideological circumstances. Also a historical awareness guards against the impression that features of mental handicap handling are either entirely new, or conversely are much the same as ever. (Chapters 4, 5 and 6 demonstrate this point). As Rex<sup>54</sup> - a leading exponent of the view that sociology must combine a theoretical analysis with a historically grounded approach - has argued, the sociologist must be steeped in the social reality which he is studying, and particularly in its history, in order to avoid sterile theorization as an end in itself. Not only must theory be constructed through a sociology informed by history, but any analysis which purports to contribute to a sociological understanding of social policy must be made from within a historically grounded sociology.

In undertaking an historical analysis of the ways in which the mentally handicapped have been handled and conceptualized at different times in the past, we can see how practices have changed and relate these to changes in socio-economic structure. As Scott has pointed out with reference to conceptions of stigma, it is

... the basic principle of sociology that a society's core values are deeply rooted in its economic system; they reflect the system, and they change in response to changes in it. The core values of societies with one type of economic system will therefore be different from core values of societies with a different type of system.

In view of the fact that experts' conceptions of stigma reflect a society's core values, we are led to expect that the meaning of stigma that experts construct will systematically vary according to the form of the society's economic system.<sup>55</sup>

In undertaking an analysis of conceptions of and responses to mentally handicapped people in pre-industrial, industrializing, and industrial society I have sought to demonstrate that as the socio-economic structure of society changes, so do responses to those seen as outsiders/deviants, including the mentally handicapped. That is, social and economic changes influence our definitions of mental handicap, our methods of handling and the ways in which these are modified and changed: what society defines as mental handicap/incompetence and how it is handled depends on social and historical forces and is specific to particular societies at particular stages of development. Furthermore, I have suggested that conceptions in modern Western (industrial capitalist) societies are to some extent determined by the ideology of this form of society. This argument has to some extent been validated by reference to contemporary non-industrial and industrializing societies (see especially Chapter 2) and by the fact that responses to the mentally handicapped changed in all Western Societies at about the same stage in terms of their socio-economic development and are underpinned by the same philosophical approach to care today (see Chapter 6). However, to show that it is capitalism and not industrialization that shapes responses to the mentally handicapped it would be necessary to demonstrate that perceptions of and responses to the mentally handicapped are different in non-capitalist industrial societies. While there is some evidence on this available to the Western researcher, it is not conclusive (see section 4.3 below). Nevertheless, the analysis I undertook in chapters 4 and 5 suggested that we cannot take for granted our society's perceptions of the mentally handicapped - different societies do respond differently to the same social problem. Indeed, to demonstrate this point we need only to have shown that it has changed historically. (However, a comparative cross-cultural study would be necessary to demonstrate conclusively the extent to which the socio-economic structure of a society



determines social perceptions of and methods of handling mentally handicapped people). I have used the historical approach in this thesis, in line with development in sociology in other areas.

Indeed, as I shall demonstrate below, the most fruitful period for demonstrating the influence of socio-economic changes on the handling of deviant and non-deviant populations alike is the period from late pre-capitalist society through to advanced capitalist society. By focusing on English society in the transition from agrarian capitalism to industrial capitalist society it is possible to grasp mental handicap in its historical dimension, to see that definitions and practices in the field of mental handicap change across different historical periods and to understand the ways in which the handling of the mentally handicapped changes in relation to the wider economic, social, political and ideological context. Furthermore, this approach enables us to situate the problem of theory, to understand that theories of mental handicap were constructed around a logic of explanation and that theories were applied in order to explain and sometimes to put into practice methods of handling, in particular historical settings. The theoretical links which have often been 'proved' between ethnicity and handicap, degeneracy and handicap etc. make a different kind of sense and acquire a new dimension of meaning when viewed in the context of nineteenth and early twentieth century England (see Chapter 5). While a cross-cultural study would be necessary to provide a control, strong support is nonetheless given by an analysis of this period of history.

#### 4.2 The development of mental handicap as a social problem

In chapters 4 and 5 I argued that the available evidence strongly suggests that it was during the course of the nineteenth century that the mentally handicapped became seen as a separate social problem and handled as deviants. Up to that time those who were obviously handicapped and unable to support themselves economically were either cared for by their families or warehoused in the work houses, houses of correction or private madhouses. Thus the mentally handicapped were an integral part of the undifferentiated dependent population. We need to ask, then, why they became an object of official concern and

managed as deviants only as Britain moved from pre-industrial, pre-capitalism to industrial capitalism. (The mentally handicapped are social deviants in that they are part of the 'social junk'<sup>56</sup> - a costly but relatively harmless group, whose very existence, because of their inability to participate in roles supportive of capitalist society, questions the ideology of that society - they come to official attention when informal measures have been exhausted or when the magnitude of the problem becomes significant enough to create a basis for public concern).

During the nineteenth century first the severely handicapped and then the mildly handicapped came to be seen as a serious social problem that called into action agents of social control and resulted in their being handled as deviants. The 'fear' of the mentally handicapped grew as the number of individuals assessed and labelled as 'feebleminded' increased with the introduction of compulsory education, the development of social Darwinism, and the growth of the Eugenics movement. By the turn of the nineteenth century biological theories relating to heredity and evolution came to play a dominant role in determining the ways in which society viewed the problem of mental handicap and methods of handling. (Indeed, the conception of the mentally handicapped at this time continues to influence public knowledge of and reaction to mental handicap - see Chapter 7).

In the nineteenth century official and public reactions to the mentally handicapped, especially the 'feebleminded', were conditioned by the fact that they were seen as part of the 'dangerous classes' - a group that threatened the stability of society. This fear developed out of the fear of the mob that grew in late eighteenth century England with the development of the beginnings of the modern working class. It was argued that there was a connection between poverty and moral degeneracy and hence with criminal behaviour; that is, the conditions of the poor became associated in the mind of the authorities with the preconditions of crime. This resulted in the production of a perceived deeper and more serious potential danger from the lower orders -

a belief that poverty, bad habits and propensity to crime might provoke them into riotous behaviour and escalate into a threat to civil order itself. This led to a declension from the poor to the criminal classes to the 'dangerous classes'. The fear grew that the 'mob' or 'sunken 10%' would contaminate the respectable working class and create social unrest. Victorian England's image of the poor as a dangerous residue resulted in them being regarded as an alien class, as human refuse, outside of civil society, a constant threat to the stability of society, a group that needed to be constrained and controlled, managed as deviants. Although by the end of the nineteenth century the fear was no longer of riots and rebellion, fear remained of the physical and mental degeneration of the race as the residuum bred faster than the respectable classes.

When compulsory schooling was introduced, the 'feebleminded' were 'discovered' and this 'new' group was found to come from poor, working class backgrounds - from the social degenerate group (see Chapter 5). New methods for identifying and justifying the handling of this group were needed. Thus the management of the mentally handicapped as deviant is inextricably tied to the rise of science to a place of dominance in nineteenth century Britain and the introduction of mass schooling as part of the process of meeting the need for new forms of social control in an industrial society. (The school replaces the family and the church as the main agent of socializing children into the norms and values of society).

Political agitation at the end of the eighteenth century precipitated legal and political reform. It was clear that the older forms of social control could no longer withstand the industrial and economic change and the political challenge. Reform was the method by which the new social order was constructed, and in the process social control was strengthened and the threat of revolution held at bay (e.g. by changes in custodial institutions, including the workhouse, prisons and asylums). In the period up to 1850 Britain was transformed from a largely rural, basically agrarian economy to one which was urban, industrial and based on wage-labour.

At this time the foundations of the modern British state were laid. Major reforms resulted in the state increasingly encroaching on social, economic and political institutions. This state intervention was accompanied by increasing attempts to segregate and classify the working class into various categories - the respectable and the non-respectable, the industrious from the dangerous. The latter group were conceptualised as a major threat to the social order, and various ideological mechanisms, including charity and education, were utilized in an effort to moralize and regulate the behaviour, life-style and leisure activities of this group.

This fear of the poor was not new in the nineteenth century, but it took on a different dimension as social change heightened class consciousness and the problem took on a new level of intensity.<sup>57</sup> Reforms were aimed at the maintenance of order; the evolutionary and benevolent conception of social reform is misleading.

The history and development of social policy is in large part the history of an economically dominant class organising to become a ruling class, stamping its authority and control over the entire spectrum of social life. In this process of social reforms have played a crucial role.<sup>57a</sup>

The attitude of reformers in the first part of the nineteenth century was that the idle needed to be disciplined, instilled with the habits of industry - but the need was for a particular type of disciplined individual to work in the factories.<sup>57b</sup>

Studies of the introduction of mass schooling in the nineteenth century suggest that it was seen as the solution to the problem of social control, in a situation where the family was no longer able 'adequately' to socialize children.

Schools at once supply labour to the dominant enterprise and reinforce the racial, ethnic, sexual and class segregation of the labour force.

and

The emergence and evolution of this educational system ... (was an) ... outgrowth of the political and economic conflict arising from this continued widening and deepening of capitalist control over production ... 58

While it can be argued that mass schooling became necessary because of technological changes or a demand for more 'educated' workers<sup>58a</sup>, it was also clearly a measure aimed at social control, to check delinquency, encourage religious observance and inculcate a work discipline. (By the mid-nineteenth century children were no longer employed in factories because of protective legislation and technological changes in the production process.<sup>59</sup>)

The introduction of mass schooling resulted, as I have already indicated, in the discovery of the 'feebleminded' children who appeared normal, but who would not learn to conform to the educational system and consequently presented a problem. This group posed a 'threat' to the dominant ideology of the protestant ethic - a group who could not support themselves economically and were dependent on society. These children came mainly from poor homes, frequently had unemployed, alcoholic, unmarried mothers and the mentally ill or other 'degenerates' for relatives. It was also observed that this group had larger families than average and the fear grew that this group would swamp society and consequently posed a threat to civilization. By the early twentieth century it was generally accepted that this group needed to be shut away and prevented from breeding for the protection of society (see Chapter 5).

With the growth of capitalism and the challenge to religion by rational-scientific explanation there was a need to justify an unequal society, to develop an ideology that rationalized a particular kind of social relationship as natural, not on religious grounds but on scientific ones. Scientific theories replaced religion as the final arbiter of truth; that is, they were seen to provide value-free, reliable and valid accounts of the world. However, scientific theories do not develop in a vacuum, but in particular societies at certain stages of their development - that is, theories are shaped by the requirements and

constraints placed on them by the society in which they are developed.

Britain at the end of the nineteenth century and the beginning of the twentieth was in a state of transition from laissez faire to monopoly capitalism. One consequence of this transition was the expansion of the middle class. Mackenzie<sup>60a</sup> argues that eugenics justified and sustained the position of the middle class, and especially of the professionals<sup>60b</sup>. It 'proved scientifically' that the difference between the professional and the working classes was due to inherited differences in ability, and therefore the divisions of mental and manual labour were given the force of a natural division between different types of people. At the same time the Eugenists had an analysis of the practical problems of Victorian and Edwardian capitalist society; most importantly, they offered a practical programme for dealing with the situation of chronic deprivation and unrest among the residuum. This group were seen as unfit in an extreme form and were therefore a prime target for elimination by a programme of eugenics. Eugenists were concerned with the 'fitness' of society or of the race - national efficiency - but the fitness of a society was seen as the sum of the fitness of the individuals comprising it. Social failure was identified with biological unfitness, and progress was seen as coming through the elimination of the unfit. However, the eugenists rejected the laissez faire attitudes of, for example, Spencer and advocated state intervention.

In the nineteenth century the growing dominance of science and rational explanations is seen in the way in which medical men intervened in and gained control over the adjudication of normality (abnormality in the case of mental disorders - the handicapped and the ill). The mentally handicapped were at first seen as sick and the condition curable, but the failure to 'cure' them - and the large increase in the numbers diagnosed, especially after the introduction of mass schooling - necessitated the development of alternative rational explanations of mental handicap and for their handling as a group seen as a threat to social stability (see Chapter 5).

By the end of the century Darwin's theory of the origin of the species and natural selection resulted in the development of scientific theories (Social Darwinism and Eugenics) that not only enabled the 'scientific' identification of the mentally handicapped but also justified policies of segregating the subnormal in order to protect society from the perceived threat of degeneracy. (The treatment of a socially dependent group, it was argued, should not be such that it would encourage others to become idlers or allow them to 'breed' and create an even larger group dependent on society). The poor and specifically the degenerates were seen to be held down by biological deficiencies, not divine ordination nor environmental/social factors, and it became seen as necessary to 'invent' scientific means of measuring 'intelligence' in order that the biologically unfit could be suitably dealt with.

The eventually successful attempts to develop intelligence tests, together with social evolutionary theories and studies of degenerate families, were used not only to justify the segregation of the mentally handicapped but as a justification for the existing patterns of social inequality, by arguing that they were the outcome of the social struggle for the survival of the 'fittest' - the inevitable working out of the 'iron law' of biology; social inequality was seen as the result of biological differences between individuals. (Intelligence tests - developed in the early twentieth century - confirmed this and provided a scientific method for screening out the most feared group - the feeble-minded - see Chapter 5).

Science and scientific theories came to provide a rational explanation for 'stupidity', a justification for 'fearing' the surplus population and a means of scientifically identifying the 'feeble-minded'. Once they were screened out, this group could be segregated and society protected.

It is important to point out that the Eugenics Movement was influential for a very short period - from 1900 to 1914. In terms of eugenic programmes for racial improvement its only achievement was the 1913 Mental Deficiency Act. Furthermore, while it had a large number of influential supporters, including many leading Fabians, it was not without its critics. Apart from the Fabians, who were not working class but from the professional middle classes<sup>61</sup> and perhaps concerned with protecting the interests of their own class<sup>61a</sup>, eugenicists were opposed by socialists, right-wing conservatives, the Catholic church and defenders of traditional individual liberties. After the First World War, academics such as J.B.S. Haldane attacked eugenics as a paradigm case of anti-working class use of science, and the defeat of the eugenicist ideology was a prime target<sup>61b</sup>. The extreme right-wing and fascist forms taken by eugenics in the 1930's accelerated the decline in the movement's influence. However, in its time it had considerable influence on attitudes towards and methods of handling the mentally handicapped, and elements of its approach can still be seen underlying current concepts.

#### 4.3 What can be learned from history

The above account suggests that the creation of mental handicap as a deviant category and of subnormal people as stigmatized (and feared) deviants is inextricably linked with changing socio-economic conditions. The perceived challenges to the hegemony of the capitalist class in the nineteenth century necessitated new methods of classifying and handling deviants. (The maintenance of hegemony by the ruling class is not inevitably based on the use or threat of force, but rather on a range of mechanisms, some objective products of the economic process and others subjective phenomena arising through the manipulation of attitudes). In this process the mentally handicapped, a socially and economically dependent group, became regarded as part of a social problem group, necessitating management as deviants. Despite apparent changes in social attitudes towards and methods of handling the mentally handicapped, the legacies of this 'fear of contamination' and regarding the mentally handicapped as 'dangerous' can still be seen in the stigma that attaches to the label 'mentally handicapped' (see Chapter 7 - indeed it may be argued that the more



severely handicapped are the ones who are 'feared' while the mildly handicapped are considered less of a danger today - the reverse of the situation at the turn of the century - see Chapter 5) and the way in which the mentally handicapped remain a 'forgotten' group in terms of economic and social support (see Chapter 6). The mentally handicapped are seen not only as different, but as inferior, and they are treated as such:

To recognise a specific difference ... (in natural endowment) ... is one thing, to pass a general judgement of superiority or inferiority, still more to favour the first and neglect the second, is quite another. 62

The mentally handicapped are created as a deviant group not only because of their inherent characteristics but also because of the ways in which these differences (to the extent that they really exist) are socially interpreted, and this interpretation appears to change as society changes. There appears to be a relationship between socio-economic structure, social change and changing social perceptions and treatment of deviant groups, including the mentally handicapped. Thus we can see that in the late nineteenth and early twentieth century

... many of the transformation underlying the move towards institutionalization can be ... tied to the growth of the capitalist market system and to its impact on economic and social relationships. 62a

In the same way I have suggested (see Chapter 6) that moves towards decarceration and community care in the 1960's were not solely the outcome of humanitarianism and a growing understanding of what mentally handicapped people can achieve, or a result of criticism of hospitals, but came about because it was apparently a viable alternative with the growth of the welfare state - and it was cheaper.

A macro-historical account enables us to begin to understand how and why social perceptions of the mentally handicapped change as the socio-economic structure of society changes and it is within this framework that we

can see the contribution that sociological research into mental handicap can make. It enables us to understand current social perceptions of the mentally handicapped and current methods of handling them. Within this context we can see the important contribution that sociological research in the field has made - but research which I have argued is inadequate as it stands because of its ahistorical and consensual paradigm. This thesis has stressed that we can only adequately understand mental subnormality when it is placed in a social context, and that explanations which concentrate on the mentally subnormal individual and his pathology are inadequate.

#### 4.4 A comparative perspective

One main argument throughout this thesis has been that mental handicap, especially mild mental subnormality, has only become a social problem in industrial societies and I have also suggested that the specific responses to this social problem in Western industrial society is probably a result of the capitalist socio-economic structure and ideology of these countries. While I am not able here to report on extensive cross-cultural research, the available research material (in English) would seem to support this contention.

As far as non-Western, non-industrial countries are concerned there is a lack of systematic research on the problems of mental handicap. My own analysis suggests that there are considerable problems in distinguishing between mental handicap and mental illness in such societies, but that the severely handicapped are recognised in all societies. The available anthropological evidence on contemporary primitive societies suggests (as appears to be the case in Western society prior to the modern period) that responses to the obviously handicapped range from infanticide, to leaving them to care for themselves, to the families providing 'good' care.<sup>4</sup> However, as is the case with the mildly mentally handicapped they are not seen to provide a large, separate social problem. In the case of mild mental handicap many apparently go unnoticed (it is of course difficult to determine who is

and who is not mildly mentally handicapped in the sense <sup>in which</sup> we use the word) although stupidity is often recognised, but the 'stupid' are not accorded special treatment.<sup>64</sup>

When countries begin to industrialize, however, the problem of mental subnormality becomes more acute, especially in urban areas.<sup>65</sup> As a society advances technologically there is less employment for the mildly retarded - mainly because of social attitudes and ideology (many mildly subnormal people could be employed on mass production jobs if attitudes changed<sup>66</sup>), but more importantly, retarded people find it difficult to make the social adjustment to urban living. This point is well brought out by the study undertaken in Puerto Rico (see Chapter 2)<sup>67</sup> which, using a quasi-experimental research design, attempted to demonstrate that industrialization (and the introduction of compulsory schooling) 'causes' the problem of mild mental subnormality. In industrializing societies the problem of severe mental retardation also grows, as with improved medical knowledge and social care more handicapped babies survive birth, handicapped people live longer, and work becomes an activity separated from the home. This necessitates the development of new methods of handling.

The difficulties with respect to evidence on non-capitalist industrial societies appear to be even more complex. As far as I am aware there is no published material in English on the social perceptions of mentally handicapped people in those countries; there is, however, some material on the education of mentally handicapped children in the Soviet Union,<sup>68</sup> China<sup>69</sup> and other Communist societies.<sup>70</sup> The reliability of this material as a 'true' account of the educational process is difficult to assess. It comes from two main sources: that written by academics living and working in these countries (and translated into English), and that written by those with an interest in the Soviet system, some of whom have visited these countries. Censorship and state control ensure that only what is acceptable to the authorities is published, and visitors are strictly controlled and only permitted to visit certain institutions,

which may not be representative. It is consequently easier to say what is the officially stated policy and the philosophy that underlies it than to recount what happens in practice.

Most of the available material is on the Soviet Union's<sup>71</sup> methods of handling mentally handicapped children, and the philosophy underlying diagnosis and handling. A short article on China<sup>72</sup> seems to suggest that the country still tends not to regard mentally handicapped children as a problem - the severely handicapped are excluded from schooling and left to stay at home while the mildly retarded are handled in the 'normal' schools. The authors of the report suggest that this is because China is still a developing country and has not yet reached the stage of development where subnormality is seen and responded to as a social problem. This is not, however, the case in the Soviet Union,<sup>73</sup> where special provision is made for all those diagnosed as mentally handicapped.

In the Soviet Union the mentally handicapped are divided into three groups/categories - the severely retarded (idiots), the moderately retarded (imbeciles) and the mildly retarded (debiles). (Most of the available information is on the diagnosing and handling of the latter group as the emphasis has been on education and the educational system). The major influences on the selection and education of mildly retarded children has been the research and writings of Soviet psychologists, especially the work of Vygotsky and Luria (see Chapter 3). Soviet philosophy does not accept genetic (intelligence) determinants or cultural causation of mental handicap; all mental handicap is assumed to be due to C.N.S. damage, and consequently mental handicap is seen as a purely physiological condition. Intelligence tests are officially banned in Russia because they are thought (because of their cultural bias) to discriminate against peasants and the working class in favour of the culturally advantaged; diagnosis is, therefore, based solely on neurophysiological evidence. Great care is taken not to mis-diagnose children as mildly subnormal on the basis of poor school

work and level of current attainment - the emphasis is placed on whether or not the child appears to be capable of learning in the normal classroom and every effort is made (including individualised learning programmes) to help the slow-learning child in the normal school before he is sent to a defectologist. (It is worth noting that the prevalence rate for Educational Subnormality is much lower than in the West; for example, 1% compared with 3% in the United States<sup>74</sup>). When a child has been diagnosed as mildly mentally handicapped he is sent to a special school - the emphasis is placed on preparing the child for a useful work career by the age of eighteen years, and it is claimed that the majority of mildly and moderately mentally handicapped children obtain open employment on leaving school. (In Britain the vast majority of moderately retarded and some mildly retarded school leavers go to Adult Training Centres).

It is possible to glean some understanding of attitudes towards the mildly retarded from the way in which they are handled in the educational system. As is the case in Britain, they go to special schools, but in Russia these schools are usually boarding ones that care for the health and recreational needs of the child as well as the educational ones. The staff-pupil ratio is low and teachers of the mentally handicapped are held in high esteem, as they have a longer training than teachers of 'normal' children and command a considerably higher salary.

Official policy in the Soviet Union is, then, that mentally handicapped children are given all the care and help they need and every effort is made to enable them to develop to their full potential and take on adult social roles. Special emphasis is placed on correct diagnosis, intelligence tests are rejected because they are seen to be culturally biased, and every effort is made not to mis-diagnose a child. However, the extent to which this theory is put into practice is an unknown, nor is it possible to determine social perceptions of the mentally handicapped or official attitudes, reactions, behaviour towards them. Nonetheless this analysis does suggest,

as does the historical analysis, that we cannot take for granted our society's perceptions of and methods of handling the mentally handicapped.

#### 4.5 Conclusion

In this section I have argued that, within a historically (and cross-culturally) informed macro-framework, sociology can make an important contribution to our understanding of mental handicap. This framework enables us to understand that social definitions and understanding of mental handicap, and responses to those who are seen as different/incompetent, cannot be taken for granted but are conditioned by the socio-economic and ideological framework within which they are perceived and interpreted. Within this framework we can see the contribution that micro-sociological, psychological and other social science disciplines can make to a social theory of mental handicap, and this will be the subject of my final section.

## 5. Requirements in a Social Theory

### 5.1 Introduction

Up to now in this chapter I have concentrated on summarising my criticisms of the dominant medical and psychometric models of mental handicap and demonstrating what an historically informed macro-sociological approach can contribute to an understanding of mental handicap as a social phenomenon. Indeed, with the exception of chapter 7 this has been the main concern of the thesis. In this final section I will broaden the analysis in order to demonstrate the contribution that can be made by micro-sociological/psychological perspectives as well as the other social science disciplines to a social theory of mental handicap. (It is also important to bear in mind that biological constraints on behaviour cannot be entirely written off, and that medical and clinical perspectives on mental handicap are of extreme important in terms of finding ways of preventing mental handicap, and also of developing programmes that will enable mentally handicapped people to develop their full potential). Finally, I will suggest possible future directions for sociological research in the field of mental handicap.

An argument that we should develop a social theory is not a plea for multi-disciplinary research, but a recognition that all the social science disciplines can make a contribution to our understanding of social phenomena. It is, however, necessary to recognise that interests and 'perceived' requirements in an account/understanding do vary between (and within) social science disciplines, and that different social science disciplines take certain aspects of social reality for granted (psychologists, for example, assume the structure of society, and sociologists the unique individual) and concentrate on others. A fully social theory can take nothing for granted; it must take into account all the relevant factors, from biological to social constraints including individual, social, economic

and political factors. In this way it will be designed to build a total picture within which specialist research can play a vital role, but without which we fail to conceptualize the totality of what mental handicap means as a social phenomenon as well as a biological/medical condition.

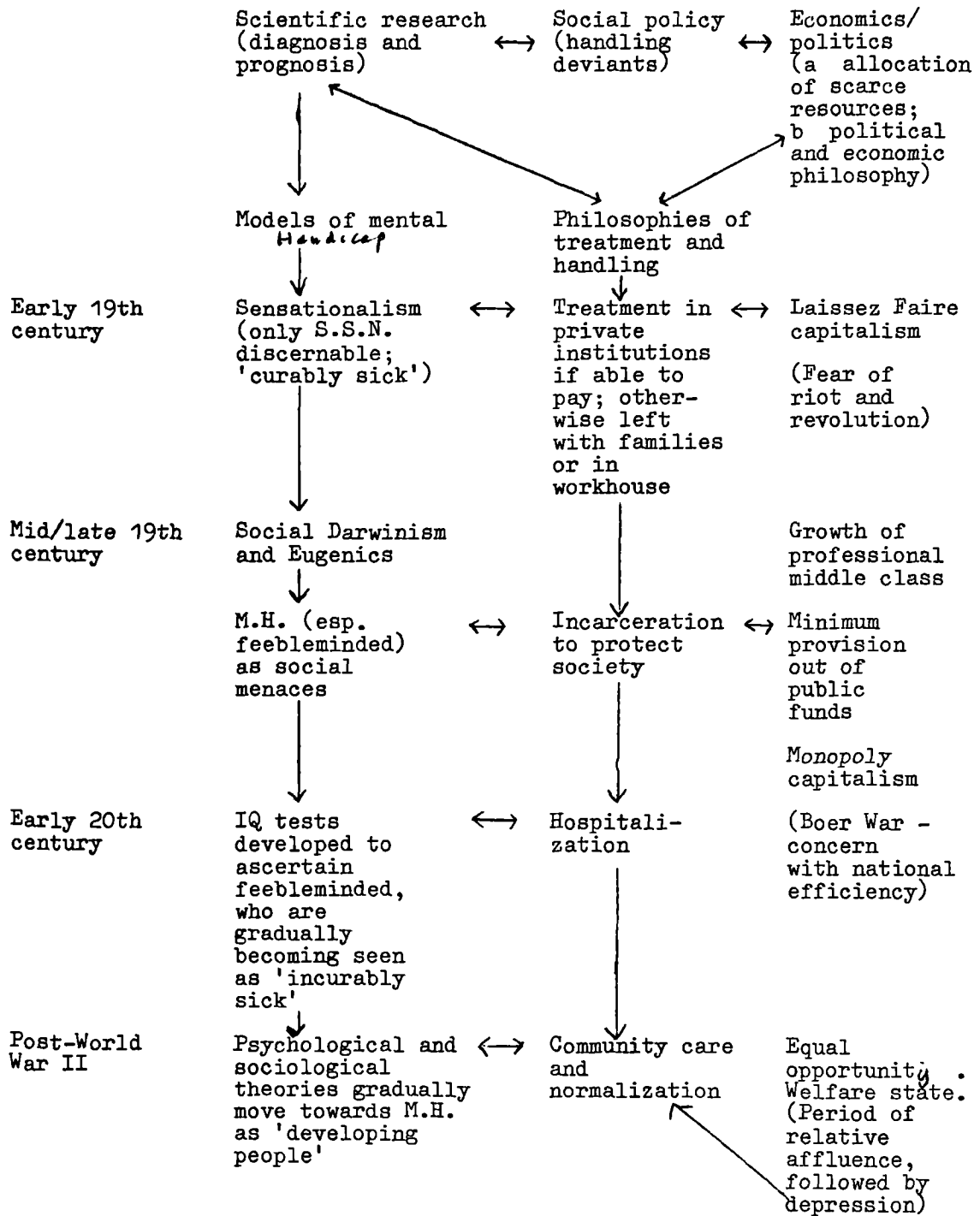
## 5.2 Going Beyond a Macro-Sociological Theory.

In Chapters 4, 5 and 6 I examined the ways in which social perceptions of mental handicap and ways of handling the subnormal have changed as societies have changed. In Chapters 5 and 6 I have also pointed out the important ways in which scientific factors interact with social/political/economic factors to influence social policy towards the mentally handicapped. Thus in order to understand current patterns of handling mentally handicapped people, we need research into the history of science, as well as the politics and economics of social policy.

In Table 12 I illustrate the interaction between scientific research findings, social policy and economic/political factors in determining methods of handling the mentally handicapped in the last two hundred years. I am not suggesting a simple causal relationship, but rather one of circular causality; nor am I suggesting that scientific research findings directly determine the form of social policy. (A number of alternative ways of dealing with the problem are always available given the acceptance of research findings). However, there is a definite relationship between the production of knowledge, social policy and the economic/political climate, and the interaction of these three factors does seem to determine methods of handling. The way in which knowledge is produced, validated, distributed and changed is interpenetrated by social/political/economic phenomena; that is, science does not develop independently of other developments in society. However, in order for a scientific 'discovery' to be recognised it must be taken up and used. At any given time



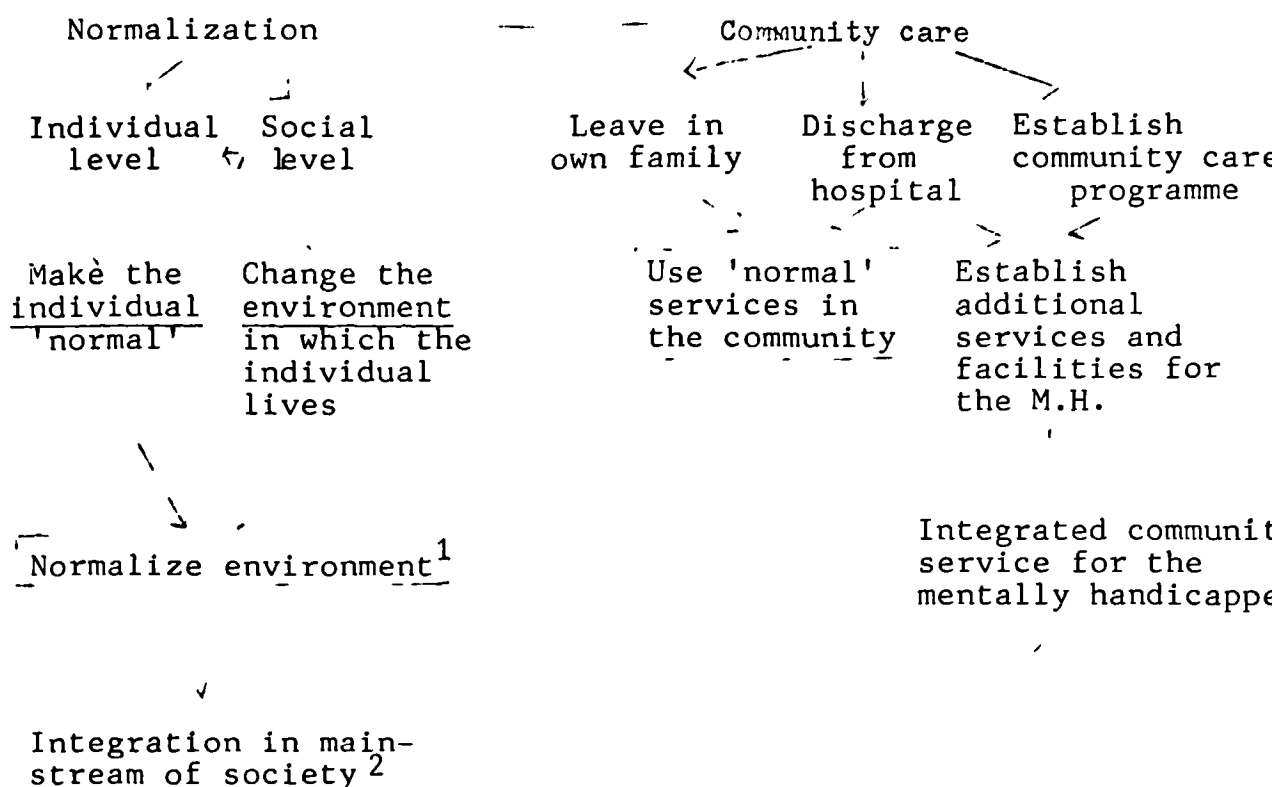
12: Scientific research, social policy and economic/political factors



there are a number of competing scientific explanations, and policy-makers can choose between them in determining what course to take. Thus in the late nineteenth century some medical men were advocating community care, but policy-makers 'listened' to those who advocated incarceration as the best method of handling social problem groups, including the mentally handicapped. It is also possible that scientists and politicians are reacting to the same situation. Thus in the late nineteenth century the growth of the Eugenics and Testing movements were at least partly a response to the 'discovery' of the feeble-minded with the introduction of compulsory schooling. The government were also faced with the problem of handling this group of children who could not be coped with in the normal school in a situation where traditional methods of social control were no longer appropriate. In deciding what areas to research into, scientists are influenced by two factors: the likelihood of funding (certain projects - especially those involving issues of current concern - are more likely to be funded by others) and the possibility that the research findings will be taken up and used. Finally economic/political factors will influence what alternative policies are realistically open to decision-makers.

The constraints of economic/political factors are illustrated by current policies in the area of mental handicap. (I have discussed this in Chapter 6, and in Chapter 7 I have indicated that community attitudes play an important role here). In Table 13 I summarise the ways in which the concepts of 'normalization' and 'community care' can be (and have been) used to justify quite different methods of handling. The ideas of community care and normalization grew out of psychological/sociological research findings in the period immediately following World War II, when the Welfare State ideology of equality of opportunity was developing (see Table 12). At this time the main method of handling the mentally

Table 13: Normalization and community care



Services and facilities provided enabling the M.H. to lead as near a normal life as is compatible with their degree of handicap

and

Community 'educated' to react and behave towards the M.H. as ordinary citizens.

- Notes:
1. This does not necessarily mean living in the community; it could result in 'normalizing' the institutional environment.
  2. This is not inevitably seen as the outcome (see note 1).

handicapped was by incarceration in large, isolated hospitals, but by the 1970's governments in Britain, the United States and Western Europe were apparently accepting the notion of community care and making plans to implement it. In Britain this coincided with a period of economic recession, and community care has tended to be implemented, in such a manner that it enables a reduction in expenditure. Spending on the large hospitals is reduced, but additional facilities are not provided in the community and the main burden of care falls on 'Mum' and the rest of the family when this is possible. (In the case of mildly subnormal adults, who tend to be socially incompetent, they are likely to become destitute and exchange one unsatisfactory institutional setting for a different but equally unsatisfactory one).

While a historically informed macro-sociological account enables us to understand more fully current social policy in the field of mental handicap, we need also to consider political and economic factors (and indeed, as I shall argue below, to work at the micro- as well as the macro- level). This approach can also be utilized to provide greater understanding of other social phenomena.

### 5.3 The Integration of Experience

In constructing macro- accounts of social phenomena it is all too easy to forget that individuals are as important as social structures. Ultimately one is concerned with mentally handicapped people, the members of their families, their relatives, those involved in helping roles, and the people living in the community, as well as the people who make decisions affecting the lives of the mentally handicapped and their families. Individuals

are shaped by society, but they also have ideas, feelings and reactions, and they can in turn influence that society - they are not totally determined by it.

Thus I have argued in Chapters 6 and 7 that the attitudes and reactions of community members to the mentally handicapped (influenced as they are by social factors) do influence the policy decisions made by decision-makers. We need to go beyond this and try to understand not only how individuals and communities feel about and react to mental handicap (as an abstract concept) and mentally handicapped people but also how mentally handicapped people and their families understand and react to their situation.

In Chapter 7 I have reported on three small ethnographic studies which illustrate the type of micro-sociological research that could make a contribution at this level. I have argued that abstract studies of attitudes do not enable us to understand how people react to and behave towards mentally handicapped people. We need not only to understand why people react in the way that they do, but also how the behaviour of others is understood by mentally handicapped people and their families. My main conclusion was that it appears not to be central or salient in the lives of most people, but that when a community is faced with a group of mentally handicapped residents there tends to be considerable adverse reaction, justified by reference to stereotyped images, influenced by outdated views of the 'dangers' presented by mentally handicapped people. (It was also interesting to find that many of these (mis)conceptions were also shared even by those who were prepared to act as voluntary helpers in a hostel). The families of mentally handicapped people generally tended to feel that they were stigmatized, as was the mentally handicapped member, not only by strangers, but also by relatives, friends and many of the professionals they came into contact with. (Experiences did vary, however, and it may be that parents' own reactions to mental

handicap influence the way they experience the reactions/behaviour of others).

The possible contribution of micro-sociology and human potential psychology can also include trying to understand what it is like to be mentally handicapped in our society. A small start has been made in this direction. The Participation Conferences<sup>75</sup> have given a voice to mentally handicapped people, and enabled them to express their views. Bogdan and Taylor<sup>76</sup> have constructed a life history of 'Ed', a mildly subnormal man, and Heshusius<sup>77</sup> has reported on an ethnographic study of how labelled mentally handicapped people experience their lives in a hostel. All of these reports give us a greater insight into what it is like to be labelled and handled as retarded in our society and have clearly demonstrated that it is possible for mentally handicapped people to have views on how their lives should be structured and that they have 'human feeling'. Mentally handicapped people are seen as feeling, understanding, reacting human beings, not machines or animals who are acted on and do not have 'real human feelings'.

However, while research at the micro-level (sociological and psychological) is a vital element of any social theory, it is imperative that we do not forget that this takes place within a social context, a society with a history that influences its organisation and structure. As Marx has said, 'Men make history, but not in circumstances of their own making'.<sup>78</sup>

#### 5.4 Future Directions

Mental handicap has been neglected as an area of study until very recently, and still is in sociology, social psychology, anthropology and the other social science disciplines. Most research has been concerned with discovering the biological 'causes' of the mentally handicapped (to find ways of preventing some types), refining diagnostic tools and comparing normals and sub-normals matched for chronological or mental age.

More recently some effort has been made to find new (better) methods of helping mentally handicapped people to develop to their full potential. All this research effort is essential and needs to be expanded, but so does more social research. Indeed, without a framework the meaning and the ways that research findings are utilized are difficult to understand. An example of this is prevention of Down's Syndrome; this condition could be almost eliminated if all pregnant women were screened by amniocentesis and karyotyping, but there are financial and ethical constraints that need to be taken into account.

Social research needs to be undertaken in a number of areas. There is an obvious need for more cross-cultural research, especially into social reactions and behaviour towards the mentally handicapped in contemporary non-industrial societies, and non-capitalist industrial societies. However, at the present time I see the main need to be more micro-studies expanding on the types of ethnographic research reported on in Chapter 7 - research into what it is like to have to care for a mentally handicapped child, to be labelled mentally handicapped or to be confronted with mentally handicapped people living in one's neighbourhood. This type of research is made imperative given current social policy in the area. However, it must be borne in mind that social policy is influenced by political and economic factors as well as 'scientific' research findings, and all these factors underlie the present set of policies. Finally, the purpose of such research (which is itself influenced by political/economic factors as well as the social values of the researcher) is not necessarily to promote social change, or influence social policy, but to give insight and understanding to both those in the situation and those outside.

REFERENCE NOTES, CHAPTER EIGHT

- 1: Craft and Craft, 1978                      2: Ryan, 1976
- 3: Birch et al, 1970
- 4: E.G. Rutter has argued that relatively low levels of lead pollution, such as those found in inner city areas, can cause I.Q. to drop by as much as 5 points. This would result in a two-fold increase in the incidence of mental handicap, given current cut-off points. (Quoted in Tucker, 1980).
- 5: Haldane, 1938                              6: See, e.g., Doyal, 197
- 7: See Chapter 3 and, e.g., Mittler, 1974; Locke, 1978.
- 8: See also Tomlinson, 1981, and Mercer, 1973.
- 9: See, e.g., Clarke and Clarke, 1973, 1978; Mittler, 1979; Bogdan and Taylor, 1976; Tizard, 1964.
- 10: Clarke and Clarke, 1973a.
- 11: See, e.g., Adorno, 1967; Hurst, 1972.
- 12: Mills, 1958 p248 (Penguin ed 1970)
- 13: Dexter, 1956a, 1963, 1964; Mercer, 1972, 1973; Booth, 1978; Edgerton, 1967.
- 14: Farber, 1978
- 15: Dexter, 1956a, 1963, 1964; Mercer, 1973.
- 16: Edgerton, 1967                              17: Booth, 1978
- 18: Mercer, 1973                              19: Akers, 1967
- 20: Farber, 1968, 1968a                      21: Eugenics Society
- 22: Farber's view of the trend see Stacey, 1978
- 23: Farber's parental view of the dominant power of doctors in the field of mental handicap see MacCormack, 1978.
- 24: J.G. Vosey, 1975                              25: Booth, 1978
- 26: E.C. Blaker and Harbin, 1975      27: E.C. MacCormack, 1978
- 28: See also, e.g., Scull, 1975, 1977, 1979; Parry and Parry, 1976.
- 29: Edgerton, 1967 p209
- 30: Edgerton (1967) describes the ways in which the mentally retarded are able to manipulate people to obtain help in coping with the demands of everyday life.
- 31: Mercer, 1973                              32: Dexter, 1964
- 33: E.G. Edgerton, 1967                      34: Lemert, 1967



- 35: Edgerton, 1967
- 36: Mercer, 1973
- 37: Stein and Susser, 1960
- 38: Mercer, 1973
- 39: Plumer, 1979
- 40: Gouldner, 1968 P11
- 41: For a more detailed account see Pearson, 1975.
- 42: Spitzer, 1975 P639
- 42a: See Tomlins, 1981, for a very recent attempt to develop such a perspective with respect to the mildly educationally subnormal.
- 43: Farber, 19
- 44: Haldane, 1938
- 45: Tizard, 1964
- 46: Coard, 1971. (This analysis applies specifically to children from West Indian backgrounds. Asian children do not appear to have the same problem.)
- 47: See, e.g., Bowles and Gintis, 1976; Sharp and Green, 1976.
- 48: Dexter, 1964.
- 49: Farber, 1968
- 50: Hindness, 1974 P47
- 51: Fay, 1975 P96
- 52: Ford, 1975
- 53: Haldane, 1938 P182
- 54: Rex, 1963
- 55: Scott, 1970 P273
- 56: See Snitzer, 1975, for a fuller development of this perspective.
- 57: Hobsbawn, 1968
- 57a: Jones and Novak, 1980 P5150-51
- 57b: Thompson, 1968
- 58: Bowles and Gintis, 1976 P234
- 58a: See Johnson, 1976
- 59: Simon, 1960
- 60: It is interesting to note in this context that the inheritance of intelligence was not universally accepted in informed circles. Stiles (1859) did research concerning the origins of eminent men which came to contrary conclusions from Galton's, and J.S. Mill (1873) maintained that
- I have long felt that the prevailing tendency to regard all the marked distinctions of human character as innate, and in the main indelible, and to ignore the indisputable proof that by far the greater part of these differences.. are such as not only might but naturally would be produced by differences in circumstances, is one of the chief hindrances to the rational treatment of great social questions and one of the chief stumbling blocks to human improvement.
- 60a: Mackenzie, 1976, 1978
- 60b: Frenell, 1970. The professional middle class constituted the overwhelming majority of the membership of the Eminent Education Society.
- 61: Hobsbawn, 1968
- 61a: See Mackenzie, 1978
- 61b: Wersky, 1972
- 62: Tawney, 1931 P49

- 62a: Scull, 1977 #24
- 63: Edgerton, 1970
- 64: Abliz-Miranda et al, 1966
- 65: Dybwald, 1970; Abliz-Miranda et al, 1966
- 66: Tizard, 1964
- 67: Abliz-Miranda et al, 1966
- 68: See Kety, 1962; Sutton, 1980
- 69: See Robinson, 1978
- 70: F.G. Cjajel et al 1980
- 71: See Sutton, 1980
- 72: Robinson, 1978
- 73: Sutton, 1980
- 74: Kety, 1962
- 74a: Leach and Wing, 1980
- 75: C.M.H. 1973
- 76: Bogdan and Taylor, 1976
- 77: Heshusius, 1981
- 78: Marx, 1844
- 79: Stein, Susser and Guterman, 1977
- 80: Open University, 1982.

## REFERENCES

- ABELSON, R.P. (1972). Are Attitudes Necessary?  
In King and McGinnies (eds.) Op.cit.
- ABRAMS, P., ABRAMS, S., HUMPHREY, R., and SNAITH, R. (1981). Action for Care - a Review of Good Neighbourhood Schemes in England.
- ACHERH, E. (1959). A Short History of Psychiatry. Hafner.
- ADAMS, M. and LOVEJOY, H. (1972). The Mentally Subnormal: Social Work Approaches. Heinemann.
- ADAMS, S.M. (1971). Mental Retardation and its Social Dimensions. Columbia University Press.
- ADORNO, T.W. (1967). Sociology and Psychology; Part 1, New Left Review, 46, 67-80; Part 2, New Left Review, 47, 79-97.
- AKERS, R.L. (1967). Problems in the Sociology of deviance Social Definitions and Behaviour. Social Forces, 46, 455-465.
- ALBIZU-MIRANDA, C., MARTIN, N. and STANTON, H.K. (1966). The Successful Retardate. Department of Health, Education and Welfare, Puerto Rico.
- ALTHUSER, L. (1971). 'Lenin and Philosophy' and other essays. New Left Books.
- ANDERSON, M. (1971). Family Structures in Nineteenth Century Lancashire. Cambridge University Press.
- ANON (1853). Cretins and Idiots: a short account of the Institution for their relief and care. W.A.Wighton.
- ASHMORE, R. (1975). Background considerations in developing strategies for changing attitudes and behaviour towards the Mentally Retarded. In M.J. Began and S.A. Richardson (eds.) Op.cit.
- ATKINSON, P. (1977). The Reproduction of Medical Knowledge. In R. Dingwell (ed.) Op.cit.
- ATKINSON, P. (1979). The Production of Medical Practitioners. In P. Atkinson et al (eds.) Op.cit.
- ATKINSON, P., DINGWELL, R. and MURICOTT, A. (1979). Prospects for the National Health Service. Croom Helm.
- AUDEN, G. (1909). Report of the Medical Superintendent for Birmingham.
- AUDEN, G. (1910). Report of the Medical Superintendent for Birmingham.

- AUDEN, G. (1911). Report of the Medical Superintendent for Birmingham.
- AUDEN, G. (1912). Report of the Medical Superintendent for Birmingham.
- AUDEN, G. (1913). Handbook for Birmingham and the Neighbourhood. Cornish
- BAKAL, Y. (ed.) (1973). Closing Correctional Institutions. Lexington Books.
- BAKER, B.W. (1930). History of the care of the feeble-minded. Bulletin Mass. Department of Mental Diseases, XIV, April
- BALL, S. (1896). The Moral Aspects of Socialism. The Fabian Society, Fabian Tract no. 72.
- BARNARD, K. and LEE, K. (eds, 1977). Conflicts in the National Health Service. Croom Helm.
- BARR, M.W. (1903). Mental Defectives; their history and treatment and training. Blackeston.
- BARRETT, Cannon and Mrs. S.A. (1909). Towards Social Reform.
- BARRING, B.G. (1965). The classes of stupidity. Scientific American, 213, 113-119
- BARTON, L. and TOMLINSON, S. (eds, 1981). Special Education: policies, practices and social issues. Harper and Row.
- BARTON, R. (1959). Institutional Neurosis. Wright
- BAXTER, W.F. (1962). An Historical Survey of Attitudinal Variations regarding the Mentally Retarded. Maryland State Medical Journal, Oct. 576-580.
- BAYLEY, M. (1973). Mental Handicap and Community Care. Routledge and Kegan Paul.
- BEACH, F. (1895). The Treatment and Education of Mentally Feeble Children. Churchill.
- BECKER, H. (1964). Outsiders: Studies in the Sociology of Deviance. Free Press.
- BECKER, H.S. (ed.) (1964). The Other Side. Free Press.
- BECKER, H.S. (ed.) (1966). Social Problems: A Modern Approach.
- BEGAN, M.J. and RICHARDSON, S.A. (eds.) (1975). The Mentally Retarded and Society: A Social Science Perspective. University Park Press.
- BELINKOFF, C. (1960). Community Attitudes towards Mental Retardation. American Journal of Mental Deficiency, 65, 221-226

- BELL, C. (1968). Middle-class Families. Routledge and Kegan Paul.
- BERRY, C.S. (1925). The case for the mentally retarded. Mental Hygiene, 9, 725-734.
- BEVERIDGE (1906). The problem of the unemployed. Sociology Papers, 3
- BICKMORE, A. (1913). Industries for the Feeble-minded. Bartholomew Press.
- BINET, A. and SIMON, T. (1905). Upon the Necessity of Establishing a Scientific Diagnosis of Inferior States of Intelligence. In Rosen, M., Clark, G. and Kivitz, M. (eds.) Op.cit.
- BIRCH, H.G. (ed.) (1964). Brain Damage in Children. Williams & Wilkins.
- BIRCH, H.G., RICHARDSON, S.A., BAIRD, D., HOROBIN, G. and ILLSLEY, R. (1970). Mental Subnormality in the Community. Williams and Wilkins.
- BIRENBAUM, A. (1970). On Managing a Courtesy Stigma. Journal of Health. 196-206.
- BIRENBAUM, A. and RE, M. (1979). Resettling Mentally Retarded Adults in the Community. American Journal of Mental Deficiency, 83, 4, 323-329.
- BLACKER, C.P. (1952). Eugenics: Galton and After. Gerald Duckworth.
- BLAKESTONE, W.L. ( ). Commentaries on the Laws of England 1765-9. Clarendon Press.
- BLOCK, N. and DWORKIN, G. (1972). The IQ Controversy. Quartet Books.
- BLOOR, A. and HOROBIN, G.W. (1975). Conflict and Conflict Resolution in Doctor/Patient Interaction. In C. Cox and A. Meade. Op.cit.
- BLUNT, H.P. (1907). The Moral Hazard in Fire Insurance. Journal of the Insurance Institute of Great Britain and Ireland, 10.
- BOGDAN, R. and TAYLOR, S. (1976). The Judged, Not the Judges. American Psychologist, 31, 47-52.
- BONE, M., SPAIN, S. and MARTIN, F.M. (1972). Plans and Provision for the Mentally Handicapped. George Allen and Unwin.
- BOOTH, T.A. (1978). From Normal Baby to Handicapped Child. Sociology, 12, 2, 203-322.
- BOSWELL, D. and JAEHNIG, W. (1975). The Social Integration of Mental Handicap. In Disability and Assisted Independence; Open University Course P251: The Handicapped person in the community.

- BORING, E.G. (1950). A History of Experimental Psychology (3rd edition). Prentice Hall.
- BOSANQUET, H. (1914). Social Work in London - a history of the Charity Organization Society. Murry.
- BOWER, T.G.R. (1979). Human Development. Heinemann.
- BOWLBY, J. (1954). Maternal Deprivation. Penguin.
- BOWLES, S. and GINTIS, A. (1976). Schooling in Capitalist America. Routledge and Kegan Paul.
- BRANNIGAN, A. (1980). Naturalistic and sociological models of the problem of scientific discovery. British Journal of Sociology, 31, 2, 559-573.
- BROMLEY SOCIETY FOR MENTALLY HANDICAPPED CHILDREN (1975). A Life Apart.
- BROOKS, P.H. and BAUMEISTER, F. (1977). A plea for consideration of ecological validity in the experimental psychology of mental retardation. American Journal of Mental Deficiency, 81, 5, 407-416.
- BURT, C.L. (1913). The inheritance of mental characteristics. Eugenics Review, 4.
- CAMPAIGN FOR MENTAL HANDICAP (1972). Our life: the first conference for mentally handicapped people. C.M.H.
- (1973). Listen: a weekend conference for mentally handicapped people. C.M.H.
- (1973a). The Action Needed Now. C.M.H.
- (1974). Integration or Segregation: the choice in practice. C.M.H., Enquiry Paper no. 2.
- (1978). Encore: the way ahead. C.M.H.
- CAMPBELL, A.C. (1968). Comparison of family and community contacts of mentally subnormal adults in hospital and in local authority hostels. British Journal of Preventive and Social Medicine, 22.
- CAMPBELL, A.C. (1971). Aspects of personal independence of moderately subnormal and severely subnormal adults in hospital and local authority hostels. International Journal of Social Psychiatry, 17, 4.
- CARR, J. (1975). Young Children with Downs' Syndrome: their development, upbringing and effects on their families. Butterworth.
- CARVER, V. and RODDA, M. (1978). Disability and the Environment. Elek.
- CASLETT, M. and MITTLER, P. (1964). Hospital and community care of the subnormal. Lancet, 18 april.
- CENTREWALL, S.A. and CENTREWALL, W.R. (1960). A study of children with mongolism reared in the home compared with those reared away from home. Pediatrics, 25, 678-685.

- CHAMBLISS, W. (1970). A Sociological Analysis of the Law of Vagrancy. In: W. Carson & P. Wiles (eds.) Crime and Delinquency in Britain. Martin Robertson.
- CHARITY ORGANISATION SOCIETY (1877). Report of a Subcommittee on the Education and Care of Idiots, Imbeciles and Harmless Lunatics. Charity Organisation Series, Longman, Green & Co.
- CHARLESWORTH, W.R. (1978). Ethology: Its Relevance for Observational Studies of Human Adaptation. In: Sackett, G.P. Op.cit.
- CHAZAN, M. (1979). Identification, assessment and treatment: the role of the educational psychologist. In YOUNG, A.F. (ed) Young Children with Special Needs. Department of Education, University College of Swansea.
- CLARKE, A.D.B. (1968). Learning and Mental Development. British Journal of Psychiatry, 114, 1061-78.
- CLARKE, A.D.B. and CLARKE, A.M. (eds.) (1973). Mental Retardation and Behaviourist Research. Churchill Livingstone.
- CLARKE, A.D.B. and CLARKE, A.M. (1973a). What are the Problems? An Evaluation of Recent Research relating to theory. In: A.D.B. Clarke and A.M. Clarke. Op.cit.
- CLARKE, A.D.B. and CLARKE, A.M. (1975). Recent Advances in the Study of Subnormality. Mind.
- CLARKE, A.D.B. and CLARKE, A.M. (eds.) (1974). Readings from Mental Deficiency: The Changing Outlook. Methuen.
- CLARKE, A.D.B. and CLARKE, A.M. (1974a). Prospects for Prevention and Amelioration of Mental Subnormality: An Overview. In: Clarke A.D.B. and Clarke, A.M. Op.cit.
- CLARKE, A.D.B. and CLARKE, A.M. (1974b). Criteria and Classification of Subnormality. In: Clarke, A.D.B. and Clarke, A.M. Op.cit.
- CLARKE, A.D.B. and CLARKE, A.M. (1974c). Genetic-environmental interactions in Cognitive Development. In: Clarke, A.D.B. and Clarke, A.M. Op.cit.
- CLAUSEN, J. (1967). Mental Deficiency - Development of a Concept. American Journal of Mental Deficiency, 71, 5, 724-745.

- COARD, B. (1971). How the West Indian Child is Made Educationally Subnormal in the British School System. New Beacon Books.
- CONDILLAC, (1755). Traité des Sensations. Originally published in Oeuvres de Condillac (1798), prepared by the Abbé de Mably. English translation by G. Carr, 1930.)
- COX, C. and MEADE, A. (eds, 1975). A Sociology of Medical Practice. Collier-MacMillan.
- CRAFT, M. and CRAFT, A. (1978). Sex and the Mentally Handicapped. Routledge and Kegan Paul.
- CRAFTS, L.W. and DOLL, E.A. (1917). The Proportion of Mental Defectives among Juvenile Delinquents. Journal of Delinquency, 2, 119-143.
- CRANFIELD, P.C. (1960). The History of Endemic Goitre and Cretinism in the thirteenth to the fifteenth Century. Proceedings of the Royal Society of Medicine, 53, 995-1002.
- CRANFIELD, P.C. (1961). A Seventeenth Century view of Mental Deficiency and Schizophrenia: Thomas Willis on Stupidity or Foolishness. Bulletin of the History of Medicine, 35, 291-316
- CRANFIELD, P.C. (1962). The Discovery of Cretinism. Bulletin of the History of Medicine, 36, 489-511.
- CRANFIELD, P. and FEDORN, W. (1967). The Begetting of fools: An Annotated Translation of Paracelsus' 'De Generatione stultorum'. Bulletin of the History of Medicine, 41, 56-74.
- CRUIKSHANK, D. (1924). The Mongol in our Midst. Kegan Paul.
- CZEIZEL, A., LANGI-ENGELMAYER, A., KLUJBER, L., METNEKI, J. and FUSNADY, G. (1930). Etiological Study of Mental Retardation in Budapest, Hungary. American Journal of Mental Deficiency, 85, 2, 120-128.
- DALE, R., ESLAND, G. and MacDONALD, M. (eds.) (1976). Schooling and Capitalism. Routledge & Kegan Paul.
- D'ALTON, S.O. (1970). Conceptions of Retardation in Industrial Society. Australian Journal of Mental Retardation. I, 38-39.
- DARLING, R.B. (1979). Families Against Society: A Study of Reactions to Children With Birth Defects. Sage Publications.
- DAVENPORT, C.B. (1911). Heredity in Relation to Eugenics. Henry Holt & Co. (Re-printed Ed 1972, Arno Press)



- DAVID, S. (1975). Point of View. British Journal of Mental Subnormality, 21, 58-60.
- DAVIS, A.G. and STRONG, P.M. (1976). Aren't Children Wonderful: A Study of the Allocation of Identity in Development. In: Stacy, M. (ed.) Op.cit.
- DAVIS, K. and MOORE, W. (1945). Some Principles of Stratification. American Sociological Review, 10.
- DEACON, J.J. (1974). Tongue-Tied. Fifty Years of Friendship in a Subnormality Hospital. National Society for Mentally Handicapped Children.
- DEFOE, D. (1697). An Essay upon Projects. Cockerill. (Re-printed in H. Morley (1889) *The Earlier Life and Works of Daniel Defoe. Born Franklin*)
- DENT, H.E. (1968). Operant conditioning as a tool in the habilitation of the mentally retarded. Proceedings of the First Congress of the International Association for the Scientific Study of Mental Deficiency, 873-876.
- DEPARTMENT OF HEALTH AND SOCIAL SECURITY (1968). Report of the Committee on Local Authority and Allied Social Services. H.M.S.O., Cmnd. 3703.
- (1971). Better Services for the Mentally Handicapped. H.M.S.O., Cmnd. 4683.
- (1976). Priorities in the Health and Personal Social Services in England; a consultative document. H.M.S.O.
- (1976a). Prevention and Health; everybody's business. H.M.S.O.
- (1977). The Way Forward: priorities in the health and personal social services. H.M.S.O.
- (1978). Review of the Mental Health Act 1959. H.M.S.O.
- (1979). Report of the Committee of Enquiry into Mental Handicap Nursing and Training (The Jay Report). H.M.S.O.
- (1980). Mental Handicap: progress, problems and priorities. D.H.S.S.
- (1981a). Report of a Study on Community Care. D.H.S.S.
- (1981b). Care in the Community; a consultative document on moving resources for care in England. D.H.S.S.
- (1981c). Ware in Action: A handbook of policies and priorities for the health and personal social services in England. H.M.S.O.

- DEUTCHER, I. (1973). What we say/What we do. Scott Freeman.
- DEXTER, L.S. (1956). Heredity and Environment re-explored. Eugenics Quarterly, 3, 88-93.
- DEXTER, L.S. (1956a). Towards a Sociology of Mental Deficiency. American Journal of Mental Deficiency, 61, 10-16.
- DEXTER, L.S. (1958). A Social Theory of Mental Deficiency. American Journal of Mental Deficiency, 62, 920-928.
- DEXTER, L.S. (1958a). A Note on Selective Inattention in Social Science. Social Problems, 6, 176-182.
- DEXTER, L.S. (1960). Research Needs of the Mentally Subnormal. American Journal of Mental Deficiency, 64, 835-838.
- DEXTER, L.S. (1960a). Who decides who is Mentally Deficient. American Behavioural Scientist. 4. Oct. 13-15.
- DEXTER, L.S. (1963). Sociology of the Exceptional Person. Indiana Journal of Social Research.
- DEXTER, L.S. (1964). The Tyranny of Schooling. Basic Books.
- DEXTER, L.S. (1966). What the Practitioner in the Field of Mental Retardation can learn from Social Science. Mental Retardation (Canada).
- DEXTER, L.S. (1973). Organisational and Governmental Aspects of the Clinically Relevant. Journal of Clinical Child Psychology, 11, 1.
- DICKENS, P. (1978). The defective psychologist: clinical psychology and mental handicap. Bulletin of the British Psychological Society, 31 (February), 40-41.
- DINGWALL, R. (ed.) (1977). Health Care and Health Knowledge. Croom Helm.
- DINGWALL, R. (1979). Inequality and the National Health Service. In: P. Atkinson et al (eds.) Op.cit.
- DOUGLAS, J.E. and SUTTON, A. (1978). The Development of Speech and Mental Processes in a Pair of Twins: a Case Study. Journal of Child Psychology and Psychiatry, 19, 49-56.
- DOWN, J.L. (1887). On Some Mental Afflictions of Childhood and Youth. Churchill.
- DOYAL, L. (1979). The Political Economy of Health. Pluto Press.
- DUGDALE, R.L. (1877). The Jukes. A Study in Crime, Disease and Heredity. Putnam.
- DUNCAN, P.M. and MILLARD, W. (1866). A Manual for the Classification, Training and Education of the Feeble-Minded, Imbecile and Idiotic. Longman.

- DYBWAD, G. (1970). Treatment of the Mentally Retarded: a cross-national view. In Haywood (ed), op. cit.
- EAST, E.M. (1923). Mankind at the Crossroad. Scribner.
- EDGERTON, R. and MacANDREW, C. (1966). On the Possibility of Friendship. American Journal of Mental Deficiency, 70, 612-21.
- EDGERTON, R.B. (1967). The cloak of Competence: Stigma in the lives of the Mentally Retarded. University of California Press.
- EDGERTON, R.B. (1968). Anthropology and Mental Retardation. A Plea for the Comparative Study of Incompetence. In: Prehm, H.T. Op.cit.
- EDGERTON, R.B. (1970). Mental Retardation in non-western Societies: Towards a Cross-Cultural Perspective on Incompetence. In: Haywood, H.C. Op.cit.
- EDGERTON, R.B. (1980). Mental Retardation. Fontana.
- EDGERTON, R.B. and BERCEVICI, S.M. (1976). The Cloak of Competence; Years later. American Journal of Mental Retardation. March. 5.
- EDGERTON, R.B. and EDGERTON, C.R. (1973). Becoming Mentally Retarded in a Hawaiian School. In: G. Tarzan et al. (eds.). Op.cit.
- EDGERTON, R.B. and LANGRESS, L.L. (1978). Observing Mentally retarded Persons in Community Settings: An Anthropological Perspective. In: G.S. Sackett. Op.cit.
- ELIAS, N. (1972). Theory of science and history of science. Economy and Society, 1, 117-133.
- ELSTON, M. (1977). Medical Autonomy: Challenge and Responses. In: K. Bernard and K. Lee (eds.) Conflicts in the National Health Service. Croom Helm.
- ELY COMMITTEE (1969). Report of the Committee of Inquiry into Allegations of Ill-Treatment of Patients and other Irregularities at the Ely Hospital, Cardiff. H.M.S.O.
- EMERSON, R.M. (1969). Judging Delinquents. Aldine Publishing Company.
- ERIKSON, K. (1966). Wayward Puritans.
- ESQUIROL, E. (1845). Treatise on Insanity (translated by E.K. Hunt). Lea and Blanchard.

- ESTABROOK, A.H. (1916). The Jukes in 1915. Carnegie Institution.
- EVANS, B. and WAITES, B. (1981). IQ and Mental Testing. MacMillan.
- FARBER, B. (1968). Mental Retardation: Its Social Context and Social Consequences. Houghton Mifflin.
- FARBER, B. (1968a). Sociological Research in Mental Retardation. In: H.J. Prehm et al (eds.) Op.cit.
- FARRALL, L.A. (1970). The origin and growth of the English eugenics movement 1865-1925. Unpublished PhD thesis, University of Indiana.
- FAY, B. (1975). Social Theory and Political Practice. Allen & Unwin.
- FERNALD, W.E. (1904). Care of the feebleminded. In: Proceedings of the National Conference on Charities and Correction.
- FERNALD, W.E. (1912). The burden of feeblemindedness. Journal of Psycho-Asthenics, 17, 87-111.
- FERNALD, W.E. (1918). A History of the Treatment of the Feebleminded. In: W.E. Fernald (ed.) Researches in the Pathology of the Feebleminded. G.H. Ellis.
- FERRARA, D. (1979). Attitudes of Parents of Mentally Retarded Children towards Normalization Activities. American Journal of Mental Deficiency, 14, 2, 145-151.
- FISHBEIN, M. (1967). Attitude Theory and Measurement. John Wiley & Son.
- FITZHERBERT, Sir A. (1534). La Nouvelle Natura Brevium, 1st edn., London. Translated and published 1538 as The New Booke of Justices of Peas, made by A.F. Judge, lately translated out of French into English.
- FLAVELL, J.H. (1963). Developmental Psychology of Jean Piaget. Van Nostrand.
- FORD, J. (1975). Paradigms and Fairy Tales: an Introduction to the Science of Meaning. Routledge and Kegan Paul.
- FOTHERINGHAM, J.B. and CREAL, D. (1974). Handicapped children and handicapped families. International Review of Education, 20, 354-371.
- FOUCAULT, M. (1971). Madness and Civilization. Tavistock.
- FOUCAULT, M. (1976). Mental Illness and Psychology. Harper Colephon.

- FOX, A.M. (1975). They Get this Training but They Don't Really Know How You Feel. National Fund for Research into Crippling Diseases.
- FREIDSON, E. (1966). Disability as Social Deviance. In: M.D. Sussman. Op.cit.
- FREIDSON, E. (1970). The Profession of Medicine. Dodd, Meade & Co.
- FREIDSON, N. (1967). The Nature of Psychological Research: The Psychological Experiment as a Social Interaction. Basic Books.
- FREIDSON, E. and LORBER, J. (eds.) (1972). Medical men and their Work. Aldine Atherton.
- FULLER, T. (1640). The Holy State. Cambridge, Williams.
- GALTON, F. (1869). Hereditary Genius. Recent Edition (1972) published by Peter Smith (Gloucester, Mass.)
- GALTON, F. (1908). Local Associations for Promoting Eugenics. Nature, 22 Oct.
- GALTON, F. (1909). The Problem of the Feebleminded. P.S. King.
- GATH, A. (1973). The school-age siblings of mongol children. British Journal of Psychiatry, 123, 161-167.
- GATH, A. (1978). Down's Syndrome and the Family. Academic Press.
- GATTRELL, V.A.C. (1980). The decline of theft and violence in Victorian England. In Gattrell, V.A.C. et al (eds), The Social History of Crime in Western Europe since 1500. Europa.
- GEORGE, V. (1973). Social Security and Society. Routledge and Kegan Paul.
- GODDARD, H.H. (1910). Four hundred immigrants classified by the Binet Method. Journal of Psychoaesthetics, 15, 17-30.
- GODDARD, H.H. (1910). Heredity in Feeblemindedness. American Breeders Magazine, 1, 165-178.
- GODDARD, H.H. (1912). The Kallikak Family: A Study in the Heredity of Feeblemindedness. Macmillan.
- GODDARD, H.H. (1915). Proceedings of the National Conference of Correction and Charities.
- GOFFMAN, E. (1961). Asylums. Anchor Books.
- GOFFMAN, E. (1968). Stigma: The Management of Spoilt Identities. Penguin.
- GORDON, R.A. (1975). Examining labelling theory: The Case of Mental Retardation. In: W.R. Gove: The Labelling

- of Deviance: Evolution and Perspective.  
John Wiley & Sons.
- GOTTLIEB, J. (1975). Public, Peer and Professional Attitudes towards Mentally Retarded Persons. In: M.J. Began and S.A. Richardson (eds.) Op.cit.
- GOTTLIEB, J. and CARMEN, C. (1975). Public Attitudes toward Mentally Retarded Children. American Journal of Mental Deficiency, 80, 72-80.
- GOTTLIEB, J. and SIPORSTEIN, L. (1976). Attitudes toward Mentally Retarded Persons: Effects of Attitude Deferment Specificity. American Journal of Mental Deficiency, 80, 376-381.
- GOTTWALD, H. (1970). Public Awareness about Mental Retardation. Research Monograph 4: The Council for Exceptional Children.
- GOULDNER, A.W. (1968). The sociologist as partisan: sociology and the Welfare State. American Sociologist, May, 103-116.
- GRALIKER, B.V. (1971). Societal attitudes toward the mentally retarded. In Koch and Dobson (eds), Op. cit.
- GREENGROSS, W. (1976). Entitled to love. Marriage Guidance Council.
- GROSSMAN, F.K. (1972). Brothers and Sisters of Retarded Children. Syracuse University Press.
- GROSSMAN, H.J. (1973). Manual on Terminology and Classification in Mental Retardation. Special Publication Series No. 2. American Association on Mental Deficiency.
- GRUNWALD, K. (1969). The Mentally Retarded in Sweden. Swedish Institute.
- GRUNWALD, K. (1969). Psykist utvecklingsstörda. Albert Bonniers Forlag (English Translation 1978 - The Mentally Handicapped. Hutchinson).
- GRUNWALD, K. (1972). The Practical Experiences of Settling the Mentally Handicapped in the Community - the Swedish Model. In: Gunzburg, H.C. (ed.) Op.cit.
- GRUNWALD, K. (1977). Community Living for Mentally Retarded Adults in Sweden. Current Sweden, 159, May 2.
- GRUNWALD, K. (1979). Sex-liberation and Parenthood for the Mentally Retarded in Sweden. The National Board of Health and Welfare.

- GRUNWALD, K. and LINNEN, B. (1979). Mentally Retarded: Sexuality and Normalization. Current Sweden, 237, Dec. 2.
- GUNZBURG, H.C. (1970). The Hospital as a Normalizing Training Environment. Journal of Mental Subnormality, XVI, 2, 37, 71-83
- GUNZBURG, H.C. (ed.) (1973). The Guiding Environment: The Dynamics of Residential Living. U.S. Dept. of Health, Education and Welfare.
- GUSKIN, S.L. (1974). Research on Labelling Retarded Persons: Where do we go from here? American Journal of Mental Deficiency, 79, 3, 262-264.
- HAFFNER, C. (1968). The Changeling: History and Psychodynamics of Attitudes to Handicapped children in European Folklore. Journal of the History of the Behavioural Sciences, IV, 1, 55-6.
- HALDANE, J.B.S. (1938). Heredity and Politics. George Allen and Unwin.
- HALE, Sir M. (1736). Historia Placitorum Coronae ... Now first published from his Lordship's original manuscript. London.
- HAYWOOD, H.C. (1970). Social and Cultural Aspects of Mental Retardation. Appleton-Century.
- HEBER, N. (1970). Epidemiology of Mental Retardation. Charles C. Thomas.
- HENSCHEL, A.M. (1972). The Forgotten Ones. University of Texas Press.
- 
- HESHUSIUS, L. (1981). Meaning in Life as Experienced by Persons Labelled Retarded in a Group Home. C.C.Thomas.
- HEWETT, S. (1972). The need for long-term care. In KIRMAN, B. (ed), Mental Retardation: Occasional Papers. Butterworth.
- HEWETT, S. with NEWSON, J. and NEWSON, E.C. (1970). The Family and the Handicapped Child. George Allen and Unwin.
- HINDNESS, B. (1974). The Use of Official Statistics. Free Press.
- HITCH, D. (1977). What help can parents get? A Family Fund analysis. Concern, 25 (Spring)
- HOBSBAWM, E. (1968). Industry and empire. Penguin.
- HOBSBAWM, E. (1968a). Labouring men: studies in the history of labour. Weidenfeld and Nicholson.

- HOBSON, J.A. (1955). Psychiatric Evidence in Murder Trials. Howard Journal. 9.
- HOLLANDER, B. (1913). Abnormal Children. Kegan Paul Trench Trubner & Co.
- HOLLINGER, C.S. and JONES, R.L. (1970). Community Attitudes toward Slow Learners and Mental Retardation: What's in a name? Mental Retardation, 8, 19-23.
- HORSEFIELD, E. (1940). Mental Defectives at the Court of Philip IV of Spain. American Journal of Mental Deficiency, 45, 152-157.
- HOWE, S.G. (1848). Report made to the legislature of Massachusetts upon idiocy. Ed. Coolidge and Wiley. Senate, 51, February.
- HOWE, S.G. (1850). On the Causes of Idiocy. Maclacklan & Stewart.
- HUNT, J.M. (1961). Intelligence and Experience. Ronald Press.
- HUNTER, J.D. (1973). Changing Patterns of Organization and Management. In: A.D. Forrest et al (eds.) New Perspectives in Mental Handicap. Churchill-Livingstone.
- HUNTER, R.A. and MacALPINE, I. (1963). Three hundred Years of Psychiatry 1535-1860: A History presented in Selected English Texts. Oxford University Press.
- HURST, P.G. (1972). Marx and Engels on law, crime and morality. Economy and Society, 1, 28-56.
- IGNATIEFF, M. (1978). A just measure of pain. MacMillan.
- INHELDER, B. (1958). The Growth of Logical Thinking. Routledge and Kegan Paul.
- IRELAND, W.W. (1898) The Mental Afflictions of Children: idiocy imbecility and insanity. Churchill.
- ITARD, J. (1801). The Wild Boy of Aveyron: of the first developments of the young savage of Aveyron, In Malson, L., op. cit.
- ITARD, J. (1807). Report on the progress of Victor of Aveyron. In Malson, L., op. cit.
- JAEHNIG, W.B. (1974). Mentally Handicapped Children and their Families: Problems for Social Policy. Unpublished Ph.D. Thesis, Dept. of Sociology, University of Essex.
- JAEHNIG, W.B. (1979). A Family Service for the Mentally Handicapped. Fabian Tract.
- JOFFE, J. (1966). Attitudes of Adolescents towards the Mentally Retarded. American Journal of Mental Deficiency. 76, 907-912.



- JOHNSON, G.E. ( ). Contribution to the psychology and pedology of feeble-minded children. Journal of Psychoaesthetics, Sept.
- JOHNSON, R.C. (1976). Notes on the schooling of the English working class, 1780-1850. In Dale et al, op cit.
- JONES, C. and Novak, T. (1980). The state and social policy. In Corriagan, P. (ed), Capitalism, state formation and Marxist Theory. Quartet Books.
- JONES, K. (1970). Mental Health and social Policy 1845-1959. Routledge & Kegan Paul.
- JONES, K. (1972). A History of the Mental Health Services. Routledge & Kegan Paul.
- JONES, K. (1974). Opening the Door: A Study of New Policies for the Mentally Handicapped. Routledge & Kegan Paul.
- JONES, R.L. (1974). The Hierarchical Structure of Attitudes towards the Exceptional. Exceptional Children, March.
- JORDON, J.E. (1974). The Mentally Retarded (1st edn.) Charles E. Merrill.
- KAMIN, L.J. (1974). The Science and Politics of I.Q. Penguin.
- KANNER, L. (1964). A History of the Law and Study of the Mentally Retarded. Charles C. Thomas.
- KANNER, L. (1967). Medicine in the History of Mental Retardation, 1800-1965. American Journal of Mental Deficiency, 72, 2, 165-70.
- KATZ, D. and KAHN, R.L. (1966). Social Psychology of Organizations. Wiley.
- KENNEDY, I. (1980). Unmasking Medicine. (The Reith Lectures). The Listener, 6, 13, 20 November.
- KERSHAW, J.D. (1973). Public Attitudes. In: Handicapped Children. Heinemann.
- KERSHNER, J.R. (1970). Intellectual and social development in relation to family functioning: a longitudinal comparison of home vs. institutional effects. American Journal of Mental Deficiency, 75, 276-284.
- KETY, S.C. (1962). Report of the Mission to the U.S.S.R., President's Panel on Mental Retardation. U.S. Department of Health, Education and Welfare.
- KIERNAN, C.C (1974) A location of behaviour modification in the ward situation. In H.C.Gunzberg (ed), Experiments in the
- Kiernan, C.C. (1974) Behavior Modification  
in A.M. Clarke and A.D.B. (eds) op cit

- Rehabilitation of the Mentally Handicapped. Butterworth.
- KING, B.T. and MCGINNIES, E. (eds, 1972). Attitudes, Conflict and Social Change. Academic Press.
- KING, R.D., RAYNES, N.V. and TIZARD, J. (1971). Patterns of Residential Care. Routledge and Kegan Paul.
- KIRMAN, B. (1975). Mental Handicap. Crosby, Lockwood, Staples.
- KNIGHT, I.F. (1968). The Geometric Spirit. Yale University Press.
- KOCH, R. and DOBSON, J.C. (eds, 1971). The Mentally Retarded Child and his Family. Brunner/Mazel.
- KURTY, E.A. (1964). Implications of Recent Sociological Research in Mental Retardation. American Journal of Mental Deficiency, 69, 16-20.
- KURTY, E.A. (1977). Social Aspects of Mental Retardation. Lexington Books.
- KUSHLICK, A. (1966). A Community Service for the Mentally Subnormal. Social Psychiatry, 2.
- KUSHLICK, A. (1967). A Method of evaluating the Effectiveness of a Community Health Service. Social and Economic Administration, Oct.
- K KUSHLICK, A. and COX, G. (undated). The Ascertained Prevalence of Mental Subnormality in the Wessex Region of 1 July, 1963. Wessex Regional Hospital Board (Mimeograph).
- LAPAGE, C.P. (1920). Feeble-mindedness in Children of School Age. Manchester University Press.
- LASLETTE, P. (ed.) (1972). Household and Family in Past Time. Cambridge University Press.
- LATTIMER, R. (1970). Current Attitudes towards Mental Retardation. Mental Retardation, 8, 30-32.
- LAWLER, J.M. (1978). I.Q., Heritability and Racism. Lawrence & Wishart.
- LEADBETTER, A. (1933). Heredity and the Social Problem Group. Edward Arnold & Co.
- LEMERT, E.M. (1967). Deviance, Social Problems, and Social Control. Prentice Hall.
- LEWIS, J.F. (1973). The Community and the Retarded: A Study in Social Ambivalence. In: G. Tarzan et al (eds.) Op.cit.
- LICHTMAN, R. (1970). Symbolic Interactionism and Social Reality: Some Marxist Queries. Berkeley Journal of Sociology, 5, 75-94.
- LIPPMAN, L.D. (1972). Attitudes towards the Handicapped. Charles C. Thomas.

- LOCKE, A. (1978). The case against assessment. Bulletin of the British Psychological Society, 31, 322-324.
- LOCKE, J. (1690). An essay concerning human understanding. Barnet.
- LEACH, J. and WING, J. (1980). Helping Destitute Men. Methuen.
- LONDON, P. (1972). The end of ideology in behaviour modification. American Psychologist, 27, 913-920.
- LURIA, A.R. (1958). How Soviet schools teach the retarded and handicapped. New World Review, 26, 23-36 .
- LURIA, A.R. (ed, 1960). The Mentally Retarded Child. Academy of Pedagogical Sciences of the Russian Socialist Federative Soviet Republic. (English edition (1963). Pergamon Press. Translated by W.P. Robinson and edited by B. Kirman.)
- LURIA, A. (1960a). The problem of mental retardation and its study. In Luria (1960), above.
- LURIA, A. (1960b). The role of speech in the formation of temporary connections and in the regulation of the behaviour of child oligophrenics. In Luria (1960), above.
- LURIA, A.R. (1961). The Role of Speech in the Regulation of Normal and Abnormal Behaviour. Pergamon.
- LURIA, A. (1961a). An objective approach to the study of the abnormal child. American Journal of Orthopsychiatry, 31, 1-16.
- LURIA, A.R. (1976). Cognitive Development. Harvard University Press.
- LURIA, A.R. and VYGOTSKY (1961). Speech and the Regulation of Behaviour. Pergamon.
- LUTHER, M. (1961). Selections from his Writings. Anchor.
- LYLE, J. (1959). The Effect of an Institutional Environment upon the Verbal Development of Imbecile Children.  
 I. Verbal Intelligence. Journal of Mental Deficiency, 31, 122-128.  
 ----- II. Speech and language. Journal of Mental Deficiency 4, 1-13.  
 ----- III. The Brooklands Residential Family Unit. Journal of mental Deficiency, 4, 14-22.
- MacANDREW, C. and EDGERTON, R. (1966). On the possibility of friendship. American Journal of Mental Deficiency, 70, 612-621.
- MacCORMACK, M. (1978). A Mentally Handicapped Child in the Family. Constable.

- McCORMACK, M. (1979). Away from Home. Constable.
- MacIntyre, S. (1977). Old age as a Social Problem. In R. Dingwall et al (eds), op. cit.
- MACKENZIE, D. (1976). Eugenics in Britain. Social Studies of Science, 6, 499-532.
- MACKENZIE, D. (1978). Statistical theory and social interests: a case-study. Social Studies of Science, 8, 35-83
- MAJOR, R. (1945). Classic Descriptions of Diseases. Charles C. Thomas.
- MALSON, L. (1976). Wolf Children. New Left Books.
- MANNING, M. (1977). Into the Uncaring Community. Community Care, April 6.
- MARAIS, E. and MARAIS, M. (1976). Lives worth Living. Souvenir Press.
- MARTIN, D.V. (1955). Institutionalisation. The Lancet, 1188-1190.
- MARX, K. (1852). Das Achzehnte Brumaire des Louis Buonaparte. Hamburg, O.Meissner.
- MASLAND, R., SARSON, S. and GLADWIN, R. (1958). Mental Subnormality. Basic Books.
- MATTESON, J. (1970). Marriage and Mental Handicap. Duckworth & Co.
- MENDELSON, H. (1954). A Sociological Approach to Certain Aspects of Mental Deficiency. American Journal of Mental Deficiency, 58, 506-510.
- MERCER, J.R. (1971). The meaning of mental retardation. In Koch and Dobson (eds), Op. cit.
- MERCER, J.R. (1972). I.Q., The Lethal Label. Psychology Today, Sept. 44-47.
- MERCER, J.R. (1973). Labelling the Mentally Retarded. University of California Press.
- MERKE, F. (1960). The History of Endemic Goiter and Cretinism in the thirteenth to the fifteenth century. Proceedings of the Royal Society of Medicine, 53, 995-1002.
- MERRISON, Sir A. (Chairman) (1979). Royal Commission on the National Health Service. Cmd. 7615. H.M.S.O.
- MEYERS, R. (1979). Like Normal People. Souvenir Press.
- 'MILES' (1902). Where to get men. Contemporary Review, January.
- MILLS, C.W. (1959). The Sociological Imagination. Oxford University Press.

- MILLS, J.S. (1873). Autobiography. Oxford University Press, 1969.
- MITTLER, P. (1970). Changing Attitudes to the Mentally Subnormal. Journal of Mental Subnormality, 16, 3-8.
- MITTLER, P. (ed.) (1973). Assessment for learning in the Mentally Handicapped. Churchill-Livingstone.
- MITTLER, P. (1974). The Psychological Assessment of Mental and Physical Handicap. Tavistock.
- MITTLER, P. (1979). People not Patients. Methuen.
- MITTLER, P. (Chairman) (1980). Improving the Quality of Services for the Mentally Handicapped. National Development Group for the Mentally Handicapped. H.M.S.O.
- MONCRIEFF, J. (1966). Mental Subnormality in London: A Survey of Community Care. P.E.P.
- MORGAGNI, C.B. (1769). The Seats and Causes of Diseases. (Translated Alexander, B. and published in 1900 by the New York Academy of Medicine and the Hafner Publishing Company).
- MORONCY, R.M. (1976). The Family and the State. Longman.
- MORRIS, P. (1969). Put Away. Routledge & Kegan Paul.
- MORRIS, P. (1973). Social Research and Social Policy. In: A.D.B. Clarke & A.M. Clarke (eds). *Op.cit.*
- MORRISON, A. and MacINTYRE, D. (1971). Schools and Socialization. Penguin Books.
- NATIONAL SOCIETY FOR MENTALLY HANDICAPPED CHILDREN (1971). Action for the Retarded. N.S.M.H.C.
- NAVARRO, V. (1976). Medicine under Capitalism. Croom Helm.
- NAVARRO, V. (1978). Class Struggle, the State and Medicine. Martin Robertson.
- NEAMAN, J. (1975). Suggestion of the Devil. The Origins of Madness. Doubleday.
- NEUGEBAUER, R. (1978). Treatment of the Mentally Ill in Medieval and Early Modern England: A Reappraisal. Journal of the History of the Behavioural Sciences, 14, 2, 158-169.
- NORRIS, D. (1975). Day Care and Severe Handicap. British Association for the Retarded.
- NORRIS, M. (1978). Those we like to help. New Society, 6 July.
- NOTTON, J. (1978). Karl Pearson and statistics: the social origins of scientific innovation. Social Studies of Science, 8, 3-34.
- NOWNY, J.E. (1945). A Brief Synopsis of Mental Deficiency. American Journal of Mental Deficiency, 49, 319-357.

- OAKLEY, A. (1974). The Sociology of Housework.  
Martin Robertson.
- OAKLEY, A. (1976). Housewife. Pelican.
- O'CONNOR, J and TIZARD, J. (1956). The Social Problems of Mental Deficiency. Pergamon Press.
- OFFICE OF HEALTH ECONOMICS (1978). Mental Handicap: Ways Forward. O.H.E.
- OPEN UNIVERSITY (1982). D335 Issues in Crime and Society, The Open University Press.
- OSWIN, M. (1971). The Empty Hours: a Study of Weekend Life of Handicapped Children in Institutions. Penguin Books.
- OSWIN, M. (1978). Children Living in Long-Stay Hospitals. Longman.
- OSWIN, M. (1978). Holes in the Welfare State. Bedford Square Press for National Council of Social Service.
- P.E.P. (1937). Report on the British Health Service. P.E.P.
- PARRY, N. and PARRY, J. (1976). The Rise of the Medical Profession. Croom Helm.
- PARRY-JONES, W. (1972). The Trade in Lunacy. Routledge & Kegan Paul.
- PARSONS, T. (1951). The Social System. Routledge & Kegan Paul.
- PEARSON, G. (1975). The Deviant Imagination. Macmillan.
- PEARSON, K. (1905). National deterioration. The Times, 25 August.
- PEARSONS, N.R., KOSTNER, L.S. PEPPUCCI, N. and PEGGOLI (1979). Assessing Community Attitudes towards Mentally Retarded Persons. American Journal of Mental Deficiency, 84, 2.
- PENROSE, A. (1946). Propagation of the Unfit. The Lancet, I, 949-953.
- PENROSE, L. (1947). The Biology of Mental Deficiency. Sidgewick & Jones.
- PERRY, S. (1954). Some Theoretical Problems of Mental Deficiency and their Action Implications. Psychiatry, 17, 45-73.
- PINNEL, (1802). A Treatise on Insanity. Hafner Publishing Co. (Republished 1962).
- PINSENT, E.E. (1903). On the Permanent Care of the Feeble-minded. The Lancet, 21 Feb, 513-15.
- PLATO (1966). The Republic. (Edited and translated by I.A. Richards). Cambridge University Press.

- PLUMMER, K. (1979). Misunderstanding labelling perspective. In  
Downs and Rook (eds), Deviant Interpretations. Martin  
Robertson.
- POSTER, M. (1978). Critical Theory of the Family.  
Pluto Press.
- POTTS, W.A. (1908). The Recognition and Training of  
Convential Mental Deficiency. British Medical Journal,  
9 May, 1097-99.
- POWELL-DAVIES, (1930). The Social Control of Mental  
Deficiency. Constable.
- PUBLIC RECORD OFFICE. Calendar of Inquisitions Post Mortems  
Henry III to Richard II and Calendar of Inquisitions  
Post Mortem and other Analogous Documents, 2nd Series:  
Henry VII (3 vols.) H.M.S.O. 1898-1955.
- PUBLIC RECORD OFFICE. Calendar of Inquisitions Miscellaneous  
(Chancery) 1219-1422 (7 vols.) H.M.S.O. 1916-1968,  
4, 127-128.
- PUBLIC RECORD OFFICE. Exchequer King's Remembrancer:  
Various Accounts E101/415/3, Memoranda 1.  
October 15, Henry VII f. 298.
- PUCETTI, R. (1968). Persons: a Study of Possible Moral Agents in  
the Universe. MacMillan.
- THE RADNOR REPORT (1908). On the Care of the Feeble-minded:  
Report of the Royal Commission. H.M.S.O.
- REES, S. (1978). Social Work face to face. Edward Arnold.
- REID, M. (1975). The Development of Medical Sociology  
in Britain. Discussion Paper No. 13. Discussion  
Papers in Social Research. University of Glasgow.
- REISS, P. (1967). Implications of Piaget's development psychology.  
American Journal of Mental Deficiency, 72, 361-369.
- REX, J. (1973). Discovering Sociology: studies in sociological  
theory and meaning. Routledge and Kegan Paul.
- REX, J. (1973). Race, colonialism and the City.  
Routledge & Kegan Paul.
- RICE, B. (1979). The Brave New World of Intelligence Testing.  
New Society, 11 Oct. 50, 888, 63-66.
- RICHARDSON, S.A. et al. (1961). Cultural Uniformities in  
reaction to physical disabilities. American Sociological  
Review, 26, 241-6.

- RICHARDSON, S.A. (1975). Reaction to Mental Subnormality  
In: M.J. Began and S.A. Richardson (eds.) Op.cit.
- ROBINSON, N.M. (1978). Mild Mental Retardation. Does it  
 Exist in the People's Republic of China? Mental  
 Retardation, 16, 295-299.
- ROSE, H. and ROSE, S. (1970). Science and Society. Penguin.
- ROSE, S., HAMBLY, T. and HAYWOOD, J. (1976). Science,  
 Racism and Ideology. In: A. Blowers and G. Thompson  
 (eds.) Inequalities, Conflict and Change. Open  
 University Press.
- ROSE, S. and ROSE, H. (1976). The Politics of Neurobiology:  
 Biologism in the service of the State. In: R. Dale  
 et al (eds.) Op.cit.
- ROSEN, G. (1968). Madness in Society: Chapters in the  
 Historical Sociology of Mental Illness. University of  
 Chicago Press.
- ROSEN, G. (1974). From Medical Police to Social Medicine.  
 Neale Watson.
- ROSEN, M., CLARK, G.C. and KIVITY, M.S. (1976).  
The History of Mental Retardation - Collected Papers  
 (Vols. I & II). University Park Press.
- ROSENTHAL, R. and JACOBSON, L. (1968). Pygmalion in the  
 Classroom: Teacher Expectation and Pupils'  
 Intellectual Development. Holt, Rinehart & Winston.
- ROSENTHAL, R. (1973). On the Social Psychology of the  
 Self-fulfilling Prophecy: Further Evidence for the  
 Pygmalion Effect and their Mediating Mechanism.  
Psychology Today, 7, 56-63.
- ROTH, D. (1974). Intelligence Testing as a Social Activity.  
In: A. Cirouicel et al (eds.) Language and School  
 Performance. Academic Press.
- ROTH, D.J. (1971). The Discovery of the Asylum: Social Order  
 and Disorder in the New Republic. Little Brown & Co.
- ROWITZ, L. (1974). Social Factors in Mental Retardation.  
Social Science and Medicine, 8, 405-412
- ROWITZ, L. (1974a). Sociological Perspectives on  
 Labelling. American Journal of Mental Deficiency,  
79, 3, 265-267.
- ROYAL COMMISSION ON THE LAW RELATING TO MENTAL ILLNESS  
 AND MENTAL HANDICAP (1957). Report of the Commission  
 1954-1957. H.M.S.o.
- RUSH, B. (1812). Medical Inquiries and Observations upon  
 the Diseases of the Mind. Kimber & Richardson.



- RUSSELL, B. (1924). Icarus, or the Future of Science. Kegan Paul.
- RYAN, J. (1973). Scientific research and individual variation. In Clarke and Clarke (eds), op cit.
- RYAN, J. (1976). The Production and Management of Stupidity: the involvement of medicine and psychology. In Wadsworth, M.E. and Robertson, D. (eds), Studies in Everyday Medical Life. Martin Robertson.
- RYAN, J. and THOMAS, f. (1980). The Politics of Mental Handicap. Penguin.
- SACKETT, G.P. (ed, 1978). Observing Behaviour Vol I: theory and application in mental retardation. University Park Press.
- SAPSFORD, R.J. and EVANS, J. (1979). Evaluation of Research. Block 8 of Open University course DE304 Research Methods in Education and the Social Sciences. The Open University Press.
- SARASON, S.R. and DORIS, J. (1969). Psychological Problems of Mental Deficiency (4th edition). Harper and Row.
- SARASON, S.R. and DORIS, J. (1979). Educational Handicap, Public Policy and Social History. The Free Press.
- SARASON, S.R. and GLADWIN, T. (1958). Psychological and cultural problems in mental subnormality; a review of research. Genetic Psychology Monographs, 57, 3-290.
- SCARSE, R. (1976). Images of progress; Sweden. New Society, 30 Dec. 1976-5
- SCHILD, S. (1971). The family of the retarded child. In Koch and Dobson (eds), op cit
- SCHOEGGEN, D. (1978). Ecological psychology and mental retardation. In Sackett (ed), op cit
- SCHWEISO, J. and HASTING'S, N. (1980). The role of theory in the teaching of behaviour modification to teachers. In Wheldall, K. (ed). The Behaviourist in the Classroom: aspects of applied behavioural analysis in British educational contexts. University of Birmingham, Educational Review Publications.
- SCOTT, R.A. (1970). The construction of conceptions of stigma by professional experts. In Douglas, J.B. Deviance and Respectability. Basic Books.
- SCULL, A.T. (1975). Medical Men to Moral Entrepreneurs: From Madness to Mental Illness. European Journal of Sociology, 16, 2, 218-261.
- SCULL, A.T. (1977). Decarceration: Community Treatment and the Deviant. Prentice Hall.
- SCULL, A.T. (1979). Museums of Madness. Allen Lane.

- SEEBOHM COMMITTEE (1968). Report of the Committee on Local Authority and Allied Personal Social Services.  
H.M.S.O.
- SEGUIN, E. (1846). Traitement moral, hygiène et education des idiots et des autres enfants arriérés.  
Baillière Tindall.
- SELDON SOCIETY PUBLICATIONS (1887). Select Pleas of the Crown (London) 66. Seldon Society.
- SHANKS, K. (1976). Future Accommodation Needs of the Mentally Handicapped in the London Borough of Bexley.  
London Borough of Bexley.
- SHARP, R. and GREEN, A. (1976). Education and Social Control. Routledge & Kegan Paul.
- SHEARER, A. (1972). A Right to Love? A Report on Public and Professional Attitudes towards the Sexual and Emotional Needs of the Handicapped People.  
Spastics Society/National Association for Mental Health.
- SHEARER, A. (1975). No Place like Home? Campaign for Mental Handicap. Discussion Paper No. 5.
- SHEARER, A. (1980). One that Got Away. Guardian, 9 Jan.
- SHEARER, A. (1980a). Handicapped children in residential care.  
Bedford Square Press.
- SHEARER, A. (1981). Disability: whose handicap? Blackwell.
- SHENNA, V. (ed.) Action for the Retarded. National Society for Mentally Handicapped Children.
- SHOTTER, J. (1974). What is it to be Human? In:  
Armistead, N.(ed.) Reconstructing Social Psychology.  
Penguin.
- SHRUBSALL, F.C. and WILLIAMS, A.C. (1932). Mental Deficiency Practice. University of London.
- SHUTTLEWORTH, G.E. (1912). Exceptional School Children.  
The Teachers Encyclopaedia, 15, 214-8.
- SHUTTLEWORTH, G.E. and POTTS, W.A. (1895). Mentally Deficient Children: Their Treatment and Training.  
Lewis
- SIMON, B. (1960). Studies in the History of Education 1780-1870. Lawrence & Wishart.
- SIMON, B. (1971). Intelligence, Psychology and Education.  
Lawrence & Wishart.

- SKINNER, B.F. (1972). Beyond Freedom and Dignity. Jonathan Cape.
- SKULTANS V. (1975) Madness and Morals. Routledge and Kegan Paul.
- SKULTANS U. (1979). English Madness: ideas on insanity 1580-1890.  
Routledge and Kegan Paul.
- SLACK, I. Learning and conditioning. Unit 3 of Open University  
course DS262 An Introduction to Psychology. The Open University  
Press, 1981.
- SMILES, S. (1859). Self-help; the art of achievement illustrated  
by accounts of the lives of great men.
- SOCIALSTRELSEN REDOVISOR (1979). Facts and Figures on the Mentally  
Retarded and their Living Conditions in Sweden. Socialstyrelsen.
- SODER, M. (1972). Housing integration of mentally retarded persons.  
Epilepsia, 13, 249-251.
- SINCLAIR, H. (1851). Social Statics.
- SPITZER, S. (1975). Towards a Marxian Theory of Deviance  
Social Problems, 22, 5, 638-651.
- STACEY, M. (1977). Concepts of Health and Illness: A Working  
Paper on the Concepts and their Relevance for Research.  
Appendix III in Health and Health Policy Priorities  
for Research. The Report of an Advisory Panel to the  
Research Initiatives Board. S.S.R.C.
- STACEY, M. (1978). The Sociology of Health and Illness:  
Its Present State, Future Prospects and Potential  
for Health Research. Sociology, 12, 2, 281-307.
- STEDMAN, D.J. and EICHORN, D.H. (1964). A comparison of the growth  
and development of institutionalised and home-reared mongoloids  
during infancy and childhood. American Journal of Mental  
Deficiency, 69, 391-401.
- STEDMAN-JONES, L. (1971). Outcast London. Clarendon Press.
- STEIN, L. and SUSSER, M. (1960). The families of dull children -  
a classification for predicting careers. British Journal of  
Preventive Social Medicine, 14
- STEIN, L. and SUSSER, M. (1960a). Families of dull children Part II  
- identifying family types and subcultures. Journal of Mental  
Science, 106, 445.
- STEIN, L. and SUSSER, M. (1960b). The families of dull children  
Part III - social selection by family type. Journal of  
Mental Science, 106
- STEIN, L. and SUSSER, M. (1960c). The families of dull children Part  
IV - increment in intelligence. Journal of Mental Science, 106

- STEIN, L., SUSSER, M. and GUTERMAN, A.W. (1973). A screening programme for prevention of Down's Syndrome, Lancet, 10 February, 305-310.
- STODDARD, T.L. (1922). Revolt against Civilization. Scribner.
- STRIVENS, J. The Use of Behaviour Modification in Special Education: a critique. In Barton and Tomlinson (eds), op cit
- SUSSMAN, M.B. (ed.) (1966). Sociology and Rehabilitation. A.S.A. in Cooperation with Vocational Rehabilitation Administration, U.S. Department of Health, Education and Welfare.
- SUTTON, A. (1980). Cultural disadvantage and Vygotsky's stages of development. Educational Studies, 6, 3 October.
- SUTTON, A. (1980). Backward children in the U.S.S.R.: an unfamiliar approach to a familiar problem. In BRINE, J. et al (eds) Home, School and Leisure in the Soviet Union. George Allen and Unwin.
- SZASZ, T. (1970). The Manufacture of Madness. Harper & Row.
- TALBOT, E.S. (1898). Degeneracy.
- TARZAN, G., EYMEN, R. and MEYERS, C.E. (eds.) (1978). Sociobehavioural Studies in Mental Retardation. Monograph of the American Association on Mental Deficiency.
- TAWNEY, R.H. (1931). Equality. George Allen and Unwin.
- TAYLOR, H.G. (1975). Social Perceptions of the Mentally Retarded. Journal of Clinical Psychology, 31, 100-2
- TAYLOR, I. and WALTON, P. (1970). Values in Deviancy theory and Society. British Journal of Sociology, 21, 4, 362-74.
- TAYLOR, W. and TAYLOR, I. (1967). The Ascertainment of the Mentally Handicapped in England and Wales. Mental Retardation, April, 23-27.
- TERMAN, L.M. (1914). The Measurement of Intelligence. Houghton, Mifflin & Co. (English Edition 1919 George Harrap).
- THOMAS, B., KENDALL, A. and FIRTH, H. (1978). Encore - The Way Ahead. Campaign for Mental Handicap.
- TITMUSS, R.M. (1958). The Hospital and its Patients. In: R.M. Titmuss (ed.) Essays on the Welfare State. Allen & Unwin.

- THOMPSON, E.P. (1963). The making of the English working class. Pelican.
- TIZARD, J. and GRAD, J.C. (1961). The Mentally Handicapped and their Families. Oxford University Press.
- TIZARD, J. (1964). Community Care for the Mentally Handicapped. Oxford University Press.
- TIZARD, J. (1967). Survey and Experiment in Special Education. Harrap.
- TOMLINSON, S. (1981). Educational Subnormality: a Study in Decision-making. Routledge and Kegan Paul.
- TOWNSEND, P. (1969). 'Introduction' to P. Morris, Op.cit
- TOWNSEND, P. (1973). The Social Minority. Allen Lane.
- TOWNSEND, P. (1974). The Political Sociology of Mental Handicap: A Case Study of Policy. In: B. Boswell and J. Wingrove (eds.) The Handicapped Person in the Community. Open University Press.
- TREDGOLD, A.F. (1908). Mental Deficiency. Baillière, Tindall & Cox.
- TREDGOLD, A.F. (1910). The Feeble-Minded. Contemporary Review, June, 717-27.
- TREDGOLD, A.F. and SODDY, K. (1970). Tredgold's Mental Retardation (11th edn.) Bailliere, Tindall & Cassell.
- TUCKER, A. (1980). More evidence of lead harm to Children Guardian, March 10.
- TURKE, D.H. (1882). Chapters in the History of the Insane in the British Isles. Kegan Paul.
- TYNE, A. (1976). Handicap: A Rejoinder. New Society, 8 July.
- TYNE, A. (1979). Who's Consulted. Enquiry Paper No. 8. Campaign for Mental Handicap.
- TYNE, A. (1978). Looking at Life. Enquiry Paper No. 7. Spastics Society/Campaign for Mental Handicap.
- VERNON, P.E. (1969). Intelligence and Cultural Environment. Dockerill.
- VOYSEY, M. (1975). A Constant Burden. Routledge and Kegan Paul.
- WADE, I.O. (1973). The Structure and Form of the French Enlightenment. Princeton University Press.
- WALKER, N. (1968). Crime and Insanity in England Volume I: the Historical Perspective. University of Edinburgh Press.
- WALKER, N. and McCabe S. (1973). Crime and Insanity in England Volume II: New Solutions and New Problems. University of Edinburgh Press.

- WALLACE, T.R. (1929). Are the feeble-minded criminals?. Mental Hygiene, 13, 93-98.
- WALTERS, E.V. (1972). Dreadful Enclosure; detoxifying an urban myth. Unpublished paper.
- WATSON, J.B. (1913). Psychology as the behaviourist views it. Psychological Review, 20, 158-178.
- WATSON, J.B. (1924). Behaviourism. University of Chicago Press.
- WATSON, P. (1972). I.Q., the Racial Gap. Psychology Today, Sept., 48-50.
- WEBB, S. (1896). The Difficulties of Individualism. The Fabian Society, Fabian Tract no. 69.
- WEBB, S. (1901). Lord Roseberry's escape from Houndsditch. Nineteenth Century, 366-386.
- WEBB, S. (1906). Physical degeneracy or race suicide.  
Part I. The Times, Thursday 11 October.  
Part II. The Times, Tuesday 16 October.
- WEBB, S. and WEBB, B. ( ). English Poor-law History, vol. 2.
- WEBB, S. and WEBB, B. (1935). Soviet Communism; a new civilization? Longman, Green.
- WEIR, S. (1981). Our image of the disabled, and how ready we are to help. New Society, 1 January.
- WELLER, L. et al (1974). Social variables in the perceptions and acceptance of retardation. American Journal of Mental Deficiency, 79, 274-278.
- WELLS, H.G. (1904). Mankind in the Making. Chapman and Hall.
- WELLS, H.G. (1905). A Modern Utopia. Chapman and Hall.
- WELLS, H.G. (1908). Socialism and the Family. Fifiield.
- WELLS, H.G. (1930). The New Machiavelli. John Lane.
- WERSKY, P G. (1972). The Visible Colleges; a study of left-wing scientists in Britain 1919-1939. Unpublished PhD Thesis, Harvard University.
- WEYGENALT, (1915). A Classical Monograph on Idiocy and Imbecility. Leipzig, Frau Deutsch.
- WILKIN, D. (1979). Caring for the Mentally Handicapped. Croom Helm.
- WILLCOCKS, A. (1967). Changing Opinion: Optimism for the Future. Mental Health, Autumn, 14-16.
- WILLIS T. (1672). De anima brutorum....exercitationes duae. Prior physiologica...altera pathologica. Translated (1863) by S. Pardage, Student in Physick, London, as Two discourses

concerning the soul of brutes...The first is physiological  
...The other is pathological.

- WING, J.K. and BROWN, G.W. (1970). Institutionalism and Schizophrenia. Cambridge University Press.
- WINTHROP, and TAYLOR, (1957). An Inquiry concerning the Prevalence of Popular Misconceptions relating to Mental Deficiency. American Journal of Mental Deficiency, 34, 4-348.
- WOLFENBERGER, W. (1970). Models of mental retardation. New Society, 15, 51-53.
- WOLFENBERG, W. (1976). The Origin and Nature of our Institutional Models. Human Policy Press.
- WOOD COMMITTEE (1929). Report of a Joint Committee on Mental Deficiency 1925-1927. H.M.S.O.
- WOODWARD, M. (1959). The Behaviour of the Idiot interpreted by Piaget's Theory of sensory-motor development. British Journal of Educational Psychology, 29, 60-71.
- WOODWARD, M. (1963). The Application of Piaget's Theory to Research in Mental Deficiency. In: Ellis, D. (ed.) Handbook of Mental Deficiency. McGraw-Hill.
- YOUNG, M. (ed.) (1974). Poverty Report.  
Maurice Temple Smith
- YOUNG, M. (ed.) (1975). Poverty Report.  
Maurice Temple Smith
- YOUNGHUSBAND, E. (1970). Living with Handicap: the Report of a Working Party on Children with Special Needs. London, National Bureau for Co-operation in Child Care.
- ZALENY, L.D. (1933). Feeblemindedness and Criminal Conduct. American Journal of Sociology, 38, 564-76.
- ZILLOORG, G. (1941). A History of Medical Psychology.  
Martin.
- ZIMAN, D. (1972). Unwanted Neighbours. British Hospital Journal and Social Science Review, 2001-2

At the time of the interview all but one family were still involved in some kind of treatment for their child. Being unable to predict whether their child would require further hospital treatment or when the end point for their child's rehabilitation would be reached seemed to generate hope in some parents regarding the future appearance of their child's scar. Other parents remained more cautious. This depended on how the situation was appraised and continued to be appraised by individual parents. (See Section 4.3 for further discussion of hope and caution).

A related sub-theme was identified in connection with parents' difficulties in coming to terms with the uncertainty regarding their child's condition. Families expressed **fears for the future** almost exclusively surrounding the issue of their child's scars and the possibility that they could be stigmatised or become self-conscious. This was viewed as inevitable by some parents, although others remained more hopeful.

Harriet's mother expressed her concerns for her daughter when she got older but remained hopeful that this could be tackled:

*M: well my main concern is how is she going to react when she is getting older cause she will, she will be marked and when she is a teenager it will cause her problems. She is never going to be comfortable wearing little shoe string tops and stuff like that. But it is how we bring her up, to be able to deal with that. (Text unit 470)*

Predictions for when children were likely to be affected varied between families.

*M: Doesn't bother him ... I'm worried what it'll be like when he gets to mingle with other kids  
F: When he gets to school - when he has swimming lessons at school that's what I worry about. (Text units 443-444)*

Three parents observed that their children had already been exposed to experiences during which they could have felt stigmatised. Of the eight parents who expressed these fears for the future, all felt that the current age of their children protected them from the negative impact of stigma and predicted that they would experience difficulties as they got older. Karen's mother felt the future was going to be particularly difficult for her child as she had an identical twin sister:

*M: I have been thinking, yes, how she's going to be you know. Like she's going to see S\*\*\*\*\* [sister], is it going to be all right? There's not a mark on S\*\*\*\*\*. I think it's going to get harder as she grows up. I think it's easier now because she doesn't understand as much, she's only four, but when she starts school and you know things like that, I think its going to be, its going to get worse I think... (Text unit 623)*



## 2.2 Perception that accident and related events have had a negative impact on family

Parents described the difficulties of dividing their time between the injured child and the rest of their family. Parents of six of the seven families who had more than one child at home described their worries about the impact the experience had had on their other children. To a varying degree they expressed their difficulties with separation from their other children and trying to ensure their well-being whilst their sibling was in hospital. This appeared to be a threat regardless of whether they perceived their family or partners as offering support in terms of caring for the rest of their family.

*M: Yes I'd say it was they had been affected not just Karen you know. Cos, like I'd been away and coming back and F\*\*\*\* the baby she's quite close to me, err, how can I say, she's mummy's girl she doesn't do much with her father, with me, you know and she felt, I used to come home. I used to be so tired, I used to try and do the best I could with them you know, but it affected them, you know. Cos my mum used to say, err, they've been ok today, when I used to phone. They have been a bit quiet and I think it affected them as well you know.*  
(Text unit 345)

This mother was also concerned for her husband's well-being as she felt unable to offer him sufficient support.

## 2.3 Others' responses perceived as a threat to well-being

Parents readily identified the reactions of other people as unhelpful or distressing. Three related sub-themes emerged - perceptions that others were **blaming** or **evaluating** them, and **comments or actions that were unhelpful**.

Appraising family or medical professionals' reactions as **blaming** them for the accident or **evaluating** them as parents was a source of concern for several participants. John's mother recalled:

*M: M\*\*\* [ambulance driver] went up and felt the water and he come back and he made a comment I didn't quite catch what he said he just went and tutted and I thought you know what do you want me to do you know I didn't throw him in it or anything.*  
(Text unit 130)

Three parents also believed that their child may currently blame them or would blame them in the future for the experiences they had gone through. For example, Karen's mother described her daughter wanting her mother to remove her scar:

All parents also described **comments and reactions that were unhelpful**. These varied from people being too sympathetic, becoming upset themselves or being insensitive to parents' feelings or needs. For example, Harriet's mother recalled her feelings when she returned to work, where she had only been employed for a week before the accident:

*M: But it's quite a big place where I am working and nobody asked, nobody knew about it which was another thing*

*I: Mmhm*

*M: Once I got into work I found it really strange because if it had been where I was working previously everybody would have known about it. (Text units 335-337)*

*M: And I don't know which was worse the complete indifference because nobody knew or everybody been overly concerned for me 'cause if they had been overly concerned I would probably have spent all day skrying (sic) (crying). (Text unit 339)*

#### 2.4 Healthcare professionals perceived as failing

Eight families considered that some aspect of the service they had received from healthcare professionals was worthy of criticism and exacerbated the levels of distress they were experiencing. Parents' descriptions of professionals suggested that overall they had a mixed opinion. However, clear cut distinctions were made by seven parents between those staff whom they felt to be non-supportive or who behaved in a manner that upset them and those who they found to be helpful. Parents placed these health service staff in mutually exclusive categories, distinguishing between those who they felt were protective and those who were not. The intensity and nature of the criticism levelled at services varied. Four parents described how difficult they found it when they perceived themselves to have been "fobbed off", not listened to or felt that information they had requested had not been forthcoming. Three participants also considered that staff behaviour, such as offering parents a choice over medical decisions, was handing over too much control to parents. The manner in which they were spoken to by medical staff was also criticised by some parents.

Elizabeth's mother recalled:

*M:... and they were sort of going away and coming back and in the end they said, well we'll put some cold stuff... No one seemed to want to take control of the situation. They were all running around and didn't know what to do. It seemed like I was having to cope with me, her and take control which I wasn't particularly happy with. (Text unit 74)*

**Table 6b** - Stability of coping strategies over time

<b>Super-ordinate theme 4:Coping strategies</b>	<b>More intense during event/hospitalisation</b>	<b>More intense after discharge/now</b>
<b>4.1 Distancing self from emotions generated by accident and its consequences</b>		
Cut off from emotions/'auto -pilot'	✓	
Disbelief	✓	
Using humour/euphemisms avoiding emotive language		✓
Explaining away impact on child.	✓	✓
Normalising child's reaction	✓	✓
Avoiding accident reminders		✓
<b>4.2 Overcoming difficulties/regaining control</b>		
Using 'practical' coping	✓	✓
Belief in own resources or developing strengths	✓	✓
Monitor child's medical care/question professionals	✓	✓
Beliefs about ensuring child's safety		✓
<b>4.3 Maintenance of hope</b>		
Gaining hope from healing signs	✓	✓
Gaining hope from child's "strength"	✓	
Beliefs in recovery	✓	
Caution		✓
Social comparison	✓	✓
<b>4.4 Managing blame/guilt</b>		
Attributing the accident to a unique set of circumstances		✓
No one to blame/concluding the event was an accident		✓
Avoiding blame discussions		✓
Making up for the accident to child	✓	✓
<b>4.5 Making sense of and justifying own reactions</b>		
Normalising the event		✓
Justifying		✓
Normalising their own reactions		✓
<b>4.6 Systemic management strategies</b>		
Allocation of roles	✓	✓
Being strong for their child or partner	✓	
Polarised views		✓

Family interventions have been suggested as important by both proponents of PTSD models of parental adjustment and the stress-resiliency models. Interventions aimed at facilitating coping skills have been trialed for parents of children with leukemia and although helpful at the time of diagnosis, were not related to subsequent parental adjustment (Kupst and Schulman, 1988). In line with Le Doux et al. (1998), the current study suggests that more systemically oriented family therapy interventions may be more appropriate. Coping strategies described by parents that involved or affected other family members included being allocated a role, not discussing the event, being strong on someone else's behalf and adopting polarised views regarding key issues. Whilst it is not suggested that these are generally pathological, for some parents the use of these strategies was detrimental to their well-being. The issues identified therefore do not appear to be around coping skills per se but are associated with open communication and the development of a mutually satisfactory response to the event. Therefore, proposals by Figley (1989) for systemic working with traumatised families may be useful to consider. These include: allowing each family member to tell their story of the event and encouraging others to hear them; reframing ideas about the event or problem such as blame; developing a family consensus about the event; shifting attention from the identified patient to consider "individual's healing theories" and identifying alternative family and individual coping strategies if necessary.

Finally, the commonly adopted strategy of parents distancing themselves from the emotions generated by the accident and its consequences, may affect both the depth and pace of therapeutic interventions offered. In addition, the importance of strategies that allowed parents to remain hopeful, may interfere with therapists who wish to help parents 'accept' the potential injury consequences. Other authors have suggested cognitive restructuring so that parents gain more realistic expectations about their child's recovery (e.g. Holaday & McPhearson, 1997), but the current study implies that these interventions should be approached with caution. When parents reflected on the interview process, they acknowledged that even if they had wanted to have such a conversation when their child was in hospital, it would have been difficult to do so practically. In addition, they suggested that intervention from a mental health professional might be viewed as suggesting that they were not coping and prevent them from accessing such a service. Low key interventions from known medical staff or facilitated groups, aimed perhaps at normalising some of the parents' reactions, may prove at least initially, to be more appropriate.

Our ref: **R/E/16/99**

7 July 1999

Dear

**RE: APPLICATION R/E/16/99: THE IMPACT ON PARENTAL WELL BEING OF CARING FOR A PRE-SCHOOL CHILD WHO HAS BEEN ACCIDENTALLY BURNED: A PHENOMENOLOGICAL INVESTIGATION OF PARENTS' EXPERIENCES OF THE HOSPITALISATION AND AFTER CARE OF A CHILD WHO HAS BEEN BURNED**

Thank you for submitting the above protocol which will be considered at the next meeting of the Paediatric Research Ethics Committee on Thursday 15th July 1999 at 4.40 pm in the Boardroom, NHS Trust.

You are invited to attend to answer any specific questions raised.

Please contact the above extension to confirm your attendance.

Thank you.

Yours sincerely

**Chairman**  
**Paediatric Research Ethics Committee**



Our ref: 1r/e/16/99

16 July 1999

Dear

---

RE: APPLICATION R/E/16/99: THE IMPACT ON PARENTAL WELL BEING OF CARING FOR A PRE-SCHOOL CHILD WHO HAS BEEN ACCIDENTALLY BURNED: A PHENOMENOLOGICAL INVESTIGATION OF PARENTS; EXPERIENCES OF THE HOSPITALISATION AND AFTER CARE OF A CHILD WHO HAS BEEN BURNED

Thank you for attending the 15th July meeting of the Paediatric Research Ethics Committee.

As you are aware the Committee requested a minor amendment to the consent form and copies of the letters of support from \_\_\_\_\_ Consultant Clinical Psychologist and \_\_\_\_\_, Consultant Burns & Plastic Surgeon.

The Committee are happy to approval this study and look forward to receiving the revised consent form and letters of support.

We wish you well with this study.

Yours sincerely

**Chairman**  
**Paediatric Research Ethics Committee**



**Appendix 2 -Recruitment criteria for Burns Unit staff**

- How had did your child behave after the accident at home/nursery/other people's houses? What did you make this?

### **Discharge from hospital ward and rehabilitation:**

- How did you feel when ..... was discharged from hospital ? What were you most concerned about ?
- What was the experience like for the rest of your family?
- How long do you think it will take .....to recover? What do you think will help?
- What was/is the experience of attending the clinic/ follow-up appointments like?
- What type of treatment /burn care were you involved in after your child was discharged from the ward? Was anybody else involved in this treatment ?How did this effect you and your family? How did you cope?
- How did you feel when .....went to school /nursery after the injury?

### **Impact on parent**

- Do you feel you have changed since the injury? How?
- What affect as the burn had on you as a parent?
- What affect has the injury had on your approach to parenting....?
- How if at all has this changed since the injury

### **Coping / Support**

- How do you feel you coped at the time of the injury /accident ? How do you feel you coped whilst ..... was in hospital / when he/she came home ? How do you feel you are coping now? What did you find most difficult?
- What helps you cope? What has been most helpful? What methods do you use? Have you used these methods before? How useful have these methods been?
- Overall how has ..... being burned effected you family?
- What helps your family cope?
- What type of support (if at all) have you received? Who has supported you? What type of support have you found most helpful?
- How often has the accident/injury been talked about since it occurred? With whom do these discussions occur?

### **Expectations for the future**

- What concerns do you have about the future?
- How do you think the burn will effect your child in the future?
- How do you think the burn injury will effect you and your family in the future?

### **Reflections on interview**

FINALLY – How have you found doing this interview?

When would you have preferred to have this conversation?

**End interview:** Thank participant for their co-operation and remind them that will be contacted once more. Discuss contact numbers if upset or feel upset when researcher leaves.